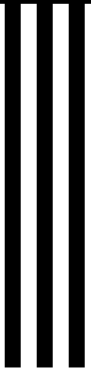


Eighth in
a Series of
Technical
Reports



Reducing the Use of Seclusion and Restraint Part III:

Lessons From the Deaf and Hard of Hearing Communities

**National Association of State Mental Health Program Directors
(NASMHPD)**

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December 2002



Final production, duplication, and distribution of this document were provided by the National Technical Assistance Center for State Mental Health Planning (NTAC) which is funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Division of State and Community Systems Development and operated by the National Association of State Mental Health Program Directors (NASMHPD). This publication's content is solely the responsibility of the author(s) and does not necessarily represent the position of SAMHSA or its centers.

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Acknowledgments

On behalf of the National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, I want to acknowledge the many people who contributed significantly to the development of this report.

This report is the eighth in a series of technical reports produced by the Medical Directors Council, and the third report dedicated to the topic of reducing the use of seclusion and restraint. We were guided by the lessons of our earlier reports and the principles of NASMHPD's Position Statement on Seclusion and Restraint and NASMHPD's Position Statement on Culturally Competent and Linguistically Appropriate Mental Health Services. We remain indebted to the individuals who developed and adopted those earlier documents.

This report is the product of a 2-day experts meeting held January 30-31, 2002. Officially, the meeting was focused specifically on reducing the use of seclusion and restraint among individuals who have mental illnesses and who are deaf or hard of hearing. In the process, however, a new understanding of deafness and the Deaf community was achieved by mental health administrators, professionals, educators, consumers, and advocates participating in the meeting, and a new relationship between the mental health and Deaf communities was born. Each of the participants, identified in Appendix C, shared unique experiences and expertise to build that relationship and develop this report, and we thank them.

In particular, Steve Hamerdinger, director of Deaf and Linguistic Support Services at the Missouri Department of Mental Health, spent many hours helping to plan the meeting, educating us about key cultural competency issues applicable to the Deaf community, identifying leading researchers and providers among the Deaf and hard of hearing communities for participation in this project, and reviewing countless drafts of this report. This publication could not have succeeded without his energy, commitment, and patience.

Deborah Guthmann, Ed.D., director of Pupil Personnel Services at the California School for the Deaf, and Robert Q. Pollard, Jr., associate professor of Psychiatry at the University of Rochester Medical Center, greatly facilitated our review of the academic literature related to mental health services for people who are deaf or hard of hearing, generously shared their research, and provided extensive comments on several drafts of this report. Neil Glickman, Ph.D.; Carole Schauer; A. Barry Critchfield, Ph.D.; Peter Martineau; Roger C. Williams; Raymond J. Trybus, Ph.D.; and McCay Vernon, Ph.D. also provided valuable comments on earlier drafts. Jerry Connor, director of the Deaf Services Center in Largo, FL, and Meryl Troop, director of the Office of Deaf Services and Multicultural Diversity at the Maine Department of Behavioral and Developmental Services, and representatives from the Deaf Services Center in Largo, FL were an enormous help in facilitating consumer participation and review of the document from many perspectives.

The experts meeting could not have succeeded without the expert facilitation provided by Eric Rosen, Ph.D., FPPR. While meeting facilitation is always a difficult task, seldom has a facilitator needed to bridge two cultural groups with such subtle but meaningful differences in style and perspective. Eric recognized those differences and brought them to the attention

of the group to enhance, rather than disrupt, the dialogue. Sign Language Associates staff provided interpretation services to facilitate communication.

We thank NASMHPD and the National Technical Assistance Center for State Mental Health Planning (NTAC) for assisting with this endeavor. In particular, NASMHPD Executive Director Robert W. Glover, Ph.D. inspired these technical reports and has made the reduction of seclusion and restraint for all populations a principal goal of NASMHPD and the states. With this report and related initiatives, Dr. Glover has added the complementary goal of ensuring that individuals who are deaf or hard of hearing have access to effective, culturally and linguistically appropriate mental health services.

Several additional NASMHPD staff were also instrumental in the development of this report. Kevin Huckshorn, director, Catherine Huynh, assistant director, and Rebecca Crocker, media/meeting coordinator of NASMHPD's National Technical Assistance Center planned and hosted the experts meeting and provided oversight in the development of this report. Jenifer Urff, NASMHPD Senior Policy Counsel, participated in the experts meeting and wrote the final report. Rob Hennessy, NTAC's editor and publications coordinator, provided critical editing and administrative oversight. Ms. Crocker also provided thoughtful and creative formatting and document design.

And finally, although he is no longer a member of the Medical Directors Council, Rupert Goetz, M.D., medical director for Clackamas County Mental Health in Oregon, graciously agreed to serve as chief editor of this technical report. Dr. Goetz has served as chief editor for each of the previous reports focused on reducing the use of seclusion and restraint and is truly irreplaceable in that role. His expertise, sensitivity, and keen analytical insights ensure that this report will inspire and challenge state mental health agencies to improve the delivery of services to individuals who are deaf and hard of hearing and to reduce the use of seclusion and restraint for all populations.

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Introduction

Medical Directors Council Technical Report Series

This Technical Report, prepared by the National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, is eighth in a series intended to provide information and assistance to state mental health commissioner/directors on matters of clinical concern. Topics for Technical Reports are identified by the Medical Directors Council in consultation with the NASMHPD leadership.

This Technical Report is the third in the series to address the critical goal of reducing the use of seclusion and restraint for people with mental illnesses. This goal is a priority for the Medical Directors Council, NASMHPD members, staff of mental health programs, and consumers of mental health services. Seclusion and restraint cause significant psychological trauma and may result in physical injury to those subjected to the practices. NASMHPD believes that seclusion and restraint are safety measures, not treatment interventions, and “should be used only where there exists an imminent risk of danger to the individual or others and no other safe or effective intervention is possible.” (See NASMHPD “Position Statement on Seclusion and Restraint,” July 1999, included in this report as Appendix A.) NASMHPD’s principal goals are: (1) to prevent, reduce, and ultimately eliminate the use of seclusion and restraint; (2) to ensure that, when such interventions are necessary, they are administered in as safe and humane a manner as possible; and (3) to preserve, to the greatest extent possible, the dignity, privacy, and safety of people who are restrained or secluded.

The first Technical Report on this topic, entitled *Reducing the Use of Seclusion and Restraint: Findings, Strategies, and Recommendations*, was published in July 1999. The report suggested a public health framework for reducing the use of seclusion and restraint in the context of primary, secondary, and tertiary prevention. The report defined general policies and principles related to seclusion and restraints, with an emphasis on facilitating culture change within psychiatric institutions and identifying effective, earlier interventions to reduce the need for seclusion and restraints.

The second Technical Report on seclusion and restraint was published in March 2001. The report focused on the unique needs and strategies for reducing the use of these emergency safety measures with special populations, including children and adolescents, older people, people with co-occurring mental illnesses and developmental disabilities and/or mental retardation, people with co-occurring mental illnesses and substance abuse, and people served in forensic psychiatric programs. In doing so, the report demonstrated how principles regarding seclusion and restraint for these special populations contribute to our efforts to reduce the use of these interventions for all populations and in all settings. This critical lesson was a motivating factor in the development of this third Technical Report.

The third Technical Report also complements a series of reports on cultural competency and diversity developed by the National Technical Assistance Center for State Mental Health Planning (NTAC), located at NASMHPD. A report in that series, *Meeting the Mental Health Needs of Persons Who Are Deaf* (Critchfield, 2002) provided critical insight into providing

services to people who are deaf, redefining many clinical issues as issues of cultural and linguistic competence instead. This Technical Report also was guided by NASMHPD's Position Statement on Culturally Competent and Linguistically Appropriate Mental Health Services, included in this report as Appendix B.

Preparation of This Report

This Technical Report was prepared from proceedings of a meeting held January 30-31, 2002 in St. Petersburg Beach, FL. Meeting participants included leading experts on services for people who are deaf and hard of hearing, including several with specific expertise related to mental health services and treatment for this population, deaf consumers of mental health services, mental health administrators, and staff from NASMHPD and the NASMHPD Research Institute (NRI). A roster of participants is included in this report as Appendix C.

Prior to the meeting, participants reviewed current literature related to the use of seclusion and restraint with people who are deaf or hard-of-hearing and who have a mental illness. The materials were not a comprehensive survey of all available information on deafness and mental health, although it included nearly all published material on the use of seclusion and restraint with people with hearing loss. The materials sought to establish a common, informed basis for group discussion. Meeting participants also reviewed data collected by the NRI related to the use of seclusion and restraint among people in state psychiatric hospitals who are deaf or experience other hearing loss.

The two-day meeting took place in a single room with approximately 25 people, both hearing and deaf. Some of the hearing participants were professionals who work with people who are deaf and are familiar with the clinical, social, and cultural issues important to that population. Others were professionals in the mental health field who have had limited exposure to people who are deaf. Interpreters fluent in American Sign Language and English provided simultaneous interpretation throughout the meeting.

Despite efforts to ensure effective communication through interpreters at all stages of the meeting, consequences of the language and culture barriers became immediately apparent. Hearing participants unfamiliar with Deaf Culture quickly learned a truism known to all deaf people who rely on interpretation; even the best interpreters cannot accurately and consistently convey the meaning of another's words and expressions.

Throughout the course of the meeting, new ground rules were needed to facilitate more equal participation by all members. Deaf participants observed that the pace of the meeting, the structure of the discussion, and even the seating arrangements reflected a hearing culture that did not accommodate the subtle but critical needs of deaf participants. For example, the time delay between a hearing participant's spoken comments and their interpretation into American Sign Language often meant that the conversation had moved on to a new point before deaf participants had an opportunity to share their insights. New ground rules were established to ensure that all

comments were fully interpreted before the facilitator recognized a new speaker, but the unintentional bias toward hearing participants that was reflected in the original design of the meeting spoke volumes as to the therapeutic gap that must be bridged.

The degree to which some hearing participants were unfamiliar with the realities of deafness was also made personal as signing participants engaged in a lively sidebar discussion. In complete silence, animated and intense signs flashed across the room, leaving those unable to understand the language unable to ascertain even the broad topic under debate. The summary interpretation provided minutes later was a powerful reminder to hearing participants of what it means to be excluded from a conversation.

This report first attempts to provide an understanding of cultural issues that are critical to addressing the service needs of people who have a mental illness and are deaf or hard of hearing. Next, the report attempts to integrate key treatment principles for this population with effective approaches to reducing the use of seclusion and restraints, while gleaned new lessons for the overall effort that these three seclusion and restraint-based Technical Reports represent. With its powerful focus on culture, this report emphasizes the major lessons of the first two reports: That to reduce the use of seclusion and restraint will require a broad cultural change in mental health treatment settings. Included in this report are key principles and value statements identified by meeting participants, recommendations for clinicians and other mental health staff serving people who are deaf or hard of hearing, and recommendations for policy and research. Where meeting participants were not in consensus, the report attempts to reflect the diversity of views.

Drafts of this report were prepared by the writer and chief editor. Drafts were circulated for review and comment to all meeting participants and members of the Medical Directors Council. This report is a product of that Council and does not necessarily reflect opinions held by all NASMHPD members or the experts participating in the January 2002 meeting.

Background on Issues Related To People Who Have Mental Illness and Are Deaf or Hard of Hearing

When meeting participants gathered in January 2002 to discuss reducing the use of seclusion and restraint with people who are deaf and hard of hearing, several issues were immediately apparent. First, public mental health systems in the United States poorly serve this population, and the communication and cultural barriers inherent in the entire system are a root cause of the use of coercive interventions such as seclusion and restraints. Therefore, before launching into a specific discussion of reducing seclusion and restraints, this Technical Report begins by reviewing the cultural and linguistic context of providing mental health services to people who are deaf and hard of hearing.

Second, the concepts of “seclusion” and “restraints” take on new dimensions in the context of a population sensitized to isolation and societal barriers to achievement. Without specialized programs and accommodations for people who are deaf and hard of hearing, the mental health system is, by its very nature, seclusionary and it imposes significant obstacles to recovery. That is, mental health systems often mirror and perpetuate the isolation that many people who are deaf and hard of hearing face in everyday life by placing them in situations in which they can’t communicate and can’t fully participate. These barriers also require exploration and discussion.

Cultural and Linguistic Context

To the hearing world, deafness is a disability with tragic consequences, impeding the ability to communicate and to participate fully in daily life activities. But to many people who are deaf, especially those who have been deaf since birth or infancy, deafness is viewed not as the physical disability of being unable to hear, but as a rich and meaningful culture, complete with its own language, customs, values, and communities. Understanding and respecting this culture and the unique needs of people who are deaf or hard of hearing is the critical first step to the effective delivery of mental health services to this population (Critchfield, 2002) and to the reduction of the use of seclusion and restraints.

Definitions and Terms Used

All people with hearing loss face challenges in communicating with mental health treatment providers and others. However, there are important differences among the deaf and hard of hearing population that have significant implications for communication and providing effective mental health services.

As used in this report, a person who is “deaf” is one who has a significant hearing loss and who, with or without amplification, cannot understand speech. A deaf person relies principally on visual, rather than auditory, cues for communication. A person who is “hard of hearing” has a hearing loss that, with or without amplification, can understand speech in

some settings.¹ A person who is hard of hearing relies significantly on auditory cues for communication, but many also depend on visual cues. They generally communicate through speech or some version of a spoken language, although they may also know some form of signing.

Beginning with this section, this report will adopt the custom described by Padden and Humphries (1988) of using the capitalized word “Deaf” to refer to cultural experience or identity, and the lower-case word “deaf” in other contexts, such as clinical references, in reference to people with hearing loss who do not generally associate themselves with Deaf Culture, or in reference to the broad population of people who rely principally on visual, rather than auditory, signals for communication.

Because this report is focused on reducing the use of seclusion and restraint for people who are deaf or hard of hearing in the United States, and because English is the dominant language in the public mental health system in this country, this report occasionally refers to an individual’s fluency in English as part of its overall discussion. In some contexts, this would include other spoken and written languages in which the individual is fluent.

Understanding the Populations and Languages

More than 22 million Americans—nearly 9% of the total U.S. population age 3 and over—have some degree of hearing loss (Critchfield, 2002). The vast majority of these people are hard of hearing or older adults who lose their hearing late in their lives. (Ibid.) Conservative estimates suggest that about 1 million people have a hearing loss significant enough to be considered deaf.

The level of hearing loss and the age when a person becomes deaf or hard of hearing have significant implications for his or her language acquisition and, thus, for his or her cultural identity, communication preferences, and mental health treatment.

- People who are hard of hearing generally acquire some level of English language skills. The age of onset and the degree and nature of the hearing loss have significant implications for how fluent in English he or she may be. For example, a person who loses hearing after developing English language skills likely will have a higher degree of English fluency than someone who has a congenital hearing loss. They may, however, experience a significant sense of loss and struggle to continue to function in their established culture and surroundings. On the other hand, a person who is hard of hearing from birth likely will experience less of a sense of “loss” but may still feel caught between worlds as neither part of the larger English-speaking culture, nor part of the Deaf community. People who are hard of hearing often can benefit from assistive devices, such as hearing aids and TTY access (keyboard devices that enable people who are deaf to use telephones).

¹ The ability for a person who is hard of hearing to hear speech is influenced by many factors, including lighting, background noise, the person’s fatigue or stress level, and his or her general health. Providers should not assume that a person who can hear in some settings will be able to hear under changed circumstances.

- People who are deaf may differ widely:
 - People who have been deaf since birth or infancy—that is, before they developed language skills—are more likely to be fluent in American Sign Language and to identify themselves with Deaf Culture. People with “early onset” deafness are far less likely to experience a sense of loss associated with their deafness or to view their deafness as a disability. Rather, they often view themselves as members of a cultural and linguistic minority. They are significantly less likely to be fluent in English than people who became deaf later in life. Approximately 90% of all deaf children in the United States have been deaf since birth or infancy (Dolnick, 1993).
 - It is almost impossible to generalize about people who become deaf after the acquisition of language skills but relatively early in childhood. Some become fluent in American Sign Language and associate themselves with Deaf Culture; others continue to use English as their primary language and attempt to communicate through speechreading, reading and writing in English, or an English-language version of signing. Contrary to popular misconception, only a small minority of people who speechread are able to communicate effectively using this method.
 - People who become deaf in late adolescence or adulthood—“late deafened” individuals—are much more likely to perceive their deafness as a disability. Many of these people are fluent in English, rather than American Sign Language, and face significant communication barriers in both hearing and Deaf settings. The percentage of late deafened adults among the deaf population is smaller than in the past, in large part because medical intervention (especially antibiotics) prevents and controls childhood diseases that used to result in permanent hearing loss (Dolnick, 1993). On the other hand, as the incidence of head injury trauma in the United States increases, so does the number of people with clinically significant hearing loss caused by trauma.
 - A significant subset of people who are deaf have minimal or no proficiency in any language. This is especially common among individuals with early onset deafness whose hearing loss was not diagnosed early and who were not exposed to an accessible form of language until later in childhood, if at all. It is also common among individuals whose hearing loss is one symptom of a myriad of other medical and cognitive problems, including developmental disabilities and other co-occurring sensory deficits (such as blindness). This population poses the most complex challenges when attempting to communicate with them and requires flexibility and creativity on the part of mental health providers. Because of communication difficulties, this population is also particularly vulnerable to misdiagnosis, especially inappropriate diagnoses of mental retardation.

The following table attempts to capture some of this complexity while suggesting areas of emphasis to facilitate culturally appropriate services, adequate choice of communication preferences, and improved mental health treatment.

	Hearing Capacity	
LANGUAGE FLUENCY	High	Low
High	Individuals with high levels of hearing capacity and high language fluency may experience their hearing loss as a disability, may be fluent in a written/spoken language (such as English), and may identify themselves more with hard of hearing persons. They may benefit particularly from assistive devices.	Individuals with low levels of hearing capacity but high language fluency (for example: American Sign Language) may not experience themselves as having a disability and are most likely to identify themselves with Deaf Culture. They may benefit particularly from specialized Deaf programs.
Low	Individuals with high levels of hearing capacity but low language fluency may have difficulty in any language, may not identify themselves with a particular support community, and may have co-occurring medical and cognitive disorders. Usefulness of possible assistive devices and clearly defined communication strategies appropriate for their level of language development should be made explicit in the person's treatment plan.	Individuals with low levels of hearing capacity and low language fluency are likely to have difficulty in any language, may not identify themselves with any particular support community, and may have multiple co-occurring medical and cognitive disorders. They are likely to benefit from specialized programs; however, they will face many challenges in any setting and staff will require particular expertise and creativity in communicating.

It is important, both for cultural and clinical understanding, to recognize that American Sign Language is a distinct language, rich with its own meaning, colloquialisms, and etiquette. It is *not*, as is often assumed, a signed version of the English language. As the third most common language in the United States (behind English and Spanish), it is complex in its customs and nuances, does not have a spoken or written equivalent, and, like any “foreign” language, is difficult to learn fluently late in life.

Hearing participants unfamiliar with Deaf Culture received a crash course in the nuances of American Sign Language in the opening minutes of the experts’ meeting that is the basis for this report. Deaf participants immediately were confronted with differences in the signs they each used to communicate “restraint.” As is often the case with words that are technical in nature or

reflect regional differences in usage, the signs for the word had completely different sub-meanings. While one sign translated roughly into English as “hold,” another common sign for restraint was translated to mean “prison.” Deaf participants acknowledged the validity of each nuance, and held a brief sidebar discussion to select a common term to facilitate interpretation. Participants agreed to use the sign that meant “hold,” although they also agreed that this sign, in and of itself, understated the invasiveness and violence of physical restraint.

People with early-onset deafness who are fluent in American Sign Language may not communicate well in written English any more than a Spanish-speaking person could effectively communicate in that way. Conversely, people who are late-deafened may be able to communicate, at least in a limited way, through a signed adaptation of English or other “pidgin” form of signing, but they may be unable to communicate effectively using American Sign Language.

Other Cultural Issues

More than 90% of deaf children are born to hearing parents (Schein, 1989). The resulting communication gap is significant both for its impact on the child’s ability to become fluent in any language and for its implications for the child’s mental health.

There remains a schism among some educators and people affected by deafness regarding whether deaf children should be taught American Sign Language or English as their primary language. Prior to the 1900s, public education for people who were deaf generally included teaching American Sign Language and written English concurrently. From the turn of the century until the 1960s, however, many professionals believed that deaf children should learn to communicate through speech—learning to read speech, talk, read and write in English. Even today, many parents, struggling to cope with their child’s hearing loss, share this view and encourage their children to become as integrated as possible into the cultural mainstream of hearing people. However, even the most accomplished speechreaders are able to absorb less than half of the words spoken to them and learning to speak is an enormously difficult task for children who have no memory of speech (For example, see Jeffers & Barley, 1971, noting that only about 20% of sounds are visible on the lips). As a result, deaf children raised in hearing families often have limited skills in any language, and Deaf educators point out that this effort to integrate children actually has the effect of isolating them from opportunities for meaningful communication and social interaction.

Deaf children who are raised with American Sign Language, on the other hand, may become fluent in that language but often demonstrate only limited English skills. The average 16-year-old who is deaf reads English at an elementary school level, and only 2% go on to college (as compared to 40% of the general population). Even college-educated people who are deaf often read and write English as if it were a foreign language (Dolnick, 1993).

Within the Deaf community, professionals and people who are deaf increasingly support American Sign Language and participation in Deaf Culture as a legitimate alternative to a

hearing, English-speaking culture. They support primary language education in American Sign Language and specialized schools (often residential) even for young children. The resulting cultural gap between a Deaf child and the rest of his or her family may create tensions that are relevant both to understanding and effectively treating mental illnesses.

Impact on the Public Mental Health System

Many fundamental concepts underlying Deaf Culture—especially the belief that people who are deaf do not have a disability and are most successful when they live and learn in environments specially designed to support them—are at odds with current trends in mental health treatment. Most mental health professionals believe that successful recovery should take place in integrated, community environments and that people are most fulfilled when they participate fully in mainstream community life. This belief mirrors the goals of the larger disability advocacy community, which generally denounces institutions and other forms of segregation and supports “mainstreaming”—in schools, at work, and in all aspects of community life.

Deaf professionals and other members of the Deaf community, however, observe that “mainstreaming” is designed to ensure the delivery of services in the “least restrictive setting.” For people who are deaf, that setting may be a Deaf community or specialized program that understands their needs and in which communication is most accessible. When viewed in this light, broader mainstreaming for people who are deaf is far more isolating and deprives them of opportunities for communication with their peers. For people who are deaf and have experienced such isolation or seclusion in other settings, mainstreaming into the general population can be re-traumatizing, just as it would be for others who are not fluent in English or American culture. In treatment settings, mainstreaming into predominantly hearing populations often results in miscommunications that can lead, unnecessarily, to the use of seclusion and restraints.

Prevalence of Psychiatric Disorders and Other Mental Health Needs

Partly because of barriers to the effective diagnosis of mental illnesses among people who are deaf or hard of hearing (discussed below), there are no reliable data regarding the prevalence of psychiatric disorders among people who are deaf or hard of hearing. However, assuming rates of mental disorders that mirror rates within the general population, approximately 40,000 people who are deaf and more than 2 million people who are hard of hearing have a serious mental illness (Pollard, 1996; see also Critchfield, 2002). In a review of the literature, Hamerdinger and Murphy suggest a rate of severe emotional disturbance that is three to four times higher than in the general population (2000).

Available literature also suggests that people who are deaf experience physical and sexual abuse at extremely high rates, especially those individuals with mental illnesses, substance abuse disorders, or developmental disabilities. In one recent study involving 58 deaf children and adolescents receiving services at a residential treatment facility for youth with serious emotional disturbances, researchers found that 100% of the children had strong or confirmed indications of sexual abuse (Willis & Vernon, 2002). Because identifying and addressing past

trauma is critical both to providing effective treatment and reducing the use of seclusion and restraints, meeting participants agreed that providers should *assume* that people have a history of trauma in planning admissions and developing treatment plans.

Implications for Services and Treatment

People who are deaf or hard of hearing pose significant treatment challenges to a public mental health system lacking in resources, expertise, and cultural understanding of the population.

Diagnosis and Assessment: Although about 40,000 deaf Americans suffer from serious psychopathology, only about 2% in need of mental health services actually receive them (Pollard, 1996). One reason for this shocking treatment gap is that diagnosis of mental illnesses among people who are socially and linguistically isolated is very difficult. Primary health care providers may be unable to communicate well enough with their patients to identify a problem at all, and even those patients with an identified disorder are often misdiagnosed by mental health providers who are not fluent in American Sign Language.

Signs of co-occurring disorders also may be overlooked or exaggerated. Cues about substance abuse, for example, are often missed by family members and providers because they are attributed generally to deafness, are not visible because children attend residential schools, or are masked by the cultural gap that often exists when a person who is Deaf has hearing parents. Mental retardation and learning disabilities, on the other hand, are often overdiagnosed because communication gaps lead providers to make inaccurate assumptions about cognitive skills.

Problems with diagnosis and assessment are compounded by the fact that most diagnostic tools are not “normed” for Deaf Culture. That is, the tools are not sensitive to the nuances of Deaf Culture and often are not appropriate for use with people who are Deaf. Many diagnostic and assessment tools cannot be administered in American Sign Language.

Treatment: In 1983, a deaf woman committed to a Maryland state psychiatric hospital successfully sued the state for failing to provide her with appropriate services. The resulting consent decree, known as *Nancy Doe v. Wilzack*, Civ. Act. H83-2409 (Md. 1986), is often heralded by people who are deaf or hard of hearing as the most important legal document supporting the assertion that deaf patients deserve more than medication when they are hospitalized for mental illnesses.

Several subsequent cases have clarified and expanded on the rights of people who are deaf to receive culturally and linguistically appropriate mental health services. In *Tugg v. Towey*, 865 F.Supp. 1201 (S.D. Fl. 1994), for example, a federal district court found that simply providing interpreters did not meet the requirements of the Americans with Disabilities Act. In that case, the court reasoned that inserting a third person, the interpreter, into the therapeutic dyad changed the nature of the treatment and, thus, did not provide the same service that a hearing person would have received.

Realizing the potential of the Wilzack and other favorable court cases, however, has proven elusive. As will be discussed in greater detail in this report, obstacles to treatment for people who are deaf or hard of hearing often mean that mental health services are inadequate to support any meaningful form of recovery. The underlying treatment barrier, of course, is the lack of effective communication between providers and people who are deaf or hard of hearing. This barrier is reflected in the following system flaws.

- Lack of appropriate, specialized mental health treatment settings (inpatient, residential, outpatient and other community-based services such as psychosocial rehabilitation, self-help groups, and consumer-run services) for people who are deaf or hard of hearing.
- Lack of trained, qualified mental health providers and staff, especially those who are fluent in American Sign Language and knowledgeable about Deaf Culture.
 - Lack of training to meet the unique challenges presented by people who are hard of hearing. For example, many may appear to be fluent in American Sign Language but they really use a limited, “pidgin” form of signed English or rely on simultaneous communication, in which signing accompanies speech and serves as an aid to speech reading.
 - Lack of training in techniques to communicate with people who do not have any formal language system.
- Lack of qualified American Sign Language interpreters with mental health experience or training.
- Reluctance by hearing providers to hire qualified interpreters to consult with patients who are deaf.
- Lack of access to appropriate assistive devices and specialized accommodations.
 - Lack of TTY access (keyboard devices that enable deaf to use telephones) and visual alert systems for fire alarms, door knocks, and telephone rings.
 - Lack of access to other specialized accommodations for people who are hard of hearing or were deafened after acquiring fluency in English. These accommodations may be as simple as providing a quiet, distraction-free environment or as sophisticated as providing computer-assisted, real time captioning (CART), which uses court stenography equipment to transcribe a discussion verbatim. The specific accommodations needed vary depending on the individual receiving services and the situation.
- Lack of access to prevention and wellness materials, self-help information, captioned public service announcements, and other educational materials.

- Lack of treatment choices. Where a specialized program or provider fluent in American Sign Language is available, that program or provider is the only choice reasonably available to people who are Deaf, regardless of quality or other access issues.

Because of these barriers, which exist to some degree in all state mental health systems, many people who are deaf or hard of hearing mistrust treatment providers (especially hearing professionals) and may be unwilling to seek treatment or comply with treatment plans. This may result in deteriorating conditions and a need for more intensive treatment.

Perhaps as a combined result of barriers to effective diagnosis, assessment, and treatment, people who are deaf often receive a different array of services than people who are hearing. For example, deaf patients have been found to receive less psychotherapy and more behavior modification therapy than hearing patients (Pollard, 1994).

Discharge: Most people who are deaf or hard of hearing receive inpatient psychiatric services in state hospitals or other psychiatric specialty hospitals that do not have special Deaf units or programs. The limited ability to communicate between the patient and hospital staff has an obvious impact on the effectiveness of treatment, but also affects the staff's ability to accurately assess readiness for discharge. Perhaps most important, the lack of community providers specializing in working with deaf populations significantly limits discharge options and may extend hospital stays far beyond the where inpatient services are required.

Outpatient Services: Again, the lack of trained, qualified providers of mental health services means that people who are deaf or hard of hearing have few choices of providers and significantly less opportunity for peer support than other consumers of mental health services (Guthmann, Sandberg, & Dickinson, 1999).

Because the deaf population in the United States is relatively small, state mental health agencies must struggle with balancing services for people who are deaf or hard of hearing with other demands for services and resources. Some states have found that special Deaf units in state hospitals and residential settings can efficiently be established and administered, but even these states are challenged by the general lack of qualified, trained staff (both professionals and paraprofessionals) and the difficulty of creating meaningful treatment choices and alternatives for people who are deaf and hard of hearing.

Patients at the Deaf Unit at Westborough State Hospital (administered by the Massachusetts Department of Mental Health) in Westborough, MA, receive mental health services in a treatment milieu designed by and for deaf people. The 11-bed unit serves only people who are deaf and uses specialized tools and methods to apply standard, effective means of mental health treatment. Services are provided in an environment that affirms Deafness as a valid cultural difference, says Unit Clinical Director Neil Glickman, Ph.D., creating a level of respectfulness that is the foundation of mental health treatment.

The Deaf Unit is equipped with special features to facilitate communication and independence among patients, including light systems for all alarms and bells and numerous TTYs. Paintings by deaf artists or pictures with Deaf themes adorn the walls. Usually, about one-third of the staff is Deaf, and most of the hearing staff are good, if not fluent, signers. A Communication Department includes two full-time interpreters and a Deaf Communication Specialist who performs language evaluations, teaches American Sign Language, and assists staff in communicating with patients who have impaired sign language skills or who rely principally on gestures to communicate. Two social workers work with other service providers to ensure coordination between inpatient and outpatient services and to facilitate the movement of deaf patients along a continuum of culturally appropriate mental health care.

One of the most difficult aspects of this work is accommodating the great variety of communication styles and abilities deaf people have. Many deaf "signers" are not fluent in American Sign Language and can not make effective use of sign language interpreters to access treatment activities. Staff at the Westborough Deaf Unit have both communication and clinical expertise to work with non-fluent signers. Evidence-based approaches such as psychosocial skill development (coping, social and recovery skills training) have been refashioned for deaf-only treatment groups and use techniques like role-playing, drawings, and other interventions that match the language and conceptual abilities of patients. Staff at the Deaf Unit have developed a set of "skill cards" to assist patients in addressing such complex behavioral problems as aggression, paranoia, and sexual inappropriateness and to provide psychoeducation regarding mental illnesses and psychiatric medications.²

Although the Deaf Unit has not completely eliminated the use of seclusion and restraints with violent and self-harming patients, enormous efforts have been put into minimizing their use. The presence of a signing environment facilitates communication among staff and patients to de-escalate crises. When restraints are used, great attention is paid to communicating with patients and debriefing immediately with patients and staff. The frustrating and even traumatizing effects of being unable to communicate with people who don't use your language, a lifelong experience for many people who are deaf, occur infrequently in the treating environment, Glickman notes. Therefore, he says, patients who are deaf experience a higher level of emotional validation that, in turn, decreases the need for behavioral acting out.

Deafness and some mental illness or psychiatric crisis are generally the only characteristics shared by patients who otherwise show a great range of

² More information on the Westborough Deaf Unit and a CD-ROM containing the skill cards referred to above are available in Glickman and Gulati (in press).

cognitive functioning as well as racial, ethnic, and cultural diversity. For this reason, Glickman acknowledges, the Deaf Unit may not be the best treatment setting for some well-educated, high-functioning people who are deaf or those with unique cultural needs (e.g., a deaf person who is primarily Spanish speaking). "As is true for any patient," Glickman says, "deaf people must be offered a range of treatment options and be permitted to choose the treatment setting that best meets their needs."

Reducing the Use of Seclusion and Restraint Among People Who Have A Mental Illness and Are Deaf or Hard of Hearing

Principles and Values

This report recognizes the significant flaws that exist across the continuum of care in the public mental health system in providing services to people who are deaf or hard of hearing. While understanding and respecting the culture and unique needs of people who are deaf or hard of hearing is the first critical step, acknowledging and addressing system flaws is the second essential step toward reducing the use of seclusion and restraint among people who are deaf or hard of hearing.

Participants in the experts' meeting affirmed support for principles, value statements, and recommendations included in the first two Medical Directors Council Technical Reports on reducing the use of seclusion and restraints. In particular, participants emphasized the need for a culture change within psychiatric institutions to support the important values of privacy, dignity, and respect for consumers. This culture change is critical in reducing the need for emergency measures such as seclusion and restraint in the first place, offering appropriate alternatives when it appears some kind of emergency intervention is necessary, and minimizing the harm that results when these measures are used.

Participants also confirmed that seclusion and restraint are traumatizing events and risky interventions that should be used only where there is an imminent risk of danger to the individual or others and no other safe and effective intervention is possible. The use of seclusion and restraint are traumatizing for any person, but especially for people who are unable to understand what is happening and/or are unable to communicate their questions, fears, or anger. Often, people who are unable to speak may also be unable to communicate any pain or discomfort, making these dangerous interventions even more risky for people who are deaf or hard of hearing.

On November 9, 1990, a student at Gallaudet University—a prestigious university in Washington, D.C. for people who are deaf—died while being restrained by University police officers. Carl Dupree, a 41-year-old father whose wife also attended Gallaudet and whose two children attended an elementary school located on the university campus, confronted a teacher about a grade that he had received and an argument ensued. Two security officers, who did not know sign language, handcuffed Mr. DuPree behind his back, forced him to the ground, and restrained him there. With his hands behind his back, Mr. Dupree was unable to communicate in any way that he was suffocating.

Meeting participants noted that the emphasis in earlier reports on verbal communication (through spoken languages) as a driving force for culture change, de-escalation, and harm reduction is not practical, culturally appropriate, or effective in providing services to people who are deaf and poses challenges in serving people who are hard of hearing. Reliance on a

method of communication that is inaccessible will do little to reduce the use of seclusion or restraints despite the best of intentions. Instead, participants suggested, administrators, providers and others must acknowledge the importance of cultural and linguistic competency and must emphasize effective communication methods. Meeting participants identified the following core principles and values as necessary pre-conditions to reducing the use of seclusion and restraint among people who are deaf or hard of hearing.

Understanding cultural values of the deaf or hard of hearing community is essential to preventing the need for seclusion and restraints.

In many ways, the goal of reducing seclusion and restraint among people who are deaf or hard of hearing is more closely tied to principles of cultural and linguistic competency than to any other clinical practice. Failure by providers to appreciate the cultural context and linguistic preferences of consumers can lead to inappropriate diagnoses and ineffective treatment. As a result, encounters with the mental health system often are particularly negative, frustrating, and traumatizing, and can lead to reluctance by people who are deaf or hard of hearing to seek treatment following negative encounters.

- **All principles of cultural and linguistic competency are relevant to deaf populations.**

Reducing the use of seclusion and restraint for people who are deaf or hard of hearing begins with cultural and linguistic competency. However, providers must also remember that these consumers are a heterogeneous population with many other cultural influences—family structure, religion, race and ethnicity, gender, and sexual preference and orientation. Even a thorough understanding of Deaf Culture cannot replace the need for an individualized approach to treatment.

- **People who are deaf or hard of hearing should be empowered to choose the modes of communication to be used during their treatment, treatment modalities (including non-medical approaches such as psychosocial rehabilitation, peer support, and self-help services), treatment settings, and living arrangements.**

The same rights and opportunities that are recognized for hearing people who receive mental health services should also extend to people who are deaf or hard of hearing. Often, these people instead are required to communicate in ways they are not comfortable with, or in languages in which they are not fluent. For most people who are Deaf, treatment choices and modalities are limited to those provided by signing providers or those for which an interpreter is available. Living arrangements designed to provide the “most integrated setting,” as advocated by most mental health professionals, may not meet the cultural, linguistic, or social needs of Deaf consumers.

In 1991, a Deaf man with a severe mental illness was living in a group home in Charleston, SC. He was the only Deaf resident in the home, and none of the staff were fluent in American Sign Language. One

evening he became extremely agitated over a misunderstanding with another resident of the home. Being unable to effectively communicate with staff members, he initiated a violent outburst, which escalated to the point where the home had to be evacuated, leaving him alone with a knife, which he brandished in a threatening manner towards anyone who tried to intervene.

The local police were notified and, ultimately, deployed a SWAT team to intervene. Local news stations carried the incident live on the evening news, showing the man on the porch of the home, being “hosed” with water from a fire department vehicle. Police sources said that two SWAT snipers had weapons trained on him for 45 minutes, with orders to kill him should he actually touch anyone trying to intervene.

Finally, against police advice, a local interpreter who knew the man well from previous assignments approached the man. Upon recognizing her, the man sat on the veranda with her and explained what had happened and why he was so upset. He agreed to go to the local Emergency Room with the interpreter and was so calm that he rode with the interpreter in her personal vehicle. He was admitted to the local hospital and then transferred to a psychiatric hospital with a Deaf unit, where his medication was adjusted and there were no recurrences of inappropriate or dangerous behavior toward others.

Access to effective communication at all times and in all settings is an essential element of treatment for reducing seclusion and restraint.

Achieving effective communication is an ambitious but achievable goal. Of course, the goal is most easily met when mental health providers are skilled in American Sign Language and trained to detect signs of hearing loss. Access to appropriate assistive devices and staff training in using them are also critical. People who are Deaf point out that effective treatment is best accomplished in specialized treatment programs, which may be established as freestanding programs or embedded as specialty units within existing programs.³

³ Meeting participants discussed a range of models and options for system redesign in both inpatient and outpatient settings.

Without the ability for staff to communicate effectively with their patients, misunderstandings can easily escalate into situations in which the use of seclusion or restraints is deemed “necessary.” The following example, a composite of several consumer experiences reported to one state coordinator of mental health services for people who are deaf, is typical of the kind of misunderstanding commonplace for deaf patients in psychiatric hospitals.

Janice A. awoke with a start to find a psychiatric nurse shaking her bed. Other patients were routinely wakened by knocks on their door, but Janice is deaf and could not hear the knocks. Janice was the only deaf patient on the unit at that time, and the unit was not equipped with flashing alarms or other adaptive devices more commonly used in specialized units for deaf patients.

Embarrassed that the male psychiatric aide had walked into her room, uninvited, while she was in bed and partially unclothed, Janice tried to yell at him to leave. She does not have intelligible speech, however, and her utterances were interpreted as signals of aggression. The aide grabbed her arm and, as Janice struggled to get away from him, the aide called for help. Unable to quiet Janice, staff administered Ativan and the episode was attributed to Janice’s “impulsivity.”

- **Providing services to people who are deaf or hard of hearing requires a high level of specialized expertise.**

Effective providers of mental health services for people who are deaf or hard of hearing generally are fluent in American Sign Language and knowledgeable about deafness from audiological, developmental, legal, social, and cultural perspectives. Although many people can learn basic signing skills (finger spelling, for example), achieving fluency in American Sign Language and Deaf Culture sufficient to permit a provider to make diagnoses and conduct treatment is comparable to becoming competent to provide clinical services in any other language and “foreign” culture.

One meeting participant observed, only partly tongue-in-cheek, that it may be easier to teach someone fluent in American Sign Language how to be a psychiatrist than it is to teach a psychiatrist to be fluent in American Sign Language and Deaf Culture.

Equally important, effective providers—whether professional or paraprofessional—must have a solid foundation in mental health. While this may seem an obvious point, the need for mental health expertise can sometimes be forgotten in the search for qualified, Deaf staff. Compromising on the mental health training or expertise of staff can result in ineffective treatment and increased incidences of abuse, neglect, and staff and patient injuries (Guthmann, in press).

Meeting participants acknowledged that a shortage of trained and competent staff to provide services to people who are deaf and hard of hearing complicates achievement

of this goal in the immediate future. However, participants made recommendations, listed below, to maximize communication in the short term and work toward a more comprehensive approach to effective communication over time.

- **Seclusion and restraint due to miscommunication are never the “fault” of the individual.**

Despite enormous policy and clinical improvements over the last several years, the culture in many large psychiatric hospitals remains characterized by staff control over patients. People who are deaf or hard of hearing report being restrained because they did not understand staff instructions or because staff felt frustrated or threatened by the inability to communicate effectively. Although data related to the use of seclusion and restraint with people who are deaf or hard of hearing are inconclusive, there was a clear consensus among meeting participants that most uses of these interventions were the result of communication barriers, rather than unavoidable emergencies, and could be prevented if communication gaps were appropriately addressed.

It is not uncommon for staff to exacerbate the trauma of the intervention by blaming the individual or the individual’s behavior for the incident. This is particularly easy to do when misunderstandings are likely in the first place. Therefore, administrators and staff must be vigilant to avoid “blaming the victim.” Seclusion and restraint should never be used as punishment and should not be considered the “fault” of the individual, especially where more effective communication between the individual and staff might have prevented the need for the intervention in the first place.

Recommendations for Systems Change

In developing recommendations for systems change to reduce the use of seclusion and restraint for people who are deaf and hard of hearing, meeting participants quickly reached a consensus regarding the essential, core components of an ideal system of care—quality mental health services delivered in specialized settings by trained, experienced staff fluent in American Sign Language and knowledgeable about Deaf Culture and providing access to a range of specialized assistive devices and medical care. However, some participants observed that such a comprehensive system of care may not be immediately attainable. Therefore, the following recommendations were developed with the understanding that they represent only what is needed to provide *minimally competent* treatment for people who are deaf or hard of hearing and to take the first steps toward developing a more appropriate and effective system of care.

In developing a framework for these recommendations, this report relies on the public health model articulated in the first Technical Report on seclusion and restraint. Specifically, this report identifies recommendations for the following interventions: (1) primary interventions designed to prevent and reduce the need for seclusion and restraint; (2) secondary prevention designed to encourage earlier, alternative interventions; and (3) tertiary interventions designed to reduce the harm that occurs when seclusion and restraint are used.

Recommendations for primary prevention:

- **Conduct timely and thorough communication, medical, and psychological assessments at admission.**

Meeting participants agreed that comprehensive assessments within the first 24 hours after an individual is admitted to the hospital would improve treatment outcomes and reduce the need for seclusion and restraint among people who are deaf or hard of hearing.

The competency of the person conducting the assessment, however, is critical to its reliability and effectiveness. If the individual being admitted is Deaf and fluent in American Sign Language, the assessment should be administered by a person who has native-speaker fluency in American Sign Language and is knowledgeable about Deaf Culture. When admitting an individual for whom past physical or sexual trauma is suspected, the gender of the person conducting the assessment may also be critical.

Mental health facilities that do not have appropriate staff to conduct assessments for people who are deaf or hard of hearing should consider making prior arrangements with outside specialists. Facilities may contract with a range of sources to provide these services, including professionals in private practice, language specialists at schools for the Deaf, and certified Deaf interpreters (CDIs).⁴ If an appropriate mental health professional is not available to complete the assessment, meeting participants agreed that involving a qualified interpreter in the assessment is the next best alternative. If this alternative is necessary, it is essential that the interpreter has mental health experience or has been trained in the subspecialty of interpreting in a mental health setting.

If the individual being admitted prefers to communicate in English—either through the spoken word or in writing—this preference generally should be honored. However, meeting participants cautioned that the individual’s stated preference for the mode of communication is not always the most effective one. In some cases, the person may refuse an interpreter not because they actually communicate better in English but because they fear a loss of confidentiality—a legitimate concern in the small Deaf community where dual relationships are sometimes unavoidable. In addition, meeting participants observed, critical components of communication are lost in the back-and-forth of writing brief notes. If the person uses adaptive or assistive devices, they should be made available during the assessment.

⁴ A certified Deaf interpreter (CDI) is a native signer of American Sign Language who is deaf and functions as an intermediary between a deaf individual who has limited proficiency in any language and professionals who are not able to communicate with that individual. They usually are fluent in a variety of signing systems and are used in conjunction with another qualified interpreter who is hearing.

Every assessment should begin with a comprehensive communications assessment conducted by a qualified individual with communications and linguistic expertise, including:

- family communication background;
- individual's communication skills with people of various hearing and signing abilities;
- preferred language or other mode of communication; and
- individual's use of interpreters and adaptive devices (Guthmann, in press).

Assessments should include questions about the person's educational background—that is, where the person attended school, whether or not it was a specialized school for the Deaf, and how long the person attended school. In addition, assessments should try to determine the individual's skill levels on various fronts—social skills, the ability to carry out daily living skills, and the ability to maintain housing and employment. Communication deficiencies should not be interpreted as skills deficiencies (Long & Alvares, 1995).

To conduct an effective assessment, the provider should go beyond asking survey questions and engage the individual being admitted in general conversation to assess communications skills. Specifically, the provider should note such things as uses of facial expression and the individual's general comprehension in his or her preferred language.⁵ The conversation should avoid sensitive areas of discussion (Guthmann, in press).

Similarly, assessing the individual's use of interpreters and assistive devices requires more than simply asking the individual about his or her skills and experiences. The provider should ask about their perceptions of the helpfulness of various devices, for example (Ibid.).

In developing a communication assessment tool, keep in mind that the principal goals of the assessments should be to identify communication barriers and to distinguish those barriers from symptoms of mental illness. Several communication assessment tools currently are available to assist in developing an effective assessment process.⁶

In addition to a communication assessment, a medical and psychological assessment should also be conducted within 24 hours of admission. This assessment should also

⁵ However, unless the provider is fluent in the nuances of American Sign Language, he or she should take care not to over or under value affect and expression and should reserve judgment about signing style and speed.

⁶ For example, the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals has developed procedures and a template assessment tool that is available online at http://www.mncddeaf.org/articles/students_ad.htm See also Long and Alvares (1995).

be conducted by fluent signing clinicians or, at a minimum, with the assistance of a qualified interpreter and should include the following activities.

- **Screening for hearing loss.** Some people, especially those who are late-deafened or hard of hearing, may deny or not fully be aware of the severity of their hearing loss. Others, because of hallucinations or delusions, may believe that they have more extensive hearing loss than is actually the case. Providers should not rely solely on self reports.
- **Screening for medical problems.** This is critical for all admissions to psychiatric facilities, but especially for people who are deaf or hard of hearing since communication gaps may make it difficult for them to describe medical symptoms to hospital staff. Of course, the presence of other medical problems makes the use of seclusion and restraint particularly dangerous.
- **Screening for trauma, including any prior history of the use of restraints or seclusion.** As described in earlier Technical Reports in this series, people with past trauma are at high risk for re-traumatization when seclusion or restraints are used. Individuals being admitted should be carefully screened so that staff may take appropriate steps to avoid the use of these interventions and, when seclusion or restraints are deemed necessary, select interventions that will be medically safe and least traumatizing for the individual.
- **Screening for alternatives to seclusion and restraints.** Each individual is his or her own best expert in knowing which de-escalation techniques or alternatives to coercive interventions might be most effective in calming them. Sometimes these alternatives are as simple as access to space alone or a gentle touch. Individuals being admitted should be asked to help identify these calming interventions, as well as words or actions that may trigger inappropriate or threatening responses.

Whenever the providers conducting or utilizing information from medical and psychological screenings are not the same as those who conduct the communications assessment, the providers must be aware that confused or conflicting responses may well be attributable to a communication or cultural barrier, rather than a lack of cognitive abilities, a reluctance to cooperate or be truthful, or intentional non-responsiveness. It is critical that the person conducting the screenings be familiar with the “psychological and behavioral characteristics of the well-adjusted, healthy deaf person” (Brauer, Braden, Pollard, & Hardy-Braz, 1998).

Whenever interpreters are used to conduct admission screenings and assessments, they must be knowledgeable about Deaf Culture and specially trained in mental health interpreting to permit them to understand the terms used and to recognize

altered language patterns, disorganization, and other communication nuances that may indicate the presence of a mental illness.⁷

Whenever the individual being screened lacks formal language skills or uses a type of sign language not recognized by the providers or interpreters, providers must be creative to facilitate actual communication. The use of CDIs in these instances is generally recommended (See footnote 3). Other options may include showing clients pictures of certain activities, asking clients to draw pictures, or to role play (See Guthmann et al., 1999).

2. Provide information and training for people who are deaf or hard of hearing regarding their rights and responsibilities in receiving mental health services.

Most state mental health agencies have established aggressive programs to inform people—including patients in state hospitals—of their rights and responsibilities as consumers of mental health services. However, people who are deaf or hard of hearing often lack access to this information, either because it is provided only in written or spoken languages in which they are not fluent or because hospital staff mistakenly perceive their inability to communicate in English as a lack of capacity to understand their legal and other rights.

Information regarding consumers' rights should be conveyed not only through sign language but, if the individual lacks a formal language system, also through the use of CDIs or other creative methods of communication—drawing pictures or role playing, for example. All people who are deaf or hard of hearing should have access to TTY and other assistive devices to facilitate their communication with legal representatives who can advise and advocate for them regarding their rights as consumers.

3. Develop and implement plans for more aggressive and creative recruiting of staff who are culturally and linguistically competent to provide services to people who are deaf and hard of hearing.

Many state mental health agencies have developed cooperative agreements or other collaborative approaches toward working with local colleges and universities to recruit and train professional and paraprofessional staff in the mental health field. Similar arrangements can and should be developed with colleges, universities, and other programs emphasizing cultural and linguistic competence in working with

⁷ One tool to help providers determine if an interpreter is qualified to work in a mental health setting is available on-line at http://www.modmh.state.mo.us/deaf/mhirp_std.htm

people who are deaf and hard of hearing.⁸ Internships and other training programs should be promoted as part of these efforts.

Recommendations for secondary prevention:

1. If interpreters must be used, they should be specially trained to work with people needing mental health services and mental health providers.

When a conflict or potentially dangerous situation arises, clear communication between staff and patients is essential to avoiding the need for seclusion or restraints or other coercive interventions. Interpreters do not provide an adequate substitute for qualified, trained professionals skilled in American Sign Language and Deaf Culture. Inevitably, even with the most competent interpreters, important content information is “lost in the translation.” However, individuals who are deaf or hard of hearing and experts agree that, when qualified professionals are not available, interpretation is the next best thing.

Interpreters must be highly competent in English and in the communication system used by the client, whether that is American Sign Language, signed English, a combination of the two, or another system. As noted earlier, this may require the skills of two interpreters. This high level of competence is necessary in order to effectively interpret in the context of technical medical discussions and potential emergencies. We note that even certified interpreters often do not adequately perceive or translate emotion, emphasis, or other nuances that are an integral part of communication for native signers.

Many people who are deaf and hard of hearing report having been asked to interpret on behalf of other deaf or hard of hearing people in mental health settings simply because they happened to be there, even though they are not professional or trained interpreters. This practice clearly violates the privacy rights of the individual being served and places both people in an uncomfortable situation. Most important, it casts doubt on the reliability of the information being conveyed and should not be relied upon in escalating situations.

Except in the most extreme emergencies, family members should *not* be relied upon to serve as interpreters. Using family members as interpreters may intimidate the individual needing services from providing critical information that may reflect poorly on the family member. In addition, family members generally lack needed mental health training. Because family members often lack objectivity about the individual, they may also, consciously or unconsciously, modify the individual’s

⁸ One example of this type of collaboration is the Bachelor of Social Work with Emphasis on Deafness, a partnership between the Missouri Department of Mental Health and William Woods University. Information about this program is available online at http://www.williamwoods.edu/Academics_at_WWU/UndergraduateStudies/SocWkITP.htm

communications to reinforce the family member's perspective. Of course, family members may also be the source of past or current trauma experienced by some people, and using them as interpreters could mask critical information needed for assessment, diagnosis, or effective treatment.

When Collette (not her real name), a social worker with the Missouri Department of Mental Health's Office of Deaf Services, began working with Sarah, a 9-year-old girl with autism and deafness, she was immediately confronted with obstacles to communicating directly with Sarah or her mother, Mary, who was also deaf. Although Mary was fluent in American Sign Language, her hearing boyfriend, David, had learned sign language from her and participated in their meetings. David repeatedly interrupted Mary's responses, answered questions for her, and attempted to control the topics discussed. When Collette learned that David was interpreting for Mary at treatment planning meetings for Sarah, she asked Mary whether she wanted an interpreter for future meetings. David immediately responded: "I will interpret for her."

Collette later learned that David had been unemployed since he and Mary began dating. Because he was dependent on SSI benefits provided for Mary and Sarah, he had a clear conflict of interest in interpreting on their behalf. In fact, Mary wanted Sarah to attend a school for the Deaf because she felt Sarah would have better social and educational opportunities. David opposed this change, which would have resulted in a decrease in SSI income for the household. Mary was not aware of the statements David was making in interpreting for her during treatment planning and other meetings.

2. Provide ongoing training and consultation for professional and paraprofessional staff working with people who are deaf and hard of hearing.

Recognizing that it may be several years before states are able to develop a specialized workforce of professional and paraprofessional staff adequately skilled in working with people who are deaf or hard of hearing and have mental health needs, training for current staff is essential. Consumers should be directly involved in developing and implementing any training curriculum. This is particularly important when developing alternatives to seclusion and restraints. It is here that deaf and hard of hearing consumers can most effectively demonstrate their skills as communications experts.

Training should include an understanding of communication from the individual's perspective to help staff develop techniques for de-escalation and avoiding the need for seclusion and restraints. While staff should begin by reviewing the preferred approaches to calming and de-escalation identified by the individual during routine assessments at admission, some general guidelines are also applicable. For example,

staff should be aware that their emotions—frustration, anger, compassion—often are displayed as visual cues and are open to interpretation. Individuals who are deaf or hard of hearing rely heavily on interpreting these visual cues in assessing another person’s intent.

For many people who are deaf, a staff person or interpreter who is signing rapidly or with extreme emphasis may be perceived as threatening or intimidating. Also, while some people who are deaf may welcome or be calmed by an appropriate touch, this usually is not the case when the touch is a surprise (such as when the person is facing in the opposite direction).

While better training may sensitize staff to cultural and language issues, the limitations of staff training efforts must be articulated and explicitly recognized. For example, well-meaning providers of mental health services often attempt to meet the needs of people who are deaf or hard of hearing by arranging for hearing staff to attend sign language courses. Such a strategy will almost always be unsuccessful, since American Sign Language, like any other language, is complex, and fluency is difficult to achieve.

Staff who already are professionally well qualified also have ongoing training needs.⁹ A common issue of concern and professional ambiguity is related to “boundary issues.” While mental health professionals generally draw clear boundary lines that require avoiding personal relationships with patients and others with whom they have an established professional relationship, such a rigid ethical standard may be hard to maintain for deaf professionals who often co-inhabit the same small Deaf community as their patients. Some deaf professionals may opt not to participate in Deaf community activities to avoid inadvertent social interactions that may make patients feel awkward or jeopardize their privacy. However, failure to participate in the community may be interpreted as aloofness or arrogance—a sense that the professional believes that he or she is “better” than other Deaf people. In a close-knit community, this could result in suspicion and distrust, with patients and others wondering whether the deaf professional really is sympathetic to the needs of people who are Deaf.

Hearing professionals face another issue related to boundaries and acceptance. While involvement in the Deaf community may be necessary to establish legitimacy and credibility within the community and with patients, it may also be interpreted as an unwelcome attempt to “infiltrate” the Deaf community.

Recommendations for tertiary interventions:

- 1. If restraints or seclusion are necessary, implement practices that minimize both psychological harm and the potential for physical injury.**

⁹ Much of the discussion of “boundary issues” was informed by literature reviews and research conducted by Debra Guthmann. (See, esp., Guthmann, Heines, & Kolvitz, 2000; and Guthmann & Blozis, 2001.)

Any time restraints or seclusion are used with people with mental disorders, they should be applied in a way that maximizes respect and dignity and minimizes psychological and physical harm. A key component to accomplishing these goals is to emphasize clear communication between staff and the individual before, during, and after the intervention.

As noted throughout this report, effectively addressing communication barriers likely would lead to significantly reduced “need” for restraints or seclusion with people who are deaf or hard of hearing. However, when these interventions are determined to be necessary for whatever reasons, clear communication during the use of the intervention is critical and, to the maximum extent possible, disruptions to communication must be minimized. To accomplish this, the following modifications to the intervention may be necessary.

- Staff applying the intervention should be familiar with the individual’s communication assessment and be competent to explain what is happening—on an ongoing basis—in a language or manner that the individual understands.
- To the maximum extent possible and safe for the individual, staff should select or modify an intervention to permit the individual—especially Deaf individuals who communicate principally by signing—to keep their hands free. This will enable them to express not only frustration, anger, or confusion, but also to articulate if they are experiencing physical pain or distress. If it is not possible to keep both hands free, staff should consider ways to keep at least one hand free and should refer to the communications assessment to determine the individual’s preferred hand for finger spelling.
- Interventions should be implemented in a way that keeps the individual’s vision unobstructed. All people who are deaf or hard of hearing rely—to varying degrees—on sight to inform their understanding of situations. For an individual who is deaf and has no formal language, this may be his or her only method of receiving messages. Obstructing vision unnecessarily heightens fear, anxiety, and trauma related to the intervention. **The person being restrained should have a constant, unobstructed view of his or her surroundings and of a staff person communicating in sign language as the intervention is being implemented and monitored.** To the greatest extent possible, the person being restrained should be able to keep and rely on eyeglasses, contact lenses, or other aids to vision. Staff should be trained in and sensitive to the significant effect that certain drugs may have on the person’s vision and sign communication.
- Assistive devices should be checked and accommodated as the intervention is being implemented. Staff should be aware that applying physical restraints may dislodge a hearing aid, for example, and lessen the ability of an individual who is hard of hearing to receive instructions or understand what is happening. Similarly, staff should understand that background noise may

interfere with the proper functioning of assistive devices and may heighten fear, anxiety, and trauma.

Recommendations for NASMHPD and the NRI

Meeting participants recommended that NASMHPD and NRI consider several activities that would improve cultural and linguistic competence in mental health services for people who are deaf and hard of hearing and, ultimately, reduce the incidence of seclusion and restraint for this population.

1. Foster collaboration among state mental health agencies and deaf and hard of hearing communities.

Meeting participants agreed that NASMHPD is uniquely qualified to promote dialogue and cooperation among state mental health agencies and deaf and hard of hearing communities regarding access to effective mental health services.

2. Develop and disseminate information regarding best and promising practices for providing mental health services to people who are deaf and hard of hearing.

Meeting participants agreed that more information is needed regarding promising practices, especially with respect to diagnosis and treatment of mental disorders among people who are deaf and hard of hearing. Some states have developed “model” programs—especially specialized deaf units in state psychiatric hospitals and coordinators of deaf services within the state mental health agency—that could be replicated in other areas. Information regarding the costs of developing such specialized programs should also be shared.

3. Collect and report accurate data regarding people who are deaf and hard of hearing and in need of mental health treatment or are receiving treatment through the public mental health system.

Currently, data collection efforts are hampered by frequent misdiagnoses (either of the mental disorder or the hearing loss) and a lack of uniform definitions regarding what constitutes hearing loss or deafness. Accurate data regarding the numbers of people who are deaf or hard of hearing with a mental disorder, who need treatment, and who are receiving treatment are essential to assist the public mental health system in developing appropriate program strategies.

Other data that would be valuable in planning and improving systems of care include: (1) data describing the range of settings in which people who are deaf and hard of hearing receive mental health services; (2) data evaluating the effectiveness of different programs’ designs and settings; and (3) rates of seclusion and restraint for people who are deaf or hard of hearing

- 4. Consider establishing a division or council within NASMHPD specifically designed to address the needs of people who are deaf and hard of hearing on an ongoing basis.**

Meeting participants suggested that establishment of a specialized division or council within NASMHPD would encourage greater understanding of cultural and linguistic issues and would facilitate the dissemination of research findings and promising practices regarding the delivery of mental health services to people who are deaf or hard of hearing.

Conclusion

This third report in a series of Technical Reports on Reducing the Use of Seclusion and Restraint builds on the previous two and advances the series goal by examining issues raised by persons who are deaf and hard of hearing. The first report identified effective communication as an essential driving force for: (1) achieving cultural change to reduce the power imbalance between individuals receiving services and staff; (2) encouraging earlier, alternative interventions and de-escalation techniques to minimize the need for coercive interventions; and (3) reducing the physical and psychological harm that results when seclusion and restraint are deemed necessary.

The second report identified unique needs of and strategies for five special populations: children and adolescents; older persons; persons with co-occurring mental illness and developmental disability and/or mental retardation; persons with co-occurring mental illness and substance abuse; and persons served in forensic settings. In doing so, it also demonstrated that each population taught valuable broader lessons, including the following: (1) the need to focus on physical and cognitive development; (2) the importance of complex medical, psychological and physical conditions; (3) the importance of considering behavior as communication; (4) the need to assess the capacity for self control; and (5) the need to consider issues of public safety.

The theme of behavior as communication raised in the second report opened the door to a re-examination of the overall reliance on verbal communication suggested by both earlier reports. Such reliance is clearly not culturally appropriate or effective in reducing the use of seclusion and restraint among persons who are deaf and hard of hearing.

This third Technical Report particularly emphasizes that effective communication for persons who are deaf and hard of hearing requires an in-depth understanding of complex cultural and linguistic issues, specific provider expertise, and an investment in critical resources, such as medical and assistive devices. Ideally, providers of services will be fluent in American Sign Language and knowledgeable about cultural issues important to people who are deaf and hard of hearing. Where necessary, they must be flexible, creative, and willing to employ a range of techniques in order to communicate effectively with individuals who may have limited skills in any language. Communication and efforts to reduce the use of seclusion and restraint generally are most effective in specialized programs designed specifically for people who are deaf or hard of hearing.

In a broader sense, this report emphasizes that achieving the goal of reducing the use of seclusion and restraint will require particular expertise in effective communication at all levels—from systems of care to agencies, providers, and individuals seeking and offering help—based on a clear understanding of the cultural, linguistic and communication needs of every individual served in public mental health.

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Relevant Web Sites

Gallaudet University: <http://gri.gallaudet.edu>

Deaf Wellness Center at the University of Rochester School of Medicine, Department of Psychiatry:
www.urmc.rochester.edu/smd/psych/Education/psychology/predoc/psycho_deaf.htm

Missouri Department of Mental Health Office of Deaf and Linguistic Support Services:
<http://www.modmh.state.mo.us/deaf>

National Association of State Mental Health Program Directors: www.nasmhpd.org

Resources for Improving Health Care to Deaf and Hard of Hearing People (a project of the Centers for Medicare and Medicaid Services (CMS), Gallaudet University, and Delmarva Foundation for Medical Care: <http://www.deafhoh-health.org>

The Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals:
www.mncddeaf.org

Appendices

Appendix A: NASMHPD Position Statement on Seclusion and Restraint

Appendix B: NASMHPD Position Statement on Culturally Competent and Linguistically Appropriate Mental Health Services

**Appendix C: Third Technical Report Meeting on Seclusion and Restraint
Special Focus: Persons Who are Deaf or Hard of Hearing
Participants List**

Appendix A: NASMHPD Position Statement on Seclusion and Restraint

National Association of State Mental Health Program Directors

POSITION STATEMENT ON SECLUSION AND RESTRAINT

The members of the National Association of State Mental Health Program Directors (NASMHPD) believe that seclusion and restraint, including “chemical restraints,” are safety interventions of last resort and are not treatment interventions. Seclusion and restraint should never be used for the purposes of discipline, coercion, or staff convenience, or as a replacement for adequate levels of staff or active treatment.

The use of seclusion and restraint creates significant risks for people with psychiatric disabilities. These risks include serious injury or death, re-traumatization of people who have a history of trauma, and loss of dignity and other psychological harm. In light of these potential serious consequences, seclusion and restraint should be used only when there exists an imminent risk of danger to the individual or others and no other safe and effective intervention is possible.

It is NASMHPD’s goal to prevent, reduce, and ultimately eliminate the use of seclusion and restraint and to ensure that, when such interventions are necessary, they are administered in as safe and humane a manner as possible by appropriately trained personnel. This goal can best be achieved by: (1) early identification and assessment of individuals who may be at risk of receiving these interventions; (2) high quality, active treatment programs (including, for example, peer-delivered services) operated by trained and competent staff who effectively employ individualized alternative strategies to prevent and defuse escalating situations; (3) policies and procedures that clearly state that seclusion and restraint will be used only as emergency safety measures; and (4) effective quality assurance programs to ensure this goal is met and to provide a methodology for continuous quality improvement. These approaches help to maintain an environment and culture of caring that will minimize the need for the use of seclusion and restraint.

In the event that the use of seclusion or restraint becomes necessary, the following standards should apply to each episode:

- The dignity, privacy, and safety of individuals who are restrained or secluded should be preserved to the greatest extent possible at all times during the use of these interventions.
 - Seclusion and restraint should be initiated only in those individual situations in which an emergency safety need is identified, and these interventions should be implemented only by competent, trained staff.
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- As part of the intake and ongoing assessment process, staff should assess whether or not an individual has a history of being sexually, physically or emotionally abused or has experienced other trauma, including trauma related to seclusion and restraint or other prior psychiatric treatment. Staff should discuss with each individual strategies to reduce agitation that might lead to the use of seclusion and restraint. Discussion could include what kind of treatment or intervention would be most helpful and least traumatic for the individual.
- Only licensed practitioners who are specially trained and qualified to assess and monitor the individual's safety and the significant medical and behavioral risks inherent in the use of seclusion and restraint should order these interventions.
- The least restrictive seclusion and restraint method that is safe and effective should be administered.
- Individuals placed in seclusion or restraints should be communicated with verbally and monitored at frequent, appropriate intervals consistent with principles of quality care.
- All seclusion and restraint orders should be limited to a specific period of time. However, these interventions usually should be ended as soon as it becomes safe to do so, even if the time-limited order has not expired.
- Individuals who have been secluded or restrained and staff who have participated in these interventions usually should participate in debriefings following each episode in order to review the experience and to plan for earlier, alternative interventions.

States should have a mechanism to report deaths and serious injuries related to seclusion and restraint, to ensure that these incidents are investigated, and to track patterns of seclusion and restraint use. NASMHPD also encourages facilities to conduct the following internal reviews: (1) quality assurance reviews to identify trends in seclusion and restraint use within the facility, improve the quality of care and patient outcomes, and help reduce the use of seclusion and restraint; (2) clinical reviews of individual cases where there is a high rate of use of these interventions; and (3) extensive root cause analyses in the event of a death or serious injury related to seclusion and restraint. To encourage frank and complete assessments and to ensure the individual's confidentiality, these internal reviews should be protected from disclosure.

NASMHPD is committed to achieving its goals of safely preventing, reducing, and ultimately eliminating the use of seclusion and restraint by: (1) encouraging the development of policies and facility guidelines on the use of seclusion and restraint; (2) continuing to involve consumers, families, treatment professionals, facility staff, and advocacy groups in collaborative efforts; (3) supporting technical assistance, staff training, and consumer/peer-delivered training and involvement to effectively improve and/or implement policies and guidelines; (4) promoting and facilitating research regarding seclusion and restraint; and (5)

identifying and disseminating information on “best practices” and model programs. In addition, NASMHPD supports further review and clarification of developmental considerations (for example, youthful and aging populations) that may impact clinical and policy issues related to these interventions.

Approved by the NASMHPD membership on July 13, 1999.

**Appendix B: NASMHPD Position Statement on Culturally Competent
and Linguistically Appropriate Mental Health Services**

National Association of State Mental Health Program Directors

**POSITION STATEMENT ON CULTURALLY COMPETENT
AND LINGUISTICALLY APPROPRIATE
MENTAL HEALTH SERVICES**

The National Association of State Mental Health Program Directors (NASMHPD) recognizes that state mental health agencies face a growing challenge to accommodate an increasingly diverse constituency for mental health services nationwide. The provision of culturally and linguistically appropriate and accessible mental health services regardless of race, gender, age, disability, sexual orientation, national origin, language, religion or socioeconomic status challenges state mental health agencies to develop, expand, and evaluate effective, culturally competent services and treatment methods.¹⁰

As the U.S. population changes dramatically, so does the mental health system consumer base. Public mental health systems and staff may be unprepared for differences in language, cultural perspective, traditions, perceptions about mental illness and preferences for services and supports. For example, more than 1 in 4 Americans are non-white and/or Latino, but by the year 2050, the U.S. Census Bureau projects that nearly 1 in 2 Americans will be so. New and changing cultural perspectives, emerging cultural groups, and the growing realization that cultural identity contributes in essential ways to mental well being require new attention to the need for culturally appropriate mental health services.

Members of ethnic, racial, linguistic, and culturally diverse groups are often underserved or inappropriately served by the public mental health system. Culturally competent and appropriate services can: reduce inappropriate diagnoses; increase the utilization of mental health services by population groups that traditionally underutilize services; and change perceived negative encounters that are often experienced by population groups that seek treatment from systems that often do not provide culturally sensitive and competent services. It is, therefore, in the best interest of both mental health consumers and the public mental health system that serves them, that culturally competent services be consistently available, accessible and effective.

In recognition of this fact, NASMHPD supports states in their ongoing efforts to become more culturally competent in the provision of mental health services to ethnic, racial,

¹⁰ While definitions for cultural competency abound, for the purposes of this position statement, NASMHPD members embrace the values and goals expressed in the following amalgam of existing definitions. Culturally competent services incorporate understanding of racial and ethnic groups, their histories, traditions, beliefs and value systems (U.S. Surgeon General's Report on Mental Health, 1999). Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals, and that enables them to work effectively in cross-cultural situations (Cross et al., 1998). Cultural competency is also the integration and transformation of knowledge, information and data about individuals and groups of people into specific clinical standards, skills, service approaches, techniques and marketing programs that match the individual's culture and increase the quality and appropriateness of health care and outcomes (Davis, 1997).

linguistic, and culturally diverse populations. Services to these individuals should be based on concepts, policies, and procedures that provide a voice and choice; they should be flexible, individualized, and promote respect, dignity, and recovery. NASMHPD fully supports States' efforts to recruit and retain mental health professionals and paraprofessionals who can both represent these groups and understand their mental health needs and deliver the most effective methods of successfully responding to them.

NASMHPD is committed to working with states, representatives of culturally diverse communities and all care providers to explore ways to improve services and supports for these mental health consumers and their families. These efforts may include, but are not limited to: developing and disseminating information and technical assistance on best practices in culturally competent services; providing forums for state and national dialogues on the need for and effective provision of culturally competent mental health services; and cooperating with other State and national organizations to develop research, education, training and performance-based initiatives to ensure the provision of culturally competent mental health services.

Approved by the NASMHPD membership on June 6, 2000.

**Appendix C: Third Technical Report Meeting on Seclusion and Restraint
Special Focus: Persons Who are Deaf or Hard of Hearing
Participants List**

(See separate online .pdf file)
