National Association of
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TRAUMA IN THE DEAF POPULATION:

DEFINITION, EXPERIENCE, AND SERVICES

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PREFACE

Trauma experiences in the Deaf population are far too common, the personal and societal consequences are enormous, and the problem is increasing. The Center for Mental Health Services (CMHS), within the Substance Abuse and Mental Health Services Administration (SAMHSA) commissioned this report to gain a clear understanding of what information exists on trauma in the Deaf population and its ability to access trauma treatment services. This information will help inform policy makers and stakeholders about trauma in Deaf communities and how to address service gaps in the behavioral health system of care.

This report is not intended to be an exhaustive research review or an extensive discussion on cultural mores and issues within the Deaf population. Rather, it is a sampling of the collective knowledge within this area to provide individuals in the process of transforming systems of care with a resource for action. The findings in this report show that trauma must be addressed on research, policy, treatment, and public education levels to help Deaf individuals who have experienced trauma to recover.

This publication is intended to shine a light on an alarming issue and to encourage system transformation to address this issue. Towards this end, it provides background and recommendations on collaborative action from the Deaf population and the public behavioral health system of care to address the needs of Deaf individuals with trauma backgrounds.

EXECUTIVE SUMMARY

This paper consists of three main sections – background, key consumer and professional interview findings, and recommendations. The main theme expressed throughout these sections is that today's behavioral health system both public and private rarely meets the trauma treatment and/or behavioral health needs of Deaf individuals. There are a myriad of factors that contribute to this theme, including insufficient research and training on how trauma affects Deaf individuals, lack of available evidence-based trauma treatments, and lack of a culturally and linguistically accessible workforce.

In the background section, definitions are provided for hearing loss, language dysfluency, trauma, and trauma-informed care. Prevalence data on hearing loss and trauma is presented. Further, a brief overview of resources on Deaf culture is provided and some of the major issues in behavioral health and Deaf culture are discussed.

In the key consumer and professional findings, the report details expert findings based on the experiences and observations of Deaf consumer and professional key informants in Deaf-related fields. Key professionals noted barriers across all system and service areas, as well as noted significant gaps in research and knowledge. The findings from the key consumer informant interviews encompassed four main themes:

- Communication barriers are a significant impediment to trauma recovery.
- Misunderstandings of cultural differences can lead to misdiagnosis.
- Trauma is often experienced as a result of communication barriers and vulnerabilities.
- There is a lack of awareness of the concept of trauma, trauma symptoms, and resources, if available.

Finally, recommendations are based on the literature review and key informant interviews. They are targeted towards researchers, policy makers, stakeholders, and the Deaf community. These recommendations are intended to assist these target audiences in taking collaborative action to provide a culturally and linguistically accessible system of care to serve the needs of Deaf individuals who have trauma backgrounds.

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INTRODUCTION

It was a shock to find out that all of my Deaf female friends had experienced some kind of sexual molestation, every single one of us.

— *Key consumer informant female*

> *Deaf children are more than twice as likely to experience physical and sexual abuse compared to their hearing peers.*

There were a surprisingly high percentage of Deaf individuals with trauma experiences. In my research, I needed a comparison group of Deaf individuals with no history of trauma. I had great difficulty finding any.

— *Key professional informant male*

Deaf individuals experience trauma at unacceptably high levels, the personal and societal consequences are enormous, and the barriers to trauma treatment for the Deaf Community must be ameliorated to foster a safer, healthier, more equitable society.

Deaf individuals are disproportionately victims of trauma. Deaf children are more than twice as likely to experience physical and sexual abuse compared to their hearing peers (Sullivan, 1987). Deaf female undergraduates experience physical assault, psychological aggression, or sexual coercion at *twice* the rate of hearing female undergraduates (Anderson, 2010).

Providing appropriate care presents challenges for the professional care providers and for the Deaf individuals who experience trauma. Because of these challenges, it is possible that as few as 2% of Deaf individuals needing support for any behavioral health issue receive appropriate care (Vernon, 1983). As a result, we need specific, well-justified recommendations for local, state, and federal systems as well as Deaf consumers that lay a

foundation for providing timely access to appropriate trauma-informed care for Deaf individuals.

> *...as few as 2% of Deaf individuals needing support for any behavioral health issue receive appropriate care.*

Historically, Deaf consumers have had limited input on trauma policy and practice issues. However, extensive Deaf consumer input is necessary to ensure their needs and concerns are being addressed. Similarly, the needs and concerns of the professionals who provide care for the Deaf individual following trauma must also be taken into account. Therefore, this report incorporates key insights from structured interviews of both consumer and professional informants when making specific recommendations, all towards the goal of a fully accessible behavioral health community for Deaf individuals with experiences of trauma.

This report is arranged in four sections. Section I provides background regarding hearing loss and trauma. Section II delineates barriers to care, from the perspective of the Deaf consumer and from the perspective of the professional service provider. Recommendations follow in Section III. The appendices in Section IV detail the interview methodology and provide resources to assist the reader in finding additional information on Trauma and the Deaf population.

SECTION I: BACKGROUND

To lay the foundation for understanding trauma in the Deaf population, this section provides background on the key concepts of hearing loss and Deaf culture; language dysfluency; the prevalence and characteristics of trauma in the Deaf population; and common misperceptions regarding the Deaf population and behavioral health treatment. Additionally, major issues in behavioral health and Deaf culture are discussed throughout to provide appropriate context to fully appreciate the experiences of trauma and system barriers described in Section II and the recommendation offered in Sections III. The following section begins with the conceptualizations and prevalence of hearing loss.

HEARING LOSS AND DEAF CULTURE

The three major conceptualizations of hearing loss are medical, functional, and cultural. The type of definition used by the consumer, the direct care professional, or the service organization can shape the behavioral health care surrounding the Deaf individual. It is important to distinguish between Deaf and 'hearing impaired', to determine eligibility for disability benefits, and to define Deaf Culture.

1. Medical – The term 'hearing-impaired' covers the broad spectrum of any individual with a less-than-average hearing level. The term 'deaf' describes those who are unable to benefit from a hearing aid due to the severity of their hearing loss. While the term 'hearing-impaired' is appropriate for use within the medical community, some Deaf individuals may consider the term inappropriate for general use because impairment may imply a physical deficit rather than a cultural difference.

2. Functional – The US government defines hearing loss in terms of eligibility for disability benefits based on the ability to function within society. Section 504 of the Rehabilitation Act of 1973 is a national law that protects qualified individuals from

discrimination based on their disability. The following definition is taken directly from the Act:

Individuals with disabilities are defined as persons with a physical or mental impairment that substantially limits one or more major life activities. People who have a history of, or who are regarded as having a physical or mental impairment that substantially limits one or more major life activities, are also covered. Major life activities include caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning[1].

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

3. Cultural – In the Deaf community, there is a distinction between *deaf* and *Deaf* (Padden, 1988)*.* Lowercase deaf is more indicative of the medical condition and indicates individuals who are not associated with the Deaf community. The Deaf community (using uppercase 'D') is comprised specifically of those who identify themselves with Deaf culture, which was formed around the use of American Sign Language (ASL) as the primary means of communication. Individuals who self-identify with Deaf culture are referred to as Deaf (The American Heritage® Dictionary of the English Language, 2009). There are deaf individuals who use ASL but do not self-identify with the Deaf community, as well as individuals who self-identify with the Deaf community but either do not use ASL or have no hearing loss.

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[1] http://www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf (Retrieved July 20, 2010)

The National Center for Health Statistics reported that approximately 37 million adults in the United States have trouble hearing.

The National Center for Health Statistics reported that approximately 37 million adults in the United States have trouble hearing (Schoenborn, 2008). Of those 37 million adults aged 18 or older, 3.3% were Deaf or had significant difficulty understanding speech. The National Institute on Deafness and Other Communication Disorders website statistics show that two to three out of every 1,000 children are born Deaf or hard of hearing[2].

It is important to recognize the importance of including all members of populations with hearing loss including those with mild hearing loss, Deaf-blind individuals, and aging adults with late-life hearing loss. This paper highlights Deaf individuals with the greatest difficulty locating and utilizing public behavioral health services due to linguistic and cultural barriers. Generally, this population includes those who use ASL as their primary language and self-identify with the Deaf culture as a minority culture in the United States[3].

LANGUAGE FLUENCY AND DYSFLUENCY

Language dysfluency is the inability to communicate fluently in any language (Glickman, 2008).

Deaf individuals may communicate fluently in a variety of ways. Some use lip-reading and speech, while others use manual communication, such as ASL, Cued Speech, Pidgin Signed English, Signed English, and Signing Exact English (SEE), while still others use a mixture of

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[2] http://www.nidcd.nih.gov/health/statistics/quick.htm (Retrieved July 20, 2010)

[3] In this report, all individuals with hearing loss are referred to as Deaf (with a big 'D'), from the Deaf community, and part of Deaf culture. This is stated with the understanding that there are individuals that do not identify as Deaf, but will benefit from the findings and recommendations of this paper.

verbal and manual communication. However, even fluent communication skills using ASL may not always be understood by the hearing community.

They took away my kids because I am Deaf. I am so frustrated I could scream. I ache to hold them again. There are no interpreters to tell social services that I am a good mother. They think my children are language delayed because they sign instead of speaking.

> *"They took away my kids because I am Deaf. I am so frustrated I could scream. I ache to hold them again."*

—   *Key consumer informant female*

Some Deaf individuals are dysfluent because they never learned language.

My son received a cochlear implant at age 6. The cochlear implant team told me to stop signing with him and force him to speak English. That was two years ago. He has not learned any English since receiving his implant and I have started to sign with him again. His behaviors are getting out of control and I do not know what to do with him. He is angry and frustrated and refuses to behave in school. He is not learning anything and functions like a 3 year old. However, he is intelligent! He just does not have any language.

—   *Key consumer informant male*

Language dysfluency etiologies fall into three general categories: 1) Physical causes, 2) Mental illness, and 3) Language deprivation. The first two categories of language dysfluency, physical causes and mental illness, are seen in both hearing and Deaf individuals. The third category, language deprivation, is seen almost exclusively in individuals with hearing loss (Gulati, 2003).

Physical causes encompass a range of etiologies that either: 1) prevent the individual from learning language as a child or 2) cause deterioration or sudden loss of acquired language. Etiologies that prevent or slow language acquisition due to organic causes include birth defects, developmental delays, prematurity, and syndromes (i.e. Usher Syndrome, Fetal

Alcohol Syndrome, etc.). Etiologies that cause loss of acquired language (both spoken and visual) range from strokes and tumors to traumatic brain injuries.

75% of Deaf individuals receiving services in a psychiatric hospital have some level of language dysfluency...

Mental illness can cause language dysfluency in both hearing and Deaf individuals. Certain forms of mental illness, such as schizophrenia, mania, and dementia, cause specific language dysfluency symptoms, including disorganized thinking, inability to put thoughts together, inability to use abstract concepts, and difficulty with cause and effect terms. These symptoms occur after an individual has acquired language, with the fluency loss due to the progression of the mental illness. The prevalence of adults with serious mental illnesses (SMI) and children with serious emotional disturbances (SED) is 3 to 5 times greater in the Deaf population than in the hearing population (Hamerdinger and Murphy, 2000). In addition, research suggests that approximately 75% of Deaf individuals receiving services in a psychiatric hospital have some level of language dysfluency (Black, 2005), while State administrators suggest that the dysfluency percentage is likely greater among Deaf individuals with serious mental illness in the public behavioral health system (Hamerdinger, 2010). Research is needed to determine the exact prevalence as well as the causes and co-occurrence of language dysfluency and serious mental illness.

Language deprivation can cause language dysfluency. Language deprivation is the failure to develop fluency in any language and refers to individuals who have poor or no language skills in American Sign Language, spoken English, or any other language. This phenomenon is caused by lack of sufficient exposure to language and thus the individual does not acquire language at the expected rate and developmental levels. This cause is rarely seen in hearing individuals, as it is extremely difficult to deprive a hearing child of spoken language without total social isolation.

Deafness *per se* does not cause language deprivation. Deaf children with normal cognitive abilities who are exposed to an accessible language from birth by parents with fluent/native signing skills do not demonstrate language deprivation. Rather, language deprivation is potentially caused when a Deaf child is unable to access environmental communication, either spoken or manual. A significant warning sign is when a Deaf child of normal intelligence is not at the same developmental stage of language as hearing peers, regardless of what language is being taught. Failure to recognize and rectify this warning sign can be a serious sign of systemic neglect (Gulati, 2003).

Language deprivation has serious consequences. Sanjay Gulati, a Deaf physician states in his book, the *Mental Health Care of Deaf People: A Culturally Affirmative Approach* (2003):

Those with first exposure to usable language *after* very early childhood develop permanent cognitive damage and permanent language deficits. Almost all emotional and social development and almost all vocational and academic success depend on language (Chapter 2, Section 2, Language Deprivation).

As Dr. Gulati suggests above, emotional and social development depends on the acquisition of language. Deaf individuals with language deprivation may not develop the emotional and social skills that either prevent traumatic experiences or increase resiliency during trauma recovery.

Language dysfluency likely leads to increased vulnerability to trauma. Individuals that have difficulty utilizing language are likely to become easy targets for perpetrators of sexual abuse (National Child Traumatic Stress Network, 2006).

These individuals may be perceived as being unable to communicate their experiences to others. In addition, the potential lack of social interaction noted above may create a deficit in understanding of unacceptable behaviors. Further, language dysfluent individuals may

> *"Language dysfluent Deaf individuals do not have enough of a language base to utilize public education efforts related to trauma symptoms and services."*

desire closer inappropriate intimacy with other individuals as a maladaptive method to fulfill their social and emotional needs (Critchfield, 1983). Among caregivers, the frustrations of providing care to language dysfluent children and adults may lead to abuse or neglect (Ammerman, Van Hasselt, & Hersen, 1988). For these reasons, the communication isolation from language dysfluency makes this population vulnerable to disproportionately high rates of experiencing trauma.

The language dysfluent population generally does not utilize behavioral health services after experiencing trauma mainly because they are unaware that they have experienced trauma or that services even exist. They often do not have a schema or map for understanding the concept of trauma counseling, and they do not have the linguistic tools to understand the processes involved. Trauma treatment is primarily language-based and the concepts utilized, tend to be too abstract for this population to understand (i.e. the concept of 'flashback' or the concept of cause and effect).

Language dysfluent Deaf individuals do not have enough of a language base to utilize public education efforts related to trauma symptoms and services. This hampers the education of language dysfluent Deaf individuals regarding recognizing trauma and its resulting symptoms.

– *Key professional informant male*

With the language dysfunctional population, there is no ability to describe their trauma experiences. They do not reference time/tense and place/object in conversation.

This makes it extremely difficult to describe whom, when, and where any abuse may have happened through the linguistic confusion. It is hard to know exactly what they mean.

– *Key professional informant male*

PREVALENCE AND CHARACTERISTICS OF TRAUMA IN THE DEAF POPULATION AND THE IMPORTANCE OF TRAUMA-INFORMED CARE

It is critical to examine trauma in the Deaf community. Preliminary data show that trauma is significantly higher in the Deaf population than in hearing populations. Little is known about how trauma is experienced or defined by the Deaf community.

Within the hearing community, there is no single definition of trauma. For the purpose of this paper, we will use the consumer-informed definitions provided by The National Center on Trauma Informed Care (NCTIC) and The National Association of State Mental Health Program Directors (NASMHPD).

NCTIC stresses that the trauma experience results from both the traumatic event *and* how the individual experiences that event. NCTIC modified its operating definition of trauma in 2009 to reflect the developing knowledge in the field and the expertise of consumers/survivors:

"Traumatic experiences can be dehumanizing shocking or terrifying, singular or multiple compounding events over time and often include betrayal of a trusted person or institution, and a loss of safety.

Trauma can result from experiences of violence. Trauma includes physical, sexual, and institutional abuse, neglect, intergenerational trauma, and disasters that induce powerlessness, fear, recurrent hopelessness, and a constant state of alert.

Trauma impacts ones spirituality and relationships with self, others, communities and environment, often resulting in recurring feelings of shame, guilt, rage, isolation and disconnection. Healing is possible[4]."

This definition was developed through national meetings where consumers, survivors, state administrators, medical directors, advocates, and hospital administrators came together for two days to describe trauma-informed practice.

In addition, the following premises were taken from The Damaging Consequences of Violence and Trauma (National Association of State Mental Health Program Directors, 2004; NASMHPD):

- The experience of trauma can be extremely damaging and often has enormous costs.
- Unresolved, untreated trauma is central to the development of multiple, severe, and persistent health and mental health problems, substance abuse, criminal behavior, and social problems in our society, and should therefore be a key consideration for policy making in each of these fields.
- Addressing trauma must be central and pivotal to public health and human service policy making including fiscal and regulatory decisions, service systems design and implementation, workforce development, and professional practice. Unless trauma is addressed, the damage to individuals and to society will continue.

Deaf consumer input was not included in these definitions. It is important to recognize that Deaf consumers may have valuable contributions to update the definitions to include their

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[4] From http://mentalhealth.samhsa.gov/nctic/ (Retrieved, July 20, 2010).

unique experiences with trauma. These updated definitions may increase the visibility of the Deaf community and assist in development of appropriate policy and system changes.

TRAUMA-INFORMED CARE WITH THE DEAF POPULATION

As with all hearing individuals seeking trauma-care services, Deaf individuals deserve trauma-informed care. Trauma-informed care shifts the fundamental premise of treatment of individuals with trauma experiences from a disease/symptom focus to an individual's self-determined focus. The

> *A system of care that does not implement culturally and linguistically accessible services for Deaf individuals cannot inherently be trauma-informed for this community.*

following is from the Center for Mental Health Services' (CMHS) National Center for Trauma Informed Care (NCTIC) website[5]:

When a human service program takes the step to become trauma-informed, every part of its organization, management, and service delivery system is assessed and potentially modified to include a basic understanding of how trauma impacts the life of an individual seeking services. Trauma-informed organizations, programs, and services are based on an understanding of the vulnerabilities or triggers of trauma survivors that traditional service delivery approaches may exacerbate, so that these services and programs can be more supportive and avoid re-traumatization.

A system of care that does not implement culturally and linguistically accessible services for Deaf individuals cannot inherently be trauma-informed for this community. The experience of trauma in Deaf individuals is compounded by the lack of culturally and linguistically accessible services that can trigger and exacerbate vulnerabilities caused by the multiple communication barriers encountered across the person's lifespan.

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[5] http://mentalhealth.samhsa.gov/nctic/trauma.asp (Retrieved July 20, 2010)

> *"It was a shock to find out that all of my Deaf female friends had experienced some kind of sexual molestation, every single one of us."*

Deaf individuals experience trauma at higher rates than hearing individuals. Interpersonal trauma[6] exposure is higher and more severe in Deaf individuals (Sullivan, 1987; Sullivan, 2000). In a comparison of Deaf and hearing female undergraduate students, Anderson and Leigh (2010) found that Deaf females were twice as likely to have experienced physical assault, psychological aggression, or sexual coercion in the past year when compared to their hearing counterparts. Schild and Dalenberg (Schild, 2010) found that in a sample of 79 Deaf individuals, 20.6 percent of men and 37.8 percent of women reported a history of sexual assault, and 38.2 percent of men and 42.2 percent of women reported "other unwanted sexual experiences." Physical assault was reported in 73.5% of men and 71.1% of women.

The rates of trauma are equally high among Deaf children. A 1991 survey of behavioral health therapists for Deaf individuals found that 69% of their clients reported some form of childhood abuse or maltreatment (Skinner, 1991). Among Deaf children, 50-54% have experienced sexual abuse compared to 10 to 25% of hearing children (Sullivan, 1987).

Among inpatients at the Westborough State Hospital Deaf Unit in Maine, 51% of Deaf patients had a known history of trauma, and abuse history was unknown or suspected in an additional third of the patients (Black, 2006).

While there are still gaps in the knowledge on the prevalence of trauma in Deaf communities, it is clear from the preliminary research that trauma is a significant issue and

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[6] Examples of interpersonal trauma include sexual violence, child abuse, domestic abuse, elder abuse, institutional abuse, and abuse by professionals.

that a large percentage of Deaf individuals have experienced trauma and the resulting symptomatology that accompanies it. The next section details the little we do know on the manifestation of trauma symptoms in Deaf individuals.

CHARACTERISTICS OF TRAUMA IN THE DEAF POPULATION

There is scant research on the risks of trauma and resulting symptoms in the Deaf community. Towards this end, the National Center for Injury Prevention and Control, a branch of the Centers for Disease Control and Prevention (CDC), has awarded the Deaf Wellness Center (DWC) at the University of Rochester School of Medicine a 3-year grant entitled "Factors Influencing Partner Violence Perpetration Affecting Deaf Individuals." This large-scale research project will investigate and describe risks and protective factors associated with interpersonal violence in the Deaf community across the country.

Smaller localized studies have begun to examine the manifestation of trauma symptoms in various subgroups of the Deaf community and preliminary unpublished results are available. In general, Deaf individuals are likely to experience the full range of trauma symptoms and high-risk coping mechanisms that hearing individuals do (Schild, 2010). These symptoms and high-risk coping mechanisms include (but are not limited to) depression, anger, anxiety, Posttraumatic Stress Disorder, and substance abuse. There are some preliminary indications of how trauma symptoms in Deaf individuals may differ from those in hearing individuals arising either from cultural communication differences or from the experiences of living as a minority in a majority culture.[7]

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[7] There is a great deal of heterogeneity in the Deaf population, especially surrounding linguistic choices. This report continues to focus on the segment of the Deaf population that has the greatest challenges utilizing public mental health services, namely those individuals that do not utilize hearing or speech for communication, instead using some form of manual communication, generally American Sign Language.

In a report from a private practitioner, Deaf patients with trauma experiences are more likely to show visual hallucinations and dissociation[8] (Gulati, 2003). In a recent study in California, Deaf individuals also reported significantly more symptoms of dissociation than hearing people reported (Schild, 2010).

Schild suggests that in addition to different types of trauma symptoms, some Deaf individuals may experience a unique type of trauma altogether. The following information is pulled from his dissertation (Schild, 2007) and elaborated on in his article *Trauma Exposure and Trauma Symptoms in Deaf Adults* (Schild, 2010):

Information Deprivation Trauma or IDT is defined here as an event that is experienced as traumatic or more traumatic because information or knowledge about the event is limited or not available. The lack of information increases factors that have been found in the trauma literature related to traumatization, such as suddenness, unpredictability, and uncontrollability.

According to Schild, IDT may occur for a number of reasons: families trying to protect Deaf individuals, lack of access to communication to find out about well-being of loved ones in disasters, or lack of foreknowledge of significant events (such as hurricanes and earthquakes). He notes that these types of information deprivation experiences create a strong reaction in the affected individual and heighten the traumatic response.

While it is important to understand the characteristics of trauma in the Deaf population, it is equally important to understand the common behavioral health treatment misunderstandings that can negatively affect Deaf victims of trauma.

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[8] Dissociation is the disruption of consciousness or psychological functioning. In this case, dissociation occurs in response to a trauma.

COMMON MISUNDERSTANDINGS: DEAF CULTURE AND BEHAVIORAL HEALTH TREATMENT

Deaf culture is often misunderstood. In his chapter "Culturally Affirmative Mental Health Treatment for Deaf People," Neil Glickman (2003) describes common misunderstandings that the typical Deaf individual experiences at the hands of the majority hearing culture, including:

- Drawing erroneous conclusions from inappropriate psychological testing;
- Inappropriately diagnosing Deaf individuals with developmental disabilities, autism, or schizophrenia and allowing them to languish in institutions;
- Believing that Deaf people are disabled not just in being unable to hear, but intellectually, emotionally, and morally;
- Promoting the idea of the 'psychology of deafness', that Deaf people are unintelligent, egocentric, concrete, irresponsible, impulsive, immature, or paranoid;
- Exclusion of the Deaf community from decision-making on key matters, such as educational policies and medical procedures that pertain to Deaf people.

For these reasons, the Deaf population faces challenges in navigating the behavioral health system under any circumstance, including when dealing with trauma. In addition, Dr. Glickman emphasized that the absolute core of negative experience for Deaf people is communication isolation. Communication isolation has important consequences, particularly when a Deaf person is the victim of trauma.

Communication isolation is a significant impediment to trauma recovery. There can be profound frustrations when encountering communication barriers at every point in service access for trauma-informed care needs. These frustrations can lead to maladaptive behaviors that compound the recovery from trauma.

Suggested readings on Deaf culture are presented in Appendix E: Deaf Culture Literature.

SUMMARY OF SECTION I: BACKGROUND

Section I provided a foundation for understanding hearing loss and Deaf culture, language fluency and dysfluency, the characteristics and prevalence of trauma in the Deaf community, and common misunderstandings regarding Deaf culture and behavioral health treatment. However, to fully appreciate the impact and limitations of service providers in assisting Deaf individuals following trauma, it is important to delineate the first-hand experiences of Deaf consumer informants who have personally been trauma victims. To provide a comprehensive perspective, it is equally important to seek first-hand experiences from expert professional informants who have personally treated Deaf individuals with trauma experiences. The next section provides first-hand accounts from key consumer and professional informants to illustrate trauma experiences of Deaf individuals and system barriers to receiving trauma informed care for this population.

SECTION II: TRAUMA AND THE DEAF POPULATION: EXPERIENCES, SERVICES, AND BARRIERS

"My parents did not take the effort to understand me as a Deaf child. I was 'left' at school because they did not want to deal with it. They would hit me in the head for not hearing something they said. If it landed on my hearing aid, my ear would bleed. My parents were my worst enemies."

This section details 1) first-hand trauma experiences in Deaf individuals, 2) the difficulties with access to services, 3) difficulties in providing services, 4) diagnostic issues, 5) the barriers to providing appropriate care for the Deaf individual following trauma, and 6) the crucial role interpreters and signing professionals play in bridging the communication gap. This section is built upon interviews with key consumer and professional informants towards making recommendations in the section that follows.

The key consumer informant quotes are representative of the key consumer informants' experiences with trauma in their lives once they understood the concept of trauma. These findings are based on a small sample of Deaf interviewees and not representative of all experiences within the Deaf community. [9] The key professional informants brought up many of the same issues that the key consumer informants did suggesting that there are a number of similar characteristics and perspectives among the experiences of Deaf individuals with trauma experiences. However, they also brought up issues that were not

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[9] Due to the highly sensitive nature of the key informant stories and the intimate nature of the Deaf community, the identifying details of the interviewees' stories were changed substantially to protect their identities. Additionally, it was necessary to omit or change some details from their stories to protect their confidentiality. The consumer quotes are an English transcription of the interviewees' ASL stories as set-down by the interviewer for readability. They are not a direct transliteration of the consumer's ASL narratives.

touched on by the key consumer informants, which may be reflective of the differing education levels, social knowledge, and/or access to spoken information. This section begins with the trauma experiences in the Deaf population.

TRAUMA EXPERIENCES IN THE DEAF POPULATION

Each of the key consumer informants willingly and openly described their experiences with trauma, including physical, sexual, and systemic trauma. Their narratives were deeply moving and most shared their stories with tears and obvious pain. A few noted that they had never shared their story directly with a signing professional before, which may reflect the difficulty Deaf individuals have in accessing services.

While Deaf individuals may experience trauma anywhere during the lifespan, key consumer informants described trauma they experienced as children, often via parents, family members, peers, or by teachers in school. The high incidence rate of trauma in Deaf children reflected here and in the literature review, points to the imperative need for greater trauma prevention and identification efforts for this highly vulnerable group.

"My mom always called me names. It broke my heart. My dad abused my mom and she would take it out on me....They were cold and mean, even now."

My parents destroyed my life. "Shut up!" If a friend walked by the house and I was in the yard signing to her, my parents would become enraged and would scream at me to "Get in the house!!!" "We look like animals."

— *Key consumer informant female*

My parents did not take the effort to understand me as a Deaf child. I was 'left' at school because they did not want to deal with it. They would hit me in the head for not hearing something they said. If it landed on my hearing aid, my ear would bleed. My parents were my worst enemies.

— *Key consumer informant female*

I told my mom when I was three or four that I wanted to wear baby diapers again. I thought it would stop my cousin from molesting me, I thought the diapers would protect me. My mom asked why and I told her and she did not believe me.

— *Key consumer informant female*

> *"We were walking to school one day when a man came up to us with money in his hand (to buy sex). We were only 8 years old."*

My mom always called me names. It broke my heart. My dad abused my mom and she would take it out on me. My dad was an alcoholic. "Why are you so wrong?!? Why do you embarrass me?" They were cold and mean, even now.

— *Key consumer informant female*

One teacher was VERY mean. She often punished the low language Deaf students by refusing them lunch. She would not allow the kids to play during recess or look at the other students during class. There were even separators between the desks so students could not see each other.

— *Key consumer informant female*

One source of trauma for Deaf children is being unable to meet expectations and being severely punished for their physical inability to comply with those expectations. The teachers for the Deaf forced all of the students to come down to their level of sign language ability. If we signed better than they did and they could not understand us, they punished us.

— *Key consumer informant male*

In middle school, there was one girl, age 9, who was having a bad day and could not pronounce a word correctly. Our speech teacher had her say it repeatedly. Finally, our teacher became so frustrated with the girl that she grabbed her by the hair and yanked her head violently back and forth several times. I was terrified! The teacher asked me to say the word and I desperately did my best, afraid to have the same thing happen to me. I said the word correctly and the teacher seemed to calm down. Afterwards, she gave us candy and

told us to hush and pretend nothing happened. I worked desperately on my speech after that just to survive.

– *Key consumer informant female*

Deaf children are often traumatized by peers.

Growing up, I always had bad days. I was the only student in the program who had to ride a special giant yellow bus reserved for kids with severe disabilities. When I would get off at school, other kids would say, "Why doesn't someone rape you? Why doesn't someone kill you?"

– *Key consumer informant female*

Sexual abuse experiences were described by the key consumer informants.

One teacher constantly touched my breasts with her elbows. I never told my parents because I had to look after myself.

– *Key consumer informant female*

Perpetrators of abuse may view Deaf children as easy targets due to their inability to share their experiences with others because of the communication barriers.

We were walking to school one day when a man came up to us with money in his hand (to buy sex). We were only 8 years old.

– *Key consumer informant female*

Culture can compound the abuse experiences. The key consumer informants that were members of a minority culture in the United States, talked about isolation not only as a result of their hearing loss within majority culture but also of being Deaf within cultures that view hearing loss as an embarrassment to the family unit.

I hate the fact that my culture could not accept my hearing loss. My family would constantly pray that my hearing loss would go away. "You are pretty, but Deaf. Too bad." Women in this culture are substandard, but Deaf women even more so. I want to celebrate my heritage. I am proud of both but not fully accepted by either. Neither one made me feel empowered.

> *"The pain of my rape continues. Instead of being able to communicate with doctors about the reasons for my symptoms, they just shove medication at me...medication to calm down...medication to stop the pain. Now they suspect drug abuse. I feel hopeless and betrayed."*

– *Key consumer informant female*

I experience some anger when I see children treated the way I was. White professionals try to tell families with culture what is right and wrong. How do they know?

– *Key consumer informant female*

Trauma has long-term consequences for the Deaf population.

I just needed help sleeping. I cannot sleep ever since that police officer raped me when I was a child. He was a friend of my father. Police came to my house recently and I was hysterical when the male cop came near me. He scared me but I could not tell the police why I was refusing to let him near me (because there was no interpreter). Luckily, there was a female cop there.

– *Key consumer informant female*

I was placed in an orphanage. We were well cared for but the director is now under arrest for sex abuse. I will never forget what he did to me.

– *Key consumer informant male*

The pain of my rape continues. Instead of being able to communicate with doctors about the reasons for my symptoms, they just shove medication at me...medication to calm

down…medication to stop the pain. Now they suspect drug abuse. I feel hopeless and betrayed.

– *Key consumer informant female*

Combined, these findings from first-hand consumer informants indicate that trauma is often experienced by Deaf individuals, that trauma may take many forms, ranging from verbal taunting to physical abuse to sexual molestation, that culture can compound the abuse experience, and that trauma has long-term negative consequences for Deaf individuals. The next section focuses on the barriers Deaf individuals experience in accessing trauma-informed services.

TRAUMA IN THE DEAF POPULATION: ACCESS BARRIERS

"There simply is not any information out there. Where could I go to find information or help? I live in a small town. To get services, I have to drive 2 hours to the nearest city."

Key consumer informants noted that they were unable to receive treatment for their trauma when needed. This inability to access services may be due to resource limitations, or because Deaf individuals with experiences of trauma do not know how to locate treatment resources, or that the Deaf person feels too isolated to even attempt to access care for trauma. While all of these barriers are experienced by hearing individuals, the Deaf individual's experience is compounded by communication barriers.

Basic behavioral treatment resources were non-existent in their communities.

Basic access to services for Deaf individuals is not available in most communities. There can be a resistance from the public behavioral health system to provide money and resources because the number of Deaf individuals within any given service area is so small.

– *Key professional informant female*

It is extremely difficult to locate services and find a counselor who can help me.

— *Key consumer informant male*

We live in the middle of nowhere! I have begged for services. I have contacted everyone I can think of to get services but we are too remote. I thought of moving but I cannot right now. I do not have enough money. We just need to hang on for two more years until I can move. I hope things will be ok.

— *Key consumer informant male*

There simply is not any information out there. Where could I go to find information or help? I live in a small town. To get services, I have to drive 2 hours to the nearest city.

— *Key consumer informant female*

There is a perception among some key consumer informants that the hearing community has complete and effortless access to needed services and this perception exacerbates the feeling of not being seen and understood.

Hearing people have everything they need. I cannot just go into a behavioral health center and get a counselor.

— *Key consumer informant female*

If accessible trauma treatment resources existed, the consumers did not know where to locate them or how to access them.

The referral list of agencies for extra services/support is not accessible for Deaf consumers, which adds more barriers/challenges to an already traumatized individual.

— *Key professional informant female*

There should be someone in every county who can sign and knows where all of the resources are.

— *Key consumer informant male*

"I am in a drug rehabilitation program. The staff does not know how to present the material well in sign language so I end up teaching others. They do not help me. I should not have to teach. I should have a counselor listening to my story and helping me to understand my behavior."

If accessible trauma treatment resources existed, the consumers did not know which agency or department to contact.

There is often confusion as to which public behavioral health department should serve Deaf clients (Mental Health, Vocational Rehabilitation, Substance Abuse, or Developmental Disabilities).

— *Key professional informant female*

We are a private practice that provides culturally and linguistically accessible services. However, there can be problems with Medicaid, as generally there are only limited sessions approved. If a client comes in with a limit of 8 sessions but needs more, we are supposed to refer them to a public agency. No such agency exists. We have to drop the client or provide free/reduced services.

— *Key professional informant male*

If the consumer was able to access services, there was a delay while the organization located either interpreters or a signing professional to serve them. None of the consumers was able to identify if their services were trauma-informed.

It would be helpful to have educational outreach and trainings for providers and professionals. Some Deaf individuals do not know where to go. Only some outreach is available, but not nearly enough.

— *Key professional informant female*

Culturally and linguistically accessible trauma treatment is especially hard to find for Deaf individuals. If the Deaf key consumer informants found a service provider that could sign, they considered themselves lucky simply to find linguistically accessible care. However, even if the quality of service provided was not a good match for their therapeutic needs, they stayed with the service provider because it was their only treatment option to address their trauma and behavioral health.

> *"After someone threatened to kill me, my family moved me to a small town that did not have any other Deaf people or even internet access….*
> *For 5 years...I had no communication with anyone except for paper and pencil with people at the marketplace. I was scared and alone. I used drugs to cope with the fear and isolation."*

I am in a drug rehabilitation program. The staff does not know how to present the material well in sign language so I end up teaching others. They do not help me. I should not have to teach. I should have a counselor listening to my story and helping me to understand my behavior.

— *Key consumer informant male*

Even if accessible trauma treatment resources existed, the consumers felt too isolated to contact them.

Most Deaf consumers feel isolated and unable to receive care.

— *Key professional informant female*

After someone threatened to kill me, my family moved me to a small town that did not have any other Deaf people or even internet access (and therefore, no access to linguistic or culturally accessible services). For 5 years until the police caught the person who threatened me, I had no communication with anyone except for paper and pencil with people at the marketplace. I was scared and alone. I used drugs to cope with the fear and isolation.

— *Key consumer informant male*

He put his fingers up there (inside me) and I could not call out to anyone. After I got away, I hid and no one came to check on me. I felt it was my fault and the shame was painful. I never told anyone about this hole inside of me. What for? What difference would it make? I struggle everyday just to communicate with others about normal things.

– *Key consumer informant female*

Some clients are not able to understand the psychological terminology and concepts or understand public education documents/brochures with jargon or English idioms that do not translate well to ASL. Therefore, they do not know when to seek treatment for their trauma symptoms or even where to go if they did.

> *"It is likely that most Deaf individuals have chronic trauma issues because there are no services and they are not able to share their experiences. Their symptoms become worse over time and are compounded due to lack of services."*

– *Key professional informant male*

This lack of culturally and linguistically accessible care has damaging personal and societal consequences. When appropriate culturally and linguistically accessible community services are not in place to provide support, it can lead to an increase in inpatient treatment for Deaf individuals. Additionally, due to the lack of culturally and linguistically accessible information on behavioral health services, there is a significant portion of Deaf individuals, and language dysfluent individuals in particular, that are either unaware their experiences fall under the definition of trauma or do not know how to seek available services.

Lack of family and community support hampers the recovery process in clients receiving services.

– *Key professional informant female*

In summary, Deaf individuals who have experienced trauma have barriers to care access. These barriers include the lack of resources available to treat their needs, a lack of knowledge regarding where the resources are located, and confusion regarding which

agency has jurisdiction. Further, Deaf individuals experiencing trauma have difficulty finding care providers who are fluent in ASL, and may have to settle for sub-optimal care. Worse, some Deaf individuals lack treatment following trauma because they feel too isolated to even attempt to seek access. While all of these barriers are experienced by hearing individuals, the Deaf individual's experience is compounded by communication barriers.

If a Deaf individual who has experiences of trauma gets through these compounding barriers, the next challenge is to acquire appropriate services.

TRAUMA IN THE DEAF POPULATION: SERVICE BARRIERS

There are simply too many clients and not enough providers to serve them all.

— *Key professional informant female*

There appears to be an alarming lack of service providers who are culturally and linguistically competent to provide trauma-specific treatment. Clearly, there is a need for workforce analysis and development to determine where the service gaps are located.

It is likely that most Deaf individuals have chronic trauma issues because there are no services and they are not able to share their experiences. Their symptoms become worse over time and are compounded due to lack of services.

— *Key professional informant male*

Hearing service providers with little knowledge of Deaf culture or American Sign Language attempt to fill this void, especially when organizations are mandated by the ADA[10] to provide accessible and appropriate services. Faced with the lack of service providers that

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[10] The Americans with Disabilities Act prohibits discrimination or unequal treatment of Americans with disabilities by organizations that provide mental health services to the public.

are culturally and linguistically competent to provide trauma-informed care, these organizations resort to hiring an interpreter for their hearing service providers. Unfortunately, the complexities involved in utilizing an interpreter along with a cross-cultural component are overlooked.

A hearing therapist using an interpreter is not necessarily culturally competent to provide treatment.

— *Key professional informant male*

In addition, there are often insufficient numbers of service providers qualified to provide trauma-informed care and trauma-specific services and treatment to meet the significant trauma treatment needs of the Deaf population. As a result, existing service providers are likely faced with high caseloads and consumers needing multiple services. This can lead to burnout and turnover of service providers that are qualified to provide culturally and linguistically accessible care.

If there is only one qualified service provider for Deaf consumers, there can be a higher rate of burnout due to large demand, few resources, multiple roles, and increased advocacy for clients as compared to their hearing providers. Deaf service providers often 'wear more hats' than their hearing peers in assisting their clients to find resources. They are also fighting the system for their client's additional needs.

— *Key professional informant female*

When services are stretched thin, ethical conflicts can arise.

One therapist may need to serve both victims and perpetrators because there are no other provider options. This leads to potential difficulty with boundary issues, confidentiality, trust, and change in therapy dynamics.

— *Key professional informant male*

When services are needed, funding becomes a priority.

Funding is likely to be based on lawsuits, not collaboration and understanding of the needs and gaps in services. There are limited resources for funding in some counties while other counties have more resources. This is frustrating and may require consumers to travel long distances, pay more, or relocate to receive services. Some counties are open to paying for specialized services in different counties for Deaf individuals, which may be the best solution; some are not open which causes more challenges, especially delayed services for the consumer.

—   *Key professional informant male*

In summary, the main barrier to services is a lack of on-site service providers who are culturally and linguistically competent to provide trauma treatment, which may result in services not rendered. When services are rendered, the next challenge for Deaf individuals after a trauma experience is acquiring the appropriate diagnosis.

TRAUMA IN THE DEAF POPULATION: DIAGNOSTIC BARRIERS

...Deaf individuals are more likely to be diagnosed and misdiagnosed as having a personality disorder than their hearing counterparts.

The validity and reliability of diagnosed disorders within the Deaf community are highly questionable (Schild, 2007; Black, 2006). Evidence shows that Deaf individuals are more likely to be diagnosed and misdiagnosed as having a personality disorder than their hearing counterparts (Pollard, 1998). An inaccurate diagnosis by a professional based on misunderstandings of cultural and linguistic differences is an example of institutional abuse that can worsen the symptoms of trauma.

I would like to see a revision of the DSM-IV Posttraumatic Stress Disorder (PTSD) definition to include the diagnostic issues I encounter when working with Deaf individuals with trauma experiences. The suspected level of abuse in the Deaf population is high; however,

many Deaf individuals are not properly diagnosed with PTSD. Service professionals that are not trained to work with Deaf individuals do not diagnose PTSD in the Deaf population carefully.

– *Key professional informant male*

Trauma experiences are often misidentified by both Deaf and hearing individuals. Trauma misidentification combined with the lack of access to trauma-informed care could contribute to the significant under-reporting of trauma in the Deaf community. Further, without this critical knowledge of what constitutes trauma, many Deaf individuals perceive their trauma experience as a normal experience, and not as trauma.

No one understands (the experiences that I have had).

– *Key consumer informant male*

In 1998, Pollard asserted that differences might exist in the manifestation of signs and symptoms of mental illness in hearing and Deaf individuals (Pollard, 1998). Most of these differences stem from cultural and linguistic differences rather than the former majority viewpoint of deafness as a disability utilizing the medical model (Glickman, 2003). For example, American Sign Language (ASL) can be much more emotionally expressive than English, potentially leading to under-diagnosis of depression or over-diagnosis of mania.

When I was collecting data for my research project, I was surprised to find that with all types of trauma, there was a higher level of dissociative symptoms in Deaf individuals than for hearing individuals. My research also showed increased physical/psychosomatic issues in the Deaf population with trauma experiences.

– *Key professional informant male*

There is likely a higher rate of misdiagnosis when a hearing professional without training on how to communicate with Deaf individuals attempts a diagnosis using an interpreter or

pencil and paper writing (Pollard, 2002). ADHD or mood disorders are potential misdiagnoses due to the Deaf individual's signing speed appearing manic or differences in the cultural story-telling style of many Deaf individuals appearing tangential. In addition, the increased communication barrier of using an interpreter or back and forth writing may encourage simplification of diagnoses or the incomplete collection of history.

The doctors say I have ADHD. The medication does not help. Now I am dizzy all the time.

– *Key consumer informant female*

I recently told a nurse using back and forth writing that I experienced painful intercourse with my partner. Instead of investigating possible medical causes, she wanted to know if she could show us how to have sex. She assumed we were doing it wrong. She did not ask any other questions. The doctor's office refused to provide an interpreter. I still have pain.

– *Key consumer informant male*

Dismissal of these linguistic and cultural differences, deliberately or through ignorance, can be harmful (as in misdiagnosis) and disrupt the necessary recovery process. English-based therapies do not necessarily accommodate these differences and may or may not provide the needed support to Deaf individuals with trauma experiences.

There are few grants available for researching diagnostic issues within the Deaf population.

– *Key professional informant male*

In summary, trauma is often misidentified at the diagnostic stage of care for Deaf individuals who have experiences of trauma. The use of an interpreter with a provider untrained in working with interpreters or Deaf cultural issues may lead to misdiagnosis, inappropriate trauma treatment, and further traumatization of the Deaf individual needing trauma treatment. The next section further discusses treatment barriers.

> *"There is no empirically valid 12-step recovery program for Deaf individuals with trauma treatment needs. Even if there was, it is very difficult to get them into a hearing group with an interpreter….many do not want to admit to their peers that they have an issue. The stigma is very strong and the community is small."*

Many clients are hospitalized for simple anxiety or depression and then end up with PTSD due to inappropriate care.

— *Key professional informant male*

The Deaf individual deserves trauma-informed care. Trauma-informed care shifts the fundamental premise of treatment of individuals with trauma experiences from a disease/symptom focus to an individual's self-determined focus.

I want to go back to my home but they will not let me. They say I am not ready. I do not know how to get them to let me go. No one will tell me.

— *Key consumer informant female*

Unfortunately, there are no evidence-based treatments specifically designed for treating trauma in the Deaf community. Culturally and linguistically accessible trauma specific treatments based on empirical research with the Deaf population are desperately needed.

It is essential to not take a hearing trauma treatment, modify it slightly, and call it a Deaf treatment.

— *Key professional informant male*

Various organizations are beginning the process of educating the behavioral health field about treatment of trauma with the Deaf population in the absence of evidence-based trauma-informed care practices. The National Child Traumatic Stress Network's (NCTSN) *Facts on Trauma and Deaf Children* (National Traumatic Stress Network, 2004) provides guidelines on how to modify existing treatments for application with Deaf children. The NCTSN produced a second paper in 2006 *Addressing the Trauma Treatment Needs of*

Children Who Are Deaf or Hard of Hearing and the Hearing Children of Deaf Parents
(National Child Traumatic Stress Network, 2006). This report describes healthy identity development in children with hearing loss, ways in which that identity development can be derailed and a guide for therapists to modify existing treatments for the maximum benefit to the client.

These guidelines provide programs with a foundation for establishing culturally and linguistically appropriate trauma-informed care and measuring the efficacy of such care. Implementing programs and gathering data are the first steps to filling the research/knowledge gaps and establishing evidence-based treatments for trauma-informed care for the Deaf population.

There is no empirically valid 12-step recovery program for Deaf individuals with trauma treatment needs. Even if there was, it is very difficult to get them into a hearing group with an interpreter. They do not feel connected to the group. Getting a group of Deaf consumers together is difficult too. There are very few and many do not want to admit to their peers that they have an issue. The stigma is very strong and the community is small.

— *Key professional informant male*

One promising program is the Our Deaf Sisters' Survivor Support Project[11] (ODSSSP) which was developed by the Rape Crisis of Central Massachusetts (RCCCM) with collaboration with Our Deaf Sisters' Center and The Deaf/Hard of Hearing Independent Living Program of The Center for Living & Working, Inc. This program provides some culturally appropriate and accessible counseling and advocacy for Deaf Survivors of sexual assault and sexual abuse. They are in the process of developing a 12 step trauma recovery program specifically for Deaf survivors of trauma based on an existing 12 step program at RCCCM. In addition, they are also working on adapting their current training for Peer Support Certification to be culturally and linguistically accessible for Deaf individuals with trauma

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[11] http://www.rapecrisiscenter.org/services.html Retrieved August 25, 2010.

experiences. ODSSP is also working with the Our Deaf Sister's Center (ODSC), a non-profit agency in Massachusetts. This is an agency in development by and for the Deaf community that will begin to train professionals and community members in 2011 on recognition and treatment of various types of trauma. These programs are being developed and run by self-identified consumers in the Massachusetts Deaf community. However, no empirical data is publicly available to show if these modified treatments are efficacious for Deaf individuals who have experienced trauma.

Deaf individuals with trauma experiences lack evidence-based treatments specifically designed for their needs. The result is often suboptimal treatment. If communication is difficult with trauma treatment professionals, the Deaf individual may not seek the maximum benefits of trauma treatment. For these reasons, it is crucial to explore the roles and limitations of interpreters and signing professionals in bridging the communication gap.

BRIDGING THE COMMUNICATION GAP: ROLES AND LIMITATIONS OF INTERPRETERS AND SIGNING PROFESSIONALS

Interpreters and signing professionals[12] play a vital in providing care for the Deaf individuals who experience trauma by bridging the communication gap between consumer and provider.

I was lucky to find my counselor (who can sign). She has helped me more than anyone else has because I can communicate with her. With her, I have been able to find support.
— *Key consumer informant female*

In providing emergency services, agencies are heavily reliant on interpreters to bridge the communication gap.

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[12] Professionals with sign language skills can be hearing or Deaf.

In domestic emergencies, there are rarely interpreters available to facilitate the communication between the professional and victim. Traumatized individuals may be trying to report to the police or hospital but it usually takes a while to get an interpreter at a last minute request.

— *Key professional informant female*

> *It took numerous explanations in American Sign Language using various analogies such as 'HEART TOUCH-HURT' to help them understand the concept of trauma and differentiate it from physical injury.*

If there is no interpreter available, then services may be postponed.

— *Key professional informant female*

Police/Dispatchers/Hospitals are not likely to be familiar with requesting interpreters or have list of interpreting agencies ready for emergencies.

— *Key professional informant female*

However, even with an interpreter or signing professional, communicating about trauma can be challenging depending on the level of signing ability of *both* the consumer and the signing professional or interpreter.

Some consumers had never encountered the word 'trauma'[13] or considered the impact their experiences had on their lives. It took numerous explanations in American Sign Language using various analogies such as 'HEART TOUCH-HURT' to help them understand the concept of trauma and differentiate it from physical injury. There was enormous shock and an outpouring of emotion when they understood the concept and were able to put a name to the experience. They explained that no one had thoroughly defined the concept to them or asked them of their experiences. Furthermore, not all interpreters or signing

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[13] The word 'trauma' is typically finger-spelled in ASL, which generally indicates that there is not an exact translation for the global concept of trauma This is contrasted with the subtypes of trauma such as physical abuse, rape, or molestation, each of which has a specific set of signs.

professionals have superior or near-fluent signing ability, which may hamper communication with the Deaf consumer. Thus, if the communication and cultural needs of the Deaf population are not met, then misdiagnosis will continue, trauma treatment will not be fully effective, and the personal and societal consequences of untreated trauma symptoms will continue.

I have a counselor but she is unable to keep up with my signing speed. My ASL is not that good and she often does not understand me.

— *Key consumer informant female*

I did go to a signing counselor once but he kept falling asleep during our sessions. He had no patience. When I become emotional, my signing speeds up. He was unable to understand me and became impatient.

— *Key consumer informant female*

Therefore, communication standards for interpreter and signing professional communication are paramount to providing quality care for the Deaf individuals who experience trauma.

The language dysfluency field needs communication standards, the use of certified Deaf interpreters, and therapy models. Very few clinicians have the signing skills and the clinical skills necessary to serve the language dysfluency population.

— *Key professional informant male*

Standards for interpreter ethics are also important to protect the dignity of the Deaf community. One key consumer informant noted that as a Deaf adolescent in a mainstream setting, she would have needed to utilize her everyday classroom interpreter to share her experience of sexual abuse with the school counselor. She was unable to overcome the embarrassment of the sexual abuse enough to divulge this information in front of her

interpreter of the opposite sex whom she needed for everyday communication in the classroom.

Standards for interpreter behavior are also important. Behavioral health interpreters who are not trained on trauma-informed care practices may inadvertently attempt to make decisions for Deaf consumers when their vulnerability is high from experiencing trauma related symptoms instead of explaining the situation to the Deaf individual and allowing them to make their own decisions.

The interpreter was very bossy. She would not interpret everything I said, saying 'that doesn't matter.' She would tell me 'hush' when I tried to speak up for myself.

– *Key consumer informant female*

In smaller rural areas with fewer interpreters, the likelihood of having an interpreter for more than one venue (i.e. trauma-informed care services and classroom services) is high. The interpreter's dual role made the key consumer informants uncomfortable.

Interpreters were few and often I would have the same interpreter for different things. One interpreter interpreted for us when we were in the hospital. She also interpreted for me in the community. I felt very uncomfortable that she knew about our issues. I asked for a different interpreter but they told me to put up with it, that they had no one else.

– *Key consumer informant female*

The consumers were mistrustful of the interpreters' confidentiality and felt their private traumatic experiences were shared with other interpreters.

My interpreter shared my issues with other interpreters. Now I feel as if they are all watching me.

– *Key consumer informant female*

The confidentiality and dignity of the Deaf community must be preserved. Further, interpreters and signing professionals can play a positive or a negative role in bridging the communication gap. Therefore, standards for interpreter communication, interpreter behavior, and interpreter ethics are crucial towards fostering appropriate care for Deaf individuals who experience trauma.

SECTION III: RECOMMENDATIONS

It is essential to understand and incorporate the concept of Deaf culture as a way of life and a minority status rather than as a disability.

The following sections provide recommendations based on the findings in this paper. In particular, the first section addresses gaps in research knowledge. The second section provides policy recommendations for local, state, and federal administrators to assist in making services more culturally and linguistically accessible for Deaf individuals who have experienced trauma. The third section identifies recommendations for the Deaf community, including trauma survivors.

Deaf individuals should provide input on the implementation of these recommendations. It is essential to understand and incorporate the concept of Deaf culture as a way of life and a minority status rather than as a disability. This perspective is important to prevent cultural misunderstandings when working with Deaf individuals with trauma.

RECOMMENDATIONS FOR RESEARCH

There is a paucity of knowledge of the risk and preventative factors of traumatic events, the symptoms of trauma, and evidence-based trauma assessment and treatment within the Deaf population, as shown by the literature review. To address these knowledge gaps, the following recommendations are proposed:

° **Include Deaf trauma survivors' input in the NCTIC definition of trauma.**
Hearing individuals with trauma experiences and stakeholders developed the NCTIC
definition of trauma to ensure a consumer-oriented approach. Including Deaf trauma
survivors in an updated NCTIC definition will support the visibility of the Deaf
community and encourage policy makers and providers to recognize the needs of Deaf
individuals who have experienced trauma. An updated definition will also assist
researchers in their efforts to research trauma in the Deaf population.

° **Utilize the updated NCTIC definition to gather basic data on trauma in the Deaf
population.**
This data includes the prevalence of trauma, risk factors, prevention needs, and service
access barriers. This basic data is necessary for states and federal government systems
to make the crucial decisions necessary to serve the Deaf population's trauma-informed
care needs. Without this data, providers and administrators cannot plan programs,
implement culturally and linguistically accessible assessments and treatments, or
evaluate outcomes.

° **Research the impact and symptoms of trauma in Deaf individuals.**
As noted in the literature review, preliminary evidence shows the presentation of
symptoms of trauma in Deaf individuals is likely different in some ways from that of
hearing individuals; however, there is little organized data available. This knowledge is
essential to make accurate diagnoses for Deaf individuals who have experienced
trauma. In addition, it is crucial to have this information to develop trainings to
disseminate to the service community.

° **Research the social and fiscal consequences of untreated trauma in Deaf
individuals.**
This research would provide a greater understanding of the need for trauma-informed
care for the Deaf community. In particular, the research would help determine the fiscal

and organizational impact on local, state, and federal systems of care. This information may provide support for policy and system changes that would meet the needs of Deaf individuals who have experienced trauma. Finally, it may provide further justification for research funding on trauma within the Deaf population.

○ **Develop evidence-based, consumer-oriented trauma interventions for Deaf individuals with trauma-informed care needs.**
These evidence-based trauma treatments are necessary to assist providers in delivering appropriate and targeted care. When trauma-informed programs become evidence-based practices, they are more likely to receive funding and become sustainable as some grantors stipulate the use of evidence-based practices for receipt of funding.

○ **Research promising practices for their potential to become evidence-based practices.**
There may be promising practices that have been developed by independent service providers and organizations for Deaf individuals with trauma backgrounds. However, there is little funding or resources to gather the intensive research needed to formalize them into evidence-based practices. This review of promising practices should include peer support service programs for Deaf trauma survivors.

○ **Develop empirically validated tools for trauma risk assessment, screening, and early diagnosis of trauma symptoms for Deaf individuals.**
These tools can be used for prevention of trauma and early detection of symptoms. When a high risk for trauma is discovered, preventative measures (i.e. education and monitoring) can be put in place to protect the individual from the further exacerbation of trauma symptoms. These assessment and screening tools should also be developed for children, young adults, and individuals with language dysfluency.

° **Research unique populations within the Deaf community.**

As in hearing communities, specific populations within the Deaf community may have unique trauma symptoms and trauma treatment needs. Knowing the unique trauma symptoms of each of these groups will assist in prevention, early screening, and treatment efforts. Knowledge is needed on the impact of trauma, the prevalence of trauma, and what is most helpful and not helpful for these populations:

- ° Children and young adults
- ° Individuals with language dysfluency
- ° Minority ethnic populations
- ° Deaf-Blind individuals
- ° Forensic populations

° **Develop training for providers on trauma-related symptoms in the Deaf community.**

This training should include how trauma symptoms manifest, how to assess them, and Deaf cultural competency issues that may arise. Without this knowledge, there may be a greater possibility of misdiagnosis and mistreatment. There are currently trainings developed for providers that address Deaf cultural competency in behavioral health settings. However, these trainings may not specifically address trauma. In addition, specialized training is needed for these issues in Deaf individuals with language dysfluency.

RECOMMENDATIONS FOR LOCAL, STATE AND FEDERAL SYSTEMS

Leadership is needed at the federal, state, and local levels to provide culturally and linguistically accessible services to meet the needs Deaf individuals with trauma backgrounds. The following recommendations provide ways in which the federal government can encourage and support state and local initiatives to improve the system of care for Deaf individuals with trauma-informed care needs.

° **Develop a trauma-informed system of care model for Deaf individuals.**
This model should be research-based and include Deaf consumer input. A trauma-informed system of care should include prevention, early detection, and treatment procedures that benefit the Deaf individual. Further, this system should also include culturally and linguistically accessible procedures that can reduce the barriers typically experienced by this community.

At minimum, this model should also include the following:

- ° training on cultural competency in behavioral health and the Deaf population for providers;
- ° training, when it becomes available, on trauma in the Deaf community, how the symptoms manifest, and the risks and protective factors of trauma in the Deaf community;
- ° a comprehensive handbook of trauma assessments and evidence-based treatments once they are developed and validated for Deaf individuals;
- ° specific safeguards—such as outcome studies and linguistically accessible consumer questionnaires—to prevent system re-traumatization;
- ° a checklist for providers and organizations that identifies each component of a culturally and linguistically accessible trauma-informed system of care for providers and organizations. This checklist should include input by Deaf trauma survivors to ensure that any barriers they have experienced are addressed.

Deaf individuals who have experienced trauma need a workforce composed of an adequate number of competent, culturally appropriate behavioral health professionals and peer supports with demonstrated knowledge and experience in Deaf culture and trauma-

specific assessments and treatments. The current workforce does not appear to meet this need. To increase this workforce, the following actions are recommended:

° **Conduct a comprehensive workforce analysis.**
  This analysis is needed to determine what public and private services currently exist for Deaf individuals with trauma backgrounds. This information will provide an in-depth review of the gaps in services across the country.

° **Compile an online database of available private and public trauma-informed care providers and services.**
  This database will help link Deaf individuals needing trauma-informed care with providers in their geographic area or via telemedicine. Once these providers and service organizations are identified, this information should be made easily available for providers and Deaf individuals seeking services for trauma symptoms.

° **Recruit members of the Deaf community into the behavioral health service professions that treat trauma.**
  Encourage and support educational institutions to recruit individuals from the Deaf community into their behavioral health programs. Deaf individuals are more likely to know American Sign Language and Deaf culture, and thus are uniquely situated to learn and provide behavioral health services to Deaf individuals.

° **Train existing behavioral health providers to recognize trauma symptoms in Deaf individuals and provide culturally accessible trauma-specific services.**
  Existing trauma treatment providers are a valuable workforce resource for providing treatment to local Deaf individuals once they are trained to provide culturally and linguistically accessible care.

- **Develop trainings on the recognition of trauma symptoms and a list of trauma-informed service resources for emergency response teams, assertive outreach teams, and crisis service organizations to identify Deaf individuals in need of specialized care and referral.**

  First responders to crises need to immediately recognize the symptoms of trauma and how to provide immediate assistance to Deaf individuals needing crisis services. They also need to be aware that utilizing hearing friends and family of the Deaf individual needing services is inappropriate as those individuals may be perpetrators of the trauma and hence unreliable informants. Quick access to interpreters and emergency referral resources in these situations is crucial.

  > *…the Deaf population is not included as a 'traditionally underserved population', rendering potential service organizations ineligible to apply for many state and federal funding programs.*

- **Expand telemedicine access to culturally and linguistically trained trauma-informed providers to treat Deaf individuals that lack local access to providers of accessible trauma treatment.**

  It is essential to utilize telemedicine to access non-local providers when there are no local trauma treatment providers available. Currently, policies on the provision of behavioral health services via telemedicine to the public vary widely between service organizations and state licensure boards. These policies affect the ability of qualified trauma service providers to obtain funding or reimbursement for their services to Deaf individuals via telemedicine.

- **Include the Deaf population in federal grant programs.**

  Inclusion as a 'traditionally underserved population' in grant programs may encourage greater access to research and service funding on trauma in the Deaf population. Currently, the Deaf population is not included as a 'traditionally underserved population', rendering potential service organizations ineligible to apply for many state and federal funding programs. With access to this funding, service organizations have

greater support to develop the services needed to address the trauma treatment needs of the Deaf population.

The quality of interpreters can vary widely, with some interpreters potentially unequipped to interpret in a trauma-informed care setting…. there is no national certification program for training interpreters to work in behavioral health settings.

The National Association of the Deaf has drafted a model Mental Health Bill of Rights[14] for easy adoption into existing systems (Please see Appendix D). This bill of rights provides a template for a plan of action tailored to organizational, state, or federal systems of care. While this bill of rights is directed at the general behavioral health needs of the Deaf community, its implementation will directly benefit those with trauma treatment needs by ensuring access to culturally and linguistically accessible care. The following changes in state, local, and organizational policy would assist the Deaf community in accessing appropriate trauma-informed care.

- **Develop and adopt behavioral health standards of care for the Deaf population.** Behavioral health standards of care help ensure quality services are available when needed. They also provide a guide to service organizations and state systems of care as to the minimally acceptable standards available. These standards should include provisions for trauma-informed care and culturally/linguistically competent trauma-specific interventions.

- **Standardize behavioral health interpreter qualifications for interpreting for Deaf individuals with trauma experiences.**

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[14] http://www.nad.org/issues/health-care/mental-health-services/model-mental-health-deaf-and-hard-hearing-individuals-bil-0 (Retrieved July 20, 2010).

The quality of interpreters can vary widely, with some interpreters potentially unequipped to interpret in a trauma-informed care setting. At present, there is no national certification program for training interpreters to work in behavioral health settings. In addition, specific training and certification should be trauma-informed.

○ **Establish a sign proficiency standard for signing behavioral health professionals.**
The sign proficiency of individuals who learn American Sign Language later in life can vary widely. Not all professionals that use ASL meet the proficiency level needed to provide complex behavioral health care. Professionals that are hired into the public system of care for providing services to Deaf individuals should meet an established proficiency standard.

○ **Analyze the impact of health care reform and parity as it relates to providing behavioral health services for Deaf individuals.**
In the current financial structure, Deaf consumers may need to spend their first few behavioral health sessions training the provider on how to utilize an interpreter as well as the basic cultural differences between Deaf and hearing populations. As a result, those initial provider-initiation sessions are less likely to provide therapeutic approaches and therefore reduce the number of sessions available for the Deaf individual to receive appropriate trauma treatment. As health reform and parity are implemented, it would be important to address this issue and ensure that Deaf individuals' behavioral health service needs are included overall.

TECHNICAL ASSISTANCE

○ **Provide a National Technical Assistance Center (TAC) where consumers, stakeholders, and providers across the country can access all available information and resources on trauma.**
A TAC can provide a database of information on the few available culturally and linguistically accessible resources for assessment, symptom recognition, and treatment

within the Deaf community to provide the best match to the Deaf individual with trauma treatment needs. While there is currently a paucity of information and resources available on trauma and the Deaf population, compilation of available information is essential to enhance the responsiveness and capacity of service providers and organizations. Multiple language modes and levels of cultural variation within the Deaf community make it difficult for any professional or system to be prepared to provide quality services for all potential Deaf individuals. Any single organization or provider is not likely to have the resources for every type of Deaf consumer with trauma-informed care needs.

○ **Resources should be provided for states to receive technical assistance from the TAC on how to implement trauma-informed care for Deaf consumers in their behavioral health systems of care.**
A TAC can provide targeted and detailed technical assistance on organization review and policy implementation to increase service accessibility for the Deaf population. However, not all states have the resources to access a National TAC for the assistance they need in transforming their systems of care.

○ **The National Center on Trauma Informed Care (NCTIC) should integrate the perspective of Deaf individuals with experiences of trauma into all aspects of its operations, including trauma-informed care trainings, publications, and meetings.**
NCTIC is exceptionally positioned to address the issues of trauma in the Deaf population through its own focus on trauma. By integrating Deaf perspectives into its practices, it can enhance the visibility of the issues and bring tremendous benefit to the Deaf community.

A prominent theme throughout this paper has been the cultural and linguistic barriers that exist for Deaf individuals to access any trauma services that may exist and the misunderstandings that occur between hearing providers and Deaf individuals. In order for the Deaf Community to have this access, public communication needs to be Deaf-friendly.

> *State and Federal department phones and websites can provide crucial public education on trauma as well as where to find trauma-informed care resources.*

○ **Centralize public education efforts targeted towards the Deaf community.**
Public education efforts need to be centralized and linguistically and culturally accessible so they are easily located and accessed when needed. This education should focus on the recognition of trauma and the resulting symptoms. In addition, it should provide resources on where a Deaf individual can seek assistance.

○ **Make state and federal department phones and websites Deaf-friendly and accessible.**
State and Federal department phones and websites can provide crucial public education on trauma as well as where to find trauma-informed care resources. Navigating complex automated phone menus is difficult to do with an interpreter through videophone. Provide direct numbers for videophone users.

○ **Compile, index, and supplement online American Sign Language instructional videos.**
Web-based instructional videos developed by and for Deaf individuals, found on various independent websites, offer an important source of information on trauma delivered in a culturally and linguistically accessible format. These videos should be placed in a single accessible directory for dissemination to the Deaf community in public education efforts.

Develop peer support specialist programs for individuals with trauma experiences as peer support specialist programs appear to have great benefit to consumers in their recovery process.

Prevention of trauma and early recognition of trauma symptoms often begins in the community. The following strategies are typically employed in hearing communities and would likely be of great benefit to the Deaf community with trauma-informed care needs. While these comments are intended for the Deaf community, they can also be utilized and supported by providers, service organizations, and administrators.

- **Locate and recruit key contacts within the Deaf community to disseminate accurate information on recognizing trauma symptoms and accessible resources to obtain trauma treatment.**
  Key contacts in any community are an important source of information to others. This is true for the Deaf community as well. Training these individuals about prevention and recognition of trauma so they can share this information with others is an efficient way to disseminate education to the Deaf community in a culturally and linguistically accessible format.

- **Develop self-assessment tools for Deaf consumers, their supporters, and the Deaf community**
  Accessible self-assessment tools, especially when presented in American Sign Language, can offer a valuable method for Deaf individuals to recognize their trauma symptoms. These self-assessment tools should include a resource list of available and accessible providers or service organizations to seek assistance.

- **Educate hearing and Deaf families and educators on trauma symptom recognition and prevention to assist their Deaf children.**

It is important to train families and educators on trauma symptom recognition and prevention since they tend to have the most contact with their Deaf children and students. These trainings can include take-home risk and symptom checklists and other self-assessment tools to encourage greater utilization of the information. In addition, families and educators should be provided with resources for further information and treatment if needed.

○ **Develop and implement child abuse prevention programs for families with Deaf children.**
Child abuse prevention strategies can offer support for families to cope with the unique aspects of raising a Deaf child. For many parents unfamiliar with hearing loss, this can be an added stressor to the challenges of parenting. These strategies can encompass such activities as education on the normal stages of Deaf child development and self-help/peer support groups.

○ **Develop and disseminate stigma reduction strategies to help Deaf individuals with trauma experiences come forward and request the treatment they need.**
As with any community, the Deaf community can hold stigmatizing beliefs about behavioral health issues. It can be difficult for a Deaf individual to overcome these perceived or real stigmas and seek treatment. Stigma reduction strategies can include collaborating with organizations such as the National Alliance for Mental Illness (NAMI) to create accessible education and awareness programs.

○ **Develop peer support specialist programs for individuals with trauma experiences.**
Peer support specialist programs appear to have great benefit to consumers in their recovery process. These programs can train current or former Deaf consumers of behavioral health services to assist their peers with their recovery from trauma.

At first glance, providing trauma-informed care to the Deaf population can be expensive and hard to justify. The cost of implementing the above suggestions may appear prohibitive; however, many of the implementations can be shared with other groups with high incidence of trauma to reduce the cost impact. For example, a telemedicine system could be set up for Deaf consumers in emergency rooms to meet with service providers outside of their geographic region. This telemedicine system could also meet the needs of other professionals and linguistic minority consumers for long-distance consultation and immediate crisis services. Shared resources across state lines and at the national level help a greater number of individuals for a lower cost.

There are multiple benefits of implementing these recommendations, including potentially reducing the misunderstandings between hearing providers and Deaf consumers who have experienced trauma. As the key professional informant interviews highlighted, there are Deaf consumers in the public behavioral health system who are not receiving the care they need through the current system. Anyone, hearing or Deaf, with traumatic experiences should have access to services that are trauma-informed to have the opportunity for healing and increase their quality of life.

CONCLUSION

Trauma experiences in the Deaf population are far too common and the personal and societal consequences are enormous. Key informants indicated that inherent language barriers and culture differences hamper utilization of trauma treatment services by the Deaf. These barriers include:

- lack of providers trained to serve the Deaf population with experiences of trauma
- misdiagnosis based on misunderstandings of cultural differences
- lack of interpreters trained to work in trauma-informed care settings
- culturally and linguistically inaccessible behavioral health education on trauma

The current system of care can create and perpetuate these barriers. Through research and understanding of the systemic, cultural, and linguistic barriers faced by Deaf individuals seeking trauma treatment, the system of care can take steps to reduce these barriers. Recommendations are targeted towards local, state, and federal entities and range from public policy changes to research needs. These recommendations are intended to encourage collaborative action to provide a culturally and linguistically accessible system of care to serve the needs of Deaf individuals who have experienced trauma. Gathering and utilizing this knowledge will serve to enhance the recovery process of Deaf individuals with trauma symptoms. As with hearing individuals with traumatic experiences, implementation of these recommendations will likely reduce the long-term societal costs of treating and supporting Deaf individuals with traumatic experiences.

SECTION IV: REFERENCES, APPENDICES, AND RESOURCES

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A literature search was conducted using several different databases to identify sources of information on trauma in Deaf communities. These databases included Academic OneFile, Expanded Academic ASAP, General Reference Center Gold, Google Scholar, and the researcher's own collection of articles and reports. In addition, various researchers were contacted for further reference resources. Bibliographies of retrieved articles were searched manually for literature not indexed by any of the aforementioned databases.

Published, peer-reviewed academic articles were the focus of the literature search. Web-based instructional videos developed by and for Deaf individuals were not searched due to time constraints and lack of indexing. The literature search involved combinations of the following keywords: hearing, hearing impairment, hearing loss, deaf, deafness, hard of hearing, trauma, posttraumatic stress disorder, trauma-informed care, trauma and mental health, abuse, violence, restraint, institutional trauma, systematic trauma, trauma-informed treatments, domestic violence, and sexual abuse.

Gaps in the literature review were found in the following areas:
- Trauma as defined by Deaf consumers
- Trauma screening and assessment tools validated for the Deaf population
- Evidence-based trauma specific treatments for Deaf individuals
- Trauma-informed systems of care and Deaf culture
- Comprehensive evaluation of the Deaf trauma-informed care workforce
- Comprehensive database of culturally and linguistically accessible services and resources for Deaf individuals with trauma backgrounds

Consumer input was solicited at each step in the research process. Requests for key informants were sent to a network of professional contacts and organizations and a master list of 25 key informants was obtained. To ensure and protect patient confidentiality, this list included only the following information:

- geographic region
- age range
- ethnicity
- gender
- whether or not the key informant was a Deaf consumer or from a cohort of mental health and addiction service providers, researchers, higher education professors, and others selected for their knowledge and experience of Deaf culture and fluency in ASL
- referring person or agency

From this master list, five Deaf consumers were selected to be key informants based on racial/ethnic and geographic diversity as well as a range of hearing loss and communication levels. In addition, five service providers/professionals were selected to be key informants based on their knowledge and experience of Deaf culture across the workforce spectrum.

The findings were gathered using semi-structured interviews with key informants. The interviews began with structured questions to provide a guide for the consumer and eventually led to open questions to encourage the consumer to share their story in their own way. The interviewer conducted consumer interviews in person or via the use of Video Phone (VP). Because the interviewer is hard of hearing and fluent in American Sign Language, the interviews were conducted without the need for an interpreter. The questions (included in Appendix B) were written by the project team and provided to a focus group consisting of Deaf volunteers for review of the content and clarity. It was understood that the questions were written in English and that the interviewer would be

able to translate them into ASL in a manner that matched the communication level of the consumer.

Due to the highly sensitive nature of the key informant stories and the intimate nature of the Deaf community, the identifying details of the interviewees' stories were changed substantially to protect their identities. It was necessary to omit some of the detail from their stories to protect their confidentiality.

The consumer quotes provided in this paper are an English transcription of the interviewees' ASL stories as set-down by the interviewer for readability. They are not a direct transliteration of the consumer's ASL narratives. The consumers were provided with a written summary of the research goals along with an in-depth explanation of how the information would be kept private. This consent form was reviewed with the consumer prior to the interview and signed. Great care was taken to reduce the potential for re-traumatization of the consumers as they related their stories and the interviewer reviewed safety procedures for follow-up supports if necessary.

The service professionals' interviews were conducted either face to face or via telephone with the interviewer using VP as needed. Questions varied for each interview depending on the area of expertise (Please see Appendix C for a sample of questions asked). These professionals included a victim's advocacy coordinator, a hospital program director, a clinical psychologist, a state commissioner, and a researcher. Each of the professionals works extensively with the Deaf community and a few have hearing loss themselves. Everyone who was approached to be interviewed agreed to participate and was eager to share their knowledge and be involved in the process.

Did you seek mental health care?

Where or Describe what that was like or Was that hard or easy to do?

What helped?

What would you like to see changed?

What would you recommend to someone else who needed help?

What was hurtful to you on the inside?

What was hurtful to your heart?

Share with me what hurt your emotions or heart.

What are the cultural, systemic, and personal barriers to accessing and utilizing trauma-care services for Deaf individuals?

What research is available on trauma in Deaf communities?

What are the unique symptoms of trauma in Deaf individuals?

Does your organization provide direct services targeted towards trauma for Deaf individuals?

What works in the system for providing care for Deaf individuals with trauma?

Do you know of any resources out there to inform the Deaf community on trauma symptoms and care?

What would you like to see changed?

This Bill of Rights Act for the provision of mental health services to deaf and hard of hearing individuals is intended solely as a model for advocates to promote and for state legislatures to consider for codification into state law. Some words that are defined in this Act may already have definitions in existing state laws, and advocates and legislators are encouraged to refer to the definitions already used in their state laws. The definitions included in this model Bill of Rights Act are provided as one option, and may be compared against the prevailing definitions prior to submission to the state legislature for consideration of enacting this bill into law. Similar considerations should be accorded to structuring the state mechanism for oversight and funding of mental health programs directly serving the deaf and hard of hearing population.

SECTION 1.

This Act shall be known and may be cited as the "Mental Health for Deaf and Hard of Hearing Individuals Bill of Rights Act."

SECTION 2.

(a) The Legislature finds that:

(1) Individuals who are deaf or hard of hearing, as a group, represent an underserved population in many respects, particularly mental health services; and

(2) Individuals who are deaf or hard of hearing often require highly specialized mental health services.

(3) Research shows that individuals who are deaf or hard of hearing are subject to significantly more risks to their mental health than individuals who are able to hear due to many factors including but not limited to: lack of communication access in general as well as with family members, educators, and treating professionals; lack of access to appropriate educational services; and lack of appropriate physical and mental health treatment services.

(4) Some individuals who are deaf or hard of hearing may have secondary disabilities that impact the type and manner of mental health services to be provided to such

individuals.

(b) The Legislature further finds that:

(1) Being deaf or hard of hearing impacts the most basic of human needs, which is the ability to communicate with other human beings. Many deaf and hard of hearing individuals use a specific communication mode, sign language, which may be their primary language, while others express and receive language orally and aurally, with or without visual signs or clues. Still others lack any significant language skills.

(2) It is essential for the mental health well-being of deaf and hard of hearing individuals that mental health programs recognize the unique nature of being deaf or hard of hearing, and ensure that all deaf and hard of hearing individuals have appropriate and fully accessible counseling and therapeutic options;

(3) It is essential that deaf and hard of hearing individuals have mental health options in which their unique communication mode is respected and utilized, and the mental health professionals are proficient in the primary language mode of these individuals;

(4) It is essential that deaf and hard of hearing individuals have mental health options in which psychiatrists, psychologists, therapists, counselors, social workers, and other mental health personnel understand the unique nature of being deaf or hard of hearing and are specifically trained to work with deaf and hard of hearing individuals;

(5) It is essential that deaf and hard of hearing individuals have access to mental health professionals who are familiar with their unique culture and needs;

(6) It is essential that deaf and hard of hearing individuals are involved in determining the extent, content, and purpose of mental health programs and services;

(7) It is essential that deaf and hard of hearing individuals have programs in which they have direct and appropriate access to a full continuum of services, including, but not limited to all modes of therapy and evaluations;

(8) It is essential that deaf and hard of hearing individuals have specialized programs in which their unique mental health needs are provided for, including appropriate research, curricula, programs, staff, and outreach;

(9) Each deaf or hard of hearing individual should have a determination of the most accessible mental health treatment program and/or services that takes into consideration these legislative findings and declarations; and

(10) Given their unique communication needs, deaf and hard of hearing individuals would benefit from the development and implementation of state and regional programs for the mental health needs of such individuals.

SECTION 3.

The Legislature intends for the words used in this Act to have the following definitions:

(a) "Deaf individual" means an individual who has a hearing loss which is so severe that the individual has difficulty in processing linguistic information through hearing, with or without amplification or other assistive technology.

(b) "Hard of hearing individual" means an individual who has a hearing loss, whether permanent or fluctuating, which may be corrected by amplification or other assistive technology or means but nevertheless present challenges in processing linguistic information through hearing.

(c) "American Sign Language" means the visual language used by deaf and hard of hearing people in the United States and Canada, with semantic, syntactic, morphological, and phonological rules, which are distinct from English.

(d) "English-based manual or sign system" means sign systems which use manual signs in English word order, sometimes with added affixes that are not present in American Sign Language.

(e) "Oral, aural, or speech-based system" means a communication system which uses a deaf or hard of hearing individual's speech and/or residual hearing abilities, with or without the assistance of technology or cues, to any extent possible.

(f) "Communication mode, style, and language" means one or more of the following systems or methods of communication applicable to deaf and hard of hearing individuals:

(1) American Sign Language;

(2) English-based manual or sign systems;

(3) Minimal sign language system to communicate with those who use home-based signs, idiosyncratic signs, or a sign system or language from another country;

(4) Oral, aural, or speech-based systems.

(g) "Primary communication mode, style, and language" means the communication mode, style, and language which is preferred by and most effective for a particular individual, as determined by appropriate language assessment undertaken by individuals proficient in the communication mode, style, or languages being assessed.

(h) "Culturally and linguistically affirmative mental health services" means the provision of the full continuum of mental health services to a deaf or hard of hearing individual through appropriately licensed mental health professionals fluent in the primary communication mode, style, and language as well as the cultural needs of the individual requiring such services. These services are provided directly between the individual being served and the service provider. Such services are to be distinguished from "accessible mental health services" defined in subsection (i) below, which involves the use of interpreters or other auxiliary aids and services that provide access to mental health providers and services.

(i) "Accessible mental health services" means the provision of the full continuum of mental health services with the use of auxiliary aids and services necessary for a deaf or hard of hearing individual to communicate with appropriately licensed mental health professionals who are not fluent in the primary communication mode, style, or language of the individual requiring such services. Such auxiliary aids and services include but are not limited to: qualified interpreters (utilizing whichever language or mode used by the individual in need such as ASL, Signed English, Cued Speech, or oral); Certified Deaf Interpreters; written communications, assistive listening devices.

SECTION 4.

(a) It is the intent of the Legislature that the State mental health authority shall ensure the provision throughout the State of all of the following:

(1) Implementation and maintenance of mental health programs or options that provide for appropriate culturally and linguistically affirmative mental health services to

deaf and hard of hearing individuals in their primary communication mode, style, and language.

(2) Development, training, and maintenance of sufficient professionals needed to ensure appropriate culturally and linguistically affirmative mental health services to deaf and hard of hearing individuals in their primary communication mode, style, and language.

(3) Development, training, and maintenance of sufficient resources and professionals needed to ensure appropriate accessible mental health services to deaf and hard of hearing individuals in their primary communication mode, style, and language. Such professionals include but are not limited to: qualified interpreters certified or otherwise able to render effective communication in the mental health setting; relay or certified deaf interpreters; foreign sign language interpreters; occupational therapists familiar with such individuals' unique needs; prevention specialists; chemical dependency counselors; social workers.

(4) Monitoring of all mental health programs subject to the jurisdiction of the State mental health authority to ensure that deaf and hard of hearing individuals of all ages are adequately served, including but not limited to: children in need of various services in school, private therapy, or hospitals; parents needing services to qualify for restoration of child custody; adults needing the full continuum of services; chemical dependency services for all ages; prevention and psycho-educational programs for all ages; and senior citizens in need of elder care services.

(5) Adequate funding of all mental health programs that provide appropriate mental health services to deaf and hard of hearing individuals.
(b) In geographical areas where there are insufficient mental health professionals adequately trained in any communication mode, style, or language necessary to treat deaf or hard of hearing individuals, the State mental health agency shall develop and implement strategies and plans to address such a need, including but not limited to:

(1) Permit treatment by qualified mental health professionals licensed by another state to treat or otherwise service the needs of deaf or hard of hearing individuals in this State.

(2) Permit treatment through technology (including but not limited to: videophones or tele-psychiatry or tele-medicine) which would allow deaf or hard of hearing individuals to

get appropriate culturally and linguistically affirmative mental health services from mental health professionals who are licensed in this State or another state.

(c) No deaf or hard of hearing individual shall be denied access to appropriate culturally and linguistically affirmative mental health services in a particular communication mode, style, or language solely because:

    (1) The individual has residual hearing ability, whether assisted or not; or

    (2) The individual has previous experience with some other communication mode, style, or language.

(d) Nothing in this Code section shall preclude mental health treatment in more than one communication mode, style, or language for any particular individual. Any individual for whom treatment in a particular communication mode, style, or language is determined to be beneficial shall receive such treatment as part of the individual's mental health services.

SECTION 5.

All laws and parts of laws in conflict with this Act are repealed.

DEAF AND MENTAL HEALTH LITERATURE

There has been a growing awareness of the inability of the current behavioral health system to meet the mental health needs of the Deaf population. Deaf individuals experiencing trauma are no exception. This awareness has taken the form of several reports, which describe current problems and possible solutions to improving responsiveness to Deaf individuals. These reports include:

- Call to Action to Improve the Health and Wellness of Persons with Disabilities (U.S. Department of Health and Human Services, 2005).
- Identification of Performance Standards for the Deaf and Hard of Hearing: Report on the Analysis of Data Sources for Assessing the Health Status of Deaf and Hard of Hearing People (Delmarva Foundation for Medical Care & Gallaudet Graduate Research Institute, 2002).
- 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, 2002.
- Standards of Care for the Delivery of Mental Health Services to Deaf and Hard of Hearing Persons (Myers, 1995).
- Cultural Diversity Series: Meeting the Mental Health Needs of Persons who are Deaf (Critchfield, 2002).
- The National Coalition on Mental Health and Deaf Individuals' Report on the 2009 Deaf Expert's Meeting, Year in Review, and a Framework for Action (National Coalition on Mental Health and Deaf Individuals, 2009).

DEAF CULTURE LITERATURE

Deaf culture is a rich and vibrant entity in the United States and is described in detail in the popular and academic literature. The following selected resources offer in-depth studies, reviews and self-analysis of Deaf culture in general and behavioral health issues specifically.

- *Inside Deaf Culture* by Carol A. Padden and Tom L. Humphries (Padden, 2005)
- *Deafness as Culture* by Edward Dolnick (Dolnick, 1993)
- *Train Go Sorry*: Inside a Deaf World by Leah Hager Cohen (Cohen, 1995)
- *A Journey Into the Deaf-World* by Harlan Lane, Robert Hoffmeister, and Ben Bahan (Lane, 1996)
- Mother Father Deaf: Living Between Sound and Silence by Paul Preston (Preston, 1995)
- Mental Health Care of Deaf People: A Culturally Affirmative Approach by Neil S. Glickman and Sanjay Gulati (Glickman, 2003)
- Psychotherapy with Deaf Clients from Diverse Groups by Irene W. Leigh (Leigh, 1999)

BEHAVIORAL HEALTH SERVICES FOR THE DEAF POPULATION

In 2001, the Office of Minority Health (OMH), within the US Department of Health and Human Services (HHS) published the *National Standards for Culturally and Linguistically Appropriate Services in Health Care* (U.S. Department of Health and Human Services Office of Minority Health, 2001). This report established 14 national standards for health care delivery to populations that are culturally and linguistically different from mainstream America, including standards related directly to the importance of providing health care in the client's preferred language and culture. These standards highlight and support the need for the development of evidence-based practices for trauma-informed care as they apply to

the Deaf population. These standards can be found on The Office of Minority Health's website at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15

SELECTED INTERNET RESOURCES

This list of selected Internet sites includes a variety of information on trauma by and for Deaf individuals. The sites that are directly relevant for this area are few at this time. Many of the sites are from programs or grants that serve women and children with trauma experiences. Other sites provide general information that may be relevant. *This list is provided as a resource. It is not exhaustive, nor does the content necessarily reflect the views, opinions, or policies of SAMHSA, NASMHPD, or NCMHDI.*

Abused Deaf Woman's Advocacy Services
www.adwas.org

Deaf Abused Women's Network
http://deafdawn.org/

Deaf Abused Women Warrior's Web Network
http://dawwwn.homestead.com/files/intro.htm

Deaf Hope
http://deaf-hope.org/

Deaf MD
This video provides information on the definition of rape, the effects, how to obtain treatment and follow-up care and prevention.
http://www.deafmd.org/pub/topic/Rape/What-is-it

Deaf Vermonters Advocacy Services

http://www.dvas.org/

DOVE

http://deafdove.org/

L.E.A.D. Institute

http://www.deaflead.org/

What is Abuse?

This video from the Deaf Vermonters Advocacy Services presents the definition of abuse in American Sign Language.

http://www.dvas.org/dv-sa/video-in-asl-what-is-abuse