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# Understanding How Ethnic and Cultural Minorities Perceive Peer Support and Recovery: Final Report

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## **Comments**

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# Understanding How Ethnic and Cultural Minorities Perceive Peer Support and Recovery FINAL REPORT

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- A: Key Informant Interview Guides
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## **Executive Summary**

### **Project Overview and Study Objectives**

Mental health systems transformation has had the promotion of recovery and peer support at its core. In order to better understand how people of different cultural, linguistic, and ethnic backgrounds understand and interpret the concepts of mental health, mental illness, recovery and peer support, the Massachusetts Department of Mental Health (DMH) and MassHealth asked the Center for Health Policy and Research at UMass Medical School to conduct a study exploring these issues. Two specific cultural groups were identified to be the focus of this study – Latinos and individuals who are Deaf and/or Hard of Hearing (D/HH).

### **Study Methods**

The overarching goal of our study was to inform DMH and MassHealth about the current thinking and feelings of these marginalized populations regarding mental illness, as well as recovery and peer support. We first identified key informants and conducted telephone interviews with them about their own research and experience in our area of interest. Key informants were either nationally recognized published experts in their field or a direct provider of services for our population of interest.

Our study utilized the services of cultural brokers who we included as members of our study team. These individuals belonged to the cultural groups of interest and had a self-identified mental health condition. We identified brokers who were seen as respected leaders in their respective communities and who had connections that would facilitate the identification of individuals to participate in data collection. The cultural brokers participated in all aspects of the study, including recruitment, question set development, interviews/focus groups, and aiding in the analysis of our qualitative data. Interviews and focus groups were then held with peers from the communities of interest. Eighteen Latino peers and 12 D/HH peers participated in either an interview or focus group.

### **Study Findings**

#### **Latino Population**

Respondents described the negative views of mental health shared among many members of their community. There were reported feelings of shame and embarrassment associated with having a family member with a mental health condition which often led to attempts of dealing with the mental illness within the family instead of seeking professional help. We heard from many of the Latino peers in our study about the rejection they've faced from their family due to their mental health condition.

Latino peers expressed varying experiences with utilizing mental health services. Some have had positive experiences with accessing necessary services and have found providers with whom they can communicate. For others, their experience with the mental health system has been filled with long wait lists for services, a lack of interpreters (or ineffective interpreters), and working with clinicians who they don't connect well with.

Peers recognized that the process of recovery is not easy and that a commitment from within is

required. Peers also recognized that while the concept of recovery was understood and accepted by many Latinos, the actual term may not be used frequently. People will say “I’m feeling better” or “I feel good” rather than saying “I’m in recovery”. There are some Latinos, however, who saw themselves as “sick” and unable to get well. They reported that it is not within their power to get well. There was also the perception that many Latinos don’t want to work on their recovery and get well because of the fear of losing the government benefits they currently receive.

Many of the Latino peers we spoke to were part of a peer support group. They found the support received from these groups to be invaluable, and often what has helped them the most in their recovery. They cited the need to make peer support, particularly Spanish-speaking peer support, more widely available.

### Deaf/Hard of Hearing Population

We heard from both peers and key informants about the high level of stigma in the D/HH community surrounding mental health issues. One reason for this is the lack of education the deaf community at large has regarding mental health conditions. The difficulties in providing broad-based public education to the deaf community about mental health issues appears to be correlated with higher levels of mental health stigma in the D/HH community.

Because the D/HH community is small and somewhat insular, gossiping was noted to frequently occur. D/HH individuals noted fear of being labeled “crazy” and some refused mental health treatment because of fear of others finding out. Therefore, confidentiality and privacy concerns are paramount, especially with regard to mental health treatment.

The D/HH peers in our study expressed a preference for receiving mental health services from someone who could communicate in American Sign Language (ASL). However, there are a limited number of providers who can offer mental health services in ASL. The use of interpreter services, therefore, becomes a necessity, yet sometimes not made available. Working with an interpreter can also be frustrating because of the lack of ease in directly communicating with someone and a fear of things being misinterpreted. Not all D/HH individuals are fluent in ASL. Therefore, multiple modes of communication need to be offered in order to provide optimal mental health services.

The majority of D/HH peers we spoke with identified being more active and social as an indication of feeling better about their mental health and therefore associated with recovery. While there was general consensus that peer support from another D/HH person with mental illness was valued, we received mixed responses about receiving peer support from others. Some D/HH individuals would like to receive peer support from someone who has mental illness so they do not feel alone. Others would prefer to work with a non-peer for reasons that were not well described, while still others preferred to receive services from both peers and non-peers.

## **Conclusion**

In recent years, racial and ethnic disparities in health care have been consistently documented across a wide range of medical conditions and health care services, including mental health care. Communication issues are one area where such disparities exist. There is a lack of mental health providers who can communicate in languages other than English. The peers we spoke with also cited inadequate interpreter services as posing a challenge to accessing mental health services. Both Latinos and D/HH peers reported difficulties in accessing a range of mental health services in their preferred language. Accessing recovery-oriented services and peer support was perhaps secondary to accessing basic therapy and psychiatric services in a language they feel comfortable with.

Both Latino and D/HH peers understood recovery as feeling better, being active and resuming normal activities. Though recovery is very individually defined, this understanding is in alignment with the mainstream perception of recovery. Recovery can also be understood along a continuum, with feelings of empowerment, advocacy and personal responsibility being components. All components of recovery must be infused throughout the mental health system.

Among the peers we spoke to, peer support was valued among everyone. All study participants preferred peer support to be offered in a language they could fully participate in. However, there are limited peer support groups available in Spanish and even less available in ASL. Therefore, this is a limited resource that both Latinos and D/HH peers would like to see expanded.

## **Recommendations**

Based on our interpretation of findings, we offer the following recommendations to MassHealth and DMH for consideration.

- DMH and MassHealth need to work with their providers to establish creative outreach strategies to reach a greater number of people from underserved communities and make a range of culturally- and linguistically-competent mental health services available to them.
- DMH and MassHealth need to consider what they can do to expand the number of mental health professionals who can offer services to people who are Latino and D/HH. At a minimum, qualified interpreters need to be available to facilitate communication between the provider and service user.
- DMH and MassHealth should work with mental health service agencies to ensure that a sufficient number of providers are able to serve these special populations and that adequate transportation options are available for people to attend their appointments.
- DMH and MassHealth need to further support their providers in delivering recovery-oriented and peer support services to all populations they serve, even if their numbers are small.

- MassHealth should seek to better understand how to best serve a variety of culturally and linguistically diverse populations in the mental health system in order to ensure that everyone has access to culturally- and linguistically-competent and high quality mental health services as well as services that are based in recovery, such as peer support.

## **I. Background and Significance**

The Massachusetts Department of Mental Health (DMH) reprocured its adult community-based mental health service delivery system in July 2009. Through these new contracts, DMH is requiring mental health service providers to be more recovery-oriented and offer peer support services to their clients. Providing recovery-oriented and peer support services in a culturally and linguistically appropriate manner is essential to providing effective mental health care. DMH has expressed a need to better understand how people of different cultural, linguistic, and ethnic backgrounds understand and interpret the concepts of mental health, mental illness, recovery and peer support. The implementation of these concepts in Massachusetts' mental health system may not be widely available to these unique populations. In order for mental health providers to effectively serve these populations, culturally-tailored approaches to recovery and peer support are needed.

DMH and MassHealth have asked the Center for Health Policy and Research (CHPR) at UMass Medical School for a study that would explore the issues surrounding mental health recovery and peer support for certain cultural groups. The objectives of this study are to answer the following questions for the specific cultural, linguistic and ethnic groups of focus for this project:

- 1) How do people of these different cultural, linguistic, and ethnic groups understand the concepts related to mental health, mental illness, recovery, and peer support?
- 2) Is peer support an acceptable approach for supporting individuals' recovery for these different cultural, linguistic, and ethnic groups?
- 3) If peer support is an acceptable approach, what type of peer support is most meaningful for these populations?
- 4) How can recovery-oriented and peer support services be made more accessible and culturally- and linguistically-competent for these populations?

Phase 1 of this study included a literature review and in-depth interviews with key informants knowledgeable in culturally and linguistically competent mental health services and/or peer support in the following communities: Deaf and Hard of Hearing, Latino, African American, and Cambodian. After reviewing Phase 1 findings with DMH, we targeted the Deaf and Hard of Hearing and Latino communities to be the focus in Phase 2 (i.e., the focus of this report). This allowed for more in-depth data collection with peers from each cultural group.

### **A. Literature Review**

#### **Latino Population**

Latinos are the fastest growing minority group in the United States with an estimated 41 million Latinos residing in the US in 2004 increasing to a projected 61 million in 2030 (National Council of La Raza: Institute for Hispanic Health, 2005). Latinos are a diverse population and represent the largest racial/ethnic minority in the United States. In Massachusetts, 7.7 % of the population reports being Latino. A variety of Latino groups reside in Massachusetts, with Puerto Ricans and Dominicans representing over 60% of all Latinos in the state (Shea & Jones, 2006).

Several large epidemiological studies including the National Latino and Asian American Study (NLAAS) indicate that the lifetime prevalence estimates for depression, anxiety, and/or substance use disorders among Latinos is 28% for men and 31% for women (Alegria, Mulvaney-Day, Torres et al., 2007). The ever-growing population of Latinos suggests that more individuals will be needing mental health services. With the abundance of literature that exists regarding preventable racial and ethnic disparities in mental health services, access to quality mental health care that meets the cultural needs of this population is vital (Blanco et al., 2007; Primm et al., 2010; Washington et al., 2008).

Latinos born in the US experience higher rates of psychiatric disorders as compared to foreign-born Latinos (Alegria, Mulvaney-Day, Torres et al., 2007). A study by Cook, Alegria, Lin, and Guo (2009) found that greater exposure (acculturation) to the United States increases rates of mental illness among Latino immigrants, which can potentially be explained by higher rates of perceived discrimination and greater family cultural conflict. Latino immigrants who have been in US for a longer amount of time also have higher rates of mental health problems (Alegria, Mulvaney-Day, Woo et al., 2007; Mulvaney-Day, Alegria, & Sribney, 2007). According to the National Council of La Raza, more than 80 million people in the United States are at risk of suicide due to mental illness and substance use disorders with Latinos having higher rates of attempted suicide (10.7%) compared with African Americans (7.3%) and non-Hispanic whites (6.3%) (National Council of La Raza: Institute for Hispanic Health, 2005). In that same report, suicide is reported as the third leading cause of death among young Latinos 10-24 years old. Appropriate utilization of culturally- and linguistically-competent mental health services is therefore necessary and further addressed in the section below.

#### Utilization of mental health services

Mental health service utilization among Latinos is varied. Many studies conducted on Latinos' use of services for mental health conditions have shown that fewer than 1 in 11 Latinos with a mental health condition sought specialty mental health services and that fewer than 1 in 5 obtained general medical services for mental health problems (Alegria, Mulvaney-Day, Woo et al., 2007).

Studies have found that Latinos residing in the United States for less than 10 years had significantly lower mental health service use rates than those who have resided in the United States for 21 years or more (Alegria, Mulvaney-Day, Woo et al., 2007; Berdahl & Torres Stone, 2009; Mulvaney-Day et al., 2007). Latino adults in an established immigrant community utilized services at a significantly higher rate than in the recently immigrated community, 8.2% and 5.2%, respectively (Aguilera & Lopez, 2008). Interestingly, utilization rates were higher in the recently immigrated community if they had higher incomes.

#### Barriers and facilitators to accessing mental health services

While there are a number of reported barriers to accessing mental health care, there are also some factors that are associated with higher rates of utilization among Latinos. These include:

recognizing the need for mental health services; having health insurance; and speaking and understanding English (Alegria, Mulvaney-Day, Woo et al., 2007; Vega et al., 2007). In a study by Cardemil et al. (2007) and colleagues, Latino participants who had health insurance were significantly more likely to report seeking mental health services than those who did not have health insurance, 64.6% and 28.6%, respectively.

Several recent studies, however, reported a number of barriers Latinos face when trying to access mental health services (Aguilera & Lopez, 2008; Alegria, Mulvaney-Day, Woo et al., 2007; Berdahl & Torres Stone, 2009; Ojeda & McGuire, 2006; Vega, Kolody, & AguilarGaxiola, 2001). Many of these studies indicate that language is a major barrier when accessing services with Vega et al. (2007) specifically noting that 30% of Latinos reported difficulty in communicating with providers. Lack of health insurance has also been reported as another barrier for Latinos accessing mental health care. In the study by Alegria, Mulvaney-Day, Woo et al. (2007), only 19.1% of uninsured Latinos utilized mental health services compared to 38.6% of those with private insurance. Other factors posed as barriers include level of education, foreign-born status, and working in temporary or unstable jobs that do not support taking time off for health care.

#### Cultural beliefs about mental health

According to the literature, Latinos share some key cultural beliefs that may impact their understanding of mental health and their help-seeking behaviors. Some of these include: *familismo*, which stresses attachments and loyalty to family members beyond boundaries of the nuclear family and emphasizes the importance of holding family/group values above those of the individual; and *personalismo*, which refers to a preference for relating on a personal, rather than formal or institutional level, which can challenge traditional boundaries in therapeutic relationships (AndresHyman, Ortiz, Anez, Paris, & Davidson, 2006). Additionally, religion and spirituality can play an important part in a Latino's life and can impact how Latinos view and pursue help for their mental health problems (AndresHyman et al., 2006). Clinicians need to be aware of the cultural beliefs of those they serve in order to develop a respectful and trusting relationship with clients. As described in more detail below, improved relationships will likely translate into improved care and better outcomes.

#### **Deaf and Hard of Hearing Population**

In the United States, approximately 8.6% of the populations age three and older are reported to have hearing problems (Critchfield, 2002). The same percentage rate (8.6%) can be applied in Massachusetts as there are approximately 546,022 deaf or hard of hearing (D/HH) residents (Office of Health and Human Services, Mass.Gov Health and Human Services, 2011). Regardless of the prevalence, D/HH people view themselves as a cultural and linguistic minority, rather than being afflicted with a handicap, which must be minimized or overcome (Critchfield, 2002).

Among racial and ethnic minorities, disparities in both medical and mental health needs have been clearly established (Blanco et al., 2007; Primm et al., 2010; Washington et al., 2008). These disparities have also been seen in the D/HH community, among a number of other cultural and linguistic minorities, where studies report an inadequate amount of mental health

services available to serve these populations. In one study, 90% of D/HH individuals ages 20 to 85 indicated that there were not enough mental health services for deaf individuals and that more are needed (Feldman & Gum, 2007). Not surprisingly, communication difficulties are frequently cited as contributing to problems in accessing mental health services among D/HH people. Lack of communication between providers has been cited to be the cause for some individuals to be misdiagnosed as psychotic and others having their psychotic symptoms ignored by virtue of poor interpretation, deafness, or minimal language skills (Mueller, 2006; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). As described in detail below, these disparities result in numerous barriers to mental health care and the utilization of culturally and linguistically appropriate services.

#### Utilization of mental health services

It is estimated that 80-90% of D/HH people with severe and persistent mental illness or severe emotional disturbance are not accessing the mental health system (Critchfield, 2002). Results of a study on multigenerational perceptions of mental health services among D/HH people showed that younger respondents are more likely to seek help from a mental health professional as compared to older adults. Respondents who were older and/or elderly showed a stronger preference to seek help from family, friends or their primary care physician. Older D/HH adults also reported to be less likely to be aware of available services, less trusting of mental health professionals, and less knowledgeable about where to go to access services (Feldman & Gum, 2007).

#### Barriers and facilitators to accessing mental health services

Several studies have documented that communication barriers exist in various forms for individuals who are D/HH. In a study by Steinberg et al. (2006), D/HH respondents reported poor understanding of instructions by their clinicians due to difficulty with communication. Many mental health professionals assume that D/HH peers are literate in English (Haskins, 2000; Steinberg, Sullivan, & Loew, 1998). The abstractness of psychiatric questions posed to individuals during an evaluation is another barrier for people who are D/HH (Mueller, 2006). For a person with a limited language system, these questions may lead to poor assessment resulting in barriers to treatment and ongoing appropriate intervention.

American Sign Language (ASL) is the most prevalent sign language of D/HH people in the United States. ASL is the third most used language in the United States, next to English and Spanish (Critchfield, 2002). However, not all D/HH people are fluent in ASL which can affect their use of mental health services. One study of people in a D/HH psychiatric unit found that 75% of the individuals lacked ASL fluency (Black & Glickman, 2006). Even with ASL fluency, sometimes having an ASL interpreter assumes that effective communication is occurring between the peer and the mental health professional. However, an interpreter may filter information either to protect the peer or to ease a situation in which they are uncomfortable which can be a disadvantage for both the peer and the mental health professional when trying to accurately inform and educate each other (Critchfield, 2002).

Several studies have shown that D/HH individuals prefer a therapist who can sign and understands the deaf culture. If that is not available, then the preference is for a qualified interpreter to act as a liaison between the person and the mental health professional. However,

some peers are apprehensive around confidential issues and the ASL competency of the interpreter (Critchfield, 2002; Feldman & Gum, 2007; Steinberg et al., 1998; Steinberg et al., 2006).

Studies indicate that individuals who are D/HH often seek support from other members of the D/HH community. As Steinberg, Sullivan, and Loew (1998) indicate, receiving support from other D/HH individuals is a preference among many individuals; 81% of their study participants preferred D/HH-only groups as opposed to receiving support in a mixed hearing group. In a report by Critchfield (2002). D/HH individuals also look to community agencies that they have previous contact with for information on mental health services, such as vocational rehabilitation services and residential schools for support.

### Cultural beliefs about mental health

Mental health stigma and distrust of the mental health system exists among people who are D/HH. Unfortunately, there have been times when people who are D/HH have been sent to the hospital without just cause simply because of miscommunication. In one qualitative study by Steinberg et al. (1998), D/HH people viewed both mental health institutions and practitioners as authoritarian, restrictive, and prejudiced and referred to the “mental hospital” by signing PRISON, STRAIGHT-JACKET, or CRAZY-HOUSE.

### **Role of the Cultural Broker**

Many studies that examine sensitive topics within the context of different cultural groups utilize the services of a cultural broker. As defined by the National Center for Cultural Competence (NCCR), culture brokering is the act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change (National Center for Cultural Competence, 2004). The culture broker acts as a go-between, one who advocates or intervenes on behalf of another individual or group. There are a number of benefits for the consumer by working with a cultural broker. If a positive relationship develops, this may lead the patient to continue to access services which could potentially improve health outcomes and reduce health disparities. The consumer may seek care sooner if they know agencies understand and respect their cultural values and beliefs. Additionally, they may encourage others in their community to access care, which will impact the health of the entire community.

An effective cultural broker takes on many roles and requires numerous skills. According to Singh, McKay, and Singh (1999), within mental health, the role of the cultural broker can be to: facilitate a clinician’s understanding of a person’s problem; help the person understand how the clinician is treating the problem; explain western mental health concepts to the individual; and explain the ethnic-specific mental health concepts to the clinician. Additional skills needed to be an effective cultural broker include: adequate language skills, both in the individual’s native culture as well as the language of the mainstream culture; knowledge of mental illness as conceived and perceived by the individual seeking the services as well as by the mainstream culture; ability to accurately describe the individual’s problems without distorting the information or being judgmental; and the ability to keep all information about the individual confidential, regardless of whether material is perceived to be sensitive or not (Singh, McKay, & Singh, 1999). As cited in numerous articles (National Center for Cultural Competence, 2004; Schwab,

Drake, & Burghardt, 1988; Singh et al., 1999), although a cultural broker requires numerous skills, a critical component of the cultural broker role is establishing a relationship based on trust and respect.

## **II. Study Methods**

In this section, we will describe our evaluation approach, including the role and expectations of the cultural brokers. We employed various data collection methods which will also be described, along with our data analysis approach.

### **A. Description of Study Approach and Use of Cultural Brokers**

Our review of the literature helped to inform us of the types of studies that have been completed with Latino and D/HH mental health consumers and the types of approaches that have been used for data collection. Qualitative methods have shown to be an effective way to gain insights and impressions on complicated and/or sensitive topics. Because the goal of the study was not to create generalizable knowledge, but rather to inform DMH and MassHealth about the current thinking and feelings of these marginalized populations regarding mental illness, as well as recovery and peer support, creating a comfortable environment in which to collect data was essential. It also quickly became evident that, in addition to our study team, we needed to partner with leaders from these two communities to work with us on gaining entry and confidence in these communities.

We sought recommendations on appropriate cultural brokers from our contacts at DMH, as well as from the Transformation Center, a peer-run training and technical assistance center for mental health issues. The study team then interviewed individuals to discuss the project with them, and assess their comfort level in talking about their mental health, their experience in leading support groups, and other relevant experiences. We contracted with three individuals to serve as cultural brokers for this project. Two of them were individuals who are deaf and have mental illness; one person was a Latino with mental illness<sup>1</sup>. All were currently receiving mental health services. These cultural brokers were seen as respected leaders in their respective communities and had connections that facilitated the identification of individuals to participate in data collection. These individuals were responsible for working with us on recruitment, question set development, facilitating interviews/focus groups and aiding in the analysis of our qualitative data. Additionally, we also contracted with two American Sign Language (ASL) interpreters to participate in all D/HH data collection efforts as well as project meetings with the deaf cultural brokers.

### **B. Data Collection**

The first phase of data collection began in June 2010 with key informant interviews. Key informants are known experts in their particular field of interest or practice. We identified individuals who had published manuscripts and/or other reports in Latino or D/HH mental health issues as potential key informants. We also relied on their recommendations and the

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<sup>1</sup> The original plan was to have two cultural brokers for each cultural group in order for them to be able to work together and provide support and ideas to one another. However, one of the cultural brokers identified for the Latino work was not able to devote the time necessary for the project.

recommendations from our colleagues at MassHealth and DMH for other potential key informants. We completed interviews with three D/HH mental health key informants and five Latino mental health key informants. All of the Latino mental health key informants were university-based researchers who were Latino themselves. One of the D/HH key informants was a university-based researcher while the other two worked for the Massachusetts Department of Mental Health exclusively with D/HH clients. Some of the key informants were based in states other than Massachusetts; therefore, we did not explore knowledge of the Massachusetts mental health system with any of our key informants. A semi-structured interview guide (Attachment A) was used with all interviews. Findings from key informants helped to shape future data collection efforts.

Qualitative data were collected from people using mental health services from the two cultural groups of interest via a mix of focus groups and interviews. The cultural brokers used their personal connections as well as linkages to mental health service agencies to identify people who might be interested in participating in this project. A fact sheet was developed for the cultural brokers to distribute (one in English and one in Spanish; see Attachment B). If a person was interested, they were asked if they had a preference for participating in an interview or a focus group. The cultural brokers were largely responsible for setting up a time and place for the data collection to occur.

Interview and focus group guides were developed by the study team with input from the cultural brokers (Attachment C). The cultural brokers used these guides to lead the interview/focus groups. One other CHPR team member was present to record notes from the data collection. One of our team members is proficient in Spanish and participated in all Latino data collection efforts. ASL interpreters were used for all D/HH data collection efforts to interpret the conversation between the cultural broker and the participant(s) to the CHPR note taker.

All participants were people who identified themselves as someone with a mental health condition. No other confirmation of their mental illness was required to participate in this study. Given the connections of the cultural brokers to clubhouses and Recovery Learning Communities, some of the individuals who participated in the study also participated in activities in these settings. A \$15 Target gift card was offered to all those who participated in either a focus group or interview. The Institutional Review Board (IRB) at UMass Medical School approved the study.

Key informants suggested that D/HH individuals would feel more comfortable talking about mental health issues on an individual basis instead of in a group. Because of this, more individual interviews took place within this population. Table 1 shows a breakdown of participants and data collection method.

**Table 1: Number of Interviews/Focus Groups completed by Cultural and Linguistic Group**

	Latino	D/HH	Total
<b>Focus Group (FG)</b>	2 FGs (13 people)	1 FG (4 people)	3 FGs
<b>Individual Interviews</b>	5 people	8 people	13 interviews
<b>Total</b>	18 Latinos	12 D/HH	30 individuals total

**C. Data Analysis Approach**

CHPR used a systematic and rigorous process to conduct the qualitative analysis of all interview and focus group data. Once the note taker typed the notes into Microsoft Word ©, the cultural broker reviewed them and revised as needed. Interview notes were then transferred into the qualitative data analysis tool Atlas.ti © for analysis.

Throughout data collection, team meetings were held with the cultural brokers to identify initial themes that we heard from the interviews and focus groups. Once the data was in Atlas, CHPR staff were able to more methodically review the data to see if these themes were indeed present and what new themes emerged. CHPR staff members worked together to identify a draft coding structure and took the initial approach in coding all data. In-person meetings were then held with the cultural brokers to review the coding approach and come to consensus on how these codes should be applied. CHPR staff then completed all coding and reviewed each other’s work to ensure consistency in the application of codes. Discussions were held about what conclusions could be drawn from the data and the CHPR team came to agreement about how to present our findings.

**III. Findings**

In this section, we present findings from the key informant interviews, individual interviews and focus groups. Because the findings are distinct for each of the two cultural groups identified, we present the findings separately. For each cultural group, we address:

- i) Cultural understanding of mental health, mental illness, recovery, and peer support
- ii) Personal experience of mental health, the mental health system, and recovery
- iii) Use and experience of peer support
- iv) Expanding recovery-oriented and peer support services

As applicable, we use the words of individuals who participated in this study to enrich our description of findings and present these in italics.

**A. Latino Population**

In this section, we will synthesize the information we collected from Latino mental health key informants as well as Latino mental health peers.

- i) Cultural understanding of mental health, mental illness, recovery, and peer support

There are various countries of origin and varying levels of acculturation that make up Latinos in Massachusetts. Because of this, it is difficult to broadly generalize how the Latino culture understands mental health, mental illness, recovery and peer support. However, based on our data collection, there are some strong themes surrounding this issue.

Key informants (KIs) gave us a different perspective on the community's understanding of mental health as compared to the peers we spoke with. Some KIs felt that the Latino community has a higher level of acceptance for people with depression and anxiety as opposed to those with more serious mental health (MH) conditions. KIs also suggested that a person's level of acculturation has an impact on their level of understanding and acceptance, with those being more acculturated having less acceptance.

*Each group has a different understanding and view of mental health. Some Latinos share western cultural ideas and others do not. Some Latinos think only of extreme mental illness versus milder mental illness such as depression or anxiety. Some Latinos feel that people with mental illness just need to rest.*

Among the peers we interviewed, we heard very strongly how negatively their community views MH issues. They are seen as "crazy" and a "vergüenza" (embarrassment/shame). Many have been rejected by their family and community. Others describe the secrecy surrounding MH issues and the lengths some family members go to hide mental illness within the family. Many families have faith traditions and beliefs that those with MH conditions are possessed by evil spirits and therefore getting help from outside the faith community is not an option. Some will therefore refuse MH services because of social expectations.

*We're crazy. We can't achieve anything. They don't believe you. They judge and reject you and fear you. You get no family support. They believe my hallucinations are made up. They laugh at me.*

When speaking about family issues, we heard different perspectives from the KIs and the peers. KIs strongly felt that family members want to be involved in helping their loved one with mental illness and that involving the family in all aspects of treatment was necessary. KIs indicated that families prefer to deal with things as a family unit and not in isolation. However, as mentioned above, the peers we interviewed spoke of the minimal connections they have with their family, the rejection they've faced, and the lack of support they've received. Other peers indicated that their families are not aware that they are dealing with a mental health condition; they've kept it a secret because they know their family would not accept it. While this was the case for most of the participants in this study, it should be noted that a few individuals found a great deal of support and help from their family.

#### ii) Personal experience of mental health, the mental health system, and recovery

Most of the peers we spoke with saw their mental health condition as a disease like any other (i.e., similar to a medical condition). It comes with struggles, but recovery is possible. We heard of many different experiences with the mental health system. Some have had positive

experiences with accessing necessary services and have found providers with whom they can communicate. For others, their experience with the mental health system has been filled with long wait lists for services, lack of interpreters (or ineffective interpreters), and working with clinicians who they don't connect with.

*There are no services [in Spanish] for us in Haverhill. It's hard to get to Lawrence. You need an interpreter sometimes. I've brought my 10 year old daughter to be my interpreter. There is a wait list - 2 or 3 months. If you want to commit suicide, you can't wait that long. With interpreters, you can never get all the information. When I requested more information, the doctor told me I was manic.*

Latinos reported experiencing several barriers in accessing services. These included:

- Limited Spanish-speaking services – There are few providers who offer bilingual services. Those that do often are located in urban areas and have long wait lists for new clients. Peers cited the need for Spanish-speaking psychologists, psychiatrists, support groups, and conferences. The lack of Spanish-speaking services limits Latinos' ability to fully participate in these services. It also prevents many from seeking out needed services. There is also a lack of awareness of the few programs that are available for Spanish-speaking peers, particularly support groups.
- Transportation – Spanish language mental health services primarily exist in certain geographic locations (i.e., Boston, Lawrence, Worcester). For people outside these areas with limited transportation options, accessing needed services is problematic. Some mental health programs are able to offer bus passes or transportation vouchers, but these offerings are limited.
- Use of interpreters – While having access to interpreter services is important, there are barriers associated with this. Many peers gave examples of interpreters not being available with they arrived at an appointment with a non-Spanish speaking clinician. Many then had to rely on a family member (often their child) or a friend to interpret for them at the appointment. When an interpreter was made available, people had mixed feedback on their experiences. Some with limited English understanding were able to discern when things they said were not interpreted correctly, thereby causing frustration.
- Ineffective relationships with clinicians – Some peers we interviewed questioned the motives of their clinicians, feeling that most are motivated only by a paycheck and not a genuine desire to help people. Some received contradictory messages from their providers about their ability to recover. Others gave examples of clinicians presenting them with a dismal outlook for the future with no chance for recovery.

Some KIs felt that the concept of recovery is not well understood by Latinos. They indicated that recovery was tied to cultural expectations of being able to work, contribute to the family, and establish healthy relationships. However, among the peers we spoke with, all were familiar with the term and most indicated that they were in the process of recovery. For them, recovery meant being active and resuming daily tasks like getting up in the morning, showering, and

getting out of the house. Also mentioned was a willingness and acceptance to take medication regularly.

*There is no concept of recovery. It is a modern American invention. [Key Informant]*

Peers recognized that the process of recovery is not easy and that a commitment from within is required. Peers also recognized that while the concept of recovery was understood and accepted by many Latinos, the actual term may not be used frequently. People will say “Estoy mejor” (“I’m feeling better”) or “Me siento bien” (“I feel good”) rather than saying “Estoy en recuperación” (“I’m in recovery”). There are some Latinos, however, who see themselves as “sick” and unable to get well. They reported that it is not within their power to get well. There was also the perception that many Latinos don’t want to work on their recovery and get well because of the fear of losing the government benefits they currently receive.

*To be in recovery means you don’t want to be sick anymore. Things that didn’t appeal to you before now do. You feel as if a person of worth has come from within. I have to be in recovery for me, not for anyone else, like my kids. I feel proud to see where I’ve come. I’ve achieved a lot. But I haven’t healed completely.*

*I believe in our recovery. I am a living example. Recovery doesn’t come right away, but little by little.*

### iii) Use and experience of peer support

Again, there were different perspectives about peer support reported to us by the KIs compared to the peers themselves. Many KIs were not aware of peer support being available for Latinos. Others thought that Latinos would prefer to get support from their family as opposed to others with mental health conditions. We also heard from KIs that Latinos may be reluctant to share their mental health experiences with others because of a fear that the whole community will find out. Lastly, some KIs felt that peer support for Latinos should not be limited to only those with MH conditions, but should include anyone who a peer feels comfortable with.

*The issue of peers and peer support takes on a different characteristic where Latinos are concerned. Because of the high respect that Latinos pay towards medical professionals, they tend to seek out professional level services as opposed to less structured peer services. [Key Informant]*

*I haven’t experienced anyone in the community getting peer support. I think it is a new concept. [Key Informant]*

For many peers we interviewed, peer support was cited as helping them the most in their recovery. The support that they are able to give and receive is healing. For some, participating in a support group is the only thing that makes them feel better and is their sole source of support. Others mentioned feeling better by talking to family members, friends or a therapist.

*It's great to be part of a group of Latinos to get support. I feel like my soul is being put together again.*

*This group is good for us. We learn something good every day. You can come sad, but you leave happy. Before coming to this group, I thought I was the only one suffering. I thought I had it the worst. But I see others going through the same things.*

Most peers felt that the support they received from their fellow peers was essential - for some, their most important source of support. Participating in a support group with other Latinos was valued by many. Groups provide a comfortable level of privacy and intimacy as well as a non-judgmental approach to healing, unlike what many have experienced with their family. Participating in peer support offered the opportunity to see others overcome their mental illness thereby providing hope and inspiration. Being with others who share similar life experiences offered mutual understanding of the challenges faced. Peers indicated that it was easier to relate to someone with lived mental health experience than someone without this similar experience.

However, a few participants still cited the value of individual support (rather than from within a group), whether it be from another peer or a professional. There was agreement that getting and receiving support has to be from the right person. Peers often wanted to receive support from someone who was further along in their recovery than themselves.

*It depends on the person. Are they in recovery? It's helpful to see someone further along in their recovery. It gives me strength and hope.*

#### iv) Expanding recovery-oriented and peer support services

More important than expanding recovery-oriented and peer support services for Latinos was a need to have basic mental health services, such as psychiatry and counseling, available in Spanish. As mentioned above, not having these services available in a language that people can understand presented a major barrier in seeking out services. These services also need to be easily accessible, as transportation options for many Latinos are limited.

Respondents felt strongly that Latinos need to be made more aware of the types of services that are available. Education is needed specifically about how people can receive mental health services and supports while still maintaining their government benefits.

Most peers mentioned two components that would expand recovery-oriented and peer support services for Latinos. The first component was an adequate number of Spanish-speaking clinicians that understand recovery and support peers in their journey to get well. The other component was expanding Spanish-speaking support groups and having transportation available to them.

*There are more services for Americans. We don't know where to get services or what's available. We can show up somewhere, but no one speaks Spanish. They tell me to go to Lawrence, and I get put on a wait list. So the problems are language, culture, transportation and wait lists. Also there is a lack of communication between providers.*

## **B. Deaf and Hard of Hearing (D/HH) Population**

Similar to the Latino section, we will synthesize the information we collected from Deaf and Hard of Hearing (D/HH) mental health key informants as well as D/HH mental health peers.

### i) Cultural understanding of mental health, mental illness, recovery, and peer support

The D/HH population is a relatively small community in Massachusetts and the United States as a whole. As outlined in the Background section above, it is difficult to generalize how the D/HH culture understands mental health, mental illness, recovery, and peer support – given the vast number of communication issues that arise. However, based on our data collection, some insight can be provided around this issue.

Individuals who are D/HH reported feeling most comfortable interacting within their D/HH community on a day-to-day basis. However, as previously noted, a lack of understanding of mental health issues among this population often leads to issues of stigma. Therefore, people who are D/HH are often hesitant to be open about their mental health issues within their community. Though the community at large (i.e., hearing) may have a better understanding mental health, it has a limited understanding of D/HH culture. Respondents expressed how difficult it is to exist between these two worlds. They felt a double stigma where they constantly had to explain their needs as a deaf person and/or as a person with a mental health condition.

*It's very hard to approach deaf people who don't have mental illness. Even if working with professionals, they often become overly concerned. I want people to accept me for who I am. As a deaf person, I have found that people draw away from me. So I'm between deaf people without mental illness and hearing people with mental illness. It's a tough place to be.*

*The deaf population has small numbers and is struggling. They want to go to their own community but they don't understand the mental illness. But, if they go to the larger community, they understand the mental illness but not being deaf. [Key Informant]*

There is a great deal of stigma in the D/HH community surrounding mental health issues. One reason for this is the lack of education the deaf community at large has regarding mental health conditions. Both KIs and peers agreed that it is important to educate the D/HH population about mental health issues. Public education and public health campaigns on mental health and mental illness do not seem to reach D/HH individuals in the same way this information gets to hearing people. This lack of success in providing public education about mental health issues generally leads to high levels of mental health stigma in this community.

Because the D/HH community is small and somewhat insular, gossiping frequently occurred. Therefore, peers may choose not to disclose their illness due to a fear of others in the community knowing about their mental health issue. D/HH individuals noted fear of being labeled “crazy” and some refused mental health treatment because of fear of others finding out.

*I really wish deaf schools and other programs for the deaf would explain about mental illness and make it more explicit. This would help deaf people understand it better, which*

*would be helpful.*

*People started to spread rumors and it made me feel uncomfortable. They were saying all these things so finally it was better for me not to be around them anymore. These people were both hard of hearing and from the deaf club.*

Both KIs and peers raised the issue of confidentiality in the D/HH community. As mentioned previously, the deaf community is small in number, and often times D/HH individuals seek services from the same agencies. There were concerns raised about the community's ability to keep things private and confidential.

*People in the community know that some things that are said are confidential but it depends on the issue with them and sometimes they talk.*

An interesting insight made by one key informant was the 'internalized stigma' present in many D/HH individuals where they felt that clinicians who are D/HH have less knowledge and skills than their hearing counterparts and therefore D/HH individuals would prefer to work with a hearing therapist.

*I prefer deaf. They can more easily understand who I am. But I do understand why some deaf people want to work with hearing people. They feel hearing people have more knowledge and experience.*

*I prefer to work with someone who is deaf for the ease of communication and to be able to understand each other easily. But at times, I want to get the perspective of a hearing person, because they get a lot more incidental learning than deaf people. A deaf person's perspective isn't wide enough.*

Many of the participants we interviewed grew up in hearing families which made communication difficult. When discussing the family, there were mixed responses by participants, some who got along with their families and others who did not. The amount of support D/HH individuals received from their family on their mental health issues varied. Some indicated that they preferred not to have their families involved because of their lack of understanding.

*My family was the one who hospitalized me at first and that was supportive.*

*My family isn't of any help. They don't know anything about my issues.*

*I'm the only deaf person in my family. They don't understand mental health issues. There's no one I can share with in my family.*

ii) Personal experience of mental health, the mental health system, and recovery

The majority of the peers cited that they would only share their personal experience of mental health with individuals whom they trust. A number of peers also mentioned that the person needs to have an understanding of mental illness.

*I might give very basic information about myself, nothing in-depth. Especially if they don't understand mental illness. If they understand mental illness than I am more open.*

*I look for someone I can trust and usually that is a professional. I have a very hard time telling people things when I don't trust them.*

Both the KIs and the peers acknowledged several barriers that people who are D/HH and have mental health conditions face. Not surprisingly, almost all of the barriers had to do with communication issues. There was a great variability noted in how deaf people communicate. D/HH individuals have varying levels of fluency in ASL, ranging from proficient to limited. According to the literature, as well as one KI, people who are D/HH have about a 4<sup>th</sup> grade English reading level; therefore, relying on written correspondence as an effective means of communication is not likely to be effective with many D/HH individuals. A number of peers discussed the low literacy skills of people who are D/HH and the unequal access to health education materials, as compared to their hearing counterparts.

*There is also low health literacy. Public health campaigns for mental health generally reach people via radio and print materials so very little reaches the deaf population. [Key Informant]*

*There is so much information that deaf people don't have access to. They have never learned about mental health issues. They don't have access to the media like hearing people do.*

D/HH people reported experiencing several other barriers in accessing services. These included:

- Limited D/HH Mental Health Services – There are a lack of services targeted at D/HH mental health consumers. There are a very limited number of all deaf peer support groups. Only a few mental health service agencies in the state have experience in working with D/HH individuals and have only a limited number of therapists who sign.

*There is no full deaf peer support group; that is missing, for sure.*

*I want to be part of the mental health services that is lacking for deaf people.*

*There is a respite program but it cannot adequately serve the deaf population. [Key Informant]*

- Use of interpreters - The use of interpreter services is a necessity, yet not often available. Even when requested, interpreters are not always made available. People who are D/HH have been told there is no funding for interpreters or have been refused an interpreter. Unfortunately, a hospital is often the first place a person who is D/HH is sent when they need mental health services because: a) hospitals are required to provide interpreter services; and b) there are few other options. However, even in a hospital, a person can wait an inordinate amount of time for an interpreter, causing further isolation, especially when a

person is in crisis. Working with an interpreter can also be frustrating because of the lack of ease in directly communicating with someone and a fear of things being misinterpreted.

*Local hospitals don't have an understanding of how to serve the deaf. When you are in crisis in an ER, you have to wait hours for interpreters to come. It's very difficult.*

*Beth Israel and MGH are the only hospitals with interpreters readily available but they are for the whole hospital, not just the psychiatric ward.*

- Ineffective relationships with clinicians - A barrier often exists when there is a lack of direct communication between the peer and therapist. There is a strong preference to work with someone who signs and knows the deaf culture. Some KIs and peers indicated that many D/HH mental health individuals prefer to work with a therapist who signs, but who does not have personal mental health experience. This person, they feel, is perhaps better skilled and more professional than someone with mental health experience.

*I was working with a therapist in East Boston for a while. It was hard for me to get to. The therapist had no expression in her face. She had me repeat things. The interpreters would misinterpret things. I had another therapist who was hearing, but could sign, but not very well. I got frustrated.*

*People who are D/HH want clinicians that have sign language fluency and familiarity. Having sign language clinicians are at the top of the D/HH list, nothing else matters so much. However, deaf participants don't necessarily want to work with deaf clinicians who are known to them personally and are part of their community. [Key Informant]*

*I am deaf. I cannot hear and I cannot lip read. I always prefer someone deaf. I am more comfortable with that.*

Most of the KIs had different perspectives than D/HH peers on recovery. They felt the term recovery was not understood, largely due to literacy capacity and the general lack of understanding of mental health and mental illness. However, all of the peers we spoke with had a general understanding of recovery which to them meant being more independent, feeling better, being more active, and taking care of yourself. The ASL sign most frequently used to signify recovery was an upward movement on the arm, meaning to "get better" or "improve". The process of recovery, per the peers, is challenging and requires hard work, but is possible.

*There are many different signs for recovery. To me it's about being able to handle everyday life. When I learn something new everyday and learn how to deal with things, that is recovery. When I can handle times that are hard.*

*Mental illness is a daily struggle for people. They have good days and bad days. Some people refer to climbing a mountain of recovery, with up and down trails. [Key Informant]*

iii) Use and experience of peer support

Many of the peers who participated in our focus groups and interviews noted a desire to receive services and supports from another deaf person. They felt that there was a deeper level of understanding and trust present when working with another peer, partly due to sharing a similar language and culture. There was also an increased level of comfort in dealing with another deaf person. They have shared similar experiences and can learn from one another. This helped peers realize they are not alone.

*I prefer deaf people for cultural reasons. I can communicate who I am. If hearing people, they have to understand my culture and sign.*

*I have one person who understands because she is deaf and has mental illness, too. But most don't know my experience.*

We received mixed responses on how open peers are to receiving support from another person with mental illness. Some D/HH individuals would like to receive peer support from someone who has mental illness so they do not feel alone. Others would prefer to work with a non-peer for reasons that were not well described, while still others preferred to receive services from both peers and non-peers.

*As long as there is the use of sign language, I like it either way. If someone is not deaf, I try my best to communicate with them. I'm comfortable with all.*

*I like peer support. It makes me realize I'm not alone. I feel like in our sharing that I can learn something new from them.*

*I would like someone who has a mental health condition like me. They would understand me better. They can help me feel better. They have the same life experiences I have. They know what it is like. I can learn from their mistakes and learn coping skills to help me.*

The majority of peers identified being more active and social as an indication of feeling better with their mental health. Some peers mentioned concrete things like taking medication regularly, coping skills, attending peer groups and developing a Wellness Recovery Action Plan (WRAP) plan as being helpful to them. Many peers talked about the helpful support they received from a clinician, therapist or other staff at a mental health agency. They also noted that when they are not feeling well, they will seek help from those mentioned above only if a trusting relationship has developed. In addition to these formal services and supports, some peers mentioned reaching out to family and friends in times of need.

*I am in WRAP right now, working with professionals and it has helped clarify things for me. It helps me understand my triggers and to notice my symptoms so I can get the help I need.*

*I've learned coping skills. I have been using them a long time. I use medication. It's been helpful and I need it.*

*The staff at this Agency is the best and the clients have been helpful. I also talk with my parents, psychiatrist and therapist about issues.*

Some KIs mentioned the challenge of offering peer support in mixed literacy groups. Because there is such wide variation in communication abilities among persons who are D/HH, peer support group may not be effective when people use ASL at different levels. Because of this, some people may prefer to receive 1:1 peer support as opposed to in a group. This also reduces confidentiality concerns.

*There are wide variations in language abilities. Some consumers may be illiterate. There is a disparity in how they communicate, it is significantly different. [Key Informant]*

iv) Expanding recovery-oriented and peer support services

Even before expanding recovery-oriented and peer support services for individuals who are D/HH, respondents felt it was more important to expand D/HH mental health services available to individuals including having more therapists who can sign.

Respondents identified concrete support and services they would like to see such as more community-based service options for deaf consumers, such as respite, WRAP and day programs. In addition, respondents would like more education on mental health issues, diagnoses, and medication options. D/HH participants also cited a desire to have hospitals with expertise in working with D/HH consumers in locations other than Westborough State Hospital. Finally, D/HH individuals expressed a desire to have local Recovery Learning Community (RLCs) be more accessible for the deaf community.

*A respite house would be good - a quiet house to go to when you need it. Deaf people shouldn't always have to go to the hospital. It's ridiculous.*

*There should be more open hours at RLCs for deaf people.*

## **IV. Discussion**

In this section, we provide our assessment of the strengths and limitations of the study conducted by CHPR as well as the role of the cultural broker in this study. Additionally, we reflect on similarities and differences between the two populations studied.

### Strengths and Limitations of the Study

We view the role of the cultural broker as part of this study to have been a tremendous strength, and have addressed this in more detail below. Another strength was being able to interview key informants prior to data collection with peers. Key informants provided us with guidance as to the issues we should explore and confirmed our approach for using a cultural broker. As with any study, a few limitations should be noted. Given the resources for this project, a limited number of interviews and focus groups were conducted. While the data generated provided us with strong themes, additional data collection would perhaps have provided an opportunity to elaborate further on these themes, particularly for the D/HH population. Latino data collection occurred with participants only in two geographic regions of the state. While these areas have a

high concentration of Latinos, the study would have benefitted from hearing from people in other regions.

Data collection with individuals who are D/HH brought its own unique set of challenges. We completed eight of the nine individual interviews planned for this study. Most of the D/HH interview participants received their services from the same mental health service agency. Despite the best efforts of our cultural brokers, recruitment was difficult. This could perhaps be attributed to a lack of comfort among people who are D/HH to participate in a study, their lack of complete understanding about the study's purpose, or a hesitation to talk about their mental health with strangers. Lastly, having an ASL interpreter to communicate what was being discussed between the cultural broker and the participant(s) likely filtered some of the information being shared.

### Importance of the Cultural Broker

For both cultural groups, the cultural broker played a critical role in connecting the study team to study participants. The cultural brokers were able to establish a rapport and level of trust that would be impossible for CHPR study team members to have achieved. This rapport was important not only during the recruitment phase, but during the data collection itself. Being able to communicate in the way participants felt most comfortable allowed them to express their thoughts on mental health, recovery and peer support in a more natural way. Conversations were always fluid and effortless. We heard many times the challenges in speaking via an interpreter. Being able to collect data without an interpreter removed a barrier that participants often cited. As the literature suggests (Schwab et al., 1988; Singh et al., 1999), utilizing cultural brokers in this study provided a bridge between two worlds, allowing for individuals to share information in a natural environment. Our findings confirm that clients want to be able to establish a relationship with someone who they can easily communicate with and who understands their mental health problems.

### Language Barriers

Among our participants, language barriers pose the greatest challenges in accessing mental health services for both Latinos and people who are D/HH. As reported in the literature, language proficiency influences access to medical services and may contribute to health outcomes disparities. Ethnic minorities are less likely to be treated for mental disorders or receive guideline-concordant care, and foreign-born minorities use fewer mental health services than their US-born counterparts (Bauer, Chen, & Alegria, 2010; Pippins, Alegria, & Haas, 2007). Based on what was reported by the KIs and peers in this study, there is a lack of qualified mental health professionals who either are Spanish-speaking or proficient in ASL and those providers with qualified language skills may have long wait lists to access services. The preference among both Latinos and people who are D/HH is to work directly with someone in the language they feel most comfortable with and to avoid the use of interpreters. Experiences with interpreters vary, with many feeling that interpreters do not always accurately communicate between the parties. This is supported by the literature which suggests that interpreters can add a filter that impacts the relationship between a therapist and client (Critchfield, 2002). For D/HH individuals, multiple modes of communication must be offered in order for the most effective care to be provided. English is not often their first preference, and their fluency in ASL may be

limited. Augmentative and alternative communication options, such as the use of visual aids, may be needed.

### Understanding of Recovery

Both Latino and D/HH key informants suggested to us that the concept of recovery is not well understood by these cultural groups. However, this is contrary to what we found when speaking with individuals from these populations. All respondents understood recovery as feeling better, being active, and taking care of yourself. Additionally, all wanted to be surrounded by therapists and peers who believed they could recover. However, their experience in accessing recovery-oriented services varied. Latinos in particular cited examples of working with therapists more comfortable with the medical model.

Recovery is best defined on an individual basis. The respondents in our study recognized recovery as a process of feeling better and not as a cure from mental illness. This is in alignment with the mainstream understanding of recovery and therefore not specific to either cultural group (Davidson et al., 2007; Farkas, Gagne, Anthony, & Chamberlin, 2005). However, it should be noted that the people recruited for this study (from both cultural groups) were generally connected with recovery groups and peer support and likely had a deeper understanding of recovery than some of their peers.

Recovery may also be seen on a continuum, with feelings of empowerment, personal responsibility, and advocacy being at the higher end of this continuum. While we didn't necessarily hear these components of recovery being referred to by the individuals in our study, these elements should be part of discussions with people in recovery at the appropriate stage. Having mental health services better grounded in the concept of recovery, and having these services readily accessible, would serve to promote a fuller understanding of recovery among people from different cultural and linguistic groups.

### Use of Peer Support

Latinos in our study reported much more access to peer support than individuals who are D/HH. There are a few mental health peer support groups hosted at mental health service agencies or Recovery Learning Communities that are targeted at Latinos. Latinos largely reside in certain geographic regions; therefore, peer support can be organized in these areas. Individuals who are D/HH are spread out across the state and organizing a D/HH-only peer support group can be more challenging. People who are D/HH described themselves as being more isolated and desired more opportunities for being able to connect with other D/HH individuals, whether they have mental health conditions or not.

Latinos seem to place a higher value on peer support as compared to individuals who are D/HH. Many Latinos cited peer support as the most valued mental health service they received. As supported by the literature, confidentiality and stigma concerns are prevalent among people who are D/HH and have mental health conditions (Scheier, 2009; Steinberg et al., 1998). Because the D/HH community is small in number, some members are concerned about

speaking about their mental health condition with other D/HH individuals for fear of sensitive information being shared more broadly than intended.

It is preferred, as explained to us by the study's participants, for members of both cultural groups to receive peer support in a group of people with the same cultural background. Some have participated in mixed peer support groups and had difficulty in communicating, despite an interpreter being available. Therefore, preferences about other peer support options will vary from person to person depending on their English communication skills and past experiences in interacting with others. The need for culturally and linguistically appropriate peer support and recovery-oriented services is clearly evident from the data presented in this study and leads us to offer some conclusions and recommendations, presented in the following section.

## V. Conclusions and Recommendations

In this section, we offer our conclusions and recommendations for DMH and MassHealth to consider as they continue to advocate for more culturally and linguistically competent, recovery-oriented mental health care. While our data collection sought to get at detailed and concrete suggestions from the individuals in our study, very detailed recommendations weren't forthcoming. Rather, they presented higher level system recommendations that addressed key barriers they've encountered.

There is a definite linkage between our findings and the national attention being paid to racial and ethnic disparities in health care. Racial and ethnic disparities in health care have been consistently documented across a wide range of medical conditions and health care services, including mental health care (Blanco et al., 2007; Primm et al., 2010; Washington et al., 2008). Washington et al. (2008) identify four aspects of clinical practice that need to be transformed in order to address health care disparities. These four areas are: financial; structural; communication and cultural/linguistic competence; and quality of care monitoring and assessing patient views of care. By addressing these aspects within the mental health system, care to Latinos and people who are D/HH would certainly be improved.

The peers in our study were generally well connected to the recovery movement and advocates of peer support. Among the Latinos, most in our study were connected to peer support groups. There was, however, recognition among the peers that not everyone in their community is aware of the types of mental health services available to them. DMH and MassHealth need to work with their providers to establish creative outreach strategies to reach a greater number of people from underserved communities and make a range of culturally- and linguistically-competent mental health services available to them.

There were more similarities than differences noted among how Latinos and people who are D/HH and have mental health conditions understand the concepts of recovery and peer support. Both groups cited difficulties in accessing a range of mental health services in their preferred language. Accessing recovery-oriented services and peer support is perhaps secondary to accessing basic therapy and psychiatric services in a language they feel comfortable with. DMH and MassHealth need to consider what they can do expand the number

of mental health professionals who can offer services to people who are Latino and D/HH. At a minimum, qualified interpreters need to be available to facilitate communication between the provider and service user.

Only a few mental health service agencies throughout MA specialize in working with Latino or D/HH mental health clients. Since it is often the client's responsibility to arrange for transportation to any appointment, if the preferred provider is not located in the same or neighboring geographic region, transportation barriers may pose challenges for a person to access these needed specialized services. DMH and MassHealth should work with mental health service agencies to ensure that a sufficient number of providers are able to serve these special populations and that adequate transportation options are available for people to attend their appointments.

People who are D/HH or Latino appear to have the same understanding of recovery and peer support as the general mental health community. Not surprisingly, they also want the same access to providers who understand and support recovery as well as peer support groups that they can fully participate in. DMH and MassHealth are working to promote mental health services and support that are recovery-based across the mental health system. DMH and MassHealth need to further support their providers in delivering recovery-oriented and peer support services to all populations they serve, even if their numbers are small.

In summary, Massachusetts is home to people of various cultural and linguistic backgrounds. This study only focused on two such populations. While we noted a number of similarities between the two diverse cultural groups studied herein, the issues faced by other populations of diverse cultural backgrounds in accessing mental health services and their understanding of recovery and peer support may be different from the ones presented in this report. DMH and MassHealth should seek to better understand how to best serve a variety of culturally and linguistically diverse populations in the mental health system in order to ensure that everyone has access to culturally- and linguistically-competent and high quality mental health services as well as services that are based in recovery, such as peer support.

## **Attachment A: Key Informant Interview Guides**

## Interview Guide for Latino Key Informants

### Introduction

- The Massachusetts Department of Mental Health (DMH) and MassHealth want to better understand how people of different cultural groups understand and deal with their mental health issues - specifically, how people from different cultural groups feel they can improve their lives and have future goals despite having a mental illness. DMH has identified Latinos as a population of interest.
- The Center for Health Policy and Research (CHPR) is doing this project to better understand how Latinos think about and get help for mental health problems. We are conducting interviews with select key informants to help us deepen our understanding of how Latinos think about mental health recovery and peer support.
- What we learn from these key informant interviews will be summarized and used to shape future data collection efforts with Latinos facing mental health conditions.
- In our report, you will be identified as someone we spoke with, but specific quotes will not be directed back to you.

---

### Oral agreement to be interviewed and identified in written reports provided to the MA Department of Mental Health and the Office of Medicaid

1. Do you agree to participate in today's interview? \_\_\_YES \_\_\_NO
2. Do you agree to be identified by name as a key informant in reports we provide to DMH and MassHealth? \_\_\_YES \_\_\_NO
3. Do you have any additional questions about how the results of this interview will be used?  
\_\_\_YES \_\_\_NO

**Participant's Name:** \_\_\_\_\_

**Date of Agreement:** \_\_\_\_\_

---

### Interview Questions

1. What is your background and experience in working on Latino mental health issues?
2. What kinds of help do Latinos want for their mental health problems?
3. How commonly understood is the mainstream concept of *recovery* in the Latino world?
  - o Does *recovery* mean something else?
  - o What words/concepts do Latinos use to indicate they are feeling better from their mental illness?
4. What would services that support people's recovery look like for this community?
  - o Are these types of services currently offered? If yes, where and by who?
  - o What would be ways to engage Latinos in these services and supports?
5. How commonly understood and used is peer support for Latinos with mental health needs or other needs? What might be some general preferences about who they receive peer support from?
  - o Latino, not mentally ill
  - o Latino and mentally ill
  - o Non-Latino and mentally ill?
6. From the perspective of a Latino consumer, how does receiving 1:1 peer support versus in a group compare?
7. In the mainstream, recovery is connected to the idea of community and empowerment. How does this connect with someone who is Latino and mentally ill?
8. We will be conducting interviews and focus groups with people who are Latino and living with mental illness to get their perspectives on mental health recovery and peer support. What advice do you have for us in terms of maximizing participation and comfort in focus groups? How about for interviews?
9. Is there anything else do you feel is important for us to know as we move forward with this project?

## Interview Guide for DH/H Key Informants

### Introduction

- The Massachusetts Department of Mental Health (DMH) and MassHealth want to better understand how people of different cultural groups understand and deal with their mental health issues. DMH has identified people who are deaf or hard of hearing (D/HH) as a population of interest.
- The Center for Health Policy and Research (CHPR) is doing this project to better understand how people who are D/HH think about and get help for mental health problems. We are conducting interviews with select key informants to help us deepen our understanding of how people who are D/HH think about mental health recovery and peer support.
- What we learn from these key informant interviews will be summarized and used to shape future data collection efforts with people who are D/HH and facing mental health conditions.
- In our report, you will be identified as someone we spoke with, but specific quotes will not be connected back to you.

---

### Oral agreement to be interviewed and identified in written reports provided to the MA Department of Mental Health and the Office of Medicaid

1. Do you agree to participate in today's interview? \_\_\_YES \_\_\_NO
2. Do you agree to be identified by name as a key informant in reports we provide to DMH and MassHealth? \_\_\_YES \_\_\_NO
3. Do you have any additional questions about how the results of this interview will be used? \_\_\_YES \_\_\_NO

**Participant's Name:** \_\_\_\_\_

**Date of Agreement:** \_\_\_\_\_

---

## Interview Questions

- 1) What is your background and experience in working on D/HH mental health issues?
- 2) What kinds of help do people who are D/HH want for their mental health problems?
- 3) How commonly understood is the mainstream concept of *recovery* in the D/HH world?
  - a. Does *recovery* mean something else?
  - b. What terms/signs/concepts do people who are D/HH use to indicate they are feeling better from their mental illness?
- 4) What would services that support people's recovery look like for this community?
  - a. Are these types of services currently offered? If yes, where and by who?
  - b. What would be ways to engage people who are D/HH in these services and supports?
- 5) How commonly understood and used is peer support for people who are D/HH with mental health needs or other needs? What might be some general preferences about who they receive peer support from?
  - a. Deaf, not mentally ill
  - b. Deaf and mentally ill
  - c. Hearing and mentally ill?
- 6) From the perspective of a D/HH consumer, how does receiving 1:1 peer support versus in a group compare?
- 7) In the mainstream, recovery is connected to the idea of community and empowerment. How does this connect with someone who is DH/H and mentally ill?
- 8) We will be conducting interviews and focus groups with people who are D/HH and living with mental illness to get their perspectives on mental health recovery and peer support. What advice do you have for us in terms of maximizing participation and comfort in focus groups? How about for interviews?
- 9) Is there anything else do you feel is important for us to know as we move forward with this project?

**Attachment B: Fact Sheets**



[Docket # 13939]

## Hoja Informativa-Grupos de Dialogo sobre Recuperacion y Cultura

### ***Quien esta conduciendo este dialogo?***

Personal del Centro de Investigacion y Polizas de Salud (CHPR- siglas en Ingles) de la Escuela de Medicina de la Universidad de Massachusetts estara conduciendo los grupos de dialogo. Los miembros de este grupo son: Linda Cabral y Kathy Muhr. Vivian Nunez nos esta proyendo ayuda como enlace cultural.

### ***Cual es el proposito de estos grupos de dialogo?***

El Departamento de Salud Mental y el Masshealth le ha pedido al "CHPR" que les facilite el aprendizaje acerca de como las personas de origen Latino hablan acerca de su salud mental y que los hace sentir mejor. El grupo de dialogo se compondra de 5 a 9 personas que juntas hablaran de este tema comun a todos. Un facilitador hara las preguntas y guiara la conversacion.

### ***Quienes han sido seleccionado para participar?***

Hemos estado trabajando con un grupo de personas Latinas que actualmente tienen condiciones de salud mental. Ellos han identificado personas de la comunidad que tienen condiciones de salud mental y están dispuestas a hablar con nosotros.

- **Su participacion es voluntaria. Usted puede presentarse al grupo y decidir no contestar algunas preguntas si no se siente comodo en hacerlo.**
- **Su participacion y/o su desicion de no participar no le afectara su habilidad de continuar recibiendo los servicios que ahora tiene.**

### ***Que se preguntara durante el grupo de dialogo?***

Le estaremos preguntando lo siguiente:

- Que usted piensa sobre la salud mental
- Que piensa acerca de la salud mental la gente de su comunidad
- Que servicios de salud mental usted a encontrado que son mas efectivos

### ***Cuanto tiempo durara el grupo y como sera conducido?***

El grupo de dialogo tomara acerca de 2 horas y se llevara a cabo en un lugar y tiempo conveniente y comodo para la mayoría de los participantes. Dos o tres personas del equipo de investigacion estaran presentes. Una persona guiara la conversacion mientras la otra toma notas. **Para agradecerle su participacion, se le dara una targeta de regalo de \$15 para la tienda Target.** Usted recibira su targeta al finalizar el grupo de dialogo.

### ***Quien vera mis respuestas luego de finalizar el grupo de dialogo?***

Solo el equipo de investigacion de "CHPR" tendra acceso a sus respuestas. Cuando escribamos el reporte acerca de la informacion obtenida durante el grupo de dialogo, no utilizaremos nombres o ninguna otra informacion que pueda identificarlo de manera alguna. Se utilizaran citas o frases que se hallan dicho durante el grupo, pero solo si no pueden ser conectadas con usted.

### ***Cuales son los posibles riesgos, inconvenientes que podria experimentar al participar en el grupo?***

Nosotros consideramos que de haber algun riesgo sera muy leve. Quizas pueda sentirse un poco incomodo al contestar algunas preguntas, pero usted puede decidir no contestarla y/o terminar su participacion en el dialogo en cualquier momento. Hay muy poco riesgo de romper la confidencialidad durante el dialogo del grupo ya que los participantes podran compartir information que han escuchado de otras personas.

Para reducir aun mas el riesgo de romper la confidencialidad de los participantes, al principio del grupo se le recordara a todos los presentes la gran importancia de no repetir la informacion compartida en el grupo ni mencionar nombres de las personas que participaron en el grupo.

**Si usted tiene alguna pregunta o duda acerca de su participacion en el grupo de dialogo, por favor llame o mande un correo electronico a**

Judy Savageau, MPH  
Associate Professor  
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333 South Street, Shrewsbury, MA 01545  
774-442-6535  
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Si en algun momento durante o despues de haber completado el estudio, usted desea discutir el estudio sus derechos relacionados al mismo con alguien que no este relacionado con el estudio. Por favor comuniquese con el Coordinador Administrativo del Comite de Proteccion de Sujetos Humanos en Estudio de la Escuela de Medicina de la Universidad de Massachusetts. El numero de telefono para llamar es: (508) 856-4261.



[Docket # H-13939]

## **FACT SHEET – Recovery and Culture Interviews**

### ***Who is conducting the research?***

Staff from the Center for Health Policy and Research (CHPR) at the University of Massachusetts Medical School are conducting the interviews. Members of this team include Kathy Muhr and Linda Cabral. We are being helped by [insert the names of the relevant cultural brokers].

### ***What is the purpose of the research?***

The Department of Mental Health and MassHealth have asked CHPR to help them learn more about how people who are Latino [Deaf/Hard of Hearing] talk about mental health and what makes them feel better.

### ***How was I selected to participate?***

We are working with a team of people who are Latino [Deaf/Hard of Hearing] who are also mental health consumers. They have tried to find people in the community who would be interested in talking to us.

- **Your participation is voluntary – you may choose not to participate at all or not to answer certain questions during the interview.**
- **Your participation – or decision not to participate – does not affect your relationship with any services you may be receiving now.**

### ***What will I be asked in the interview?***

We will like to ask you questions about:

- What you think about mental health
- What people from your community think about mental health
- What kind of mental health services are most helpful

### ***How long will the interview take and how will it take place?***

The interview will take approximately one hour, and will be conducted at a time and place convenient and comfortable for you. Two members from the team will interview you; one will conduct the interview, while the other takes notes.

To thank you for your time and sharing your thoughts, you will get a \$15 Target gift card at the end of the interview.

***Who will see my responses to the interview?***

Your responses will be seen by members of the CHPR study team only. When we write our report about the interviews, we will not use names or any other information that could be traced back to you. Quotes from the interview may be used, but only if the quote does not lead back to you.

***What are the risks or inconveniences I may experience?***

We anticipate any risks or inconveniences to you to be low. You may experience discomfort in answering some of the questions in the interview. You can choose not to answer a question and can stop the interview at any time.

**If you have any questions or concerns about your participation, please call or email:**

Judy Savageau, MPH  
Associate Professor  
Center for Health Policy and Research  
University of Massachusetts Medical School  
333 South Street, Shrewsbury, MA 01545  
774-442-6535  
[judith.savageau@umassmed.edu](mailto:judith.savageau@umassmed.edu)

If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.



[Docket # 13939]

## **FACT SHEET – Recovery and Culture Focus Groups**

### ***Who is conducting the research?***

Staff from the Center for Health Policy and Research (CHPR) at the University of Massachusetts Medical School are conducting the focus groups. Members of this team include Kathy Muhr and Linda Cabral. We are being helped by [insert the names of the relevant cultural brokers].

### ***What is the purpose of the research?***

The Department of Mental Health and MassHealth have asked CHPR to help them learn more about how people who are Latino [Deaf/Hard of Hearing] talk about mental health and what makes them feel better. A focus group is when approximately 5-9 people come together to talk about a common topic. A facilitator asks questions and guides the conversation.

### ***How was I selected to participate?***

We are working with a team of people who are Latino [Deaf/Hard of Hearing] who are also mental health consumers. They have tried to find people in the community who would be interested in talking to us.

- **Your participation is voluntary – you may choose not to participate at all or not to answer certain questions during the focus group.**
- **Your participation – or decision not to participate – does not affect your relationship with any services you may be receiving now.**

### ***What will I be asked in the focus group?***

We will like to ask you questions about:

- What you think about mental health
- What people from your community think about mental health
- What kind of mental health services are most helpful

### ***How long will the focus group take and how will it take place?***

The focus group will take approximately 2 hours, and will happen at a time and place convenient and comfortable for the majority people invited. Two or three people from the team will be there; one will guide the conversation, while the others take notes.

To thank you for your time and sharing your thoughts, you will get a \$15 Target gift card at the end of the focus group.

### ***Who will see my responses in the focus group?***

Your responses will be seen by members of the CHPR study team only. When we write our report about the focus groups, we will not use names or any other information that could be traced back to you. Quotes from the focus group may be used, but only if the quote does not lead back to you.

***What are the risks or inconveniences I may experience?***

We anticipate any risks or inconveniences to you to be low. You may experience discomfort in answering some of the questions in the focus group. You can choose not to answer a question and can stop your participation in the focus group at any time. There is a low risk of a breach in confidentiality during the focus group, as participants may share information they heard from others in the group. In order to minimize the risk of a breach in confidentiality, focus group participants will be reminded at the start of the group about the importance of confidentiality and will be advised not to share with others information on what was discussed or who attended the group.

**If you have any questions or concerns about your participation, please call or email:**

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If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.

## **Attachment C: Interview and Focus Group Guides**

**Individual Interview Guide**  
**Latino [Deaf/Hard of Hearing]**

**Introduction**

Summarize the goal and pertinent objectives of the evaluation:

- The Department of Mental Health and MassHealth asked for a review to help them learn more about how people who are Latino [Deaf/Hard of Hearing] talk about mental health and what makes them feel better.
- UMass Medical School is conducting a series of interviews and focus groups with Latino [Deaf/hard of hearing] mental health consumers across the state to help us deepen our understanding of how people who are Latino [Deaf/Hard of Hearing] think about getting help for mental health and feeling better.
- We are interested in learning what the mental health consumers from the Latino [Deaf/Hard of Hearing] population think about mental health, what people from their minority community think about mental health, and what kind of mental health services are most helpful.
- The final evaluation report will go to staff at the Department of Metal Health and MassHealth.

Assure privacy and confidentiality:

- Please know that the information you provide today will be kept private and confidential.
- We will be looking at themes across interviews and focus groups with training team members, and the oral and written reports we prepare will be based on those themes and will not reference any one by name.
- To enrich our reports, we may use a few direct quotes but we will not identify the individual by name and will not use quotes if the content could readily identify the source.

Obtain verbal consent to conduct the interview and consent to record.

Ask if the respondent has any questions before starting the interview and respond as appropriate.

## QUESTIONS

1. Please tell us your first name, and briefly, why you decided to come today.
2. How do people in your community talk about mental health issues?
3. How do you talk to people in your community about your mental health issues?
4. What type of mental health support have you found to be the most helpful?
  - a) Who do you like to talk to about your mental health issues?
    - i) Professional
    - ii) Family member
    - iii) Friend
    - iv) Religious leader
    - v) Other
5. When you are starting to feel better from your mental health condition, what do you notice differently about yourself?
6. What do you think it means when someone says they are “in recovery” from their mental health condition?
7. Do you like the idea of getting support from someone who also has a mental health condition? Why or why not?
8. Would you prefer the person you are getting support from also be Latino [Deaf/Hard of Hearing]? Why or why not?
9. What services or support would you like to see in the community to help you when you are not feeling well?
10. Is there anything else you would like to share about Latinos [Deaf/Hard of Hearing] and mental health?

## **Focus Group Guide**

### **Latino [Deaf/Hard of Hearing]**

#### **INTRODUCTION**

The focus group facilitator will review the following with focus group participants.

#### **Protocol:**

- Introductions: facilitator and assistant and focus group participants.
- Indicate that the anticipated length of the discussion is approximately 1.5-2 hours.

#### **Brief overview of the UMass Study:**

- The Department of Mental Health and MassHealth asked for a review to help them learn more about how people who are Latino [Deaf/Hard of Hearing] talk about mental health and what makes them feel better. UMass Medical School is conducting a series of interviews and focus groups with Latino [Deaf/hard of hearing] mental health consumers across the state to help us deepen our understanding of how people who are Latino [Deaf/Hard of Hearing] think about getting help for mental health and feeling better.
- The final report will go to the Department of Metal Health and MassHealth.

#### **Purpose of Focus Group:**

We are interested in learning what the mental health consumers from the Latino [Deaf/Hard of Hearing] community think about mental health, what people from their minority community thinks about mental health, and what kind of mental health services are most helpful.

The information that you provide to us today will help us respond to DMH and MassHealth on how to be culturally responsive for mental health consumers from these communities.

#### **Ground rules for the discussion today:**

- Everyone will have a chance to voice their experiences and opinions, although it is ok to not feel the need to answer every question if you have similar feelings and experiences as expressed by the other focus group participants.
- Respect all points of view.
- Assure confidentiality of responses.
- One at a time. Please do not interrupt one another; however, there is no need to raise your hand to be called on.
- There are no right or wrong answers, but rather differing points of view. We encourage you to share your point of view even if it differs from what others have to say.

Everything you share with us will be confidential. Only general themes will be reported across all the interviews we conduct. Quotes will only be used if they cannot be tied back to the respondent.

Does everyone agree to this level of confidentiality?

Do you have any questions before we begin?

## QUESTIONS

1. Please tell us your first name, and briefly, why you decided to come today.
2. How do people in your community talk about mental health issues?
3. How do you talk to people in your community about your mental health issues?
4. What type of mental health support have you found to be the most helpful?
  - a) Who do you like to talk to about your mental health issues?
    - ii) Professional
    - iii) Family member
    - iv) Friend
    - v) Religious leader
    - vi) Other
5. When you are starting to feel better from your mental health condition, what do you notice differently about yourself?
6. What do you think it means when someone says they are “in recovery” from their mental health condition?
7. Do you like the idea of getting support from someone who also has a mental health condition? Why or why not?
8. Would you prefer the person you are getting support from also be Latino [Deaf/Hard of Hearing]? Why or why not?
9. What services or support would you like to see in the community to help you when you are not feeling well?
10. Is there anything else you would like to share about Latinos [Deaf/Hard of Hearing] and mental health?

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