



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

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# Presenter Disclosure

I, and my colleagues, have no conflicts of interest to disclose....

# Background

- Mental health systems transformation has the promotion of recovery and peer support at its core.
- Providing recovery-oriented and peer support services in a culturally- and linguistically-appropriate manner is essential to providing effective mental health care.
- The implementation of these concepts in mental health systems may not be widely available to certain unique populations.
- In order for mental health providers to effectively serve these populations, culturally-tailored approaches to recovery and peer support are needed.

# Background

- Several large epidemiological studies indicate lifetime prevalence estimates for mental health conditions among Latinos to be 28-31%.
- Latinos born in the US experience higher rates of psychiatric disorders and mental illness as compared to foreign-born Latinos – potentially explained by higher rates of perceived discrimination and greater family cultural conflicts.
- Mental health service utilization among Latinos is varied; some studies suggest less than 10% of Latinos with a mental health condition seek specialty mental health services, and fewer than 20% obtain general medical services for mental health problems.
- Latinos share some key cultural beliefs that may impact their understanding of mental health and their help-seeking behaviors.

# Background

- While the prevalence of being deaf/hard of hearing (D/HH) is low (8-9%), D/HH people view themselves as a cultural and linguistic minority, rather than being afflicted with a disability.
- The prevalence of mental illness in the D/HH population is not well described, though disparities in both medical and mental health needs have been established.
- 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.
- Coupled with communication barriers, studies suggest that mental health stigma and distrust of the mental health system exists among people who are D/HH and affect service utilization.

# Evaluation Objectives

- 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 the focus of this study – Latinos and individuals who are deaf or hard of hearing.

# Evaluation Objectives

Our study questions included:

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?

# Methods

- Key Informant Interviews (n=8)
  - Nationally recognized published experts in their field or a direct provider of services for our populations of interest
- Focus groups and interviews with members of our populations of interest (n=30)
  - Latino population: 2 focus groups (n=13) and 5 individual interviews
  - D/HH population: 1 focus group (n=4) and 8 individual interviews

# Methods

- In order to more efficiently and competently complete data collection with these cultural groups, we decided to partner with a cultural broker.
  - 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.
  - The culture broker acts as a go-between, one who advocates or intervenes on behalf of another individual or group.
- We contracted with 2 D/HH cultural brokers and 1 Latino cultural broker.

# Methods

- All cultural brokers were currently receiving mental health services.
- They were seen as respected leaders in their respective communities and had connections that facilitated the identification of individuals to participate in data collection.
- They were responsible for working with us on recruitment, question set development, facilitating interviews/focus groups, and aiding in the analysis of our qualitative data.
- 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.

# Results: D/HH – Stigma and Privacy

- We heard from both peers and key informants about the high level of stigma in the D/HH community surrounding mental health issues.
  - Lack of education the deaf community at large has regarding mental health conditions
  - Difficulties in providing broad-based public education to the deaf community about mental health issues
  
- Confidentiality and privacy concerns are significant.
  - Because the D/HH community is small and somewhat insular, gossiping frequently occurred
  - Fear of being labeled “crazy”
  - Refusal of mental health treatment because of fear of others finding out

## Results: D/HH – Stigma and Privacy

*“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.”*

# Results: D/HH – Communication Issues

- Strong preference for receiving mental health services from someone who could communicate in American Sign Language (ASL).
  - 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.
  
- Frustrations in working with an interpreter.
  - Lack of ease in directly communicating
  - Fear of things being misinterpreted

## Results: D/HH – Communication Issues

*“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.”*

*“I was working with a therapist in XXXXXXXXXXXX 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.”*

# Results: D/HH – Communication Issues

- 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.
  - Visual communication/diagrams
  - Gestures
  - Use of Certified Deaf Interpreter

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

# Results: D/HH – Understanding of Recovery

- Key informants felt the term recovery was not understood, largely due to literacy issues and a 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”.

# Results: D/HH – Understanding of Recovery

*“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]*

# Results: D/HH – Understanding of Peer Support

- 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.

# Results: D/HH – Understanding of Peer Support

*“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 communication with them. I’m comfortable with all.”*

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

# Results: Latino – Community Views

- We heard very strongly how negatively their community views mental health issues. They are seen as “crazy” and a “vergüenza” (embarrassment/shame). Many have been rejected by their family and community.
- Some will therefore refuse mental health services because of social expectations.
- Many spoke of the family rejection they’ve faced and the lack of support they’ve received.
- 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.

## Results: Latino – Community Views

*“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.”*

*“Most of my family doesn’t know I have mental health problems. Many of them are sick too, but they’re not getting help. They don’t want to recognize they have a mental health issue.”*

# Results: Latino – Experience with the Mental Health System

- 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
  - Barriers cited included:
    - Limited Spanish-speaking services
    - Transportation
    - Ineffective interpreters
    - Ineffective relationships with clinicians

# Results: Latino – Experience with the Mental Health System

*“There are no services [in Spanish] for us in XXXXX. It’s hard to get to YYYYY. 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.”*

# Results: Latino – Understanding of Recovery

- Latino Peers recognized that the process of recovery is not easy and that a commitment from within is required.
- They 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 were some Latinos 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.

# Results: Latino – Understanding of Recovery

*“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.”*

# Results: Latino – Understanding of Peer Support

- 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.

# Results: Latino – Understanding of Peer Support

*“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.”*

# Conclusions

- Communication issues are significant in both populations, presenting barriers to adequately 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.

# Conclusions

- 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.
- 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.

# Recommendations

- 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 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.

# Recommendations

- 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.

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