ENGAGING THE UNDERSERVED: PERSONAL ACCOUNTS OF COMMUNITIES ON MENTAL HEALTH NEEDS FOR PREVENTION AND EARLY INTERVENTION STRATEGIES

UC DAVIS CENTER FOR REDUCING HEALTH DISPARITIES

UCDAVIS
Health System
ENGAGING THE UNDERSERVED:
PERSONAL ACCOUNTS OF COMMUNITIES ON MENTAL HEALTH NEEDS FOR PREVENTION AND EARLY INTERVENTION STRATEGIES

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UC DAVIS
CENTER FOR REDUCING HEALTH DISPARITIES

Report #1 in a Series
Report #2 is Building Partnerships: Key Considerations When Engaging Underserved Communities Under the MHSA

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ACKNOWLEDGMENTS

This project conducted by the UC Davis Center for Reducing Health Disparities (CRHD) in collaboration with the California Department of Mental Health represents an effort to reach out, to engage, and collect community voices that have previously not been heard. Through this project, CRHD developed relationships with historically unserved and underserved communities, community-based agencies, and a group of dedicated and passionate community advocates who are serving and understand the needs of these communities. Although CRHD staff led the process for drafting and reaching the conclusions and recommendations presented in this report, in many ways it was the participants who participated in our focus groups who “wrote” this report. Their willingness to share their perspective was based on the trust that was established and the belief that their message would be presented to mental health decision-makers. We are appreciative and grateful to the individuals and communities for sharing their time and wisdom and hope that they find their voices well represented in this report.
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FIGURE 1—COUNTRIES WHERE FOCUS GROUPS WERE CONDUCTED
I. EXECUTIVE SUMMARY

PURPOSE AND OVERVIEW

This report summarizes a nine-month project conducted by the Center for Reducing Health Disparities (CRHD) at UC Davis and funded by the California Department of Mental Health. The project’s purpose was to develop a process for community engagement with diverse underserved communities on the Prevention and Early Intervention (PEI) component of the Mental Health Services Act (MHSA). The project involved engaging with and learning from:

• Cultural brokers: state, county, and community leaders with knowledge about specific underserved populations and with established trust in communities;

• Key informant interviews with community leaders and mental health and social service providers; and

• Focus groups with community members of varied ethnicities, ages, gender, sexual orientation, and geographic locales from selected underserved populations (see Table 1).

The findings in this report come from 30 focus groups that were conducted primarily in community-based locations in 10 counties across California (see Figure 1). Focus group participants included:

• Specific ethnic groups: African American, Native American, Native Hawaiian and Pacific Islander, Asian (including Hmong, Cambodian, and Chinese), and Latina/o (Mexican and Central and South American);

• Other underserved groups from rural and urban locations: LGBTQ (lesbian, gay, bisexual, transgender, and questioning), foster youth, young adults with juvenile justice history, and older adults; and

• Community-based providers that serve these communities.

The community engagement process undertaken by CRHD was based on the principles of Community-Based Participatory Research and Asset-Based Community Development. These principles promote collaborative relationships with communities that are built on existing community strengths and knowledge and are sustainable, cooperative, involve co-learning, and encourage systems development and capacity building. This approach recognizes that the people who live in communities in which data is being collected have the right to participate in the process of defining problems, in mobilizing assets and strengths, and in designing and implementing
### TABLE 1 — FOCUS GROUP PARTICIPANTS

<table>
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<tr>
<th>FOCUS GROUP</th>
<th>TOTAL PARTICIPANTS</th>
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<th>AVERAGE AGE</th>
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interventions and solutions. Embracing these principles, CRHD began conversations with communities (community leaders, cultural brokers, key informants, and general community members) across California using interviews and focus groups (for more details see Appendix 2).

This report focuses on the findings from community members who participated in the focus groups, and not on the data we obtained from interviewing cultural brokers or key informants. (Content from cultural broker and key informant interviews will be described in a future report.) Therefore, the voices found in this report are those of the community members themselves as they convey their mental health and other needs, their strengths and assets, and their recommendations for strategies and programs.

**KEY FINDINGS**

The accounts of the historically unserved and underserved communities are sobering and provide us with an understanding of the problems that concern the most vulnerable Californians. This report will give readers a deeper appreciation of the multiple factors affecting the mental health of underserved communities and of how challenging it will be to find solutions toward a healthier California.

The stories shared in the focus groups by members of historically underserved communities emphasized their isolation from “mainstream” society, their history of poverty and oppression, examples of discrimination by health care and social service providers, as well as accounts of their despair and suffering. The participants in our focus groups shared their experiences of:

- **Mental health problems** and the quality of life of those with mental illness among historically underserved communities;
- **Problems accessing mental health care and the quality of services received**;
- **Social determinants of health** such as poverty and discrimination; and
- **Social exclusion** of underserved communities based on current and historical experiences with government agencies (e.g., police, justice, education, and social services, as well as mental health care) and their lack of knowledge of the activities and motivations of service organizations.

**COMMUNITY MENTAL HEALTH CONCERNS**

Among the many mental health concerns described by focus group participants, the most common were violence and trauma, illicit drugs, depression, stress, and suicide. Mental health concerns reflected a complex interplay of individual problems, personal and family history, community environment, and limited resources to deal with the problems experienced.
EXECUTIVE SUMMARY

PROBLEMS ACCESSING HEALTH SERVICES AND QUALITY OF CARE

Limited or no access to mental health care and other social services was a significant factor affecting the mental health of underserved communities. Barriers cited by focus group participants included:

- Lack of availability of services,
- Lack of awareness of existing mental health services,
- Stigma,
- Barriers within the mental health system (e.g., waiting periods and eligibility requirements),
- Lack of continuity of community programs,
- Geographic isolation and lack of transportation,
- Undocumented or uncertain legal status in the U.S.,
- Lack of culturally and linguistically appropriate services, and
- Perceptions of mental health system as punitive (e.g., treatment that worsens the individual's overall condition, and use of restraints and locked facilities).

A major theme in the focus groups was the scarcity of services available to address community mental health concerns. Those who were able to access services expressed frustration interacting with a health care system that was perceived as unfriendly, impersonal, and insensitive. Participants complained of the poor quality of care they receive, inappropriateness of some services, and some shared examples of coercive and involuntary mental health care services.

SOCIAL DETERMINANTS

Social determinants refer to the social conditions in which people grow, live, work, and age that have a powerful influence on people's health. Inequalities in these conditions lead to disparities in health. Participants overwhelmingly identified social determinants such as poverty and discrimination as major factors affecting mental health in their communities and the quality of life of those with mental illness. They recommended that the improvement of social conditions be a key objective of prevention and early intervention efforts.
SOCIAL EXCLUSION

Members of underserved communities felt isolated and perceived that they were regarded as unimportant by government-run agencies and that they were powerless to provide input or affect change. Focus group participants discussed the mistrust they have of governmental agencies as these have traditionally determined “needs” of a community without consulting with the community itself, promised particular services that were never delivered, or implemented services or programs that were not sustained.

Most focus groups reported that they had not heard of the Mental Health Services Act (MHSA) and were not aware of any new outreach or intervention efforts in their communities. Many participants were surprised to learn that the California Department of Mental Health wanted to hear directly from them about their needs as well as their strengths, assets, and resources. Focus group participants were also unaware of county mental health care agencies’ work to improve access to and the quality of mental health care.

Focus group findings suggest that new, concerted, and ongoing efforts to engage communities in the development and dissemination of new programs, to promote social inclusion, and to build sustainable relationships with underserved communities are critically needed.

COMMUNITY ASSETS

Community members portrayed themselves as strong, motivated, and capable, not as passive victims. Focus groups identified community assets that promote the mental health of their communities: individual and community resiliency, community-based organizations, formal and informal support networks, community leaders, and connections to native culture and language. Focus group members felt that these assets were not utilized or were underutilized by existing mental health care systems.

Focus group participants suggested that mental health services need to build on existing community resources. In addition, it was recommended that new efforts include comprehensive community programs that are culturally and linguistically relevant with opportunities for practicing traditional arts, music, and religious practices.
# RECOMMENDATIONS

PEI programs recommended by focus groups participants included the following:

<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>REASONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programs to address broader social concerns</td>
<td>Mental health problems are inextricably tied to lack of housing, employment, and poverty for many participants.</td>
</tr>
<tr>
<td>School and after-school programs, including mental health programs,</td>
<td>Schools are easily accessible and provide a convenient venue for both mental health treatment and prevention programs.</td>
</tr>
<tr>
<td>sports, academic assistance, and LGBTQ counselors</td>
<td></td>
</tr>
<tr>
<td>Mentoring programs</td>
<td>Existing programs often provide services with professionals who do not resemble their clients in terms of ethnicity, socioeconomic status, or age. Engaging youth with role models with whom they can relate is a critical approach to prevention.</td>
</tr>
<tr>
<td>Support groups and group therapy, including programs for ethnic</td>
<td>Discussing problems in a group setting is preferable in some cultures and minimizes stigma associated with mental health or adjustment problems.</td>
</tr>
<tr>
<td>identity development, cultural adjustment, and socialization.</td>
<td></td>
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<tr>
<td>Education about mental health issues</td>
<td>Participants noted the lack of awareness and understanding of mental health problems and how this contributes to underutilization of services.</td>
</tr>
<tr>
<td>Parenting programs</td>
<td>Family violence, family disintegration, family conflict, and intergenerational stress contribute to mental health problems.</td>
</tr>
<tr>
<td>Foster youth programs</td>
<td>Many foster children/youth do not obtain mental health treatment and are unaware of mental health resources available to them. There is a lack of services for youth transitioning out of the foster care system.</td>
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<tr>
<td>Programs for adults and youth in the criminal justice system</td>
<td>Participants who had been involved in the juvenile and criminal justice systems described insufficient and disjointed care, lack of support programs, and lack of caring providers.</td>
</tr>
<tr>
<td>Programs for older adults</td>
<td>Older adults experience significant social isolation and lack awareness of symptoms of mental health problems and available services.</td>
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Based on the findings detailed above as well as the lessons learned in the implementation of this project, the Center for Reducing Health Disparities has the following recommendations for Prevention and Early Intervention efforts at the county level:

<table>
<thead>
<tr>
<th>RECOMMENDATIONS</th>
</tr>
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<tbody>
<tr>
<td>Give priority to the needs of the local community.</td>
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<tr>
<td>Build ongoing, sustainable relationships with community members, organizations, and advocates and involve them in meaningful ways in PEI planning and mental health programs.</td>
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<tr>
<td>Establish and maintain collaborative and trusting relationships with community partners to improve the delivery of mental health care.</td>
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<tr>
<td>Address past and present experiences of violence and trauma in the development and implementation of PEI programs.</td>
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<tr>
<td>Build on existing community assets and resources in PEI planning and programs.</td>
</tr>
<tr>
<td>Develop integrated, community-based services that integrate mental health services with other social services.</td>
</tr>
<tr>
<td>Broaden the scope of prevention to include the social and economic determinants of mental health.</td>
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</table>
“The violence now is my main concern. … I am 37. I have been almost killed two or three times myself. But thing that bothers me is everybody got guns.”

Native American Adult

“There were two killings this year… where police went into a home and there were mental health issues there and they gunned them down because they were acting erratic.”

Cambodian Father

“I personally witnessed several shootings, one of which involved a 14-year old girl who was shot by a random bullet because she was in a crowd of people when some gunfire happened…. I sat with her for an hour until the police showed up…."

African American Youth

“Where I live everyone suffers from domestic violence…. Many times in Mexico you keep quiet because you fear that he will hit you again. Here this is the country of opportunities where you have to speak. If you don’t give yourself the opportunity to speak and tell people or report it to the police, he will continue to do it always.”

Latina Parent
II. COMMUNITY MENTAL HEALTH CONCERNS

KEY FINDING
Among the many mental health concerns, violence and trauma, illicit drugs, depression, stress, and suicide were the most common.

The following is a summary of the analysis of the mental health-related content from the focus groups. All focus groups had extensive discussions of mental health concerns. The most common mental health concerns across groups included violence and trauma (domestic, family, war-related trauma, historical trauma, general youth, and gang), illicit drugs, depression, stress, and suicide.

VIOLENCE AND TRAUMA

Violence and trauma were pervasive themes across focus groups. Conversations about violence and trauma focused on exposure to violence in the home, school, and community. Family violence (both domestic violence and child maltreatment) was a concern for many communities and was reported to be largely hidden. For immigrant communities, intergenerational and cultural differences were seen as barriers to overcoming violence in the home. Participants suggested that violence in the home and community is often coupled with limited coping or support resources, becoming a cycle that is perpetuated and which spirals into more severe situations.

In addition to violence in the home, youth reported witnessing violence in their schools and neighborhoods. This exposure to violence contributed significantly to youth's experience of anxiety and fear. Youth described their personal struggles with violence and how they gained awareness to cope or overcome it. Many of the youth and young adults who participated felt that schools often missed an opportunity to assist students in coping with family, economic, and academic struggles. They suggested that youth often enter the juvenile justice system because schools have failed to address mental health needs related to exposure to violence.

Concerns about gang violence were common among participants living in both rural and urban areas. Many participants suggested that despite the fact that typically only youth are directly involved in gang violence, the quality of life of members of the entire community suffers. Critical in the intervention for and prevention of gang violence was the role of the schools, parents, law enforcement, and social service agencies. Participants suggested that ignoring experiences of gang violence only leads to other problems within the community.
“Selling drugs and using drugs and to cope with financial stress. Then to cope with personal—feeling a little better in terms of their well-being.”

Youth Provider

“The drugs are just so bad, they are everywhere. There is no safe place—I don’t care what anybody says. The drugs and alcohol are just taken over and it is sad.”

Native American Adult

“I went through a lot because my dad was sick. He had three strokes. I had him at home and he got depressed. He didn’t want to eat. He would close his eyes all day long and didn’t want to know anything about who was doing what and when.”

Older Adult Group Participant

“I believe what is affecting a lot is the salary. For that reason, people are suffering a lot of depressions.”

Latino Migrant Worker
In addition to these global concerns regarding community violence, some communities described experiences of trauma particularly relevant to their groups. For example, exposure to and experience of war-related violence was a common theme among immigrant and refugee groups. In particular, many participants in Hmong focus groups reported directly experiencing war-related violence. These focus group participants described feeling haunted by memories of the violence perpetrated against themselves, their husbands, children, and other family members.

Historical trauma was a concern addressed in Native American focus groups. Participants in these groups described the lasting impact of violence perpetrated against their elders and the generations preceding them. Group members saw exposure to historical trauma as contributing to the current fragmentation of their communities and the high levels of substance abuse and family violence.

I LLICIT DRUGS

Concerns about drugs included the use, availability, and exposure to drugs and drug selling. Although participants did not always specify what types of drugs were of concern, group members commented that drugs are readily available in their communities and that there is significant opportunity for economic advancement through drug selling. Given poverty and limited access to resources, drug selling becomes an attractive option for many youth in these communities. Furthermore, focus group members reported that drug and alcohol use are often used as ways to cope with difficulties in life. Participants described clearly the impact of drugs on the quality of life in their community, pointing to high rates of neighborhood violence and crime, the presence of mental illness related to drug use, and the fragmentation of community and familial bonds due to the presence of drugs. Little optimism was expressed about defeating the drug-use problem, and many group members suggested that few resources exist in their communities to address this problem.

D EPRESSION

Notably, all participating groups irrespective of their cultural differences identified the presence of depression in their community. When describing depression, focus group participants often associated pervasive feelings of sadness and hopelessness with life events and life stress. Many carry the burden of unrecognized, untreated, or poorly treated symptoms which they described as depression. Often untreated “depression” created significant stress for families. In some immigrant communities, especially refugee groups, depression was related to difficulties adjusting to different cultural norms and expectations and coping with economic pressures associated with life in the U.S.
“What stresses us as parents is that we get home from work and have to deal with the children. … You don’t have time to have a friendship with your children… You’re at work all day, and you’re tired but we have to do work around the house…. You don’t have the closeness with your child.”

Latina Migrant Worker

“Other things that make things harder for us are high rent, no decent job, illnesses, and many others, especially for those new arrivals. … For many, they speak no English, but have to face the judge, forced to defend themselves with law enforcement officers…. All those things are causing major depression, difficulty, and create emotional hardship.”

Hmong Community Leader

“We have kids that commit suicide, and even their friends, they don’t even know what signs to look for. One of the girls that committed suicide she went and told her friend that she was going to do it and nobody did anything about it…. Someone should know what are the signs to prevent that from happening.”

Native Hawaiian/Pacific Islander Adult

“Yes, reaching the point of attempting against your own life due to ataques de nervios and like you say the desperation. You reach the point of attempting against your own life.”

Latino Migrant Worker

“It is not the same being with family that is always a big support such as parents and family and here most of the time we feel alone. You feel alone and you don’t find your way.”

Latino Migrant Worker
STRESS

Focus group participants described their communities and neighborhoods as having shared experiences of stress. Stress was often attributed to factors such as drug use, violent neighborhood and home environments, poverty, and lack of access to resources such as employment and education. As described further in a following section (see Role of Social Determinants), for immigrant communities, stress due to cultural change after arriving in the U.S. was significant.

SUICIDE

Concerns around suicide (both thoughts and attempts) were expressed by many of the focus group participants. Many participants talked about family members or close friends who had committed suicide. Hmong and Native Hawaiian/Pacific Islander communities expressed serious concerns regarding the frequency of suicidal behaviors in their communities. For the Hmong community, the difficulties in acculturation led to a sense of desperation and frequent thoughts of suicide.

In contrast, the Native Hawaiian and Pacific Islander community felt that this was a serious concern, but there was no clarity as to the triggers for this behavior. Focus group participants from this community felt that the lack of information and understanding of what caused these behaviors had to do with the lack of attention from policy makers and service providers on the unique needs of this community.

Focus group participants from the other communities also expressed concerns with suicidal behaviors, especially among youth. Youth providers and youth themselves shared their concerns and experiences with suicidal thoughts, attempts, and completed suicides. This theme was particularly relevant for LGBTQ youth, who suggested that rejection by family, community, and schools contributed to feelings of hopelessness, despair, and suicidal thoughts and actions.
III. PROBLEMS ACCESSING HEALTH SERVICES AND QUALITY OF CARE

KEY FINDING
Limited or no access to mental health care and other social services was a significant factor affecting mental health of underserved communities. Barriers to access to care included: lack of availability of services, lack of awareness regarding mental health and mental health services, stigma, lack of affordability, lack of continuity of community programs, geographic isolation, lack of transportation, lack of citizenship, cultural and linguistic barriers, and perceptions of the mental health system as punitive.

Difficulty accessing services to address mental health needs was a pervasive and prominent theme in the focus group discussions. In fact, this theme represented the most frequently cited issue among all communities surveyed. A myriad of barriers to care were identified by groups including linguistic, cultural, and geographic obstacles. Amidst these discussions were powerful stories about problematic interactions with mental health providers and agencies. These stories conveyed a disappointment and mistrust in mental health systems. In this section we highlight the communities’ specific discussions related to accessing health services and frustrations regarding interactions with mental health systems.

LACK OF AVAILABILITY OF SERVICES

The predominant concern regarding access to mental health care was the scarcity of services. Across community groups, participants reported that there are not enough mental health programs and treatment services. When asked about where people in the community go when they need help, participants often responded by stating that there is no place for community members to go: “there is just nothing out there.”

LACK OF AWARENESS REGARDING MENTAL HEALTH CONDITIONS AND MENTAL HEALTH CARE

In some groups, particularly immigrant groups, participants felt that there is a general lack of knowledge in their communities regarding the signs and symptoms of mental illness, and this contributes to underutilization of services. Participants also commented that even when services are available, those that need the services are not always aware of them. It was suggested that individuals in need may not have enough familiarity with the mental health care system to access services. That is, people with mental health problems may not know where to go, who to talk to, or how to receive services within their financial means.
“There is a lot of shame… [some people] tell you I’m not crazy, I don’t need to go see anybody. Why are you telling me I need to get help?”

Asian Parent

“Tell the elderly to go to a psychologist or a support group and the first thing they’ll tell you is, ‘I’m not crazy.’ And they get upset.”

Older Adult Group Participant

“By the time you get an appointment, if you have insurance, you have to start with the pediatrician. And then they have to refer you. By the time you get a referral, it is six months down the line. By that time, either the problem got worse or it went away or a lid got slapped on it.”

African American Adult

“It is like the resources are there, you have to wait… you call somebody to make an appointment, they don’t ever call you back. You got to keep bugging them… your child is too young, or your child is not old enough, or you have to live in this community.”

Native American Adult

“You are so poor, that if you make a little above welfare, you don’t get no assistance. None. You are shut down. You can’t get the help you need.”

African American Adult

“By the time she was old enough, the whole program was abolished and then you go to another program and then you say, okay, one more year to join the girls’ group and then that goes away. The funding was taken away from our center.”

Native American Adult
STIGMA

Receiving mental health care for emotional problems was often perceived as a weakness and a suggestion that one is “crazy.” Focus groups members suggested that people in their communities are often reluctant to seek care for mental health problems because of the way that others in their family or community might perceive them.

BARRIERS WITHIN THE MENTAL HEALTH CARE SYSTEM

Many participants who actively sought mental health treatment described significant barriers to accessing services within the mental health system. A common theme in focus groups was the experience of lengthy wait periods. For some participants, the wait period was so long that by the time they were offered services, the problems had escalated and a higher level of care was required (e.g., hospitalization). Others reported that despite significant need, they were turned away from services due to ineligibility. For some participants, this was due to income requirements— incomes that were just over the maximum amount required to qualify for services. Other participants did not meet diagnostic criteria, despite clearly suffering from debilitating symptoms. These experiences created frustration, fatigue, and disappointment for individuals caring for loved ones with mental illnesses.

LACK OF AFFORDABILITY

The cost of treatment and medication, doctor visits, and hospitalization was another barrier to accessing health services discussed by focus group participants. Not only did participants feel that they could not afford to pay for services, they often lacked the time to attend appointments given the competing demands of caring for children and sustaining employment.

LACK OF CONTINUITY OF COMMUNITY PROGRAMS

The lack of money to sustain the (few) programs available in these communities was an issue discussed by many participants. Group members frequently identified programs that had once existed in their communities but were cut due to changes in funding priorities. In addition, participants expressed frustration with services that were discontinued abruptly with little attention to the ongoing needs of the individuals.

GEOGRAPHIC ISOLATION AND LACK OF TRANSPORTATION

Geographic isolation and lack of transportation severely limited the access of these communities to systems of care.
“You don’t have a way to go out. You don’t have a car. You have nothing. You feel desperate because there is no way to get to town. … If you get sick or you need something, all that you can do is squeeze your hands together because there is no way of getting out.”

Latina Migrant Worker

“If the family is not a legal alien, I don’t know where to get them help from. If they don’t have the green card and they don’t go to the EDD department, I don’t know how to help them.”

Asian Parent

“The way in which the law treats you because you cannot be comfortable because you cannot go about normally as any other person because you are fearful of immigration.”

Latino Migrant Worker

“We’re going to be intimidated walking through the … hospital. They cut our heads open, they take out our spleen, or they give us medication to change who we are. We’re a population who have not used these. People … have some type of delusions or psychosis and is considered possessed….”

Hmong Community Leader
UNDOCUMENTED OR UNCERTAIN LEGAL STATUS IN THE U.S.

Although most service systems do not inquire about legal status, many undocumented immigrants feared being reported to the Bureau of U.S. Citizenship & Immigration Services (USCIS) and consequent deportation. Thus, because of its implications on perceived eligibility and service availability as well as fear of deportation, legal status in the U.S. is a significant barrier to mental health treatment for immigrants.

LACK OF CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES

In the focus groups, cultural incompatibility was one of the most cited explanations of service underutilization by unserved or underserved community members. Many providers do not speak the language of the client or lack cultural competence. Service providers often have difficulty understanding mental disorders within a context of culture and do not have expertise to dispense culturally sensitive and acceptable treatments. Focus group participants expressed frustration at care providers who misdiagnosed clients due to a lack of awareness of cultural issues. The failure of care providers to attend to cultural issues contributed to participants’ reluctance to seek care, follow-through on referrals, or comply with treatment recommendations.

CULTURAL BELIEFS

Culture influences the way individuals interpret psychological distress and explain the causes of illness and its consequences. Culture also determines the treatment or help sought and may affect individuals’ willingness to access services in the traditional mental health system. For example, many Native American participants discussed the ways in which dominant theories regarding mental health conflict with and undermine Native beliefs and traditions. Hmong participants suggested that Hmong traditional beliefs in the spiritual origin of mental health problems may contribute to reluctance to seek mental health services and to comply with therapeutic regimens.

USE OF TRADITIONAL HEALERS OR ALTERNATIVE HEALING PRACTICES

Many unserved or underserved community members rejected established medical care and were mistreated when they sought formal services; thus, they preferred to seek health and mental health care from informal service providers. Alternative approaches in dealing with mental illness were described by many members of the communities interviewed. Within the Latina/o groups, participants reported that they often preferred to seek help from trusted friends, family members, or clergy members. Hmong participants reported using Shamans and herbal remedies. For Native American group members, cultural and religious ceremonies such as Pow Wows were critical for promoting physical, mental, and spiritual wellness in their communities.
“The sad thing is, the uncle that ... take[s] care of this particular teenager doesn’t speak English. So, there was no accessible social workers or therapist in the Samoan community to provide services. ... That is what I saying, advocating accessible to our community either through translation [or] through interpreters being available....”

Native Hawaiian/ Pacific Islander Adult

“My son did well when he had a black man as a therapist and he only had that one, and when he was with this guy, he was on point, everything was well.... And they switched his therapy. He flipped on him real quick. He could not relate.”

African American Adult

“White people that they have here, I don’t think most of them really understand Native American, what they are feeling, what they are thinking. It is really hard... it is hard to open up to a stranger like that.”

Native American Adult

“In terms of healing or treating the sick, many of us still want to practice the traditional way of healing. But many times, the law prohibit. Many times we are told we can’t practice the traditional way of treating or healing the sick person. This also causes a lot of misunderstanding.”

Hmong Community Leader

“But then how they do the evaluation is they take you first and they handcuff you to a bed. They are making you worse. They do stuff to make you go even more crazy.”

Native American Adult
PERCEPTIONS OF MENTAL HEALTH SYSTEM AS PUNITIVE

Some community members felt threatened by mental health treatment they described as punitive. Focus group participants described incidents in which contact with mental health institutions had led to negative outcomes such as removal of children from their custody and involuntary hospitalization and physical restraint. These incidents served to reinforce feelings of fear and mistrust that participants described when discussing mental health providers and institutions.
“Always stress and depression. Not knowing what will happen tomorrow. You never know if your car will start tomorrow, if the kids will go to school, or any thing like that.”

Latina Migrant Worker

“We have no education like others; we wouldn’t be able to work…. I cannot work for myself, my children are all grown up, but they could only work enough to feed themselves, they cannot share anything with me. … I have no house to live in. First choice, I want to kill myself. Second choice is, if we can get Laos back, then we want to go back to live in our Laotian Country, so that our hearts would not ache this much, but I’m old, I reached half life already, I’m nearing death, even if I went back to Laos, I would not be able to work to live.”

Hmong Refugee Woman

“In and out of penitentiary. I want to work. I am tired of doing time. I am hungry for work more than ever. That is my whole day. I need work, I am hungry, just like many of the young youths around the community….”

African American Adult

“I’m worried about a crack-head trying to kill me. … Like we have all these like grown men, like pimps and stuff in our community, and a lot of them. I have had trouble walking down the street having someone yell at me, and try to talk to me, like try to get me to do that type of work…”

Native American Youth
IV. ROLE OF SOCIAL DETERMINANTS

KEY FINDING
Participants identified social determinants such as poverty and discrimination as major causes of mental health problems in their communities and recommended that the improvement of social conditions be a key objective of prevention efforts.

One of the most consistent themes that emerged across groups was an emphasis on social determinants of mental health. Social determinants refer to the social conditions in which people grow, live, work, and age that have a powerful influence on people’s health. When asked about mental health problems in their communities, participants overwhelmingly began by identifying significant social concerns such as unemployment and poverty. Participants across groups asserted that social determinants are a major cause of mental health problems in their communities and an important area for intervention. The social factors that were identified most consistently across groups were: (1) economic and physical living conditions; (2) cultural loss, cultural stress, and vulnerability; and (3) social conditions such as discrimination, racism, and lack of power.

ECONOMIC AND PHYSICAL LIVING CONDITIONS

Participants overwhelmingly cited poverty and inadequate living conditions as contributors to mental health problems in their communities. In many focus groups, the impact of poverty was identified at the outset of the session as an overarching concern and comprised a significant portion of the discussion. Common problems related to poverty included obtaining and maintaining housing, transportation, and food for their families.

While many focus group members discussed poverty as a problem in and of itself, others identified it as a primary cause of mental health problems. For those that linked poverty directly to mental health problems, mental health concerns frequently fell into two categories: internalizing disorders (depression, stress, anxiety, and suicide) and violence or criminal activities. Many participants reported that they experience a significant degree of anxiety related to providing food and housing for themselves and their families. Group members expressed despair, depression, and suicidal thoughts related to the burden of poverty and the responsibility of providing for family members.

Some focus groups identified poverty as a key contributor to violence and crime in their communities. Participants described continual frustration with the lack of opportunities for employment. They suggested that unemployment and financial instability lead individuals in their communities to resort to illegal activities to support themselves and their families. Many group members asserted that for youth in their communities participation in illegal activities such as selling drugs and prostitution is the only way of “making ends meet.”
“Back in Laos… our own farm does our own chores, and… everything seemed to be working perfectly. This is a great country, great opportunity, but it’s like we are scattered within the family, and wife doesn’t listen to the husband, husband doesn’t want to listen to wife, the kids… involved in gang and cut school and it seem like everyone is scattered.”

Hmong Refugee Woman

“I just think that a lot of Southeast Asians kids they just forgot where they come from. They got more adapted into the American society…. Lost their boundaries. Lost what they were taught. Lost they’re going to a home and bow down their heads for the elders. … They are so disrespectful now. … Especially where we come from, respect is the main thing that our parents teach us. And it is not passed…..”

Cambodian Father

“It happened to me once now with the immigration laws. These people came to insult and yell at me. One tries to avoid them because that way you show that you are here to work and not to look for violence. You put up with it in order to find work.”

Latino Migrant Worker

“I was kicked out when I was 15…. There was already violence in my home, but it got worse after I came out. [My father] had thrown a [heavy object] at me and broke my shoulder blade and collar bone. I told the school and nothing really happened, like it was crazy. The police came and they said if it happened again. It was hard. I felt that it was because I had come out.”

LGBTQ Youth

“He was shooting him in the back, while he was just lying there. And he did it until the tazer did not work anymore… the charge was gone. He wasn’t even resisting. … It was like six of them on one dude. They were just shocking him.”

African American Youth
In addition to concerns related to financial stress, many participants reported living in substandard housing conditions, some with no access to running water, others with high levels of neighborhood violence and drug use. For agricultural workers, poor living conditions contributed to stress and depression. These participants reported that they were unable to obtain running water and lived in geographically isolated areas where access to grocery stores, water, laundry facilities, and recreation for their children is extremely limited.

In contrast, many focus group participants who reside in inner city neighborhoods described difficult living conditions related to unsafe neighborhood environments. In particular, youth living in the inner city expressed fears about being outdoors in their neighborhoods. These participants described witnessing fights, drive-by shootings, drug selling, and prostitution.

Thus, the impact of economic and physical living conditions cannot be underestimated. Participants described their lives as dominated by stress, depression, and despair related to poverty and inadequate living conditions and fear, anxiety, and exposure to trauma related to unsafe neighborhoods.

CULTURAL LOSS, CULTURAL STRESS, AND VULNERABILITY

For this project, significant outreach efforts were aimed at obtaining input from immigrant and refugee communities. Immigrant participants in the focus groups included Hmong, Cambodian, Pacific Islander, Chinese, Mexican, and Central and South American-origin individuals. For these participants, issues related to their immigrant and refugee status figured prominently in their assessment of community needs. As discussed in other sections of this report, immigrant and refugee status was sometimes related to exposure to severe trauma as well as difficulty accessing needed social services. In addition to these concerns, themes around acculturative stress and cultural loss emerged from these focus group discussions.

Acculturation refers to the transition from patterns of behaviors of the culture of origin to those of the host cultural environment producing changes in behaviors. These changes are behavioral shifts (e.g., in ways of speaking, dressing, eating, and in one’s cultural identity) producing acculturative stress as manifested by uncertainty, anxiety, and depression. Acculturative stress is related to mental health status in that it predicts the onset of mental disorders and affects the utilization of services. For focus group participants, acculturative stress was related to adjusting to new everyday activities such as riding a bus or going to the bank. For example, Hmong participants consistently described significant stress in coping with the demands of daily living in this country. In addition to stress related to daily activities, participants expressed experiencing a significant degree of stress related to adjusting U.S. laws, cultural values, and practices.
In many groups, participants discussed the loss of cultural ties and pointed to this loss as a factor contributing to the problems experienced in their communities. Many participants described cultural traditions and beliefs that were eroded through the immigration process. These beliefs and traditions were viewed as protective and strengthening to their communities. The erosion of these important cultural values and practices contributed to feelings of depression and isolation in many adult participants.

Cultural loss and acculturative stress also contributed significantly to family disruption. Participants across several groups described the intergenerational conflict that results from differing levels of acculturation among parents and children. Many parents reported that their children do not respect their values and beliefs and that this disrespect contributes to parent–child conflict. This cultural divide was also discussed in youth focus groups. Youth described their difficulties navigating different environments at home and at school and also lamented the lack of closeness with their parents.

In addition to stress associated with the acculturation process, immigration status was also associated with fears and vulnerability, particularly for Latina/o focus group members. These participants reported that because of their status as immigrants, they are often subject to discrimination, harassment, and violence. Furthermore, for undocumented immigrants, the fear of deportation impacts access to services as well as the ability to carry out daily living activities. For example, participants reported feeling fearful of leaving home to go to work or the grocery store.

Cultural loss and cultural disconnection were also factors affecting other groups as well, including Native Americans, African Americans, and LGBTQ members. For Native Americans, this was a particularly salient theme. Across the three Native American focus groups conducted, participants discussed the loss of connection to cultural traditions, rituals, and values. Participants pointed to this cultural loss as a key factor contributing to the fragmentation of their communities and the problems resulting from this fragmentation. Group members suggested that the erosion of cultural traditions and values contributes to the alcohol and drug use, family violence, and school dropout prevalent in their communities.
A major theme that emerged from the focus groups was the impact of oppressive social conditions, such as racism, on underserved and vulnerable communities. Because of the large quantity of quotes that addressed these social conditions, experiences described by participants under this theme were grouped into the following subcategories: discrimination, racism, social exclusion, and lack of power.

For this project, discrimination was defined as experiences in which individuals’ rights were violated or perceived to be violated based on their membership in a group (such as LGBTQ). Racism was coded when these instances of discrimination referred specifically to differential and harmful treatment based on ethnicity or race.

Social exclusion was coded when group members described the experience of being excluded from broader activities and mainstream culture. This was closely related to the category “lack of power,” which was coded when participants reported feeling disempowered, and described having no voice or ability to participate in decision making and opportunities for advancement. Participants’ experiences, observations, and perceptions that fall under the themes of social exclusion and lack of power are described in the next section.

Participants discussed both personal experiences with racism and discrimination as well as the global impact of racism and discrimination on their families and communities. Personal experiences with racism and discrimination involved violence and harassment. Migrant workers described being provoked with racist comments and having to continually walk away from racist taunts and insults. LGBTQ youth reported teasing, taunting, and bullying by peers, family, members of religious congregations, and school personnel including teachers and administration. Some LGBTQ participants described being beaten by family members and by strangers and receiving death threats from peers.

African American, Native American, and Cambodian youth recounted experiences of victimization by law enforcement officials. Many described being detained or threatened by police officers. These participants clearly perceived racism to be at the root of criminalization in these communities. African American youth in particular reported feeling a deep lack of trust for law enforcement. Stories such as the one described in the adjacent quote illustrate the potential trauma related to race-based discrimination and violence. Experiences of criminalization were linked to feelings of powerlessness. Participants reported that they do not feel protected by law enforcement and instead feel that their safety and well-being is threatened by the actions of law enforcement officers motivated by racism. These experiences of racism, discrimination, and criminalization contributed to a feeling of overall social exclusion and isolation described in the next section.
“There is just a big huge gap between a farm worker, somebody living in poverty and hungry and somebody who is disenfranchised, living in the rural areas, unincorporated cities. A big difference in walking into an office with a gentleman or female sitting up here taking notes with a Montblanc pen. They aren’t going to open up!”

Rural Provider

“There are many resources in other communities, but we have none in this community.”

Hmong Community Leader

“You have more people [with mental health problems] … because there is a definite, definite lack of communication between the mental health system that would say, ‘Okay, what kind of people should we treat, should we treat that man, or should we treat the rich man who has more money and they can pay for services.’”

African American Adult

“They throw you in the hole instead of saying why did you act that way…. They make a quick evaluation when you first get there… then they just toss you out.”

Urban Youth
V. SOCIAL EXCLUSION

KEY FINDING
Members of underserved communities felt isolated and perceived that they were regarded as unimportant by government agencies and that they were powerless to provide input and create change. This exclusion is not only manifested in mental health care, but according to the focus group participants, it is an exclusion from everyday activities and everyday services. Social exclusion creates a challenge for mental health systems to develop new strategies for engaging communities to improve delivery of mental health services.

Social exclusion describes the process by which individuals or groups of people are wholly or partly excluded from full participation in society. In this process, some individuals due to their background, experiences, or circumstances are denied access to society's resources, resulting in poor living standards, physical and mental health problems, and other interrelated problems. Social exclusion is not only measured in an individual's or community's living conditions (i.e., poverty), but it also involves the feeling of an individual not belonging to a community—or a community not belonging to the larger society.

Focus group members discussed their inability to participate effectively in economic, social, political, and cultural life; their isolation from mainstream society; and their exclusion from major activities that contribute to advancement in society. For example, African American youth discussed their inability to improve their living conditions when their access to educational opportunities is limited. They also expressed feeling ignored or forsaken by health systems. For foster youth, exclusion was most pronounced at transition age, when services become difficult to access and youth are left to fend for themselves in finding employment and housing. Migrant workers described a complete lack of power to address the racism, violence, and oppressive social conditions that characterize their daily living. Recently immigrated Hmong refugees reported that they have no means to improve their situation despite a strong desire to obtain education, employment, and housing and to be self-sufficient.

Focus group participants also emphasized their frustrations and mistrust toward government agencies that have historically failed to meet their needs. Group members discussed the problematic ways in which they have experienced governmental attempts to "help" in the past, which included stories of how government agencies have determined "needs" of a community without consulting with the community being served, promised particular services that were never delivered, or introduced a service or program that was not sustained. For example, Native American leaders pointed to repeated failed attempts to gain services from state and local administrations. Mistrust of government agencies extended to interactions with mental health providers and systems. Participants discussed the difficulties they had when accessing mental health care in a system which they described as foreign, unfriendly, impersonal, and insensitive.
As discussed in the previous section, past and present experiences with law enforcement and the justice system contributed to the general mistrust of government agencies. Participants felt that reaching out for help may place them at risk for involvement with law enforcement or child protective services. These institutions were seen as discriminatory and punitive. For this reason, many participants refused to seek services when facing family disruption and conflict or existing mental health conditions.

In sum, a clear message conveyed by participants was the central role oppressive social conditions such as racism, criminalization, and social exclusion play in limiting their ability to improve their living conditions and ultimately, in determining the health and mental health of individuals in their communities.
When you talk to a person that lives in your neighborhood, in a ghetto area, when you talk with them, it is like they have their negative points but they also have their positive points…. It is not all just about drugs or gangs or shootings…. They want to do something positive. They don’t want to be there dealing with that situation all their life. They want to make a change.”

African American Youth

“They are still whole despite the fact that they are dealing with such huge, huge burdens and so many painful issues in terms of fractures in their support network. There is a lot of resiliency.”

Youth Provider

“When you are taking Hawaiians… they revere their elders. So, we have the Kupuna which is the elder. … I know we would feel very comfortable going to them and kind of relating some pains and maybe they may help you.”

Native Hawaiian/Pacific Islander Adult

“A lot of the cultural leaders, the pastors, and the shamans have started to educate the community on how to be more independent, how to develop coping skills and management skills, and I think that those have given our community skills to manage themselves and I think that that has worked.”

Hmong Community Leader

“They are traditional healers in the sense of medicine people recognized in the community…. And those take different forms of healing. It could be singing, it could be prayer, it could be spiritual counseling, it could be a number of things that are really important from a cultural perspective to our people that haven’t been recognized a lot. And now, we are able to help our community recognize those things that have kept all of our families healthy.”

Native American Provider
VI. COMMUNITY ASSETS

KEY FINDING
Focus groups identified community assets that promoted the mental health of their communities. These included individual and community resiliency, community-based organizations, informal and formal support networks, and community leaders and advocates.

Focus group participants identified resources within communities that enhance and improve health and mental health. They identified individual resiliency, traditional and faith-based healers, informal networks of support, mentoring and school programs, reconnection with native cultures, community-based organizations (e.g., social service agencies, tribal communities, faith-based organizations, and youth after-school programs.

RESILIENCY

One asset discussed by participants was resiliency, or the ability of people who experience social exclusion to keep going during very hard times. Other community strengths discussed by focus group participants included strong motivation, willingness to learn, desire to improve their lives, as well as the capacity to adapt to challenging situations.

TRADITIONAL AND SPIRITUAL HEALERS

Many community members reported that they rely on alternative approaches and traditional healers for dealing with mental illness. Traditional healers were described as respected and trusted community leaders who are a source of strength and empowerment for many community members. The reliance on traditional and spiritual healing approaches was particularly prominent in Hmong and Native American communities.

RELIGIOUS LEADERS

Some community members identified the churches as significant sources of strength and support in their communities. Group members discussed their preference for seeking support in times of emotional crisis from informal service providers such as church pastors.
“I really feel the strength in Islanders is the fact that we have families. We haven’t quite lost all of our families…. But we try to keep the families together so we can leverage and strengthen and solidify….”

Native Hawaiian/Pacific Islander Adult

“One tries to interact with other people to unburden oneself with a platica or heart to heart conversation. We are able to forget about it at least during that time.”

Latino Migrant Worker

“When there was sports, when the schools had sports, they had programs…. I mean, hey, you have that kid with the anger problem, stick him [with] football. That will give him something to do. When he goes home, he will be cool.”

African American Adult

“Fatherhood programs are good because then we will be able to come together like we are right now and just talk about things that are going on, like things going on with the kids and stuff and they will have someone to relate to.”

Cambodian Father

“I grew up being a Latino in my area when a white guy comes up … to the front of the class and he is trying to teach me something and he is telling me, you could do this, you could that. I really don’t see no hope in it because his mom and dad might have been rich, they paid his way through college. And he didn’t go through a lot of adversity. But I see a guy that has ink on him and comes into the classroom and says, you could do this, I went through this, this and this and I overcame that and look at where I am at now. Then it gives me more vision, a big brother like that or someone that I could look up to, a mentor, someone that I could admire.”

Urban Youth Leader

“[We have a program so youth] won’t forget where they came from… and what their culture is…. I am constantly talking to my grandsons and I am telling them, this is who you are, don’t forget it. So, one of my grandsons… he decided to go to the dance class. His mom worked on his regalia, the teacher over there, they teach you how to dance.”

Native American Adult
FAMILY AND FRIENDSHIPS

Trusted family members and friends were also identified as important resources when coping with mental health issues or dealing with daily stress and worries.

RECONNECTION TO NATIVE CULTURES

Existing community resources and assets identified by many Native American participants included strong community involvement, tribal athletics and arts programs, and additional programs that support learning native cultures such as language classes and dance. Communities’ connections to native cultures were identified as a key asset and a potential mechanism for addressing multiple health and social concerns.

ROLE MODELS AND MENTORSHIP

The importance of role models and mentoring programs was a prominent theme across groups. Urban African American youth and adults, in particular, mentioned successful and effective programs within their communities: Big Brother/Sisters programs, sports programs (when affordable), and employment programs for people coming out of detention facilities.

RECREATIONAL, SPORT, AND AFTER SCHOOL ACTIVITIES

Focus group participants discussed the benefits of recreational activities, sports, and other after school programs.

COMMUNITY-BASED ORGANIZATIONS, SOCIAL SERVICE/HEALTH PROGRAMS

Focus group participants also discussed different community organizations and programs, the work they do, and most importantly how these programs and organizations are trusted and safe spaces. These included community-based health centers; community-based advisory committees; promotoras; support groups for women, mothers, and fathers; and parenting classes. For Latina/o migrant participants, sources of support included informal support networks (often defined by country or community of origin), such as family and friends, as well as existing health services for the immigrant community.
“I would like a program that taught us English. English classes in the evenings after work because when you leave work is when you begin to worry.”

Latino Migrant Worker

“At my school... we had CHAC, a community healthy awareness council. ... They also had an outside-of-school place that I could go to at seven o’clock at night if I needed to if something was happening with my family, and ... they would talk to me. And it was like counseling. I don’t know how to describe it, but it was an awesome thing that I had, and they helped me through some tough times... I think that would be a great program to put in high school because high school is tough.”

LGBTQ Youth

“As far as the children, having more activities, free, at a low cost... maybe have like a teen night... where they are doing fun activities, learning about things, but just being a part of something that doesn’t have to do with violence, that doesn’t have to do with drugs, [doesn’t] have to do with sex....”

African American Adult
VII. COMMUNITY RECOMMENDATIONS FOR PREVENTION AND EARLY INTERVENTION PROGRAMS

KEY FINDING
Recommended programs for PEI by focus groups participants included: programs to address social concerns, school and after-school programs (including recreational activities and life-skills programs), mentoring programs, support groups and group therapy, education about mental health issues, parenting programs, programs for youth exiting the foster care system, programs for adults and youth in the juvenile justice system, and programs for older adults.

Focus group participants were asked about the kinds of programs that could improve the mental health of their communities. Participants recommended several programs and types of interventions and suggested that these programs be provided in locations that are frequented by community members such as schools and community and family resource centers.

PROGRAMS TO ADDRESS BROADER SOCIAL CONCERNS

Across groups, participants emphasized the importance of addressing basic needs as part of promoting mental health. For many participants, mental health problems were inextricably tied to lack of housing, employment, and poverty. Group members suggested that mental health problems could not be resolved if these issues were not addressed. Accordingly, participants recommended that prevention and early intervention initiatives include social services including employment and housing assistance.

SCHOOL AND AFTER SCHOOL PROGRAMS

A common theme in focus group discussions was the need for more school-based programs to address mental health. Participants noted that schools are easily accessible and provide a convenient venue for both mental health treatment and prevention programs. Groups discussed mental health education, early detection, and prevention programs, as well as health promotion and school retention programs. Health promotion programs included mentoring, life-skills education, transition programs for foster youth, and sports and recreational activities. In many of the groups, participants noted that free sports programs and mentoring programs had been effective in promoting the mental health of their children and youth, but that many of these programs had been cut. Participants suggested that providing recreational activities after school is an effective way of keeping youth “out of trouble.” For Native Americans in particular, academic assistance programs such as tutoring and school counseling were seen as key strategies to prevent school dropout and to promote school achievement.
“Whatever issue, unfortunately, it’s that [foster youth community] they don’t receive the necessary treatment or the necessary attention which allows the problems to snowball and become real hurdles…. Things that if had they been treated earlier, the symptoms could have been prevented.”

Foster Youth

“One of the greatest concerns for me is how to access mental health services and also at the same time, to understand what is mental health and how does it work in different regions. Mental, spiritual, education is to me, I think it’s the most important thing.”

Hmong Community Leader
ENGAGING THE UNDERSERVED: PERSONAL ACCOUNTS OF COMMUNITIES ON MENTAL HEALTH NEEDS FOR PREVENTION AND EARLY INTERVENTION STRATEGIES

COMMUNITY RECOMMENDATIONS FOR PREVENTION AND EARLY INTERVENTION PROGRAMS

LGBTQ participants recommended LGBTQ counselors in schools, diversity trainings in the public curriculum, parenting resources, comprehensive sexuality education (inclusive of LGBTQ issues), and youth-led programs and support groups. Because of the alienation, discrimination, and violence that LGBTQs experience in the schools, these strategies were seen as critical steps towards reducing rates of depression, feelings of isolation, discrimination, and suicide in LGBTQ youth.

MENTORING PROGRAMS

A theme that arose frequently across focus groups was the need for mentoring programs. Participants suggested that children and youth lacked guidance and positive relationships with adults in their communities. Many suggested that existing programs often provide services with therapists that do not resemble their clients in terms of ethnicity, socioeconomic status, or age. Mentorship programs such as Big Brothers and Big Sisters were seen by group members as an effective means of reaching youth. Participants recommended that programs be staffed by individuals with whom youth and young adults can connect with culturally and socially. They pointed to the increased benefit of positive role models that come from the target communities.

SUPPORT GROUPS AND GROUP THERAPY

Participants suggested that group treatments were an effective manner of promoting mental health while reducing stigma associated with treatment. It was suggested that group interventions to promote mental health be interpreted more broadly to include health promoting activity groups such as gardening, socializing programs, recreational activities, and parenting. Furthermore, for individuals with mental health problems, group approaches were seen as particularly effective. For some participants, discussing problems in a group setting was more culturally appropriate. In addition, the stigma associated with mental health treatment was reduced when programs were referred to as “classes” or “support groups.” Regarding the focus of the group interventions, participants recommended mentoring, socializing programs (to address isolation), parenting, and recreational activities (e.g., gardening, community arts) to promote communication across families and generations. For youth in particular, community members discussed the need for group interventions which address ethnic identity development, cultural adjustment, and intergenerational cultural conflict.

EDUCATION ABOUT MENTAL HEALTH ISSUES

Participants discussed the importance of efforts to provide education about mental health. In many of our community groups, group members had limited knowledge of mental disorders. When asked about mental health problems in their communities, a number of focus group members requested that the facilitator provide further education regarding the definition of mental health and mental health problems. Given this lack of knowledge and awareness, participants suggested that programs to educate their communities about mental health problems, signs and symptoms, and treatment
“If the state could create a more youth-based… counseling, or more appropriate for foster youth, or for kids coming from probation. Not just seeing a state-appointed clinical therapist but someone who has some experience… people who can relate to our experiences and can offer relevant suggestions and information, rather than just looking to diagnose as one thing or another. ‘Cause that’s where you get that sense of disconnectedness like just feeling like why?”

Foster Youth

“I strongly believe that counseling and continuing to educate those people who are at my age, my generation or older would certainly help. … If they understand things better, they may know how to deal with all these things. Creating a cultural counseling, resource, or informational center for those who are in need, so that they know how, when, and where to go and look or ask for help.”

Hmong Community Leader

“Like if you wanted to enter a rehab program after jail or go even just to go see you, go with you to court, to help you out, there used to be someone here at the clinic, used to have a job like that. But that has been gone….”

Native American Adult
could be effective mechanisms for the promotion of early detection and treatment. In our provider groups, participants noted the lack of awareness and understanding of mental health problems and suggested that this contributes to underutilization of services.

**PARENTING PROGRAMS**

As noted above, family violence, family disintegration, family conflict, and intergenerational stress contributed to mental health problems noted by focus group participants. Accordingly, many participants recommended parenting programs to address parenting deficits, to prevent child maltreatment, and to strengthen families.

**FOSTER YOUTH PROGRAMS**

The youth in foster care that were interviewed emphasized the lack of appropriate and sufficient mental health services for foster children and youth. They noted that many foster children do not obtain mental health treatment and are unaware of mental health resources available to them. They also discussed the difficulties experienced when transitioning out of foster care and described how many youth in foster care feel lost and fearful about what to do after they get out of foster care. They recommended that mental health treatment be provided to all children and youth entering the foster care system. In addition, they recommended that foster youth obtain assistance with transitional issues (such as obtaining housing and employment). Finally, foster youth recommended education about mental health issues for foster youth regarding the types of emotional difficulties encountered by children and youth entering and navigating the foster care system.

**PROGRAMS FOR ADULTS AND YOUTH IN THE CRIMINAL JUSTICE SYSTEM**

Participants who had been involved in the juvenile and criminal justice systems described disjointed care, lack of consistency with counselors, and lack of caring providers. Descriptions of mental health treatment within the juvenile justice system suggested that these services were ineffective. Recommendations for prevention efforts included programs specifically targeting youth in the juvenile justice system, and training adults who were former “problem kids” to serve as mentors. In addition, participants recommended programs for adults and youth exiting the criminal justice system to assist them in obtaining employment.

**PROGRAMS FOR OLDER ADULTS**

When discussing the mental health of the elderly population, most participants recommended providing education about mental and physical health problems and increasing recreational activities for elders to decrease social isolation.
“I hope that this program becomes a reality. That it not be left as a dream. That funds not be spent in finding out what our illness is and then not be given the medicine because unfortunately…. They made us dream that they would help us and it was all left in a dream.”

School-based Advocate

“I believe that with the help of agencies or organizations, if they are willing to provide more training and education, we are able to expand and reach more Hmong people in the Hmong community. Working and collaborating through agency such as Lao Family or any other non-profit organization, it’s certainly helpful and useful. Group discussion is also useful, helpful, and beneficial. Because by discussing and sharing problem or issue to one another, you start to realize that you are not alone.”

Hmong Community Leader

“I never heard of these services prior to you coming here. I probably would never have heard of this mental health legislation that came through. So, we need to open up those doors, we need to go in there and talk to them and ask them what is rightfully ours….”

Rural Provider
VIII. GENERAL RECOMMENDATIONS FOR THE PREVENTION AND EARLY INTERVENTION PLANNING PROCESS

The Center for Reducing Health Disparities has the following recommendations for Prevention and Early Intervention efforts at the county level. In contrast to the recommendations in the preceding section, the strategies listed below are our recommendations for PEI based on what we heard from focus group participants. These recommendations reflect the hopes of unserved and underserved communities for how MHSA might impact their communities in relevant and meaningful ways.

1. Give priority to the needs of the local community.
   - PEI planning should involve community members, organizations, and advocates to determine community needs and to develop effective strategies for prevention.
   - Violence and trauma, illicit drugs, depression, stress, and suicide were found to be the greatest mental health concerns in the communities represented in this project. Community engagement is the best way to determine local mental health needs and priorities that may differ within different local communities.
   - Optimal strategies for PEI programs must consider the experiences and cultural context of communities. Programs should be culturally and linguistically responsive to the characteristics of local communities.
   - Participants in our project emphasized a desire for comprehensive prevention and care that brings together physical, spiritual, emotional, and mental health with a regard for their community’s culture.
   - Programs would best be located where people normally gather, such as in schools, after-school programs, community centers, workplaces, and family resource centers. This will help address barriers to care.

2. Build ongoing, sustainable relationships with community members, organizations, and advocates and involve them in meaningful ways in PEI planning and mental health programs.
   - Many counties have begun to establish relationships with community partners, but it is challenging to sustain relationships across time and through the implementation of different components of the MHSA.
Many community groups experience impatience, fatigue, and disappointment with the implementation process. Participants in our project expressed concern about the lack of follow up after they have given input and expressed a desire for ongoing community engagement. Efforts to make community–county relationships sustainable should address these inherent challenges.

Experiences of mistrust with other institutions and government agencies (e.g., the health care system, educational institutions, law enforcement and justice system, and government policy makers) need to be acknowledged in the process of creating meaningful partnerships with underserved communities.

See the CRHD report *Building Partnerships: Key Considerations When Engaging Underserved Communities Under the MHSA* for strategies to develop community participation.

3. Establish and maintain collaborative and trusting relationships with community partners to improve the delivery of mental health care.

- Mental health care delivered when needed and in a timely manner can prevent the development of more severe problems.

- One of the most frequently cited themes in this project was lack of access to mental health care. Participants described a multitude of barriers to accessing care including lack of awareness of existing services, waiting time and “red tape” barriers to get services, lack of trust in providers and institutions, and stigma associated with mental health.

- Many participants were fearful of seeking mental health care through large county, medical, or academic institutions. Many participants, however, expressed a willingness to reach out to trusted community leaders and community-based organizations. Establishing relationships with community partners may be a helpful strategy to overcome many of the barriers to mental health care for underserved communities.
4. Address past and present experiences of violence and trauma in the development and implementation of PEI programs.

- Exposure to violence and trauma was pervasive in the communities who participated in our project. These experiences can have a lasting impact over generations as communities struggle to cope with untreated sequelae of trauma in older adults, families, youth, and children.

- Programs should incorporate strategies to prevent violence and to assess and treat symptoms of trauma.

- To adequately address violence in cultural minority communities, it is critical to provide support to overcome factors that perpetuate the victimization of these groups, particularly racism and discrimination.

- Prevention programs should support cultural minority groups in developing strategies to combat violence and developing programs to promote the strengthening of cultural ties and pride.

5. Build on existing community assets and resources in PEI planning and programs.

- Community leaders and local activists can provide key perspectives to county mental health agencies and should be regarded as important resources in community engagement efforts.

- Peer mentoring, role models within the community, and outreach workers (e.g., promotoras) are vital assets for providing meaningful services, outreach, and education in communities.

- Community-based organizations, which often have long history of providing services within ethnic minority and underserved communities, are also important resources for counties.
6. Develop integrated, community-based services that integrate mental health services with other social services.

- The importance of social conditions in perpetuating the emergence of mental disorders in their communities cannot be underestimated. Social inequities, social exclusion, and lack of access to social services were themes that predominated in focus group discussions.

- To further increase the relevance and effectiveness of PEI programs, traditional preventive mental health interventions should be paired with programs that help individuals meet basic needs.

- County mental health agencies should consider partnering with other community-based agencies to build capacity for providing an array of services such as job training and employment, housing, child welfare and parenting programs, socialization programs for isolated individuals, recreational programs, English classes, immigration, and legal assistance.

7. Broaden the scope of prevention to include the social and economic determinants of mental health.

- Historically, mental health prevention has focused on the development of psychosocial skills that reduce an individual's likelihood of engaging in at-risk behaviors. The findings of this study suggest that to successfully prevent the occurrence of mental health problems, prevention should be re-conceptualized to include activities that address social and economic determinants that contribute to mental illness.

- Addressing social determinants will require a paradigmatic shift in mental health prevention to include social justice and equal access to society's resources as legitimate targets for prevention efforts.
IX. CONCLUSIONS

MENTAL HEALTH PROMOTION, HEALTH DISPARITIES, AND SOCIAL JUSTICE

This project in community engagement was implemented in a context of increasing recognition of the prevalence and impact of health disparities on state, national, and international levels. Since the release of the Institute of Medicine’s report in 2003, Unequal Treatment\textsuperscript{10}, there have been efforts both nationally and locally to identify and address disparities in health and mental health. Many policy makers and health organizations have turned their attention to the social determinants of health as critical factors in the reduction of disparities. Most recently, the release of the documentary Unnatural Causes\textsuperscript{11} has brought widespread attention to the social and economic roots of health disparities. These efforts document the impact of social and economic inequalities on health and mental health.

Locally, in a recent meeting of the California Mental Health Directors’ Association (CMHDA), the county directors developed strategic goals to guide decision making. The first goal entitled “Social Justice” states, “CMHDA will advocate for equity and full inclusion of vulnerable populations and secure social justice as measured by access to necessary quality services that promote mental health, wellness, resiliency, and recovery in our communities.” This goal suggests that CMHDA members acknowledge the central role that social and environmental conditions play in determining the mental health of communities and that health disparities have multiple determinants and none operates in isolation. This acknowledgement is in line with an increasing understanding at the federal, state, and local levels that social circumstances and environmental factors place minority groups at a distinct disadvantage in health and at increased risk of disease\textsuperscript{12, 13}. In addition, it also suggests that the CMHDA is willing to consider within its purview not only traditional mental health services but also services that address the inequities and social exclusion experienced by underserved communities. These goals remarkably coincide with the input received from community voices through this project.

Given the confluence of voices calling for changes in social and economic conditions that impact the health and mental health of communities, the opportunity presented by the implementation of PEI initiatives is timely. By using the strategies detailed above—integrating mental health services with social services and expanding the scope of prevention to include social determinants—counties may begin to make strides in addressing the conditions that national and international research as well as the community voices collected in this project have identified as critical precursors to mental health problems.
WHAT WAS NOT SAID

The results detailed in this report reflect the responses of community members and leaders when asked about mental health issues in their communities. What is missing from this analysis is what communities did not say. Most notably, the vast majority of the participants in this project (with the exception of a few mental health providers) did not mention the Mental Health Services Act. In fact, participants overwhelmingly indicated that they had never heard of the MHSA and were not aware of any new outreach or intervention efforts in their communities. This lack of exposure to mental health policy and program development processes emerged as a pervasive deficit that facilitators encountered when explaining the purpose of the project to participants. This finding suggests that counties should consider redoubling dissemination efforts and identifying new avenues to engage communities in this process.

SCOPE OF THIS PROJECT

The current project was limited in scope as it was conducted in a relatively brief timeframe. Given this limitation, the results do not represent a comprehensive assessment of community needs, and instead were intended as a “first step” in engaging communities in ongoing and bidirectional conversations about their mental health needs and recommended strategies and programs to address them.

In addition, the results of this community consultation are intended to inform the state policy and program development and implementation process. This project involved the survey of diverse groups in several counties across the state of California. The results therefore reflect a breadth of perspectives, rather than an in-depth survey of individual community needs. Individual county outreach and engagement efforts may yield different results. Thus, the current consultation is not intended to guide mental health priority-setting at the county level, but rather the results detailed in this report will inform state development of plan requirements. Counties are encouraged to review a prior document, Building Partnerships: Key Considerations When Engaging Underserved Communities Under the MHSA, for suggestions on effective community engagement approaches that will assist them in ensuring the involvement of underserved communities in their MHSA processes. Outreach conducted by counties for PEI may serve as a base for future engagement in priority setting and policy implementation and will foster sustainability of programs.

The considerations detailed in this document stem from the principles of community engagement, lessons learned in this process, and the input of community leaders and community members. It is our hope that this information will assist counties and other stakeholders in both engaging communities more effectively and in increasing the participation of historically marginalized groups in mental health policy and service decision-making at county and state levels.
APPENDIX 1

Rationale for Selection of Groups

Focus groups were selected following two basic principles underlying the project's goals and community engagement methods. First, the groups are comprised of members of communities that are historically underserved by mental health services in California. To the greatest extent possible, identification of underserved communities has been driven by available data. Second, input into the focus group selection process was solicited from key informants and cultural brokers who were interviewed in the initial stages of community engagement. This allowed the selection process to emerge from the engagement with communities. The groups that have been selected represent the outcome of a collaborative process between researchers and community members from underserved populations.

In most cases, we were led to make initial contacts with representatives of particular communities by data on mental health disparities at the state or national level. Once initial contacts in a community were made the broad target groups were narrowed to the level of specificity required to have a meaningful focus group discussion through a collaborative process.

To define historically underserved populations, we examined data concerning four interrelated issues:

1. Groups with low levels of use of mental health services;
2. Groups that face barriers to participation in the policy making process in public mental health;
3. Groups with low rates of insurance coverage for mental health care; and
4. Groups that have been identified as priorities for mental health services.

1. GROUPS WITH LOW LEVELS OF USE OF MENTAL HEALTH SERVICES.

Disparities in the use of mental health services across ethnic groups in the United States were highlighted by a supplemental report of the U.S. Surgeon General in 2001 entitled Mental Health: Culture, Race, and Ethnicity14. According to that report a combination of cultural, economic, and healthcare access factors result in lower levels of mental health service use among ethnic minorities in the U.S. as a whole. Recent evidence from the 2005 California Health Interview Survey (CHIS15) confirms that the patterns noted at the national level are also reflected within the state. Figure 2 presents results from the 2005 CHIS on the use of mental health services in the past year among those who considered themselves in need of mental health services, broken
These data show that in California, use of mental health services by people who recognize a need for those services is lower among African-Americans, Latina/os, and Asian-Americans compared with non-Latina/o Whites. Moreover, within ethnic groups, immigrants are more likely to go without mental health services than the U.S. born.

*Any past 12-month mental health services use was based on a positive response to either of the questions: Not counting overnight stays, emergency room visits, or visits for drug or alcohol problems, in the past 12 months, have you seen a psychiatrist, psychologist, social worker, or counselor for emotional or mental health problems? or During the past 12 months, did you take any prescription medications, such as an antidepressant or sedative, almost daily for two weeks or more, for an emotional or personal problem?

†Self-reported need was based on a positive response to During the past 12 months, did you think you needed help for emotional or mental health problems, such as feeling sad, anxious or nervous?

Similar differences between immigrants and the U.S. born have also been found in other studies. According to the Mexican American Prevalence and Services Survey (MAPSS), a study done in Fresno County with adults of Mexican origin, only one in four (27%) persons who had one or more psychiatric disorders in the last 12-months received any kind of service. This means that approximately three out of four with a diagnosable mental disorder and who are in need in services remained untreated.
The problem of underutilization is even more pronounced in Mexican immigrants. According to the MAPSS, 85% of Mexican immigrants who needed mental health services remained untreated\textsuperscript{16}. This extreme underutilization of mental health services is even more pronounced among Mexican migrant agricultural workers (only 9% of those who need mental health services received services). Research has repeatedly shown that this population receives no care unless they are extremely ill (affecting ability to function) or a danger to themselves or others\textsuperscript{17}.

The consistent association between low levels of mental health service use, minority ethnicity, and nativity lead us to focus on these groups in this project.

2. GROUPS THAT FACE BARRIERS TO PARTICIPATION IN THE POLICY MAKING PROCESS IN PUBLIC MENTAL HEALTH.

Participation in the policy-making process in mental health at the state or county level is a complex activity that requires groups to have a high degree of organization and access to appropriate information and resources. In many communities, local organizations have built up a wealth of information from their experiences attempting to address the social and mental health needs of their communities. However, these groups rarely have the capacity to directly participate in the policy process so that their valuable experience and knowledge of practice-based evidence is unlikely to inform planning for services without active solicitation of their input.

Two of the most important determinants of political participation are nativity and language. First-generation immigrants and communities with high levels of linguistic isolation (households in which no one over the age of 14 is a proficient English speaker) are much less likely to be politically active\textsuperscript{18}. Eleven percent of California households, a higher percentage than any other state, meet this definition of linguistic isolation. These households include about 900,000 children.

These findings led us to a particularly intense focus on the Hmong population in California, a population of former refugees and their U.S.-born children with a large proportion of persons living in poverty and the highest levels of linguistic isolation. In addition, communities of migrant workers which are largely isolated Spanish-speaking communities were also prioritized.
3. GROUPS WITH LOW RATES OF INSURANCE COVERAGE FOR MENTAL HEALTH CARE

Table 2. Past-Year Service Use and Health Insurance among People with Psychological Distress below 200% of the Federal Poverty Level Incomes in California by Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>HAD HEALTH INSURANCE</th>
<th>INSURANCE INCLUDED MENTAL HEALTH COVERAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>81%</td>
<td>82%</td>
</tr>
<tr>
<td>Latina/o</td>
<td>68%</td>
<td>63%</td>
</tr>
<tr>
<td>US-Born Latina/o</td>
<td>80%</td>
<td>81%</td>
</tr>
<tr>
<td>Foreign-Born Latina/o</td>
<td>62%</td>
<td>50%</td>
</tr>
<tr>
<td>African American</td>
<td>85%</td>
<td>70%</td>
</tr>
<tr>
<td>Asian</td>
<td>65%</td>
<td>82%</td>
</tr>
</tbody>
</table>

*Source: 2005 California Health Interview Survey*

The table above presents data from the CHIS on the percentage of low-income people in need of mental health services who have health insurance. The table also shows the percentages of those with health insurance whose insurance includes coverage for mental health treatment. Notably, foreign-born Latina/os have the highest rates of uninsurance (50%). The pattern is consistent with the findings regarding the use of services: minority ethnic groups, particularly those with high proportions of immigrants, are less likely to have insurance coverage.

Not reflected in these data are findings from other studies of very low rates of insurance coverage among Native Americans. A 2001 UC Irvine study found that nearly 45% of the urban Native Americans surveyed lacked health insurance and it was estimated in 2000 that throughout California 22% of adult Native Americans were uninsured. Research demonstrates that the uninsured use fewer preventive and screening services, are sicker when diagnosed, receive fewer therapeutic services, have poorer health outcomes (higher mortality and disability rates), and have lower annual earnings because of poorer health.
4. GROUPS THAT HAVE BEEN IDENTIFIED AS PRIORITIES FOR MENTAL HEALTH SERVICES.

Efforts were also made to include specific groups that have been identified by the California Department of Mental Health as priority populations. Particular emphasis has been placed on vulnerable and marginalized youth including youth in stressed families, trauma-exposed children, youth at risk for school failure, and youth with juvenile justice involvement. A significant number of children receive some mental health interventions in schools, but are not necessarily receiving care within the mental health system. Children of color are less likely to access mental health care and yet are overrepresented in emergency settings. African American and Latina/o children are still more likely than Whites to underutilize certain services (especially preventive and primary care), end up in the most intensive care settings, and to experience poorer outcomes\(^{21, 22, 23}\).

Of children with serious emotional and behavioral disorders, over 50% drop out of high school, compared to 30% of students with other disabilities. Latina/o students are more likely than White and African American students to have attempted suicide, with 15% of Latina girls reporting having attempted suicide\(^{24}\). Native American youth have the highest suicide rates of all ethnic groups\(^{25}\). Addressing mental health needs, both preventive and therapeutic, among children and youth is critical to improving the health of children and adolescents overall, and in particular, the health of those vulnerable populations described above.

Many adolescent risk behaviors and poor health outcomes (including depression, substance use, suicide, unprotected intercourse, and unintended pregnancy) are significantly more prevalent in sexual minority (LGBTQ: lesbian, gay, bisexual, transgender, and questioning) youth. LGBTQ youth who have chosen to be open about their sexual orientation are more likely to become victims of abuse in the home; 25% experience verbal abuse and nearly 10% experiencing threats or physical abuse\(^{26}\). Studies have identified higher rates of social anxiety, depression, and suicidality in sexual minority youth\(^{27, 28}\). In 1995, the Massachusetts Department of Education reported that students who described themselves as LGB or who have had same-sex sexual contact were four times more likely to have attempted suicide, five times more likely to have used cocaine, and five times more likely to miss school because of feeling unsafe\(^{29, 30}\).

Foster care children and youth represent a particularly vulnerable population, again with significant racial and ethnic disparities. African American and Native American children are overrepresented in the foster care system. Nationally, 45 percent of the children in out-of-home care are African American\(^{31}\). In California, approximately 77,000 children were in foster care in 2005, of these 41% were Latina/o, 30% were African American, 27% non-Latina/o White, 2% were Asian, and 1% were Native American. African American and Native American children are overrepresented in California’s foster care system, with African American and Native American children more likely to be in foster care (4.7 and 1.9 times respectively) than non-Latina/o White children\(^{32}\). Data from the California Healthy Kids Survey demonstrate that substance use and mental health problems are much higher among youth in foster care than among youth living with their families\(^{33}\).
Gang-involved youth and young adults in the U.S. are disproportionately represented in juvenile offending programs and prisons. This overrepresentation in juvenile detention and correctional facilities is more pronounced in poor, minority youth, and juvenile justice institutions have been characterized as the de facto mental health system for these youth. Gang-involved youth experience high levels of mental health problems, with some studies estimating over 70% of this population having at least one mental health disorder, including depression, anxiety, post-traumatic stress disorder, and self-harming behaviors. These mental health problems often go unrecognized and untreated in the disjointed context of juvenile halls, prisons, and probation systems. Substance abuse disorders compound the problem, further complicating case identification and intervention, including adherence to mental health treatment. Additionally, many gang-involved youth experience multiple traumas, including street, family, and interpersonal violence.
APPENDIX 2

Summary of Community Outreach and Engagement Processes

The specific goal for this project as outlined above was to provide specific input from diverse underserved communities on prevention and early intervention initiatives, mental health concerns, recommendations for programs, and to encourage community participation in the PEI planning process.

The community engagement process utilized in this project is grounded in the principles of community-based participatory research and asset-based community development (see the Building Partnerships: Key Considerations When Engaging Underserved Communities under the MHSA report for an in-depth discussion of these principles). Built into the process of community engagement described below has been ongoing dialogues with participants about engaging actively in the key stakeholder input process for the Mental Health Service Act; in addition, the CRHD team plans to disseminate the findings from the interviews and focus groups within all of these communities.

After underserved communities and specific special populations to be contacted in this project were identified (based on selection criteria discussed above in Appendix 1), program managers contacted persons within state, county, city, and university networks known to the UC Davis Center for Reducing Health Disparities for having a trusting relationship with specific groups and/or extensive networks in communities and willing to assist with the community engagement process. Cultural brokers assisted the research team to identify grass-roots organizations and community leaders from multiple different vantage points (e.g., legal, health, social services, education, and housing). Contact was made with these various agencies and individuals by phone, e-mail, or in-person to begin to map existing community-based services, community resources, and assets, as well as community concerns regarding mental health. Once the level of interest among community leaders (primarily directors of grass-roots, community-based agencies) was determined, in-person meetings were arranged to discuss potential collaboration in this project and to review the MHSA PEI objectives and the purpose of the project. Key informant interviews (both within and outside specific agencies) were then arranged.

In addition, program managers participated when appropriate in existing interagency collaborative meetings and community meetings to learn more about community-wide concerns, as well as to support interested community members to engage in the county MHSA process. Key informants assisted the program managers in determining the feasibility of focus groups.
Cultural brokers and key informants reviewed the informed consent documents and descriptions of the project for readability and understandability, and provided assistance with interpreting when necessary. Community agencies, cultural brokers, and key informants were all reimbursed for their time and effort in helping to recruit participants and organize the focus groups. Community agencies received stipends to cover use of their space, staff time and effort, and assistance with recruitment. Some of the cultural brokers generously offered their time and shared their perspectives without compensation even when it was offered. They regarded their collaboration as part of their job in connecting people of different backgrounds to each other. Others received stipends for their time at $50 per hour (some required additional effort to assist with recruitment and extended hours). Key informants who were interviewed received $30 stipends to thank them for their time.

**Cultural brokers** included state officials working within the Department of Mental Health (such as ethnic outreach managers) or outside DMH (such as public health and education) with prior knowledge and trusting relationships with particular communities. In addition, some cultural brokers were community activists or advocates working at the state or county level, as well as county or state level non-governmental organizations with close ties to particular communities (with established trust in the communities). The role of cultural brokers included:

- Describing the history of particular communities, in particular, experiences with governmental agencies (levels of mistrust, degrees of marginalization);
- Sharing knowledge of community-based organizations and community leaders who may be able to assist with the engagement process;
- Assisting with formal introductions to particular community leaders (who can serve as key informants) to begin the process of outreach and engagement; and
- Reviewing documents including informational flyers, drafts of memorandums of understanding, and consent forms.

**Key informants** were generally directors of community-based agencies, individuals who serve key roles within particular communities (e.g., religious leaders, community activists, and health educators), and those who are actively engaged in community health promotion at the grass-roots level within communities of interest. The role of key informants included:

- Assisting with mapping existing community-based services, community resources, assets, as well as community concerns regarding mental health (during the interview);
- Identifying interagency collaborative meetings, community meetings, and other events for our research staff to familiarize themselves with community assets and concerns and to share PEI initiatives;
• Helping to determine the feasibility of conducting focus groups (if that was thought to be a useful method for engaging community members in discussion), the priority groups to include, and identifying participants for focus groups, including helping to find the appropriate venue, child care (if needed), transportation, language needs and identifying interpreters, and type of food to order; and

• Ensuring that any gathering of community participants (including focus groups) occurred in safe places, at times that were feasible for interested participants, and was accessible.

Cultural brokers, key informants, and focus group participants who expressed interest in learning more about the MHSA have been invited to join the project team to attend stakeholder meetings, and also to connect with their local county mental health services. Findings from this project will be disseminated back to respective communities as a second phase of this project. Dissemination plans will necessarily involve direction from the community agencies, cultural brokers, and key informants, including appropriate venues and methods for dissemination (e.g., town meetings, flyers, community and school presentations).

KEY INFORMANT INTERVIEWS

Key informants were identified with the assistance of cultural brokers as described in the community engagement section above. Most of the key informants were directors and staff of grass-roots organizations working with specific underserved communities. We recruited a convenience sample of 29 key informants, and conducted one-on-one semi-structured interviews in private spaces in their respective communities at times and places convenient for participants.

The specific aims of the key informant interviews were to identify specific populations with whom to conduct focus groups (i.e., specific populations within a community with particular needs that key informants identify as priorities), to review the focus group questions and adapt these as necessary to the specific groups planned, and to determine strategies for recruiting and organizing focus groups (including the logistics of where and how to conduct the groups). The interview also explored overall community concerns, existing community resources and assets, specific mental health problems, existing prevention and early intervention programs, and challenges of outreach and engagement in the community, as well as ideas for improving PEI efforts. The interviewers explained the procedures and goals of the project, including confidentiality of responses, and obtained written consent. Interviews lasted approximately 30 to 60 minutes.

Analyses of the key informant interviews are not reported here, but will be described in a future report. Community assets, key mental health concerns within communities, and PEI recommendations are incorporated into the results described in this report.
FOCUS GROUPS

Overall focus group selection was guided by two basic approaches underlying the project’s goals and community engagement principles:

- First, the groups were comprised of members of communities that are historically underserved by mental health services in California. To the greatest extent possible, selection of underserved communities was driven by available data as described above in Appendix 1.

- Second, key informants and cultural brokers who were interviewed in the initial stages of community engagement provided significant input on the focus group selection process and assistance with logistics.

The groups selected represented the outcome of a collaborative process between project staff and community members from selected underserved populations. In most cases, we were led to make initial contacts with representatives of particular communities by data on mental health disparities at the state or national level. Once initial contacts in a community were made, the broad target groups were narrowed to the level of specificity required to have a meaningful focus group discussion through a collaborative discussion with key informants and community agencies.

As the overarching goal for this particular project was to solicit a breadth of perspectives from a range of diverse communities within a short project timeline, the number of focus groups conducted in each community was limited.

In order to illustrate some of the heterogeneity within any particular community, a few additional focus groups were conducted with Hmong participants, in order to highlight differences among new arrivals and established community members as well as youth and elder perspectives. Ideally, this kind of heterogeneity could be demonstrated within the other target communities, and we hope will be the focus of related community engagement efforts across the state.

The groups consisted of community members (see Table 1), ranging from 4 to 15 participants. Each focus group was conducted by a facilitator, and a recorder also took notes. In some instances, for groups conducted in Hmong in particular, trained Hmong facilitators led the groups (with simultaneous translation for the program manager who observed the groups and took notes). The focus group schedule was similar to the interview schedule, with discussion of overall community-level concerns, perceptions of mental health problems in their communities (and what might be done to prevent these), existing resources and community assets, and specific recommendations for prevention and early intervention efforts.
Written consent forms were reviewed verbally in detail, confidentiality discussed, and questions answered about how the information would be utilized and disseminated back to communities. All consent forms were translated into appropriate languages, and back translated for accuracy. For youth ages 14–17, parental consent was obtained along with youth assent. The focus groups generally lasted about 60 minutes. The protocols for both key informant interviews and focus groups were approved by the Institutional Review Board.

Focus groups were conducted at times most convenient for participants (often in the evening and weekends) and in locations that were safe, accessible, and known to participants. Food that was recommended by key informants was served. When necessary, transportation and child care during the focus groups were arranged with the assistance of the community agencies. Focus group participants received $30 pre-paid gift cards to thank them for their time.

DATA ANALYSIS

All focus groups were audiotaped and transcribed verbatim. Those conducted in Spanish were transcribed into Spanish first then translated into English. Those in Hmong were transcribed directly into English by a bilingual transcriptionist/interpreter. The facilitator conducting the focus group reviewed all the transcripts for accuracy.

Transcribed data were analyzed using a content analysis approach with Atlas-TI v.5 software. Content analysis is a qualitative data analytic strategy that involves generating and applying codes to “chunks” of text, and then reviewing the text by its code category to detect themes. According to Ryan and Weisner, codes are developed a priori, and may also emerge after a preliminary read-through of the data. For this present project, a preliminary read of several focus group transcripts as well as the existing focus group schedule guided the development of an initial a priori code list, agreed upon by the entire coding team.

Initial codes related to key themes of interest such as community mental health concerns, definitions of prevention and early intervention, and experiences of isolation and social exclusion. Pursuant to this exercise, an expanded code list emerging from the focus groups was generated. No new codes were added after the eighth transcript was reviewed by the team in order to maintain consistency of coding definitions and avoid splitting into multiple subcodes. The expanded code list included additional codes pertaining to additional topics raised by participants, such as impact of poverty, lack of access to education and services, and emphasis on health promotion. Utilizing a consensus coding approach, each transcript was coded by two coders, with discrepancies discussed and resolved by each pair. Resolution of any unresolved discrepancies in coding as well as addition of new codes occurred in weekly coding meetings. In addition, every third transcript was reviewed by a third member of the team for additional quality control.
For this particular analysis, we reviewed themes that reflected community concerns, community resources, specific mental health problems, where community members currently seek help, reasons for not seeking help, ideas for prevention efforts, challenges in outreach and engagement, and recommendations for PEI. Themes were generated based on frequency and patterns of comments. Additional themes were added as these emerged, and the range of responses confirmed through an iterative process of reviews of the transcripts, using the method of thematic analysis described by Ryan and Bernard. We retrieved coded chunks of text regarding major themes related to community mental health concerns, barriers in accessing service systems, social determinants of mental health outcomes, community assets, resources, opportunities, resiliences, and recommended PEI programs. Additional subcodes related to observed patterns in the narratives that appeared related to these broader themes were explored; subcodes were then applied to all passages related to these broad, overarching themes (as code families), in order to facilitate further inferences and selection of illustrative quotations. Quantitative data collected through the survey given at the start of focus groups were analyzed descriptively to help characterize the sample and complement qualitative findings.

In our implementation of the community participatory research process, community leaders, cultural brokers, and key informants provided specific recommendations on salient issues and areas of discussion to address with the communities which they represented. The dialogue with community members (which occurred through focus groups) did not use a structured question format. Instead, the recommendations provided by cultural brokers and key informants informed general content areas that were addressed across all communities (e.g., primary mental health concerns, help-seeking pathways, etc.). Given this approach, it is important to acknowledge that differences in needs and priorities across groups do not imply that those issues are important to some communities and not others. There are important issues that these communities face but which were not addressed due to time limitations. Likewise, given the short time frame to conduct this project, the findings from a limited number of underserved communities can be neither exhaustive nor summative with recommendations; rather, this report documents some key, recurrent themes that may assist in the planning and implementation of the PEI component of the MHSA as counties make concerted efforts to reach out and engage underserved communities.
REFERENCES


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