# BUILDING PARTNERSHIPS:
## KEY CONSIDERATIONS WHEN ENGAGING UNDERSERVED COMMUNITIES UNDER THE MHSA

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Report #2 in a Series
Report #1 is *Engaging the Underserved: Personal Accounts of Communities on Mental Health Needs for Prevention and Early Intervention Strategies*

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**The purpose of this document, based on feedback from underserved communities on outreach and engagement that emerged in the context of a project on prevention and early intervention, is to:**

1. Introduce guiding principles of community engagement with underserved communities;
2. Outline some guiding questions to assist counties in their MHSA community outreach and stakeholder processes;
3. Suggest specific strategies for County Mental Health Departments to nurture sustained and equitable partnerships with communities.

# I. BACKGROUND

In November 2004, California voters passed Proposition 63, which became a state law entitled the Mental Health Services Act (MHSA) on January 1, 2005. The Act has created the expectation of a comprehensive planning process within the public mental health system that is inclusive of underserved communities over-represented among California's most vulnerable populations, such as ethnically diverse, poor, uninsured, and geographically isolated. The Act seeks to *transform* the mental health system to a "help-first" approach, such that ethnic communities, clients, family members, community-based agencies, providers, public agencies, and other stakeholders in the mental health system are key partners in the decision-making process. Given the fact that California is leading the nation in diversity, partnering with diverse communities is essential to transforming the state's mental health system.

In this document, we present an example of a community engagement process conducted by the UC Davis Center for Reducing Health Disparities. This nine month project in community outreach and input was designed to extend the California Department of Mental Health (DMH) stakeholder process to increase the participation of underserved communities in providing input on DMH principles and priorities for the Prevention and Early Intervention (PEI) component of the MHSA, and to lay the foundation for ongoing engagement with and input from underserved communities. To that end, this preliminary process utilized both key informant interviews and focus groups to gather information on the needs, priorities, community assets and views on PEI of underserved groups. Given the short time frame, this process was not exhaustive. In the context of collaborating with various community groups, participants shared particular perspectives on outreach and engagement, and more broadly, their hopes for how MHSA might impact their communities in meaningful ways. These stories and the principles of community engagement that guided the data gathering process may provide County Mental Health Departments with an example of community engagement processes and illustrate some key considerations in conducting community outreach and engagement. We begin by defining key terms, then present principles of community engagement, lessons learned, and future directions. Through out the document we include quotes from individuals from unserved and underserved communities with whom we began a conversation around the MHSA PEI opportunities and needs.

# II. DEFINITION OF KEY TERMS

**Historically unserved and underserved communities** are those groups that either have documented low levels of access and/or use of mental health services, face barriers to participation in the policy making process in public mental health, have low rates of insurance coverage for mental health care, and/or have been identified as priorities for mental health services.

**Cultural brokers** may be state and county officials working within county mental health departments (such as Cultural Competence/Ethnic Service Managers) or administrators and providers working outside County Mental Health Departments (in departments such as public health, social services, and education) who have prior knowledge and trusting relationships with particular communities. In addition, cultural brokers may be community activists, advocates working at the state or county level, as well as county or state level non-governmental organizations (with established trust and credibility in particular communities). For Native American communities in particular, contact with appropriate tribal organization leaders is a critical first-step. The role of cultural brokers includes:

- Describing the history of particular communities in accessing services via governmental agencies (e.g., levels of trust, degrees of marginalization, etc.).
- 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.
- Reviewing appropriateness of documents to be disseminated to communities including informational flyers in different languages, drafts of memoranda of understanding, consent forms, etc.

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

- Assisting with mapping existing community-based services, community resources and assets, and gathering information about community concerns and priorities regarding mental health (interview formats may be useful in systematically gathering this information).
- Identifying opportunities within the respective counties for collaboration and co-learning to take place between PEI initiative staff and agencies serving the communities of interest. This coming together can help PEI initiative staff to familiarize themselves with community assets and concerns and to share PEI opportunities for communities.

- Helping to determine the most culturally and linguistically appropriate methods to engage community participation. If focus groups are being considered, it is important to consult with key informants regarding the feasibility of conducting focus groups (if that is thought to be a useful method for engaging community members in discussion), the priority groups and participants to include, the appropriate venue, the need for child care and transportation, and the type of incentives to offer. The key informant should be well versed in the purpose of the community gathering. Often it is helpful to have the key informant present at community engagement meetings and focus groups.
- Ensuring that any gathering of community participants (including focus groups) occurs in safe places, is accessible by public transportation and other means, and occurs at times that are feasible for the target and interested participants.
- Facilitating the sharing and dissemination of information gathered as well as discussions about planning and implementation of programs.

*Questions for County Mental Health Departments to consider in seeking input from cultural brokers and key informants:*

- Who are the community leaders (where does power reside within the community)?
- How are the governmental agencies providing services in the community perceived?
- What have been the history and/or perceptions in terms of relationships or lack thereof between targeted communities and county mental health departments?
- What are meaningful and feasible ways to transfer resources into the community? (e.g., hire and train facilitators and outreach workers from within these communities, ensure that community organizations providing care to underserved vulnerable populations have infrastructure support).

**Background information on the project given by CRHD to all community participants:**

"In 2004, California voters passed the Mental Health Services Act (MHSA). The MHSA makes additional tax money available to counties to improve their public mental health system. Last year, the state began distributing some of this money to counties for programs that focused on treatment of mental health problems. This year the state is entering a second phase of spending in which they will give counties funding from the MHSA tax for programs that prevent mental health problems before they occur or prevent them from recurring.

But before beginning this process, the state DMH wants to hear directly from communities about their needs as well as their assets and resources. This information will be used to help counties develop their plans and programs for preventing mental health problems. We have been asked by the California State Department of Mental Health to help them reach out to communities and find out more about their thoughts on mental health, the kinds of mental health problems they see in their communities, and the types of services that might help prevent mental health problems from developing…"

Engaging these communities also meant that all input on the improvement of access and utilization of mental health programs and services by these vulnerable population groups obtained from community members would be shared with DMH, as well as with the communities themselves. In addition, the research team assured participants that the recommendations made regarding how to encourage ongoing, meaningful input and participation in the planning and implementation of PEI initiatives of the MHSA would be passed along to County

# III. INITIAL STEPS FOR OUTREACH TO UNDERSERVED COMMUNITIES

## A. Identifying Historically Unserved and Underserved Communities

To define historically unserved and underserved communities in a given county in California, County Mental Health Departments might:
Use US Census data, which is readily available via internet, to determine which populations (1) are geographically isolated from service providers; (2) are linguistically isolated from service providers; (3) are culturally and socially isolated from county and state agencies; and/or (4) have limited social and economic resources to access available care.

Use DMH data on county-level penetration rates in various ethnic communities.
Identify, assess, and analyze available sources of data that can be used to better identify and characterize underserved communities (e.g. national and statewide data sources such as the California Health Interview Survey (CHIS), the National Comorbidity Survey-Replication (NCS-R), or local data bases from other agencies).

Link county level service utilization data to census data on county populations so that County Mental Health Departments can determine the type and amount per capita of services that are being provided to each of the groups that are likely to be underserved. By linking these data, County Mental Health Departments may map the locations of their services, the residences of those using county mental health services, the distribution of diverse communities within their service areas, and identify gaps in services by geographic locations.

## B. Community Engagement

**Community engagement** has been defined over the last two decades in multiple, evolving ways [1]. One definition of community engagement is "the process of working collaboratively with relevant partners who share common goals and interests" [2]. It involves "building authentic partnerships, including mutual respect and active, inclusive participation; power sharing and equity; mutual benefit or finding the 'win-win' possibility" in the collaborative project [3]. The emphasis on community engagement promotes a focus on common ground and recognizes that communities have important knowledge and valuable experience to add to public stakeholder discussions.

The community engagement process undertaken by the UC Davis Center for Reducing Health Disparities is based on **Community Based Participatory Research** and **asset-based community development** [4,5,6]. The Community Based Participatory Research and asset-based community development perspectives recognize that people who live in communities where any data gathering is conducted have the right to participate in the process of defining problems, in mobilizing assets and strengths (individuals, social networks, and institutions) as well as in designing and implementing interventions and solutions.

In the next section we describe principles for initial engagement with racial and ethnic minority and underserved communities (see Table 1). In Table 2, we further these principles with more general considerations by providing a framework that counties can use as they strive toward the transformation of the mental health system espoused by the MHSA. The principles of engagement outlined and discussed in Table 2 are significant for underserved groups. However, when engaging with these communities, there is the additional need to observe and acknowledge cultural and language protocols needed to establish trusting and meaningful relationships. County mental health departments without significant experience working with diverse communities may consider seeking additional technical assistance and guidance from other counties with successful models of community partnership building, and/or consulting groups who share the same culture and language of target population subgroups and who have a track record of working effectively with underserved communities.

"I think that when you have this type of thing, you have to start it at grass roots level. And it is all about language access. It is about confianza (trust building) and it takes a lot of work. And you are talking about going out to the community and talking to la gente (the people) about what it is they want or they see or they need. If you start thinking that you need more clinics when you really need a baseball diamond or a soccer field. You know, you are not going to see what the people really want."

Rural provider

"One of the meetings that I attended was, there was a recommendation from one of the county staff to have our mental health patients come to a public forum and tell their story. Well, this is something that is done frequently in mental health…Because of what my value and my traditions tell me, you know, my patient comes to see me and we're in session and you know, that, I tell this all the time, that is holy ground, you know. They come and they spill their guts. A lot of pain there and so that area is sacred. They ask me, county people say, come and parade your patients in front of us. Have them tell their story. I think that is such a disgrace for you to ask me to do that. I will not do that. And I put it this way, doing your probe of the swine, because the same thing will happen, they will sit there and say, oh that is a sad story, and it will get shuffled, it will get put away. That is all for naught. And I am not willing to do that with my patients. I value them too much. Their stories, their lives, their pain is not to be paraded around like that in the name of gaining funds, in the name of providing consumer comments and things like that. You know, this is the approach that counties have with our people and that really goes against traditional values. That is sacred. That area is sacred. They are sacred , what they have gone through is sacred…and I don't think county understands that because they are there, they are insulated. They don't understand. They need to come to a circle, a healing circle and hear the stories themselves. We can't go to them and parade them around like that. And I really resent when I am asked to do that. It hurts me, as you can see."

Native American provider

## C. Principles of Community Engagement

For a successful community engagement process, counties need to: (1) pay attention to histories of marginalization and mistrust; (2) have transparent discussions of power; (3) build on community strengths and local knowledge; (4) encourage cooperation; (5) identify opportunities for co-learning; (6) make important efforts towards sustainability, systems development, and capacity building; and (7) make important efforts to protect the well-being, interests, and rights of communities. (Summary of **Principles of Community Engagement** can be found in Table 1).

### 1. HISTORY OF DISCRIMINATION, MARGINALIZATION, AND MISTRUST

Racial and ethnic minority groups are at increased risk for mental health problems given exposure to discrimination and racism as well as elevated levels of poverty and social and geographic isolation. Racism and discrimination are directly associated with psychological distress and major depression. The Surgeon General concludes, "Racism and discrimination are clearly stressful events…[that] adversely affect health and mental health…and place minorities at risk for mental disorders" [7].

Despite this heightened risk for mental illness, racial and ethnic minorities have limited access to mental health services. A major barrier for racial and ethnic minority communities to accessing mental health services is the lack of appropriate language services. In 2000, more than 12 million Californians age five and over spoke a language other than English (including Spanish, Hmong, Vietnamese, Cambodian, Laotian, Armenian, Korean, Russian, Arabic, Mandarin and Tagalog). Despite Title VI of the Civil Rights Act of 1964, which mandates that health systems receiving federal financial assistance have a responsibility to ensure meaningful access to their programs and activities by persons with limited English proficiency (LEP), and requires that language services be provided free of charge, language barriers continue hinder access to mental health treatment.

The mental health of racial and ethnic minority communities is also threatened by the differential treatment and poor quality of care they receive. Although these communities are underserved in the voluntary mental health care system, racial and ethnic communities—in particular African-Americans and Native Americans—are overrepresented in coercive and involuntary mental health care services [8, 9].

In addition, these communities, in particular African Americans, are disproportionately misdiagnosed, resulting in incorrect treatment. African-Americans, at twice the rate of whites, are prescribed the older generations of antidepressant or antipsychotic medications [10] and as a result suffer from tardive dyskenesia, an irreversible movement disability caused by antipsychotic medications. Finally, communities of color, at significantly higher rates than whites, receive higher doses of high side-effect medications, are subject to involuntary medications and are disproportionately subjected to restraints.

Major disparities also exist in access to and appropriateness of mental health care for Native Americans. For Native American communities, difficulties in access to mental health treatment are compounded by concerns regarding high rates of suicide and substance abuse. For many Native American communities, traditional healing practices play a central role in addressing mental health concerns. However, these practices are often not afforded the attention or respect given to mental health treatments espoused by Western psychological theory. This dismissal of traditional practices exacerbates the mistrust that Native American communities have of county and state mental health systems.

Lesbian, gay, bisexual, transgendered or questioning identified people (LGBTQ) are also at risk of mental health problems as they "have been killed for their sexual orientation, had their children taken away, gone to jail, been forced into treatment, been hospitalized against their will, been hassled and beaten by the police, denounced in religious institutions and forced out of jobs" [11]. The discrimination experienced on a daily basis by LGBTQ identified people is harmful to their mental health and is reflected in high rates of depression, substance abuse and suicide. According to a 1989 United States Department of Health and Human Services report "…gay youth are 2 to 3 times more likely to attempt suicide than other young people" [12].

"If [place] doesn't like the way he [mentally ill person] is acting after 72 hours, according to them, they observed him up to 72 hours, and they don't like the way he is acting within that period of time, they can lock him up for another 14 days. They keep him, worse thing they do for a mental health, somebody who is mentally unstable or whatever you want to call it, you know what I mean. Lock them up. …but you haven't heard the worse of it. The next part of that is, they don't see you are acting properly. They can keep you 30 days. And if they don't think that you are properly, the system is designed to take that person and put him in a mental health system, lock him up for a period of six months in a mental institution. Six months to a year."

African American adult

Engagement of historically unserved and underserved communities – such as racial and ethnic minority groups and LGBTQ identified people - by county or state departments of mental health has thus been limited by marginalization. *Marginalization* refers to their isolation from 'mainstream' society due to linguistic barriers, geographic isolation, history of oppression, racism, discrimination, and poverty. Such experiences are inextricably linked to community perspectives on social services and health care delivery, often tied to frustrations interacting with a system that may feel foreign, unfriendly, impersonal, and insensitive.

Connected to marginalization and frustrations with a system that fails to meet local needs is a sense of *mistrust* of governmental agencies grounded in these communities' oppression. Any engagement with unserved and underserved communities requires attention to the ways in which they have experienced governmental attempts to 'help' in the past. Mistrust may include stories of how governmental agencies have determined 'needs' of a community without consulting with the community being served, promised particular services that were never delivered, or come into a community with a service or program that was not sustained.

*Questions for County Mental Health Departments to consider with input from unserved and underserved community members:*

- What types of marginalization is this community experiencing (e.g., geographic, linguistic, poverty, limited education, discrimination)?
- What is the history of local, state, and federal agency interactions with this particular community?
- What mistakes have been made in the past?
- What are the sources of mistrust?

## 2. POWER

Related to the experiences of marginalization and mistrust among unserved and underserved communities is their awareness of the significant differential in power between governmental agencies and local communities. The power differential creates challenges for developing meaningful and genuine partnerships. Both symbolically and practically, governmental agencies have access to resources (e.g., financial, institutional, people, social networks) that many underserved communities do not.

While the power differential can appear insurmountable, explicit recognition of and transparency about power can begin to shift the conversation with unserved and underserved communities. Community participation in policy and programming can be explicitly encouraged through specific activities, including creation of community advisory boards comprised of grass-roots level individuals, memoranda of understanding with community groups assisting with outreach and engagement, as well as employment of multilingual/multicultural cultural brokers as part of the County Mental Health Department workforce. When appropriate, resources should be allocated to the communities, including reimbursing community agencies, leaders, and members for their time in providing input to governmental agencies.

"[Health care officials ask], 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…it is quite obvious, you know, money is the root of all-evil when it comes to the United States. I feel, you know, because who ever got money, you know, is going to the best of whatever."

African American adult

"There are many, many native professional people and they really don't get the recognition that they deserve. And I go to a lot of different trainings and things like this. They are very seldom offered by a Native professional person. They are offered by somebody who has picked the information up from somewhere that, but they are not offered by a Native person and also very important is when you look at a Native professional person, is that person also representative of the community. Are they involved in the community itself? Are they in touch with that? Because if they are not, then maybe the information that I am getting is not as relevant as it could be."

Native American provider

"In term 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

Information can be gathered using in-depth interviews or focus groups, as well as in community forums or stakeholder meetings. There are pros and cons to each of these ways of eliciting information. For example, some immigrants may be unaccustomed to discussing topics in the ways presented in a formal interview [13]. Formal structured interviews often lack cultural sensitivity and fail to address different manners of symptom expression across cultures and different ways of communicating [14].

"When you are taking Hawaiians, you know, they revere, and I am sure with all the cultures that we have here, they revere their elders. So, we have the Kupuna which is you know, the elder. And I think you would feel very comfortable. I know we would feel very comfortable going to them, and you know, kind of relating some pains and maybe, you can kind of, they may help you, or you think maybe they are..."

Pacific Islander adult

## 3. COMMUNITY STRENGTHS AND LOCAL KNOWLEDGE

Members of communities that have been marginalized and underserved describe frustrations with agencies from the outside defining their problems without attending to community assets, strengths, resources, and local knowledge.

*Asset-based community development* [5] is an approach to enhancing the health of communities that focuses on identifying key community strengths as well as mapping the range of assets within a community:

- Individuals (i.e., community leaders, tribal councils healers, elders, coaches, youth, parents)
- Community resources (i.e., community centers, schools, youth programs)
- Institutional infrastructure (buildings, roads, transportation, etc.)
- Financial resources (funding sources)

Beginning the process of engaging communities to address mental health concerns can be facilitated by approaching those within the community from this asset-based perspective, i.e., focusing not on what is wrong in the community, but on what appears to be working well.

Taking a positive stance toward community strengths and local knowledge (what people know from their experiences living in the community) encourages the building of trusting partnerships.

While a thorough community mapping may provide too much detail for County Mental Health Departments' purposes, county mental health departments may find that certain straightforward strategies to focus on community assets help to build sustainable partnerships. With the guidance of cultural brokers and key informant interviews, county mental health departments can:

- Identify community based organizations (e.g., social service agencies, tribal communities, faith based organizations, youth after-school programs) that are serving the most vulnerable within these selected communities.
- Describe these community organizations (the work they do, participant demographics, numbers served) and the degree of trust and safe spaces they represent.
- Identify key community leaders (including tribal councils or board, traditional healers, elders) and other respected individuals who are actively involved in community change.
- Explore the current and potential roles of these 'community change agents' in addressing mental health concerns.
- Increase awareness and sensitivity when working with tribal communities. Recognize that there are defined protocols for each tribal community in regards to reaching tribal leadership. A starting point is to contact tribal councils or board offices to be assisted on identifying appropriate tribal leaders (urban tribal contacts may differ). Recognize and honor tribal sovereignty issues.

CRHD was asked to solicit input regarding the mental health needs and priorities, existing community assets, and recommendations for Prevention and Early Intervention. Given the short time frame, a focus group methodology was deemed the most expedient method of obtaining in-depth information from community groups that had previously had little to no exposure to the MHSA stakeholder process. Focus groups are one way to elicit information about how culture shapes mental health concerns and needs. Focus groups "provide us with direct access into the language participants use to structure their experiences and to think or talk about a topic and allow us to better understand the nuances and complexities of certain constructs, especially as they are represented in different cultures. Focus groups, most importantly, facilitate culturally anchored research [15].

In conducting focus groups with underserved communities, several challenges were encountered related to the implementation of research with diverse groups. Differences in cultural understanding of mental health and in perceptions of wellness affected participants' willingness to discuss mental health issues. Some topics, such as mental health problems, drug and alcohol abuse, or gendered-based violence, may be taboo or culturally insensitive to certain groups [17]. Furthermore, for communities in which English is not the preferred language, the impact of translations on the data can vary greatly. Prior research indicates that concepts do not necessarily have the same meaning or any meaning at all across cultures, and even when particular terms have the same meaning across cultures, these might not be uniformly understood by all. Consequently, when translating questions into another language, the meaning and usage of certain key terms may need to be validated [18].

## 4. COOPERATION

Enlisting the support and cooperation of key informants within communities requires being explicit about the *goals of the partnership*. In particular, communities where promises have been made but not kept, memoranda of understanding coming from a governmental agency may be suspect. Early, explicit, and transparent discussions about why DMH is interested in hearing from community members, what will be done with the information, how the information will be gathered and shared, and how the community might benefit from participating are critically important to share with communities upfront.

With input from cultural brokers and key informants, County Mental Health Departments may:

- Create an informational sheet about outreach and engagement efforts.
- Utilize multiple linguistically and culturally relevant media sources to describe the role of the local mental health department and its interest in partnering with a particular community (local newsletters, radio, community television, and other media).
- Work with key informants and tribal councils or boards and other community leaders to draft memoranda of understanding about the engagement process, sharing of information, and ownership of data gathered.
- Ensure that any community participants assisting with outreach and engagement efforts are appropriately compensated for their time and effort.
- Discuss dissemination of information with participants early on – how information gathered will be used and shared with community members.

## 5. IDENTIFYING OPPORTUNITIES FOR CO-LEARNING

As described above, communities have much to teach us about the power of social networks, traditions, beliefs about healing and wellness, traditional health practices, concepts of prevention, and community assets and needs. Unserved and underserved communities are willing partners in addressing the multiple, often overwhelming, needs that emerge in the context of marginalization, discrimination, and poverty. While County Mental Health Departments may not have the resources to participate in an in-depth mapping of community assets and needs, other non-governmental, governmental, and academic organizations may have conducted such assessments that may be of significant benefit to this effort.

Strategies County Mental Health Departments might consider in creating an opportunity for co-learning:

- Enlist the support of community participants, community-based organizations, tribal communities, nongovernmental agencies, governmental and academic institutions to identify what kinds of efforts around community assessments have been conducted in the past (if any) in a particular community.
- With the guidance of community leaders, engage community participants in discussing strategies for sharing stories of community assets and needs (e.g., focus groups, town meetings, facilitated community meetings, community mapping exercises).
- Ensure that educational materials created by County Mental Health Departments about particular prevention and early intervention initiatives are appropriately translated, culturally relevant, and in an understandable format (with attention to literacy levels) with input from community participants.

## 6. SUSTAINABILITY

Underserved communities may describe experiences where well-meaning individuals have come in with programs, completed detailed needs assessments, and then left when funding ended. Certain communities may be particularly hesitant to engage in discussions with county mental health departments because of historical patterns of such non-sustained efforts.

Plans for sustainability around any prevention and early intervention initiatives within a community should be addressed in early discussions, with guidance from cultural brokers and key informants and attention to avenues for sustained funding. In addition, sustained engagement and effective programming are more likely when community participants are active partners in the process, as leaders, outreach workers, interpreters, data gatherers, and so forth.

County Mental Health Departments may consider specific strategies such as:

- Creating a specific action plan in partnership with community leaders for planning and implementing prevention and early intervention initiatives that addresses sustainability as a priority.
- Whenever feasible, recruiting community participants in the planning process and reimbursing them for their time and effort.
- Hiring personnel to assist with county efforts and engaging in active recruitment efforts from underserved communities.

"We have other programs where we depend from grants, when we run out of grants then we are out of luck, and we get grants to pay the counselors. You [counselors] see kids, definitely some mental issues so they come for therapy but these counselors are coming in here really looking for hours, you know, to fulfill towards their license. So they come…and take this man (Name) seventeen years old and I start working with him. Two months and when I'm done with my hours, I'm gone and he's got to look at somebody else and start his story all over again or usually the cases drop you know. We already gave him two months, right when you were beginning to get some changes and something working. You drop him and you change counselor and things."

Parent/Facilitator

## 7. ETHICS OF ENGAGEMENT

Protecting the rights, interests, and well-being of communities is of great importance when counties ask communities to be part of an ongoing conversation on prevention and early intervention initiatives.

Particular considerations need to be taken into account when working with *vulnerable populations* including participants with limited English proficiency, children, prisoners, and wards of the state. Guidance on appropriate consent procedures should be sought from local or state ethics boards or committees prior to conducting any interviews, focus groups, surveys, or similar data gathering procedures.

"They made us dream that they would help us and it was all left in a dream."

Parent Facilitator

# IV. ONGOING INCLUSION OF COMMUNITY PERSPECTIVES

The goal of the community engagement process is the **ongoing inclusion of community perspectives** in the implementation of the PEI component of the MHSA.

County officials need to invite, on an ongoing basis, the participation of unserved and underserved communities in the drafting of county MHSA proposals and work plans. The outreach and engagement processes will only be successful when the needs and recommendations provided by underserved communities are integrated into county plans.

*Some steps to ensure a successful engagement of marginalized communities by the county include:*

- Counties should engage in persistent efforts to protect the rights of unserved and underserved communities to participate in the process of defining problems, in mobilizing assets and strengths (individuals, social networks, and institutions), and designing and implementing interventions/solutions.
- Counties and unserved and underserved communities need to discuss the different procedures that will be initiated to include unserved and underserved communities in the PEI and MHSA planning process.
- County Mental Health Departments must be willing to meet at community facilities like tribal council offices and other community-based settings.
- County mental health departments must implement, in a timely fashion, the procedures identified in collaboration with unserved and underserved communities as key for democratizing the county's planning process.
- Communities must be allowed to continually provide feedback to the county on how the engagement process is being conducted, as well as on all planning processes supported by county mental health department officials.
- Counties need to be flexible and make appropriate changes to the engagement and planning processes to honor the feedback of communities.
- Counties need to make the engagement of marginalized communities a priority, and secure funding so that any effort sponsored by the county is ongoing and sustainable.

# V. CONCLUSIONS

The community outreach and engagement project conducted by the CRHD in collaboration with the State Department of Mental Health represents an initial effort to reach out, engage, and collect community voices that have previously not been heard. Through these efforts, the CRHD developed relationships with unserved and underserved communities, community-based agencies, and a group of dedicated and passionate community advocates. 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. 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.

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# TABLE 1

## PRINCIPLE MENTAL HEALTH SYSTEM TRANSFORMATION IN UNDERSERVED COMMUNITIES

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Attention to Histories of Discrimination and Marginalization** | Identify barriers to participation and sources of mistrust (e.g., linguistic barriers, geographic isolation, histories of oppression and slavery, racism, discrimination, poverty, and inadequate systems of care). | What types of marginalization is this community experiencing?<br><br>What are specific barriers to participation in the mental health planning process?<br><br>What is the history of County DMH interaction with this particular community, if any?<br><br>What are other experiences with county or state departments?<br><br>What mistakes have been made in the past?<br><br>What attempts have been made to correct mistakes?<br><br>What are the sources for mistrust?<br><br>What advice can be obtained from communities to increase positive, constructive and effective outreach efforts? | • Ask cultural brokers and key informants to provide histories, including examples of both positive and sub-optimal descriptions of engagement by county and state representatives.<br>• Meet with community leaders to learn about community expectations for outreach and engagement, i.e., what culturally and linguistically relevant approaches might look like.<br>• Create opportunities for community forums or town meetings (if appropriate based on current context, community expectations) to share information about MHSA and the role of CMHDs, and to learn about mental health concerns, needs, expectations, from communities. |

## TABLE 1 CONTINUED

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Transparent Discussions of Power** | Make explicit the differentials in power between government agencies and local communities, with goal of shifting the balance and nurturing meaningful and genuine partnerships.<br><br>Community members need to see and experience 'real' benefits for the extra time, effort and involvement they are asked to give.<br><br>Work with tribal councils in each tribal community in your county to identify who are the tribal leaders you should be working with. Be aware of the complexity navigating different tribal communities and respect and value the differences. | Who are the community leaders (where does power reside within the community of interest)?<br><br>How is the governmental agency perceived?<br><br>What are meaningful and feasible ways to transfer resources into the community? | • Reimburse community agencies, leaders, and members for their time in providing input.<br>• Work with cultural brokers, key informants, community leaders to create a community advisory board comprised of grass-roots level individuals (include discussion of transportation, locale, incentives, and child care to facilitate participation).<br>• Create memorandum of understanding with community groups assisting with outreach and engagement (with shared expectations for what will be accomplished with each specific project).<br>• Employ multilingual/ multicultural cultural brokers as part of the County MHD's workforce.<br>• Hire and train facilitators and outreach workers from within these communities.<br>• Ensure that community organizations providing care to underserved, vulnerable populations have necessary infrastructure support to assist with outreach and engagement. |

## TABLE 1 CONTINUED

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Document community strengths and local knowledge** | Identify key community strengths and map the range of assets and resources within a community: | Who are the individual assets (e.g., community leaders, healers, religious leaders, elders, coaches, youth, parents, etc.)?<br><br>What are the community resources (e.g., community center, churches and temples, schools, youth programs)?<br><br>What are some institutional assets (e.g., infrastructure such as public transportation, specific buildings, local businesses)?<br><br>What are the financial resources (e.g., funding sources, local businesses)? | • Identify community-based organizations that are serving the most vulnerable within these selected communities.<br>• Describe these community organizations and the degree of trust and safe spaces these represent..<br>• Identify key community leaders and other respected individuals (who are involved in community change activities).<br>• Explore the current and potential roles of these 'community change agents' in addressing mental health concerns.<br>• Engage community participants in community mapping activity around support for mental health concerns. |

## TABLE 1 CONTINUED

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Encourage Cooperation** | Enlist the support and cooperation of key informants within communities by being explicit about the goals of the partnership. | Who should be defining the goals of the partnership? Who should be at the table?<br><br>What are the specific cultural, historic, and linguistic considerations to ensure that information is gathered in respectful and collaborative ways?<br><br>How will information gathered be shared with participants? | • Create an informational sheet about the outreach and engagement efforts.<br>• Utilize multiple linguistically and culturally relevant media sources to describe the role of DMH and DMH's interest in partnering with a particular community media.<br>• Work with key informants and other community leaders to draft a memorandum of understanding about the engagement process, sharing of information, ownership of data gathered.<br>• Ensure that any community participants assisting with outreach and engagement efforts are appropriately compensated for their time and effort.<br>• Discuss dissemination of information with participants early on – how information gathered will be used and shared with community members. |

## TABLE 1 CONTINUED

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Identify opportunities for co-learning** | Create forums for communities to teach County providers about social networks, traditions, concepts of prevention, and community assets and needs. | What types of trainings can communities offer County providers and vice versa?<br><br>Who are some key community members who might benefit from participating in trainings offered by Counties? | • Enlist the support of community participants, community-based organizations, nongovernmental agencies, governmental and academic institutions to identify what kinds of efforts around community assessments have been conducted in the past (if any) in a particular community.<br>• With the guidance of community leaders, engage community participants in discussing relevant and appropriate strategies for sharing stories of community assets and needs (e.g., focus groups, town meetings, facilitated community meetings, community mapping exercises, individual interviews).<br>• Ensure that educational materials created by County DMH about particular prevention and early intervention initiatives are appropriately translated, culturally relevant, and in an understandable format (with attention to literacy levels) with input from community participants. |

## TABLE 1 CONTINUED

| Guiding Principles | Description | Questions to Consider | Examples of Strategies |
|---|---|---|---|
| **Build capacity, focus on systems development and sustainability** | Address strategies for sustaining efforts; increase probability of sustained engagement and effective programming when community participants are active partners in the process.<br><br>Find ways in which interest, energy, and momentum could be sustained and convey commitment to the project and the process.<br><br>Be willing to work on capacity building efforts aimed at increasing contracts with agencies with a track record of commitment and effectiveness in working with underserved communities and community-based providers. | What are the different ways in which community members can be active partners in the planning and implementation of DMH initiatives (as leaders, providers, healers, outreach workers, interpreters, data gatherers, etc.)?<br><br>What are the different stakeholders' expectations about sustainability? How long will a program last?<br><br>What ways County MHDs can expand and diversify the contracting and procurement process within your county to include more providers with experience and proven track record of working with targeted underserved communities?<br><br>How can you build capacity for more diversity in provider network? | • Organize brainstorming meetings, allowing issues to emerge in an inductive manner, without fixed agendas.<br>• Share information gathered from conversations with key stakeholders before community members, and ask questions of the community to collectively identify significant issues.<br>• Create a specific action plan in close partnership with community leaders for planning and implementing prevention and early intervention initiatives that addresses sustainability as a priority.<br>• Whenever feasible, recruit community participants at the beginning into the planning process and reimburse them for their time and effort.<br>• Hire personnel to assist with DMH efforts through active recruitment efforts in underserved communities. |
| **Ethics of Engagement** | The rights, interests, and well-being of communities and individuals are consistently held as the utmost priority. | | • Review all plans for any data gathering with a research ethics board.<br>• Pay particular attention to requirements related to working with 'vulnerable populations' as defined by federal regulations. |

# TABLE 2

## KEY CONSIDERATIONS NEEDED TO FACILITATE THE TRANSFORMATION OF THE CALIFORNIA MENTAL HEALTH SYSTEM

| Guiding Principles | Description | Questions to Consider Along the Way |
|---|---|---|
| **Clarity of purpose** | • Understand clearly the purpose, goals, and context of the engagement effort in order to plan and resource an effective process.<br>• Ensure that the choice of engagement techniques is suitable for the objectives of the community engagement process, the target community and the time and resources available.<br>• Be clear about how participants can influence the decisions that may be made and what issues cannot be influenced.<br>• Be clear about the desired outcome.<br>• Be clear about who should be engaged. | • Why are we seeking participation?<br>• What will participation look like?<br>• What can we offer and what we can't offer?<br>• What will the benefit be for the community in participating in such an engagement process?<br>• What is planned to address the "culture", as well as the cultural, language, racial, and ethnic issues of all staff and collaborators?<br>• What are the attitudes toward the target communities, based on history as recounted by the County MHD and the target communities?<br>• What current collaborations are in place between the County MHD and the target communities?<br>• What is the political climate as seen by multiple parties in the target communities and in the County MHD? |
| **Commitment** | A demonstration of commitment is important to establishing and maintaining credibility. Without adequate demonstration, the whole process can be undermined.<br>• Show commitment by allocating sufficient time and resources to the community engagement processes.<br>• Ensure that senior level commitment is visible, so that commitments can be kept and that those responsible for the process or parts of the process are adequately skilled and prepared.<br>• Provide and encourage feedback during the process.<br>• Properly record and document the process and feedback so that participants (and others) can see if and how their input has influenced the process and its outcomes.<br>• Make community engagement integral to normal development assessment and plan to make practices and operations. | • What level of expertise is needed?<br>• Are the proposed salaries adequate to attract and retain skilled staff?<br>• What kind of staff will be needed to coordinate community activities?<br>• How many staff will be needed to coordinate community activities?<br>• How will positions be advertised? Internally and/or externally? |

## TABLE 2 CONTINUED

| Guiding Principles | Description | Questions to Consider Along the Way |
|---|---|---|
| **Ongoing Communication** | Community engagement and collaboration is primarily about communication, the two-way process of providing accurate and timely information, and demonstrating that feedback is heard. Ongoing communication is vital to building relationships.<br>• Communicate openly, honestly and accountably with those you are seeking to engage.<br>• Ensure that the team engaging with the community is well informed so that it can answer questions during the process. Remember that communication is multi-faceted. It does not just include information giving but information gathering, information sharing, collaborative discussion and decision making.<br>• Clearly communicate the purpose and limitations of the community engagement process at the outset. Agree to the basic procedures and mechanisms at the planning stage.<br>• Avoid creating false expectations about what community engagement can achieve.<br>• Acknowledge community input and the time and resources people put into the process.<br>• Communicate well with your peers and avoid duplication of process. Many communities, particularly those that require special consideration, are faced with an ongoing stream of agencies aiming to consult with them, often on similar matters. | • How will trust issues be addressed at all levels of the community, e.g., potential participants, their families, primary care providers (PCPs), community health and social workers, etc.?<br>• How will the target community be involved in the planning of the collaborative?<br>• How will the target community be involved in the conduct of the collaborative?<br>• How will participants be consented and what language and literacy level options will be available?<br>• Who will carry out the consent process, MOUs?<br>• How much time will be allotted for the process?<br>• Have plans been made and staff trained to understand that different cultures make important decisions differently? |
| **Evidence** | Good engagement practice is based on practice-based, evidence-based and quality information.<br>• Use latest available research and a sound understanding of history to plan the process, and who should be involved.<br>• Provide quality information to the participants at different stages during the process.<br>• Ensure accuracy and consistency of information throughout.<br>• Recognize that there are differences of what constitutes evidence or indicators of successful outcomes for different communities. | • What mental health interventions work within your community?<br>• What indicators of success do you use?<br>• What constitutes evidence for your community?<br>• How do you know that it works/does not work?<br>• What do you look at to know that it works/does not work?<br>• How do you communicate the interventions that work within your community to the rest of your community? Communicate to other communities?<br>• How does your community address health related disparities?<br>• What are your barriers to reducing health related disparities? |

## TABLE 2 CONTINUED

| Guiding Principles | Description | Questions to Consider Along the Way |
|---|---|---|
| **Flexibility and Responsiveness** | •Flexibility is of critical importance for developing and sustaining a true engagement process.<br>•Engagement plans have to be flexible during the course of a process; timetables may change, comments may require change, the political environment may change.<br>•Be flexible at both the planning and implementation stages.<br>•Be prepared to continually review and revise the way you engage the community during the process.<br>•Select a range of techniques that enable different communities or sectors to participate effectively. | • What are the practical needs and circumstances of community members involved in the engagement process?<br>• What is the timing of meetings and events (e.g., holding meetings in the evenings, or on the weekends, providing child care, having more than one meeting in order to give members the opportunity and flexibility)?<br>• What techniques can be useful to achieve maximum participation and input from this particular community? |
| **Timeliness** | It is important that participants know how long an engagement and collaboration process is expected to last, and when feedback is expected at each stage of the process.<br>• Recognize that communities have their own pace and recognize your agency has its own pace and both may differ.<br>• Be clear about the time you have for the task.<br>•Ensure participants receive information in enough time to make effective contributions.<br>•Inform participants as to when they can expect feedback on their contributions.<br>•Make sure that feedback is given to participants on time. | • What is "the pace" of this community?<br>• How fast are community members willing and able to go?<br>• Who in the community can and will drive the pace of change?<br>• Who is expected to provide feedback to the participating communities and on which timetable? |

## TABLE 2 CONTINUED

| Guiding Principles | Description | Questions to Consider Along the Way |
|---|---|---|
| **Inclusiveness** | Being inclusive means understanding who is likely to be interested in, or feel the impact of, a particular plan or development. Affected individuals and communities should be encouraged to participate actively in the creation of health programs in their community.<br>• Aim to be as inclusive as possible but accept that in few circumstances is it feasible to involve everybody.<br>• Know and understand the communities you want to engage.<br>• Acknowledge and respect their diversity.<br>• Accept different agendas, but ensure that dominant special interest groups are not the only voices heard.<br>• Choose a variety of engagement techniques that offer the widest possible opportunities to participate.<br>• Avoid jargon and technical language.<br>• Aim for accessibility. Consider the timing, location and style of engagement events and strategies, as well as the support available to participants (such as translators, childcare, out-of-pocket expenses).<br>• Pay particular attention to the needs of groups that tend to be under-represented. | • Who is included on this team?<br>• What additional voices are needed to ensure success?<br>• What issues will impact recruitment?<br>• What will be done to address those issues?<br>• What outreach will be necessary and how will the relationships developed be maintained with participants?<br>• What experience/ knowledge is needed to recruit in your targeted area?<br>• What types of activities are initially planned to facilitate recruitment?<br>• How many activities, over what period of time?<br>• Who will be needed to participate in these activities and over what period of time or at what intervals?<br>• What other strategies will be used?<br>• What will be expected of site staff?<br>• How will success be measured?<br>• How will progress be measured?<br>• How often will all staff gather to discuss progress? |
| **Collaboration** | Leading practice processes require early involvement of community interests at a level that is appropriate for their involvement.<br>• Adjust for scales of involvement – different interests require different involvement along the engagement spectrum.<br>• Aim for a participatory approach to development assessment and plan making, particularly in larger, more complex processes.<br>• Involve the community as early as possible in the process.<br>• Seek community input at the planning stage of a community engagement process, particularly in the selection of engagement techniques.<br>• Work with other agencies operating in the area to avoid repetitive consultations with a community on the same or similar subject matter.<br>• Work with tribal communities in your county and understand their organization. | • How will participants' needs be addressed? (Transportation, childcare, waiting areas, adequate space, etc.)<br>• What plans have been developed to address issues of community participants and their health providers regarding trust and the understanding of research?<br>• Have community providers been notified and invited to an information session about the project?<br>• What is planned to notify PCPs and other community providers?<br>• Have the issues of trust been addressed? |

## TABLE 2 CONTINUED

| Guiding Principles | Description | Questions to Consider Along the Way |
|---|---|---|
| **Continuous Learning** | • Monitor and evaluate as you go – modify your approach as necessary.<br>• Encourage community feedback on the process itself as well as the subject of the engagement.<br>• Build on past experience – acknowledge mistakes so that you can learn from them.<br>• Find out what has happened before in an area relevant to the engagement process subject matter – past consultations may have occurred with or without success.<br>• Report back within your organization to ensure that the organization learns from the process. | • What types of training are appropriate?<br>• For which staff?<br>• How often will refresher/ update trainings be needed?<br>• Who will be available to conduct training? Would it be contracted out, or from within? |
| **Ethical Conduct** | Health programs should explicitly consider ethical guidelines and values in their decisions about implementation:<br>• To ensure the consideration of ethical values such as integrity, reciprocity, respect for human dignity and worth, equality (commitment to distributive fairness and justice), and responsibility (do no harm).<br>• To demonstrate engagement with the values and processes of participating communities?<br>• To take into account the ethical hazards that may be part of the social, economic, and political landscape of the community.<br>• To develop awareness of the settings that may lead unintentionally to imprudent or untrustworthy behaviors.<br>• To avoid exploitation, by ensuring a fair distribution of the resources made available in the implementation of programs from, by, and for the target communities. | • How the planned program demonstrates intent to contribute to the advancement of the health and wellbeing of underserved communities and their members.<br>• How the plan is linked to community priorities and responds to existing or emerging community mental health needs?<br>• How willing is the program to modify plans in accordance with participating community values and aspirations?<br>• Would the proposed program enhance the capacity of communities to draw benefit beyond the project, for example, through the development of skills and knowledge or through broader social, economic or political strategies at the local level? |

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