CalMHSA is an organization of county governments working to improve mental health outcomes for individuals, families and communities. CalMHSA operates services and education programs on a statewide, regional and local basis.

2012 Stigma and Discrimination Reduction Focus Group Report

United Advocates for Children and Families
United Advocates for Children and Families (UACF) was recently awarded a Stigma and Discrimination Reduction contract with the Prevention and Early Intervention Statewide Projects implemented by the California Mental Health Services Authority (CalMHSA). CalMHSA is an organization of county governments working to improve mental health outcomes for individuals, families and communities. CalMHSA operates services and education programs on a statewide, regional and local basis. Prevention and Early Intervention (PEI) Statewide Initiatives are CalMHSA’s three initial mental health programs aimed at improving student mental health, eliminating and/or reducing suicides, stigma and resulting discrimination. The Statewide PEI Initiatives include: 1) Shift California’s mental health services approach to meet the needs of our diverse communities and reach individuals before they reach the crisis point. 2) Provide an up-front investment that will pay off with sustained cost reductions in health, social services, education and criminal justice programs. 3) Voter-approved paid for through the Mental Health Services Act (Proposition 63).

UACF through the management of its Institute for Family and Youth Leadership, in conjunction with CalMHSA and its partners, will initiate strategies to engage and empower local communities across the state to provide a supportive environment for consumers, families, youth and children by recognizing that mental health is integral in everyone’s wellbeing. The strategies will target people with lived experience, their family members and caregivers across the lifespan, ethnically and racially, and will engage culturally diverse populations. UACF will collaborate with established local organizations to strengthen and empower local leadership to address stigma and resulting discrimination throughout the twelve (12) geographic regions (See Attachment 1); a grassroots leadership development approach.

UACF contracted with the Axis Group I, LLC (www.axisgroup1.net), a national technical assistance and consulting firm, to perform the needs assessment, gaps analysis, and report for this project.
Stigma and Discrimination Reduction Initiative Needs Assessment and Gaps Analysis Focus Group Report

One Step Back Before Moving Forward

For the most part, studies have overlooked the fact that stigma is a characteristic of the social structures that make up society. Stigma is also evident in the way laws, social services, and the justice systems are structured as well as ways in which resources are allocated (Corrigan, et al. 2002). Furthermore, research indicates that while mental health stigma is universal, experiences are generally local (Goldney et al, 2001).

Mental health disorders carry a strong stigma in almost all cultures. Stigma may be expressed in different ways depending on cultural values. Where individualism is highly valued, these problems may be viewed as a personal failing. When family and community are valued, these problems may be viewed as a family or community inadequacy. The goal of to get rid of stigma is critical, but it is clear that one type of initiative is not going to work for all communities or all people. By gathering information from the broader community, programs often find that community members have different ideas about what is needed (CAMH, 2007).

Research indicates that the diversity of impressions, assumptions, and ideas that are locally, culturally, or experientially influenced are critical in the planning and implementing stigma and discrimination reduction at the community levels. Given the vast cultural, geographic, and social diversity within the state of California, UACF deemed it critical to the planning of appropriate approaches to reduce stigma and discrimination to listen and gather impressions within a sampling of diverse populations.

UACF will develop a Capacity Building Needs Assessment or Gap Analysis Tool for local counties, community-based organizations, family members, consumers and youth that will provide the project with a snapshot of “where we are” which is a critical first step in determining the vision of “where we need to be” relative to the impact of stigma on access to care, healthy behaviors and health outcomes. The tool will include a demographic and socio-economic profile of each county in the 12 Regions. UACF will utilize focus groups in the region, interviews with service providers and surveys to counties and community-based organizations.
The population and cultures across California demand an all-encompassing approach when assessing mental health stigma and discrimination needs and developing a program that is responsive as well as effective. Before launching a targeted stigma and discrimination reduction program, it is necessary:

- To better understand what people know about mental health and stigma;
- How they view mental illness; and
- Where they get their information from that guides these beliefs.

The utilization of Focus Groups as a source of information emerging from targeted conversations provided a snapshot and better understanding of issues, interpretation, and influences of mental health stigma and discrimination and provided. Informal focus groups provide a discussion board to gain insight into how people think and afford a deeper discussion of the stigma and discrimination experiences and needs of participants.

Gathering information regarding mental health stigma and discrimination from a broad and diverse representation encouraged the project to select Focus Groups discussions as the first phase of the needs assessment. The second phase will include surveys to query a series of questions that complement the Focus Group discussions from all socioeconomic, cultural, and geographic populations.
Although this was not considered a research activity, practical principles of focus group protocol were utilized within the planning process to preserve fidelity and collation of the data and outcomes (See attachment 2). The subcontractors participating in the planning, hosting, facilitating, and reporting of the Focus Groups included:

- Christian Partnerships Inc. (CPI)
- California Association of School Psychologists (CASP)
- California Youth Empowerment Network (CAYEN)
  - Racial and Ethnic Mental Health Disparities Coalition (REMHDCO)

The process and outcomes of outreach to targeted populations was critical to ensure that enough information was gathered would assist the program in developing approaches to reduce stigma and discrimination that would assist the largest and most diverse populations possible. During a face to face meeting and follow up phone training/discussion the subcontractor partners shared ideas, approaches, and discussed what populations they served would be prime representatives for the focus groups. The subcontractors selected their own target populations based upon accessibility, selection pool to ensure participation, and to facilitate opportunities to listen to high risk groups such as military and returning vets, those with alternative lifestyles, and minority populations. Each outreach focus group outreach was customized to the population and location. The types of outreach utilized included:

- **Phone**: Direct calling selected and invited individuals
- **Website**: Posting of information and invitations to the group
- **Mail**: Sending flyers to advertise the focus group
- **Email**: Sending a mass mailing to email lists
- **Social Media**: Using Face Book, Twitter, text, and other social media resources
- **Posters**: Posters in waiting rooms, offices, and other locations utilized by the population
- **Personal Invitation**: Calling or actively reaching out to specific individuals
- **Co-location with another event**: Holding the focus group in conjunction with another event such as a meeting

Each group followed a set process and protocol to ensure that the information gathered was relevant and could be cross compared with the outcomes of the other groups.

The basic steps for the protocol included:

1. Welcoming Participants
2. Garnering Participation
3. Securing signatures on the Consent Form
4. Asking the Five Core Questions
5. Closing

Each step and direction was reviewed by subcontractor leaders to ensure that it was culturally relevant and would be a viable tool within their representative populations. Suggestions were integrated throughout the protocol. A special section on hosting focus groups for culturally diverse populations was inserted to ensure that the approach addressed culture, race, ethnicity, language, and was executed in a manner that would facilitate diverse participation. All hosts were also granted permission to alter the questions as long as the resulting discussion and data related to the original query. This allowed hosts to use their knowledge of targeted populations to facilitate conversations and gather data.

The actual questions depended upon the audience and subcontractor understanding of the best way to facilitate participation. Discussions around the core (numbered) questions served as the base query, but questions were altered to accommodate the diversity and needs of the participants. The core questions and potential alternative questions included:

1. What does mental health stigma and discrimination mean to you?

   Alternative questions:
   - When I say mental health stigma or discrimination, what do you think I mean?
   - Can you tell me what mental health stigma and discrimination means to you?
   - If I told you we were going to talk about mental health stigma and discrimination, what do you think we will be discussing?

2. Have you ever experienced stigma or discrimination because of your or a family members mental illness or mental, emotional, or behavioral disorder? Please share (if you are comfortable) that experience with us.

   Alternative questions:
   - Would you like to share about a time when you felt mental health stigma or discrimination?
   - Has anything like this ever happened to you? Would you like to share with us?
   - Have you ever seen anything like that before? Would you mind sharing?

3. Why do you think stigma and discrimination of those with mental illness and mental, emotional, and behavioral disorders exists?

   Alternative questions:
   - Why do you think these kinds of things happen?
   - Do you know why people with mental health disorders experience this? Would you like to share more about that?

4. Please describe any stigma and discrimination reduction activities and programs that exist in your area? This might be a program or person who is teaching others why stigma and
discrimination is bad or it may be someplace you can call to get help if you feel stigma or discrimination has occurred.

Alternative questions:

- Can you tell us about any programs or an activity that you know of or have heard about that is supposed to reduce this kind of stigma and discrimination?
- Have you heard of or seen any programs that are working to change stigma and discrimination in your community? Would you like to tell us about that?
- If you feel that this has happened to you or someone you care about, do you know of a program or person to call to get assistance? What kind of assistance do they offer?

5. If you had a magic wand and you were asked to create a new CA mental health environment, free of stigma and discrimination, how would that look (where money, laws, politics, or other barriers are not allowed to interfere with the magic of the vision)?

Alternative questions:

- If laws, money, and other things were not an issue, what would your perfect world for those with mental illness look like?
- What would a community free of stigma and discrimination look like to you?
- If there were no stigma or discrimination in this community, what would that look like?
- Do you have any ideas on how we can make this community free of stigma and discrimination for those with mental illness?

Hosts and facilitators were required to:

- Host at least two Focus Groups between February 15 and March 20, 2012;
- Identify the place and time that would be convenient and most supportive to target population attendance;
- Ensure that the location and process was ADA Compliant;
- Notify UACF of the date, time, and location of the group no less than one week prior to the event.
- Implement an outreach effort that would yield at least 10-15 participants that were a representation of the population(s) you serve;
- Document outreach efforts, where outreach occurred, how many individuals were invited, and the response to these efforts;
- Adjust necessary components to ensure relevance to the participant population;
- Make translation arrangements when warranted;
- Facilitate the Focus Group in a manner that was best suited for the audience;
- Document responses;
- Submit participant Consent Forms to UACF; and
- Submit notes (in Word, not a PDF) and Participant Information Forms data from the Focus Group using The Reporting Form no later than ONE WEEK AFTER THE FOCUS GROUP DATE.
There were obvious and identifiable trends throughout the discussions that resulted from the Focus Group discussions. Few threads emerged as a dominant issue or topic across all groups. Also, because of the selected diversity of the each group, they tended to discuss and describe those issues that were directly related to their lives. In addition, each group had their own “language” or vernacular. Some would describe fear one way and another would frame it differently. Specific emerging trends and insight from the Focus Groups are described below.

**Outreach and Participation:** Four subcontractors invited 154 individuals from diverse cultures, geographic locations, and socioeconomic backgrounds to 7 different Focus Group events. The outreach was varied and included all of the proposed outreach activities:

- Emails
- Personal Invites
- Social Media
- List Serves
- Posters
- Phone Calls
- Face Book

Of those known to have been invited, 55 individuals attended and participate in the events. Our targeted participation was for an average of 10 per focus group and this was slightly lower at 7.8 per group. A majority of those participating (41) responded for themselves with the lesser number for their child, youth, a spouse or partner, a friend, or other. Most of them represented the 25-59 year old age group. The largest representative race and ethnicity was from the Latino/Hispanic/Chicano population (26). Gender representation was nearly split, male to female. When asked how they describe their sexual orientation, most identified “Straight/Heterosexual” (32) but a significant number indicated “Gay” (17). None of the participants identified themselves as refugees, but a significant number (15) stated they were immigrants. Of those immigrating to the country, the number of years they have lived here ranged from 6 to 70 years. Many of the participants were fluent in other languages than English (20), including Spanish, Korean, Mandarin, American Sign Language, French, and Punjabi.
Most participants indicated that if they had a mental health diagnosis or were responding for an individual with a diagnosis, it was Depression (13), Anxiety Disorder (9), ADHD (8), Bipolar Disorder (6), Schizophrenia (4), PTSD (4), or other unspecified disorders.

Recent research has identified some evidence of increased stigmatizing beliefs among racial/ethnic minorities, men and older persons, but the findings vary across studies and do not support an evidenced conclusion. Inconsistencies of available studies suggest that sociodemographic differences in stigma may not be as important as other factors such as diagnosis or symptoms (Angermeyer and Dietrich, 2005). The California Strategic Plan on Reducing Mental Health Stigma and Discrimination recommends an elevated consideration of unique cultural approaches to stigma is particularly necessary in California as the state is anticipated to become even more diverse in the near future. Studies to date suggest that various racial or ethnic groups often experience and express stigma differently. (Mental Health Services Oversight and Accountability Commission, 2009)

This participation rate of the Focus Groups does not represent statewide averages or representation. As described earlier, the subcontractors hosted groups based upon diversity, accessibility, and risk in an attempt to go to those underrepresented populations to learn more about the influence of these characteristics on mental health stigma and discrimination.

What Is Stigma and Discrimination?

Corrigan (Corrigan, 2005) has proposed a framework in which stigma encompasses three components: stereotypes, prejudice, and discrimination and is further categorized as either public stigma or self-stigma. Prejudice is defined as a negative attitude toward a person or group; stereotypes are a set of beliefs about members of a group; discrimination is the behavioral aspect of stigma and is presumed to result from prejudice and/or stereotypes. The personal stigma of mental illness can also be considered in three main ways: 1) perceived stigma, 2) experienced stigma, and 3) self-stigma (Brohan et al. 2010).

Most of the participants described stigma and discrimination within the scope of how individuals are treated, using such words as “labeled”, “unfair exclusion”, or “stereotyped”. Labeling, by one description or another, surfaced as a key word or thread across most groups. Many of the discussions centered on what people “think” of individuals with mental health challenges. They also discussed how what people think impacts how they are treated. People have preconceived ideas on what they think you will do as a result of the label they have assigned. For example, you are “crazy” therefore you will “snap” someday.
Many of the individuals related mental health stigma and discrimination to their lifestyle and profession. The participants in two of the groups felt that the stigma was related to their sexual orientation and a lack of today’s society to recognize and accept them. They shared that they encounter many people that think that not being straight or heterosexual is a mental illness. Professionals shared that just working with individuals with mental health issues was a cause for stigma, questions, and isolation by other professionals who did not work in the field.

Of interest, many of the respondents did not seem to understand the meaning of stigma and discrimination, even with an introduction and clarification of what it meant within the scope of the project. They related stigma and discrimination to how an individual with mental illness behaves, using phrases such as “unpredictable people” and “acting out”. Similarly, many individuals included an actual diagnosis in their description of stigma and discrimination. They used words like “depressed” to describe stigma and discrimination.

Stigma and Discrimination Experiences

Stigma and discrimination experiences resulting from a mental illness are widespread. Individuals with mental illnesses have a double burden. Not only must they cope with disabling disorders, but they also must contend with the negative attitudes of the public toward those disorders (Wahl, O., 1999). Mental health stigma and discrimination can have a ripple effect; hitting the individual with the diagnosis in a public manner due to perceptions around those with mental illness that is fostered by the media and misinformation. Eventually their families (especially parents) can become a target for stigma and discrimination for their acceptance of the individual and their “willingness” to allow them to continue being mentally ill. Eventually, the stigma cycles back around to the person with the mental health issue of condition as they self-stigmatize themselves for “being mentally ill”. An entire social and familial system becomes a target within the progression of stigma and discrimination (Mukolo, et al., 2010).

Each group readily shared experiences with stigma and discrimination. They discussed how hard it is to get rid of a label, once it has been handed out. They stated that the label seems to travel with you and interfere with the perception of others. They talked about being “shunned” because of the ongoing drama in their lives, being turned down for services, and how professionals often use the mental health issue as an excuse to not provide the level of services and supports needed. In addition, participants discussed how professionals, family members, and others openly state that they are using their mental health challenges as an excuse to not behave, not work, or not “be like everyone else”. 
The military and LGBTQ populations shared poignant stories about being turned away, attempting to hide everything that made them different, and losing medals or promotions due to their mental health issues. Having a mental health disorder within the military was portrayed as a professional hazard. Even when the mental health issue (PTSD) was a direct result of military involvement, they found that it was still frowned upon and felt pressure to minimize its impact. One of the respondents shared that their culture only wants to “talk about what is good” and that they are not able to share or discuss what happens relative to their mental health challenges.

The Causes of Discrimination and Stigma

Our understanding of what stigma is and how it develops is not matched by our knowledge of why it develops, although a model suggests that the impetus is an initial perception of tangible or symbolic threat (Stangor et al., 2000). Tangible threats are those that are considered a risk to material or concrete goods and symbolic ones are those that threaten beliefs, values, ideology or the way in which a group organizes its social, political or spiritual domains. The first promotes a belief that mental illness is under the control of the individual and that the individual is lazy and will not hold a regular job (Stuart H. Arboleda-Flórez J. 2001). The second is based upon an unpredictable and dangerous individual, representing a material threat to personal security. While the first threat fails to recognize that there is a spectrum of disability in mental illness not unlike that found in any other type of illness, the second is based on sensationalistic media and misleading measures of community risk (Stuart H. Arboleda-Flórez J. 2001).

The few causes of discrimination and stigma shared across all groups followed trends described in existing research. Fear was discussed in a variety of ways as a precipitator of discrimination and stigma. The fear was of individuals, their mental health challenges, and what they would do as a result. They felt that the media had made this much more difficult, with news, movies, and stories about persons with mental health issues doing terrible things. Another common cause was a lack of understanding. This was discussed as a lack of “knowledge”, a lack of “education”, and not being “informed”. Comments were shared such as “Doesn’t know how to deal with the mentally ill” and “not knowing how to help”.

Participants also shared other thoughts, such as one cause might be because there is a human need for “sameness”, and persons with mental health issues just are not the “same”. They also felt that it was easy for people to stigmatize and discriminate against those with mental health issues because they couldn’t “stand up for themselves”.

Page 11 of 35
The participants also described “self-discrimination and stigma” as a problem due to beliefs, culture, or self-confidence of those impacted by mental health issues.

**Stigma and Discrimination Programs and Services**

Past anti-stigma efforts have utilized activities, services, and programs that promote a change in attitudes and behaviors. These efforts have been used alone or in combination. Past and existing stigma and discrimination reduction programs are used as examples of the range of tools available. The methods most often used include:

- Direct interpersonal contact – includes working directly with individuals to assist them skill building and acceptance.
- Education – educating the public as well as individuals to ensure that they are accepting, supportive, and nondiscriminatory towards individuals with mental illness and their families.
- Advocacy, coalition building, and support

Most groups did not feel that they were aware of existing stigma and discrimination programs or services. Those shared were either within an existing center or program or related to another population specific program, such as a program for youth or LGBTQ individuals and their families. Several, especially professionals, described the efforts of individuals as the only “program or service” available, but expressed the success and difference it made in individual lives.

**The “Perfect World”**

In moving toward a world that is free of stigma and discrimination we would need to develop a view or concept of what that would look like; what it would mean. The “perfect world” would likely be different for each individual as it is shaped and influenced by race, culture, ethnicity, language, family traditions and customs, geographic location and neighborhood, experiences, profession, and the list would be endless. One could anticipate some common threads.

Despite potential variances, each focus group described a world free of labeling, assumptions, bullying, ridicule, and discrimination. They related that this could occur because there would be readily available services that were based upon need and they would be fully funded so there would be no waiting, easy access, and affordable or free. Programs and services would be
relative to culture, with culturally representative therapists and providers. Staff would be competent, knowledgeable, and well trained to meet the needs of persons with mental health challenges and their families and significant others. There would be no barriers and everyone would have free access to whatever they needed, without jumping through hoops or begging.

In addition to the actual system serving them, they also discussed the need for attitude changes throughout society. They used terms such as “unconditional love”, “no judgments”, and “more peaceful” within their perfect world. The people that live around them and those serving them would stop treating them as a label and begin treating them as individuals.

They also described an education system that prepared individuals to relate better and have accurate information on mental health, even at a very early age in life. Participants believed that persons with mental health issues would be able to care for themselves better through education knowledge and support.
While this is a preliminary report and further analysis will be done, several themes emerged as critical in understanding the development of mental health stigma and discrimination reduction activities across the state and to provide UACF and other program partners with information about how to better direct capacity building efforts.

- Many individuals do not understand stigma and discrimination. In addition, they do not always know what services, supports, policies/procedures and activities can be defined as efforts that reduce self of public stigma vs. eradicate discrimination.
  - Programs, supports, services, and education will need to include a simple, understandable, culturally and linguistically relevant, and consistent message that clarifies the issues.

- Some individuals cannot separate causes of stigma and discrimination; allowing perceptions shade their views, options, and choices. It does not seem prudent to attempt a separation of causes.
  - Programs will require support an eradication of stigma and discrimination, regardless of the perceived or labeled cause. To force a separation would be another form of label driven service delivery.

- Education of the public, professionals, families, friends, and individuals with mental health challenges is a key in a movement to reduce mental health stigma and discrimination.
  - Programs will need to target educational needs and knowledge gaps to raise the capacity of society, the system families, and individuals to live and work within a stigma and discrimination free community.

- While the desired goal is the same, change will have to be addressed through a cultural lens.
  - Changes and supporting programs within the domains of targeted populations will have to respect traditions, culture, ethnicity, language, and population trends. The changes necessary for those in the military will be different than youth or individuals who have immigrated to the country.
References

Angermeyer, M. C. and Dietrich, S., Public beliefs about and attitudes towards people with mental illness: a review of population studies, Article first published online: 5 DEC 2005, DOI: 10.1111/j.1600-0447.2005.00699.x


ATTACHMENT 1

REGIONS:
1. North Coast
2. Shasta/Cascade
3. North Central
4. Bay Area
5. Central
6. Central Coast
7. South Central
8. Eastern Sierra
9. Inland Empire
10. Los Angeles
11. Orange County
12. San Diego
ATTACHMENT 2

Focus Group Host and Facilitator Guide*

*REMEMBER: This is a “guide” and the approach and words should be customized for your audience. You are responsible for making this “fit” and work with your target population.

The population and cultures across the state demand an all-encompassing approach when assessing mental health stigma and discrimination needs. Focus groups provide insights into how people think and provide a deeper understanding of the stigma and discrimination experiences and needs of participants. Focus groups offer the ability to capture deeper information more economically than individual interviews. There are several components of hosting a successful Focus Group. As a Host, you will be expected to:

- Host at least two Focus Groups between now and March 15, 2015;
- Identify the place and time that will be convenient and most supportive to target population attendance;
- Ensure that the location and process is ADA Compliant;
- Notify Sireyia of the date, time, and location of the group no less than one week prior to the event.
- Implement an outreach effort that will yield at least 10-15 participants that are a representation of the population(s) you serve;
- Document outreach efforts, where outreach occurred, how many individuals were invited, and the response to these efforts;
- Adjust necessary components to ensure relevance to the participant population;
- Make translation arrangements when warranted;
- Facilitate the Focus Group in a manner that is best suited for the audience;
- Document responses;
- Submit participant Consent Forms (Attachment 1) to UACF; and
- Submit notes (in Word, not a PDF) and Participant Information Forms data (Attachment 2) from the Focus Group using The Reporting Form (Attachment 4) no later than ONE
WEEK AFTER THE FOCUS GROUP DATE.

PLEASE NOTE: We are interested in ideas and issues, not exact words, lengthy narratives, or direct quotes. Please submit your notes in bullets on the Focus Group Report Form, Attachment #4.

Focus Group Facilitation

We will follow a consistent yet flexible process that will enhance participation and success and allow us to collate and cross compare results. While this is NOT a scientific process, we do need to follow basic steps in process to ensure a common analysis of the outcomes. Our core process will include five steps:

1. Welcome
2. Garnering Participation
3. Securing signatures on the Consent Form
4. Asking the Five Core Questions
5. Closing

Step One: Welcome

a. Introduce yourself and anyone assisting you.

b. Explain the SDR Initiative and offer information regarding UACF, CalMHSA, and the Host program (UACF needs to provide a handout describing the project).

c. Discuss the purpose of the gatherings and answer questions.

d. Disseminate and review the Focus Group Information sheet (Attachment 2)

e. Explain that they cannot get in trouble for sharing their concerns and ideas and that there will be no personal identifiers in the final report.

f. Offer to send them the final report and display the website where they can locate the report.

g. Distribute the confidentiality forms (Attachment 1) and ask them to sign and return it.

Sample: Hello, my name is: [insert your name], I am assisting [name of organization you represent] and the United Advocates for Children and Families with The SDR Focus Group Study, Understanding Community Perceptions of Mental Health Stigma and Discrimination in
order for everyone to better appreciate and understand the real issues relative to mental health stigma and discrimination. The Stigma and Discrimination Reduction Project is a project of the United Advocates for Children and Families and funded by CalMHSA. The overarching goal of the program is to work with communities through partners across the state to provide education and reduce stigma and discrimination of persons, children and youth with mental illness. We are interested in learning from you and would appreciate your help. The focus group will last about 1.5 to 2 hours and your participation is voluntary. Participants may choose to withdraw from the study at any time. We plan to tape record the group’s responses, but they will be kept confidential and no names will appear in the report. We hope to use this input to improve breast health services and education. Are there any questions?

**Step Two: Garnering Participation:**

We wish to maximize the time invested by everyone, especially those who came forward to participate in the Focus Groups. Dedicate some time to reinforce their importance in the project and to ensure they are comfortable. Please note the section dedicated on Page 5 regarding Focus Groups for diverse cultures, races, and ethnicities.

**Sample:** A focus group is like a group interview. We are interested in everyone's responses to the questions, and there is no right or wrong answers. We appreciate your input in the discussion. Would you like to participate in the focus group? If so, please fill out the brief participant information sheet. Pass out and collect the participant demographic form.

**Step Three: Consent Form:**

The consent form serves several purposes, including a documentation of agreement for participation as well as a promise to the participants that their information will be protected and kept confidential. **Please have all of the form filled out with the exception of the participant name, the signatures and dates.**

**Sample:** I would like to review the Consent Form (read this and answer questions). If there are no more questions, are you still interested in participating? Good, first let’s sign the release form and we can get started.
**Step Four: Questions** (ask and probe for responses):

The actual questions will depend on your audience and your understanding of the best way to facilitate participation. We need answers to the core (numbered) questions, but you may have to adjust the questions, depending on your target audience. Please refer to the section **Hosting a Focus group with Diverse Cultures, Races, and Ethnicities** on Page 5 before planning your approach for garnering answers to the questions posed.

1. **What does mental health stigma and discrimination mean to you?**

   Alternative questions:
   
   - *When I say mental health stigma or discrimination, what do you think I mean?*
   - *Can you tell me what mental health stigma and discrimination means to you?*
   - *If I told you we were going to talk about mental health stigma and discrimination, what do you think we will be discussing?*
   - *OTHER:*

6. **Have you ever experienced stigma or discrimination because of your or a family members mental illness or mental, emotional, or behavioral disorder? Please share (if you are comfortable) that experience with us.**

   Alternative questions:
   
   - *Would you like to share about a time when you felt mental health stigma or discrimination?*
   - *Has anything like this ever happened to you? Would you like to share with us?*
   - *Have you ever seen anything like that before? Would you mind sharing?*
   - *OTHER:*
7. Why do you think stigma and discrimination of those with mental illness and mental, emotional, and behavioral disorders exists?

Alternative questions:

- Why do you think these kinds of things happen?
- Do you know why people with mental health disorders experience this? Would you like to share more about that?
- OTHER:

8. Please describe any stigma and discrimination reduction activities and programs that exist in your area? This might be a program or person who is teaching others why stigma and discrimination is bad or it may be someplace you can call to get help if you feel stigma or discrimination has occurred.

Alternative questions:

- Can you tell us about any programs or an activity that you know of or have heard about that is supposed to reduce this kind of stigma and discrimination?
- Have you heard of or seen any programs that are working to change stigma and discrimination in your community? Would you like to tell us about that?
- If you feel that this has happened to you or someone you care about, do you know of a program or person to call to get assistance? What kind of assistance do they offer?
- OTHER:

9. If you had a magic wand and you were asked to create a new CA mental health environment, free of stigma and discrimination, how would that look (where money, laws, politics, or other barriers are not allowed to interfere with the magic of the vision)?
Alternative questions:

- If laws, money, and other things were not an issue, what would your perfect world for those with mental illness look like?

- What would a community free of stigma and discrimination look like to you?

- If there were no stigma or discrimination in this community, what would that look like?

- Do you have any ideas on how we can make this community free of stigma and discrimination for those with mental illness?

- OTHER:

**Step Five: Closing**

The closing is an important component of the overall Focus Group. It should reinforce their importance and validate the time they spent with you.

**Sample:** Thank you very much for your responses. We hope to use them to improve the lives of all individuals in this community. You can learn more about the project and read the report when it is finalized: {insert website here}. 
Hosting a Focus group with Diverse Cultures, Races, and Ethnicities

If you will be hosting a focus group with persons of diverse cultures, races, or ethnicities you may have to make some adjustments to accommodate them and facilitate their full participation. It is imperative that you use your knowledge and understanding of the populations you work with to make the necessary adjustments that will enhance their participation and ensure cultural and linguistic competency at all levels. This may include:

**Language:** If the participants will require any component (such as the questions, consent, or for a facilitator) in another language, you will perform that translation. It is hoped that any translations will be shared with others and should be submitted to Sireyia.

**Framing the questions for the desired responses:** For many people of color, the word “discrimination” is so associated with (or they experience so much) racial discrimination that it is difficult for them to think about discrimination based solely on a mental health diagnosis. Many people of color or people from oppressed groups, such as the LGBT community, believe that the discrimination they experience because they are of color (or gay or whatever) is so omnipresent and severe that this either causes the mental health condition/illness or certainly exacerbates a condition. This is such an over-riding or over-lapping situation that it may be difficult or impossible to separate or tease out the stigma and discrimination felt due to racism verses the stigma and discrimination felt due to having a mental health diagnosis. In addition, the stigma of having a mental health condition may be more severe or strong among some ethnic communities or cultures. (This may be related to how a person’s identity in some cultures is more closely associated with their family or community than in Western cultures.) Wanting to identify as a client, consumer, or family member may not be as acceptable in these communities.

With these groups, you may choose to add additional questions such as:

“If you experience discrimination or stigma because you are of a different race, ethnicity, or sexual orientation, do you feel you can separate this from the discrimination or stigma you may experience due to your mental health diagnosis or condition?”

“What is relationship between the discrimination/stigma one experiences due to one’s race, ethnicity, or sexual orientation and the discrimination/stigma one experiences due to one’s mental health condition/diagnosis? Is one more common or strong than the other? Do you feel one might cause the other?”
“When the words ‘discrimination’ and ‘stigma’ are used, do you immediately think about the discrimination based on race, ethnicity, sexual orientation, etc., rather than discrimination based on mental illness or mental health diagnosis? Why?”

These questions would be added at the beginning, before Question #1. This would help them frame their answers to the core questions that will follow in a manner that focuses on mental health stigma and discrimination.
INFORMED CONSENT AUTHORIZATION TO PARTICIPATE IN FOCUS GROUP

Mental Health Stigma and Discrimination Focus Group in collaboration with the United Advocates for Children and Families

NAME: (Please Print Your Name) ______________________________

I. STUDY PURPOSE

The SDR Focus Group Study, Understanding Community Level Perceptions of Mental Health Stigma and Discrimination goal is to document and better understand the real issues as reflected by communities relative to mental health stigma and discrimination.

II. STUDY PROCEDURES

You are being invited to participate in a research study, Understanding Community Level Perceptions of Mental Health Stigma and Discrimination that uses focus groups to obtain a better understanding of the level of stigma and discrimination within communities and how to develop activities to improve individual mental health and wellbeing.

You will be asked to complete a demographic form.

The focus group will last approximately 1.5 to 2 hours and will be led by two group facilitators. They will ask open-ended questions about mental health stigma and discrimination in your community and take notes to report responses. The discussion in the focus group may be tape recorded and transcribed following the session, but you will not be identified individually on the transcripts. All tapes and notes will be destroyed after they are transcribed.

III. RISKS AND DISCOMFORTS OF THE STUDY

There are no anticipated possible risks and/or discomforts of your involvement in this research study. You may withdraw from this study at any time without penalty. Your name will not be on the transcripts of the focus group or your demographic form.

In addition, your responses will not be seen by any provider or program with any direct decision making regarding your mental health services.
There is a potential risk of breach of confidentiality of focus group responses and study data; however, the special precautions taken to ensure confidentiality and voluntary participation, along with the significant potential benefits, ensure an acceptable risk/benefit ratio.

IV. CONTACTS

If a study related problems should occur or if you have any questions any time about the study you may contact: Sireyia Ratliff at 916-643-1530.

V. BENEFITS

Your voluntary participation in this study may assist your community to respond in a more supportive manner to individuals, children, youth, supporters, and families relative to mental health. You will receive no direct benefit from your participation in the study.

VI. CONFIDENTIALITY

All measures will be taken to protect your confidentiality. The confidentiality and participation form (this form) will be kept in a locked file cabinet in the office of the principal investigator.

No information will be accessible to your employer, school, providers or peers. Your participation in programs and services will not be affected by your participation (or non-participation) in the study or by any answer you give on the surveys.

VII. COMPENSATION FOR INJURY

The United Advocates for Children and Families, Inc. has not set aside any funds for financial compensation for costs of medical treatment should you be injured as a result of your participation in this research.

By signing this form, you are neither waiving any of your legal rights against nor releasing the principal investigator, the ____________________________________ (host), United Advocates for Children and Families, Inc., or any of their respective agents from liability for negligence with respect to this study. If you believe your injury justifies pursuing a legal remedy, you have the right to do so.

VIII. LEAVING THE STUDY

If you leave the study, your relationship with the ____________________________________ (Host) will not be negatively affected. Your
participation or non-participation will not affect your work status or academic standing.

IX CONSENT

You voluntarily agree to participate in this study. You have had the chance to ask the hosting program and United Advocates for Children and Families, Inc. any questions you have regarding the study.

YOU HAVE RECEIVED A COPY OF THIS SIGNED INFORMED CONSENT AGREEMENT.

Name (Print):

________________________________________

Signature: Date:

________________________________________

Facilitator (Print):

________________________________________

Signature: Date:

________________________________________
Focus Group Participant Information Form

Please fill out this form by circling the correct answer or writing in the required response. Please note that this information is not associated with your name, minimizing the possibility of anyone knowing your answer.

1. Are you responding to this for:
   a. Self
   b. Child
   c. Youth
   d. Spouse/Partner
   e. Friend
   f. Other:

2. Are you or the individual you are responding for receiving mental health services?
   a. Yes, I/they are receiving mental health services now
   b. No, I/they have never received mental health services
   c. I/they used to receive mental health services, but are no longer

3. What is your zip code?

4. What age group do you represent? If you are reporting for another person or child, please use their age):
   a. 0-5
   b. 5-11
   c. 12-18
5. **How do you identify your race and ethnicity? Please check all that apply.**

   a. African American/Black/Person of African Descent
      
      What country or ethnicity? _____________________________

   b. Asian/Asian American
      
      What country or ethnicity? _____________________________

   c. White/European American
      
      What country or ethnicity? _____________________________

   d. Latino/Hispanic/Chicano
      
      What country or ethnicity? _____________________________

   e. Middle Eastern
      
      What country or ethnicity? _____________________________

   f. Native American/American Indian/Alaska Native
      
      What Tribe? _____________________________

   g. Native Hawaiian or other Pacific Islander
      
      What country, territory, or ethnicity? _____________________________

   h. Other - Please describe:_______________________________________

Please use this space to write anything that would help us better understand how you identify your race and ethnicity.
6. How do you identify your gender? Please check all that apply.
   a. Male
   b. Female
   c. Intersex
   d. Transgender
   e. Transsexual
   f. Transman
   g. Transwoman
   h. Two spirit

   Please use this space to write anything that would help us better understand how you identify your gender identity.

7. How do you identify your sexual orientation? Please check all that apply.
   a. Lesbian
   b. Gay
   c. Bisexual
   d. Pansexual
   e. Queer
   f. Questioning
   g. Straight/heterosexual
   h. Two spirit

   Please use this space to write anything that would help us better understand how you identify your sexual orientation.
8. Would you consider yourself or your family immigrants or refugees?

**Immigrants** move on their own volition because they want to relocate. They relocate for the promise of better economic condition, education, or family reasons. **Refugees** usually cannot return to their own country. They move out of fear or necessity. They are forced to relocate for reason such as fear of persecution due to war, religion, or political opinion, or because their homes have been destroyed in a natural disaster.

a. Immigrants     ____yes     ____no     ____not sure

b. Refugees      ____yes     ____no     ____not sure

If so, approximately how many years have you or your family been living in the United States?  ________ years

9. Are you fluent in a language other than English?  ____yes  ____no

If yes, which language(s)?________________________________

10. Do you or the person you are responding for have a mental health diagnosis?

    a. Yes
    
    b. No

11. If you or the person you are responding for has a mental health diagnosis, please indicate below:

    a. Depression
    
    b. Bipolar disorder
    
    c. Anxiety disorder
    
    d. ADHD
    
    e. Schizophrenia
    
    f. Post-Traumatic Stress Disorder
    
    g. Other (please specify)
SDR Focus Group Checklist

☐ Host before March 15, 2015;

☐ Identify the place and time that will be convenient and most supportive to target population attendance;

☐ Ensure that the location and process is ADA Compliant;

☐ Notify Sireyia of the date, time, and location of the group no less than one week prior to the event;

☐ Implement an outreach effort that will yield at least 10-15 participants that are a representation of the population(s) you serve;

☐ Document outreach efforts, where outreach occurred, how many individuals were invited, and the response to these efforts;

☐ Adjust necessary components of the process and questions to ensure relevance to the participant population;

☐ Make translation arrangements when warranted;

☐ Prepare necessary papers such as the Consent Forms (Attachment 1) and Participant Information Forms (Attachment 2);

☐ Facilitate the Focus Group in a manner that is best suited for the audience;

☐ Document responses;

☐ Submit consent forms to UACF for safe storage; and

☐ Submit notes (in Word, not a PDF) and Participant Information data from the Focus Group using The Reporting Form no later than ONE WEEK AFTER THE FOCUS GROUP DATE to Sireyia at sratliff@uacf4hope.org.
## Focus Group Event Reporting Form

<table>
<thead>
<tr>
<th>Name of Host Agency:</th>
<th>Date of FG:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact Person:</td>
<td>Phone Number:</td>
</tr>
<tr>
<td>Facilitator</td>
<td>Phone Number:</td>
</tr>
<tr>
<td>Location of Event:</td>
<td></td>
</tr>
<tr>
<td>Target Audience:</td>
<td></td>
</tr>
<tr>
<td>(Please describe your targeted audience, i.e. families, professionals, youth, diverse cultures, under represented populations, etc.)</td>
<td></td>
</tr>
<tr>
<td>Date UACF was notified:</td>
<td></td>
</tr>
</tbody>
</table>

### How was the outreach and marketing for the event accomplished?

<table>
<thead>
<tr>
<th>Email</th>
<th>List Serve</th>
<th>Phone Calls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited by provider</td>
<td>Posters</td>
<td>Other (describe):</td>
</tr>
</tbody>
</table>

### How many total individuals were invited:  
How many individuals attended?

### What supports were provided to ensure participation?

<table>
<thead>
<tr>
<th>Transportation</th>
<th>Meal</th>
<th>Other (describe):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite Care</td>
<td>Translator</td>
<td></td>
</tr>
</tbody>
</table>
Refreshments          Stipend

**Focus Group Notes:**

Start Time:

End Time:

Number of Consent Forms distributed:

Number of Consent Forms collected:

Please type notes from the Focus Group in the appropriate section below. Please do not provide lengthy narrative, but instead report in bullet form. We are interested in ideas, not quotes or exact words.

**Question #1: What does mental health stigma and discrimination mean to you?**

Alternative questions used (Please list):

Participant Responses:

**Question #2: Have you ever experienced stigma or discrimination because of your or a family members mental illness or mental, emotional, or behavioral disorder? Please share (if you are comfortable) that experience with us.**

Alternative questions used (Please list):

Participant Responses:

**Question #3: Why do you think stigma and discrimination of those with mental illness and mental, emotional, and behavioral disorders exists?**

Alternative questions used (Please list):
Participant Responses:

Question #4: Please describe any stigma and discrimination reduction activities and programs that exist in your area? This might be a program or person who is teaching others why stigma and discrimination is bad or it may be someplace you can call to get help if you feel stigma or discrimination has occurred.

Alternative questions used (Please list):

Participant Responses:

Question #5: If you had a magic wand and you were asked to create a new CA mental health environment, free of stigma and discrimination, how would that look (where money, laws, politics, or other barriers are not allowed to interfere with the magic of the vision)?

Alternative questions used (Please list):

Participant Responses:

Were there any other issues or needs discussed that you would like to report that do not fall within the above questions? Describe.

Did you have any difficulties or challenges in hosting and facilitating this Focus Group? Describe.