

Telling Our Stories:

An ethnographic examination of mental illness and recovery in communities of color

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Background

Over the last few years, the National Alliance of Multi-ethnic Behavioral Health Associations (NAMBHA) has been working on several projects to create greater understanding regarding disparities in public mental health care that exist within communities of color. In addition, NAMBHA has been recommending and testing strategies that might alleviate these inequalities and disproportionate outcomes and impacts.

NAHMBA has established that disparities in mental health care are multi-dimensional, and are maintained through both systemic and community barriers to care. Systemic barriers to mental health care in these communities include the lack of a culturally and linguistically diverse workforce, the lack of cultural competence in organizational structures and services, and the lack of adequate insurance coverage for many groups. Within many communities of color, mental health is viewed with great stigma. Negative attitudes and



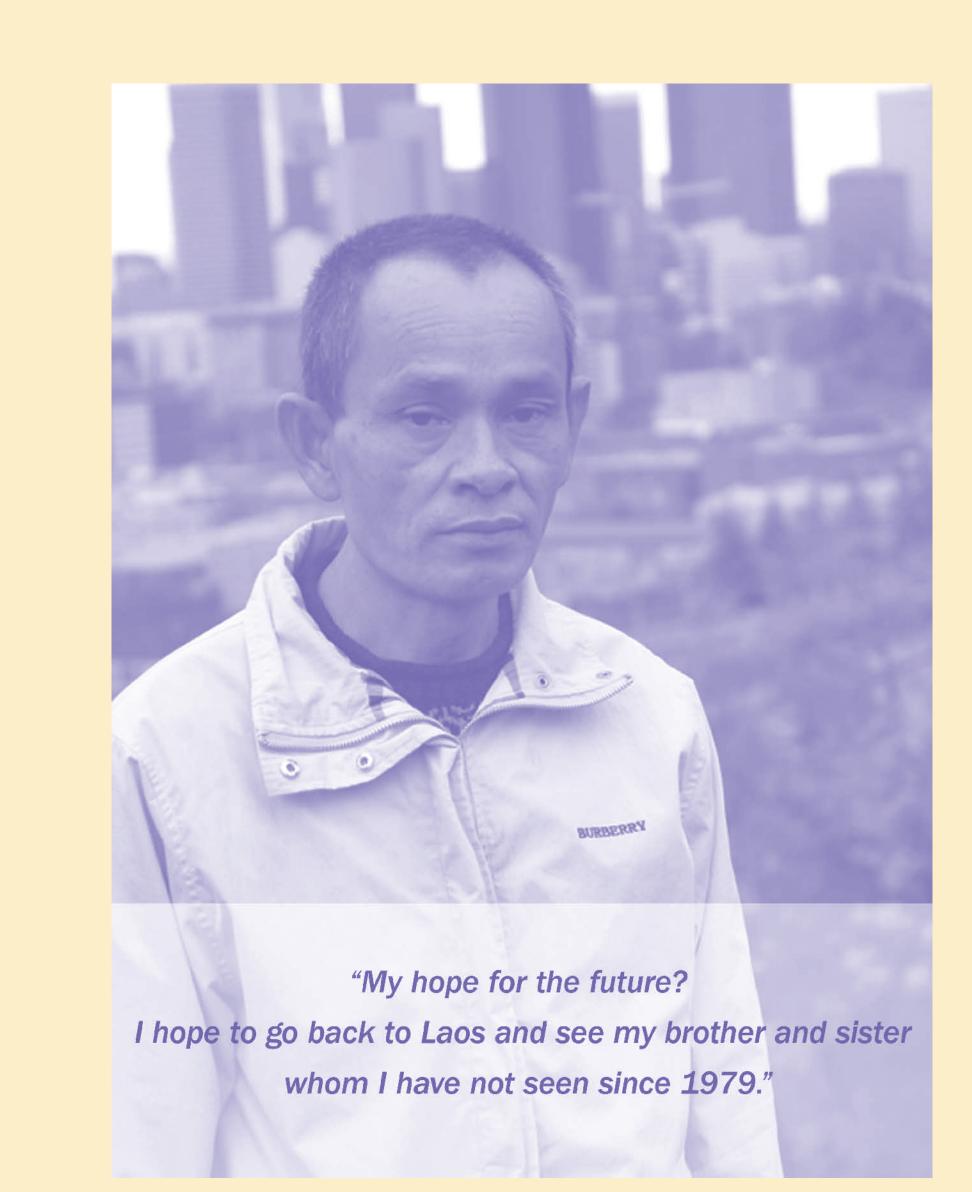
"I felt like a rag doll tossed around this way and that way as a child and through my recovery.

I find strength in the people around me.

My faith in God helps me get through the rough times.

My recovery means living life the way I want on every level."

perceptions, coupled with limited knowledge of recovery, are contributing factors to poor health outcomes. The goal of the NAHMBA and Westat "Telling Our Stories" Project is to collect the experiences of ethnic group consumers to be used as outreach, engagement, and educational tools. Effective strategies must address both



systemic and community barriers. The stories will be discussed in a way that resonates with others in their communities – putting a more personal face on the struggle to live with mental illness. The multiple audiences of this project include consumers, service providers, policy makers and the community at large.

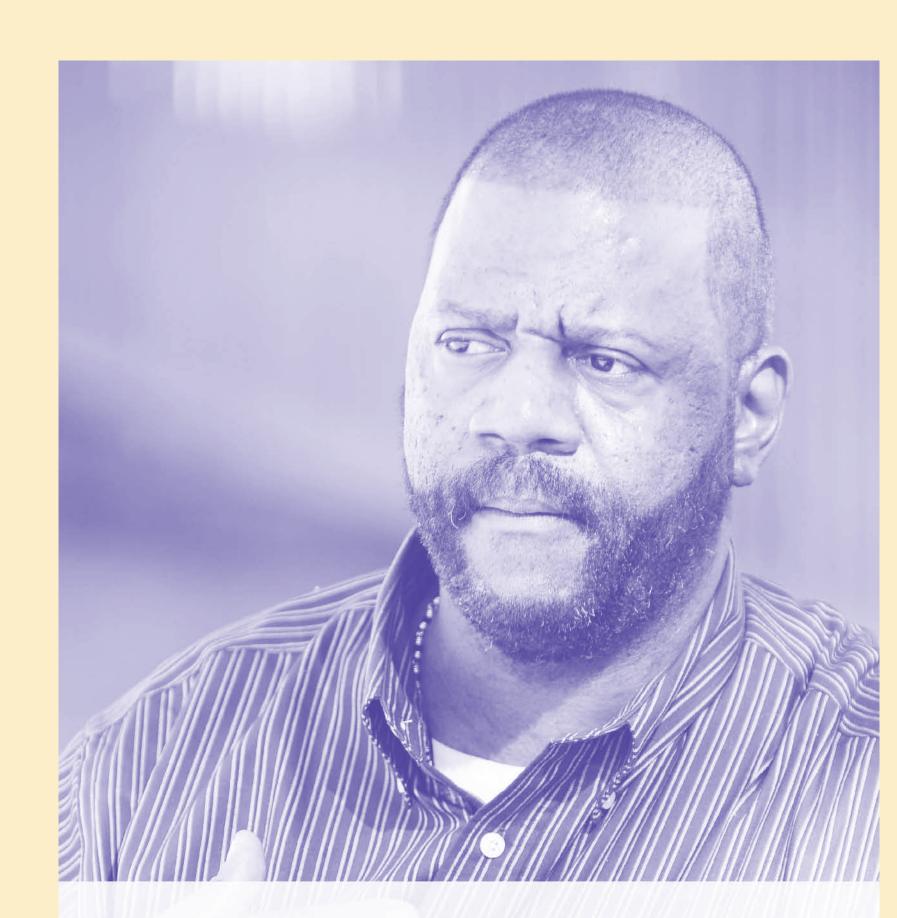
Objectives

- Demonstrate how consumers of mental health services can use stories in their own voice to present a respectful, culturally sensitive and unique perspective on mental health problems that raises the consciousness of how culture, language, historical trauma, social economic status, and other related issues impact mental health systems in communities of color and the importance of providing culturally and linguistically competent interventions.
- Discuss how opportunities for dialogues and discussions within communities of color can be facilitated so that some of the myths, mistrust, stigma and shame of coping with mental illnesses can be informed by education and greater community awareness.
- Explain how the selected format can be used as a training tool for students in the social sciences and related mental health areas

and professionals so that they gain a better understanding of what is helpful and how different ethnic groups define, experience, and recover from a myriad of mental health problems.

Methods

The best way to understand mental illness is through the stories of persons whose journey of hope and recovery are told using their words and their images. Members of NAMBHA's affiliate organizations had the primary responsibility for identifying potential consumer storytellers by contacting community-based organizations and consumer group organizations (i.e. local National Alliance for the Mentally III chapters, local Mental Health America chapters, etc.) that provide services and supports within their respective communities. In order to capture 5-6 stories from each community, the NAMBHA affiliates were

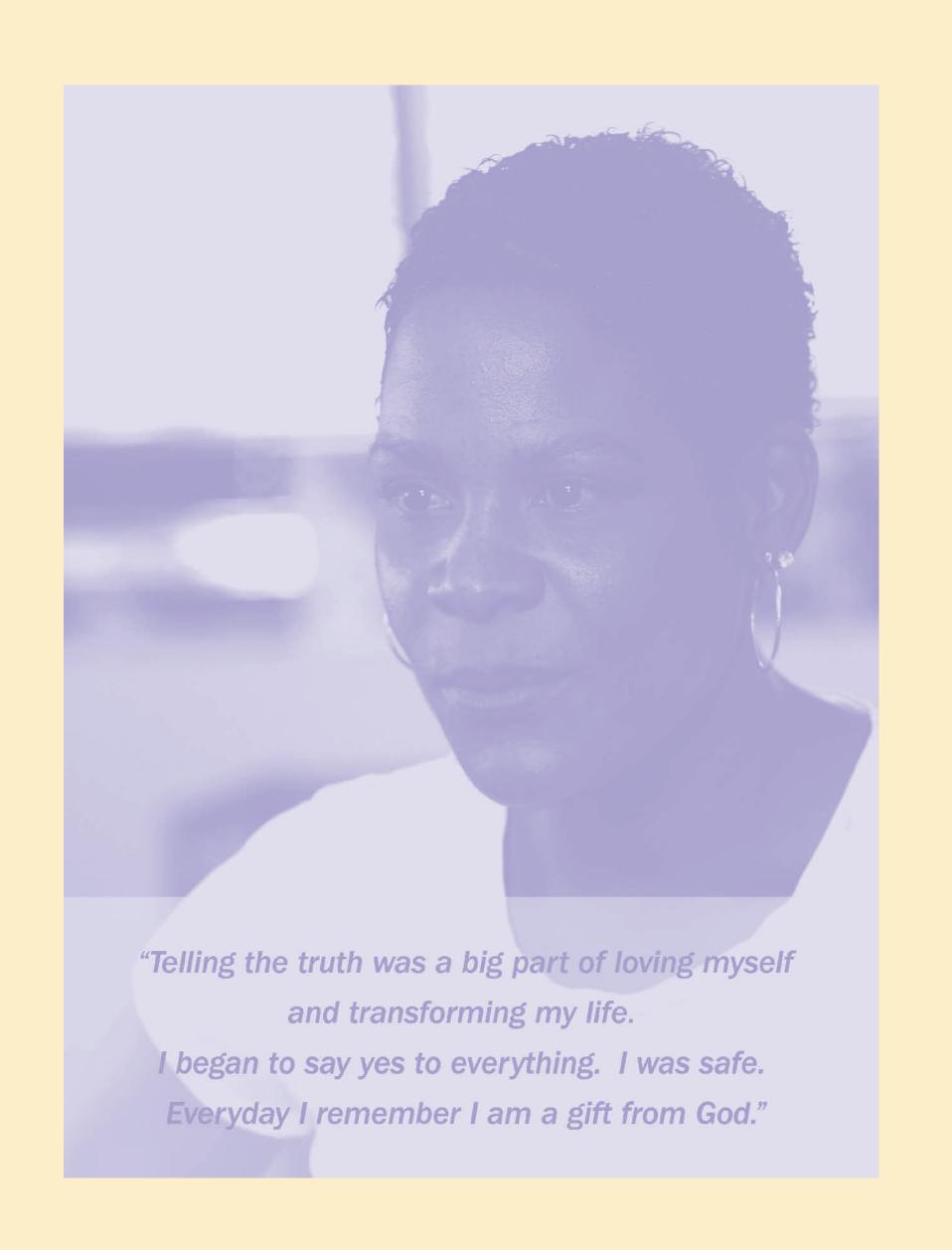


"Through my recovery I became more humble, more understanding. My recovery is my life.

It's the best thing I got going for me."

asked to identify and pre-select ten individuals. While many individuals had compelling stories, only those who were comfortable sharing their stories orally and who were willing to participate in the narrated photo collection were accepted. The pilot for the Telling Our Stories Project provides an insight into the lives of four African Americans and four Asian Americans. They are Stella Ho, Sunny Kwan, Khoune Souriyavongsa,

and Ben Wong. In order to capture a range of geographic areas, people where interviewed from New York, Seattle, Los Angeles, Baltimore, and Washington D.C. Some of them were American born, and some were foreign born, who have lived here for generations or who had just immigrated to this country as adults. The people in the stories had major diagnosis that included major



depression, schizophrenia, schizoaffective and anxiety disorders. They have followed different paths but collectively have had to navigate their way through a system that fails to recognize the importance of historical trauma, culture or language in the provision of competent services.

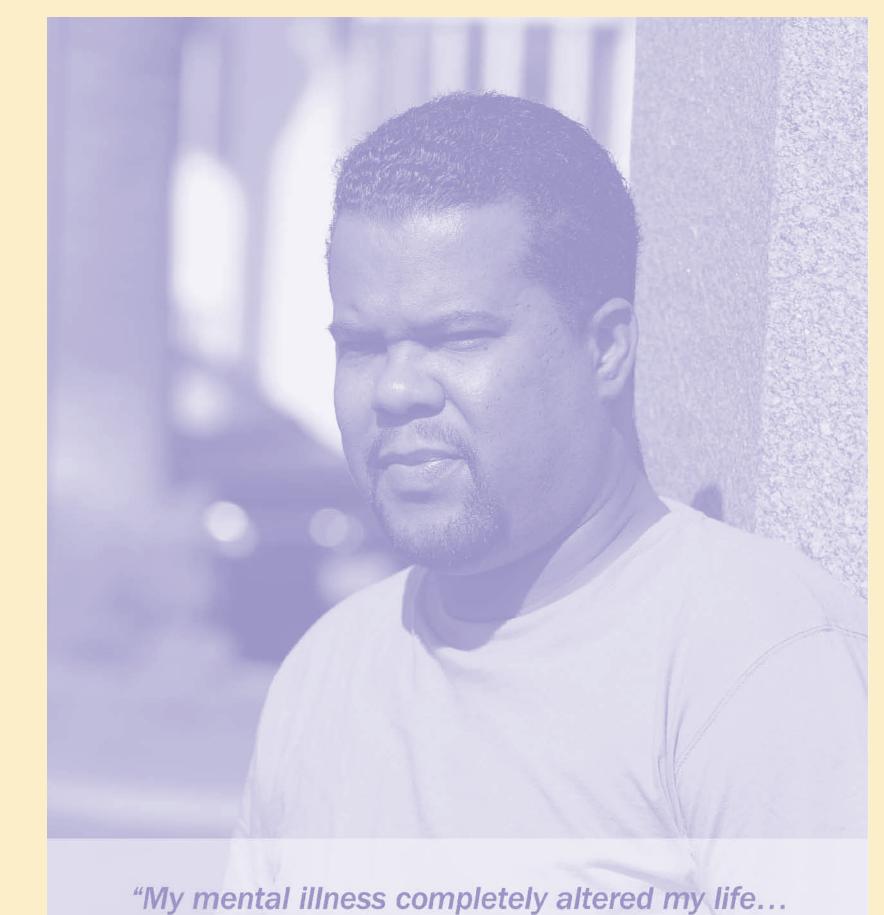
The process of developing the stories began with the creation of questions and interview protocol. The interviews were qualitative in nature, and the set of questions were developed and approved by Westat's Institutional Review Board. The interviewers all have prior experience and training in conducting clinical and/or qualitative interview processes, and were briefed regarding the intent of the interview protocol. Certain questions were used to guide the development of the narrative as well as the types of images that can help illustrate the individual's journey of recovery. Questions that that might serve as a catalyst for discussion included:

- The journey how did person get from there to here
- What were supports on their road to recovery
- How did they view their problems, how was it viewed by family and others
- What was involved in journey challenges, opportunities, obstacles, setbacks
- Where did they find their strength
- Illuminate the human aspect of mental illness –WHO are you, not WHAT are you

All of the interviews were analyzed and reviewed to extract common themes and messages. The photographs and audio passages were edited using the core themes. The results of the interviews were presented in photograph format. Photography was chosen because it is economical, can be done at multiple sites simultaneously, and can be easily used by the consumers themselves. In addition to the photographs, the consumers created voiceovers as their pictures flash across the screen, so that their stories were heard as well as seen. This will gave weight to the images and provided another opportunity to make sure the stories were told as the individuals wished it to be.

Results

A total of 8 stories, comprising Asian American/ Native American/Hawaiian/Pacific Islanders and the African American communities were captured. There was consensus that the consumer should be the driving force behind the project. They had the opportunity to portray their world as they saw it. This included taking pictures themselves or recommending persons, places and things that reflect who they are, the journey they have taken and images that gives insight into where they've been and see themselves going.



in a good way.

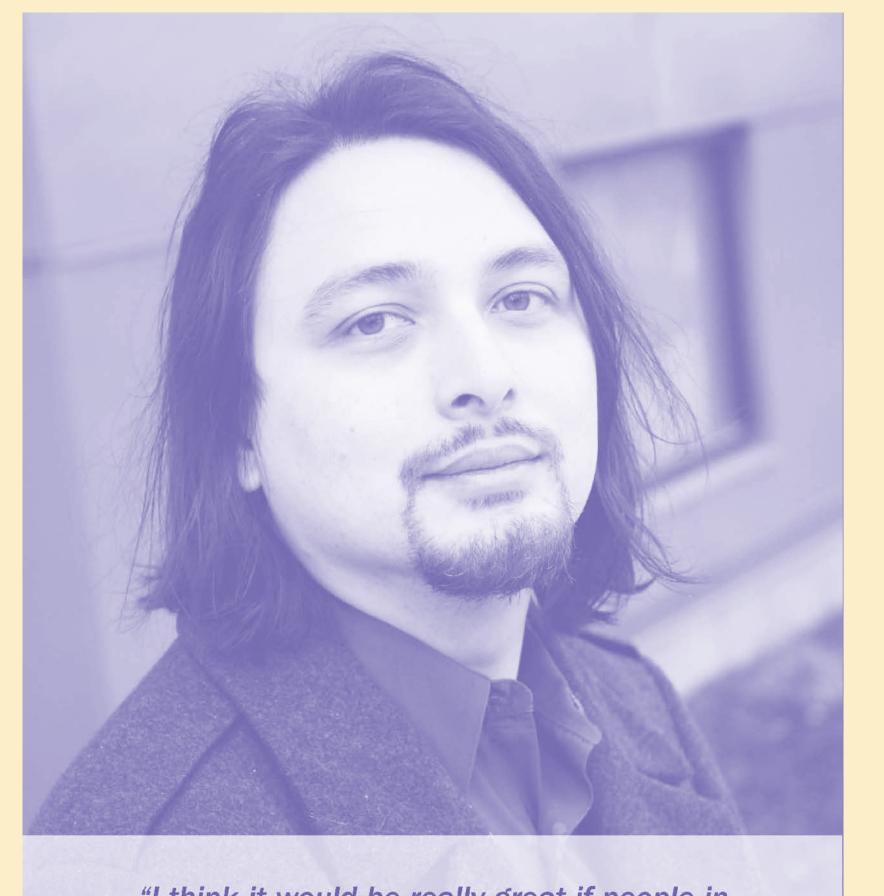
15 years ago, I saw a superstar, a movie star, a rap star...

Today I see a father, a creator, a lawyer."

Conclusion The Telling Our Store

The Telling Our Stories project employed strategies and tools to convey the message that mental health issues occur in all communities and that culture and language play an important role in helping people recover. This collection of narrated photo-stories allows consumers who have experienced mental health problems to talk about their journey. These stories put a more personal face on the struggle to live with mental illness and can be used as outreach, engagement and educational tools.





"I think it would be really great if people in our society understood about mental illness.

It is real, it isn't something someone makes up and people do get better."