



**nami**

**THE NATIONAL ALLIANCE FOR THE MENTALLY ILL**

# The Listening Project:

**Proceedings from  
A Dialogue between NAMI  
and Black Psychiatrists**

**Mental Illness Awareness Week  
October 7, 2002**

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## **Acknowledgments**

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We would also like to extend a special thank you to author, journalist, Mom, and family member Amy Alexander for her tireless efforts at combing through the transcripts and helping us to extricate and authentically present the recommendations made by forum participants.

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## **Introduction**

On October 7, 2002, NAMI's Multicultural and International Outreach Center convened a meeting to open a dialogue with leading Black Psychiatrists based in the U.S. The purpose of the meeting, according to NAMI director, Dr. Rick Birkel, was to build a stronger NAMI. Dr. Birkel explained:

“If NAMI is going to be effective, we have to be a stronger organization, and part of that strengthening is obviously to become more diverse, to reach out to communities that have experiences that we can learn from, that may have strategic agendas we can cooperate with.

So, the goal today is to determine if there are opportunities for NAMI to work with leaders in the African-American community -- of all sectors, starting with psychiatry...to help us understand what our possibilities are, perhaps how we might proceed. We're really looking for allies.”

Darlene Nipper, director of the Multicultural and International Outreach Center, introduced a “fishbowl” structure to the proceedings, in which first NAMI community members (including board, staff and consumers) and then the attending psychiatrists sat in a circle and answered key questions posed by a team of facilitators. In each session, participants sitting outside the fishbowl listened to issues raised. At the end of each fishbowl, listeners were encouraged to ask questions to clarify points. In this manner, critical issues were defined by both NAMI insiders and by leading African American psychiatrists for future engagement.

The following excerpts and summarizes the issues raised and recommendations offered during the psychiatrists' fishbowl session. Verbatim transcripts and a transcription of notes taken during the full session are available. The purpose of this document is to thoughtfully present the issues raised by some of this country's leading African American

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mental health professionals – to illuminate their viewpoints on how to create, as Dr. Birkel proposed, strategic agendas that will both strengthen NAMI and improve the quality of life and standard of care for Black Americans living with mental illness and their families.

Recommendations by the participants fall loosely into two categories: those that focus on NAMI as an organization and the work that needs to be undertaken internally to make NAMI more accessible to the Black community and those that focus more broadly on disparities in care faced by Blacks and how NAMI and others can work to improve quality of care for Black people with mental illness in the US.

### **Internal Recommendations.**

#### **1. NAMI should be more visible in Black and other communities of color.**

Participants made several concrete suggestions about how NAMI might make immediate contributions to heightening the visibility of both the organization and issues of mental illness in Black communities. These included:

- Acknowledge and collaborate with Black focused organizations/leaders that appropriately address mental illness.
- Create connections/programs between NAMI chapters, Black mental health professionals, and Black churches.
- Craft messages that are culturally appropriate and acknowledge the myriad barriers to addressing and treating mental illness in Black communities (more on this below).

#### **2. NAMI should make a commitment to focus on cultural diversity for the long haul.**

Many participants related experiences of working with white-dominated organizations that paid lip-service to issues of cultural diversity during a moment when it was critical or “popular” for that particular group. Too quickly, this interest evaporated, reinforcing a history of distrust and disconnect between the Black community and communities in power.

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Participants pointed to NAMI's *Decade of the Brain* as a long-term strategy and commitment that made revolutionary changes in the way the public perceives mental illness. *Decade of the Brain* focused critical attention on the role of biology in the development of mental illnesses. One participant suggested that a commitment to a *Decade of Culture* might similarly redefine how cultural factors, such as racism, contribute to mental illness, and raise issues of the importance of cultural competency in providing care and treatment in communities of color.

A highly visible, long-term commitment of this magnitude would put organizational resources and will behind NAMI's stated intentions to address disparities in care faced by culturally diverse consumers and family members.

**3. NAMI should broaden its membership base to be more inclusive of African Americans and other people of color.**

Two concurrent strategies were suggested in this vein. First, in some communities, there will be clear opportunities to create Black chapters of NAMI. In others, existing chapters can be expanded to integrate a significant Black membership and leadership. NAMI needs to identify these opportunities and proceed immediately to expand its Black membership base.

**4. NAMI must demonstrate leadership in addressing racism by encouraging internal discussion about how racism affects mental health and by dedicating resources to training in cultural competence.**

The disconnect that African American people experience between their community mores, values, and modes of communication and those they experience when interacting with the mental health system creates a monumental barrier to treatment and care. NAMI must begin to address this barrier by demonstrating its understanding of the key role cultural competence plays in meeting the needs of Black people with mental illness and their families.

A first step on this path is to initiate discussion within NAMI about the connection between racism and mental illness in communities of color. Black people are subject to a system of institutionalized racism from which many mental health issues flow. NAMI must devise ways to introduce dialogues at the national office and within its chapter structure and to both acknowledge the long-standing and long-range impact of racism on Black mental health and to integrate solutions into the fabric of NAMI's goals and mission. As an organization that has focused (with good reason) on the biological roots of mental illness, moving into a discussion of the how mental health is impacted by social relationships, historic and present-day oppression, and expectations that are bounded by racism, presents new and perhaps daunting challenges. However, NAMI's willingness to acknowledge and illuminate the complexities of the construction of mental illness will signal its readiness to take on issues that are pivotal to the health of the Black community.

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A second key step would be to require all NAMI officers, board members and chapter leaders to attend and complete workshops on cultural competency. These workshops help participants uncover and consider the institutional (rather than personal) nature of racism, and to consider how structural barriers affect NAMI's ability to attract, retain and serve people of color within the NAMI membership, board and staff.

By nurturing the NAMI leadership's awareness of institutional racism, and by initiating a process whereby that leadership can consider strategies to address structural racism, as well as deepen its understanding of how institutional barriers (historic and current) exacerbate cultural gaps in communication, NAMI can move toward cultural competency. This essential "uncovering" process is the key to creating authentic, dynamic cross-racial alliances (as opposed to opportunistic or superficial connections), and ultimately, a fully multicultural organization and leadership.

Cultural competency training is a cornerstone in a foundation of trust and meaningful coalition-building. By moving beyond historic barriers, addressing present-day structural inequities, and embracing the richness of divergent viewpoints and distinct cultures, the NAMI organization will emerge fully accessible to the African American community, and provide a model for NAMI to propose to other mental health advocacy groups and providers in addressing disparities in care for racial and ethnic minorities.

## **5. NAMI should build a diverse leadership.**

The first step in building a diverse leadership is agreeing on a working definition of the over-used term, "diversity." Participants offered a two-pronged definition. First, diversity means securing representation from a variety of groups in terms of race, ethnicity, gender, socio-economic status, etc. And second, diversity entails securing a wide range of skills within the organization to better serve the varied communities that NAMI hopes to call its core constituency.

Accordingly, NAMI must take concrete steps to increase African American leadership within the organization at all levels – including board, staff and chapter leadership.

## **External Recommendations.**

### **1. Focus on building mental health as well as treating mental illness.**

Participants agreed that an Afrocentric tradition of building mental health has been lost in the systematic dismemberment of the Black community. Finding ways to engage in open discussions with Black people about traditional, holistic strategies in maintaining mental health is a culturally powerful, organic approach to raising the issue of mental illness in Black communities.

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One caveat that was expressed: pursue this path with an openly expressed acknowledgement that serious mental illness exists in Black communities and must be addressed.

**2. Increase and improve treatment facilities or approaches that Black people can actually use.**

Participants noted the following:

- In most Black communities there are few accessible mental health service providers and even fewer that are run by and delivered by African-Americans.
- What role can NAMI play in increasing and improving Black-defined services?
- One outcome of this dearth of resources is that Black children's mental illnesses go overlooked and untreated, and then their presenting issues as adults are much more serious, costly, and often involve the criminal justice system.

**3. Address the issue of the disproportionate criminalization of Black people with mental illness.**

Participants made suggestions on two fronts to address this issue:

- Increase community-based health care options and address other access to care issues (outlined above) so that Black people with mental illness are identified and treated on the "front end."
- Establish chapters or partnerships within the corrections system to improve the standard of treatment for those living with mental illnesses in prison.

**4. NAMI should re-open the discussion in the mental health care community (i.e., work with medical doctors, psychiatrists, psychologists, etc.) about the connection between racism and mental health.**

Participants noted that in 1969, Black psychiatrists reported that racism was the number one mental health problem and the number one cause of other serious mental health problems within the Black community (and beyond). Today, mental health professionals are discredited for talking about racism within this framework, and there's been a shift away from talking about racism as a system of oppression and a cause of illness to discussions of such value-neutral concepts as "diversity."

NAMI must take on a role to re-open and re-invigorate a public discussion of the impact of racism on the mental health of Black people, and of all people within a culture deeply distressed by racism.

**5. Improve diagnosis of mental illness in African Americans**

Participants reported that racist constructions of Black identity severely impede appropriate mental health diagnoses. For example, one participant noted that racist perceptions of Black people as inherently violent, as inherently unable to have stable families, and as unable to nurture community lead practitioners to find no illness to



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treat. Other participants noted that Blacks tend to be over-diagnosed as psychotic paranoid, and under-diagnosed as depressed or bipolar. Still others noted that “paranoia” is a survival tool in a racist society that is pathologized in mental health settings, reinforcing Black distrust of the system.

NAMI could use its considerable platform to raise awareness about how racism creates barriers to both proper diagnosis and treatment for Black people with mental illness.

## **6. Articulate and promote issues important to the Black community as NAMI issues**

Participants noted that key mental health issues in the Black community are already key NAMI issues, but that NAMI has failed to articulate the specific ways in which racism creates a situation of double jeopardy for Black people with mental illness. One issue that illustrates this disconnect is criminalization. While NAMI is a powerful voice against the criminalization of persons with mental illness, the organization has not drawn attention to the plight of people of color with mental illness, who are at a far greater risk of incarceration than their white counterparts.

NAMI’s central mission – eliminating stigma concerning mental illness – offers another key opportunity. Reducing stigma and discrimination based on mental illness is absolutely critical to making mental health services accessible in Black communities because racist constructions of Black identity already place an enormous stigma burden on the community. NAMI’s messages about stigma and mental illness could illuminate the additional stigma racism poses for Black families trying to cope with mental illness.

NOTE: Participants noted that because of this fundamental need for Black families to protect their integrity, stigma of mental illness looms large in Black communities. This points to the help seeking behaviors of Blacks, who are much less likely than their white counterparts to seek appropriate treatment for mental illness. Participants noted a fundamental need for Black families to protect their integrity given the challenges of racism in the larger world. Mental illness is often experienced as an additional threat to family safety and integrity. And while the stigma of racism makes treatment and care of mental illness less accessible across the board, it most certainly results in the under-treatment of children of color with mental illnesses.

## **7. Strategize about ways to diminish the African-American “brain drain” within the health care community.**

The process of cultural assimilation in America entails that people of African descent who are trained professionals are encouraged to devote their energies and expertise toward institutions that serve a “broad based” constituency, which generally means institutions that are Eurocentric of origin, with a white-dominated leadership base. This kind of “brain drain” has meant that trained Black professionals are not employing their skills to build or improve structures of quality that have been defined

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or are directed by African Americans. At NAMI, there is an opportunity to cultivate a strong network of African-American mental health care professionals who are able or willing to devote at least a portion of their service specifically to improving mental health within institutions based in communities of color.

Participants also thought that NAMI might address the “brain drain” problem by undertaking policy positions that would facilitate increased resources and funding for Black community-based mental health institutions and programs.

### **Conclusion.**

NAMI’s stated goal of becoming a truly diverse organization represents a great challenge. Its attempt must begin internally, with a concerted effort to bring all NAMI officers, staffers, board members and chapter presidents to agreement on two key points: that racism – in American history as well as in modern times – plays a role in the mental health of all citizens. The organization must also agree on a definition of diversity, and to a commitment to making NAMI a top-down diverse organization. Initially, this might involve revisiting the NAMI mission statement or other NAMI vision/planning documents, to consider language describing the organization’s commitment to increasing the public’s awareness of the link between racism and mental health, and to underscore NAMI’s commitment to the improved mental health of communities of color.

After building consensus internally about the critical value of building a diverse organization, NAMI must move to expand on its existing network of NAMI members who are Black, Latino, Asian, Native American, Arab, etc. There is a dire need to increase the ranks of people of color within the NAMI membership, as well to recruit and retain people of color to serve on the NAMI staff, board and chapter leadership.

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Externally, NAMI must demonstrate its commitment to addressing disparities in care by shifting its resources and advocacy to address key issues facing the Black community, such as (but not limited to) the disproportionate criminalization of Black people with mental illness; the connection between racism and mental health in communities of color; the double jeopardy that racism and mental illness poses to Black families seeking care in terms of stigma; and the tremendous need to create community-based care options that are situated within and staffed by Black communities.

Along these lines, NAMI must actively seek partnerships and affiliations with traditional social service organizations in Black communities – churches, schools, fraternities and sororities. Non-traditional venues – prisons, jails, drug rehabilitation programs, youth guidance groups – must also be targeted as entry points for raising NAMI’s profile among Black families in need.

In conclusion, as one of the participants at the Oct. 7 meeting observed, NAMI’s challenge is staggering. Yet, given the organization’s hard-earned reputation as a reliable, effective advocate for the nation’s mentally ill, success is guaranteed, as long as the will exists.

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