

African American Outreach Resource Manual



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Message from Margaret Stout President NAMI Board of Directors

Recent research points to significant disparities in health care for African Americans in the United States. These studies conclude that mental health outcomes for this population are far bleaker than outcomes for Caucasians. According to researchers at Harvard University, in areas raging from diabetes to mental health, African Americans receive WORSE medical care than their white counterparts. That study, released March 13, 2002 in the Journal of the American Medical Association, concluded that the largest gaps in the delivery of quality care were found in the mental health arena. According to the report, blacks released from inpatient mental health care received follow-up care 33 percent of the time, compared with 54 percent for whites. This data as well as data from the Surgeon General's 2001 Report, *Mental Health: Culture, Race and Ethnicity*, address one of the most unfortunate realities of our time: African Americans, and other communities of color in the United States, face significant barriers to quality mental health care.

One of the guiding principles driving the work of NAMI organizations at the national, state, and local levels is improving access to treatment for individuals and families affected by mental illness. Therefore, it is only appropriate for NAMI to develop strategies that will address the many barriers faced by African Americans.

The purpose of this manual is to provide valuable information about the current mental health status of the African American community and resources for NAMI and other organizations who want to engage this community in a meaningful and culturally appropriate manner. On behalf of the NAMI Board of Directors, I want to thank our African American NAMI leaders for all OF their work and dedication. Their commitment and hard work truly makes us the Nations Voice on Mental Illness.

Margaret Stout

President

NAMI National Board of Directors



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Chapter 1

Mental Health Status of the African American Community

In April 2002, president George W. Bush established the President's New Freedom Commission on Mental Health to eliminate inequalities in mental health care. The Commission was charged with identifying policies to improve public mental health systems at federal, state and local levels in order to maximize existing resources, improve coordination of treatments and services, and promote successful community integration for Americans with mental illness.

After analyzing both public and private mental health systems, the Commission released its final report: *Achieving the Promise, Transforming Mental Health Care in America*. The report finds America's mental health systems to be "in shambles," resulting in millions of Americans not receiving much needed mental health care. Furthermore, it calls for the transformation of our currently fragmented mental health services into a system focused on early intervention and recovery.

Recognizing the current bleak status of America's mental health systems, the report highlighted six goals and provided recommendations to improve mental health services for people with mental illness. Goal 3 in the Commission's final report is titled *Disparities in Mental Health Services Are Eliminated*. In describing this Goal the Commission said:

"Racial and ethnic minority Americans comprise a substantial and vibrant segment of the U.S. population, enriching our society with many unique strengths, cultural traditions, and important contributions. As a segment of the overall population, these groups are growing rapidly; current projections show that by 2025, they will account for more than 40% of all Americans.

Unfortunately, the mental health system has not kept pace with the diverse needs of racial and ethnic minorities, often underserving or inappropriately serving them. Specifically, the system has neglected to incorporate respect or understanding of the histories, traditions, beliefs, languages, and value systems of culturally diverse groups. Misunderstanding and misinterpreting behaviors have led to tragic consequences, including inappropriately placing minorities in the criminal and juvenile justice systems.

While bold efforts to improve services for culturally diverse populations currently are underway, significant barriers still remain in access, quality, and outcomes of care for minorities. As a result, American Indians, Alaska Natives, **African Americans**, Asian Americans, Pacific Islanders, and Hispanic Americans bear a disproportionately high burden of disability from mental disorders. This higher burden does not arise from a greater prevalence or severity of illnesses in these populations. Rather it stems from receiving less care and poorer



quality of care."

This chapter provides an in-depth analysis of the barriers to treatment acknowledged by the Commission.

Mental Health: Culture, Race, and Ethnicity. A Supplement to Mental Health: A Report of the Surgeon General. U.S. DHHS. Chapter 3 -Mental Health Care for African Americans

Introduction

African Americans occupy a unique niche in the history of America and in contemporary national life. The legacy of slavery and discrimination continues to influence their social and economic standing. The mental health of African Americans can be appreciated only within this wider historical context. Resilience and forging of social ties have enabled many African Americans to overcome adversity and to maintain a high degree of mental health.

Approximately 12 percent of people in the United States, or 34 million people, identify themselves as African American (U.S. Census Bureau, 2001a). However, this figure may be lower than the actual number, because African Americans are overrepresented among people who are hard to reach through the census, such as those who are homeless or incarcerated (O'Hare et al., 1991). Census takers especially miss younger and middle-aged African American males because they are overrepresented in these vulnerable populations and because they often decline to participate in the census (Williams & Jackson, 2000).

The African American population is increasing in diversity as greater numbers of immigrants arrive from Africa and the Caribbean. Indeed, 6 percent of all blacks in the United States today are foreign-born. Most of them come from the Caribbean, especially the Dominican Republic, Haiti, and Jamaica; in 1998, nearly 1.5 million blacks residing in the United States were born in the Caribbean (U.S. Census, 1998). In addition, since 1983, over 100,000 refugees have come to the United States from African nations.

Historical Context

The overwhelming majority of today's African American population traces its ancestry to the slave trade from Africa. Over a period of about 200 years, millions of Africans are estimated to have been kidnapped or purchased and then brought to the Western Hemisphere.

Ships delivered them to the Colonies and later to the United States (Curtin, 1969). Legally, they were considered chattel—personal property of their owners. By the early 1800s, most Northern States had taken steps to end slavery, where it played only a limited economic role, but slavery continued in the South until the Emancipation Proclamation in 1863 and passage of the 13th Amendment to the U.S. Constitution in 1865 (Healey, 1995).

The 14th Amendment (1868) extended citizenship to African Americans and forbade the States



from taking away civil rights; the 15th Amendment (1870) prohibited disfranchisement on the basis of race. However, these advances did not eliminate the subjugation of African Americans. The right to vote, supposedly assured by the 15th Amendment, was systematically denied through poll taxes, literacy tests, grandfather clauses, and other exclusionary practices. Racial segregation prevailed. Many Southern State governments passed laws that became known as Jim Crow laws or "black codes," which reinforced informal customs that separated the races in public places, and perpetuated an inferior status for African Americans.

The economy of the South remained heavily agricultural, and most people were poor. Exploited and con-signed to the bottom of the economic ladder, most African Americans toiled as sharecroppers. They rented land and paid for it by forfeiting most, if not all, of their harvested crops. Some worked as agricultural laborers and were paid rock-bottom wages. With very low, irregular incomes and little opportunity for betterment, African Americans continued to live in poverty. They were kept dependent and uneducated, with limited horizons (Thernstrom & Thernstrom, 1997).

As late as 1910, 89 percent of all blacks lived in legalized subservience and deep poverty in the rural South. When World War I interrupted the supply of cheap labor provided by European immigrants, African Americans began to migrate to the industrialized cities of the North in the Great Migration. As Southern agriculture became mechanized, and as the need for industrial workers in Midwestern and Northeastern States increased, African Americans moved north in even greater numbers. Following World War II, blacks began to migrate to selected urban centers in the West, mostly in California.

Segregation continued until the early 1950s. Then in 1954, in Brown v. Board of Education, the Supreme Court declared racially segregated education unconstitutional. In the 1960s, a protest movement arose. Led by the 1964 Nobel laureate, the Rev. Dr. Martin Luther King, Jr., activists confronted and sought to overturn segregationist practices, often at considerable peril. New legislation followed. The Civil Rights Act of 1964 prohibited both segregation in public accommodations and discrimination in education and employment. The Voting Rights Act, passed in 1965, suspended the use of voter qualification tests.

While the African American experience in the United States is rife with episodes of subjugation and displacement, it is also characterized by extraordinary individual and collective strengths that have enabled many African Americans to survive and do well, often against enormous odds. Through mutual affiliation, loyalty, and resourcefulness, African Americans have developed adaptive beliefs, traditions, and practices. Today, their levels of religious commitment are striking: Almost 85 percent of African Americans have described themselves as "fairly religious" or "very religious" (Taylor & Chatters, 1991), and prayer is among their most common coping responses. Another preferred coping strategy is not to shrink from problems, but to con-front them (Broman, 1996). Yet another successful coping strategy is the tradition of turning for aid to significant others in the community, especially family, friends, neighbors, voluntary associations, and religious figures. This strategy has evolved from the historical African American experience of having to rely on each other, often for their very survival (Milburn & Bowman, 1991; Hatchett & Jackson, 1993).



African Americans have also developed a capacity to downplay stereotypical negative judgments about their behavior and to rely on the beliefs and behavior of other African Americans as a frame of reference (Crocker & Major, 1989). For this reason, at least in part, most African Americans do not suffer from low self-esteem (Gray-Little & Hafdahl, 2000). African Americans have a collective identity and perceive them-selves as having a significant sphere of collectively defined interests. Such psychological and social frame-works have enabled many African Americans to overcome adversity and sustain a high degree of mental health.

What it means to be African American, belonging to a certain race, can no longer be taken for granted. As noted in Chapter 1, racial classification based on genetic origins is of questionable scientific legitimacy and of limited utility as a basis for understanding complex social phenomena (Yee et al., 1993). Still, the category "African American" provides a basis for social classification. African Americans are recognized by their physical features and are treated accordingly. Many African Americans identify as African American; they share a social identity and outlook (Frable, 1997; Cooper & Denner, 1998). Scholars have defined and measured aspects of this sense of racial identity: its salience, its centrality to the sense of self, the regard others hold for African Americans, what African Americans believe about the regard others hold for them, and beliefs about the role and status of African Americans (Sellers et al., 1998).

Current Status

Geographic distribution

In spite of the Great Migration to the North, a large African American population remained in the South, and in recent years, a significant return migration has taken place. Today, 53 percent of all blacks live in the South. Another 37 percent live in the Northeast and Midwest, mostly in metropolitan areas. About 10 percent of all blacks live in the West (U.S. Census Bureau, 2001; see Figure 3-1). Nationally, 15 percent live in rural areas, compared to 23 percent of whites and 25 percent of Americans overall (Rural Policy Research Institute, 1997).

Many African Americans still live in segregated neighborhoods (Massey & Denton, 1993), and poor African Americans tend to live among other African Americans who are poor. Poor neighborhoods have few resources, a disadvantage reflected in high unemployment rates, homelessness, crime, and substance abuse (Wilson, 1987). Children and youth in these environments are often exposed to violence, and they are more likely to suffer the loss of a loved one, to be victimized, to attend substandard schools, to suffer from abuse and neglect, and to encounter too few opportunities for safe, organized recreation and other constructive outlets (National Research Council, 1993). Personal vulnerabilities are exacerbated by problems at the community level, beyond the sphere of individual control.

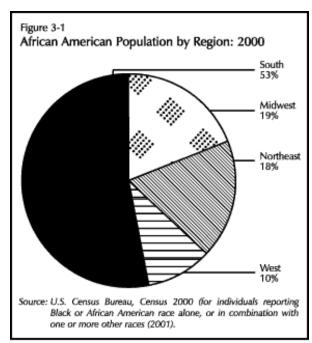


Figure 3-1 illustrates the African American population by region, based on data from Census 2000. It shows that the majority of African Americans live in the South, 19% live in the Midwest, 18% in the Northeast, and 10% in the West.

On the other hand, not all African American communities are distressed. Like other well functioning communities, stronger African American communities (both rich and poor) possess cohesion and informal mechanisms of social control, sometimes called collective efficacy. Evidence indicates that collective efficacy can counteract the effects of disabling social and economic conditions (Sampson et al., 1997). It also forms the foundation for community-building efforts (Bell & Fink, 2000).

Family structure

In 2000, there were approximately 9 million African American families in the United States. On average, African American families are larger than white families; (65% versus 54% of families had three or more members), but smaller than families from other racial and ethnic minority groups (76% had three or more members). On the other hand, many African American children grow up in homes with only one parent. Only 38 percent were living in 2-parent families compared to 69% of all children in the United States. For children who lived with one parent, African Americans were more likely to live with their mothers than were U.S. children overall (92% versus 69%)(U.S. Census Bureau, 2001c).

Those who study African American life have argued that these trends are offset by an extended family orientation that calls for mutual material and emotional support (Hatchett & Jackson, 1993). This perspective has found wide acceptance and is reflected in policies such as family foster care, where children and youth removed from their homes are placed with relatives. African Americans participate extensively in family foster care in numbers proportional to their representation in foster care in general (Berrick et al., 1994; Landsverk et al., 1996; Altshuler, 1998).

Increasingly, however, researchers have discovered gaps and limitations in extended family



support. Analyzing data from the National Survey of Families and Households, a large, community survey, Roschelle (1997) demonstrated that African American women were more likely than other women to provide assistance with child care and household tasks, but were less likely to receive such assistance in return. Respondents reported during in-depth interviews that levels of intergenerational support provided to teen mothers had waned (McDonald & Armstrong, 2001). They further indicated that several factors, including the youth of many grandmothers and the burden of problems brought on by urban poverty, had undermined supportive traditions.

Education

African Americans have shown an upward trend in educational attainment throughout the latter half of the 20th century. By 1997, there was no longer a gap in high school graduation rates between African Americans and whites. The number of African Americans enrolled in college in 1998 was 50 percent higher than the number enrolled a decade earlier. By 2000, 79 percent of Arican Americans age 25 and over had earned at least a high school diploma and 17 percent had attained a bachelor's or graduate degree. These rates are in comparsion to 84% and 26%, respectively, for Americans overall (U.S. Census Bureau, 2001c).

Income

When considered in aggregate, African Americans are relatively poor. In 1999, about 22 percent of African American families had incomes below the poverty line (\$17,029 for a family of 4 in 1999) but only 10 percent of all U.S. families did (U.S. Census Bureau, 2001c). The difference in poverty rates has shrunk over the past decade, however, and the socioeconomic distribution of African Americans has become increasingly complex.

At one end of the income spectrum, the official poverty rate may understate the true extent of African American poverty. African Americans are more likely than whites to live in severe poverty, with incomes at or below 50 percent of the poverty threshold; the African American rate of severe poverty is more than three times the white rate. Children and youth are especially affected; while the national poverty rate for U.S. children is nearly 20 percent, almost 37 percent of African Americans 18 and younger live in poor families (U.S. Census Bureau, 1999b). There is considerable turnover in the poverty population. Most of the poor move out of poverty over time but are replaced by others. African Americans move in and out of poverty, but their periods of poverty tend to last longer, making African Americans more likely than whites to suffer from long-term poverty (O'Hare, 1996).

African American families fall well below white families on an important measure of aggregate financial resources: total wealth. Net worth, the value of assets minus liabilities, is a useful indicator. The median net worth of whites is about 10 times that of blacks (U.S. Census Bureau, 1999a). This wide disparity reflects limited African American family assets, lower rates of home ownership, limited savings, and few investments (O'Hare et al., 1991). Because most are descendants of deeply impoverished rural agricultural workers, many contemporary African Americans can expect to borrow only modest sums from relatives and can expect only small inheritances. Most African Americans have little financial cushion to absorb the impact of the



social, legal, or health-related adversity that often accompanies mental illness.

African American poverty is associated with family structure. Despite historical patterns to the contrary and a slight reduction in recent years, African American children in particular, are especially likely to live in single-parent, mother-only families. This pattern reflects relatively low and declining marriage rates; the number of never-married African American adults almost equals the number of those who are married. Taking cohabitation into account reduces, but does not eliminate differences in the domestic partnership rates of African Americans versus other groups (Statistical Abstract of the United States, 1999).

The disparity in poverty rates affects older adults as well. Older African Americans are almost three times as likely as whites to be poor. The poverty rate among single African American women living alone or with non-relatives is very high (Ruiz, 1995). Older African American women are far more numerous than older African American men because of different mortality rates.

While many African Americans live in poverty, many others have joined the middle class. Between 1967 and 1997, African Americans benefited from a 31 per-cent boost in their real median household income, a raise that contrasts with an 18 percent increase for whites (U.S. Census Bureau, 1998). Nearly a quarter of all African Americans had incomes greater than \$50,000 in 1997, and the median income of African Americans living in married-couple households was 87 percent that of comparable whites. Almost 32 percent of African Americans lived in the suburbs (Thernstrom & Thernstrom, 1997).

Thus, in socioeconomic terms, the African American population has become polarized. Many African Americans are very poor and sometimes suffer an added burden from living in impoverished communities. African Americans, poor and nonpoor alike, possess relatively few financial assets. However, a large and increasing number of African Americans—more than once expected—have taken up well-earned positions in the middle class.

Physical health status

As a group, African Americans bear a disproportionate burden of health problems (DHHS, 2000a). Mortality rates until age 85 are higher for blacks than for whites (National Center for Health Statistics, 1996). Disparities in morbidity, too, are pronounced. The African American rate of:

- diabetes is more than three times that of whites:
- heart disease is more than 40 percent higher than that of whites;
- prostate cancer is more than double that of whites;
- HIV/AIDS is more than seven times that of whites (In the past decade, deaths due to HIV/AIDS have increased dramatically in the African American population, and this disease is now one of the top five causes of death for this group.);
- breast cancer is higher than it is for whites, even though African American women are more likely to receive mammography screening than are white women (DHHS, 2000a); infant mortality is twice that of whites.



The disparity in infant mortality rates, which are considered sensitive indicators of a population's health status, is particularly stark. It is not entirely accounted for by socioeconomic factors. Although infant mortality tends to decrease with maternal education, the most educated black women have infant mortality rates that exceed those of the least educated white women (DHHS, 1998).

High rates of African American HIV/AIDS pose special challenges related to mental health. HIV infection can lead to mental impairment, from minor cognitive disorder to full-blown dementia, as well as precipitate the onset of mood disorders or psychosis. Opportunistic infections, use of psychoactive substances associated with HIV infection, and adverse effects from treatment can gravely compromise mental functioning (McDaniel et al., 1997).

Disparities in access to appropriate health care partially explain the differences in health status. In 1996, about 76 percent of whites had an office-based usual point of care, which facilitates preventive and primary care treatment. This compared to only 64 percent of African Americans (Kass et al., 1999). Only 10 percent of African Americans, versus 12 percent of other Americans, made a visit to an outpatient physician in 1997; African Americans made 26 percent fewer annual visits than whites. African Americans are especially likely to obtain health care from hospital outpatient and emergency departments. In 1997, African Americans made about 22 percent of emergency department visits (U.S. Census Bureau, 1999b). As will be shown in the next section, the pattern of mental health treatment for African Americans is characterized by low rates of out-patient care and high rates of emergency care.

The Need for Mental Health Care

Historical and sociocultural factors that relate to mental health

Historical adversity, which included slavery, sharecrop-ping, and race-based exclusion from health, educational, social, and economic resources, translates into the socioeconomic disparities experienced by African Americans today. Socioeconomic status, in turn, is linked to mental health: Poor mental health is more common among those who are impoverished than among those who are more affluent (Chapter 2). Also related to socioeconomic status is the increased likelihood of African Americans becoming members of high-need populations, such as people who are homeless, incarcerated, or have substance abuse problems, and children who come to the attention of child welfare authorities and are placed in foster care. Members of these groups face special circumstances not fully explained by socioeconomic differences, however.

Racism is another aspect of the historical legacy of African Americans. Negative stereotypes and rejecting attitudes have decreased, but continue to occur with measurable, adverse consequences for the mental health of African Americans (Clark et al., 1999). Historical and contemporary negative treatment have led to mistrust of authorities, many of whom are not seen as having the best interests of African Americans in mind.

The overrepresentation of African Americans in the South, especially in impoverished rural



areas, is another result of history. Hardship in these communities is notable, and a limited safety net provides relatively few services to address high levels of mental health need (Fox et al., 1995).

Key issues for understanding the research

When seeking to explain differences between African Americans and whites, it is important that researchers first consider the impact of black-white demographic and socioeconomic differences. This is because disparities found in research sometimes are attributable to differences in poverty and marriage rates, regional distribution, and other population characteristics. However, investigators often continue to observe black-white differences after controlling for differences in social status and demographics and must look elsewhere to explain their findings. One of many possible explanations is racial bias: African Americans might, under the circumstances being investigated, be victims of adverse treatment because they are black.

Researchers must conceive and evaluate other explanations also. Differences in access to insurance and other mechanisms to defray costs, in levels of illness or pat-terns of symptom expression, in health-risk behaviors, and in beliefs, preferences, and help-seeking traditions can also explain disparities. Citing a large-scale study of Medicare beneficiaries (McBean & Gornick, 1994), Williams (1998) reported numerous black-white disparities in health care and mortality. The findings were consistent with the presence of race-based discrimination, but other possibilities were also noted: "A greater percentage of black Medicare beneficiaries made out-of-pocket payments;" "There may be higher levels of severity of illness among black patients;" "Blacks may be more likely than whites to refuse procedures recommended by their physicians;" and "Whites may be more aggressive in pursuing medical care" (p. 312).

Survey researchers face challenges when they attempt to generalize findings from household samples to the larger African American population. Because of African American overrepresentation in high-need populations, community surveys that do not include persons living in jails, shelters, foster care, or other institutional settings are likely to undercount the number of African Americans with mental illness. Furthermore, mistrust causes large segments of the African American population not to participate in the U.S. Census, making accurate accounting difficult and having what are estimated to be dramatic effects on population-based rates of health and social problems (Williams & Jackson, 2000).

The legitimacy accorded assessment procedures widely used to measure mental illness and mental health, when they are applied to African American and other minority groups, is sometimes questioned (Snowden, 1996). If African Americans do not disclose symptoms as readily as other groups, for example, or if they present their symptoms in a distinctive manner, then attempts to accurately assess African American mental illness will suffer. For many procedures, neither validity nor lack of validity among African Americans has been demonstrated; the issue has not yet been addressed. Variation in reliability and validity can be and should be assessed (Chow et al., in press).



Mental Disorders

Adults

The Epidemiologic Catchment Area study (ECA) of the 1980s sampled residents of Baltimore, St. Louis, Durham-Piedmont, Los Angeles, and New Haven and assessed samples from both the community at large and institutions such as mental hospitals, jails, residential drug or alcohol treatment facilities, and nursing homes (Robins & Regier, 1991). In total, it included 4,638 African Americans, 12,944 whites, and 1,600 Hispanics. A more recent study, the National Comorbidity Survey (NCS), included a representative sample of persons living in the community that included 666 African Americans, 4,498 whites, and 713 additional U.S. residents (Kessler et al., 1994). Participants of both studies reported whether or not they had experienced symptoms of frequently diagnosed mental disorders in the past month, the past year, or at any time during their lives.

Results for certain disorders are presented in Table 3-1. After taking into account demographic differences between African Americans and whites, the ECA found that African Americans were less likely to be depressed and more likely to suffer from phobia than were whites (Zhang & Snowden, 1999). The NCS findings also indicate that African Americans were less likely than whites to suffer from major depression.

The studies revealed gender differences in rates of mental illness. Prevalence rates of depression, anxiety disorder, and phobia were higher among African American women than African American men. These differentials paralleled those found for white women and men.

In light of the findings, whether African Americans differ from whites in rate of mental illness cannot be answered simply. On the ECA, African Americans had higher levels of any lifetime or current disorder than whites. This was true both over the respondent's lifetime (Robins & Regier, 1991) and over the past month (Regier et. al., 1993). Taking into account differences in age, gender, marital status, and socioeconomic status, however, the black-white difference was eliminated. From the ECA then, it appears that African Americans in the community suffer from higher rates of mental illness than whites, but that the difference is explained by differences in demographic composition of the groups and in their social positions.

Evidence from the NCS, on the other hand, indicated that even without controlling for demographic and socioeconomic differences, African Americans living in the community had lower lifetime prevalence of mental illness than did white Americans living in the community (Kessler et al., 1996). This difference existed for all of the disorders assessed.

The results from these major epidemiological surveys appear to converge on at least one point: The rates of mental illness among African Americans are similiar to those of whites. Yet this judgment, too, is open to challenge because of African American overrepresentation in high-need populations. Persons who live, for example, in psychiatric hospitals, prisons, the inner city, and poor rural areas are not readily accessible to researchers who conduct household surveys. By counting members of these high-need groups, higher rates of mental illness among African Americans might be detected.



Table 3-1
Results of the ECA and NCS Studies of Mental Health Care for African Americans

	ECA			NCS		
	Black n=4,638	White n=12,944	Total n=19,182	Black n=666	White n=4,498	Total n=5,877
12-month	% (se)	% (se)	% (se)	% (se)	% (se)	% (se)
Major Depression	2.2 (0.1)	2.8 (0.6)	2.7	8.2 (1.1)	9.9 (0.6)	10.0 (0.6)
Panic Disorder	1.0 (0.3)	0.9 (0.1)	0.9 (0.1)	1.1 (0.5)	2.4 (0.3)	2.2 (0.2)
Phobic Disorder	16.2 (1.5)	9.1 (0.4)	9.7 (0.4)	14.5 (1.8)	14.8 (0.6)	15.0 (0.6)
Lifetime						
Major Depression	3.1	5.1	4.9	11.6 (1.4)	17.7 (0.7)	16.9 (0.6)
Dysthymia	4.0	6.3	3.2	5.4 (1.0)	6.7 (0.4)	6.5 (0.4)
Panic Disorder	1.3 (0.4)	1.6 (0.1)	1.6 (0.1)	1.4 (0.5)	3.9 (0.3)	3.4 (0.2)
Phobic Disorder	23.4 (0.5)	9.7 (3.2)	14.3 (0.4)	19.2 (2.0)	22.3 (0.8)	21.9 (0.7)

The SE (Standard Error) is the average dispersion around the percentage.

Table 3-1 shows results from Epidemiologic t h e Catchment Area study and the National Comorbidity Survey of mental health care for African Americans and white Americans. These figures are based on 12month and lifetime prevalence rates of select mood and anxiety disorders.

Children and youth

Mental health epidemiological research on children and youth provides little basis for conclusions about differences between African Americans and whites. Certain studies suggest higher rates of symptoms or of certain types of full-blown mental illness among African American children and youth than among whites: functional enuresis (Costello et al., 1996), obsessive-compulsive disorder (Valleni-Basile et al., 1996), symptoms of conduct disorder (Costello et al., 1988), and symptoms of depression (Roberts et al., 1997). Other studies have reported no differences between rates for blacks and whites (Siegel et al., 1998). Underlying patterns are masked by differences in the regions from which the samples were drawn, in the age of respondents, in assessment methods, and in other methodological considerations.

A study discussed in the Surgeon General's report on mental health (DHHS, 1999b) included an assessment of how much mental health care children in four geographic regions received. Children were identified as having unmet need if they were impaired because of mental illness and had had no mental health care in the preceding six months; African American children and



youth were more likely to have unmet need than were white children and youth (Shaffer et al., 1996).

Box 3-1: A Child's Grief John (age 10)

A 10-year-old African American male, "John," suffered from declining grades. Formerly a B and C student, he now received Ds. His mother could not explain his drop in academic achievement. John was unable to concentrate on homework and was sick to his stomach when studying. When questioned, John said that his father, now deceased, had formerly helped him carry out his assignments.

John told this story of his father's death: He and his father had been entering an elevator. They came upon two men arguing; one drew a gun and began to shoot. John's father, an innocent bystander, was shot in the stomach. He died on the moving elevator. The shooting and death produced a nauseating smell; John became sick and threw up.

Studying reminded John of his father's death and triggered nausea. This recognition helped to guide treatment. The focus was on providing a supportive relationship in which John could grieve his father's death. Overwhelmed, his mother had been unable to tolerate John's grief. Over time, John was able to transform his remorse into academic effort as a memorial to his father. His grades gradually improved. (Bell, 1997).

Older adults

Little is known about rates of mental disorders among older African Americans. Older African American ECA respondents exhibited higher rates of cognitive impairment than did their counterparts from other groups. The rate of severe cognitive impairment continued to be higher for African Americans even after the researchers con-trolled for differences in demographic factors and socioeconomic status. Cognitive impairment is strongly related to education; simple measures may fail to assess fully the long-term impact of excluding African Americans from good schools.

Even less is known about the mental health of older African Americans whose physical health is poor. It appears that many living in nursing homes need psychiatric care (Class et al., 1996). In addition, 27 percent of older African Americans living in public housing needed mental health treatment (Black et al., 1997).

Several studies have examined rates of depressive symptoms in older African Americans living in the community. Three of the more rigorous research efforts reported few differences in depressive symptoms between African Americans and whites (Husaini, 1997, Blazer et al., 1998; Gallo et al., 1998). As with older whites, elevated symptoms of depression in African Americans have been related to health problems (Okwumabua et al., 1997; Mui & Burnette, 1994).



Mental Health Problems

Symptoms

Sometimes symptoms are considered not as markers of an underlying mental disorder but as mental health problems in their own right. Although much remains to be learned about symptom distress, it can pose significant problems. Symptoms of depression have been associated with considerable impairment in the performance of day-to-day tasks of living, comparable to that associated with common medical conditions (Wells et al., 1989). Among African Americans especially, symptoms of depression are associated with increased risk of hypertension (Pickering, 2000).

Before the advent of the epidemiological studies discussed above, parallel studies addressed symptoms of depression. Vega and Rumbaut (1991) conducted a comprehensive review of the research focusing on African American-white comparisons. Sometimes African Americans reported more distress than did whites, but investigators were often able to attribute the differences to socioeconomic and demographic differences (Neighbors, 1984).

Somatization

Somatization is an idiom of distress in which troubled persons report symptoms of physical illness that cannot be explained in medical terms. In some people, somatization is thought to mask psychiatric symptom distress or full-blown mental illness; somatic symptoms may be a more acceptable way of expressing suffering than psychiatric symptoms. Severe forms of somatization, which qualify as a disorder, are relatively rare; less severe forms are more common.

Somatization is not confined to African Americans, but somatic symptoms are more common among African Americans (15%) than among white Americans (9%) (Robins & Regier, 1991). Milder somatic symptoms, too, are expressed more often in African American communities (Heurtin-Roberts et al., 1997).

Culture-Bound syndromes

Some distress idioms are more confined to particular racial and ethnic groups. Several are characterized in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM–IV; American Psychiatric Association, 1994), in an Appendix devoted to culture-bound syndromes. One is isolated sleep paralysis, a state experienced while awaking or falling asleep and characterized by an inability to move (Bell et al., 1984, 1986). Another such syndrome, a sudden collapse sometimes preceded by dizziness, is known as falling out. (See DSM–IV, 1994, Appendix I, "Outline for Cultural Formulation" and "Glossary of Culture-Bound Syndromes," p. 846.) How widely these syndromes occur among African Americans is unknown.

These syndromes are examples of what anthropologists describe as a rich indigenous tradition of ways for African Americans to express psychiatric distress and other forms of emotion (Snow, 1993). Researchers have demonstrated that the symptoms reported in anthropological



literature resemble those of certain established mental disorders, and that they are linked among African Americans to a tendency to seek assistance (Snowden, 1999a).

Suicide

Because most people who commit suicide have a mental disorder (DHHS, 1999b), suicide rates indicate potential need for mental health care. Official statistics indicate that whites are nearly twice as likely as African Americans to commit suicide (National Center for Health Statistics, 1996).

Suicide among African Americans has attracted significant scholarly interest (Baker, 1990; Gibbs & Hines, 1989; Griffith & Bell, 1989). Attempts to explain the disparity between African Americans and whites have brought to light several qualifying considerations. It has been noted that much of the difference is attributable to very high rates of suicide among older white males. When looking at other age groups, "the risk of suicide among young African American men is comparable to that of young white men" (Joe & Kaplan, 2001). Moreover, the disparity has shrunk appreciably over time (Griffith & Bell, 1989; Baker, 1990). The increasing convergence is associated with striking increases in suicide rates among African American youth. Between 1980 and 1995, for example, the suicide rate among African Americans ages 10 to 14 increased 233 percent; the suicide rate for comparable whites increased 120 percent (Centers for Disease Control and Prevention [CDC], 1998).

A coroner judges whether someone has died by suicide. The accuracy of suicide determinations, especially in the case of African Americans, has also been called into question (Phillips & Ruth, 1993). Mohler and Earls (2001) notably reduced the gap in suicide rates between African American and white youths and young adults after correcting for attribution to other causes.

High-Need populations

Owing to a long history of oppression and the cumulative impact of economic hardship, African Americans are significantly overrepresented in the most vulnerable segments of the population. More African Americans than whites or members of other racial and ethnic minority groups are homeless, incarcerated, or are children in foster care or otherwise supervised by the child welfare system. African Americans are especially likely to be exposed to violence-related trauma, as were the large number of African American soldiers assigned to war zones in Vietnam. Exposure to trauma leads to increased vulnerability to mental disorders (Kessler et al., 1994).

Individuals who are homeless

African Americans make up a large part of the homeless population. One attempt to consolidate the best scientific estimates reported that 44 percent of the people who are homeless were African American (Jencks, 1994). Other estimates concur, concluding that the African American proportion is no lower than 40 percent (Barrett et al., 1992; U.S. Conference of Mayors, 1996). Proportionally, 3.5 times as many African Americans as whites are homeless. This overrepresentation includes many African American women, children, and youth (Cauce et



al., 1994; McCaskill et al., 1998).

Box 3-2: Fragmentation in the foster care system Michael (age 17)

A 17-year-old African American male in foster care, "Michael," was referred for mental health care. He was described as "hostile"; he had recently dropped out of school.

Michael was surly and irritable initially, but ultimately began to cry. Eventually he spoke about his past.

His father lost his job when Michael was 9 and was unable to support Michael, his mother, and his three siblings. In desperation, Michael's father began to sell drugs. Michael's mother came to use the drugs being sold by his father. She became unable to care for her four children, resulting in their placement in foster care.

Michael reported living in five foster homes; lack of continuity undermined his educational success. He had seen none of his siblings for some time and knew nothing of their whereabouts or of his parents' well-being. He revealed that he had suffered crying spells for over a year (Bell, 1997).

People who are homeless suffer from mental illnesses at disturbingly high rates. The most serious disorders are the most common: schizophrenia (11 to 13% of the homeless versus 1% of the general population) and mood disorders (22 to 30% of homeless versus 8% of the general population) (Koegel et al., 1988; Vernez et al., 1988; Breakey et al., 1989). Homeless and runaway youth also suffer from mental disorders at high rates (Feitel et al., 1992; Mundy et al., 1989; McCaskill et al., 1998).

Individuals who are incarcerated

Nearly half of all prisoners in State and Federal jurisdictions are African American (Bureau of Justice Statistics, 1999), as are nearly 40 percent of juveniles in legal custody (Bureau of Justice Statistics, 1998; Bureau of Justice Statistics, 1999). African Americans are also overrepresented in local jails (Bureau of Justice Statistics, 1999).

African American jail inmates and prisoners have somewhat lower rates of mental illness than comparable white American populations, but African American and white differences are overshadowed by the high rates of mental illness for incarcerated persons in general (Teplin,1999; Teplin et al., 1996). A study conducted on women entering prison in North Carolina (Jordan et al., 1996) is illustrative. Investigators found that while lifetime rates of mental disorders among African American were slightly lower than those for whites, rates for both incarcerated groups typically were eight times greater than rates observed among African American and white American community residents. Incarcerated African Americans with mental illnesses are less likely than whites to receive mental health care (Bureau of Justice Statistics, 1998)



Children in foster care and the child welfare system

African American children make up about 45 percent of the children in public foster care and more than half of all children waiting to be adopted (DHHS, 1999a). Children come to the attention of child welfare authorities because they are suspected victims of abuse or neglect. Often they are removed from their homes and placed elsewhere—and then again placed elsewhere if an initial placement cannot be continued. These conditions carry a high risk of mental illness, as confirmed in epidemiological research. After investigating a large representative sample, Garland, and colleagues (1998) reported that around 42 percent of children and youth in child welfare programs met DSM-IV criteria for a mental disorder.

Individuals exposed to violence

Blacks of all ages are more likely to be the victims of serious violent crime than are whites (Griffith & Bell, 1989; Jenkins et al., 1989; Gladstein et al., 1992; Bureau of Justice Statistics, 1997; Jenkins & Bell, 1997). In one area, a community survey revealed that "nonwhites," many of whom were African American, were not only at greater risk of being victims of physical violence, but also at greater risk of knowing someone who had suffered violence (Breslau et al., 1998). The greater risk could not be attributed to socioeconomic differences or differences in area of residence.

The link between violence and psychiatric symptoms and illness is clear (Fitzpatrick & Boldizar, 1993; Breslau et. al, 1998; Schwab-Stone et al., 1999). One investigator reported that over one-fourth of African American youth who had been exposed to violence had symptoms severe enough to warrant a diagnosis of PTSD (Fitzpatrick & Boldizar, 1993).

Vietnam War Veterans

Although 10 percent of U.S. soldiers in Vietnam were black and 85 percent were white, more black (21%) than white (14%) veterans suffer from PTSD (Kulka et al., 1990). Investigators attribute this difference to the greater exposure of blacks to war-zone trauma, which increases risk not only for PTSD but also for many health-related and psychosocial adversities (Fairbank et al., 2001). African American and white veterans used Veterans' Administration (VA) mental health care equally, but African Americans proved less likely to use supplemental care outside the VA system (Rosenheck & Fontana, 1994).

Availability, Accessibility, and Utilization of Mental Health Services

Availability of mental health services

The overrepresentation of African Americans in high-need populations implies great reliance on the programs and providers—public hospitals, community health centers, and local health departments—comprising the health care and mental health safety net (Lewin & Altman, 2000). State and local mental health authorities figure most prominently in the treatment of mental illness among African Americans. They may provide care either directly through the administration of mental health pro-grams, or by contracting with not-for-profit providers or



for-profit firms. The number, type, and distribution of safety net providers, as well as arrangements made for the provision of care, greatly influence the treatment options available to the most vulnerable populations of African Americans and others. Fortunately, the safety net includes programs and practitioners that specialize in treating African Americans. Several studies suggest that these care providers are especially adept at recruiting and retaining African Americans in outpatient treatment (Yeh et al., 1994; Snowden et al., 1995; Takeuchi et al., 1995).

The supply of African American clinicians is important. Studies of medical care reveal that African American physicians are five times more likely than white physicians to treat African American patients (Komaromy et al., 1996; Moy & Bartman, 1995) and that African American patients rate their physicians' styles of interaction as more participatory when they see African American physicians (Cooper-Patrick et al., 1999). Mental Health United States reported that, among clinically trained mental health professionals, only 2 percent of psychiatrists, 2 percent of psychologists, and 4 percent of social workers said they were African American (Holzer et al., 1998). African Americans seeking help-who would prefer an African American provider will have difficulty finding such a provider in these prominent mental health specialties.

The availability of mental health services also depends on where one lives. As discussed earlier, a relatively high proportion of African Americans live in the rural South. Evidence indicates that mental health professionals are concentrated in urban areas and are less likely to be found in the most rural counties of the United States (Holzer et al., 1998). Furthermore, African Americans living in urban areas are often concentrated in poor communities; urban practitioners who do not accept Medicaid or offer services to high-need clientele are not available to them.

Accessibility of mental health services

Lack of health insurance is a barrier to seeking mental health care. Nearly one-fourth of African Americans are uninsured (Brown et al., 2000), a percentage 1.5 times greater than the white rate. In the United States, health insurance is typically provided as an employment benefit. Because African Americans are more often employed in marginal jobs, the rate of employer-based coverage among employed African Americans is substantially lower than the rate among employed whites (53% versus 73%; Hall et al., 1999).

Although insurance coverage is one of the most important determinants for deciding to seek treatment among both African Americans and whites, it is clear that insurance alone, at least when provided by private sector plans, fails to eliminate disparities in access between African Americans and whites (Scheffler & Miller, 1989; Snowden & Thomas, 2000). Provision of insurance benefits with more generous mental health coverage does not increase treatment seeking as much among African Americans as among whites (Padgett et al., 1995). Overcoming financial barriers is an important step in eliminating disparities in care; however, according to evidence currently available, it is not in itself sufficient.

Medicaid, a major public health insurance program subsidizing treatment for the poor, covers nearly 21 per-cent of African Americans. Medicaid payments are among the principal sources of financing for the services of safety net providers on which many African Americans depend.



Medicaid-funded providers have been more successful than others in reducing disparities in access to mental health treatment (Snowden & Thomas, 2000).

African American attitudes toward mental illness are another barrier to seeking mental health care. Mental illness retains considerable stigma, and seeking treatment is not always encouraged. One study found that the proportion of African Americans who feared mental health treatment was 2.5 times greater than the proportion of whites (Sussman et al., 1987). Another study of parents of children meeting criteria for AD/HD discovered that African American parents were less likely than white parents to describe their child's difficulties using specific medical labels and more likely to expect a shorter term course (Bussing et al., 1998). Yet another study indicated that older African Americans were less knowledgeable about depression than elderly whites (Zylstra & Steitz, 1999).

Practitioners and administrators have sometimes failed to take into account African American preferences in formats and styles of receiving assistance. African Americans are affected especially by the amount of time spent with their providers, by a sense of trust, and by whether the provider is an African American (Keith, 2000). Among focus group participants, African Americans were more likely than whites to describe stigma and spirituality as affecting their willingness to seek help (Cooper-Patrick et al., 1997).

Utilization of mental health services

Community studies

Adults

Both the ECA and NCS investigated the use of mental health services by African Americans. Although only about 1 person in 3 of all respondents needing care received it, African Americans were distinguished by even lower levels of use (Robins & Regier, 1991). After eliminating the impact of sociodemographic differences and differences in need, the percentage of African Americans receiving treatment from any source was only about half that of whites (Swartz et al., 1998). Most African Americans who received care relied on the safety net public sector programs.

The more recent NCS also examined how many per-sons used mental health services. Results indicated that only 16 percent of African Americans with a diagnosable mood disorder saw a mental health specialist, and fewer than one-third consulted a health care provider of any kind. Table 3-2 shows that most African Americans suffering from mood and anxiety disorders did not receive care. The NCS also compared the use of mental health services by various ethnic groups and concluded that African Americans received less care than did white Americans.

Disparities between African Americans and whites also exist after initial barriers have been overcome. After entering care, African Americans are more likely than whites to terminate prematurely (Sue et al., 1994). They are also more likely to receive emergency care (Hu et al., 1991). These differences may come about because African Americans are relatively often



coerced or other-wise legally obligated to have treatment (Akutsu et al., 1996; Takeuchi & Cheung, 1998).

Besides using fewer mental health services than do white Americans, African Americans appear to choose different care providers. The National Ambulatory Medical Care Survey, which asked U.S. physicians about their patients, found that African Americans with mental health concerns were appreciably more likely to see their primary care physician than to see a psychiatrist (Pingitore et al., in press). Whites with mental health concerns, on the other hand, were only slightly more likely to see their primary care physician than to see a psychiatrist. Another study that included only private sector providers reported similar findings (Cooper-Patrick et al., 1994).

Research cited above documents a pervasive under-representation of African Americans in outpatient treatment. At the same time, it may be that African Americans have become willing to seek mental health care as much as, if not more than, other Americans. In a follow-up study at the Baltimore site of the ECA, Cooper-Patrick and colleagues (1999) discovered that all groups studied had increased their rates of mental health help-seeking. The increase among African Americans was such that the disparity between blacks and whites had been eliminated.

Table 3-2 Use of Mental Health Services by African Americans

(n=1011)

12-month disorder	Mental Health Specialist* % (se)	Any Provider** % (se)
Mood disorder	15.6 (3.5)	28.7 (4.5)
Anxiety disorder	12.6 (2.4)	25.6 (5.3)

Data from the National Comorbidity Survey (Kessler et al., 1994)

The SE (Standard Error) is the average dispersion around the percentage.

- * Psychologist, psychiatrist, or social worker
- ** Mental health specialist, general medical provider, other professional (nurse, occupational therapist, other health professional, minister, priest, rabbi, counselor), spiritualist, herbalist, natural therapist, or faith healer

Table 3-2 gives data from the National Comorbidity Survey on the use of mental health services by African Americans. The data illustrate that among people with mood or anxiety disorders who seek any form of treatment, only half seek help from a mental health specialist.

Notable differences between African Americans and white Americans have been documented in the use of inpatient psychiatric care. African Americans are significantly more likely than whites to be hospitalized in specialized psychiatric hospitals and beds (Snowden & Cheung, 1990; Breaux & Ryujin, 1999, Snowden, 1999b). Underlying the difference are a number of



factors, such as delays in treatment seeking and a high African American rate of repeat admission. One study of clients discharged from State mental hospitals found that African Americans were substantially more likely than others to be hospitalized again during the ensuing year (Leginski et al., 1990). Researchers have not yet evaluated the impact of managed care rationing on hospitalization rates.

Children and youth

African American and white American children receive outpatient mental health treatment at differing rates. Using the National Medical Expenditure Survey, a large, community survey, Cunningham and Freiman (1996) discovered that African American children were less likely than white children to have made a mental health outpatient visit. The difference could not be attributed to underlying socioeconomic, family-related, or regional differences between the groups. Among children who received outpatient mental health treatment, African Americans and whites had similar rates of receiving care from a mental health specialist.

A handful of smaller studies support this finding. One of them considered mental health care provided by specialists, by physicians and nurses, and in the schools (Zahner & Daskalakis, 1997). African American children and youth were less likely than whites to receive treatment, and their underrepresentation varied little, no matter which source of treatment was used. Other school-based studies have reported similar findings (Cuffe et al., 1995; Costello et al., 1997).

Perhaps because of lack of health insurance, few African American children are in psychiatric inpatient care (Chabra et al., 1999), but there are many black children in residential treatment centers (RTCs) for emotion-ally disturbed youth (Firestone, 1990). RTCs provide residential psychiatric treatment similar to that available in hospitals, but they are more likely to be funded from public sources.

In many cases, it is not parents, but child welfare authorities who initiate treatment for African American children. The child welfare system is a principal gate-keeper for African American mental health care (Halfon et al., 1992; Takayama et al., 1994). For this reason, several studies focusing on metropolitan areas have found an overrepresentation of African American children and youth in public mental health services (Bui & Takeuchi, 1992; McCabe et al., 1999). However, access via the child welfare system often does not result in beneficial treatment.

Older adults

Little evidence is available documenting the use of mental health services by older black adults. However, one study found that these adults, like their younger counter-parts, often do not obtain care (Black et al., 1997). In fact, this study reported that 58 percent of older African American adults with mental disorders were not receiving care. Another study indicated that older blacks in long-term care were less likely to use available community services than were older whites in long-term care (Mui & Burnette, 1994).



Complementary therapies

African Americans are thought to make extensive use of alternative treatments for health and mental health problems. This preference is deemed to reflect African American cultural traditions developed partly when African Americans were systematically excluded from mainstream health care institutions (Smith Fahie, 1998).

wever, there is scant empirical data on the use of complementary therapies among African Americans suffering from mental health or other health problems (Koss-Chioino, 2000). Preliminary community- and clinic-based studies have found that complementary therapies are used to treat anxiety and depression (Elder et al., 1997; Davidson et al., 1998) and to treat health problems that occur in conjunction with mental health problems (Druss & Rosenheck, 2000). One nationally representative survey indicated that African Americans held more favorable views toward use of home remedies than did whites (Snowden et al., 1997).

It is important to realize that alternative therapies are popular in general: As many as 40 percent of Americans use them to complement standard medical care (Eisenberg et al., 1998). Nevertheless, research from rural Mississippi and from public housing in Los Angeles suggests that African Americans may turn to alternative therapies more than do whites (Becerra & Inlehart, 1995; Frate et al., 1995; Smith Fahie, 1998).

Box 3-3: Complementary treatments are not always beneficial Joan (age 50)

A 50-year-old African American woman, "Joan," was hospitalized following a suicide attempt. She cried and was nearly mute, reporting only her inability to sleep and having heard voices commanding her to kill herself. Her medical records indicated a previous admission for psychotic depression. Joan recovered after she took antidepressant medication.

In response to questioning, Joan indicated that she had been successfully treated before, but that she had discontinued psychiatric medication after responding to a letter from an itinerant minister. He had administered holy oil in exchange for payment and informed her to stop taking medication because she had been cured.

After relating this story, Joan was supported in her religious belief and in seeking spiritual uplift from one of many legitimate religious institutions in her community. She was warned, however, against opportunists and charlatans (Bell, 1997).

Appropriateness and Outcomes of Mental Health Services

Upon entering treatment, do African Americans receive effective care? That effective treatments do exist was documented in the Surgeon General's Report on Mental Health (DHHS, 1999b). The questions that remain are whether novel, standardized treatments and treatment-as-



usual are equally effective when administered to African Americans, and whether in settings where African Americans receive care, clinicians diagnose their problems correctly and assign effective forms of treatment.

Studies on treatment outcomes

Clearly, an effective treatment is better than no treatment at all. However, for psychosocial interventions that might be sensitive to social and cultural circumstances, there is the question of whether interventions are as effective for African Americans as they are for whites. Few researchers have addressed this question when considering either novel, standardized treatments or treatment-as-usual. Among the handful of studies available for review, many included small samples of participants and lacked adequate controls.

One preliminary effort found that African Americans and white Americans responded similarly to treatment for PTSD (Rosenheck & Fontana, 1994; Zoellner et al., 1999). Cognitive-behavioral therapy, which focuses on altering demoralizing patterns of thought, has been shown to be equally effective in reducing anxiety among African American and white children and adults (Friedman et al., 1994; Treadwell et al., 1995). Similarly, behavioral treatment for older medical patients has been shown effective for African Americans (Lichtenberg et al., 1996). A study of persons suffering from severe and persistent mental illness found that a heavily African American sample, drawn from an intensive psychosocial rehabilitation program located in an urban, predominantly African American area, demonstrated increased levels of adaptive functioning in the community (Baker et al., 1999).

On the other hand, African Americans were found less responsive than white Americans in a pilot study of behavioral treatment for agoraphobia (Chambless & Williams, 1995). In another study of treatment for depression, African Americans proved similar to whites in response to psychotherapy and medication, except that African Americans had less improvement in their ability to function in the community (Brown et al., 1999). In a study of treatment as usually provided in the Los Angeles County mental health system, African Americans improved less than whites and members of other racial and ethnic minority groups (Sue et al., 1991). Exposure therapy, which involves overcoming fears in graduated steps, proved ineffective as a treatment for panic attacks among African Americans (Williams & Chambless, 1994).

Studies of children and youth have largely shown positive effects from treatment. African American and white juvenile offenders were assisted comparably by multisystemic therapy, which engages a network of supportive figures in a helping effort (Borduin et al., 1995). In addition, African Americans showed positive out-comes for medication for attention-deficit/hyperactivity disorder (Brown & Sexson, 1988).

Diagnostic issues

Appropriate care depends on accurate diagnosis. Carefully gathered evidence indicates that African Americans are diagnosed accurately less often than white Americans when they are suffering from depression and seen in primary care (Borowsky et al., 2000), or when they are seen for psychiatric evaluation in an emergency room (Strakowski et al., 1997).



For many years, clinicians and researchers observed a pattern whereby African Americans in treatment presented higher than expected rates of diagnosed schizophrenia and lower rates of diagnosed affective disorders (Neighbors et al., 1989). When structured procedures were used for assessment, or when retrospective assessments were made via chart review, the disparities between African Americans and whites failed to emerge (Baker & Bell, 1999).

One explanation for the findings is clinician bias: Clinicians are predisposed to judge African Americans as schizophrenic, but not as suffering from an affective disorder. One careful study of psychiatric inpatients found that African Americans had higher rates of both clinical and research-based diagnoses of schizophrenia (Trierweiler et al., 2000). The clinicians in the study were well trained and included both African Americans and white Americans. However, it was found that they applied different decision rules to African American and white patients in judging the presence of schizophrenia. The role of clinician bias in accounting for this complex problem has not yet been ascertained.

Evidence-based treatments

In a nationally representative telephone and mail survey conducted in 1996, African Americans were found to be less likely than white Americans to receive appropriate care for depression or anxiety. Appropriate care was defined as care that adheres to official guidelines based on evidence from clinical trials. (Wang et al., 2000). Similar findings emerged in another large study that examined a representative national sample (Young et al., 2001). One large study of antidepressant medication use included all Medicaid recipients who had a diagnosis of depression at some time between 1989 and 1994 (Melfi et al., 2000). This study found that African Americans were less likely than whites to receive an antidepressant when their depression was first diagnosed (27% versus 44%). Of those who did receive antidepressant medications, African Americans were less likely to receive the newer selective serotonin reuptake inhibitor (SSRI) medications than were the white clients. This is important because the SSRIs have fewer troubling side effects than the older antidepressants; therefore, they tend to be more easily tolerated, and patients are less likely to discontinue taking them. Failure to treat with SSRI medications may be widespread and might help to explain African American overrepresentation in inpatient facilities and emergency rooms. Also, in a large study of older community residents followed from 1986 through 1996, whites in 1986 were nearly twice as likely, and in 1996, alomst 4 times more likely, to use an antidepressant than were African Americans (Blazer et al., 2000).

Best practices

Biological similarities between African Americans and whites are such that effective medications are suitable for treating mental illness in both groups. At the same time, recent evidence suggests that African Americans and white Americans sometimes have different dosage needs. For example, a greater percentage of African Americans than whites metabolize some antidepressants and antipsychotic medications slowly and might be more sensitive than whites (Ziegler & Biggs, 1977; Rudorfer & Robins, 1982; Bradford et al., 1998). This higher sensitivity is manifested in a faster and higher rate of response (Overall et al., 1969; Henry et



al., 1971; Raskin & Crook, 1975; Ziegler & Biggs, 1977) and more severe side effects, including delirium (Livingston et al., 1983), when treated with doses commonly used for whites. However, clinicians in psychiatric emergency services prescribe both more and higher doses of oral and injectable antipsychotic medications to African Americans than to whites (Segel et al., 1996), as do other clinicians working in inpatient services (Chung et al., 1995). Other studies suggest that African Americans are also likely to receive higher overall doses of neuroleptics than are whites (Marcolin, 1991; Segel et al., 1996; Walkup et al., 2000).

The combination of slow metabolism and overmedication of antipsychotic drugs in African Americans can yield extra-pyramidal side effects, including stiffness, jitteriness, and muscle cramps (Lin et al., 1997), as well as increased risk of long-term severe side effects such as tardive dyskinesia, marked by abnormal muscular movements and gestures. Tardive dyskinesia has been shown in several studies to be significantly more prevalent among African Americans than among whites (Morgenstern & Glazer, 1993; Glazer et al., 1994; Eastham & Jeste, 1996; Jeste et al., 1996).

Conclusions

African Americans have made great strides in education, income, and other indicators of social well-being. Their improvement in social standing is marked, attesting to the resilience and adaptive traditions of African American communities in the face of slavery, racism, and discrimination. Contributions have come from diverse African American communities, including immigrants from Africa, the Caribbean, and elsewhere. Nevertheless, significant problems remain:

- 1. African Americans living in the community appear to have overall rates of distress symptoms and mental illness similar to those of whites, although some exceptions may exist. One major epidemiological study found that the rates of disorder for whites and blacks were similar after controlling for differences in income, education, and marital status. A later, population-based study found similar rates before accounting for such socioeconomic variables. Furthermore, the distribution of disorders may be different between groups, with African Americans having higher rates of some disorders and lower rates of others.
- 2. The mental health of African Americans cannot be evaluated without considering the many African Americans found in high-need populations whose members have high levels of mental illness and are significantly in need of treatment. Proportionally, 3.5 times as many African Americans as white Americans are homeless. None of them are included in community surveys. Other inaccessible populations also compound the problem of making accurate measurements and providing effective services.

The mental health problems of persons in high-need populations are especially likely to occur jointly with substance abuse problems, as well as with HIV infection or AIDS (Lewin & Altman, 2000). Detection, treatment, and rehabilitation become particularly challenging in the presence of multiple and significant impediments to well-being.



- 3. African Americans who are distressed or have a mental illness may present their symptoms according to certain idioms of distress. African American symptom presentation can differ from what most clinicians are trained to expect and may lead to diagnostic and treatment planning problems. The impact of culture on idioms of distress deserves more attention from researchers.
- 4. African Americans may be more likely than white Americans to use alternative therapies, although differences have not yet been firmly established. When complementary therapies are used, their use may not be communicated to clinicians. A lack of provider knowledge of their use may interfere with delivery of appropriate treatment.
- 5. Disparities in access to mental health services are partly attributable to financial barriers. Many of the working poor, among whom African Americans are overrepresented, do not qualify for public coverage and work in jobs that do not provide private coverage. Better access to private insurance is an important step, but is not in itself sufficient. African American reliance on public financing suggests that provisions of the Medicaid program are also important. Publicly financed safety net providers are a critical resource in the provision of care to African American communities.
- 6. Disparities in access also come about for reasons other than financial ones. Few mental health specialists are available for those African Americans who prefer an African American provider. Furthermore, African Americans are overrepresented in areas where few providers choose to practice. They may not trust or feel welcomed by the providers who are available. Feelings of mistrust and stigma or perceptions of racism or discrimination may keep them away.
- 7. African Americans with mental health needs are unlikely to receive treatment—even less likely than the undertreated mainstream population. If treated, they are likely to have sought help from primary care providers. African Americans frequently lack a usual source of health care as a focal point for treatment. African Americans receiving specialty care tend to leave treatment prematurely. Mental health care occurs relatively frequently in emergency rooms and psychiatric hospitals. These settings and patterns of treatment undermine delivery of high-quality mental health care.
- 8. African Americans are more likely to be incorrectly diagnosed than white Americans. They are more likely to be diagnosed as suffering from schizophrenia and less likely to be diagnosed as suffering from an affective disorder. The pattern is longstanding but cannot yet be fully explained.
- 9. Whether African Americans and whites benefit from mental health treatment in equal measure is still under investigation. The limited information available suggests African



Americans respond favorably for the most part, but few clinical trials have evaluated the response of African Americans to evidence-based treatments. Little research has examined the impact on African Americans of care delivered under usual conditions of community practice. More remains to be learned about when and how treatment must be modified to take into account African American needs and preferences.

Adaptive traditions have sustained African Americans through long periods of hardship imposed by the larger society. Their resilience is an important resource from which much can be learned. African American communities must be engaged, their traditions supported and built upon, and their trust gained in attempts to reduce mental illness and increase mental health. Mutual benefit will accrue to African Americans and to the society at large from a concerted effort to address the mental health needs of African Americans.

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Chapter 2

Recovery and Support

This chapter describes experiences of recovery and the importance of education and support for African American consumers and their families through personal accounts of people touched by mental illness.

STAR [Support, Technical Assistance and Resource] Center African American Experiences of Self-Help Teleconference

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Executive Summary

August 4, 2004, 3:00-4:00 pm EST

Moderator: Maggie Scheie-Lurie (technical facilitation by conference call Operator)

Panelists: Derrick Adkins, Jacki McKinney, Roderick Waters, Ph.D.

On August 24, 2004, nearly sixty participants joined together to participate in the second of a series of STAR Center teleconferences exploring the experiences and values of self-help and peer support in diverse communities, both ethnically and culturally. The panelists, all mental health consumers themselves, were as multi-faceted as the African-American community from which they come:

- Derrick Adkins, an Olympic gold medallist and motivational speaker;
- Jacki McKinney, an award-winning, nationally-known advocate of recovery for people with mental illness;
- Roderick Waters, Ph.D., a former college professor who has taught courses in African-American history and culture, facilitated workshops on diversity, and lectured to fellow consumers on how to advocate for oneself.

The teleconference first asked the panelists to address what self-help means to them as African Americans. For Jacki McKinney, self-help means being able to identify the symptoms of her illness in time to take an active role in guiding her own recovery, getting treatment early, rather than waiting until she was so ill that she had to be taken somewhere by others. Derrick Adkins concurred that education was vital, making him aware of the great variety and spectrum of help and treatment that is available. Dr. Waters emphasized the need to go beyond a definition of self-help that begins and ends with self-reliance, to include the process of identifying that there is a problem, seeking and pursuing help, and then doing what is needed to maintain and enhance well-being.

Each of the panelists was also asked to share some examples of how self-help had made a



difference in his or her recovery. Jacki McKinney spoke eloquently about the role that the consumer movement played in helping her claim responsibility for being a partner in her own search for treatment and wellness. She also described how the skills she acquired are now serving to help her educate her family and loved ones, and helped them move past self-stigma to self-understanding. For Derrick Adkins, self-help means learning about treatment options from peers rather than professionals, and how he benefited from the unique understanding that only a person who shares your experience can offer. In addition to peer support from within his community, Dr. Waters emphasized how valuable it has been for him to overcome the stigma associated with mental illness in the African American community (and especially in the church), and to realize that he was not the only one. He also stressed his desire to expand the idea of peer support as widely as possible.

Next, the teleconference explored which organizations or facilities enabled the panelists to give or receive peer support, and asked whether they were specific to African Americans. Derrick Adkins noted that most of his peer support came from his own circle of contacts, but that his local community mental health agency did have a peer support group, which was perhaps 30 to 40 percent Black. Jacki McKinney described her lengthy service in the consumer advocacy community, and how for many years she felt marginalized. She underscored how important to her it was to go to the Alternatives conference and see many people of color participating actively. Dr. Waters indicated that he had not personally found any group addressing the needs of African Americans specifically. But he also stressed the importance of ensuring that all peer support groups be aware of the needs of members from diverse communities, and outlined his belief that rather than self-segregating, African Americans should strive to hold organizations accountable for including them as full participants in all their offerings.

When asked to explore the topic of stigma issues in the African-American community, and how to address them, each of the panelists had something urgent to say. Derrick Adkins discussed the particular burden on young African-American men: how the cultural imperative they feel to appear tough and macho makes it especially difficult for them to acknowledge and express their need for help. Dr. Waters described the "Catch-22" facing African-Americans, who can't go to their church group for support in mental illness the way they might for other difficulties, but who also then find themselves in 'outside' organizations that don't appreciate or understand their unique needs. He emphasized the importance of educating the wider mental health community to perceive and acknowledge the participation and value of African Americans in self-help and peer-support groups. For Jacki McKinney, getting past self-stigma means dealing with it "in your own house." But perhaps even more important, is getting the larger governmental systems to properly fund and develop organizations that serve African Americans.

Participants had an opportunity to ask their own questions and make remarks after the main question-and-answer segment. Some wanted more information about the Alternatives conference and the National People of Color Consumer-Survivor Network. Another asked how



the educational system might be encouraged to better prepare professionals to acknowledge and respect diversity among mental health consumers. One caller asked what strategies the panelists would recommend for learning more about self-help and what resources they would recommend.

For a full transcript of this teleconference please visit the STAR Center website (www.consumerstar.org), then click on the "Events" tab. You will find a link to the transcript (in PDF format) in the paragraph about the **African-American Experiences of Self-Help Teleconference**. A link to a full audio recording of the teleconference will appear there shortly.

The STAR Center gratefully acknowledges the support of the Federal Center for Mental Health Services.

Bridging the Gap Between African Americans and the Mental Health System

By Amy Alexander

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Between the fall of 2000 and the summer of 2001, I traveled to several American cities to talk about African Americans, mental health, and suicide. The subject was not cheery, but still I felt fortunate: my traveling colleague was Alvin Poussaint, M.D. The esteemed psychiatrist had cowritten a book with me called *Lay My Burden Down: Suicide and the Mental Health Crisis Among African Americans* (Beacon Press, 2001).

In the late 1990s, Dr. Poussaint had agreed to write this book with me after I had approached him about my brother Carl. Carl had killed himself in 1979, when he was twenty-five and I was a fifteen-year-old high school sophomore. When I approached Dr. Poussaint, it was for help in sorting out some of the clinical, historical, and psychosocial underpinnings of my brother's self-destruction. Not long after meeting with Dr. Poussaint, we decided that he would do more than just consult on my book: His own forty-plus years in psychiatry had given him a clear sense of how long and how severely the many important elements contributing to currently high black suicide rates have been under-reported, under-discussed, and misunderstood. Also, one of Dr. Poussaint's older brothers, Kenneth, had been diagnosed with a form of schizophrenia during his teens, and later struggled through years of difficulties with drugs, hospitalizations, and criminal activity before his untimely death in the 1970s. As Dr. Poussaint explained to me, the process of "slow suicide"—the drinking, drug abuse, and other forms of risky behavior that are an ongoing part of life for many black Americans—must also be examined in the context of blacks and mental health.

After Dr. Poussaint and I worked two years together, we found ourselves visiting New York,



Atlanta, St. Louis, Indianapolis, Oakland, and Los Angeles to promote our book. What we learned from our appearances at bookstores, libraries, and community halls was that there are thousands of African Americans struggling virtually alone with mental health issues— either their own or those of family members. The stories we heard from black Americans illustrated the vast disconnection between many black Americans and the American healthcare system in general, and, in particular, between blacks and the mental healthcare establishment.

In Atlanta, for example, when we spoke at the historic library on Auburn Boulevard, we heard from a nineteen-year-old African-American girl who said she had attempted suicide more than a dozen times in one year. After our talk, she ventured to the microphone to plead for our help. Her father had been in jail for many years; her mother had died of the virus that causes AIDS a few months earlier; she had been kicked out of her recent group home because of her erratic behavior; her peers had deserted her; and she was on the verge of homelessness. And she was again contemplating suicide.

The fact that a young black woman in such obvious mental and emotional distress found it necessary to turn to a couple of visiting writers said volumes about the sad state of black access to effective mental health services. Fortunately, our audience that day included workers from local minority mental health service centers, so we encouraged the troubled young woman to speak with the workers who were present. We also encouraged the healthcare professionals in the audience to step up and connect with her.

In Pasadena, where we had a radio talk-show appearance, a young black man phoned the host and asked to speak to Dr. Poussaint. He then he told us—and all the listeners of that NPR station—that he was on the verge of killing himself. He sounded like he was weeping. Gently but firmly, Dr. Poussaint urged him not to take his own life, and asked him a series of questions about his current situation. Had he taken any drugs? Had he been drinking? Did he have family or friends nearby? Did he have a gun? He then asked the young man to stay on the line. When the show was completed, Dr. Poussaint spent the next twenty minutes talking with the young man. Before hanging up, the young man assured Dr. Poussaint that he would contact a local suicide prevention hotline. We had no way of knowing what happened after Dr. Poussaint hung up.

In Oakland, at a bookstore not far from the church rooftop where my brother had jumped to his death in 1979, we heard from a thirty-five-year-old homemaker whose brother, a former high school football star, had been living on the streets, smoking crack, and engaging in criminal activity for ten years. The woman came from a middle-class black family in San Francisco, and was stumped as to how to help her thirty-seven-year-old brother positively change his life. For reasons she could not grasp, her brother had not been responding to traditional forms of drug rehabilitation. "We have tried everything," she told us. "We have tried tough love; we have put him in more rehab facilities than I can count; we have cried, prayed, lectured, pleaded. But still he seems intent on killing himself."

Our best advice to that Oakland woman involved her continued diligence, persistence, and a strong reserve of compassion. For not only do black families struggling with relatives with mental illness have to surmount the universal difficulty of convincing a person with mental



illness that he or she needs help, but they must also contend with a mental healthcare establishment that has been historically dismissive and neglectful of African American emotional and psychological lives. And, since the policymakers and legislators who control the purse strings for healthcare disbursements have continually argued that mental health services are not as critical as general healthcare services, few black Americans hold the kind of insurance that might make effective mental health care affordable.

Only very recently have Congress and the Senate—spurred by the late Senator Wellstone and a few other politicians—begun to seriously consider changing funding formulas to increase the amount patients can receive for mental health services. Yet, despite the efforts of Wellstone and the extraordinary outspokenness of former U.S. Surgeon General David Satcher—who in 1999 issued a report, *Call to Action to Prevent Suicide*—the larger question of what to do about black skepticism toward the mental healthcare establishment remains unanswered.

In historical terms, it is understandable why African Americans might be more reluctant to seek out mental health care when they experience serious emotional or psychological distress. Most Americans by now know of the notorious Tuskegee Syphilis experiments, the forty-year-long government tests that allowed hundreds of black men to die from venereal diseases in the name of science. But that is only one of many government- or university-sanctioned programs since the 1800s that neglected or mistreated African Americans. And several recent studies have shown that African Americans, even those with seemingly good insurance plans, continue to receive health care that is far inferior to that which most whites receive.

The audiences we spoke to understood these things, but like Dr. Poussaint and myself, they remain frustrated and mystified as to how to immediately correct these long-standing deficiencies.

Still, I continue to be hopeful. At the very least, it was heartening, out there in "real America," to also hear from groups like the National Organization of People of Color Against Suicide and from the Indiana Coalition on Minority Mental Health. Along with the truly heartbreaking stories of everyday people attempting to cope unaided with extremely difficult problems, we learned that in many cities, there are governments and politicians and community leaders who are seeking to close the minority healthcare gap. I plan to keep my eye on them. Perhaps in a few years, the next book on black mental health that I write will examine how this small but dedicated community has finally given people like that nineteen-year-old Atlanta woman a genuinely meaningful new start.

Journalist and editor Amy Alexander is co-author, with Alvin Poussaint, M.D., of Lay My Burden Down: Suicide and the Mental Health Crisis Among African Americans (Beacon Press, 2001). To order this book visit www.beaconpress.org



In Our Own Voice: Living with Mental Illness—Sharing the Message of Recovery, Hope, and Treatment

The power of having firsthand experience, and being given the gift of sharing that experience with the community, is healing and empowering for both the person living with a mental illness and the community. In Our Own Voice: Living with Mental Illness (IOOV) is NAMI's national program that trains consumers to share the message of recovery, hope, and treatment. The program is currently in 31 states and at more than 60 different sites.

The presentations are delivered to a wide variety of audiences. For example, the program is used to educate law enforcement officers and educate people in community colleges, universities, elementary schools, and high schools.

NAMI conservatively estimate that IOOV is reaching an audience of 3,000 people each month. Renowned researchers are doing evidence-based practice on IOOV and its potential impact on reducing stigma in those who hear the presentation. NAMI is changing the way persons living with mental illnesses are perceived—one community at a time.

Following is the story of Cynthia Ross, who found a renewed purpose and life direction after becoming a presenter for NAMI's Living with Schizophrenia and other Mental Illnesses program, now known as In Our Own Voice. Cynthia's story is both moving and powerful, and it encapsulates what can happen when desire and hope meet opportunity.

In May of 1977, I was discovered lying down, curled up in a fetal position, swimming in my own urine. I was catatonic, had my eyes closed, and was unable to stand or walk. The voices in my head told me to shut my mouth because I was evil and was going to die. My visual hallucinations were so monstrous that I closed my eyes as tightly as I could, to avoid eye contact.

It was my final semester before college graduation. Prior to this, I was a cheerleader, happy-golucky, and loved to laugh. I was found by the paramedics after three days in my dormitory room, dehydrated and malnourished. That day was to change my life forever.

I was rushed to what would become the first of many trips for the next 25 years to local mental health facilities. The first visit lasted one month. I spent my twenty-first birthday and college graduation in the hospital. I was administered Thorazine for schizophrenia. Over the next few years, my diagnosis would be changed to schizoaffective disorder and then changed again to my current diagnosis of bipolar I.

I was able to eventually return to college and complete my degree in communications, but I was a changed person. I was angry, cynical, and had given up hope of having a normal life. I battled with my doctors about compliance with medications. I had a chip on my shoulder because I felt displaced in the world. I was always in and out of the hospitals because I would not take the medication. Even though I was reaching relatively great levels of success as a



trainer in the telecommunications industry, a black cloud always seemed to travel with me. I could not understand why I had to be stricken with this disease, and I pondered what the value was in having it.

In April 2000, after yet another manic episode, a miracle happened that revealed my answer as to the value I could create with my illness. I was invited to be a presenter for NAMI's Living with Schizophrenia and other Mental Illnesses, now known as In Our Own Voice. This program became my road to recovery. One requirement to participate in the program was to be compliant with medication. My desire to be a presenter forced me to take my medication consistently for the first time ever! I started to become stabilized. As I traveled to board-and-cares and clubhouses, I started to meet other people like myself.

One incident that will be ingrained with me forever is a time when my co-presenter, Kamala, and I went to a clubhouse and met a consumer who denied that she had schizophrenia. The consumer claimed that she was a psychic and clairvoyant, but not schizophrenic. She refused to take her medication consistently. I shared my story with the consumer and the other members of the clubhouse. When the presentation was over, the woman was so encouraged. She admitted that she had an illness, and vowed to start taking her medication. She said that if I could do it, she could do it too. At the end, she rose from her chair, and came over and hugged me. I cried for joy.

This is just one of many stories of success that I had with the program. One final success story is the time I spoke to graduate students in rehabilitation counseling at San Diego State University. One of the attendants invited me to interview for a job developer position with the San Diego Community College District, Disabled Student Services. I was hired and worked there for two years. The best part is, that I am now one of those students at San Diego State University—a second-year graduate student studying rehabilitation counseling.

IOOV was the main factor that helped me to find joy and hope living with a mental illness. It allowed me to share my story with many people in San Diego. It allowed me to take pride in my life and to be happy again. And most of all, IOOV gave me a future that will provide me the opportunity to help many more people living with mental illnesses who need motivation and a reason to keep going when the times get tough.

Cynthia Ross is originally from New Jersey and currently lives in San Diego, California. She is a sales executive for national motivational speaker Eric Lofholm of Eric Lofholm International and is a second-year graduate student in rehabilitation counseling at San Diego State University/Interwork Institute. For two years, Cynthia was a presenter for Living with Schizophrenia and Other Mental Illnesses, now known as In Our Own Voice. She deeply understands the challenges of living with a disability and integrating successfully into the mainstream of society. Her goal is to complete her graduate studies and to improve the quality of life for people with disabilities. Her future plans are to become a life skills and success coach to people with disabilities.

For more information about In Our Own Voice contact:

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Out of Darkness Into Education, Support, and Advocacy - African American Leaders Commend the NAMI Family-to-Family Education Program

A sister's journey out of darkness began after reading a feature story in a Sunday newspaper about the Family-to-Family Education Program (F2F). Zina May, NAMI F2F Program Director, enrolled in the class and quickly realized that education is key to understanding mental illnesses, and she found a supportive group of others families who kept her from being isolated and alone. Zina has a brother who has been ill for about 20 years and during those years, no professional told her family about his illness, what to expect, what to do, or what the diagnosis was. He was given medication and not much more; so as a result, life was a revolving door of hospitalizations and calls to the police. Since finding NAMI and F2F, she and her family have better insight into his mental illness, medications, symptoms, and can offer him a little more support as well as advocate for better services to enhance his quality of life.

It was winter and his brother was living in an outside unheated storage shed, Dorian Parker was unaware that he was there, but when he found him he brought him to his home to stay. This arrangement did not work out and his brother left and was lost again until Dorian learned that he was hospitalized; he desperately wanted to know what was wrong. In the past when his brother would become symptomatic, all he heard was that it was confidential and he couldn't be told his diagnosis. Thankfully this time, a caring social worker provided him with the contact information for NAMI Rhode Island and he met other caring families who helped calm him and assure him that he would learn all about paranoid schizophrenia by attending a Family-to-Family class and he did. Along with his wife and mother, he learned that they were not alone and found the support they needed.

Pat Strode, whose daughter had had four hospitalizations prior to learning about NAMI and Family-to-Family, described her experience as like being in a vortex and being sucked down deeper where no one was hearing what she was saying. She was screaming and crying for help. That help came from a caring NAMI member who was persistent in letting Pat know she was not alone and that she knew what it was like to be alone with a child with mental illness. Pat is one of the first Family-to-Family teachers trained to teach the course in Georgia, and as she likes to say, "the rest is history", because she has been teaching over five years. Pat sees her daughter as a true heroine who she has a tremendous amount of respect, and knowing about the illness has helped her advocate for her daughter along the way with getting proper care and medications. What Pat cherishes most is that F2F saved her life and her daughter's life.

The NAMI Family-to-Family Education program, now in its 12th year, is a national evidence-based program that is conducted under the auspices of the NAMI national organization in 46 states. The 12-week course places emphasis on a trauma model of family healing, providing insights into, and resolution of, the profound distress experienced by families and their close relatives as they struggle to cope with serious and persistent mental illnesses.

In the African American community, stigma is still extremely pervasive which Pat feels is not necessarily because of not acknowledging mental illness as is done with other physical



illnesses, but rather it is pervasive in part because the communities are not aware of the facts. Besides, they don't have access to treatment, to community resources that provide those available treatments, to disability benefits when they're needed, and little or no support and educational services for the entire family. She wants African American families to know that NAMI provides resources and provides support and education for families and consumers. In F2F one gains so much knowledge, and for her, knowledge is power and she believes the more people know, the better they will do.

Zina wants African American families to be educated about mental illnesses and how they affect the family as a whole. She is embarking on a special project that is supported by her church pastor to offer the F2F class on Sunday mornings so families could attend it instead of going to Sunday school. She feels this is in line with other weekly program series offered by the church and should work out nicely. She will soon convene a large gathering of African American clergy and other community leaders for a presentation on NAMI and F2F and will seek their assistance in getting the word out about these resources to African American families.

As a pastor, Dorian feels too often preachers and pastors are expected to become psychiatrist when families bring their depressed child to them, and most pastors don't realize that they are out of their field. At least in his community in Rhode Island, the pastors know they can call on him and he can connect them to NAMI and F2F. He believes it doesn't matter what culture you are it's the disease and it's the illness that is his concentration. He believes African Americans need to understand mental illnesses and that they are real illnesses and stop shunning family members and viewing them as having a character problem or are antisocial; they must understand that it is a biochemical illness that can be treated and that there is hope. He would like to see the faith community – ministers and clergy – mobilized to help NAMI reach families.

Zina, Pat, and Dorian are working diligently to reach more families in their role as the program director responsible for coordinating their state F2F program. They are truly grateful that a caring NAMI member, mental health professional, and a feature story in the newspaper paved the way for them to find NAMI and F2F, and they hope others can be reached similarly through extensive outreach and marketing activities. It is a dream to one day have well-known African American celebrities like Oprah, Tom Joyner, the nationally syndicated radio host, and for younger people, DMX and Brandee engaged with NAMI to help raise awareness of the number of African Americans dealing with serious mental illnesses.

The Family-to-Family course is open to any family member, partner or friend, or consumer in recovery, who has a first-degree relative suffering from a serious and persistent mental illness (schizophrenia, bipolar disorder, major depression, borderline personality disorder, panic disorder, obsessive compulsive disorder and co-occurring addictive and brain disorders).

For more information contact:

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Sometimes My Mommy Gets Angry

Book by Bebe Moore Campbell

Review from School Library Journal. Anna DeWind Walls, Milwaukee Public Library. Copyright 2003 Reed Business Information, Inc.

When Annie wakes up in the morning, her mother is making pancakes and cheerily asking, Who wants hot, golden circles?" The woman proclaims the breakfast "yummalicious" and Annie's purple dress, "Beautastic." But when the little girl returns home from school, her mother greets her by shouting, "STOP ALL THAT SCREAMING-GET IN THIS HOUSE NOW!" An author's note explains that this is how life can be for a child living with a parent with mental illness. When Annie's mother gets upset, the girl knows that she should call her grandmother, who reassures her and reminds her that her mother loves her, even when she's yelling. The child has the option of going to a neighbor's house and waiting for her grandmother to come for her. In spite of these safety valves, she deals with the situation on her own-getting a snack, snuggling with her teddy bear, and going to bed. Annie realizes that she can't stop the dark clouds inside her mother, but that she can find sunshine in her own mind. Lewis makes excellent use of light and shadow in his watercolors, evoking both the sunny glow of a happy kitchen and the foreboding gloom of a dark porch with equal skill. The multicultural cast is depicted with realistic sensitivity. The author's goal is to offer children resilience by introducing coping strategies and helping them to understand that they are not to blame for their parents' difficulties. A skillful treatment of a troubling subject.

To order this book visit the NAMI store at www.nami.org

From Depression To Deliverance Book by Carole P. Adkins with Derrick Adkins

Depression: The chemical imbalance in the brain that attacks the very soul. Yet, as late as 1974, the American Psychiatric Association listed in their diagnostic manual "strong religious belief" as a disorder. Is depression exclusively a chemical imbalance?

And as recently as today, many pastors in the religious community discourage their parishioners from seeking medical help. Is depression exclusively a spiritual attack?

From Depression to Deliverance is a spiritual companion to your doctor's advice demonstrating that depression is an attack on the mind, body and spirit. Thus, in order to win this battle, we have to attack it on all three fronts, embracing both the scientific and spiritual communities.

You are not alone in this battle. So join us on this pilgrimage from a psychiatrist's office, to the great outdoors with a few church sermons on the way; from mourning to joy, from torment to peace, from darkness into God's wonderful light.

To order this book visit www.iuniverse.com



Chapter 3

Cultural Competence

Improving access to treatment to individuals and families affected by mental illness represents one of the guiding principles driving the work of NAMI organizations at the national, state and local levels. As we read in the previous chapter, the former Surgeon General clearly stated in his report "Mental Health Culture, Race, and Ethnicity" the need for culturally competent services that adequately provide equitable treatment for *all* communities. Therefore, it is only appropriate for NAMI to become a culturally competent organization at all levels. In order to achieve this goal, NAMI must develop strategies that will address the changing demographics in the nation so that persons from diverse cultural backgrounds will also have access to mental health treatment and support. This chapter explains what cultural competence means and what it entails for organizations like NAMI.

Report of a Cultural Competence Panel

These materials have been adapted with permission from the Report of a Cultural Competence Panel by Dr. Ernest Quimby, Dr. Albana M. Dassori, and Dr. Annelle B. Primm. November, 2001

Cultural competence is a process of applying appropriate intervention strategies which consider the role and potential impact of values, norms, attitudes, norms, perceptions, communication and behavior of providers and consumers. It involves identifying and responding to consumers' perspectives, needs, experiences and interests. Cultural competence is a practice or method of working effectively and sensitively within the cultural context(s) of specific groups.

Viewing consumers as diverse individuals

Consumers with severe and persistent mental illness do not constitute a group or a homogeneous population responsive to monolithic treatment strategies. Their heterogeneity requires complex and varied treatment approaches. Economic marginality, under-education and reliance on governmental entitlements are central issues affecting clinical approaches, bureaucratic procedures, conditioned responses and employment outcomes. Thus, for example, treatment outcomes may be different for consumers who are single mothers and whose special interests, experiences, cultural backgrounds, needs and perspectives are not identified and addressed. Additionally, consumers with special needs who desire supported employment or traditional vocational rehabilitation require culturally competent comprehensive care incorporating vocational treatment domains, active participation in vocational treatment decisions, and supportive, continuous assistance in finding and retaining jobs.



Valuing cultural data

Mental illness occurs within cultural contexts which may be identified, appreciated and incorporated into treatment protocols and support to maximize effective mental health service delivery and utilization. Attentiveness to issues of cultural competence may increase service utilization and effectiveness. Cultural background information might help connect with people of color in meaningful ways. If the material is not superficial, resulting in stereotypical or inaccurate information, it may provide clues to culturally significant factors that may frame the interventions.

Class, racial, gender and sexual orientation issues have special significance for mental health treatment. Race and class converge in certain communities. Consumers living in depressed inner-city neighborhoods may have distinctive patterns of social networks, homelessness, dual diagnosis, health impairments and under-employment than middle-income suburban consumers. Similarly, the lifestyles and support systems of rural consumers may be shaped by factors and interests which differ from those of urban residents.

Characteristics of cultural competence

Cultural competence involves several characteristics. These are:

- Recognition of and respect for cultural differences
- Cultural introspection by administrators, supervisors, case managers, vocational specialists, NAMI leaders, advocates and support staff.
- Awareness of the differences, similarities and issues brought by consumers, families, practitioners, and service providers
- Knowledge about the role of culture in prevention, diagnosis and treatment interventions
- Adaptation of effective services which incorporate diverse cultural realities

Operational principles of cultural competence

- Cultural competence includes the following principles:
- Each person is a unique individual.
- Individuals exist within a cultural context.
- Treatment involves a holistic perspective of mental, social and physical health care.
- Attention to cultural details and knowledge helps to inform and facilitate engagement and retention of consumers and their families.



- Mental health treatment involves a relationship between the consumer and clinician.
- Families and support groups can promote treatment.
- Differences and similarities between people are recognized, honored, respected and validated.

Achieving cultural competence

- Achieving cultural competence depends on the following:
- Commitment displayed by policy makers, administrators, board members, and supervisors
- Clarity of the agency's goals, objectives and procedures
- Generation of support from staff and consumers
- Collaborative planning and communication
- Creation of structural mechanisms to monitor and reinforce accomplishments (e.g., advisory board)
- Identification of cultural attributes of the agency, staff and consumers
- Assessment of how cultural factors affect service delivery and utilization
- Development of and access to resources and educational opportunities
- Attentiveness to perceived spiritual/religious needs
- Utilization of culturally sensitive and relevant materials

Cultural competence includes awareness, sensitivity, knowledge and practical application of evidenced-based interventions and supports to address a consumer's needs and interests. Cultural competence involves developing an awareness that seemingly minor actions, such as voice tone, eye contact, and hand gestures may impede or maximize communication. If these components of culture are misunderstood, regarded as offensive, or simply not even recognized as communication techniques, groups may fail to establish rapport or sustain positive encounters. For example, when conducting a NAMI support group session, it is imperative that leaders practice techniques that do not violate the cultural sensibilities of participants. Chair arrangements, use of props and drawings, exercises, and other techniques should be designed from the participants' cultural perspectives.

Methods of achieving cultural competence

Multiple approaches can be used to implement cultural competence at the level of systems and



programs. These include, but are not limited to, the following:

- Identify and acknowledge the needs, interests, concerns and preferences of consumers and families of color.
- Conduct cultural competence workshops for NAMI staff and leadership.
- Incorporate values clarification sessions among NAMI staff and leadership.
- Identify and utilize articulate `cultural informants.'
- Hire a culturally diverse staff, and provide them with regular education.
- Minimize judgments of others.
- Identify and confront one's own biases and prejudices.
- Identify cultural clues which enhance cultural competence -- e.g., non-verbal communication through body language and facial clues; bi-lingualism.
- Develop methods of assessing cultural competence efforts.

Thematic summary

- Mental health services are provided and utilized within the cultural frameworks and social settings of systems, programs, consumers, families and practitioners.
- Cultural competence is a process.
- Cultural competence is not stereotyping.
- Cultural competence is not synonymous with race and ethnicity.
- Cultural competence implies awareness of one's own preconceptions and biases.
- Cultural competence requires recognition of the impact of the organization's assumptions and practices.
- Achieving cultural competence requires commitment, training and evaluation.

Cultural competence

Integration and use of knowledge, attitudes, behaviors and skills that strengthen crosscultural communication, and enhance appropriate and effective social interactions



Cultural competence implies:

- 1. Cultural self-awareness
- 2. Awareness of cultural context of `the other'
- 3. Understanding the dynamics of the difference
- 4. Development of cultural knowledge
- 5. Ability to adapt and practice skills to fit the cultural context(s) of consumers

Culturally competent agencies or institutions demonstrate four main qualities. These include: valuing and adapting to cultural diversity, ongoing organizational self-assessment, understanding and managing the dynamics of cultural difference, the institutionalization of cultural knowledge and skills (through training, experience and literature), and instituting service adaptations to better serve culturally diverse consumers and their families. Such adaptations include addressing barriers to care (cultural, linguistic, geographic or economic), levels of staffing that reflect the composition of the community being served, needs assessment and outreach, training in communication or interviewing skills, and modifications in actual assessment and treatment procedures and modalities.

Cultural self-awareness

Understanding the assumptions and values upon which one's behavior and worldview rest. These values and assumptions are long ingrained in our worldview and affect how we perceive ourselves and our consumers. Whenever we come into an interaction, we bring our own preconceptions about `the other' and these pre-conceptions can impact our behaviors and communication styles. As much as we want to think of ourselves as culturally sensitive, we all have biases.

Awareness of the cultural context of the `other'

This encompasses a wide range of elements including ethnicity, race, country of origin, language, acculturation, gender, age, sexual orientation, religious and spiritual beliefs, socioeconomic class and education. Awareness of `the other's' cultural context also implies awareness of the consumer's own explanations of the illness/problems, (i.e., perceived causes, idioms of distress, local illness categories, meaning and severity of symptoms in relation to cultural norms), as well as cultural interpretations of social stressors, social supports and levels of functioning.

Understanding the dynamics of the difference

Unfortunately, many times we assume that culture is not relevant. Some well-meaning people are concerned with the risks of stereotyping. Although, a valid concern, we cannot conclude that there is no need for having basic knowledge of common beliefs/norms/values held by members of the sociocultural groups we come most frequently in contact. A key to cultural competence is to be flexible and constantly check whether our basic knowledge on the cultural background of the individual fits his/her reality.



Development of cultural knowledge

To be culturally competent we must familiarize ourselves with the individual's culture and country of origin, history and pertinent psychosocial stresses, family life and intergenerational issues, culturally acceptable behaviors, role of religion, beliefs about causes and treatment of illness, etc. The changing demographic characteristics of the U.S. makes it very difficult to be knowledgeable about all the potential groups. Therefore, as a first step, we should attempt to become familiar with one or two of the groups that we most commonly encounter.

Ability to adapt and practice skills to fit the individual's cultural context

As an initial step, we need to assess the cultural context of the individual. We have to attend to nonverbal and verbal cues and interpret them within the appropriate cultural context. For example, rules for eye contact and other feedback behaviors (smiling, nodding, and leaning forward) may differ across cultural groups. Mainstream Anglo-Saxon listeners are taught to maintain eye contact with the speaker. In fact, avoidance of eye contact may be misperceived as a sign of dishonesty or psychopathology by certain non-minority providers and practitioners. However, some Asian and Hispanic/Latino consumers may show deference by not engaging in eye contact with the speaker. Personal space is another variable that can be defined differently. In mainstream U.S. culture, we tend to stand about three feet apart to have an ordinary conversation. In Hispanic/Latino cultures, people typically stand closer. This can be interpreted as threatening or intrusive, if the other person is not aware of the specific norms.

Assessing and sustaining cultural competence in evidence-based practices

Cultural competence involves developing new and different relationships with consumers, families and their supports, providers, practitioners, and administrators, among others. Assessing and sustaining cultural competence in evidence-based practices requires structures which encourage and assist stakeholders to identify and articulate their needs, interests and solutions. Public and private agencies, organizations and community-based groups, must be the central agents of change to implement, monitor and sustain cultural competence in evidence-based practices. Culturally diverse and consumer-involved mental health training and research centers could play a major role.



A Guidebook to Innovative Culturally Competent Agencies: Helping African Americans Manage Mental Illness

By King Davis, Toni Johnson & Anita McClendon

This materials have been adapted with permission. University of Texas at Austin. A Sutherland Initiative Prepared for The Annie E. Casey Foundation.

The overall purpose of the "Guidebook Project" was to collect and display up-to-date information about mental health services on three populations in a user-friendly template to enable providers, policy-makers, and project directors to recognize and replicate culturally competent services in their communities. The guidebook focuses specifically on identifying exemplary mental health programs to help African American populations manage the demands of mental illness. What follows are exerts from the guidebook.

Essential elements of a culturally competent program

For the past 150 years, the majority of mental health services were based on theories developed by Freud, Jung, Adler, Rank, and more recently B.F. Skinner. These theories influenced the societal views held about mental illness, and the professional approaches and methods for diagnosis and treatment. Each of the theories associated with these men were reflections too of both the culture in which they lived and their own world views. Only minimal accommodation was made within these theories for different cultures. Their perspectives influenced the curriculum offered in professional education as well as the public polices for responding to problems of mental health.

As a result, the majority of individuals with a mental illness were likely to be provided care by a clinician who was trained and educated in one of these theories that placed only minimal emphasis on the importance of culture in mental health. And almost all public policies reflected the views held about culture, color, race, or social class. Sue (1998) labeled this approach monoculturalism. Sue and other researchers propose that the failure to consider cultural factors in mental health care increases the chances of the following problems:

These added risks are part of the basis for development of a new theoretical approach to service design and delivery: cultural competence.

Risk from Mono-Cultural Services

- 1. Mis-diagnosis
- 2. Inappropriate Treament
- 3. Involuntary Treatment
- 4. Overutilization of Inpatient
- 5. Longer Length of Stay
- 6. Slower Recovery & Rehab
- 7. Higher Risk of Relapse
- 8. Higher Insurance Costs



Defining cultural competence

Two complimentary definitions of cultural competence are helpful. The first of these stems from the work of Cross (1989) and the second from Davis (1997b):

Cultural competence is needed to adequately and appropriately respond to demographic changes in the United States.

Cultural competence is needed to reduce the incidence of diagnostic error and to better utilize limited fiscal resources. Cultural Competence by Cross (1989)
A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables them to work effectively in cross-cultural

Cultural Competence by Davis(1997) is the integration and transformation of data, knowledge, information about individuals and groups of people into specific clinical standards, skills, service approaches, techniques, and marketing programs that match the individual's culture and increase the quality and appropriateness of health care and outcomes.

Cultural competence is needed to understand specific help-seeking behaviors of minority populations and to address attitudes towards mental illness and services.

Common elements of cultural competence

Earlier studies (Center for Mental Health Services, 2000) identified a series of interrelated characteristics that were seen as comprising a culturally competent system of care. Fifteen of these items were included in a survey of African American mental health providers, academicians, and administrators. Their responses suggest that not all of the items were seen as equally important nor were the same items rated equally for African American children and adults:



Most Important Cultural Competence Elements for Children:

- 1. Treatment based on the needs of the entire family
- 2. Family oriented assessments that incorporate key members of both nuclear and extended families
- 3. Multi-dimensional assessment that includes psychiatric, medical, spiritual, environmental, and social factors
- 4. Clinicians trained in cultural competence provide all assessment and treatment services
- 5. Quality of outcomes is monitored & evaluated

Similar elements were identified as important for African American adults, although the rankings were different from those for children:

Most Important Cultural Competence Elements for Adults:

- 1. Treatment modalities are conducted within the context of the value system of the consumer, culture, family, and community
- 2. Multi-dimensional assessment that includes psychiatric, medical, spiritual, environment, and social factors
- 3. Treatment plans coordinate mental, health, substance abuse, and social services
- 4. Quality of outcomes is monitored and evaluated
- 5. Clinicians trained in cultural competence conduct all assessments and treatment



Siegel and Haugland (2002) identified a number of elements that are found in culturally competent organizations:

Cultural Competence Elements Important in Organizations:

- 1. Presence of a cultural competence plan
- 2. Identification of which cultural groups need attention
- 3. Cultural competence advisory committee
- 4. Demographic profile of target cultural populations
- 5. Language assistance
- 6. Services adapted to different cultures
- 7. Additional accommodations: transportation, evening hours etc.
- 8. Training and education of staff in cultural competence
- 9. Representation of cultures among staff members
- 10. Cultural competence outcome measures
- 11. Consumer and family education

Innovative Community Models

Elements of a culturally competent system

The pursuit of cultural competency reflects an ongoing dynamic, rather than static, process and should be seen as a process that is in continual development. The five essential elements provide the springboard necessary to ascend the cultural competency continuum toward cultural proficiency.

Cross and colleagues (Cross, Bazron, Dennis, & Isaacs, 1989) emphasize the importance of implementing the elements at all levels of the organization. Below are questions that will enable an organization to consider concrete ways of implementing the essential elements

Administrative level

 Are recruited and hired mental health practitioners reflective of the cultural and linguistic diversity of the clients being served?

Elements Essential to Becoming a Culturally Competent Organization

- Values diversity
- Capacity for cultural self assessment
- Awareness of the natural tension that develops when cultures interact
- Institutionalizes accurate cultural knowledge
- Adapt services to better fit the needs of clients
- Are consumers represented on the board? Is the board ethnically/culturally diverse?



Policy making

- Do policies support the acquisition of knowledge about clients' culture?
- Is training provided that will help practitioners navigate the tensions that arise when cultures interact?

Service level

- Are forms and other written materials provided in the language used by the client?
- When appropriate, are natural helpers used in the provision of services?

Standards of practice

After more than a decade of urging agencies to embrace the principles and values of cultural competency, the call was heeded for clear guidelines and professional standards. Several organizations have published comprehensive cultural competence standards designed to improve the quality of mental health services delivered to culturally and ethnically diverse communities (Center for Mental Health Services, 2000; NASW, 2001). One of the first set of standards, developed in 1998 with support from the Center for Mental Health Services, was consumer-driven and focused on mental health providers serving populations of African descent (Davis, 1997b).

A major premise of these Standards (CMHS 2000) is the belief that the accurate diagnosis, prevention and treatment of mental illness requires agencies to develop knowledge of the individual's culture as well as knowledge about the precipitating illness (p. 51).

The agencies profiled in this report incorporate many of the concepts identified in the standards. One of the most important tenants is the notion that culturally grounded practice is paramount in implementing an effective intervention.

Innovative organizations serving African American families

Several published works provide useful profiles of organizations that have been identified as effective in serving communities of color and in operationalizing the principles of culturally competent practice (See for example: Cross, et al, 2000; Isaacs & Benjamin, 1991; Stroul, 1996). The organizational profile used in these publications includes:

- a brief history and identification of the agency
- a description of the community in which the agency is located
- an identification of the target population
- a statement of the program philosophy and goals
- the types of services provided along with funding strategies
- methods for evaluating effectiveness, and
- an analysis of how the principles of cultural competency are operationalized

While the guidebook presents 4 agency profiles, this manual uses only one as an example. This profile is based on a similar format, in that much of the same kinds of information will be included for the organization that the guidebook profiles. Data was gathered via written



surveys, conversations with key informants, and a review of public documents such as brochures, annual reports, evaluations and websites. In addition, "site visits" were made to all of the organizations.

Cross cultural service delivery models

In the seminal work of Cross and colleagues (1989), four models of cross cultural service delivery were identified:

- mainstream agencies providing outreach services to people of color
- mainstream agencies supporting services by people of color to people of color
- agencies providing bilingual/bicultural services
- culturally focused agencies providing services to people of color

The authors assert that all of the models emphasize cultural values and helping systems <u>except</u> the mainstream agency providing outreach services to people of color. This model represents a special effort to reach communities of color without acknowledging the oppression that these communities often encounter or taking into consideration their cultural norms and values. This method reflects the "color blind" approach and is often used by agencies beginning to look for ways to improve service delivery to communities of color.

Mainstream agencies supporting services by people of color to people of color is a method still considered to be relatively new. This method is supported by the belief that communities of color are best served by "their own", including trained natural helpers. Further, it is believed that mainstream services and workers may inadvertently perpetuate the oppression of people of color through institutional racism.

The research, as well as anecdotal reports, strongly suggests the need for agencies to provide *bicultural and bilingual services*. This model suggests that cultural and linguistic barriers are more effectively handled with multi-cultural and multi-lingual staff. Staff that identify with more than one culture and speak more than one language are more likely to be better equipped to work effectively with a wider range of clients. In addition, clients are more likely to respond positively to staff from the same or similar culture.

Culturally focused agencies providing services to people of color have increased over the past decade but have experienced continuing economic challenges. This model is based on the belief that communities of color know what they need and are better equipped to meet the needs of their communities than are mainstream agencies. The lack of mainstream involvement reduces the possibility of racial oppression or paternalistic modes of operating. The three models that support cultural values support the notion that mental and emotional health increases when cultural dissonance is decreased.

Agency selection

During phase 1 of the study, 77 organizations were nominated for exemplary practice in the area of cultural competence. The nominations came primarily from African American mental health service providers (across a variety of disciplines including social work, psychiatry,



psychology, and nursing), as well as from consumers and family members, agency administrators and university researchers. Seventy-five of the seventy- seven organizations were contacted between September 1 and 11, 2001 and asked to complete and submit a 7 page survey that sought additional information about their operations. Seventeen of the 77 organizations responded. Despite the low return rate, information received from the 17 agencies was valuable and was often accompanied by supporting agency-related documents. Respondents gave thoughtful, concise information.

Agency 2

Size: 12 million (budget) **Auspice:** Private/Non-profit

Geographic location: Mid-West

Cross cultural service adaptation: Culturally focused organization provides services to people

of color

Mission

Agency 2 summarizes its mission very simply---to promote the physical and mental health of residents living in the metropolitan area with emphasis on the five communities in the Cook County area. They seek to fulfill their mission by providing high quality, culturally sensitive, state-of-the art, evidence based, innovative services. Their mission statement reflects a value for "principle-based management" tied together by teamwork and interdependency. The mission statement is supported by a philosophical statement that is committed to the prevention and early detection of mental health issues in minority communities. The philosophy contains a strategy for meeting the identified goals.

Background and history

Two African American medical doctors established this agency in 1975. It started as a day treatment program and was initially designed to augment inpatient psychiatric services at a Cook County hospital. It has expanded to three satellite offices and serves thousands of clients each year.

Governance & board structure

The organization is headed by a President/CEO and guided by a 23 member board of directors. The leadership of the board consists of 8 officers and 15 members. The board members are primarily African American but reflect a range of community members including consumers of mental health services.

Geographic area

This organization is located in Cook County, a county with 5 million residents. The county is home to approximately 42% of the 12 million residents of the state of Illinois. The population of African Americans in the state is 15.1% while the population of Cook County is 26.1%.

Target population

Currently, this multi-service agency primarily serves adults (85%) with a variety of problems such as with mental illness, substance abuse, and domestic violence. Ten percent of their clients are children and five percent are adolescents. The majority of clients served are female (60%), African American (95%), and indigent. The average annual income is approximately \$5000.



Services/Programs

Their primary focus is outpatient care with a specialty in psychiatric emergencies. A range of services is offered within specific programs.

The Child/Adolescent Program

- services offered to youth ages 4-17
- youth are often severely emotionally disturbed, have witnessed violence, or have been victims of abuse, assault, or trauma

Emergency Psychiatric Services

- emergency services available through crisis triage program located in local hospital emergency room
- assessment, diagnosis, treatment, and referral available 24 hours a day
- case management and aftercare services a strong component of the program

Intensive Day Treatment

• provides intensive psychiatric aftercare services to recently hospitalized people with mental illness or those at risk for re-hospitalization.

Screening & Outpatient Services

- provides continuing care to those at risk of hospitalization
- focus is on medication management, case management, independent living, personal productivity, and counseling

Psychosocial Rehabilitation

- individual and group counseling services available
- vocational training programs available
- day treatment and outpatient services targeting dually diagnosed adults and individuals with mental illness and substance addiction

Residential Program

- provides supervised housing and transitional living facilities for adults with mental illness
- provides basic living skills, counseling, support groups, and resource linkage

Rehabilitation and Employment Services

- offers a full range of vocational options
- offers employment readiness, job seeking skills classes, and job placement assistance
- classes offered that lead to the Adult Basic Education certification and the G.E.D.

Consumer and family involvement

Consumer involvement is considered central to the treatment/intervention plan, as is the involvement of family. Definition of family is not limited to the traditional definitions of "family" but includes extended family members as well as individuals who may not be related to the patient by blood or marriage. One of the consistent underlying philosophical and service



goals is to strengthen the family.

Staffing: size; composition; recruitment & training; retention

The agency has 375 employees lead by the President/CEO and includes a diverse group of professionals who perform as psychiatrist, clinical therapist, case managers, social workers, program managers. The staff is an appropriate reflection of the client population and the agency's philosophy that African Americans should take the lead in providing mental health services to the African American community. African Americans comprise 95% of the management /leadership, the direct service staff and the support staff.

When clinical staff do not reflect the culture of a specific client system or meet the needs of a client, services are contracted through pre-established alliances in the community. Recruiting assistance from the indigenous community has become an effective strategy for overcoming barriers to service provision.

Much effort and energy appears to go into recruiting and hiring mental health professionals that ascribe to the agency's commitment to the practice of community psychiatry and mental health. Many residents and medical students are trained through the agency and given hiring priority upon completion of their studies. When staff are hired, a substantial investment is made in their professional development. All new staff are required to participate in a four month training that covers a variety of clinical and community issues. After the orientation period is over, professional development plans are developed by the individual needs of each worker. Workshops and training on cultural and linguistic competency are made available to staff frequently throughout the year.

Funding

Funding for programs and services come from a variety of sources including the United Way, Medicaid, private insurance, research grants, city and county funding, and annual fundraising events. Funds are also received from large federal research grants.

Evaluation efforts

There is a heavy emphasis on empirically established research studies. Agency leaders feel that little is known about mental health issues in the African American community and well planned and implemented research can provide solutions. The agency has a strong desire to introduce evidence-based materials to the community and is doing so through strong ties with a local university. A small research department is maintained within the agency and is responsible for doing "culturally relevant research". This department also takes the lead on process evaluations and consumer satisfaction research.

Key issues facing the African American community

The agency reports that the key issues facing their community include:

- Absence of basic information about mental health among community residents
- lack of empirical knowledge about mental health in the African American community
- lack of resources for mental health services in ethnic minority communities
- limited resources directed toward research relevant to African Americans with mental health problems (i.e., impact of racism on mental health and psychiatric mis-diagnoses)



Poverty and community violence

Challenges in implementing culturally competent practice

- Resistance to the philosophy of cultural matching
- Lack of funding
- Professionals that arrive with traditional notions of mental health service delivery

Unique aspects of agency 2

- Culturally focused emergency psychiatric assessment and treatment
- Research dedicated to the mental health issues facing African Americans
- Ethnocentric training established for doctors, interns and other mental health professionals

-

Factors that account for success

This and the other 3 agencies credited 18 factors for their clinical success with African American clients. Factors mentioned by 50% or more of the agencies are listed below:

- 1. Understand help seeking patterns of African American clients and other clients of color
- 2. Use staff/helpers that reflect culture of clients
- 3. Implement cultural competency in policy, procedures, assessment and service
- 4. Understand the importance of religion/spirituality
- 5. "Break down" the clinical language-----be real
- 6. Involve clients in their own care
- 7. Location, location, location
- 8. Maintain a strong presence in the community
- 9. Be accessible to the clients and their families
- 10. Use culturally grounded assessment instruments
- 11. Use "one stop shopping" single point of entry
- 12. Have a strategic plan for cultural competency
- 13. Incorporate cultural competency from the top
- 14. Expect and prepare for difficult interactions (dynamic of difference)
- 15. Pay attention to recruiting and hiring ethnic minorities
- 16. Establish access to flexible funds
- 17. Be flexible in approach to services
- 18. Use innovative capacity building strategies



Cultural competence assessment tools

Cultural Competence Self-Assessment Instrument

<u>Citation:</u> Child Welfare League of America, (1993).Cultural Competence Self-Assessment Instrument. Washington, DC. (Can be ordered online at: www.cwla.org)

Cultural Competence Self-Assessment Questionnaire: A Manual for Users

<u>Citation:</u> Mason, J.L. (1995). Cultural Competence Self-Assessment Questionnaire: A Manual for Users. Portland, OR: Portland State University, Research and Training Center on Family support and Children's Mental Health. (Can be ordered online at: www.rtc.pdx.edu)

Cultural Competence Scorecard for Mental Health Facilities

<u>Citation:</u> Saldana, D. (1997). Development of a Cultural Competence Scorecard for Mental Health Facilities. Paper presented at the Seventh Annual National Conference on State Mental Health Agency Services Research and Program Evaluation.

Culturally Competent Service Outcomes Assessment Tools; Clinical, Administrative & Fiscal Performance Assessments

<u>Citation:</u> Myers (1995). Culturally Competent Service Outcomes Assessment Tools: Guidelines for Upgrading Quality Assurance. Ohio Dept. of Mental Health, Consumer Services Division.

A Practical Guide for the Assessment of Cultural Competence in Children's Mental Health Organizations.

<u>Citation:</u> Roizner, Monica (1996). A Practical Guide for the Assessment of Cultural Competence in Children's Mental Health Organizations. Boston, MA: Judge Baker Children's Center.

System of Care Practice Review: Manual and Protocol

<u>Citation:</u> Hernandez, M. and Gomez, A. (2001). System of Care Practice Review, University of South Florida.

Key definitions

Africentric perspective (also spelled Afrocentric) — A perspective that places people of African descent at the center of understanding and intervention. This perspective highlights African beliefs, values, and mores that have survived years of slavery and oppression.

Acculturation – Cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture; a merging of cultures as a result of prolonged contract.

Cultural awareness- being cognizant, observant, and conscious of similarities and differences among cultural groups.



Cultural sensitivity – Understanding the needs and emotions of your own culture and the culture of others.

Culture – refers to beliefs or practices that are shared and learned within a group, not necessarily defined by race.

Ethnicity – Defined as the representation of a common origin, shared culture, and shared activities. The defining elements include language, religion, race, and ancestral homeland. "A social-psychological sense of peoplehood in which members of a group share a unique social and cultural heritage" (Stanley Sue, et al, 1995).

Ethnic sensitive practice – involves an emphasis on and valuing of the unique worldview, distinctive history, strengths, and efforts towards self-determination of individuals from ethnic groups.

Race – a social construction with little direct biological significance. It is not a static, genetically based characteristic. There is more genetic variation within than between races.

Internet resources

African American Mental Health Research: www.isr.umich.edu/rdgd/prda/index.html

Association for Multicultural Counseling and Development: www.counseling.org

Association of Black Psychologists: www.abpsi.org

Black Health Network: www.blackhealthnet.com

Cross Cultural Health Care Program: www.xculture.org

Diversity Rx: www.DiversityRX.org

National Association of Black Social Workers: www.ssw.unc.edu/professional

National Black Child Development Institute: www.nbcdi.org

National Multicultural Institute: www.nmci.org

National Center for Cultural Competency: www.gencd.georgetown.edu/nccc

Office of Minority Health Resource Center: www.omhrc.gov



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Chapter 4

Formulating an Outreach Plan

The following steps will aid you in successfully starting an outreach plan:

1. Reach consensus

In order to begin planning for your outreach activities, it is necessary to develop an agreement within your organization to embark on an outreach effort. This phase is crucial to the future development of your project. This is because outreach activities often appear attractive "in theory" to affiliate members when, in actuality, such efforts can be quite time consuming and demanding. For these reasons, it is imperative that unanimous or near-unanimous agreement exists among the membership that an outreach effort is needed and desired.

Steps to follow:

- Hold a series of meetings to discuss the idea of engaging other communities.
- Be very clear and honest about the pros and cons of developing such an effort.
- Be aware that some of your affiliate's members may be hesitant to openly express their reluctance or disagreement with the decision to conduct outreach activities.
- Encourage open discussion. It is important that everyone is given a chance to express negative feelings about the potential of doing outreach, without fear of being accused of insensitivity to the needs of diverse communities.
- Even if the group is unable to reach a consensus about embarking on the effort, you will gain awareness of which affiliate members are enthusiastic about the effort and which have some reservations. Allowing everyone's opinions to be heard will help to ensure that as many members as possible "buy-into" the plan.

2. Identify the target group

Be realistic and specific when choosing a community. Your outreach plan will be based on the specific segment of the community that you want to reach. For example, if you decide to reach educated and upper class African American families, the strategies that you need are different than the strategies that you would use when reaching African Americans in the inner city.

3. Study the community you want to reach

Once your affiliate has discussed and decided to reach the African American community in your area, you need to learn as much as you can about this group, its characteristics and history. The more you know about your targeted audience, the more successful you will be



at engaging them in meaningful ways. Read as much as you can about your target community in order to become more familiar with it.

4. Cultural mapping

Cultural mapping is an approach used to identify the characteristics of a community's resources and features. When you finish your cultural map you will be familiar with your target community.

In order to do your cultural map, identify some community members to help you navigate it and who can also respond to your questions. Make sure these respondents are part of the community and that they are able and willing to share their knowledge with you. These people can help you determine where to go, who to contact, how you should interact with the group, what type of questions you can ask, what is culturally appropriate, etc. Remember to enter the community with humility and be ready to learn about it. It is important that you enter the community with a clear agenda of what you want to learn from it. This will help you stay focused, not feel overloaded with information, and to not seem as if you are "watching" or "studying" it. Below and on the following pages are examples of questions that you should respond to in order to map the group you are targeting. Be as specific as possible.

Identify the location of this community

- In your city, which are the predominantly African American neighborhoods?
- What are the characteristics of these neighborhoods?
- Are they safe neighborhoods?
- Are they quiet neighborhoods?
- What is the neighborhood area like?
- What are the boundaries of the neighborhood?

<u>Identify community organizations</u>

- Where do community members congregate?
- Where are the schools, hospitals, community centers, and churches?
- Are there any community-based organizations?
- What types of social services are available?
- Are there any neighborhood associations?
- Are there other less formal social groups? (e.g. clubs, fraternities/sororities, gangs, book

clubs, etc)

- What do these organizations and clubs do? What needs do they address?
- Who runs these organizations?
- What are some important businesses patronized by community members? (e.g. beauty salons, restaurants, grocery stores, etc.).

Identify community leaders

- Who are the community leaders? (e.g. pastors, local legislators, commissioners, teachers, school counselors, business owners, artists, professionals, media personalities, etc.).
- What other leadership roles are evident?
- List leaders by name and location.

Identify prevailing beliefs expressed by the community

- Is it a largely religious community?
- What are the community's symbols and ceremonies?
- What is the community's relationship with the rest of the population?
- What other characteristics and beliefs do community members have?

Identify community beliefs towards mental illness

- Is the community aware of mental illness?
- What are the levels of stigma about mental illness?
- Is there discrimination toward people with mental illness?
- Does the community have information about mental illness?
- Does the community see mental illness as an important issue?
- If this NAMI group were truly representative of the population of this community, how might its support and advocacy functions expand or change?

Identify community needs

What are the major issues that affect this community?

What are the priorities of the community?



What are the biggest needs of the community?

Where does mental health fit within the community framework?

Compile the answers to all of these and any other questions that you think may be important and share them with your group. The answers to these questions will help you in your planning and strategizing process.

5. Identify key community leaders

Thanks to your cultural map, should be able to identify key community leaders. Approach those leaders who could partner with you. Cultivate relationships with them. It might take time to gain their trust but it is essential to have their support and buy in.

These leaders are your community experts. They should be part of the entire outreach planning process. They can help you identify the community needs and how to successfully reach the group. Because they are respected and recognized by the group, these leaders can help you gain access, trust, or attention from the group.

6. Formulating your basic outreach plan

Your next meeting should involve members of your affiliate along with your informants, your key community leaders and any other members of your target community who are willing to provide you with feedback and suggestions.

It is important to involve community members at *this* stage, in order to ensure that plans are relevant, responsive to the community's needs, and as culturally meaningful as possible. It was not suggested that community members attend the initial planning meetings, because their presence may inhibit people who are opposed to the effort from making their feelings known to the group. However, at this point, affiliate members will have been given ample opportunity to air their opinions and concerns, and the attendance of community members can enrich the planning process without stifling opposition.

7. Decide the major focus of your activities

One of the most important parts of developing your outreach plan involves deciding on the major focus of your activities. Traditionally, NAMI's focus areas include: education (Family to Family, Peer to Peer, In Our Own Voice, Visions for Tomorrow and other education programs), support groups (family and consumer oriented), and advocacy on behalf of people with mental illness and their families, through lobbying for better services and a more responsive mental health system.

The decision about which components to include in your plans is totally up to you. It is important to solicit the opinions of your community members to help you make this decision. For example, they may feel that establishing support groups is more important than recruitment. A sole focus on recruitment may convey the impression that you are only



interested in increasing the size of your dues-paying membership and not in meeting the needs of your target community. Also, members of your target group may not have the financial resources to pay affiliate dues. If recruitment is a major goal of your project, consider offering free membership for a year to demonstrate your sincerity and give people an opportunity to see what you can offer before they are asked to contribute financially. As another example, your African American advisors may feel that their community needs education more than it needs advocacy. Listen to their opinions carefully because they are in the best position to accurately assess needs.

After considering their opinions, your members' preferences, available monetary resources, and the natural talents of your affiliate's members, you will be in a good position to map out the components that you want to include in your planning.

At the end of this section we highlight different successful NAMI outreach activities. For more information about these plans, please contact the identified NAMI leaders.

8. Identify specific goals

After making decisions about which components will be part of your plan, it is time to identify the specific goals that your activities will address. You should try to identify one or two goals for every component. Keep in mind that goals are statements that say exactly what you expect to accomplish through each component. For example:

COMPONENT POTENTIAL GOALS

Education

- Creation of culturally and linguistically appropriate pamphlets about the causes and treatment of mental illness.
- Creation of a videotape explaining different types of psychotropic medications and their side-effects.
- Compilation of a resource book containing the names, addresses and telephone numbers of all African American mental health treatment professionals and agencies in the community.

Ethnic-Specific Support Groups

- Establishment of an African American family support group.
- Encouragement of attendance at a support group without requiring membership in NAMI.

Recruitment

- Sponsoring the first year of NAMI membership for low-income community participants.
- Setting a target of increasing African American membership by a specific proportion.
- Making a commitment to increase the representation of African Americans on an affiliate's board of directors.

Advocacy

- Lobbying state government officials to increase funding for mental health services in the target community.



- Making surprise visits to state inpatient psychiatric facilities serving African Americans to assess conditions.

The aforementioned are examples of the many types of goals that your group may identify in your planning process. The exact nature of your goals is not as important as the requirement that they be specific and realistic outcomes of your activities. Start with a potential set of goals, but do not be afraid to add or subtract goals as you proceed in your efforts.

9. Create a community coalition

NAMI leaders know how limited resources are. We have limited funds, volunteers, staff, and expertise. Alone we cannot fix the problems faced by the African American community. For this reason, we must establish coalitions with local community organizations in order to unite our resources. Partnerships with African American organizations will benefit NAMI as much as it will benefit these organizations.

Example:

NAMI's Multicultural Partner Coalition

NAMI's Multicultural Action Center is bringing together a cadre of national and international partners to join NAMI and its members in meeting the mental health needs of individuals from diverse communities. The primary role of the NAMI Multicultural Partner Coalition is to support community organizations and NAMI organizations in grassroots activities aimed at addressing mental health needs of racial, ethnic and cultural minority groups. The NAMI Multicultural Action Center works to improve education and understanding of mental illness and to ensure access to quality treatment and services for racial and ethnic minorities and other under-served groups.

By developing and maintaining relationships with organizations that already meet many of the needs of these individuals, NAMI Multicultural Partners will provide immediate access to community members and opportunities for improved understanding and policies addressing the research, treatment, services and support needs of these communities. We are partnering with organizations with a particular interest in engaging their affiliates/members locally to meet community needs.

NAMI Multicultural Partner Coalition members will also act as advisors to the Center on strategic initiatives and opportunities. The goal is to ensure that people from all races, cultures and ethnic groups with mental illness receive the best and most appropriate treatment and services that are available. We hope to eliminate stigma and discrimination, shape governmental policies to better meet the needs of people with mental illness and their family members and ensure that these individuals live with dignity and respect regardless of their ethnic, racial or cultural identities.

Partner benefits:

• Networking with multicultural and multinational coalition members



- Assistance with addressing mental health needs of organization constituents
- Collaboration on community projects with NAMI's state organizations and local affiliates
- Use of NAMI's educational materials for coalition organization's constituents
- Collaboration on special projects
- Potential for joint funding opportunities
- Access to leading information on mental illness
- NAMI support of advocacy issues relevant to diverse cultures, races and ethnic groups
- Co-sponsoring of special events

10. Funding for your outreach effort

The next issue to consider as you proceed with your planning is how you will fund your activities. This is no easy question given that funding is limited. Some options are:

- Organize fundraising efforts such as street fairs, NAMI Walks, concerts or auctions.
- Commit a proportion of the operating budget (typically derived from dues paid by members) to pay for outreach activities.
- Obtain funds from state or local (city or county government) mental health agencies, child protection, or health agencies.
- Apply for funds from the federal government.
- Apply for funds from local philanthropic foundations such as Community Trusts or the United Way.

Given the limited funding available, it is a good idea to be aware of funding issues at the outset of your planning. However, you may wish to begin developing your plan in the absence of identified funding. This way you can establish an "ideal" set of activities and fund those you find you can afford as you go along. Having plans in place puts you in a position to apply for money once you learn it is available rather than starting from scratch after you learn of potential funding mechanisms.

11. Dissemination and publicity

A final aspect of your planning should cover the ways in which you are going to inform others about your activities. The most important group you want to engage is the community to which you are outreaching. You should pay close attention to how you are going to let community members know that your program is operating and what it has to offer. Another target for dissemination are African American mental health professionals and mental health treatment programs serving predominantly African Americans. These individuals and organizations are crucial to your success because they, in turn, can help you reach members of your target community. Still another target groups for dissemination are local community organizations such as churches, ethnic clubs, sports facilities, and public educational institutions. Many people can be reached through groups such as these, and you should have identified them in the early stages of your planning process.

Finally, if time and resources allow, you should make plans for a public relations campaign



that accesses the media most familiar to your target community. You should plan to create press releases, public service announcements, and short newspaper articles detailing your efforts. Also, consider appearing on local television programs that cover local activities and events. Identify media outlets that are frequently used by members of your target community; advertising your program in culturally appropriate media will ensure that information reaches the people you want to inform.

12. Evaluation

Whatever activities the group decides to include in their outreach project, they should plan to evaluate them. The basic idea of evaluation is to gain an understanding of how well activities worked and how participants perceived them. This kind of feedback can then be used to redesign program components that were unsuccessful and to improve activities that were successful. Another reason to evaluate activities is to show potential funding agencies that the project is successful in accomplishing its goals.

It is suggested that evaluation plans include at least the following two: client (or participant) satisfaction surveys and outcome assessments.

Satisfaction surveys

A major requirement of using a satisfaction questionnaire is that people should be easily able to receive, complete, and return it for analysis. One relatively foolproof way to administer questionnaires is by handing them out at the end of an event while people are still gathered together, asking the group to complete them, and then collecting them as people leave.

The questions or statements to which people respond on a satisfaction questionnaire are called "items." Some items force the respondent to choose between a number of pre-specified answers; these are referred to as forced-choice items. Some examples of this type of item include: true/false questions or statements with which the reader "strongly agrees," "agrees," "disagrees," or "strongly disagrees." Another kind of item asks for a written opinion or statement from the respondent; these are referred to as open-ended items. Some examples of open-ended items include: those which ask individuals to say what they liked or disliked about something and those which ask for suggestions for improvement of a program or service. It is a good idea to include both types of items in any satisfaction questionnaire you design.

Outcome assessment

Another type of evaluation to consider is to measure the degree of change that occurs as a result of the project's activities. This is a way to measure the outcome of efforts. In order to assess change, however, it is important to measure a desired outcome <u>before</u> the project begins and again at some point in time <u>after</u> activities have occurred. For example, suppose one of the project's goals is to increase the number of calls for information received from the target population. Here, an assessment will want to measure the volume of calls from



Latinos before outreach efforts begin and then after efforts are underway. Another type of pre- and post- project evaluation would concern outcomes such as the proportion of people of color serving on the group's board of directors before and after the project begins or the proportion of group members who are people of color before and after your project begins.

Whatever type of evaluation the group conducts, remember that the most important considerations are that they are done accurately and fairly.

Summary

By the end of your planning process, your group will have accomplished several major objectives:

- You will have dealt with the question of whether or not to embark on an outreach program.
- Identified a target group, found a key informant, and mapped the community.
- Formulated your basic outreach plan.
- Identified potential funding for your activities.
- Planned for publicizing your efforts to target community members, professionals, and others.

The next steps involve planning and actually implementing some specific outreach strategies. What follows are brief descriptions of successful outreach strategies and exercises that will aid you in your planning process.



Church-Based Support Groups for Families of Persons with Severe Mental Illness

Background and purpose

Studies have shown that support group participation improves families' ability both to care for their relative with severe mental illness and to cope with problems related to the illness. Compared to Caucasians, African American families have more caregiving needs; however, few African American families attend support groups. Recent literature has suggested that efforts to increase these families' support group participation should include the church, a resource many African Americans turn to in times of distress.

The goal of this project, which is supported by the <u>Great Cities Faculty Seed Fund</u>, is to examine support group participation outcomes for African American families attending church-based support groups. To accomplish this goal, Dr. Susan Pickett-Schenk is working with family support group leaders from the Community Mental Health Council and church members from two African American churches located on Chicago's south side. Project activities focus on outreach to families at each congregation and assessment of support group participation outcomes.

Outreach activities include:

- Distributing educational materials about mental illness and its treatment to church members.
- Advertising support group meeting dates and times in church bulletins.
- A Sunday afternoon workshop in which an African American psychiatrist presented information on the causes and treatment of mental illness. Families and mental health consumers then shared their stories.
- A toll-free telephone hotline
- Guest speakers at support group meetings

Assessment activities were conducted from May through June 1999. Church leaders will complete surveys measuring the extent to which the support groups have been beneficial to their congregations. A total of 26 support group members completed interviews measuring group participation outcomes. The following support group participation outcomes were assessed:

- Knowledge of the causes and treatment of mental illness
- Problem-solving ability
- Morale
- Receipt of help from the support group
- Emotional distress related to caring for the ill family member



- Relationship with the ill relative
- Service use
- Satisfaction with the support group and outreach activities

Results indicate that advertising group information in the church bulletin and families sharing their experiences with other congregants may be effective outreach strategies. Nearly all of the support group members who participated in the study (91%) stated they increased their knowledge of the causes and treatments of mental illness and the mental health service system as a result of attending the church-based support group. Increased morale was a group attendance outcome for 70% of project participants. These results suggest that church-based support groups may be a valuable coping resource for African American families of persons with mental illness.

Related materials

Pickett-Schenk, S.A. Church-Based Support Groups for African American Families Coping with Mental Illness: Outreach and Outcomes, <u>Psychiatric Rehabilitation Journal</u>.

For more information contact:

UIC Mental Health Services Research Program 104 South Michigan Avenue, Suite 900 Chicago, IL 60603 USA (312) 422.8180 (312) 422.0740/FAX (312) 422.0706/TDD



Connecticut Department of Mental Health and Addiction Services Office of Multicultural Affairs Services Addressing The African American Population

AMIR - African American Men in Recovery

This project, a federally funded, three-year culturally specific program for African American men at Community Health Services, Inc., in Hartford, Connecticut includes outpatient treatment, community and individual outreach, case management, peer mentoring, and aftercare. When the three-year federal funding ended, CHS incorporated the AMIR model into its agency operations as an ongoing program. The mental health services at CHS are made available to AMIR in the context of AMIR.

Amistad Village Project

Another federally funded, three-year culturally specific program for African American men are provided collaboratively at MAAS (Multicultural Ambulatory Addiction Services of CASA, Inc.) and The Hill Health Center Inc, in New Haven, Connecticut. Services include outpatient substance abuse treatment, community and individual outreach, case management, peer mentoring, and aftercare. Mental health services, as needed, are provided at Hill Health Center or another other culturally appropriate services for African Americans (e.g., CMHC).

PACCT - Project for Addiction Culturally Competent Training

Provides culturally competent training for 60 to 70 African American and Latino individuals annually for entry level development of African Americans and Latinos in Substance Abuse counseling. The outcome will be an applicant pool for the behavioral health field in Connecticut. PACCT is a four-year program that will train approximately 140 African American men and women in substance abuse counseling. OMA facilitates 20-week practica for PACCT students, as well as ongoing PACCT education and training which includes development in knowledge and skills that address co-occurring disorders.

Man in the Mirror

Example of a project developed in training that continues to impact delivery of Mental Health services to African American Mental Health Services in Western Connecticut Mental Health Authority in Danbury, Connecticut.

"9/11" Federal Trauma Funds

DMHAS/OMA coordinated funding resources to meet needs related to trauma for the underserved populations: African American, Southeast Asian, Cambodian, and Latino.



Amistad Village Project Conference

In October 2003, The Conference On Providing African American Culturally Competent Services was presented in New Haven's Omni Hotel. The conference was based on lessons learned in Amistad Village Project.

DMHAS Annual Multicultural Training

Behavior health clinicians and supervisors receive 96 hours of cultural competence training and develop projects that are replicable in the statewide regions. A diverse group of selected students learn clinical cultural competence with a major emphasis African American culture as well as other under-served populations.

Cultural Celebrations

Celebrations of African American role models, Black History Month, Latino and other cultural histories are expected as part of implementing Cultural Competence Plans required of all 145 funded providers and State operated behavioral health hospitals and agencies.

For more information contact:

Arthur C. Evans, Ph.D.
Deputy Commissioner
CT Dept. of Mental Health & Addictions Services
410 Capitol Ave.
P.O. Box 341431, MS#14COM
Hartford, CT 06134
860-418-6958



NAMI Prince George's County African American Outreach

NAMI Prince George's County, MD (NAMI PG) has historically maintained a program open to all of the county's citizens. It has offered its services and encouraged participation in its activities by all persons and families impacted by mental illness, regardless of age, gender, race, ethnicity, disability, and sexual preference. NAMI PG's Board of Directors is charged with management of the Affiliate and with responsibility for adherence with the NAMI policies and strategic plan. In keeping with Strategic Goal #3 of NAMI's Strategic Plan, NAMI PG has provided African Americans, as well as other diverse leaders, leadership roles and opportunities in every facet of the organization. NAMI PG's emphasis on inclusion of African Americans is important because the Affiliate is located in a County that is heavily populated by African Americans.

Although the organization was always open to African Americans, in 1992 the Affiliate's leadership convened a Steering Group to revitalize the organization. The small Steering Group included three African Americans. The resulting Board of Directors of nine persons included three African Americans. A study of the key result measures indicates that since 1992, NAMI PG's Board has never had less than three African Americans, and for several years six of the nine Board members were African Americans. African Americans hold other key positions, to include Committee Chairpersons, Support Group Facilitators, and representatives to external organizations involved in mental health care, anti-stigma activities, crisis action teams, forensics, and training.

African Americans are involved in and vital to the success of each element of NAMI PG's program, which includes mutual support, understanding, advocacy, encouragement, information and education. A summary of the key activities and programs provided, promoted and available for African Americans follows:

Support groups:

NAMI PG operates two support groups. Each of the two meets monthly and among the attendees are African Americans. The Facilitator for one of these groups is African American and the majority of the attendees are African American.

Workshops:

NAMI PG conducts a workshop each month of the year except August. The Board approves the workshop topics with input from the membership. The workshop attendees are diverse and often the majority of the participants are African American. Each year at least one topic addresses multicultural subjects and the importance of outreach to a diverse community.

Newsletter:

NAMI PG publishes a monthly newsletter. There is a conscious effort to include news articles



and general information of interest to a diverse population. African Americans are writers and contributors to the newsletter.

Advocacy:

Examples of advocacy include: Participation in state/county work groups, testimony during budget hearings at the Maryland General Assembly about the need for funding for adequate services for persons with a mental illness, and support for legislation that will improve the care for persons with a mental illness.

Education/information:

In addition to the workshops, NAMI PG has implemented NAMI signature programs such as Family-to-Family and In Our Own Voice. Several of the Instructors and many of the participants in the programs are African American.

Outreach:

NAMI PG has participated in training for Ministers and religious organizations. The training was conducted in one of the largest African American churches in the county and the participants were predominantly African American. African American members of NAMI PG serve as speakers before diverse groups in several areas of the county.

Sunrise publications:

NAMI PG publishes pamphlets and brochures about coping with mental illness. All Sunrise Publications authors are authoritative sources of information and their work is done on a voluntary basis. The pamphlets and brochures are sold for a nominal fee and are well suited for educating African Americans. African Americans have purchased many of the publications.

For more information contact:

NAMI PG County 301-577-6026



NAMI Ruston — Greater Hope Program

NAMI Ruston, Louisiana developed "Greater Hope" – A family education program designed to break down barriers and myths within the African American community regarding mental illness. The characteristics of this program are:

- Devised goals of the program based on a community survey identifying issues in need of improvement within the African American community, regarding the community's views of mental illness
 - Targeted college students at Grambling State University, a predominantly African American College by offering depression screenings, symposiums, and open invitations to join NAMI Ruston
 - Provided opportunities for students to become educators and support group facilitators
 - Focused efforts particularly on students with an interest in health, education, social work and psychology
 - Met on a quarterly basis with the affiliate president to determine continued outreach efforts
 - Scheduled events to coincide with other large campus events, such as Homecoming, in order to increase attention and publicity
- Opened "Greater Hope" program to all families in the area
 - Extended outreach efforts to religious figures, due to a tendency in the African American community in the area to rely to religious figures for emotional support and guidance
 - Engaged local pastors though a faith building forum
 - Creating an education tract for church leaders and church members for future use
- Sponsored a regional mental health symposium that included state and regional practitioners to discuss trials, trends and treatment strategies in mental health geared towards specific populations

For more information contact:

Gloria Mays NAMI Ruston 318-251-1233



NAMI South Carolina Reaches Out to the African American Community

Project goal: To revitalize a predominately African American affiliate

Overview

NAMI Batesburg-Leesville, one of seventeen affiliates in South Carolina is located approximately 30 miles outside of Columbia S.C. city limits; the total population is between 35,000 and 40,000 and 64.4% Caucasian, 34% African American, 24% Asian, and 1.46% Latino.

This affiliate was formed in 1992, with an average membership of 10 families. The affiliate held monthly meetings, but offered no NAMI education programs, very few invited speakers and virtually no support groups.

The presiding officers, having been in office since 1994 were weary and afraid that if something was not done soon the affiliate would disintegrate. The president, who is a family member and caregiver, was exhausted and wanted to resign. With no replacement in sight she was deeply concerned. For the last two years the membership went from 14 members to seven members by June 2002.

The concept was to revitalize this primarily African American NAMI South Carolina affiliate through an awareness campaign, designed to educate the community regarding the presence of NAMI, with the goal of offering a Family-to-Family education program, and then ongoing support and outreach.

Community endorsement

The kick-off event was a Town Hall Meeting, attended by fifty people. Attendees were ministers, schoolteachers, registered nurses, a police officer and a City Council Representative.

A Town Hall Meeting is one of the best places to get all of the town leaders in one place at the same time. This is a great time to share stories and information about NAMI's Education programs, to create interest and most importantly, to assess the needs of the community. Ideally, the meeting should include local clergy, police chiefs, the mayor, elected officials, mental health officials, business leaders, schoolteachers, radio personalities and the local newspaper. A Town Hall meeting is an open door to families in the community.

Marketing

• In order to make the event successful, contact the local mh center and/or chamber of commerce, obtain a list of churches, businesses and elected officials in the area.



- Make telephone contacts to gather interest in your project.
- Mail NAMI brochures to your contacts.
- Mail invitations to the Town Hall Meeting.
- Present the information at the event. For example discuss why you are having the event and other topics such as stigma and faith as they relate to mental health in the community. Family members and/or consumers are excellent choices to do these presentations.
- Give out NAMI information packets including NAMI brochures, *The Advocate*, legislative information, membership applications, and a form for feedback.
- Make sure sign-up sheets for Family-to-Family (F2F) are available.
- Provide banquet style meals, prepared by volunteers so as to minimize costs, and maximize the availability of great food.
- Make this event a big town affair!
- Place an insert inside NAMI brochures advertising the FTF class, send these brochures in mailings to potential interested parties.

Funding

Little funding is needed, as local businesses can be persuaded to provide in-kind donations.

Family support

Offer the Family-to-Family Education program, with an emphasis on Class Graduation. Make the class graduation a great event. This is a good time to praise the class participants, reemphasize to them the need for them to reach other families in the community and the need for them to join NAMI so that they can get *The Advocate*, and newsletters so that they can keep up with the latest information about brain diseases. This is also a time to meet other contacts in the community for future educational classes.

Outcomes

Family-to-Family class results (January 2003):

- a. 40 people responded with interest in taking the class
- b. 21 showed up for class the first night
- c. 17 members graduated from this class
- d. 10 new members were brought into the NAMI family
- e. The class decided to form a support group and continue meeting on class night
- f. 4 class members applied to train to teach Family to Family
- g. 4 class members applied to train to become Support Group Facilitators
- h. 4 class members signed-up to take the next Visions for Tomorrow class
- i. 2 potential Visions For Tomorrow class attendants want to train to teach Visions for Tomorrow, once they have completed the class
- j. A new slate of officers was elected!



Continued outreach

The affiliate undertook additional outreach events, including a yard sale, and a picnic.

Coordinating outreach & keeping up momentum

1. Meet with the group

- a. Speak with the leader before the meeting
- b. Identify your partners
- c. Communicate your goal to the group
- d. Ask for ideas
- e. Assess the needs of the community
- f. Decide what, where and when

2. After you meet with the group

- a. Mail thank you letters to everyone listed on the affiliate's database expressing gratitude for their graciousness
- b. Outline the decisions made at the meeting
- c. Include NAMI brochures with the letter
- d. Ask for their assistance!
- e. Outline the program and decide on a menu
- f. Decide the theme, in this case "Building Communities of Hope Through Education, Support, Advocacy and Faith".
- g. Set a tentative date for the FTF class

For further information contact:

Dorothy G. Whitley NAMI South Carolina Director Affiliate Relations PO Box 1267

Columbia SC 29202 Telephone: 803-733-9592

Fax: 803-733-9593

Dwhitleynamisc@logicsouth.com



NAMI St. Louis Multicultural Outreach Project 1996 to Present

Background

In 1978, the St. Louis affiliate of NAMI was incorporated and embarked on the formal provision of support and education services to families who were coping with serious mental illness. In the early years, the organization accomplished many good things for the people it served. However, due to its marketing strategies, planned or otherwise, the agency primarily served middle to upper middle class Caucasian families. The office and a majority of the NAMI St. Louis programs were offered in communities that provided limited contact with ethnic minority populations, and services were primarily publicized via word of mouth by family and friends. This ultimately translated into a service population that was more alike than different. Ethnic-minority families, particularly African Americans, received minimal services, due in part to location, service delivery, and lack of awareness. Recognizing this disparity and inspired by an organizational desire to expand its service base, in 1996 NAMI St. Louis designed and initiated a program to address the needs of a multicultural community.

Contextual environment & supporting evidence

A majority of the residents of the City of St. Louis are non-White. For Missouri, state-wide, minorities represent 15.1% of the total population, while in St. Louis City 56.2% of residents are non-White (U.S. Census Bureau, 2000). For this urban racial and ethnic minority group, those who need mental health services receive limited or inadequate services.

Project inception

In the summer of 1996, NAMI St. Louis applied for a grant to fund a "Multicultural Outreach Project." Funding was secured and the project was launched. Generally, the focus of this project was to serve families with support and education services that were unique to their heritage and culture. The goal was to do more than simply "wait for families to call or come to NAMI St. Louis." It was time to "look beyond the front door" and go into the community to actively identify families who could benefit from NAMI services, but who may have had limited awareness of or access to these services. Accessible and acceptable programs had to be produced, packaged, and promoted to support the unique experiences and needs of these families.

Project purpose

The purpose of the project is to ensure that culturally diverse and economically disadvantaged families and friends of people with severe mental illness, with or without co-occurring substance abuse, will be effective as caregivers, and primary consumers, through self-support,



by:

- Understanding the cause of, course of, and treatments for severe mental illness/substance abuse:
- Identifying suicide risk factors and knowing how to access suicide prevention services;
- Knowing of and how to access comprehensive resources and services necessary for optimum recovery;
- Being sufficiently stable, emotionally, to provide effective care giving direction to loved ones with severe and persistent mental illness/substance abuse disorders.

Project description

As a result of funding, the oversight of this project has been conducted by paid staff, in concert with the efforts of volunteers. Equally, a community Multicultural Outreach Advisory Council (a standing committee of the NAMI St. Louis board) provides professional and experiential advice and counsel. Through the support and suggestions of the council, a community needs assessment was conducted by a local research center to identify the unique needs of the ethnic-minority caregivers. Ultimately, a Project Marketing (Strategic) Plan was developed to chart annual progress on reaching project goals and objectives.

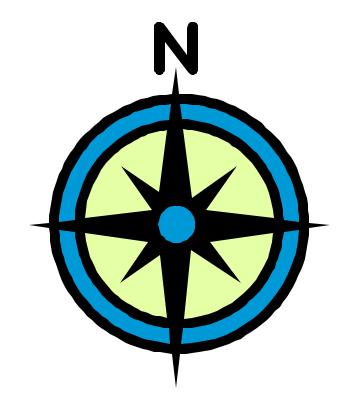
Based on lessons learned through this project, to achieve NAMI St. Louis over-arching goal of inclusive services and improved ability to reach these underserved families, the approach to outreach has evolved. Originally, the focus included marketing and awareness campaigns. Over the years NAMI St. Louis has also engaged in innovative program development and more recently has begun a more assertive campaign engagement and support at the individual family level. Services and programs offered have varied in type and kind, including awareness campaigns and events, formal education programs, support groups, and peer to peer consultation. NAMI St. Louis has collaborated with clergy members, churches, courts, substance abuse programs, community mental health centers, psychiatric hospitals, and other social service agencies. Intermediaries identified through these venues have been instrumental in helping NAMI St. Louis identify families in need and in re-structuring and marketing programs.

For more information contact:

NAMI San Louis Jacqueline A. Lukitsch, MA Executive Director 314-966-6906 jackie@namistl.org



Outreach Planning Pages



Identifying where we are now and where we want to go.....

Complete the following questions to the best of your ability. There is no "wrong" answer, only a way for you and others to determine your group's level of activity.



Where Are We Now?

What does your group offer to persons or family members from diverse communities?
Does your group offer support to minority family members and/or consumers? If your answer is positive, what type of services? Yes No
Do you have special committees that address the specific concerns/issues of the minority population in your area? Yes No
If yes, which committees?
Is your local newsletter culturally sensitive and appealing to minority populations?
Yes No
Do you have materials (fact sheets, membership application forms, etc) in any languages other than English? Do these materials meet needs of local minority community members? Yes No
Do you have education programs or support groups for diverse populations? Yes No
Do you have minority members? Yes No
Approximately how many?
Some things to consider
Pay particular attention to your "no" responses. These areas can serve as good starting points

for your group to consider implementing programs.

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What are the demographics in your area? Is there a strong minority population? Yes No				
Is there easily acces Yes No	ssible public transportation?			
Where does the mir (Please circle all that	nority population in your area lool at apply.)	x to get reliable information?		
radio	newspaper			
television	cinema			
place of wor	rship internet			
peers/family	-			
clinics	professionals (i	.e. doctors, lawyers)		

Some things to consider...

If you are interested in engaging the minority population of members, you must provide attractions tive services and benefits for this population. Review your answers to the above questions. Your answers will help you form the basis for your outreach strategies.



What attracted them to join your affiliate?	
How did your affiliate reach these individuals?	
Why did they remain active?	
Are they happy with their membership? Why? Why not?	
Some things to consider	
Think about ways to make your African American members feel welcome, supported, and	
needed. Structure support groups and program meetings so that all those who attend feel part	
of the group. Find out what your minority members need and try to supply that. Also find out what skills and resources they have so you can get them involved in helping others.	L



Do you have the necessary resources?
Do you have resources to reach the minority population? Yes No
If yes, please list all the resources that you have. Please be specific.
If not, what resources will be needed?
Have you allocated resources through strategic planning/budgeting to minority outreach, Programs, etc.?

Some things to consider...

Once you have considered the best vehicle for communicating with them, it is time to look for tools to help market your affiliate. Refer to the NAMI MAC Web site at www.nami.org for some ideas and contact information.



Where Do We Want to Go?

DEVELOPING A STRATEGIC OUTREACH PLAN TO INCREASE AFRICAN AMERI-CAN MEMBERSHIP

This exercise is designed to help you develop an outreach plan to enhance your outreach campaign. Here you are going to develop a strategy to reach the African American population in your area. The goal of the exercise is to have at least a 10% increase in your minority membership by the end of 12 months.

Remember you are working on a plan that will fit your particular affiliate group, so make certain you choose the best recommendations.

Use the 12-month Strategic Outreach Plan Form.



Twelve Months Strategic Plan

Current number of African American members in your group/affiliate/state organizations				
Your goal is to increase this affili	iate/group by%			
MONTH	Identify what tools and strategies you will use to reach the minority population in your area. Try to approximate costs involved. Include the materials that you will need and the assistance that you will need.			
October 2004				
November 2004				
December 2004				
January 2005				
February 2005				

March 2005	
April 2005	
May 2005	
June 2005	
July 2005	
August 2005	
September 2005	



Enlisting African American Leaders

To reach the African American community in your area, you need to identify what their needs are. To perform a needs assessment, you should partner with community leaders that will help you understand the non-white culture and guide you through cultural differences so that you become culturally sensitive and competent. Community leaders can help you establish bridges of communication and trust between you and the rest of the community.

Identify the African American leaders in your area. mation.	Make sure you have all their contact infor-
How can you establish a working relationship with	them?



Looking ahead

Question: Looking ahead to next year and beyond, what new and innovative ways can you identify to enhance your African American outreach activities? Think of the different approaches that you could use to include potential members in your affiliate activities.

Identify three different outreach approaches:
When an African American consumer or family member contacts you, how could you respond to his/her emotional support needs and provide information about mental illnesses and NAMI in a culturally sensitive manner?
What resources can you provide to African American consumers and their families?

Appendix

- African Americans: Facing Mental Illness & Experiencing Recovery Symposium:
 - Agenda
 - Participants List
- NAMI Multicultural Action Center
 - Technical assistance for NAMI state offices and affiliates
 - Multicultural Partner Coalition. Partners' List
 - Highlighted Partners
 - American Psychiatric Association Dept. of Minority and National Affairs
 - Howard University
 - National Organization for People of Color Against Suicide
 - STAR Center
- Revisiting NAMI's Listening Forum with Black Psychiatrists



NAMI's Multicultural Action Center Annual Symposium Wednesday September 8th, 2004 Washington Hilton & Towers

12:00 AM - 1:00 PM Registration

1:00 PM - 1:10 PM Welcoming Address: NAMI's Commitment to the African American community.

Gloria Walker, NAMI National Board of Directors Mike Fitzpatrick, Executive Director, NAMI National

1:10 PM - 2:30 PM Opening Plenary

Moderator: Roscoe Swann, NAMI National Board of Directors.

Historical & Mental Health Perspective of the African American community.

King Davis, Ph.D.

Executive Director, Hogg Foundation for Mental Health. President, African American Leadership Council.

Research Updates and Culturally Proficient Treatment for African Americans.

Dr. William Lawson

Chair, Department of Psychiatry, Howard University

Accoustic Chocolate: Depression and Suicide Awareness through a Musical

Malik Yoba

Actor

2:30 PM - 2:40 PM BREAK

2:40 PM – 3:35 PM Mental Health and African Americans – Priority Issues

Moderator: Patricia W. Cliff, J.D., NAMI National Board of Directors

The Experience of Trauma in the African American Community

Michelle Clark, MD

Chair, Black Psychiatrists Committee, American Psychiatric Association.

African Americans and Suicide

Dr. Donna Barnes

President National Organization for People of Color Against Suicide.

Dual Diagnosis: Mental Illness and Substance Abuse

Joe Powel

Executive Director, Association for Persons Affected by Addictions, Dallas, TX.

3:35 PM – 3:45 PM BREAK

3:45 PM – 4:40 PM Mental Health and African Americans – Priority Issues

Moderator: Dr. Gloria Pitts, President, Black Psychiatrist of America

Criminalization of African Americans with Mental Illness

Dr. Rahn Bailey

Director of the Law and Psychiatry section of the National Medical Association.

Access to Culturally Competent Mental Health Services

Arthur Evans, Ph.D.

Deputy Commissioner of Mental Health, CT

Greater Hope: An African American Perspective on Mental Illness and Faith

Gloria Mays

President NAMI Ruston

4:40 PM – 4:45 PM BREAK

4:45 PM – 5:40 PM Voices of Recovery: African American Families Speak Out

Moderator: Lynne Saunders, NAMI National

Cynthia Ross

In Our Own Voice Presenter, NAMI San Diego, CA



Frances Priester

Director of the Office of Consumer and Family Affairs for the District of Columbia, Department of Mental Health.

Dorothy Whitley Family to Family Program, NAMI South Carolina

5:40 PM – 6:00 PM Special Reading by Best Selling Author Bebe Moore Campbell

Sometimes My Mommy Gets Angry

6:00 PM - 6:30 PM Networking Session



NAMI's Multicultural Action Center Annual Symposium Wednesday, September 8th, 2004 Washington Hilton & Towers

Beatrice Akinpelu Consumer Advocate 11610 Bardmoor Court St. Charles, MD 20602

Ara Alexander STAR Center 815 Knight St Seffner, FL 33584

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Dorothy Bennett Eli Lilly & Co Lilly Corporate Center Indianapolis, IN 46285

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Pat Bohnet NAMI Howard County - MD 6470 Dobbin Rd Ste C Columbia, MD 21045

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Celia Brown STAR Center 3571 Barnes Ave Apt #6C Bronx, NY 10467

Patrick Brown STAR Center 501 7th Avenue Apt 2F Beaver Falls, PA 15010

Teresa Brown The BET Foundation 1235 W. Street, NW Washington, DC 20018

Tracee Bryant Black Mental Health Alliance 733 West 40th Street Ste 10 Baltimore, MD 21211 Ivy Bullock NAMI DC - STAR CTR 1319 Holbrook Street NW Washington, DC 20002

Patricia Caballero NAMI Dallas - TX 6402 Melody Ln Apt 2151 Dallas, TX 75231

Marie Campos American Association of People with Disabilities 1629 K Street NW 503 Washington, DC 20011

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Winsome Clarke NAMI National 2107 Wilson Blvd St 300 Arlington, VA 22201



Brandy Cobb NAMI Tennessee 256 Miss Helen Circle Brighton, TN 38011

Michael Cohen NAMI New Hampshire 15 Green St Concord, NH 03301

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Sandra Coleman Price Department of Mental Health 712 Bayley Pl SE Washington, DC 20019

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Melissa Downton STAR Center 4753 Weaver Avenue Indianapolis, IN 43227

Beatrice Dunn Changing Attitudes Counseling PO Box 29674 Washington, DC 20017

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Dr. Arthur Evans Deputy Commissioner of MH 410 Capitol Ave MS#14COM Hartford, CT 06134

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NAMI Multicultural Action Center

People of color face life-threatening disparities in access to high quality mental healthcare. Numerous recent reports, including the *Surgeon General's Report on Cultural, Race and Ethnicity* and the Institute of Medicine's report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, point to the great disparities of minority mental health in this country and the resulting toll on our society. NAMI recognizes that diversity goes beyond race and ethnicity, and the Center will strive to represent and advocate for America's broad cultural and life groups that are outside the mainstream.

In response to this national crisis, NAMI created its Multicultural Action Center. This Center works to focus attention on system reform to ensure access to culturally competent services and treatment for *all* Americans and to help and support families of color who are dealing with mental illness. The Center's goals are:

- To advance NAMI's policy agenda and address issues that disproportionately affect communities of color.
- Support NAMI grassroots advocacy and outreach efforts.
- Build diverse leadership at all levels of the organization.
- Develop and promote culturally competent support programs and practices.
- Develop strong partnerships with other similar organizations.
- Decrease stigma through public education that address specific cultural barriers.

Among the Center's policy priorities are:

Health Disparities –

The significant progress made in discovering effective treatments for serious mental illness has unfortunately not translated into better services for people of color living with these illnesses. The Multicultural Action Center will join forces with other organizations and coalitions to advocate for equal access to mental health treatment for diverse communities.

Lack of Cultural Competence in Service Delivery –

Mental health providers are usually ill-equipped to meet the needs of patients from different backgrounds and often times display bias in the delivery of care. The Multicultural Action Center will address this issue by highlighting current effective cultural competence standards, promoting successful programs and institutions, and promoting the implementation of laws such as Title VI of the Civil Rights Act which requires providers to ensure that limited English proficient individuals have equal access to services. Furthermore, the Center will provide training and technical assistance to NAMI states and affiliates to ensure that all NAMI programs and services are culturally competent and available to people from diverse communities.

Lack of Bicultural/Bilingual Mental Health Professionals-

There are not enough bilingual/bicultural mental health providers. This reality makes care less accessible for people of color. NAMI's Multicultural Center will highlight and advocate for programs to promote mental health careers as viable options for youth of color.

Research -

Genetic research has highlighted significant differences among racial and ethnic groups in the metabolism, clinical effectiveness, and side effects of medications. Far too often, people of color are



underrepresented in clinical trials and research studies. The Multicultural Action Center will disseminate news about existing research and advocate for increased funding for research centered in diverse communities.

Children and Adolescents with Mental Illness –

Depression and suicide rates are higher among teens of color. Youth of color face higher rates of misdiagnosis and over-institutionalization. The Multicultural Action Center will work closely with NAMI's Children and Adolescent Action Center and partner organizations to advocate for youth system reforms and to implement practices and programs appropriate for children of diverse communities and their families.

Criminal and Juvenile Justice Systems -

People with mental illness are overrepresented in the criminal and juvenile justice systems. People with mental illnesses who are from diverse communities are also overrepresented in these systems. The Multicultural Action Center will work to advocate for access to appropriate diagnosis and treatment for people in these systems, and promote culturally appropriate jail diversion programs.

For more information about the Center please contact:

Majose Carrasco, Director, at 703-312-7883 or majose@nami.org



NAMI Multicultural Action Center Technical Assistance for NAMI States and Affiliates

- **Story Bank:** For your state office or affiliate newsletter. If you would like to include an article related to underserved populations in your newsletter call NAMI MAC to get a story.
- **Public Web Site:** You can duplicate NAMI National's Multicultural Web Site. If you want to personalize the site call NAMI MAC and we will help you create 1 or 2 paragraphs that are specific to your NAMI state office or affiliate.
- **Library of Resources:** NAMI MAC has created a library of minority outreach resources. This library will have all the information about NAMI outreach campaigns taking place around the country. We will have descriptions of each program, contact information, samples of materials, and more. NAMI groups nationwide have generously shared all of this information with us.
- **Revision of Materials:** You can send your multicultural outreach materials to NAMI MAC. We can review them and provide feedback and suggestions.
- **Speakers Bank:** NAMI MAC has a list of speakers from underserved populations that have expressed interest in participating at NAMI conferences and gatherings. Contact us if you are looking for speakers.
- **Cultural Competence Presentations and Trainings:** In order to successfully reach diverse communities, NAMIs must know, understand, respect, and embrace these communities. MAC provides cultural competence trainings to facilitate this process.
- **Materials In Other Languages:** MAC currently has materials in Spanish, Portuguese, Mandarin, and Italian. You could get the electronic versions of these materials to include your local contact information.

Other Services:

- * NAMI MAC staff will conduct presentations or speaking engagements for states and affiliates.
- * Training teleconferences and town hall meetings.
- * Briefings about diverse cultures
- * Mental health outreach suggestions and planning
- * Coalition of organizations from underserved population.

For more information please contact 703-524-7600 or MACenter@nami.org

NAMI Multicultural Partner Coalition

Alianza Nacional de Salud Mental (Mexico)

Alianza para la Depresión (España)

APOIAR (Brazil)

American Psychiatric Association

American Society of Hispanic Psychiatry

Asian Community Mental Health Services

Asociación Argentina de Ayuda a la Persona que Padece de Esquizofrenia y su Familia

Asociación Maníaco Depresivos (Colombia)

Asociación Salvadoreña de Familiares y Amigos de Pacientes Esquizofrénicos

Black Psychiatrists of America

Catholic Charities of Central Texas

Center for Psychiatric Rehabilitation - Boston University

Circles of Care Evaluation Technical Assistance Center

District of Columbia Department of Mental Health

Federación Colombiana para la salud mental

Fundación Contener (Argentina)

FUCOPEZ (Fundación Costarr para Personas con Ezquizofrenia

Fundación Luz y Vida (Paraguay)

Health Watch Information and Promotion Service, Inc.

International Association of Psychosocial Rehabilitation Services (IAPSRS)

INGENIUM – Monterrey and Mexico City (Mexico)

Latino Behavioral Health Institute

Malaysian Mental Health Association

Massachusetts Mental Health Services Program for Youth

National Asian American Pacific Islander Mental Health Association

National Council of La Raza

National Latino Behavioral Health Association

National Medical Association

National Organization of People of Color Against Suicide

National Youth Advocacy Coalition

New Jersey Asian Association for Human Services, Inc.

New Jersey Mental Health Institute

New Vision Consumer Services

Richmond Fellowship (New Zealand)

Samaritans Nepal

Self Reliance Foundation

Student National Medical Association

The Alliance for the Mentally Ill of R.O.C., Taiwan

The Depression and Anxiety Support Group of South Africa

West Virginia Substance Abuse Coalition

Voz Pro Salud Mental (Mexico)



Highlighted Partners



American Psychiatric Association Department of Minority and National Affairs

The American Psychiatric Association's Department of Minority and National Affairs is charged with raising consciousness about mental health issues in the minority and underserved communities and continues to be the voice for minority and national issues at the APA. The department's primary functions are to develop and implement programs that focus on the problems and concerns of minority psychiatrists and their patients, to promote a better understanding of mental illness, and to work toward eliminating disparities in mental health and substance abuse treatment for underserved ethnic and racial groups.

The issues with which this department is concerned and its activities include recruiting minority medical students into psychiatry; fostering appropriate representation of men and women from many backgrounds, cultures, and nationalities into psychiatry; addressing legislative issues affecting minority, underrepresented, and underserved populations; fostering research on the needs of minority, underrepresented, and underserved groups; and addressing such issues as mental health disparities, cultural competence, affirmative action, and workforce development. To assist in these efforts are the APA Committees and Caucuses (coalitions of minority and underrepresented groups (MUR) psychiatrists):

- American Indian, Alaskan Native, and Native Hawaiian
- Asian-American
- Black
- Hispanic
- International Medical Graduates (IMG)
- Lesbian, Gay and Bisexual
- Women

Opportunities

Fellowships, awards and travel scholarships are available to psychiatry residents and minority medical students to assist in our recruitment efforts to attract minorities into psychiatry and develop leaders in psychiatry:



Resident Programs:

- APA/GlaxoSmithKline Fellowship for psychiatry residents with leadership potential
- Jeanne Spurlock Congressional Fellowship that provides residents with an opportunity to work in a congressional office on health policy affecting minorities and children
- APA Minority Fellowships (funded by APA/AstraZeneca and APA/SAMHSA)
 designed to increase the number of psychiatrists trained who are members of
 minority and underrepresented groups

Medical Student Programs:

- Minority Medical Student Fellowship in HIV Psychiatry for minority medical students interested in services related to HIV/AIDS
- HIV Distance Education to train psychiatrists and residents in rural and underserved communities across the U.S.
- Minority Medical Student Summer Mentoring Program and Summer Externship in Addiction Psychiatry provide minority medical students with hands-on experience while working closely with a psychiatrist for a month.
- Travel scholarships to the APA Annual Meeting and Institute on Psychiatric Services

For more information contact:

Dr. Annelle Primm APA Director of Minority and National Affairs 703 907-8540 omna@psych.org www.psych.org



Howard University — Department of Psychiatry

Howard University received a \$6.5 million 5 year contract to work collaboratively with the intramural program of NIMH to recruit minorities as subjects, to develop minority researchers, and to develop state of the art research at Howard University. Principal investigator William B. Lawson MD, PhD has used this project to recruit Tanya Alim MD as clinical director and Thomas Mellman MD as research director. So far the project has led to the recruitment of over 1000 subjects and has twenty active protocols. Studies include genetic studies in anxiety and mood disorders, infusion studies, new treatment approaches for mood and anxiety disorders and brain imaging studies.

As a result of these contracts 10 African American researchers and research assistants have heavily involved the local community and primary care providers in mental health research. This project has also led to unique approaches such as treatment in emergency room settings, and treatments for mood disordered individuals with comorbid substance abuse.

This project has served as a foundation for the development of other independent projects. Dr. Lawson has an RO1 grant studying the genetics of bipolar disorder in African Americans. This study provides an opportunity to study a population often not included in genetic studies of mental health and from the rich clinical information closes the knowledge gap of this disorder that was once thought to be rare in African Americans.

Dr. Tanya Alim was recently funded to examine exposure to severe stress and subsequent development of psychopathology such as post traumatic stress disorder and depression in a primary care population. She has shown that post traumatic stress disorder is common in this inner city population.

Dr. Thomas Mellman has a career development award and RO1 grants to study post traumatic stress disorder and sleep. He has evidence that the disrupted sleep affects symptom presentation. He is also looking at the phenomenon of isolated sleep paralysis which is common in African Americans but rare in other ethnic groups.

Use of mental health days, local media, and African American staff has made research acceptable to the inner city multiethnic community that surrounds Howard. It has also brought new treatments and more accurate diagnostic instruments to this population.

For more information contact:

Howard University 2041 Georgia Ave. N.W. Washington, D.C. 20060 (202) 865 6100



NATIONAL ORGANIZATION FOR PEOPLE OF COLOR AGAINST SUICIDE

Missions and Goals

The National Organization for People of Color against Suicide (NOPCAS) has a primary focus and mission to increase suicide awareness and education. Additionally, it is our aim to develop prevention, intervention, and postvention support services to the families and communities impacted adversely by the effects of violence, depression and suicide in an effort to decrease life threatening behavior. NOPCAS has been conducting annual conferences since 1998 in minority communities. Every effort is made to disseminate knowledge about practices within the mental health services and suicide prevention and treatment fields that will enable attendees to develop awareness and skills to take back to their respective departments, communities, and institutions. We are an organization that specializes in suicide prevention among minority populations. We have a scientific Advisory Board that consists of leaders within their field of psychiatry, psychology, and social work and generally call on them to present their latest findings in research on depression and suicide at our conferences.

Current Activities

- NOPCAS has recently completed a report for the Suicide Prevention Resource Center (SPRC) entitled Cultural Competency: Developing strategies to engage minority populations in suicide.
- We have developed a task force made up of all four major minority groups to continue
 to develop innovative approaches to promote effective community-based strategies to
 prevent suicide and the associated problems of violence and depression. Training
 modules for community based organizations, schools, churches, and law enforcement
 personnel are in the planning stages.
- We are creating a video that will effectively draw on the growing tragedy of loss and despair among minority communities and how these communities can began to work at decreasing the multiple risk-behavioral patterns that contribute to a culture of hopelessness and self-destruction.
- NOPCAS will be collaborating with the National Urban League and Howard University to began gatekeeper training to faculty and staff in the Washington, DC inner city schools
- Our next conference will be held in Minneapolis, Minnesota in collaboration with Urban Ventures Leadership Foundation of South Minnesota.



History and Background

Formed in response to the collective grief and loss of several families who lost children in the early 1990s, NOPCAS began with a "Sharing the Pain" conference in Teaneck, New Jersey after a rash of African-American suicides in that small New Jersey community. As a result of media coverage of her son Marc's suicide in The Boston Globe, the current President of NOPCAS, Dr. Donna Holland Barnes, was contacted by a Teaneck, New Jersey resident, Mrs. Lois Taliaferro, the surviving mother of another suicide victim in early 199

NOPCAS was incorporated in the state of Texas as a Non Profit, community-based organization developed to increase awareness of and create suicide and depression education and prevention programs in the minority community. NOPCAS is governed by a 12 member Board of Directors, and received its 501(C) 3 tax exemption notification from the Internal Revenue Service in 1998.

NOPCAS is also supported by a Research Advisory Board that was established to formulate effective on-going research projects and initiatives. The board is comprised of a panel of nationally recognized professionals in the fields of public health, social sciences and mental health that includes: Dr. William Lawson, Chair of the Psychiatry Department at Howard University in Washington, D. C.; Dr. Sean Joe, researcher and professor of Social Work at the University of Michigan; Dr. Quinton T. Smith, distinguished professor of Psychiatry at Morehouse College of Medicine in Atlanta, Georgia; Dr. Kay Redfield Jamison of Psychiatry at John Hopkins University; Dr. Ken Wells of Psychiatry at UCLA; and Dr. Stephen Thomas of the Center of Minority Health at University of Pittsburgh.

The current Board of Directors represents a broad array of both professional and community representatives who all volunteer their time and energy towards the mission and goals of the organization. All members of the board have previously served as either senior staff or board members of other leading service organizations and/or universities and all have become actively involved in the formation of cutting edge service initiatives and public policy development in the fields of public health, sociology, education and community service at the local and national levels. Three of the four founders of NOPCAS; Dr. Donna Holland Barnes, President; Mrs. Doris Smith, First Vice President and Treasurer; and Mr. Leslie Franklin, Second Vice President, serve as officers of the corporation, along with Mrs. Lois Talieferro, the Secretary.

Board of Directors: Dr. Sherry Molock, Dr. Carolyn Jones, Loretta Dumas, Keith Willis, Dr. Alton Kirk, Henry Westray and Stephen Akindura.

For more information contact:

Dr. Donna Barnes President NOPCAS 202-549-6039 Dbarnes@nopcas.com



The STAR [Support, Technical Assistance and Resource] Center is one of five consumer & consumer supporter technical assistance centers funded by the Center for Mental Health Services. Our efforts are planned to build on the goals of the President's New Freedom Commission Report, Achieving the Promise: Transforming Mental Health Care in American, by increasing the independence and community integration of people with psychiatric disabilities.

The STAR Center's primary focus is the area of Cultural Outreach and Self-Help Adaptation, to ensure that self-help approaches are available and accessible to various cultural groups. Cultural groups include many different diverse communities:

- Ethnicity
- Geographic (e.g. Inner-City, Urban, Rural or Frontier)
- Faith communities
- Age-Defined (e.g. youth, older adults)
- Cross-Disability (e.g. Deaf communities)
- Sexual Orientation and Gender Identity
- Linguistic preference

Background and Purpose

The purpose of this technical assistance center is to assist with the improvement of State and local level mental health service systems by providing consumers, as well as supporters, service providers, and the general public, with necessary skills to foster self-help/self-management approaches.

The STAR Center offers hands-on assistance and information to provide consumer self-help approaches, such as the establishment and operation of consumer-operated programs (self-help programs), recovery-oriented programs, planning assistance, organizational skills, and funding and information dissemination regarding mental illness and related conditions (homelessness, co-occurring disorders), services, and practices.



Programs and Services

Cultural Outreach Initiative

This is the overarching platform for framing STAR Center activities. The initiative is designed to provide an opportunity for people living with psychiatric disabilities to share their unique experiences, including;

- Self-Help successes in diverse communities
- Innovative collaborations and partnerships
- Unmet needs in diverse communities

The Cultural Outreach Initiative also seeks to:

- Support greater leadership development opportunities for consumers from diverse communities
- Provide opportunities for mentoring and outreach with recognized and emerging consumer leaders from diverse communities
- Inform policy makers, researchers, and other stakeholders of unique aspects and needs regarding self-help among diverse communities

National Teleconference Series: Experiences of Self-Help in Diverse Communities

The overarching goal of the series is to provide an interactive opportunity for teleconference participants to better understand the role of self-help as an essential ingredient to recovery. Experiential knowledge has been demonstrated to be uniquely valued in terms of building resiliency and recovery.

Cultural Outreach Leadership Forums

This series of meetings is designed to bring leaders from the national consumer self-help movement and cross-disabilities communities with policy makers, providers, administrators, and other stakeholders.

- Core Elements of Self-Help in Diverse Communities
- Leadership Development & Technical Assistance Needs
- Networking & Partnership Strategies

For more information contact:

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www.consumerstar.org



Revisiting NAMI's Listening Forum with Black Psychiatrists

By MaJosé Carrasco, Director, NAMI Multicultural Action Center

In October 2002, NAMI held a listening forum between NAMI national leaders and staff and some of the nation's leading black psychiatrists. The goal of this event was to initiate dialogue between NAMI and the black community in order to identify common interests and draft a plan of action. The listening forum produced a broad range of recommendations for NAMI, which were compiled in *The Listening Project: Proceedings from a Dialogue between NAMI and Black Psychiatrists*. This report became a guiding tool for NAMI's Multicultural Action Center and a wonderful resource for NAMI states and affiliates.

The meeting produced both internal and external recommendations for NAMI. We chose to focus our energy on the internal recommendations made by the psychiatrists, recognizing that before NAMI could pick up the banner to advocate externally for people of color, we needed to change internally and become more open to diverse communities. As one of the participants observed, "NAMI's challenge is staggering, and commitment to diversity means commitment to the long haul."

More than a year and a half after the listening forum, we are revisiting the internal recommendations made by the group and candidly speaking out about our successes and challenges. Following are the recommendations from the listening forum, and the action NAMI has taken on each one.

Recommendation: Be more visible in black communities and other communities of color.

To achieve visibility and to be accepted by diverse communities, NAMI has been partnering with national organizations that represent these communities. NAMI's Multicultural Coalition has brought together 42 diverse organizations. All of these organizations have one common goal: to reduce disparities in mental health treatment for people of color.

Since 2002, NAMI's Multicultural Action Center has organized multicultural mental health symposia. In 2002, we focused on the Latino community; in 2003, on American Indians and Alaska Natives; and this year, as part of NAMI's 25th anniversary convention, we are organizing the *African Americans: Facing Mental Illness & Experiencing Recovery* symposium. This event will bring together African American leaders from across the country to address imperative mental health issues that affect this community and to share their knowledge, challenges, and success stories. The symposium will feature African American NAMI leaders and some of our partner organizations, such as the Black Psychiatrists of America, the American Psychiatric Association, Howard University, the African American Leadership Council, and the D.C. Department of Mental Health.



Recommendation: Commit to focus on cultural diversity for the long haul.

Diversity as a priority is clearly reflected throughout the goals and measures of NAMI's new Strategic Plan (2004-2005). Goal #3 reads: "NAMI's membership and leadership draw strength from all of America's diverse communities." Our vision is to reflect America's diversity by engaging those groups who remain underserved.

Recommendation: Broaden NAMI's membership base to be more inclusive of blacks and other people of color.

During the past year and a half, we have made some progress toward fulfilling this recommendation. Some new multicultural affiliates have been created, and NAMI's efforts to engage communities of color have increased at the local and national levels. However, broadening NAMI's membership base is still one of our biggest challenges. In order for NAMI to become more inclusive and more inviting to communities of color, we need to understand, respect, and embrace these communities at all levels. To achieve this goal, NAMI must first attain cultural proficiency within the organization. Only through cultural competence, defined by Quimby, Dassori, and Primm (2001) as the "integration and use of knowledge, attitudes, behaviors and skills that strengthen cross-cultural communication, and enhance appropriate and effective social interactions," can NAMI accomplish true inclusion.

Recommendation: Demonstrate leadership in addressing racism by encouraging internal discussion about how racism affects mental health and by dedicating resources to training in cultural competence.

How do we become a culturally competent organization? The process is long and requires commitment. The good news is that it is achievable and that NAMI's leadership, as reflected by our strategic plan, has already taken the first and most important step towards this goal by making it a priority.

Currently, NAMI is working on the creation of a cultural competence plan. The goal of this plan is to ensure NAMI understands, responds to, and embraces cultural similarities and differences. To develop the plan, NAMI is creating a Cultural Competence Advisory Group. This group will be made up of representatives from each NAMI leadership council (presidents, consumers, and veterans) and representatives from other NAMI leadership groups (executive directors, affiliates, diversity group programs, and others).

To talk about racism is not easy, and quite frankly, it makes a lot of us uncomfortable. However, we must step out of our comfort zone in order to achieve change. The cultural competence trainings will address racism and other issues that affect communities of color and will open a dialogue among NAMI grassroots leaders and friends. The NAMI Board of Directors is setting a best practice example by being the first NAMI body to receive cultural competence training, which will take place at the June 2004 board meeting. Similar trainings will be offered to other NAMI leadership bodies and to NAMI staff.



Recommendation: Build a diverse leadership.

NAMI is working across teams to provide leadership opportunities to people of color. These efforts include the annual convention, NAMI Leadership Institutes, all NAMI programs, and other events and activities.

One of the major goals of the mental health care symposium organized each year by the NAMI Multicultural Action Center is to identify a core group of NAMI leaders from diverse communities and provide them with information, support, and technical assistance. Our aim is to increase their visibility within NAMI and to create new and meaningful opportunities for existing and emerging leaders of color.