National Alliance on Mental Illness

Proceedings Report:

NAMI American Indian and Alaska Native Mental Health Listening Session

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Executive Summary

NAMI's 2007-10 Strategic Plan poses a goal for NAMI to become a truly inclusive organization that embraces and celebrates the diversity of its membership, envisioning the organization to have a culturally competent presence among diverse communities. With the recognition that the American Indian and Alaska Native (AI/AN) population is one that NAMI is committed to including and effectively engaging within the organization, the NAMI Multicultural Action Center is planning new and focused efforts within this community. To kick off these efforts, the Multicultural Action Center hosted an AI/AN Mental Health Listening Session on Feb. 7, 2009.

The NAMI AI/AN Mental Health Listening Session consisted of 20 national experts from a variety of backgrounds and tribal affiliations. The group was comprised of individuals living with mental illness, family members of persons with mental illness, providers and researchers. The main objectives of the meeting were to identify opportunities to improve mental health education and support for this population and to elicit expert advice in order for NAMI to successfully engage AI/AN communities as a valued stakeholder of the organization.

This report documents what participants of the listening session identified as important historical and cultural context, pressing issues in mental health among AI/AN communities, recommendations for the mental health system as a whole and potential next steps for NAMI to increase inclusion and support of American Indian and Alaska Native communities across the nation.

Discussion of pressing mental health issues among AI/AN communities covered a broad range of topics including stigma, cultural sensitivity, discrimination, integration of AI/AN traditions in mental health care and the need for education and advocacy. Participants provided recommendations for the mental health system as a whole out of this discussion that are categorized in this report in priority areas of *barriers to quality care*, *cultural competence* and *advocacy and community collaboration*.

Participants' recommendations for NAMI are framed as short- and long-term goals regarding organizational readiness, outreach efforts, education and support programs, and meaningful membership and leadership roles for AI/AN individuals and families.

Based on the AI/AN Listening Session and follow-up dialogue with the participants of this meeting, NAMI has identified the following next steps:

- create advisory roles for AI/AN individuals to offer feedback and guidance;
- develop a list of potential partners and media outlets;
- develop and disseminate resources for providers, AI/AN individuals living with mental illness and their families;
- obtain and review feedback from AI/AN participants of education and support program; and
- collect demographic data to ensure AI/AN individuals and families are accessing NAMI programs and events and that this community is represented among NAMI membership.

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The Multicultural Action Center has already begun to move forward by creating the American Indian and Alaska Native Leaders Group to act in an advisory role to NAMI. This report will provide a foundation for the group's work to advise NAMI in addressing the needs of AI/AN communities. The support of leadership at national, state and local levels of NAMI is also imperative to effectively address AI/AN inclusion and support.

It is NAMI's hope that the wider mental health system will join our efforts to effectively address the mental health needs and recommendations of AI/AN communities.

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Introduction

NAMI's 2007-10 Strategic Plan poses a goal for NAMI to become a truly inclusive organization that embraces and celebrates the diversity of its membership, envisioning the organization to have a culturally competent presence among diverse communities. To realize this vision, NAMI is committed to face current organizational shortcomings head-on and develop strategies to address them. The Multicultural Action Center works within this framework by promoting the development of culturally competent programs and practices, encouraging NAMI grassroots multicultural advocacy and outreach efforts and building meaningful participation and support of diverse communities at all levels of the organization. Much of the work done by the Multicultural Action Center is with the help of advisory groups comprised of experts from specific targeted communities.

Efforts of the Multicultural Action Center around specific communities often begin by gathering a group of community experts and stakeholders to advise the formation of an action plan. With the recognition that the American Indian and Alaska Native (AI/AN) population—which represents 1.5 percent (4.1 million) of the total U.S. population[1]—is one that NAMI is committed to including and effectively engaging within the organization, the NAMI Multicultural Action Center is planning new and focused efforts within this community. To kick off these efforts, the Multicultural Action Center hosted an AI/AN Mental Health Listening Session on Feb. 7, 2009.

The NAMI AI/AN Mental Health Listening Session consisted of 20 national experts from a variety of backgrounds and tribal affiliations. The group was comprised of individuals living with mental illness, family members of persons with mental illness, providers and researchers.[2] The main objectives of the meeting were to identify opportunities to improve mental health education and support for this population and to elicit expert advice in order for NAMI to successfully engage AI/AN communities as a valued stakeholder of the organization. Facilitator Anthony (A.J.) Ernst Ph.D., project director of the Native American Center for Excellence, led participants through a two-part discussion. The first part of the discussion focused on pertinent cultural considerations and mental health issues within this community. Out of this broader context, participants identified priority topic areas where NAMI can take action and discussed recommendations specific to the organization.

This report has been prepared to document the proceedings of the NAMI AI/AN Mental Health Listening Session not only to identify potential next steps for NAMI, but also in the hope that both NAMI and the greater mental health system as a whole can further develop mutually beneficial relationships, inclusion and support of American Indian and Alaska Native communities across the nation.

It is important to note that this report does not attempt to include the full scope, breadth and complexity of mental health issues within the AI/AN population, nor does it attempt to represent the vast diversity of AI/AN communities nationwide based on one meeting alone. NAMI intends to continue to respectfully engage, listen and learn from members of this community.

[1] U.S. Census (2000). *American FactFinder*. Retrieved from http://factfinder.census.gov.
[2] A list of participants of the NAMI American Indian and Alaska Native Mental Health Listening Session is offered on page 14.

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Historical and Cultural Context

When addressing mental health among American Indians and Alaska Natives, it is important to acknowledge the cultural and historical contexts of this community. AI/AN communities are complex, and tribes—there are 562 federally-recognized tribes[3] and many more not federally recognized—are different in many ways but, as the participants of the listening session pointed out, there is one particularly clear commonality that is shared by many American Indians and Alaska Natives: historical oppression. Though some AI/AN individuals prefer to focus on the characteristics of strengths and resiliency that stem from historical experiences of their communities, it is important for the context of this report to note this aspect of AI/AN culture.

Historical oppression among AI/AN populations spans several centuries, from European colonization to modern federal policies which led to destruction of populations, loss of land and a strain on expression of culture.[4] Federal legislation forced AI/AN individuals to assimilate with mainstream American culture through, for example, programs of relocation and separating children from their families through foster homes and boarding schools. There are enduring views that federal policy pertaining to AI/AN communities is more harmful than helpful.

Traumatic effects of historical oppression, as noted by participants, have lasting implications such as family shame and refusal to identify with Native heritage. There are patterns of harmful behaviors among families such as substance abuse and domestic violence. Grief of historical oppression has passed on from generation to generation, and there may be a loss of cultural identity. Children may be raised to be ashamed of this part of their identity or learn to hide it from community outsiders. Several participants of the meeting shared that they grew up not knowing about this part of their identity and what it meant to be part of Native culture. As one participant explained, learning about her Native culture and connecting spiritually provided a sense of belonging, healing and had a positive effect in her mental health recovery.

Specific cultural aspects of AI/AN communities were reflected throughout the discussion related to current issues in health and mental health status. While specific examples are provided by the listening session participants, it is important to note, again, that there is significant diversity across AI/AN communities in regard to social, cultural and spiritual characteristics. A participant provided his tribal affiliation as an example of diversity within one tribe: Kumiai territory stretches from 60 miles north to 60 miles south of the U.S.-Mexico border, where three distinct dialects are spoken alone.

[3] U.S. Bureau of Indian Affairs. Retrieved from http://www.doi.gov/bia/

[4] U.S. Department of Health and Human Services. (2001). *Mental health: Culture, race and ethnicity. A supplement to mental health: A report of the Surgeon General*. Rockville, Md.: DHHS, U.S. Public Health Services, Office of the Surgeon General.

Pressing Issues in AI/AN Mental Health and Recommendations for Mental Health Systems

Participants were asked to identify pressing issues in AI/AN mental health and suggest where changes should and could be made. What followed was a rich discussion of a range of issues including stigma, cultural sensitivity, discrimination, integration of AI/AN traditions in mental health care and the need for education and advocacy. In addition to pointing out these issues, participants shared examples of what is working and what they recommend for mental health systems.

Barriers to Quality Care

Issues such as stigma, mistrust, poverty, isolation, lack of available services and lack of providers to address mental health-specific needs may act as barriers to quality mental health care among AI/AN communities. Though a large portion of the AI/AN population (up to two-thirds of the population)[5] is considered urban, there are many rural AI/AN families that may reside far from available services and lack available transportation to access care. Telemedicine can be a solution but, as one participant noted, there is an overall lack of trained psychiatrists to provide such services. Another participant expressed concern over the national shortage of psychiatrists from AI/AN backgrounds. The same participant also noted that whether residing in a rural or urban environment, AI/AN populations generally lack access to quality mental health care.

Stigma was discussed in terms of how individuals and families of AI/AN communities are reluctant to discuss mental illness or seek treatment when needed. One participant shared from her experience that many Alaska Native individuals will refrain from talking about mental illness or seeking treatment in fear of being locked away. This may relate, in part, to historical mistreatment leading to incorrect views of mental health treatment options and lack of available education. One participant noted that research done within tribal communities historically seemed to serve only to point out negative traits of AI/AN communities without bringing effective solutions. It was further noted that schools need to come together with the mental health arena within AI/AN communities to provide needed mental health information. The strength in communal approaches to problem solving within many AI/AN communities can be an asset to such collaborative efforts.

A participant observed that AI/AN families are distrustful of "outsider" initiatives, and many participants noted a general mistrust of western mental health practices among AI/AN communities. Paradoxically, participants noted that concerns among AI/AN individuals that community members will notice use of mental health services if seeking care through services within the community, such as Indian Health Services,[6] will cause individuals to instead choose to travel outside of the reservation for treatment (for example, visiting mainstream clinics that may not be as well-equipped to address cultural needs).

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[5] As cited by Dickerson, Daniel, D.O., M.P.H., in *American Indians/Alaska Natives: Addressing Mental Health Issues,* presented at the Annual NAMI Leadership Conference, Feb. 6, 2009.

[6] The Indian Health Service (IHS) is an agency within the Department of Health and Human Services responsible for providing federal health services to American Indians and Alaska Natives see www.ihs.gov for more information.

The reluctance to seek mental health treatment can have dismal effects within AI/AN communities. An example of this can be found in the documented suicide rate of Native Alaskans—one of the highest of any communities in the country at 1.9 times higher than the national average for AI/AN adolescents and young adults ages 15-34, according to Indian Health Service.[7] One participant noted the high rate of suicide in her community, the North Slope borough of Alaska, and expressed concern that risky behavior, such as reckless snow machine driving, goes undocumented when it should be considered and addressed as suicidal behavior. Participants discussed the vital need for suicide prevention interventions in AI/AN communities across the country and shared some examples of what works, such as Native H.O.P.E**.** (Helping Our People Endure),[8] American Indian Life Skills Development[9] and Project Venture.[10]

In regards to addressing historical trauma, participants noted the need to restore cultural heritage, language and traditions to promote wellness among AI/AN communities. Model educational programs (such as Native Aspirations,[11] an education program for youth that addresses historical trauma in a culturally and emotionally sensitive manner) are not widespread or well-known across the country. AI/AN youth camping programs were also brought up as examples of strength-based programs to help build leadership skills, self-esteem, identity and routine. Participants praised Indian Health Services posttraumatic stress disorder screenings as a model of important mental illness identification in AI/AN communities. But while Indian Health Services is a very valuable provider of health and mental health care among AI/AN communities, these services are sparse and vary in capacity and array of available services across the country.

Key recommendations:

- recruit, encourage and mentor AI/AN individuals interested in entering professions in mental health care;
- expand culturally relevant educational efforts to address historical trauma awareness and suicide prevention among AI/AN youth; increase promotion and widespread availability of existing successful programs;
- make culturally sensitive mental health information and screenings available within AI/AN communities; and
- increase funding for health care agencies serving AI/AN communities, including Indian Health Services, particularly mental health services.

[7] U.S. Department of Health and Human Services Indian Health Service. (2008). *IHS Fact Sheets: Behavioral Health.* Retrieved from http://info.ihs.gov/Bhealth.asp.
[8] More information on Native H.O.P.E. can be found at http://www.ihs.gov/NonMedicalPrograms/nspn/
[9] More information on American Indian Life Skills Development can be found at http://www.nrepp.samhsa.gov/programfulldetails.asp?PROGRAM_ID=118
[10] More information on Project Venture can be found at http://www.niylp.org/projects/project-venture-national.htm
[11] More information on Native Aspirations can be found at http://kauffmaninc.com/index.cfm?page=clientinfo.cfm&view=samhsa

Cultural Competence

A commonly used definition of cultural competence is "a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations."[12] Though participants had varying opinions on the term "cultural competency," all agreed that cultural recognition and sensitivity should be embedded in all aspects of mental health care among AI/AN communities. One participant noted the importance of recognizing that cultural competence is an ongoing educational process.

Many participants shared personal and family experiences related to problems in receiving quality, culturally competent care:

> "I wouldn't enter the hospital room because I needed to have it cleansed. It had nothing to do with paranoia."
>
> "There was no one there to teach us how to help our loved ones or ourselves."
>
> "When he was in the hospital, he wasn't able to have his feather to pray, or to bring his pipe. We were even told that we should consider having our own place for treatment to bring our spirituality to the hospital. There wasn't anyone to advocate for him."
>
> "My husband had a stroke and as a result had many personality changes. During that time he did all the western kind of things, but not until he used his traditional ways and went to see medicine person in Canada that he was really able to heal."

Participants provided examples of healing and building strength from spirituality and traditional medicine, such as ceremony, sweat lodges and traditions of beading and drumming. It was noted that traditional healing methods may vary according to tribal beliefs, traditions, customs and history.

The group recognized that implementing cultural preferences in treatment has obstacles. One participant noted that, often, tribes working with outside agencies are not given treatment options that are culturally appropriate. Some providers of care to AI/AN communities use a template of state-wide, best-practice services that do not include tribal and traditional practices. One participant pointed out that as states limit funding to evidence-based mental health treatments (Oregon currently puts 75 percent of mental health funding toward such practices) communities are not able to sustain traditional healing practices. For example, tribes may have unique ceremonies that may not be appropriate for randomized trials across other tribal communities, and thus may be challenged to achieve western scientific standards. Participants expressed the need to for support of practice-based evidence,[13] such as participating in the Native American Service to Science

[12] Cross, T. L., Bazron, B. J., Dennis, K. W., and Isaacs, M. R., *Towards a culturally competent system of care.* Washington, D.C.: CAASP Technical Assistance Center (1989).

[13] Practice-based evidence is determined through community consensus rather than through traditional scientific observation or trials.

Academies,[14] to support culturally relevant mental health interventions effective for AI/AN communities.

Key recommendations:

- embed cultural competence in all aspects of improving mental health care among AI/AN communities;
- incorporation of traditional healing practices to address cultural preferences in mainstream mental health treatment; include traditional practitioners on treatment teams when requested; and
- promotion of practice-based evidence as an alternative to determine efficacy of traditional healing practices on mental health outcomes.

Advocacy and Community Collaboration

Optimal mental health treatment outcomes may come with empowerment of AI/AN individuals and families to take a leadership role in developing a care plan with providers, which participants noted could reduce levels of feeling intimidated or demeaned when asserting cultural preferences. A participant brought up the example technical assistance within Circles of Care grants,[15] a program to develop culturally appropriate systems, empowering family advocates for children's mental health systems. The participant suggested that family mental health advocacy groups like NAMI can play a greater role in initiatives like this to provide education and advocacy training for AI/AN families.

Community partnerships and collaboration were noted as key in shaping a more effective mental health system for AI/AN individuals. Collaboration can make positive impacts such as increased mental health education efforts, improved crisis intervention and lower suicide rates. One participant shared the example of a learning collaborative between traditional AI/AN healers and westernized providers in Los Angeles County. The collaborative examined the potential incorporation of AI/AN cultural healing practices. Seeking feedback from AI/AN youth advisors led a Los Angeles youth mental health care facility to include beading and drumming classes among treatment programs.

Key recommendations:

- empower AI/AN individuals and families with education programs and advocacy training; and

[14] The Native American Service to Science Academies, funded by the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Prevention, is facilitated by the Native American Center for Excellence, a national initiative to promote and enhance substance abuse prevention programs serving American Indians and Alaska Natives.

[15] More information on Circles of Care program can be found on the Substance Abuse and Mental Health Services Administration website (http://mentalhealth.samhsa.gov/cmhs/ChildrensCampaign/nativeamerican.asp), in the Systems of Care Web site (http://www.systemsofcare.samhsa.gov/ResourceDir/circleshome.aspx), and through the National Indian Child Welfare Association (http://www.nicwa.org/mental_health/CirclesOfCare).

- create partnerships between policy makers, law enforcement, health and mental health providers along with tribal leadership to shape and enact policies and initiatives to improve AI/AN mental health outcomes.

As previously stated, it is important to recognize the range of issues and suggested solutions presented above as a reflection of the broader picture of mental health needs within AI/AN communities across the country. While the meeting moved into more specific recommendations for NAMI after this initial discussion, it is important to lend further time to discuss the broader issues and identify solutions for improving mental health outcomes among AI/AN communities. NAMI looks forward to continuing this conversation and further examination in terms of both efforts within the organization and what can be done within the wider mental health system.

Recommendations for NAMI

To conclude the discussion of the first half of the day, participants were asked to shift their focus from general terms to what NAMI can do. The facilitator identified themes that emerged through the initial discussion and participants subsequently decided which of these thematic areas would be discussed in further detail for breakout group work. In the second half of the Listening Session, participants were asked to think in terms of short- and long-term specific recommendations for NAMI, recognizing the organizational capacity, current resources, and structure—national, state and local levels. The topics and questions identified for small group discussions are below.

- **Needs Assessment:** How can NAMI identify the needs of AI/AN communities and further determine what is appropriate for NAMI to address? (The breakout group later decided that "Needs Assessment" was an inappropriate title to reflect the focus of their discussion, see details in "Setting a Foundation" below).
- **Outreach:** How can NAMI effectively reach and inform tribal members about mental illness, develop a relationship with AI/AN communities?
- **Program Adaptation:** What can be done to make NAMI education and support programs more accessible to AI/AN communities? How can NAMI effectively determine whether these programs are culturally appropriate for this population and what can be done to ensure this?
- **Membership and Leadership:** What can NAMI do to ensure membership is meaningful and valuable for AI/AN individuals and families? What leadership roles could be appropriate and made available to members of this community?

After participants broke into small groups to discuss these topics in detail and develop recommendations for NAMI under each topic, the full group reconvened for group reports and further discussion to reach consensus on recommendations. Below is a summary of this discussion with suggestions for next steps in each thematic area.

Setting a Foundation

After the full body of participants of the AI/AN Listening Session agreed on needs assessment as one of four areas of focus for a breakout group, the smaller breakout group for this area decided that it was not an appropriate title to frame their discussion. Rather, this group focused more broadly on cultivation of respectful dialogue and relationship building between AI/AN communities and NAMI as a means by which the various needs of the community can be determined. This serves as both a foundation and an ongoing goal related to all other areas discussed.

The group acknowledged that learning about AI/AN communities, identifying existing resources and developing new resources should all be collaborative efforts, ensuring appropriate direction and feedback from community members. Suggestions included creating advisory roles and a feedback loop to continuously identify needs of AI/AN communities and how best to address them. This process would also involve identifying and compiling a variety of available information such as models of culturally competent education programs, outreach strategies and contact information of community leaders (ceremonial leaders, herbal practitioners, tribal elders and councils). NAMI can then build from identified resources, develop further materials if needed and disseminate helpful information.

Recommendations for NAMI:

Short-term:

- identify resources (both what already exists and what is needed); and
- create advisory roles for AI/AN individuals to offer feedback and guidance.

Long-term:

- continuous needs assessment and evaluation of efforts to further engage AI/AN communities; ongoing guidance from AI/AN advisors; and
- collect and utilize data to determine if these efforts are effective.

Outreach

Concerns were expressed that many individuals within tribal communities (including individuals with mental illness, families, medical and mental health professionals and other service-oriented organizations and agencies) do not know about NAMI or may have an incorrect perception of what the organization does. Suggestions for correcting this included that NAMI make efforts to introduce itself to the AI/AN community as a grassroots organization interested in giving support in terms of the community's self-identified needs. NAMI should not be forceful in its messaging or make cultural assumptions, but form partnerships and collaborate with the community. It is important to be patient in this effort and to expect a slow process when developing a relationship with this community. There may be deeply rooted mistrust and high levels of stigma to work through. These issues underscore the need for NAMI to create well-thought collaborative plans to ensure efforts are equally beneficial and sustainable before attempting to reach out to the AI/AN community. As one

participant noted, building trust means making more than one effort to garner interest and develop a rapport with community members.

When attempting to promote NAMI education and support programs to AI/AN communities, participants noted that successful engagement of individuals and families requires incorporating cultural preferences such as framing mental illness in a positive context and being open to dialogue. One participant expressed the importance of thinking in terms of *bringing in* new individuals and families to the organization with new perspectives and personal experiences to share.

It was also noted that while models of other movements, such as substance abuse or diabetes education, have been successful in relying on providers and health clinics to provide important information to AI/AN families, higher levels of stigma around mental illness may prevent this strategy from having similarly successful reach. Participants agreed that creating ties in Native communities is commonly done through building on existing networks—who you know, who they know and so on—and slowly developing trust and increasing openness.

Recommendations for NAMI:

Short-term:

- develop a list of potential partners (individuals and organizations at the national, state and local levels) and media outlets (Tribal radio stations, newsletters, etc.) for social marketing of this information; and
- develop and disseminate resources for providers, individuals living with mental illness and their families.

Long-term:

- incorporate AI/AN specific cultural issues in outreach trainings; and
- ongoing communication/ networking/ social marketing.

Program Adaptation

Many of the participants of the Listening Session lent expertise from experiences as participants, mentors, facilitators or teachers of one or more of NAMI's signature education and support programs.[16] From their experiences, participants shared feedback on the effectiveness of these programs among AI/AN individuals and families. While all acknowledged educational and supportive value in the programs, there was concern that the programs are not reaching far enough into AI/AN communities in need of this information and support. On the other hand, for those who can access NAMI's programs, there was concern that the program models are not optimally culturally appropriate-keeping NAMI's education from having effective reach and impact. The

[16] NAMI offers an array of peer education and training programs and services for consumers, family members, providers, and the general public. More information on NAMI's education programs, such as Family-to-Family, Peer-to-Peer, In Our Own Voice, NAMI Connection Recovery Support Group, etc., are available at www.nami.org.

primary recommendation of the group in regards to NAMI programs was to integrate cultural modifications.

NAMI staff pointed out a few key points to consider in recommending modifications to education programs:

- program modification to improve cultural competence is not a simple task, but it is achievable;
- NAMI education and support programs have been studied and have a growing base of evidence of their success. It is important to keep core components of these programs intact so that any change to these programs will not adversely effect what has been studied and shown effective; and
- how do we balance fidelity to a successful model with cultural needs so that this model works more effectively within specific communities?

The group considered how NAMI can deliver a program's core components in a more culturally appropriate ways. Participants agreed that further documentation and feedback was necessary to get a clear picture of what works among AI/AN communities and what adaptations may be made to enhance effectiveness while keeping core program components intact. The group suggested working within existing avenues of evaluation and engaging individuals involved in these programs—participants, teachers, mentors and presenters—to seek feedback specifically from AI/AN individuals. Once this information is obtained from AI/AN communities, it should be assessed in order to determine the possible need for adaptation to the programs.

Participants provided examples of areas to consider in this feedback to build cultural changes onto program core components:

- allowing time for open discussion:
    - for example, provide opportunities for class participants to meet informally outside of classes, such as a short meeting prior to the beginning of the program to allow the participants to get to know each other;
- integration of cultural traditions and ceremonies, such as prayer and talking circles, into classes and support groups;
- asking participants directly, "How does your cultural affect your experience?" and
- focusing on positive impacts of mental illness on individuals and families.

Recommendations for NAMI:

Short-term:

- obtain and review feedback from AI/AN participants of education and support program through program evaluation, additional surveys and/or focus groups; and

- account for issues such as appropriateness of meeting location and transportation needs to make programs more accessible to AI/AN communities.

Long-term:

- based on this feedback and with the assistance of AI/AN advisors:
  - create supportive materials for teachers, mentors, and support group facilitators to help these individuals understand and effectively address cultural issues;
  - incorporate culture-specific information into trainings and teacher manuals; identify where this information is appropriate within the programs;
    - for example, revisit certain terms such as when treatments are deemed "traditional" and "alternative." If traditional refers to western practices, it is *not* traditional for many AI/AN individuals;
- increase AI/AN participation in NAMI programs

Membership and Leadership Roles

Participants expressed a need for cultivating visibility and a voice for AI/AN individuals and families within NAMI and suggested that, with efforts to reach out to AI/AN communities, it is important to do so with the goal of engaging individuals and families in a supportive and sustaining way. At the basic level, NAMI needs to identify levels of inclusion of AI/AN individuals through membership data collection and utilize this data to monitor growth of involvement of AI/AN communities. Ultimately, NAMI can actively encourage the visibility of AI/AN communities by providing opportunities for meaningful membership and encouraging advancement into leadership roles within all levels of the organization.

Meaningful involvement can come naturally for members of NAMI through education and support programs, outreach and advocacy. Specific opportunities can be made known and available to AI/AN individuals and families. Participants emphasized the opportunity of NAMI's Standards of Excellence[17] to serve as a means by which affiliates can be encouraged and guided to be more inclusive of diverse communities in meaningful ways.

One of the most meaningful roles an individual can play within any organization is through a leadership position. The group expressed leadership opportunities are key in furthering participation of AI/AN individuals within NAMI. These positions can be either common existing roles within the organization, such as affiliate, state and national boards, or can be positions formed for specific purposes. Parallel leadership opportunities can be created through inclusion of AI/AN individuals in groups such as multicultural or AI/AN advisory committees and partner coalitions. Even further, NAMI can advocate for the inclusion of tribal leaders in mental health stakeholder groups, advocacy coalitions or planning committees.

[17] A nationally representative Standards Work Group is currently developing "mutually agreed upon standards of operation" for the entire NAMI organization, intended to form the basis for NAMI's regular chartering and rechartering process in the future. For more information and to see the draft standards visit the NAMI Web site: www.nami.org/standardsofexcellence.

Recommendations for NAMI:

Short-term:

- collect demographic data to ensure AI/AN individuals and families are accessing NAMI programs and events and that this community is represented among NAMI membershi;
- promote general opportunities to get involved as well as existing leadership opportunities known and available to AI/AN individuals; and
- provide details to AI/AN members about how to participate in leadership trainings and get involved in leadership roles such as on committees, coalitions, or be elected to the boards of all levels of NAMI.

Long-term:

- increase AI/AN participation in NAMI programs as teachers, mentors, presenters, facilitators, etc.; and
- develop clear paths to leadership opportunities for AI/AN members, such as on governing boards, committees, etc.

Moving Forward

Based on the AI/AN listening session and follow-up dialogue with the participants of this meeting, NAMI has identified initial next steps. The Multicultural Action Center has already begun to move forward by creating the American Indian and Alaska Native Leaders Group to act in an advisory role. The group is primarily made up of participants of the listening session, but leaders from all levels of NAMI are also welcomed to join. This report will provide a foundation for the group's work to advise NAMI in addressing the needs of AI/AN communities.

NAMI's next steps*:*

- create advisory roles for AI/AN individuals to offer feedback and guidance;
- develop a list of potential partners and media outlets;
- develop and disseminate resources for providers, AI/AN individuals living with mental illness and their families;
- obtain and review feedback from AI/AN participants of education and support program; and
- collect demographic data to ensure AI/AN individuals and families are accessing NAMI programs and events and that this community is represented among NAMI membership.

The recommendations made by listening session participants and the next steps identified by NAMI call for an interwoven process that cannot be considered a clear-cut, step-by-step action plan. NAMI will work with the AI/AN Leaders Group to further clarify and address these recommendations.

This report will be continuously revisited as we move forward, and progress made will be measured by meeting each of the outlined next steps. The support of leadership at national, state and local levels of NAMI is also imperative to effectively address AI/AN inclusion and support. It is NAMI's hope that the wider mental health system will join our efforts to effectively address the mental health needs and recommendations of AI/AN communities.

The Multicultural Action Center would like to thank the participants of the AI/AN mental hHealth listening dession and the facilitator, Dr. A.J. Ernst, for taking part in this meeting to provide a sturdy foundation for our future efforts. The session is an important step in NAMI's goal to be an inclusive organization that embraces and celebrates the diversity of its membership and to promote access to culturally competent mental health services and treatment for *all*.

Participants of the NAMI American Indian and Alaska Native Mental Health Listening Session:

Peg Blakely
Coordinator
Waiver Program
Leech Lake Health Division
Cass Lake, Minn.

Susan Casias
Board Member
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