

**NATIONAL CONSUMER COUNCIL and STATE PRESIDENTS' COUNCIL  
JOINT TASK FORCE REPORT on CONSUMER INCLUSION and  
INTEGRATION in NAMI**

At the NAMI Leadership Institute in Orlando, FL in January, 2002, the State Presidents' council passed the following resolution and sought to open a dialogue with the national Consumer Council about consumer inclusion and integration in NAMI.

**“Integration of consumers and families in cooperation with the CCEC. –**  
*Debate on this item was considerable with several state leaders providing models of integration within their state, including associated consumer councils and peer agencies that were consumer run. Presidents' Council members requested a combined initiative with the National Consumer Council on the topic of integration and inclusion of consumers in NAMI at all levels, including identifying successful practices across the states.”*

The National Consumer Council and State Presidents' Council formed a Joint Taskforce on Consumer Inclusion and Integration, proceeded to meet intensively in conference calls from January to June, and presented a preliminary report to a joint meeting of the Consumer and State Presidents' Councils at the national convention in June.

After the national convention, the national NAMI Board also requested the national Consumer Council in conjunction with the Joint Taskforce on Consumer Inclusion and Integration to address the following issues to assist moving NAMI towards full consumer inclusion:

1. Develop guiding principles of consumer inclusion in NAMI.
2. Develop communication strategies/mechanisms between constituents and NAMI/NAMI Board of Directors.
3. Grow consumer leadership and membership within NAMI.
4. Conduct outreach to consumers and consumer organizations.
5. Recommend strategies to encourage
  - a. Inclusive affiliates
  - b. Consumer started/initiated affiliates
6. Look at areas of discrimination in voting and other areas and make recommendations to the Board of Directors.
7. Advise the Board of Directors of other barriers that discourage consumer membership

The Joint Taskforce continued to meet intensively in conference calls after June, culminating in a retreat in November to produce this report. It is anticipated that the National Consumer Council will be adding to the Report.

The framework of the Report is based on the following principles:

**INCLUSION** encompasses:

- A clear, unambiguous policy stating:

- The values of the organization;
- Who is a member of the organization;
- What are the practices of the organization that includes those members in its activities.

NAMI can have a non-discriminatory policy, can have full membership of consumers, but if its practices do not conform with its values, inclusion is illusory and integration is not possible.

**INTEGRATION** means that all members fully participate at all levels and in all endeavors of the organization. NAMI can design programs for various target audiences (e.g., young families with children with mental illnesses; peer-to-peer education for consumers or families), but it must also continue to move towards programming in which consumers and families can participate together (e.g., provider education; or a new educational program, called "RECOVERY").

This report addresses the following issues raised by the national Board:

***1. Develop guiding principles of consumer inclusion in NAMI:***

The Joint Taskforce endorses the *Call to Action* Report on Membership and Standards put forth by the NAMI National Board of Directors in November, 2002. In particular the Taskforce endorses:

- The development of one membership category that encompasses all members—consumers, families, friends, and supporters of NAMI’s mission. A uniform membership class also removes a misperception that we are a “family” organization, with all others in a secondary role. Inclusion begins with a very clear definition of who members are and their rights and responsibilities. The proposed standards go a long way toward providing that clarity.
- “Retain open door membership for any individual unable to afford dues.” The open door policy should be available to all who cannot pay full dues, and it must be clear that this is not a separate class of membership. The level of dues must not determine membership rights.
- Uniformity in definition and standards for Affiliates and State Organizations: The experience of Taskforce members and extensive input from members of the national Consumer Council indicates variability of practice among Affiliates. Consumers are not routinely considered fully participating members in many Affiliates, so the Taskforce believes that NAMI policy must be explicit about inclusion.

For example:

- **Setting as a standard that every level of NAMI must practice inclusion in terms of membership, governance, and participation in programs, advocacy, and education**
- Chartered Affiliates must include all members and cannot arbitrarily exclude any member. Support groups may be specific to particular needs, as long as there is access to support for all members who need it. Building capacity in local Affiliates, with state organization assistance, to assist consumers in organizing

and/or participating in local support groups is strongly encouraged. If there are no other support groups and not the membership base to create another support group, the existing support group must attempt to meet the needs of all members. Even if persons are referred for support to outside organizations, their membership in NAMI should be welcomed and sought.

## ***2. Develop communication strategies/mechanisms between constituents and the Board and NAMI at large:***

NAMI members are part of a larger culture, in which people with serious mental illnesses are regarded as less than competent. It is only through dialogue and regular and frequent interchange that we can work together. The development of an internal educational program for local, state, and national sectors that addresses the elements and culture of stigma, with discussion guides and “study circles” is required. The goal should be to open communication so that we can talk effectively with one another about the experience of mental illness, just as consumers and family members talk to providers about their experiences in Provider Education. SAMSHA has published Participatory Dialogues (SMA 3472), an interactive guide to promote communication among consumers, family members, and professionals, which may be a useful tool to promoting integration of consumers in NAMI. Presenting “In Our Own Voice” to NAMI audiences is also recommended. Family to Family should be reviewed for language and/or components which might be interpreted as contributing to stigmatization; “us vs. them” perspective.

Promoting cultural change within NAMI would also be facilitated by developing a video that models consumer participation at all levels of the organization, a NAMI “In Our Own Voice” tailored presentation. The video could highlight “best practices” for consumer inclusion and integration, and could also depict what consumers need, to feel accepted as part of NAMI at all levels.

NAMI must educate its own members about recovery, and develop a working definition of what recovery means. Members must be informed about:

- The best practices in services and treatment
- Assuring access to the most effective medical and pharmacological treatment
- Helping each individual achieve a productive life in the community.

## ***3. Grow consumer leadership and membership within NAMI:***

Consumer membership and leadership will become the norm within NAMI when policy and practices at all levels reflect full inclusion and integration. Other sections of this report also reflect ways to develop consumer leadership and membership. We believe an effective way to “grow consumer leadership” is to establish Consumer Councils because they strengthen the voice of consumers who have been disenfranchised, oversee consumer run and directed programs, and provide leadership training opportunities.

**Recommendation:**

**The Taskforce believes that NAMI Consumer Councils should be viewed as a “Best Practice” within NAMI. It recommends that every state have a Consumer Council to:**

- Advise the state Board of Directors and provide input to the National Consumer Council. If there are other strong consumer organizations in the state, they could have designated seats on the Consumer Council.
- The NAMI Consumer Council should send representatives to other mental health organizations, as well as official planning and advisory mental health groups—growing the leadership and implementing NAMI’s mission.
- State level consumer councils should be represented on the state NAMI board.
- State Consumer Councils should elect the national Consumer Council Representative and the Alternate.
- National Consumer Council Alternates should be active participants at the national level so they gain experience and are informed if they need to act as the state’s representative.
- All members of the Consumer Council must be NAMI members.
- With the assistance of the national Consumer Council, standards and a template for the development of state Consumer Councils should be crafted by the time of the national convention in 2003. These standards must assure that consumer involvement is integral to all activities of the state board.
- Financial support for Consumer Council members at the state and national level is as important as any other priority program and activity area of the state organization. Funding should be at the level required for integration of consumers in NAMI. National NAMI must expand its efforts to acquire dedicated funds for development and expansion of consumer programs at all levels of the organization.

**Recommendation:**

**We recommend that a pre-national conference symposium on the issue of consumer inclusion and integration in NAMI targeted to state and affiliate leaders and staff be offered in 2003.** A steering committee should be formed after the Leadership Institute with participation by the national Consumer Council, State Presidents’ Council, the national Board, and staff to plan the symposium. A specific goal must be to assure that the target audience is state and affiliate leaders and staff, since often such workshops are attended predominantly by consumers.

***4. Conduct outreach to consumers and consumer organizations:***

NAMI has educational programs, such as “Peer to Peer” and “In Our Own Voice” which are excellent outreach tools. These programs can be offered under the auspices of the Consumer Council. Just as with Family to Family, membership grows through the involvement of people in formal educational programs that meet their needs, and helps them establish connections with others in a mutually supportive environment.

Advocacy is another activity in which that NAMI can partner with consumer organizations, and model a desire to include consumers as full participants in NAMI activities. Coalitions can be formed to develop common positions on issues such as mental health funding, model programs, and reforming restraints and seclusion practices.

NAMI can encourage peer “in reach” to family members, to community mental health centers, and even to state hospitals. When a consumer member of an Affiliate becomes ill, some people are reluctant to reach out, but this kind of support from members of the Affiliate, regardless of whether they are family members or consumers, shows that the person is important to the group and is missed.

NAMI should support the ICCD Clubhouse model as a best practice, and encourage close collaboration by NAMI Affiliates with clubhouses. Clubhouses that are ICCD certified often reach people with serious impairments and help them become participating members of their community. Many NAMI’s throughout the country are major supporters of the clubhouses. NAMI-C.A.R.E. groups could be promoted in clubhouses. All promising new programs and practices, such as **WRAP** (Wellness Recovery Action Plan), should be disseminated by national NAMI to promote self-help and inclusion. This should include mentoring of younger people who are struggling with their first illnesses. We should not just focus on our own “signature” programs.

***5. Recommend strategies to encourage Inclusive Affiliates and Consumer started/initiated Affiliates:***

In many states and/or in Affiliates, very few consumers are involved in the programmatic life of the organization. Guidelines are needed to make this happen. Cultural change within NAMI, at all levels, is also an integral part of this process. NAMI national needs to assist states to develop an “Action Plan” for outreach, implementation of programs to involve consumers, and ways to include consumers at all levels of the organization. We recommend the following strategies related to this “Action Plan”:

**Recommendations:**

- The best practice is that all leaders of all NAMI support groups and Affiliates have facilitator training, so that difficult dialogues can be supported, and individuals who are disruptive can be addressed. (Because people who come to support groups are often in pain, regardless of who they are, their behavior can be difficult for other members of the group.) Although NAMI-C.A.R.E. offers facilitator training for consumers, the training should be generic and provided to all family and consumer members who are leading groups. Separate training is not always needed.
- Internalized stigma exhibited by consumers and family members and related to the view of diminished competence of people with mental illnesses, must be openly addressed through such means as the Participatory Dialogues. Illnesses must be talkable, and NAMI acting as a community must support people who are hurting or are ill.

- Family members who may have very ill, impaired loved ones sometimes find it difficult to understand “recovery” given their own experiences. These families, including the person who is ill, need to be embraced, perhaps in different ways than we currently do. Consumer groups [perhaps] should reach out to the individuals who are ill and/or isolated. Family members who have been in a long term support group need to retain this support, and affiliates must work to assure inclusion of all members.
- There should be a **Welcome Packet** for all who join a NAMI Affiliate or Support Group, one integrated packet that includes programming and other basic information for everyone.
- States should have technical assistance to help affiliates develop support groups that address the needs of consumers: NAMI-C.A.R.E. facilitator training, Peer to Peer Education, and In Our Own Voice are some of the tools which can be used. Leadership training for staff and volunteer leaders that promotes consumer inclusion should be offered by the national office. This can be done on a regional basis. The training should include affiliate, state, and staff leaders. It should focus on increasing the capacity of the state to apply these programs. The training should focus on the “intentional” work that must take place to reach these goals.
- As cited above, state organizations and Affiliates can reach out to local clubhouses to involve consumers in support groups. This might be accomplished by offering Peer to Peer through the clubhouse, training a clubhouse member who is part of NAMI as a facilitator, and/or offering on-going support to help the group become part of the Affiliate or form their own Affiliate.
- **Financial support is necessary to assure inclusion of consumers.** State and Affiliate budgets are necessary for all consumer activities, e.g., phone, copying, postage, conferences, scholarships, consumer programs, educational booklets that are relevant to consumer interests and needs. Travel funding is crucial so consumers can attend affiliate and/or state meetings. There also must be agreed upon fundraising methods for consumer activities, that is not an “add on”, but an integral part of the overall fundraising goals.

**6. Look at areas of discrimination in voting and other areas and make recommendations to the Board:**

The by-laws of an organization guide its policy and practice. We believe a change in national by-laws, which promotes full inclusion, is required. The proposed change is as follows:

**No discrimination based on disability, sexual orientation, and/or mental health status.**

Not discriminating based on sexual orientation is part of most progressive organizations’ policies. Mental health status is an elaboration of the “disability” section of the by-laws and makes it explicit that a person with mental illness is included in the non-discriminatory definition.

## **Recommendations:**

States vary widely in nominating, designating seats on boards, and voting practices. The following recommendations address these topics:

- It is acceptable practice to designate specific consumer seats on any NAMI Board (e.g., chair of Consumer Council, who may be a member of the executive committee of the State Board). No limit should be set on the number of consumers who are Affiliate or state or National Board members. This must be explicitly stated as NAMI Board of Directors policy.
- It is recommended that the policy for developing nominating committees at all levels of the organization should be that they are inclusive and have full consumer participation.
- It is recommended that all state Boards of Directors have at least one position designated for a voting representative of the Consumer Council who would preferably serve as a member of the executive committee. At the national level, the elected Consumer Council Director should also be on the Executive Committee of the National Board. To be in leadership means to be participating at the highest level of decision making. The goal is to promote consumer leadership.
- Article 1 of the by-laws specifies the payment of annual dues to be considered as a voting member of NAMI. When the membership section of the by-laws is rewritten, it must be very clear that voting rights are not limited or determined by the level of dues paid.
- **Methods for choosing the National Consumer Council representative and alternate:** The NAMI By-Laws do not specify the alternate from the state to the National Consumer Council and this may require a bylaw change.
- It is recommended that the designated representative and alternate to the national Consumer Council be chosen by NAMI consumer members of that state. This should take place in the NAMI Consumer Council, if a Consumer Council is operating in the state. Other consumer members of state or Affiliate Boards should be chosen by all members in the regular election process.

**Note:** When full inclusion of consumers in NAMI (discussed in the next section) is a reality, the election process should be by all members, but we have not reached this point in most states. However, in states in which there is full inclusion, like Alaska, their election process does not need to change. Consumer Councils are strongly encouraged in states in which consumers have limited involvement in NAMI, and consumer election of the national representatives must be required. In the absence of a Consumer Council, the following methods of election may be appropriate:

**Recommended Practices:** Consumer caucus at the state convention or vote by consumers in Affiliates are two other possible election practices. Indicators are needed regarding access: Are consumers able to travel to state conventions? Is there a defined process to define who consumers are and to seek their participation in a ballot process? The proposed states' election process can be applied to election by consumers of the National Council Representative and Alternate. As more consumers participate, the process becomes broader and more representative. It is recommended that states elect

their national representatives based on the candidate's ability to fulfill the duties and responsibilities required of the National Consumer Council reps.

- The Taskforce recommends that the NAMI BOD determine what protocols should be in place to allow the states and/or the National Consumer Council to remove Representatives and alternates from office for cause. Recommended qualifications/requirements for National Consumer Council Representative and Alternate are the description of duties and responsibilities adopted by the National Consumer Council and by the national Board. They include such issues as:
  - 1) Member in good standing of NAMI
  - 2) Has or has had a mental illness
  - 3) Regularly attends meetings
  - 4) Access to an e-mail account
  - 5) Ability to represent consumer interests in NAMI in his or her respective state
- Certification process by states of the National Consumer Council representatives and alternates: A useful and timely process would ask for this information within 30 days after the state annual convention or election process.

***7. Advise the National Board of other barriers that discourage consumer membership.***

It is important that structured consumer feedback be sought regarding changes in policies and practice before they are put into effect. A survey or feedback form could be available on-line, sent by e-mail to the national office, or to our 800 number, perhaps to a special voice mail box set up for this purpose.

**Recommendations:**

The NAMI BOD must define what they mean by full inclusion. We recommend that it consider at least the following indicators:

Consumer programs that are offered; consumer paid staff; consumers fully participating on Boards; in committees and in support groups; and % of budget that goes to consumer programs.

The Call to Action must include consumer issues consistently and explicitly. The present CC/SPC Consumer Inclusion Task Force should be considered by the NAMI BOD as it reconsiders and modifies its Call to Action, and it should use the on-going work of the combined Councils as part of the implementation process. Part of the implementation process should be representation and coordination between the CC/SPC taskforce and the Executive Directors Group. **A Work Plan with realistic time frames and resources for implementation should be the responsibility of a work group, which includes all levels of the organization and key staff from all levels.**

**Dispute Resolution**—There are procedures to follow between organizational levels within NAMI. As the transformation process begins to occur in terms of more consumer involvement in NAMI, there will be conflicts. Affiliates, state offices, and national should be available to mediate the resolution of these conflicts.

**Recommended practice:** A grievance procedure should be formalized at every level of the organization that is simple, direct, and expedient. The procedure(s) should be explicit with regard to complaints by individuals and complaints by organizations.

**Grassroots involvement---**The national Consumer Council and State Presidents' Council should have meaningful participation in developing components of any leadership trainings.

**NAMI National Consumer Council** is advisory to the NAMI Board of Directors. Its recommendations go to the full Board through the Governance Committee. The Consumer Council representative sits on the Governance Committee as a participating member. After discussion, the Consumer Council's recommendations are presented to the full Board by both the Governance Committee and the elected representative of the National Consumer Council. This process should not be short-circuited or undermined. The modeling of consumer inclusion and integration begins at the level of national leadership.

**Travel support** is the most important accommodation necessary to assure full participation by consumers. It can be achieved by car-pooling, reimbursing mileage, and scholarships for attendance at the statewide meetings and conferences that are not easily accessible.

NAMI has been a leader in promoting best practices in the treatment of mental illness and reform in the use of restraints and seclusion in psychiatric hospitals. NAMI must continue to be the national leader in promoting least restrictive practices. We recommend that the BOD consider adopting the NAMI Kansas vision for mental health treatment, viz.,

*Every consumer is entitled to receive the right treatment, in the right amount, at the right time, in the right place, and as long as necessary to assure a timely and durable recovery.*

NAMI must continue to be a leader in educating its members and the public about research that demonstrates the effectiveness of PACT (implemented according to the model's standards), of supported housing, and of other forms of intensive outreach to engage those whom the treatment system has failed. Our focus, energy, and resources should be on effective practices and not on narrowly focused, divisive approaches.

We believe this Report is a beginning step in an evolutionary process that will transform and strengthen NAMI's role as the most effective voice on mental illness in the nation.