CONSUMER ADVISORY BOARD MANUAL

for Health Care for the Homeless Projects

Developed by Ellen Dailey
for the

National Consumer Advisory Board

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The National Consumer Advisory Board (NCAB) is comprised of individuals who have experienced homelessness and who serve on Consumer Advisory Boards or in similar capacities as advisors to local Health Care for the Homeless projects.

Ellen Dailey, the principal author of this manual, is Chair of the National Consumer Advisory Board and Vice President of the Board of Directors of the Boston Health Care for the Homeless Program.

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INTRODUCTION

At the 2003 National Health Care for the Homeless Conference, it was decided that the National Consumer Advisory Board (NCAB) would develop a manual that could be used as a guide for local groups who are beginning to form CABs. This document is the result of that work. The manual is meant to be used as a guide only; nothing is written in cement. It is our hope that the manual will assist consumers in working with senior management and Boards of Directors of Health Care for the Homeless (HCH) projects. We, the NCAB Executive Committee, have used the experiences we have had in developing our own local CABs.

We will cover such things as recruitment, meeting management, by-laws/guidelines, and how to make recommendations for changes within the local Health Care for the Homeless Program. We hope that this manual will be helpful to you. It is also our wish for you to make recommendations to NCAB on things that should be included in another edition. At the end of the manual you will find names and addresses so that you can contact us.

One of the things that we want to stress is that there is not one way of doing things. What works for one CAB may not work for other CABs. There are many different ways that local CABs are structured. Many of the recommendations that we make can be altered to fit your locality. Please feel free to use this manual in any way that you feel will be helpful to you.
CHAPTER ONE

WHAT IS A CONSUMER ADVISORY BOARD? WHY SHOULD WE HAVE ONE?

A CAB is a group of homeless and/or formerly homeless people who have been brought together to positively affect their local Health Care for the Homeless (HCH) project. That is the simple answer. The more complex answer is that consumers need to be proactive in their own lives, which includes healthcare. It is one of the most important things that we, as a group, can do for ourselves. We should also mention that it is a requirement of the federal government that each HCH grantee have some kind of consumer involvement in order to receive federal funds. The regulations are in the Bureau of Primary Health Care’s (BPHC) Policy Information Notice 98-12, which is provided as an appendix to this manual. The BPHC web site, as well as some others, can be found at the end of this document.

In deciding to form a CAB, it is important to make sure that the CAB will be able to work closely with the management of the HCH project. In some localities, it is the Executive Director or a senior staff member who decides to form a CAB, in others it is a consumer who takes the first step. The most important thing at this step is that the people involved work together. It is beneficial to the program to have a group of consumers who will assist in developing an advocacy agenda for the program, and it is important to remember that the CAB is an advisory group, which does not make decisions about the day-to-day workings of the program.

NCAB believes that it is important for the CAB to be autonomous. The CAB must be able to make its own decisions and recommendations. The CAB must develop its own guidelines/by-laws and while the governance board of your HCH should approve this document, we don’t believe that the governance board should be able to make substantial changes to the document. However, again, that is a decision that each CAB must make on its own.
CHAPTER TWO

RECRUITMENT AND THE DEVELOPMENT OF GUIDELINES

Once you have decided to start a CAB, there are several decisions that must be made before recruitment can begin:

- How large should the CAB be?
- Who is eligible to sit on the CAB?
- Should anyone other than consumers be voting members of the CAB?
- What kind of support will the HCH project be able to give?

These are just a few of the issues that must be decided early. The answer to each of the bulleted items will decide your next steps.

How large your CAB should be is an important issue. NCAB recommends that you start relatively small, it is always possible to add people, but very difficult to go in the other direction. If you are in an urban center, then your CAB may be larger than one in a rural area. We believe that a smaller CAB of 7 or 9 people is a good place to start. That would allow the group to be representative of the population that you represent. You might notice that we have used an uneven number that helps when it comes to voting - you won’t have to worry about how to break a tie.

Another really important issue is who would be eligible to sit on the CAB. The NCAB rule of thumb is that the consumer must be homeless or formerly homeless, and the person must either currently use (and we believe that this should reflect the majority of your members) or have formerly used the services provided by the Health Care for the Homeless project. The reason for that last point is important because you can’t make recommendations to a program if you don’t know its services. NCAB also strongly recommends that you try very hard to make sure that your CAB is representative of your constituents. If your HCH project includes services such as substance abuse, mental health, services to families as well as single adults, then you must recruit your membership from those groups. A CAB cannot adequately represent the entire program if you don’t have participation from each of those segments of the population.

Many CABs have advocates from the local community as members of the CAB. These are people who are well known in the homeless community, but who are not employees of your HCH project. For instance, on the CAB in Boston, Massachusetts, there are two advocates - a public health nurse who is well known to homeless people and an Episcopal Priest who has a street ministry. They are full voting members of the CAB. They are an important part of that CAB. Some CABs only have consumers. Either way is good.
The development of guidelines (by-laws) is a crucial one. We have found that guidelines should be short and to the point. You should also remember that they are not written in cement. They can be amended, and probably should be looked at on an annual basis. Your guidelines should contain things like: number of members on the CAB; whether or not there should be advocates; how many officers, length of terms for both officers and general members - some CABs have permanent members, and others have term limits. There should definitely be a section on the responsibilities of CAB members, including how the CAB members are expected to conduct themselves. For example, there should be a section which includes procedures for removing a CAB member. In Boston, it is spelled out that what a CAB member does outside of the meeting is not the business of the CAB. However each member must come to the meetings clean and sober. The member must listen carefully, not interrupt and follow Roberts Rules.

The last bulleted point is sometimes the most important one. It is very important that there be support from the HCH project. In order for the CAB to be most effective, it is essential that you are able to make it as easy as possible for the members to attend meetings. You must have a place to hold the meetings; you must have someone to take minutes and to distribute them, and to send out reminders about the upcoming meeting. We have found it beneficial to have the meetings on the same date, time and place each month. Some programs send taxi vouchers to each member the week before the meeting. It would be beneficial to serve a meal (if possible) at the meetings. It is also important that the meeting be held at a time that is accessible to homeless people. In some cities, the CAB has an agreement with local shelters so that a bed would be held for a homeless member. If the meeting is held in the late afternoon this might allow your members to attend without losing a place to sleep that night. We have found that if the Executive Director of your program calls the local shelters, most shelters are happy to accommodate you. Some programs provide transportation after the meeting. It all depends on what your program can afford to offer. There may be other issues that we haven’t discussed, but be sure to bring them to your local HCH; usually things can be worked out.

Some Health Care for the Homeless projects assign one or two senior staff members to attend CAB meetings. These people act as the liaisons between the program and the CAB. This is important. It allows for direct communication between the groups. The staffers are not voting members of the CAB. They take recommendations from the CAB back to the program. They also bring agenda items from the program for the CAB to discuss.

Recruitment is one of the most important things that a CAB does. We have found that it is an on-going process. Your CAB will lose people along the way and you will have to have a process in place in order to replace them. NCAB recommends that you have a Recruitment Sub-committee. Some CABs have an application form that asks for very basic information (sample attached) on file and when a new member is needed, they already have a few people ready in the wings.
NCAB suggests that if you use an application form, you have it translated to Spanish, French, or whatever languages you feel are necessary. One of the most important recruitment tools that you have available to you are the providers. Doctors and nurses are excellent people to ask for recommendations. In Boston, those are the first people that are contacted when there is a need to recruit new members.

Signs posted in HCH clinics and in shelters are the next place to look. If you utilize this tactic, you must make sure that applications are available at the site. It would be up to the CAB members to check those places for completed applications on a regular basis.

Some CABs find it very easy to recruit new members; others are frustrated how often they must recruit new members. One of the things that you must remember is that the homeless population is a very transient one. It is very difficult for people who are homeless to make a long-term commitment to the CAB. The formerly homeless members must remember what it was like out there! Most CABs find that they have a core group of dedicated people who attend each and every meeting. Others come and go, and that is a good thing. This helps bring the CAB new perspectives.
CHAPTER THREE

DEVELOPING A STRONG RELATIONSHIP WITH GOVERNANCE BOARDS AND SENIOR MANAGEMENT

Another important part of being a CAB member is to develop some kind of direct relationship with the governance board of your HCH project. In some cases, the chair and vice-chair of the CAB are nominated to the governance board after they have been CAB members for a specific period of time. In other cases, it doesn't have to be an officer of the CAB, but should be a consumer member (not an advocate). One NCAB member has been a member of her local CAB for about ten years, and has been a member of the Board of Directors for about 4 years. This is a permanent seat; it does not change even though she is no longer the Chair of her local CAB. It is her responsibility as a consumer to make a report at each monthly Board meeting about the activities of my CAB.

NCAB believes that it is most important to develop that relationship. Having one or more consumer members on the board will assist the CAB in many ways:

- provides direct access to the governance board and
- lets the program at large understand that having a CAB is an important part of the program.

Another important factor in having consumer members on the governance board is that it allows the board to have a greater understanding of what consumers are thinking. We believe that a Consumer Advisory Board can be very helpful to the program by providing new insights. For example, a local CAB made a recommendation that an HCH project should change the name of the clinic that it runs. It was originally called "The Homeless Clinic". The CAB pointed out that there was a group of people who were not utilizing the clinic because they didn't like being labeled homeless. Once the name of the clinic was changed, it was shown that the numbers of people utilizing the clinic grew. This was a small thing, but it made a very large difference to consumers.

Some Executive Directors come to the CAB on an annual basis with a proposed advocacy agenda for the next year, asking the CAB to prioritize the items (as well as make a list of things that should be added). CABs should feel free to make recommendations to senior staff on anything that they feel is needed. However, the CAB must understand that they are making recommendations and they may not be acted upon.
It is important for the CAB to have a mechanism to use if the CAB feels there is an issue that needs discussion, but the management does not. This is where having a member on the governance board comes in; the CAB could then bring the issue up at a board meeting. NCAB also feels that this is something that should be reserved for important issues. For instance, one local CAB has never had to use this mechanism. If a recommendation is made to senior management that is not acted upon, the staff liaison person comes back to the CAB with an explanation why the recommendation was not acted upon. Most of this is common sense. Once a month, the chair of the local CAB meets with the Executive Director’s Administrative Assistant to set the agenda for the following meeting. The week before the meeting, a packet of information is sent out to each member. Included in the packet are the agenda minutes from the last meeting, taxi voucher and the organization’s newsletter. The packet helps to remind people of the meeting and allows them to prepare questions they may have on whatever is on the agenda.

We have found it helpful to invite different people from within the HCH project to come and make a presentation to the CAB on what they do. It is an easy way for the CAB to become acquainted with the different parts of the program and it also allows the staff to become acquainted with the CAB. Once this is instituted as a regular agenda item, different departments within the HCH often request to speak before the CAB, especially if they have suggestions for a major change within their department.

Once the CAB has been in existence for a while, we think that you will find that both staff and board will utilize the option to request the CAB to look at specific issues on a regular basis. This doesn't happen overnight; it takes a while, but it will happen. We can't stress enough that it is imperative that the CAB understand that it is an ADVISORY GROUP, and that you don't make recommendations or suggestions on staff issues or day to day operations. That is for the Executive Director and Senior Management to do. The CAB makes recommendations and suggestions on issues that affect the consumers that they represent.
CHAPTER FOUR

HOW CAN WE BE SURE WE ARE REPRESENTING OUR CONSTITUENTS TO THE BEST OF OUR ABILITY?

NCAB has found that one way to make sure that is representing consumers is the focus group. One local CAB found that they were able to amass a great deal of information by holding focus groups within the individual parts of the project. They held a meeting with about 15 to 20 people from each part of the HCH program. For example, included were people staying in family shelters; single adult shelter patients currently inpatients at Respite; and the street folks who don't use shelters at all. Each of the groups were asked the same questions, although there were some questions that were unique to each group. For example, the street folks were asked if they were bothered by the number of times that our Street Team woke them up during the night to see if they needed assistance. (The Street Team was delighted to hear that they welcomed the visits.) Each group was asked if there were services that they were not receiving that they felt the HCH should provide. They were also asked if they felt that they were receiving unnecessary services. The CAB was able to gather a lot of information that was helpful to both the program as a whole, as well as for the CAB. We also believe that the consumers felt that the CAB valued their opinions.

Another local CAB used a survey, which was distributed to shelters and to patients who came into the HCH clinics. That system did not have as many responses as was expected. You may find, however, that it could work for your group.

Let NCAB know if you have tried other methods and what your expectations and final responses were.
CHAPTER FIVE

FINAL THOUGHTS

NCAB hopes that you will find this manual helpful. Contact us with your ideas and responses. Let us know if you think that it has been helpful to you. Are there things that we should have covered and haven't or things that should be expanded? Another thing that we found to be useful is to remember that being a member of a CAB, while rewarding, is hard work. You might find it beneficial to go back over the minutes of your meetings and make a list of items that your CAB has addressed and what changes were made because of the CAB’s involvement. If you do this on an annual basis, you will be surprised at the number of changes that your CAB has achieved. Again, you should remember to congratulate yourselves occasionally. You deserve it!
CONTACT INFORMATION

Please feel free to contact any of us. We look forward to hearing from you.

Ellen L. Dailey, Chair, NCAB, edailey@bhchp.org, 237 Walnut Avenue, #3, Boston, MA 02119

Veronique Moore, Vice-Chair, NCAB, veroniquevcm@aol.com, 1217 W. North Street, Kalamazoo, MI 49006

Ulysses Maner, Vice-Chair, NCAB, ulyssesec@aol.com, House of Hope, 908 SW 1st Street, Fort Lauderdale, FL 33312

Sarah Davidson, Secretary, NCAB, sbeloved@aol.com, 128 E Main Plaza #228, San Antonio, TX 78205

WEB SITES

National Health Care for the Homeless Council
Health Care for the Homeless Clinicians’ Network www.nhchc.org

Bureau of Primary Health Care www.bphc.hrsa.gov

HCH Information Resource Center www.bphc.hrsa.gov/hchirc

National Coalition for the Homeless www.nationalhomeless.org

National Alliance to End Homelessness www.naeh.org

National Coalition for Homeless Veterans www.nchv.org
SAMPLE
CONSUMER ADVISORY BOARD
APPLICATION FORM

NAME ____________________________________________________________

ADDRESS WHERE YOU CAN RECEIVE MAIL
______________________________________________________________
______________________________________________________________

______________________________________________________________

TELEPHONE NUMBER (WHERE YOU CAN RECEIVE MESSAGES)
______________________________________________________________

WHAT SERVICES OF THIS HCH PROJECT HAVE YOU USED?
________________________________________________________________
________________________________________________________________
________________________________________________________________

NAME AND ADDRESS AND PHONE NUMBER OF A PERSON WE CAN CONTACT FOR A PERSONAL REFERENCE
________________________________________________________________
________________________________________________________________
________________________________________________________________

WHY DO YOU WANT TO BECOME A MEMBER OF THE CONSUMER ADVISORY BOARD?
BUREAU OF PRIMARY HEALTH CARE
POLICY INFORMATION NOTICE: # 98 - 12
DATE: APRIL 28, 1998

IMPLEMENTATION OF THE SECTION 330 GOVERNANCE REQUIREMENTS
U.S. Department of Health and Human Services
Health Resources and Services Administration
Bureau of Primary Health Care

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IMPLEMENTATION OF THE SECTION 330 GOVERNANCE REQUIREMENTS

I. Background

Passage of the Health Centers Consolidation Act of 1996 (P.L. 104-299) resulted in a number of
revisions to section 330 of the Public Health Service (PHS) Act. The new section 330(j)(3)(H) of
the PHS Act requires that all organizations which receive health center funding under section 330
have a governing body which assumes full authority and oversight responsibility for the health
center. The governing board must maintain an acceptable size, composition, and meeting
schedule. Furthermore, the responsibilities of the board include the authority to control the health
center's budget and major resource decisions, set center policies, and approve the selection and
dismissal of the health center program director or chief executive officer.

Community and migrant health centers were subject to governing board requirements under
previous legislation. This statute includes, for the first time, governing body requirements for
section 330(h) health care for the homeless and section 330(i) health services for residents of
public housing grantees.

II. Section 330 Governance Requirements

Section 330(j)(3)(H) stipulates that, in order to receive a health center grant, the applicant must
demonstrate that "...the center has established a governing body which...
(i) is composed of individuals, a majority of whom are being served by the center and who, as a
group, represent the individuals being served by the center;
(ii) meets at least once a month, selects the services to be provided by the center, schedules the
hours during which services will be provided, approves the center's annual budget, approves the
selection of a director for the center, and, except in the case of a public center (as defined in the
second sentence of this paragraph), establishes general policy for the center; and (iii) in the case of the application for a second or subsequent grant for a public center, has approved the application or, if the governing body has not approved the application, the failure of the governing body to approve the application was unreasonable."

These requirements of the governing body do not apply to an entity operated by an Indian tribe or tribal organization.

Most health centers are private, non-profit corporations. Public entities operating health center programs may meet the governance requirement in either of two ways. The public entity's board may meet health center board composition requirements including having a consumer majority. In this case, no special considerations are needed.

When the public entity's board does not meet health center composition requirements, a separate health center governing board may be established. The health center board must meet all the membership requirements and perform all the responsibilities expected of governing boards except that the public entity may retain the responsibility of establishing fiscal and personnel policies. The health center board can be a formally incorporated entity and it and the public entity board are co-applicants for the health center program. When there are two boards, each board's responsibilities must be specified in writing so that the responsibilities for carrying out the governance functions are clearly understood.

The statute allows for a waiver by the Secretary for any of the requirements stipulated in section 330(j)(3)(H) of the PHS Act for health centers receiving funds pursuant to subsections 330(g), (h), (i), or (p). Specifically, the statute stipulates: "upon showing of good cause the Secretary shall waive, for the length of the project period, all or part of the requirements of this subparagraph in the case of a health center that receives a grant pursuant to subsections (g), (h), (i), or (p)."

Thus, the waiver authority applies to grants under the Migrant Health, Health Care for the Homeless, and Health Services for Residents of Public Housing programs, as well as, for programs funded under subsection 330(p) in sparsely populated rural areas.

Regulations regarding governing board requirements are set forth in 42CFR§51c.304. These regulations have been and are applicable to Community and Migrant Health Center programs, but not to Health Care for the Homeless and Health Services for Residents in Public Housing programs. However, the regulations serve as a useful framework for all health center programs.

Statutory and regulatory requirements are described in further detail in the BPHC Health Center Program Expectations for the cluster.

Governance requirements for all health center programs will continue to be evaluated and monitored through the Primary Care Effectiveness Review process, the annual review of continuation applications, and other review mechanisms.
III. Implementation

A. Section 330(e) Community Health Centers

The Health Centers Consolidation Act of 1996 includes no legislative changes to governance requirements for section 330(e) as community health centers. For those community health center grantees which also receive funding designated to serve a special population (i.e., section 330(g), (h), or (i)) representation among the consumer members of the governing body should be reasonably proportional to the percentage of consumers the special population group represents. Community health center governing boards without special population representation should add such consumers or representatives with the next available vacancy(ies). The intent is not to impose quotas on board membership, but to ensure that boards are sensitive to the needs of all of their consumers.

In addition, implementation of one or more of the following options can assist the health center in its assessment of the health service needs of special populations:

- inclusion on the governing body of persons who previously have been health center consumers, but no longer receive services;
- use of a formal advisory board;
- regularly-constituted focus groups comprised of health center consumers who are migrants, homeless, or residents of public housing which advise the governance body on a routine basis; or
- inclusion on the governing body of representatives of other service provider organizations and/or local advocacy groups that have experience in serving these special populations.

B. Section 330(g) Migrant Health Centers

The Health Centers Consolidation Act of 1996 includes no legislative changes to governance requirements for section 330(g) migrant health centers, although it does permit section 330(g) grantees to request "good cause" waivers of the governance requirements. However, the Secretary will only consider a request to waive all or part of the governance requirements from section 330(g) grantees that do not additionally receive funding under section 330(e) as community health centers. This is because community health centers, with or without funding to provide health services to a special population, are not eligible for a waiver. In addition, migrant health centers that previously complied with governing board requirements will have a heavy burden to satisfy the good cause requirement for a waiver.

Migrant Health Programs (formerly known as migrant voucher programs) do not have to meet the requirements in 42CFR§56.601 for governing board composition. These entities may meet consumer participation for migrant/seasonal agricultural worker representation through advisory councils. Please refer to PIN #94-7, issued February 7, 1994, and PIN # 98-07, issued March 6, 1998, for more information regarding governance activities for the Migrant Health Programs.

C. Section 330(h) Health Care for the Homeless

As stated previously, the Health Centers Consolidation Act of 1996 includes governance requirements for all section 330(h) health care for the homeless and section 330(i) health services for residents of public housing grantees. Grantees which do not currently meet the governance
requirements must immediately come into compliance with the requirements, unless granted a waiver.

The statute permits section 330(h) and section 330(i) grantees to request good cause waivers of the governance requirements. However, the Secretary will only consider a request to waive all or part of the governance requirements from section 330(g) grantees that do not additionally receive funding under section 330(e) as community health centers. This is because community health centers, with or without funding to provide services to a special population, are not eligible for a waiver.

IV. Waiver Approval

All Section 330(h) and 330(i) grantees must provide the BPHC with a status report describing governance arrangements and, where necessary, a time frame for coming into compliance with the section 330 governance requirements. Any request for a waiver of all or any of the specific governance requirements must include a compelling argument as to why the program cannot meet the statutory requirements, as well as, alternative strategies detailing how the program intends to meet the intent of the statute for appropriate user input.

The status report (including any waiver requests) from each health care for the homeless and health services to residents of public housing grantee and any waiver request from migrant health center grantees must be submitted no later than June 30, 1998 to:
Lawrence Poole
Grants Management Officer
Bureau of Primary Health Care
4350 East West Highway, 11th floor
Bethesda, Maryland 20814

Programs should indicate "Governance Status Report" prominently on the first page of their submission, as well as include the grant number for their health care for the homeless, health services to residents of public housing, and/or migrant health center program.

Any questions regarding this Policy Information Notice should be addressed to Jean Hochron, Chief, Health Care for the Homeless program at (301) 594-4437.