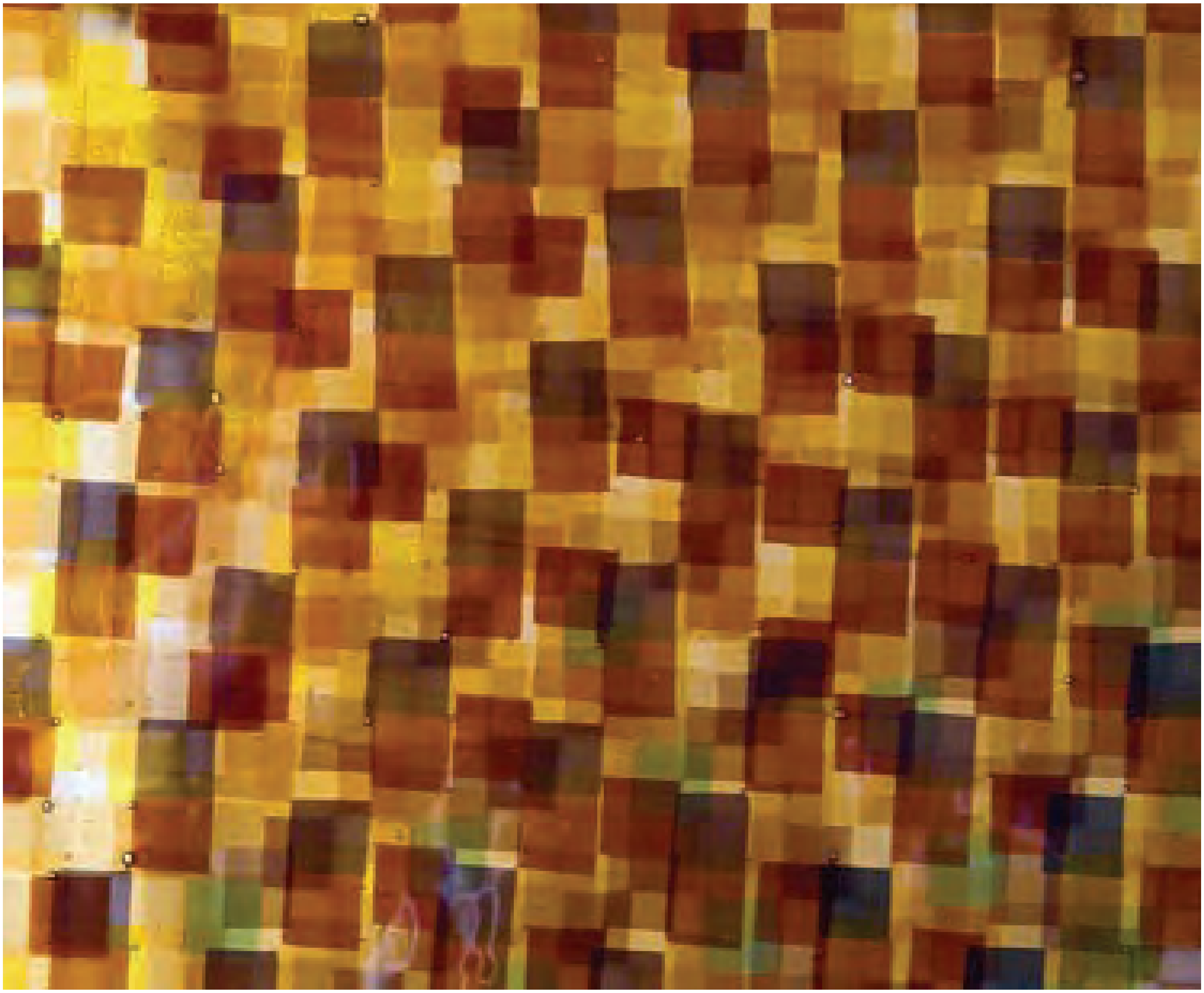
A Guide to Consumer Involvement

Improving the Quality of Ambulatory HIV Programs

New York State Department of Health AIDS Institute
Health Resources and Services Administration HIV/AIDS Bureau



"Shadow Collaboration - Colorado" 2004, Detail of fused - glass installation by Kevin Huang-Cruz, HIV-positive artist

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Improving the Quality of Ambulatory HIV Programs

Developed by the
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AIDS Institute

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New York State Department of Health
AIDS Institute

Guthrie Birkhead, M.D., M.P.H.
Director

Humberto Cruz, M.S.
Executive Deputy Director

Barbara Devore, M. P. A.
Executive Deputy Director

Bruce D. Agins, M.D., M.P.H.
Medical Director

Office of the Medical Director
HIV Quality of Care Program

Bruce D. Agins, M.D., M.P.H.
Medical Director

Clemens M. Steinböck, M.B.A.
Director of Quality Initiatives

Franklin Laufer, Ph.D.
Director for Performance Measurement

JoAnn Perou, M.A.
NQC Project Administrator

Dan Tietz
Consumer Advocate
Division of HIV Health Care

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Introduction

The New York State Department of Health AIDS Institute has, since its inception, valued and promoted working in partnership with people living with HIV/AIDS and the diverse communities and programs we serve. People Living with HIV/AIDS (PLWHA) and those affected by HIV/AIDS are represented and consulted at all levels of decision-making within the organization. The AIDS Institute employs PLWHA from diverse communities within New York State affected by the HIV/AIDS epidemic and many PLWHA serve as volunteers in advisory capacities on AIDS Institute Community Advisory Boards (CABs). The AIDS Institute has also developed and implemented specific consumer involvement standards for contracts (see appendices) with provider programs. In fact, agencies applying for and awarded AIDS Institute funding are required to demonstrate consumer involvement in policy and program design, implementation, evaluation, and quality improvement activities.

The AIDS Institute is committed to furthering and enhancing HIV/AIDS consumer involvement in relevant policy and program decision-making in the health care settings of ambulatory care programs with which it works. As a result of that commitment, the Institute established a Consumer Advisory Committee (CAC) to provide direct input to its Statewide Quality of Care (QOC) Program. Members of the CAC represent diverse communities in New York State affected by the HIV/AIDS epidemic. This guide was developed by the CAC to assist programs and consumers throughout New York State in the creation and improvement of methods to involve consumers in HIV/AIDS health care programs and, ultimately, improving the quality of HIV health care provided by those programs.

In addition to this guide, the AIDS Institute has developed other resources designed to enhance and support consumer involvement in quality improvement activities, including the consumer-training curriculum, *Making Sure That Your HIV Care Is the Best It Can Be*, and the *Patient Satisfaction Survey*. Both of these resources are available at: www.hivguidelines.gov.

The Need for Consumer Involvement

Experience has shown that PLWHA provide a critical and necessary perspective on the development, implementation, and evaluation of programs and services that are designed to ultimately meet their needs as the consumers of those services. Some of the ways an organization can involve consumers include:

- PLWHA consumer representation on the organization's Board of Directors
- Establishment of an HIV-specific Consumer Advisory Board (CAB)
- PLWHA consumer representation on an existing Community Advisory Board
- Involvement of PLWHA consumers in workgroups, committees and task forces, such as a QOC Program Committee, Community Awareness Committee, Patient Education Committee, and HIV/AIDS taskforce
- PLWHA consumer representation as volunteers, peer educators, outreach workers, or other staff in the clinic
- PLWHA consumers who serve as HIV peer trainers to assist clients in various activities like making healthy decisions, managing their health, accessing services through managed care, or considering participation in clinical trials
- PLWHA consumer input through participation in consumer satisfaction and needs assessment surveys, focus groups, suggestion boxes, and consumer forums
- Inclusion of consumers as members of Quality Improvement (QI) committees and teams
- PLWHA involvement in HIV/AIDS policy and program development
- PLWHA participation in identifying emerging HIV/AIDS service needs
- Consumer involvement in peer outreach, recruitment, mentoring and consumer training

The goal of PLWHA consumer involvement is to develop, deliver, and improve the quality of programs to effectively meet the service needs of the individuals and families that rely upon them for their HIV health care. This guide provides suggestions for the successful involvement of members of the PLWHA community as partners in reaching this goal.

How this Best Practices Guide was Developed

The Best Practices Guide to Consumer Involvement in HIV/AIDS Services Programs came about based on a recommendation from the CAC in 2005. In developing this guide, the CAC, with assistance from AIDS Institute staff, developed a survey that was sent to 119 HIV/AIDS programs in New York State to determine the ways that they formally and informally obtained consumer input into HIV/AIDS policy and program development, and implementation and periodic quality review. A total of seventy-five programs completed and returned surveys to the AIDS Institute (63%). The survey and the Consumer Involvement Survey Report can be found in the Appendix section of this guide. As a result of the survey the CAC found that:

- 93% of responding programs have instituted processes to systematically obtain consumer input
- 68% of the responding programs reported having in place an active Client/Consumer Advisory Board (CAB)
- Most (94%) of the responding programs rated their CAB as either very (59%) or moderately (35%) effective
- The most common methods of obtaining consumer input among the responding programs were client satisfaction surveys (87%), CABs (68%), consumer focus groups (36%), suggestion boxes, meetings, and other activities (27%).

In addition to the results of the survey, the CAC and AIDS Institute staff interviewed and visited over a dozen of the sites that reported having effective consumer involvement activities. The purpose of the interviews was to gain further insight into the factors that contributed to meaningful and effective consumer involvement in HIV health care programs. Barriers encountered by both consumers and facilities in ensuring consumer involvement were also discussed.

Intended Use of the Guide

In this guide you will find descriptions, rationale, and implementation ideas for proven and effective methods of promoting and enhancing HIV/AIDS consumer involvement. This guide is intended for use by clinical and non-clinical staff in HIV/AIDS health care programs to help them understand benefits to quality of care that come from optimizing consumer input. It may also be of value to consumers who are considering involvement with the clinics and agencies where they receive their care.

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Quality of Care CAC Members:

Damaris Alicea
Victor Alvarez
Cindy Aponte
Linda Beal
Robin Bonner
Julian Brown*
Danny Castro
R. Orbit Clanton
Dana Diamond
Denise Drayton
John Anthony Eddie
Deshell Fields
Laurence Francis
Tom Garruto*
Richard Paul Hahn
John Hardel
Steve Hemraj

Kevin Huang-Cruz
Vanessa Johnson – Chair
Charles Jones
Joey Lopez
Michelle Lopez – Chair
Hilda Mateo
Oliver W. Martin III
Catherine Martens
George Moore
Soraya Pares
Becky Smith
Russel Stephen
Raymond Tracy-Moran
Michael Wade*
Kim Watson
Ayo Wells
John Wikiera*

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Catholic Charities Health Systems
Adult Day Health Care Program
Catskill Regional Medical Center, AIDS Community Health Center
Central Islip Health Center
Community Healthcare Network
Coney Island Hospital
Daytop Village
Elmhurst Hospital Center

* Indicates member of CAB subcommittee

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Hudson River Healthcare, Inc:
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Jewish Board of Family and Children Services
JCAP, Inc. – Living PROOF
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Project Suiner-fur Health Services
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South Brookhaven Family Health Centers
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How To Use This Guide

If you are reading this Guide you are interested in finding ways to effectively involve consumers in the HIV quality of care improvement process. You may already be involved in activities that help gather consumer input or you may be looking for effective ways to start. Or, you might just be looking for ideas about how others solve problems that you are facing with some ongoing activities. Wherever you are on this continuum, this guide can help you.

Target Audiences

A variety of HIV/AIDS program staff are involved in obtaining and enhancing consumer input. Each of them has a different perspective and a unique set of opportunities to engage consumers in providing valuable input to improve program quality. Some of the staff that might be involved include:

- Medical Directors
- Social Workers and Case Managers
- Peer Educators
- Clinical staff (physicians, nurses, nurse practitioners, physician assistants)
- Treatment Educators
- Adherence Counselors
- HIV Program Administrators
- Outreach Workers
- Quality Improvement Staff
- Administrative Support Staff (e.g., receptionist)

Experience has shown that a coordinated effort that utilizes the expertise of a variety of staff members in different roles is most likely to be effective in gathering valuable consumer input from a broad and representative sample of consumers. Your program can benefit from including as many staff as possible in reviewing and developing your consumer involvement initiatives.

If you are a consumer of HIV/AIDS program services, and you are thinking about how best to be involved in the improvement of the quality of care you receive, you will find descriptions of the many ways you can do that. You will also get a better understanding about how you can work with your HIV health care provider to address your needs in the most helpful and satisfying ways.

How the Guide Can Help You

The statewide survey of consumer involvement activities in HIV/AIDS services programs revealed that only a small percentage (6%) of HIV/AIDS programs do not have a mechanism to obtain consumer input into their QOC programs. Most programs, however, rely upon only one or two different types of consumer involvement activities. These are, most often, either consumer satisfaction surveys or CABs.

While these initiatives are valuable mainstays of consumer involvement there are other very effective methods of involving consumers that might suit your program and both surveys and CABs can often be improved upon to make them more effective. For example, the statewide survey found that 35% of the facilities rated their CABs as "moderately effective" and 6% rated them "not effective." This is an indication of the potential value of this guide in helping to increase the effectiveness of CABs.

This guide can help you to evaluate the effectiveness of your CAB or other consumer input methods you might currently be using (ex: satisfaction surveys, focus groups, etc.). It can also help you to select the most effective method for your facility and to identify ways of making it really work. Whether you have an active consumer input method or you are just starting to develop one, this guide can help you to:

- Recognize the benefits of developing a varied and systematic approach to gathering consumer input into strengthening quality improvement programs and improving HIV service delivery
- Clearly identify the objectives of any strategies or initiatives designed to enhance consumer input and involvement
- Select the consumer involvement strategies that most suit the needs and characteristics of your program or services
- Implement and/or improve the effectiveness of components of a policy and/or program to enhance consumer input and involvement
- Evaluate the success of consumer involvement initiatives

As a consumer of HIV/AIDS services who is interested in providing your input to the clinics or agencies at which you receive care, you can use this guide to:

- Better understand why your input is meaningful and valuable to improving the quality of care you receive
- See how the clinic or agency might use the information you provide
- Select the kind of involvement you would feel most comfortable with
- Suggest ways of improving the consumer involvement activities in the clinic or agency

Finding What You Need in the Guide

If you are just beginning to explore ways of involving consumers in HIV quality of care initiatives you might make best use of the guide by reading each of the chapters in sequence. If you are looking for a particular piece of information you can locate it in the following chapters as described below.

In **Chapter III** you will find a description of the goals of consumer involvement in QOC programs and the types of consumer involvement methods. This chapter will help you clearly define your objectives in developing consumer involvement programs and to understand the ways each method can best be used to meet your objectives.

Chapter IV provides a detailed "how to" description of the many forms of consumer involvement and presents a rationale for the need for multiple opportunities for consumer involvement. The methods described in detail include: Client Satisfaction Surveys, Consumer/Community Advisory Boards, Focus Groups, and other ways to involve consumers based upon the experiences of the many sites surveyed and interviewed.

In **Chapter V** you will find ways of identifying and overcoming barriers to consumer involvement. Barriers may be organizational or structural within agencies themselves. Alternatively, there may be a number of barriers that are unique to the consumers and may be a result of living with HIV/AIDS.

In **Chapter VI** you will find Best Practices based upon the statewide survey findings, including data gathered, implications of the findings, and a compilation of lessons learned. In this chapter you will also find a description of site-specific consumer involvement practices.

In the **Appendix** are listings of sites that have participated in the survey and interview process, the detailed findings of the survey, and Standards for Consumer Involvement, including the Ryan White CARE Act Standards and the New York State AIDS Institute Standards. The appendices also contain additional resources and references to check for more information or published support for the information included in the guide.

The Benefits and Goals of Consumer Involvement

In June 1983, at the Second National AIDS Forum, in Denver, Colorado, the Advisory Committee of People with AIDS drafted the "Denver Principles." Among the 17 principles affirming the rights of people with HIV to participate in their own health care was the principle that "people with HIV should be involved at every level of decision-making" within provider organizations (Callen).

Consumer Health Benefits of Involvement

HIV consumer involvement in making personal health care decisions and in managing their own care in partnership with their health care providers is widely recognized as having positive effects on their own health outcomes and on positive health promotion and disease prevention behaviors (Gerbert).

Patients who are more involved in their health care are more likely to understand treatment plans and adhere to them. They are also more likely to communicate effectively with medical and social services providers. As a result they are likely to be better informed about HIV and its prevention and treatment. They may play a more active role in informing and educating their peers.

Provider Organization Benefits of Consumer Involvement

HIV/AIDS service provider organizations also benefit from consumer involvement. Through the involvement of consumers, agencies can learn how service users see the value and effectiveness of programs, which programs are the most effective in meeting the consumers' needs, and what service gaps exist, providing needed justification for the most appropriate use of resources. (HRSA)

The valuable contribution of HIV consumers is summarized by the following quote from a report of the National Alliance of State and Territorial AIDS Directors (NASTAD):

"PLWH [People living with HIV] play a unique role in identifying emerging trends in the epidemic, assessing unmet needs, and identifying effective services...PLWH are often able to evaluate with a "personal lens" the feasibility of propose policies and programs. Their navigation of the HIV service delivery system can inform policy making as they confront the gaps in services or barriers impeding access."

The benefits of involving a diverse and representative sample of people living with HIV and AIDS in policy and program development, implementation, evaluation and Quality Improvement (QI) activities include:

- **Providing a Consumer Perspective.** People Living with HIV/AIDS provide a unique and critical consumer perspective on service planning, delivery, and evaluation. They know firsthand the strengths and areas for improvement in the services they receive.

- **A "Wake-Up Call".** People Living with HIV/AIDS help keep the agency focused and on track by providing a first-hand perspective on issues they, their families, and their communities, all face. They can identify ways in which the agency or clinic is missing the mark in providing an essential service.

- **Help in Needs Assessment.** People Living with HIV/AIDS can help ensure that needs assessments can be written to reflect the needs of consumers from different populations and geographic locations, including those in and out of care.

- **Identifying Service Barriers.** People Living with HIV/AIDS can identify service barriers, based upon their own actual experiences accessing services across the continuum of care with multiple service providers. This may not be evident to staff, and consumers can help the agency to identify ways to overcome those barriers.

- **Outreach.** People Living with HIV/AIDS can help identify ways to reach the communities served, including minority and other special populations with unmet need for services. They may play a role in increasing the acquisition of new patients from underserved populations.

- **Quality Management.** People Living with HIV/AIDS who are clients of agency clinic services can provide direct feedback on the quality of services and provide suggestions for the quality improvement process.

- **Community Liaison.** People Living with HIV/AIDS provide an ongoing link within the communities they represent in terms of gender, race, ethnicity, age, sexual orientation, etc. Engaging a diverse group of consumers with respect to life experiences, socioeconomic, and cultural factors will ensure a variety of perspectives from populations who are not typically involved in provide agency feedback. They can bring community issues to the agency as well as help to bring research and care information to the community. This may play an important role in resolving conflicts and avoiding unnecessary confrontations.

- **Demonstrating Active Participation.** The involvement of People Living with HIV/AIDS in the processes of needs assessment, policy and program development, implementation, evaluation, QI, and decision-making enhances a climate of participation and partnership between the agency and the community it serves. It may serve to increase patient involvement in personal HIV health care decision making and in advocating for others.

The Goal of Consumer Involvement in HIV/AIDS Health Care Programs

Consumer involvement programs should be designed to increase the involvement of consumers in decision-making and to provide input into the quality improvement process within an agency. This will assist in positioning the agency to provide the highest HIV quality of care to its patients and clients. Without effective means of gaining accurate input and actively involving consumers in program evaluation, the agency will be without a critically important source of planning and evaluation information for the improvement of services.

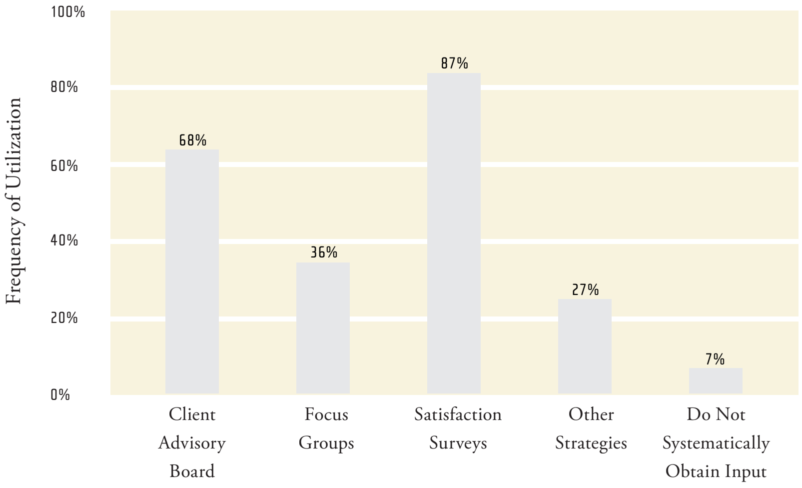
The methods of enhancing and increasing consumer involvement that are described in the pages that follow have been shown to be effective in agencies like your own.

Consumer Involvement Strategies and Practices

In a recent survey of HIV/AIDS programs with QOC service agreements with the AIDS Institute, 69 of 75 program directors (93%) reported that they had a process in place to systematically involve consumers, either formally or informally, in gathering feedback on their programs.

Some of the ways they reported that consumer input was used was in HIV/AIDS services program development, program implementation, and periodic program quality review. Figure 1 shows the variety of methods used to obtain consumer input. The most commonly used methods were client satisfaction surveys and Consumer Advisory Boards (CABs). Consumer focus groups, needs assessment surveys, suggestion boxes, and involving consumers in either paid or volunteer positions within the organization were also used.

Figure 1: Methods for Systematically Obtaining Consumer Feedback (n=75)



Many Opportunities and Methods for Involving Consumers

There are multiple and varied opportunities and methods for involving consumers in providing feedback to organizations and engaging consumers in making decisions that affect the quality and delivery of HIV/AIDS program services. Some of the most common and effective methods of gaining consumer input include:

- Consumer Focus Groups
- Client/Patient Satisfaction Surveys
- Needs Assessment Questionnaires
- Advisory Boards
- PLWHA employed as Staff members
- PLWHA on the Board of Directors
- Suggestion Boxes
- PLWHA Members participating in QI Committees and Teams
- Development of Peer Mentoring and Training Programs on communication skills/team-building

Consumer Focus Groups

Overview: Focus groups provide an opportunity for consumers to interact with one another in response to questions and ideas posed by a moderator. The focus group is designed to bring together people who share similar concerns or experiences but who may have different perspectives to share on those issues. Focus groups allow you to explore reactions to ideas and generate new ideas. They get beyond "yes" and "no" answers or responses to multiple-choice questions. Focus groups differ from almost all other forms of information gathering in that they provide open-ended group interaction.

Description: Focus groups consist of a small number of participants (ideally 6-10) selected because of their interest, experience, and perspective. A moderator is responsible for facilitating the group, which typically lasts for 90 minutes to 2 hours. The role of the moderator is to pose questions and situations that will stimulate group discussion and interaction. The moderator follows a structured, well-defined guide that is developed in collaboration with the agency and which is designed to help get answers to specific questions that the agency has. The experienced moderator is not a participant in the discussion but keeps the group on track, stimulates group interaction and allows the group to follow promising, and often unanticipated, leads. The outcome of the focus group is a report and analysis, produced by the moderator, of the group .

Best Use: Because focus groups provide a depth of information that is not routinely available through individual interviews or questionnaires, they can provide a source of "surprise" information from participants or debates on differing points of view. You don't use a focus group to get consensus. You use it to obtain a diversity of opinions and ideas. While the information you get is likely to be representative of a particular group of consumers, it is not by any means quantitative. Use it to get a sense of what consumers are thinking and feeling and perhaps some understanding about why they think and feel as they do, in their own words and based upon their own experiences.

There are four essential steps to effective focus groups:

- **Planning.** Define and clarify the problem. Decide which group of consumers is most likely to provide the information you need. Select a date, place, time, moderator, recruiters, and logistics (travel needs, food, facility coverage, emergency contacts, and incentives for participants).

- **Recruitment.** Select group size (and invite a few more). Identify the particular characteristics and compatibilities of the participants you want and write a recruitment tool and letter to be used in making contacts with all potential participants. Be sure that all participants know why they are coming and what to expect. Peers should be actively engaged in recruitment efforts.

- **Moderation.** Find an experienced moderator who will help develop the discussion guide based upon your needs and facilitate group discussion with understanding and objectivity.

- **Analysis and Reporting.** Agree with the moderator, before the focus group, on the nature of the analysis and report, when it is expected, and how it is to be presented.

Consumer focus groups are used to obtain consumer input by approximately one third (36%) of the sites responding to the statewide survey.

Effective Examples Using Focus Groups

At the Ossining Open Door Family Medical Center, located in Westchester County, the staff and patients are in the process of developing a Consumer Advisory Board (CAB). As a first step in the process, a series of consumer focus groups were held to explore patient perceptions about their care and their ideas about the potential value and use of a CAB. Consumers were very much aware of the diversity of the patient population as well as the tensions that existed among some groups of patients. They expressed the need for a more culturally diverse staff that would more closely reflect the patient population and be more understanding of and responsive to the needs of different cultural groups. Patients felt that there was a good "close-knit" feeling between patients and staff members but also felt that a more formal process of gathering consumer input from the diverse groups would be valuable. The use of the focus groups provided both consumers and staff the opportunity to learn from one another and to brainstorm new ideas for program development.

Consumer Satisfaction Surveys

Overview: Consumer or Patient Satisfaction Surveys provide a means for broad consumer input gathering. Often distributed by agency or clinical staff and administered to patients or clients on an individual basis, surveys provide a standardized method of assessing the reactions of a large group of consumers to questions and issues related to their satisfaction with program services. They provide a reliable base of information for assessing patient perceptions of the quality of care and services they receive. They may be used on an annual or more frequent basis, depending upon resources and the need to gather comparative information over time and to track the changing perceptions of the consumers as programs develop or the population changes.

Description: Consumer Satisfaction Surveys are written questionnaires that may be read by consumers themselves or read to them if they cannot read. They may also be mailed to consumers or put on an online source if that is a reliable way of reaching the consumer population. Surveys should be made available in the languages used by consumers and at appropriate reading and literacy levels.

A validated 52-item survey instrument has been developed by the New York State Department of Health AIDS Institute for use in its HIV services facilities. It is called the Patient Satisfaction Survey (PSS-HIV) and copies in either English or Spanish can be obtained online at the AIDS Institute website (www.hivguidelines.org).

Best Use: Satisfaction surveys provide a snapshot in time of the feelings and perceptions of the sampled consumer population. It is often recommended that consumer involvement in the development of the survey instrument be encouraged. This demonstrates partnership in the process and makes it more likely that the survey will be user-friendly. Consumer involvement may also help to bring up important issues and questions (as well as ways to ask them) that non-consumer staff or an outside agency may not be aware of. Another common recommendation is that the survey be confidential or anonymous. This is likely to enhance the honesty and completeness of the responses. If it is not anonymous then consumers must be assured that the information they provide will be kept confidential or not associated with their name. Consumers should be made aware of the purpose of the survey and they should be provided with a report back on the survey findings. The survey should be written as clearly and simply as possible. Surveys that are too long or complex may not get the full attention of the participant or their most thoughtful responses. A mix of multiple choice or satisfaction scale questions and a few open-ended questions may provide an opportunity to get a range of useful responses. A good tactic is to test a draft of the survey on a sample of the consumer group and with some staff who have not been involved in its development to see if it will give you the kind of answers you are looking for.

Advisory Boards

Description: Most often, advisory boards consist of representatives of the population served by the agency and selected staff members. How that population is defined then determines who will be asked to be a member of the board. This leads to three general types of advisory boards:

- Community Advisory Board
- Consumer Advisory Board
- Client/Patient Advisory Board

The type of advisory board chosen depends upon the needs and philosophy of the organization.

The Community Advisory Board consists of a representative sample of he larger community served by the organization. This might include representatives of the groups of people living in the community, other community organizations, and businesses and institutions within the community, all of whom are seen as stakeholders in the successful operation of the agency.

The Consumer Advisory Board is usually a group of individuals who are consumers of the services provided by the agency. They may be clients or patients of the agency or they may represent a group of people who could become clients or patients.

The Client or Patient Advisory Board is usually defined as a group of individuals who are actual clients or patients of the agency.

Effective examples using Consumer Satisfaction Surveys

The Arnot Ogden Medical Center HIV Primary Care Clinic provides medical care and case management services for people with HIV/AIDS living in South Central New York and Northern Pennsylvania. One of the main projects of the new HIV Consumer Advisory Board at the center was the creation and implementation of an annual consumer satisfaction survey. It was conceived of and written “by consumers for consumers” to assess what the clinic could do to enhance its services with the belief that a consumer initiative would “get more honest answers from patients.” A number of new program needs were identified as a result of the survey. For example, to help patients better understand and meet their nutritional needs, the center applied for and received a Nutritional Initiative Grant from the AIDS Institute. The survey also helped to reveal the patients’ needs for exercise and weight loss programs as well as for low cost clothing resources and personal care items. The patients also identified a desire to have a female medical provider on staff and this resulted in the recent hiring of a new female Clinic Manager.

The St. John’s Riverside Hospital Hope Center, located in Yonkers, provides HIV/AIDS services for the severely disadvantaged HIV patient population in Westchester County. The staff of the Center uses multiple approaches to ensure consumer involvement in program review and development. They use the AIDS Institute Patient Satisfaction Survey on an annual basis, augmenting it with additional questions to evaluate consumer satisfaction with specific clinic services. For example, they might ask about satisfaction with clinic hour schedules, the waiting time, the appearance, comfort, and confidentiality protections of the waiting room, and the walk-in/missed appointment policy. In the past, case managers administered the surveys but recently the task was given to staff peer educators. The result was a more rapid and efficient survey implementation process.

An advisory board may also be a mixture of each of the different types of boards described here. We will use the term "CAB" to represent any or all of the different types of advisory boards.

Advisory boards provide long-term, ongoing, involvement by a group of interested individuals in the review and development of HIV/AIDS policy and program services. The advisory board may:

- represent the community and bring their interest to decision-makers
- develop and review program policies to ensure that they address the needs of the community
- review, revise, and recommend program services
- help to establish program priorities
- solicit and communicate grievances or suggestions from consumers
- identify, review, and help design surveys and other methods of systematically gaining consumer involvement in evaluating programs
- generally represent the consumers' interests, welfare, needs, and unique characteristics and bring information from the advisory board back to the community
- interpret data related to the community in the areas of HIV/AIDS research, prevention, and health care
- serve on QI teams or committees, and employ consumers on staff

CAB membership often includes 5-15 consumer representatives and several HIV program staff members. CABs are often co-chaired by a consumer representative and an agency staff member.

Best Use: CABs function best when meetings are scheduled and held on a frequent and regular basis, often on a monthly or quarterly schedule, in a location that is easily accessible to consumers, and at a time that is convenient for both staff and consumers. Many CABs provide meals or snacks during the meetings as well as reimbursement for transportation, child care, or time lost at work for consumer members, and they distribute educational materials about selected issues and the agency. Orientation and training for CAB members is believed to be effective in preparing them to function effectively and efficiently as a group.

Typical agenda items for CAB meetings may include:

- Quality of care-related issues
- Program and policy review
- Patient satisfaction, complaints, and consumer suggestions
- Broader community resources issues (peer mentoring and training)
- Agency-sponsored events, trainings, fund-raising, and other activities
- Membership criteria and development
- Information updates

Effective examples using Consumer Advisory Boards

The Consumer Advisory Board at Montefiore Medical Center's Center for Positive Living began in 1995 with four members. Now fifteen active members represent the 2200 patients who receive their care at the Bronx-based center. All patients of the center are invited to attend the meetings but only CAB members can vote. The CAB is very much patient-run with a great deal of autonomy and responsibility. Staff representatives from each of the center's departments attend and participate in meetings (e.g., physicians, nurses, administrators, and quality improvement staff). There is a high degree of communication between the CAB and the administration of the center.

One of the key strengths of the Montefiore CAB is the active voluntary daily involvement of the CAB chair and other members in the centers activities and special events. They serve as important links between the patients and the staff. Two additional strengths of the Montefiore CAB are its high level of internal organization and its regular leadership training provided for all CAB members through the New York State and New York City PLWA Leadership Training Institute. The Montefiore staff believes that "in order to be successful, you have to invest in a CAB, respect it, and make it an important part of your program."

The Division of Infectious Diseases at Harlem Hospital Center's philosophy regarding CABs is. "You're a member if you show up." This results in part from the recognition that many of the clinic's patients have many legal, economic, housing, and other challenges that prevent a constant or long-term commitment to CAB participation. Some CAB members attend meetings when they can and then when other life events take priority, they tend to them, returning to the CAB when able. Consequently, the CAB membership ranges from 20 to 40 consumer participants and each program within the center is required to have a representative attend.

Effective examples using PLWHA as Staff

Elmhurst Hospital in Queens serves a large and diverse immigrant population, many of whom are Hispanic. The presence of a consumer on the staff of the HIV Treatment Program in the role of Consumer Outreach Coordinator increases the level of comfort patients have in actively participating in advisory board meetings. The Consumer Outreach Coordinator acts as an effective liaison between patients and other staff members, encouraging patients to communicate directly with the appropriate staff person about issues that concern them. She also acts as a role model and mentor for patients.

In a similar way, other successful examples of PLWHA in staff positions are the Access to Healthcare Initiative Coordinator at the Community Healthcare Network which serves nine sites in New York City, the Peer Outreach Community Educator at the Rochester Community Health Network AIDS Community Health Center, and peer support positions at the Albany Medical Center . In each of these cases, the staff member serves in the important capacity of consumer advocate and often brings the essential consumer perspective to the attention of the other staff members, in addition to their other job responsibilities.

Agencies with highly effective CABs report that their CAB:

- provides input into the development or refinement of the agency's mission
- appoints individuals to facilitate or chair the meetings
- develops specific policies and procedures to conduct meetings; recruits people living with HIV/AIDS
- responds to issues from clients receiving HIV services, and actively participates or links with an internal HIV QOC committee

CAB activities and responsibilities vary from agency to agency, in addition to their function as methods of ensuring consumer feedback. Some of the diverse ways that CABs have played a role in increasing the involvement of consumers in the life of an agency include: representing the agency at local, regional, or national consortia meetings (e.g., Ryan White and CDC community planning bodies), participating in consumer workshops and training programs, assisting with health fairs, helping to plan AIDS Awareness Day programs, developing and promoting HIV program activities, and conducting periodic surveys of consumers.

Two common functions of CABs is the identification and resolution of client complaints and the initiation of discussions about services improvement made by clients.

Some of the issues that have been discussed and successfully resolved by CABs include:

- addressing the need for additional health services such as gynecologic care, dental care, nutritional education, and culturally appropriate meal services
- helping clients solve transportation problems
- adding recreational activities and health education programs
- re-configuring patient flow through public areas to enhance patient privacy
- reducing waiting time and "no-show" rates
- protection of confidentiality of clients in waiting areas
- establishing a buddy or mentor program
- training staff to deal more sensitively with diverse client needs (e.g., new diagnosis and substance use withdrawal)
- adding computer resources for client use
- establishing a patient newsletter for bilingual clients

The Harlem CAB is very flexible. For example, unlike CAB rules at other facilities, patients are not discouraged from asking personal health care questions during meetings. At the same time the Harlem CAB has a set of by-laws, issue-specific sub-committees, and an elected consumer chairperson whose responsibility includes adhering with a fairly structured agenda.

Consumers (PLWHA) as Staff Members

Overview: The inclusion of consumers (PLWHA) as paid or volunteer staff can provide a source of regular consumer feedback to the agency. They bring a wealth of experience, appreciation, and understanding about the needs, resources and unique culture of the community into the agency. They also may encourage more members of the community from which they come to become clients and to trust and understand the workings of the agency, particularly if there are few staff members who reflect the racial, ethnic, or cultural composition of the community. Consumers as staff members can facilitate the exchange of information, views, and attitudes between the agency staff and the client or patient population.

Description: There are no limits to the roles that PLWHA can play within an agency. They may be part of the clinical care team, the administrative staff, the office staff, or the client education and support staff. Often, PLWHA serve in roles that bring them into direct contact with the client population, serving as outreach workers, buddies, patient educators, adherence counselors, or case managers.

Best Use: It is important that, for all PLWHA staff, whether employed or volunteers, to have clearly defined job descriptions that specify their roles and responsibilities. PLWHA staff and volunteers must have the skills, training, and expertise to fulfill their job responsibilities. PLWHA on staff are not a substitute for using others methods of increasing consumer involvement; they are likely, however, to enhance the development of both consumer involvement programs and an organizational culture that fully embraces the consumer perspective. The concern about possible disclosure of their HIV status and its consequences may discourage some PLWHA consumers from becoming involved in HIV program quality improvement activities. At the same time, agency administrators and staff may see the involvement of PLWHA consumers in staff positions as a potential threat to confidentiality. Some ways of addressing these concerns are discussed in the chapter on Lessons Learned.

Effective Examples Using PLWHA on QI Teams

At the Montefiore Center for Positive Living, the Consumer Advisory Board plays an active role in the ongoing work of the Quality Improvement Team. The Quality Improvement Coordinator attends all CAB meetings, reporting to the CAB on all projects and activities and gathering consumer input on the development of the annual QI plan. In addition, consumers participate actively in all Quality Improvement initiatives, often helping out in the clinic by participating in quality improvement research projects. In one example, CAB members participated in the QI Thru-put Study. The goal of this study is the reduction of patient time spent in the clinic and the improvement of patient satisfaction with services. CAB members, as part of the study, kept diaries of their clinic visits over a three month time period, recording the amount of time they spent during each visit to the clinic for care. The data they collected were valuable in making an assessment of quality improvement efforts aimed at increasing patient "thru-put."

Inclusion of PLWHA on Quality Improvement Committees and Teams

Overview: Including consumers (PLWHA) as equal members of the agency QI Committee and Teams allows for routine feedback from a patient perspective on ways to improve the quality of HIV care in the clinic.

Consumers can comment on the quality of care data and the way it can best be gathered. They also can participate in the development and evaluation of structural improvements in programs as well as serving as liaisons to the CAB.

As with other ongoing involvement roles for consumers, consumer members of the QI Committee and its teams should be provided with training and support to ensure that they participate as fully as possible and as equal members of the group.

Other Ways to Involve Consumers

Additional opportunities to involve consumers in the quality improvement effort are the use of Key Informant Interviews to gather one-on-one feedback from consumers on the quality of care that they receive and the degree of satisfaction they have with their overall care at the clinic.

Suggestion boxes placed in easily accessible locations in the clinic can provide an opportunity for the agency to receive anonymous suggestions or complaints from consumers. The suggestions or complaints can be brought to the CAB for review and discussion as well as for recommendations to the agency about potential solutions to problems raised or ways of implementing suggested changes. The appointment of PLWHA on the Board of Directors is another way to facilitate consumer involvement in the agency. In some cases, the consumer chairperson of the agency CAB is asked to sit on the board. In other cases, a member of the board may serve as a liaison to the CAB.

Lessons Learned: Identifying and Overcoming Barriers to Consumer Involvement

Identifying and addressing a few potential barriers to their participation can enhance the involvement of PLWHA consumers in providing input into HIV QI. While barriers encountered in each agency will be unique, in some respects, to the individual agencies, their staff, and their patient or client population, there are some barriers that are commonly seen in varied settings. Based upon the experience of facilities participating in the statewide survey and interview process, the following are suggested ways of avoiding or overcoming some common barriers to consumer involvement.

Make Sure that PLWHA Consumers are Aware of Participation Opportunities

Broad and representative consumer involvement in providing input to improve programs and services depends upon their awareness of opportunities for participation. Some things that can be done to ensure that consumers are made aware of these opportunities include:

- Inform and provide training to staff on consumer involvement activities
- Post announcements of consumer involvement activities such as CAB meetings, openings on the CAB and/or Board of Directors, staff position openings, and meetings or trainings on a bulletin board in the waiting room or lobby
- Mail flyers, information, and announcements to all patients or clients
- Involve patients or clients in peer recruitment activities
- Include consumer involvement announcements in the agency newsletter
- Announce opportunities for consumer involvement at agency-sponsored community activities
- Ensure that the process of recruitment and selection for opportunities is open and expectations and responsibilities are clearly stated

Provide Adequate Preparation for Consumer Participation

Some consumers may feel unprepared to become involved in activities designed to enhance consumer participation in the QI process. For some PLWHA consumers, the lack of experience in working with organizations may be a major barrier to involvement. This may be as true for consumers considering involvement in a CAB or QI committee as it is for those invited to participate in a focus group or survey or those taking a position on the staff of the agency. Some things that can be done to help prepare consumers to be effective participants in QI activities include:

- Orient all new committee members, staff, and other participants to their new responsibility
- Provide clear and understandable information on policies, procedures, and by-laws where appropriate
- Be sure that all participants are made aware of the purposes, mission and goals of the meeting or activity
- All participants should be made aware of the expectations and responsibilities of their involvement or participation
- Be sure that jargon, acronyms, unique terms, and shorthand phrases are clearly defined and are not used to exclude some participants
- Announce and reinforce regular activity meeting times, places, agenda topics (if appropriate) and any changes in schedules or locations to all participants
- Provide ongoing training, mentoring, and support for all participants in QI

Emphasize Equal Partnership in Improving Quality

Consumers may feel that their involvement in QI activities is not valued or that their opinions or suggestions are taken less seriously than others. Every effort should be made to ensure that staff view consumers as equal participants in the process of quality improvement. Some things that can be done to help ensure that consumers feel that they are in equal partnerships include:

- Ensure that staff are trained and made aware of the role and importance of consumer involvement in quality improvement activities
- Be sure that staff from a variety of programs or departments are represented in activities and committees in which consumers are involved
- Establish a position of staff liaison with CABs and other committees in which consumers are involved
- Create equal consumer leadership positions, such as co-chairs, for all committees and boards in which consumers are involved

Help Consumers See the Effects of their Input

Consumers may either not participate or lose interest in participating in QI activities if they do not see tangible results of their involvement. Consumers want to feel as though their participation actually makes a difference in the quality of care that people receive. Some things that can be done to help consumers see that they make a difference include:

- Acknowledge the contribution of all participants in the QI process
- Involve consumers in the process of finding solutions as well as in identifying problems
- Provide timely follow-up to consumers after they participate in a quality improvement activity (for example, provide a report on the results of a satisfaction survey or report to the CAB on actions taken on their recommendations)
- Set and meet a realistic time frame for taking action on consumer suggestions and recommendations for change
- Celebrate and promote successes as a means of recognizing and affirming the value of consumer involvement Appreciation can be used as a means to raise awareness and peak interest from other consumers to get involved

Assist Consumers to Overcome Personal Challenges

Many consumers face significant life challenges that may stand in the way of their participation in HIV quality improvement activities. They may have limited access to transportation or to child care or they may be facing family or health problems that require their attention. Some may have language or literacy challenges. These challenges may affect a consumer's ability or willingness to attend meetings, make phone calls, take on a staff responsibility, or volunteer at a community event. Some things that can be done to help overcome these challenges include:

- Provide reimbursement for travel or child care for consumer participants or provide travel and child care for them
- Offer meals or snacks at meetings and other activities
- Develop reading materials in languages and at reading and literacy levels that allow as many consumers to participate as possible
- Provide assistance for blind, deaf/hard of hearing, and other participants with special needs
- Provide flexible response to consumers who may not be able to participate temporarily as a result of illness or family obligations (for example, leaves of absence, conference calls, or proxy arrangements)
- Establish meeting times and locations that are accessible to a broad range of consumers
- Provide incentives for consumer participation in meetings and other activities
- Conduct meetings in or provide translation to languages that are spoken by the participants

Address and Reduce Burnout

The reliance on only a few consumers in quality improvement activities such as CABs, peer support positions, community activities, and QI committees may result in their inability or reluctance to continue participation. Some things that can be done to help avoid or reduce consumer burnout include:

- Involve as many different consumers as possible
- Provide ongoing training and support for consumer participants
- Encourage and support consumers in taking care of personal responsibilities as well as their agency obligations
- Establish mentorship in committees or in staff positions to allow for consumer participants to reduce some of the burdens on their participation

Ensure Confidentiality

The concern about possible disclosure of their HIV status and its consequences may discourage some PLWHA consumers from becoming involved in HIV program quality improvement activities. Some things that can be done to help ensure confidentiality of consumer's HIV status include:

- Clearly define and enforce the agency's confidentiality policies as they apply to both staff and consumers involved in QI activities
- Consider the use of signed confidentiality agreements for all participants
- Reinforce confidentiality policies and expectations in all meetings
- In meeting minutes use either initials or general terms (for example, nurse, staff member, consumer) to describe people
- Hold meetings in locations that are not identified with the HIV clinic or services
- Obtain permission to call or send mailings to the homes of PLWHA consumers

Engage Staff and Consumers in Community and Support Activities

Providing additional non-clinical programs and services for patients will encourage patients to come to the agency for more than just medical care. For example, a patient who attends the agency's computer classes may be more comfortable joining the agency's CAB or participating in a satisfaction survey. Some activities that might encourage greater consumer involvement in agency activities include:

- Provide consumer educational or skills development classes that may be un-related to HIV or disease management
- Support community activities that consumers participate
- Encourage staff to attend community activities
- Encourage consumers to suggest or to lead educational activities at the clinic
- Include activities that will assist with team building

Conclusions

PLWHA consumers provide a critical and necessary perspective on the planning, implementation, evaluation, and quality improvement of HIV/AIDS policies, programs and services that are designed ultimately to meet their needs as the consumers of those services. The involvement of PLWHA consumers in all aspects of the quality of care improvement process, as demonstrated by the examples provided here, can be accomplished at little or no cost and can produce significant benefits.

Some of the ways that PLWHA consumers can be involved in the improvement of the quality of care include: consumer focus groups, client/patient satisfaction surveys, needs assessment questionnaires, consumer advisory boards, employed staff, members of the Board of Directors, suggestion boxes, and PLWA participating in QI teams.   Attention to the needs of consumers who volunteer or who are paid to provide input to program improvement can help them overcome potential barriers that may prevent their participation.

Appendices

I. Overview of Ryan White Standards for Consumer Involvement

Title I

- The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1996 requires that Title I planning councils include representatives of "affected communities, including people with HIV disease or AIDS and historically underserved groups and subpopulations" [Section2602(b)(2)(G)].
- Since 1994, Federal policy has required that at least 25 percent of the voting members of Title I planning council members be People Living With HIV and AIDS, and other specific policy requirements were updated in 1997.
- Organizations that receive Ryan White Title I Funding through contracts with the Medical and Health Research Association of New York City, Inc. are required to have an advisory board that meets quarterly and whose membership includes HIV+ individuals, usually clients of the program.

Title II

- The CARE Act requires that People Living With HIV and AIDS be among the individuals convened by the State for development of the Statewide Coordinated Statement of Need (SCSN), and that Title II consortia demonstrate to the State that PLWH have participated in the assessment of service needs and the planning for delivery of services.
- As of July 1999, HRSA's HIV/AIDS Bureau (HAB) and Division of Service Systems (DSS) had no specific policy requirements for People Living With HIV and AIDS participation in Title II consortia or statewide advisory groups. However, it has consistently encouraged People Living With HIV and AIDS participation in Title II planning bodies.

Title III

Title III, which provides grants for outpatient HIV early intervention services/ primary care, has specific requirements for consumer involvement. Title III programs are expected to:

- Involve the affected community
- Have "written procedures to ensure consumers have the opportunity to actively participate in decision-making about their personal health care regimen."

Examples of ways in which a program may demonstrate consumer involvement are:

- Consumer representation on the organization's Board of Directors;
- Establishment of an HIV-specific Consumer Advisory Board;
- Consumer representation on an existing Consumer Advisory Board;
- Involvement of consumers in workgroups, committees and task forces, such as a Program Committee, an Outreach Task Force, the Patient Education committee, etc.;

I. Overview of Ryan White Standards for Consumer Involvement *Continued...*

- Consumers as volunteers, such as peer educators or outreach workers, or staff in the clinic;
- Consumers who serve as HIV peer trainers who assist clients in making healthy decisions and taking care of one's health in such areas as involvement in clinical trials and accessing services through managed care; and
- Consumer input that is provided through surveys and consumer forums.

To accomplish effective consumer involvement, programs should be prepared to provide necessary training, mentoring, supervision and reimbursement of expenses.

Title IV

Title IV, which supports grants for coordinated HIV services and access to research for children, youth, women and families, has specific requirements for consumer involvement. Title IV programs are expected to:

- Actively involve consumers in program planning, implementation, and evaluation;
- Carry out "formal and informal advisory activities," with People Living With HIV and AIDS "serving on boards of directors, community advisory boards, committees, task forces, etc., both within and outside the Title IV-specific boards and advisory committees (i.e., planning councils, consortia, National Institutes of Health Clinical Trials Community Constituency Groups and Community Advisory Boards); and others; and
- Allocate resources to ensure that at least two consumers attend the annual Title IV grantee meeting and other relevant training, workshops or meetings.
- Grantees are also "encouraged to hire consumers as paid consultants or permanent employees, and/or to utilize them as volunteers." Most Title IV programs have one or more Consumer Advocates on staff.

People Living with HIV/AIDS (PLWH) Sourcebook, HRSA HIV/AIDS Bureau, Section 7, Pp 6-9
Guidelines for Title I Providers on the Development of Advisory Boards, MHRA, Ryan White Title I Division, HIV CARE Services/FITA

AIDS Institute Bureau of Primary Care Programs: Consumer Involvement

A written plan is in place to ensure active consumer involvement in the continuous development and improvement of the HIV/AIDS program through advisory groups, focus groups, consumer satisfaction surveys and other mechanisms. (This is a required Standard of all Primary Care contracts.)

- The plan includes strategies to ensure ongoing and meaningful participation of clients in the development and improvement of the HIV/AIDS program.
- Opportunities for consumer involvement in the HIV/AIDS program and in community activities are promoted. Consumers actively participate in the agency's quality improvement and program evaluation processes.
- Staff at all levels, receive training on consumer involvement and strategies to encourage and support meaningful consumer participation.
- A Consumer Advisory Board (CAB) for the HIV/AIDS program (or another mechanism for consumer input, such as focus groups, or use of key informant interviews) has been established and meets preferably monthly but at least quarterly. Minutes are documented for all meetings.
- The majority of the CAB or focus group is composed of consumers who are receiving services from the HIV program.
- The CAB or focus group reflects the diversity of the client population of the program.
- The CAB reports on the progress of the HIV program to the program director and to the Board of Directors.
- Focus groups, consumer satisfaction surveys and the consumer advisory committees have sufficient participation by consumers (the agency has a target of at least 8 consumers for the CAB, 8 for focus groups, and 33 - 50% of consumers for client satisfaction surveys, based on caseload).
- Results of surveys and recommendations for improvements and changes to the HIV program by the CAB or focus groups are submitted to the HIV program director and to agency administration.
- Agency administration's response to the results/recommendations from the CAB is documented and provided to staff, CAB, and other consumers.
- Changes in the program, which result from consumer input, are publicized.
- Staff is encouraged to develop innovative strategies to engage consumers and solicit their feedback.
- Consumers are actively involved in the materials review process as required by the AIDS Institute.

Consumers are informed of and encouraged to participate actively in city/county/regional/ statewide AIDS planning groups.

- The agency encourages client involvement in planning groups.
- Consumers are informed of opportunities for orientation and training for active participation in planning groups, such as the AIDS Institute-sponsored Leadership Training Institute.
- Consumers are encouraged to participate in RFP/RFA reviews.

AIDS Institute Bureau of Primary Care Programs: Consumer Involvement *Continued...*

The agency fosters consumer participation in AIDS conferences and other related meetings outside the agency.

- Consumers are encouraged to apply for scholarships or agency aid to attend relevant area, statewide or national conferences. Contract manager approval must be obtained for out-of-state travel using grant funds.
- Consumers are kept informed of internal and external opportunities for conferences and related meetings through publicly posted information and via staff and agency communications.

AIDS Institute Office of the Medical Director HIV Quality of Care Program Standards

The New York State HIV Quality of Care Program Standards state, "consumers should be included in quality-related activities...The quality program should routinely assess patients' needs and/or satisfaction, and integrate consumer feedback into the quality program."

New York State HIV Quality of Care Program Standards, Version 4-July 19, 2001

AIDS Institute Substance Abuse Section Standards for Consumer Involvement

- Structures are in place for consumer involvement and active participation in the continuous development/improvement of the HIV/AIDS program. Indicators of consumer involvement include, but are not limited to the following:

  -advisory committee participation
  -annual consumer satisfaction surveys
  -systematic feedback to consumers
  -written policy/plan on consumer participation

- Consumers are informed of and encouraged to participate actively in city/county/area/statewide AIDS planning groups.
- The agency fosters consumer participation in AIDS conferences and other related meetings outside of the agency.

AIDS Institute Bureau of Community Support Services objective for Consumer Participation in Service Contracts (Mental Health, Nutrition, Legal, Supportive Services)

To ensure that Quality Improvement (QI) strategies are developed and implemented as part of the HIV service delivery program(s). This includes a clear and defined plan for ongoing evaluations and assessments, measurable indicators for program performance, involvement of consumers in quality-related activities and integration of staff and consumer feedback.

Activities:
Indicate by title, the individual(s), committees(s) or workgroup(s) responsible for completing each activity listed below and the projected time frames.

1. Describe the agency's plan for implementing the AIDS Institute's HIV Quality Improvement standards. Include the identified measurable indicators for program performance and the activities (e.g. needs assessments, surveys, etc.) that will be conducted to monitor and evaluate the adequacy, appropriateness, and effectiveness of the program.

2. Describe how program objectives will be monitored, the plan for revising the program deliverables and how revisions will be implemented.

3. Describe how consumer and staff feedback will be gathered and utilized to enhance/improve the delivery of program services.

AIDS Institute Bureau of Family and Youth Services Standards for Consumer Involvement

Definition: Consumer Involvement is a guiding principle in New York State Department of Health AIDS Institute funded programs. Consumer/client input provides feedback about services and makes valuable contributions to program development, quality improvement and strategic planning. Mechanisms to ensure that HIV –infected and affected individuals/families participate include surveys, community forums, focus groups and/or other measures. In particular, a Consumer Advisory Board, or similarly named committee, is established to act as liaison between consumers, the community and the HIV programs.

Standards:

1. Individuals living with HIV, affected family members and their communities have input into program design and decision-making:
    a. The HIV program has identified strategies for gathering consumer input.
    b. Consumer input is utilized for continuous quality improvement activities and strategic planning.
    c. A client complaint procedure is provided to all consumers.

2. A Consumer Advisory Board (CAB) or committee is established and provides a forum for active participation in the ongoing development and improvement of the program:
    a. The CAB has a written mission statement, and policies regarding recruitment, membership criteria, and attendance.
    b. The CAB is representative of the diversity of the client population.
    c. Recommendations for improvements and changes are included in the Quality Improvement (QI) program.
    d. In-service training on advisory roles and responsibilities is provided.

3. A consumer satisfaction survey is conducted annually, or more often, as determined by the needs of the program:
    a. The survey includes questions that collect input on key program services and principles.
    b. Results of surveys are analyzed and feedback is provided to program staff and the CAB.
    c. Recommendations for improvements and changes are included in the QI program.
    d. Data is summarized and tracked to review trends over time.

4. Funding and structures support consumer activities and feedback:
    a. Appropriate resources such as training, transportation, space, childcare, mailing materials/postage, nutritional/ supplements are provided to enable consumer participation.

AIDS Institute Bureau of Community Support Service Case Management Standards for Consumer Involvement

The standards described in this document apply to the HIV/AIDS case management services funded by the AIDS Institute through state and/or federal grants. In addition, the standards apply to case management services reimbursed by Medicaid, either on a fee-for service basis or bundled with other services required for an enhanced Medicaid reimbursement rate.

Services covered by these standards may be provided in a variety of settings, including community health centers, hospitals, or community-based organizations.

Case Management services covered by these Case Management Standards are provided under the following AIDS Institute initiatives:

- AIDS Day Health Care Program (ADHCP)
- Centers of Excellence in Pediatric HIV Care
- COBRA Community Follow-Up Program
- Community-Based HIV Primary Care and Prevention Services
- Community Service Programs (CSP)
- Designated AIDS Centers (DACS)
- Family-Centered Health Care Services
- HIV Primary Care and Prevention Services for Substance Users
- HIV Services for HIV-Infected Women and Their Families
- Multiple Service Agencies (MSA)
- Ryan White Title II Case Management Programs
- Supportive Housing Programs
- Youth-Oriented Health Care Programs (Special Care Centers)

Consumer Input – process for soliciting client views and feedback on current and planned program services including activities such as Consumer Advisory Boards, focus groups, and consumer satisfaction surveys. Include timeframe and frequency of activities.

Albany Medical College AIDS Program – Consumer Involvement in Process Improvement 2005

Consumer involvement: Albany Medical Center supports consumer involvement and input in all aspects of the institution's AIDS Program. We have a long commitment of consumer involvement and are proud of the relationship we have with our consumers. Our consumers' play an active role in helping to assess the quality of care provided and all services offered. They do this in two ways, primarily:

I. Consumer Advisory Board (CAB) Involvement:
Our CAB is comprised of AIDS Program staff, consumers and community agencies from our service area. Meetings are held on the same day and time every other month. Participants are notified via either paper or e-mail reminders 2 weeks prior to each meeting. We have 6 consumers who are active members, with at least one consumer holding the co-chair position. The CAB has taken a leadership role in administering a patient satisfaction survey, conducting focus groups to determine consumer needs and developing a flier to educate patients about clinical research, among other initiatives. Transportation assistance and childcare reimbursement is available to those who request it.

Our process improvement coordinator presents an update at each CAB meeting regarding the AIDS Program's progress toward meeting our quality goals. This is a standard item on the agenda of each meeting. Consumers ask questions and seek clarification on any items and offer advice, generally based on their own experiences, regarding things that could be tried in terms of improving outcome measures. In addition to this update, we offer free space, secretarial support, free mailing and photocopying, free parking and gas mileage, technical support (when requested), light refreshments, information about available clinical research protocols and encouragement. In return, the CAB meets 6 times per year to review and implement their agenda, make suggestions regarding what programs and processes we should offer, implement its own governance and management structure and seek input regarding consumer needs. The CAB provides feedback for various potential funding streams to investigate and helps disseminate information about our research and process improvement activities to consumers and health care providers throughout the region.

II. Meaningful Employment of Consumers:
AMC's commitment to consumers goes beyond the advice they provide through the CAB. We encourage consumers to work for us by offering them employment opportunities that match their skills and abilities. Nearly 11% of our current workforce is comprised of individuals who are open about their HIV+ status. In this manner, these employees have a voice in the day-to-day operation and management of the program. They are key stakeholders who not only help design programs to meet their needs, they help run them as well. Consumers are employed in all aspects of the AIDS Program, including primary care, case management, peer counseling, senior management, nursing, clerical support, data management and outreach activities. By actively participating in the management and evaluation of the AIDS Program's outcomes, consumers are able to offer concrete suggestions for improving the ways in which we operate. In turn, they experience the "real world" in which health care operates and have a greater understanding of the challenges and evolving issues we face from both internal and external sources.

AIDS Institute Findings Report: Consumer Involvement Survey

I. Purpose and Background

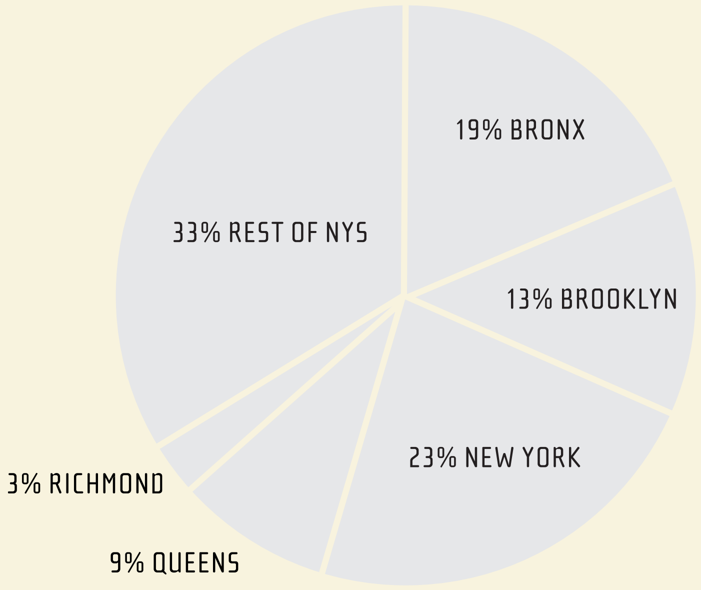
The idea for a statewide survey of HIV/AIDS health care facilities was conceived by the Consumer Advisory Committee (CAC) and spearheaded by a subcommittee of CAC members. The purpose of the survey was to assess the methods being employed by HIV programs to obtain consumer feedback and to assess the strategies and practices effective in obtaining and responding to consumer input. A special emphasis was placed on detailing the characteristics, experiences, and perceived efficacy with Consumer Advisory Boards (CABs). It was also hoped that findings from this survey could be used to identify best practices for health care providers.

II. Methods

Development of the statewide survey was an interactive process occurring over a 6 month period. The survey's format and content were developed and refined during several CAC Subcommittee conference calls, with preliminary versions presented at the CAC meetings in October and December of 2003. The Institute's Office of Program Evaluation and Research (OPER) also assisted in the development of the survey instrument. A copy of the survey instrument is included in Appendix A.

The survey was mailed out to HIV Program Directors at 119 HIV programs identified in the Institute's mailing database on December 19, 2003. HIV programs were encouraged to submit one survey for each separate site, in order to assess the nature of consumer involvement at each of their facilities. Programs were asked to complete and return surveys by January 19, 2004 Figure 1 presents the geographic distribution of survey responses. Two-thirds (67%) of all responses were from agencies located within the 5 boroughs of New York City. Appendix B provides a list of agencies that have responded to the survey.

Figure 1: Geographic Distribution of Survey Results (n=75)

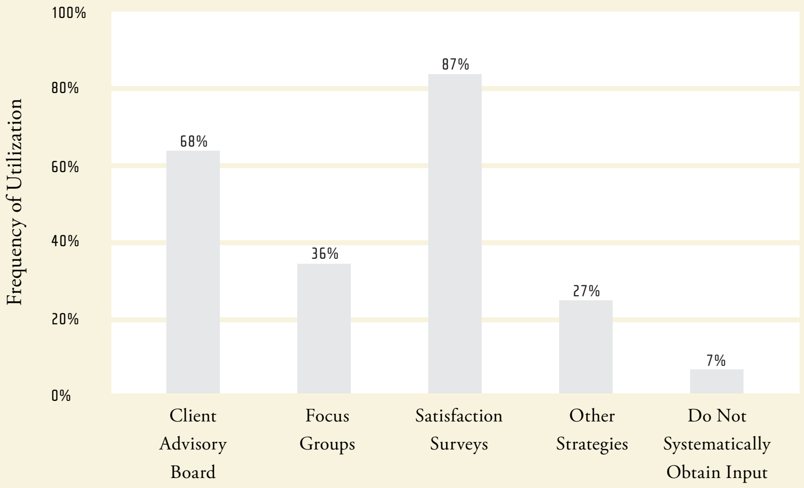


III. Results

Obtaining Consumer Feedback

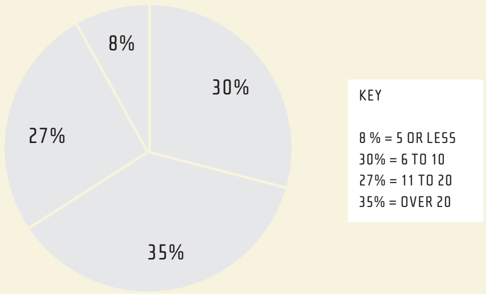
Program directors were asked whether or not their HIV program had a process in place to systematically obtain consumer feedback. Ninety-three percent (all but 5 programs) responded affirmatively to this question. Figure 2 also reveals that the most common method of obtaining consumer input was through the use of client satisfaction surveys (87%), followed by the use of CABs (68%), focus groups (36%), and "other" methods (27%). Other methods included the use of suggestion boxes, regularly scheduled meetings where consumers are invited, formalized support groups, and the use of peers to represent consumer input. Additional data analyses found that the methods of obtaining consumer input did not differ significantly between NYC and non-NYC providers (data not displayed).

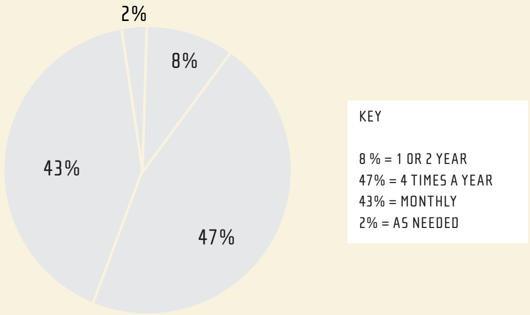
Figure 2: Methods for Systematically Obtaining Consumer Feedback (n=75)



Characteristics of Community Advisory Boards

The remainder of the Consumer Involvement Survey focused on the characteristics, experiences, and perceived efficacy of CABs. The 51 agencies with CABs were asked about the number of members on their CAB and the frequency of CAB meetings. Responses are displayed in figures 3 and 4. The size of CABs varied greatly, with agencies split roughly evenly between small (5 or less), mid size (6 to 10) and large CABs (more than 10). Meeting frequency showed less variability, with most agencies reporting either quarterly (47%) or monthly (43%) meetings.





Agency directors were asked what HIV program staff participates in CAB meetings. Responses indicate that a wide variety of HIV program staff are involved. Commonly mentioned staff include:

- HIV Medical Directors
- Behavioral Health Providers
- Social Workers/Case Managers
- Hepatitis Coordinators
- Representatives from External Agencies
- Treatment Adherence Staff
- HIV Administrators
- Peer Educators
- HIV Educators
- Outreach Workers
- Nursing Staff
- HIV Providers

Table 1 presents a summary of the main purposes of CABs identified by HIV Program Directors. The vast majority of agencies (92%) identified the recommendation of new programs or improvements to existing programs as a primary CAB purpose. Affecting agency policy toward the betterment of HIV programs was also cited as a primary purpose by almost all agencies (88%). Three-quarters (76%) of agencies indicated that their CAB served as a conduit for client input into their HIV program, while about half (49%) cited active involvement in evaluation activities as a central CAB purpose.

<u>CAB Meetings</u>
Several items were named as typical agenda items for CAB meetings, including:

- Quality of care-related issues (adherence, mental health, Hepatitis C, etc.);
- Program and policy changes (new funding, staff turnover, service enhancements, etc.);
- Patient-related issues (satisfaction surveys, complaints, etc.);
- Community issues and resources (housing, children's events, etc.);
- Consumer events, trainings, and activities (World AIDS Day, health fairs, fundraising, Leadership Training Initiative, therapeutic activities, etc.);
- Membership issues (recruitment, introduction of new members, etc.); and
- General updates (upcoming events, agenda review, review of prior minutes, etc.)

HIV program directors were asked whether or not they employed a variety of strategies to facilitate their CAB meetings, and, if so, whether or not they felt each strategy was effective. Responses are presented in Table 2. The most commonly used strategies include setting meeting specifics well in advance (98%), and scheduling meetings at times (98%) and at locations (90%) that are accessible to members with HIV/AIDS. Other commonly used strategies include having meals or snacks during meetings (80%), distributing educational materials about the agency's mission and services (78%), agreeing upon member roles and responsibilities (74%), and providing reimbursement for transportation (70%). Each of these strategies was perceived to be effective at facilitating CAB meetings. Less commonly used strategies include holding orientation sessions for new members (47%), reimbursing non-travel-related expenses (26%), providing stipends for lost wages (20%), and providing reimbursements for childcare (10%). There was less agreement about the effectiveness of these strategies, particularly those reimbursing for childcare and non transportation-related expenses (Table 2).

Table 1: Purposes of Agency CABs (n=51)

PURPOSE:	#	%
Recommend ideas for new programs or modifications to existing programs to better serve those infected by HIV	47	92%
Affect policy within the agency to improve the quality of HIV programs	45	88%
Actively involve itself in solicitation of information from clients and other consumers about HIV programs(s)	39	76%
Review survey instruments, needs assessments or other methodologies for systematic evaluations of programs	25	49%

Table 2: Strategies Used by HIV Programs to Facilitate CAB Meetings, and their Perceived Effectiveness

STRATEGY	# USING STRATEGY*	% USING STRATEGY	% RATING STRATEGY EFFECTIVE**
Set dates/time/location well in advance of meetings	49	98%	84%
Meetings scheduled during hours accessible to members with HIV/AIDS	49	98%	88%
Meetings locations accessible/comfortable for members with HIV/AIDS	45	90%	88%
Meals/snacks during meetings	40	80%	95%
Distribute educational materials about the agency's mission & services	39	78%	74%
Discuss and agree on member roles/responsibilities	37	74%	95%
Transportation reimbursement or vouchers	35	70%	94%
Orientation sessions/training materials for new members	30	47%	77%
Reimbursement for other expenses (phone calls, supplies, copying, etc.)	13	26%	31%
Stipends or compensation for lost wages for meeting participation	10	20%	70%
Reimbursement for childcare	5	10%	40%

* 50 out of the 51 agencies responded to this question; **Among those using strategy effectiveness

Perceived Effectiveness of CABs

HIV Program Directors were asked to rate the overall effectiveness of their CAB on a scale from 1 to 10, with 1 representing the lowest level of effectiveness and 10 representing the highest level. Figure 5 presents a summary of agency responses to this question. Although just three agencies (6%) perceived their CAB to be ineffective, over one-third (35%) perceived just a moderate level of effectiveness, while 59% rated their CAB as highly effective, assigning it a score of between 7 and 10.

Figure 5: Perceived Overall Effectiveness of CAB (n=49)

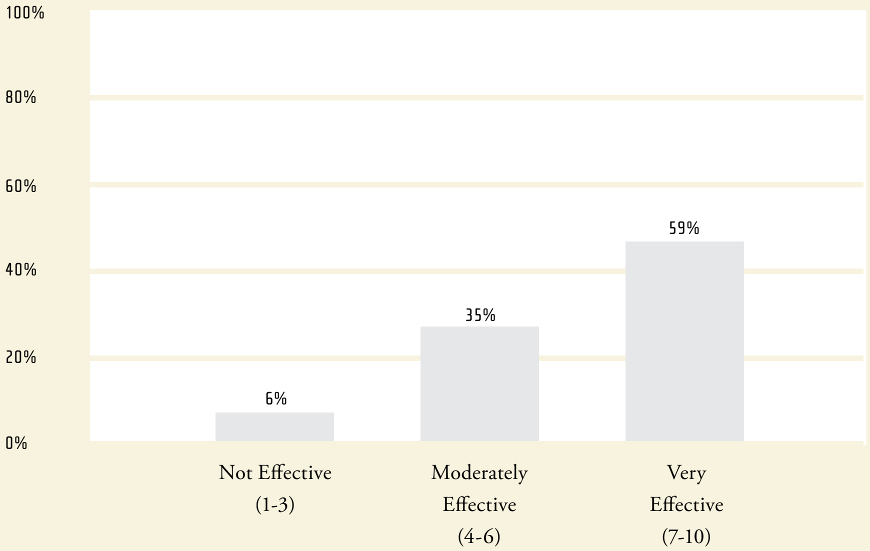


Table 3 presents the results of analyses examining the relationship between the individual characteristics of CABs and their perceived effectiveness. To facilitate these analyses, perceived effectiveness was dichotomized into two categories distinguishing highly effective CABs (perceived effectiveness score 7-10) from all other CABs (scores less than 7).

Results from Table 3 indicate that agencies with highly effective CABs were more likely to report that its CAB:

- provides input into the development or refinement of its agency's mission;
- appoints individual(s) to facilitate/chair meetings; and
- develops specific policies and procedures to conduct meetings.

Although not reaching the level of statistical significance (due to the small sample size), highly effective CABs were also more likely to report recruiting people living with HIV/AIDS, responding to client issues, and developing workplan goals and objectives (Table 3).

Table 3: Distinguishing Characteristics of Highly Effective Client Advisory Boards

	HIGHLY EFFECTIVE CABs (SCORE 7-10)		NOT HIGHLY EFFECTIVE CABs (SCORE 1-6)		STATISTICALLY SIGNIFICANT
	AMT.	%	AMT.	%	
Provide input in developing/refining HIV program mission	26	90%	11	55%	Yes
Appoint individual(s) to facilitate/chair meetings	22	76%	7	30%	Yes
Develop policies/procedures to conduct meetings	20	69%	5	25%	Yes
Recruit people living with HIV/AIDS	27	93%	15	75%	No
Respond to issues from clients receiving HIV services	27	93%	17	80%	No
Develop and set work plan goals and objectives	17	59%	9	45%	No
Develop their own agenda	20	69%	15	70%	No
Actively participate or link with the internal quality of care committee within the HIV program	23	79%	15	75%	No

Methods to Impact the Quality of HIV Programs

Program directors were asked to specify ways that their CAB is utilized to impact the quality of HIV programs. Open-ended responses were content analyzed and placed into general categories. Overall, respondents indicated a variety of ways CABs are used to improve the standard and quality of care for their HIV/AIDS patients. Agencies reported a diversity of activities used by CAB members to impact HIV programs such as:

- Representing the center at local, regional and national consortia;
- Participating at workshops and trainings both on and off site;
- Assisting with Health Fairs;
- Helping plan AIDS Awareness Day;
- Promoting department events;
- Developing recreational programming;
- QI coordinator and Medical Director attend all CAB meetings;
- Periodic survey of clients in waiting rooms to assess client satisfaction with services;
- Conducting surveys on many issues including: assessment of educational needs of staff.

One common thread that emerged was that the CAB members are truly a voice for their center's clients. The CAB members present the client's perspective to the centers so that the administration can implement changes to improve services. Several directors shared that they evaluate client's issues and needs by conducting needs assessments and making sure that their clients have easy access to staff at all times. One participant reported that client's voice complaints directly to staff and many issues are quickly resolved without the need for a formal board. Efforts are also made to determine the needs of the center and their communities.

Several participants reported that the CAB staff have also been instrumental in bringing needed services to their clinics such as: on-site OB/GYN provider, dental services, resource room with computer, support groups, client counsel as buddies for new admissions, meeting with patients after medical appointments, using a treatment adherence nurse and a bilingual newsletter about HIV/AIDS updates for clients. Participants pointed out that they make every effort to improve their client's situation.

I. Use of CAB's to resolve client issues:

Agency directors revealed a multitude of approaches to resolve an assortment of client-centered issues. Concerns and issues reach the CABs in a variety of ways. A few centers use a client complaint booth while others use a suggestion box. Some CABs implement periodic patient satisfaction surveys, and others used consumer-based surveys. Specific actions utilized to resolve issues include: meeting with center's executives/administrators or operations committee; contacting verbally or in writing necessary community officials; educating clients; inviting officials to CAB meetings; conducting studies and surveys; and setting up focus groups, work groups, staff trainings or initiating new programs. Table 1 summarizes examples how the CABs have resolved specific issues.

Table 1: List of Client Issues and Resolutions Facilitated by CAB

I. CLIENT ISSUES:	II. RESOLUTION:
Inadequate GYN services	The CAB contacted Department of Health and now a mobile GYN Unit van is available on site two times a month.
Need for dental services	The CAB invited executive to meeting and new dental procedures where put in place. One CAB acquired Ryan White Title II funding to get a Dental Hygienist on- site at the clinic.
Adjustments to nutritional meals	The CAB spoke to Nutrition Department to serve more culturally appropriate dishes for the Hispanic population.
Transportation difficulties	The CAB voiced that clients had difficulties obtaining metro cards, within one week the administration made sure cards were available.
Desire for additional recreational trips	Due to budgetary constraints there were less trips. As a result, clients organized and held a fundraiser and were able to fund three new trips.
Need for updates on staff changes and inclusion in staff hiring process	The CAB advocated for these needs to the center and now regular staff updates are posted in clinics and clients are now included in hiring process.
Desire for educational lectures, especially on Hepatitis C	The CAB set up Hepatitis C lectures at local church. Additional educational speakers provided at another center.
Lack of privacy for support groups, restrooms and in phlebotomy room.	The CAB spoke to senior administrator and the rooms were reconfigured to ensure privacy. CAB spoke to building management who restricted flow through traffic.
Extensive wait times to see providers	The CAB conducted a study to improve flow of patients waiting for providers. Changes were implemented and the wait time was decreased from 2 hours to 45 minutes.
Concerns regarding confidentiality and stigma related to being HIV positive due to the use of the word “AIDS” in Center and program names.	Program name was changed. At another center, executives meet with clients and explained confidentiality measures and clients were satisfied. The center’s name was taken off metro cards.
Complaints from the surrounding community that clients were loitering	The CAB members educated peers on loitering policies and this has dramatically reduced the loitering.
Problems of “no show” at client appointments	The CAB developed a consumer coupon incentive program to encourage attendance.
Needs of newly diagnosed clients who are HIV positive and clients going through drug withdrawal	The CAB advocated and implemented a client sensitive training for staff. A buddy program was also approved.
Protest from transgenders regarding gender specific bathrooms	The CAB met with staff and debated issue and decided that transgender clients were allowed to use any bathroom the client felt most comfortable in.

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