HIV/AIDS CARE AND SUPPORT:
A COMMUNITY RESPONSE
ACRONYMS:

AIDS  Acquired immune deficiency syndrome
ART   Antiretroviral therapy
ARV   Antiretroviral
CBO   Community-based organization
CCT   Comprehensive care and treatment
CME   Community monitoring and evaluation
CUBS  Community-Based Support for Orphans and Vulnerable Children
FBO   Faith-based organization
FRH   First Referral Hospital
HIV   Human immunodeficiency virus
HRH   Human resources for health
MSH   Management Sciences for Health
NCDA  Nwonyo Community Development Association
NGO   Nongovernmental organization
OVC   Orphans and vulnerable children
PEPFAR U.S. President’s Emergency Fund for AIDS Relief
PHC   Primary health care
PITC  Provider-initiated counseling and testing
PLAN-Health Program to Build Leadership and Accountability in Nigeria’s Health System
PLWHA People living with HIV/AIDS
PMTCT Prevention of mother-to-child transmission
ProACT Prevention and Organizational Systems—AIDS Care and Treatment
SACA  State Action Committee on AIDS
SMOH  State Ministry of Health
TB    Tuberculosis
UNAIDS Joint United Nations Programme on HIV/AIDS
USAID United States Agency for International Development

Cover Photo:
Peer to Peer counselling by Ebosoko Support Group members, as they await their monthly consultation in Bida General Hospital

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HIV CARE AND SUPPORT: A COMMUNITY RESPONSE

THE BUILDING SUCCESS SERIES VOL 4

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FOREWORD

This manual is one component in BUILDING SUCCESS, a series of guides offering practical, concrete, and innovative approaches that have proven effective in strengthening the response to HIV/AIDS and tuberculosis (HIV/AIDS/TB) in Nigeria. Each manual can stand alone, but the manuals will be most effective if you view them as components of an integrated package.

Each manual contains references to relevant information in other components of the series. The series synthesizes and expands the learning gained from MSH’s Nigerian projects, supported by the United States Agency for International Development (USAID) through the U.S. President’s Emergency Fund for AIDS Relief (PEPFAR):

- Prevention and Organizational Systems—AIDS Care and Treatment (ProACT)
- Community-Based Support for Orphans and Vulnerable Children (CUBS) Project
- Program to Build Leadership and Accountability in Nigeria’s Health System (PLAN-Health)

In 18 states, these three projects are striving to achieve USAID’s strategic objective for the country: “Increased Nigerian capacity for a sustainable HIV/AIDS and TB response.”

They are equally committed to MSH’s mission: “To save lives and improve the health of the world’s poorest and most vulnerable people by closing the gap between knowledge and action in public health.”

Project staff members work with state and local governments, CBOs, and targeted health facilities and communities to bring high-quality services to people living with HIV/AIDS (PLWHA) and TB, and to their families. (See box left.)

OUR GUIDING PRINCIPLES

This manual, with the others in the series, embodies the principles that guide the day-to-day activities of everyone who works for MSH Nigeria projects. We are grounded in the recognition that people—both the users and providers of health services—are at the core of our work. We believe that—

- Success depends on empowering all the players: community leaders and members—including people living with HIV/AIDS—as well as health providers at all levels, government officials, and employees of civil society organizations.
- The solutions to people’s problems lie within themselves.
- We can celebrate our successes and use each failure as a learning opportunity.
- Small successes add up to big changes.
- Freely shared information and insights are essential to achieving common goals.
Who Created This Series?

The staff of the ProACT Project has written BUILDING SUCCESS with input from the other MSH Nigeria projects. Most of the approaches, lessons learned, and success stories come from clients and colleagues in the six states where ProACT is working to improve systems for service delivery: Adamawa, Kebbi, Kogi, Kwara, Niger, and Taraba.

ProACT’s clients have used the approaches described here to successfully implement a quality program despite many challenges. The series is based on the belief that successes in any project can be replicated in other settings, bringing high-quality, sustainable, gender-responsive HIV/AIDS and TB services to the people who need them.

How Can You Use the Building Success Series?

The reason this project, or any development project, exists is to empower people to save lives and improve the quality of life for themselves and their fellow citizens. You, like all of our readers, can make a significant contribution to this challenge. To support you in this effort, BUILDING SUCCESS will enable you to do the following:

- Use the “software”—the approaches, concepts, processes, and examples in these manuals—to put into action the “hardware”—the systems, structures, standards, and guidelines that already exist in your professional and geographic area
- Apply proven approaches to strengthen your organization and its HIV/AIDS and TB programs
- Translate guidelines into action and apply them for the greatest possible effect
- Benefit from the examples of health professionals at all levels who have overcome challenges to bring better health to the people they serve
- Enthusiastically carry out your responsibilities for providing or supporting the quality care that will prolong and improve the lives of PLWHA and their families

The manuals provide real-life examples of these successes, drawn from experience in the six project states. The manuals also refer to some documents—tools, government guidelines, standards of practice, forms—that you and your colleagues can use in carrying out these approaches and that are readily available to those working with HIV/AIDS and TB programs. You will find a few other important documents, newly developed and not yet widely distributed, in the annexes.

The manuals in this series are yours to read, re-read, discuss, adapt, and apply. But they are not all you need—no document by itself can enable you provide all the information necessary to carry out a successful program. We strongly recommend that you and your colleagues supplement the information in each manual with other useful documents, including guidelines, standards of practice, checklists, reports, and success stories.
You can seek assistance from a variety of sources: government agencies, IPs, civil society organizations, and other groups that have successfully implemented initiatives like the one you are undertaking. With the support of these entities, you can use the manuals as a starting place and an ongoing point of reference.

We welcome you, our readers, as partners in the effort to provide the HIV/AIDS and TB services that will contribute to a long and meaningful life for all our fellow citizens.

—The MSH Nigeria Team
INTRODUCTION

Using the Care and Support Manual in Working with Communities

This manual is intended for the individuals and groups who can play a role in community engagement for care and support services. If you are a care and support practitioner or health care provider at any level of state government or with a nongovernmental organization (NGO), the manager of a comprehensive care and treatment (CCT) facility, or working for an implementing partner, it is for you. If you are living with HIV/AIDS or have a family member who is HIV-positive, it can be especially useful. In fact, if you are a resident or if you play a leadership role in any community where there are people who are living with HIV/AIDS or TB, the manual can help you to contribute to their care and support. If you work in the private for-profit sector and have a concern for the health of your fellow citizens, it is for you as well.

In the following pages, you will find guidance for engaging communities as key players in the care and support of PLWHA and their families. Health facilities are essential in identifying people who are HIV-positive and providing the medicines that will enable them to maintain their physical health. When these people return to their homes, however, they need ongoing support. It is their community—their families, friends, and neighbors—that can help them choose and maintain positive behaviors and life-enhancing changes.

What Is a Community?

A community is often defined as a group of people with diverse characteristics who are linked by social ties, share a common culture and self-identification, and engage in joint action in the same geographical location. More succinctly, in its Summary Booklet of Best Practices (2000), the Joint United Nations Programme on HIV/AIDS (UNAIDS) defines a community as “people who have something in common, who will act together in their own common interest.”

This second definition suggests the importance of “communities within the community.” It recognizes that beyond the common understanding of a community made up of people living in one geographical location, there are various groups within the same location that are also communities, or sub-communities, because they are ready to take action on common interests.

Some of the most common sub-communities are community-based organizations (CBOs), religious groups, age peers, workplace groups, clubs and sports teams, and gender-based groups. Any one of these groups can have its own reasons for joining in the effort to mitigate the impact of HIV/AIDS and TB on their own group and the others who make up their community. It is through these groups that you can help to bring about strong care and support services for PLWHA and their families.
What Are the Elements of Community-Based Care and Support?

HIV/AIDS is a chronic disease requiring care and treatment throughout life. HIV/AIDS is not only a medical issue but is also associated with a variety of psychosocial and economic challenges best addressed through strong community-based care and support services. These services should be part of an integrated health approach offering a comprehensive continuum of care for PLWHA including a wide range of services such as education, home-based care, training in income-generating activities, and treatment adherence counseling. Experience from ProACT shows that it is difficult for a single organization to provide all the services needed and instead several organizations providing different services refer and link their clients for the services they cannot offer with others in the neighborhood—this is called the service network. These networks link community-based care and support with facility-based CCT, a service delivery package that offers the minimum acceptable range of HIV-related care and treatment services (see the Comprehensive HIV/AIDS Care And Treatment: Site Startup and Management manual in this BUILDING SUCCESS series). The success of these networks has been due primarily to having community facilitators who coordinate the process, clarification of roles of the players, and recognition of their respective contributions. Figure 1 below and the box at right illustrate the interlinking systems in the continuum of care.

Figure 1. The HIV/AIDS Continuum

THE IBI NETWORK EXAMPLE

Community acceptance and support is necessary for a successful and sustainable HIV/AIDS service program. In Taraba State, MSH ProACT supported the HIV/AIDS and TB program at the First Referral Hospital (FRH), Ibi. This support was preceded by an advocacy visit to the Traditional Ruler of Ibi (the Sarkin Ibi) and a community sensitization program for all the stakeholders in the area. The Sarkin and his people welcomed MSH and accepted the program wholeheartedly.

At the sensitization program, the Sarkin Ibi personally cleared up the misconception that HIV/AIDS is inflicted on people by witchcraft and encouraged all his chiefs to access HIV counseling and testing (C&T) openly. Since then, the relationship between the community and the HIV/AIDS program at the FRH, Ibi, has been quite cordial. The Sarkin also provides volunteers from his CBO, the Nwonyo Community Development Association (NCDA), to deliver services to orphans and vulnerable children (OVC) in the communities. He established a food bank at the NCDA office in his palace to provide nutritional support to OVC and PLWHA. He also works with school administrators in his community to help OVC who have dropped out of school, either as a result of loss of parent(s) or poverty due to HIV/AIDS infection, to return to school. This networking and linkage between the facility and the community has made the HIV/AIDS and TB programs successful and sustainable in the Ibi community.

Sometimes all it takes for community leadership to accept, embrace, and commit resources to the cause of a health intervention program is having adequate background information about the program, its benefits to the people, and a shared vision of the program. With the introduction of the MSH ProACT Program at the FRH, Ibi, MSH entered the community through the local traditional ruler, the Sarkin Ibi, who showed passion and demonstrated commitment to the success of the program. All this work is done because the community leaders understand that it is their responsibility to use their resources to take care of their people who are infected with and affected by HIV/AIDS.
A STEP-BY-STEP PROCESS FOR EFFECTIVE COMMUNITY ENGAGEMENT IN CARE AND SUPPORT SERVICES

The success of community entry is crucial to effective community engagement in care and support. Community entry is a process of initiating, nurturing, and sustaining a desirable relationship for the purpose of securing and sustaining the community’s interest in all aspects of a program.

STEP 1. ENTERING THE COMMUNITY

1.1 Gathering Information about the Community

After identifying a community in which a program will be implemented and identifying contact people, groups, and committees, getting to know that community better becomes imperative. Gathering information through formal and informal means, including reading available literature and talking to people at informal gatherings such as market places, drinking bars, and festive occasions, can help you become better acquainted. Information to be gathered should include leadership structures, sociocultural and economic background, and the community knowledge, attitudes, behaviors and practices toward the proposed program.

Our approach to information gathering from the community is participatory and in line with the principles of participatory rural appraisal, an approach used by NGOs and other agencies involved in international development to incorporate the knowledge and opinions of rural people in the planning and management of development projects and programs. We use the following steps: (1) identification of key stakeholders, (2) advocacy to community leaders to create buy-in, (3) focus group discussions with community groups, and (4) key informant interviews with opinion leaders.

1.2 Identifying Community Leaders and Enlisting Their Support

To enlist the cooperation and support from community leaders, you must recognize them as gatekeepers to the community and respect them in all undertakings (e.g., in the scheduling of meetings to ensure the times are most convenient for them). This process is most effective if protocols are followed. For example, you should meet with the paramount ruler of the community first, then with the chiefs next in line, then sub-chiefs, and finally the community members (or as otherwise dictated by the leadership structure in existence in the community).
1.3 Holding Entry Meetings

The following processes have proved effective in our experience:

- Exchange greetings when entering the meeting venue, and introduce yourself adequately.
- After providing information on the purpose of your mission, listen patiently to them as they narrate their experiences, challenges, and interests on the subject or other matter.
- Share the intended benefit of the program to the community.
- Seek their permission and advice on how best to forge ahead.
- At the end of the meeting, thank them for their cooperation and clearly outline the next steps (some form of action plan and who is responsible for what).

1.4 Engaging the Stakeholders

Stakeholder engagement means initiating, nurturing, and sustaining a trusting relationship with community leaders and members for the purpose of securing and sustaining their ongoing interest in providing care and support services.

To engage the stakeholders, you must first know who they are (both individuals and groups) and what roles they play in the community. You need to hear and respect their priorities and concerns. You can draw them in from the beginning of a project—bringing them on board even before a CCT center is set up. They can participate in the site assessment and fully appreciate any infrastructural or human resources changes that are required. They are now fully engaged and ready for the next step. (See box.)

WINNING OVER STAKEHOLDERS BY EXPLAINING PROGRAM BENEFITS

When first contacted for partnership, the administration of one hospital was reluctant to take on what the hospital considered to be an additional burden of caring for people with AIDS without being paid extra. They thought USAID made provisions for staff salary top-up.

MSH, in the spirit of true partnership, provided reasons in writing why MSH could not pay using USAID funds; explained program benefits to the clients, the hospital, and the state; and firmly engaged the SMOH and SACA to help hospital staff understand these reasons.

The hospital administration shared MSH’s position with relevant health workers. They saw the points and remarked, “After all, we have been treating these same clients as ‘recurrent fevers’ and the few lucky ones were getting antiretroviral (ARV) medicines from the state government, so we now have an opportunity to care for many more people.”
STEP 2. MOBILIZING THE COMMUNITY

Community mobilization is a process of empowering community members to recognize their inherent capabilities to transform their social and health life and move from a state of inaction or ineffective action toward effective action and positive change on issues of real concern to them. This builds a sense of collective empowerment and efficacy. Even if external help may be provided, the individuals and the community must lead the change process.

2.1 Building Community Networks and Linkages

In most communities, you will find many agents whose activities and services cater to the care and support needs of PLWHA and their families. These agents can be mobilized to create partnerships and networks that will enable them to extend the scope and improve the quality of their services.

A health facility, for example, may provide excellent CCT services, but lack the capacity to offer the spiritual counseling that is already being provided by a faith-based organization (FBO) within the community. Or the facility may draw on community volunteers to follow up with clients who are not adhering to their treatment regimens. Other CBOs may have expertise in advocacy, policy change, and legal services, and still others may have developed excellent services specifically geared to women, children, or men. If the health facility and these community groups come together to share knowledge and make referrals, they will be able to offer a more robust service package to their clients.

MSH Nigeria has found that CBOs constitute the best rallying point for networking and are most able to lead the effort. Many secondary hospitals across the six ProACT Project states have built client referral networks with primary health care (PHC) clinics in their communities. The community-based feeder sites offer HIV C&T services and refer clients who test positive to the larger CCT sites (see the Comprehensive HIV/AIDS Care and Treatment: Site-Startup and Management manual). These clients then return home to find ongoing care and support within their communities.

These partnerships enable the PHC clinics to give HIV-positive clients access to the care and treatment they need. In return, the CCT sites are able to offer HIV-positive clients ongoing services in hard-to-reach communities that have few resources.

2.2 Mobilizing Human and Financial Resources

MSH Nigeria has found that most leaders, groups, and community members have a genuine interest in caring for those who are facing serious health challenges. There are many instances—in Nigeria and worldwide—in which community members and structures have been mobilized to respond to various health concerns. (See box 4.) For example, community effectiveness in promoting immunization, direct observation and treatment of TB, and oral rehydration therapy has been well documented and is widely accepted.
CONVINCING COMMUNITY LEADERS TO COMMIT RESOURCES FOR CARE AND SUPPORT PROGRAMS

Community leaders who are aware of the impact of HIV/AIDS pandemic and its relationship to TB, who trust their health facility providers and managers, and who understand the elements of community care and support services are empowered to make better choices for a sustainable approach to prevention, treatment, and care in their communities.

Community entry in the Offa local government area has always been a success. MSH got the support of various stakeholders and leaders in the community. We carried out community advocacy and resource mobilization campaigns with different community groups.

Some of the support we received included two ceiling fans, clothes, food stuff, pints of blood for PLWHA in need, and financial support.

Presently the ceiling fans are being used in the prenatal care unit of the hospital, and the clothes and the food have been distributed to PLWHA. This gesture has greatly increased the living conditions of PLWHA and advanced our collaboration with community leaders.

700 chiefs attended the workshop called by the Emir, with support from MSH.
3.1 Fostering Meaningful Involvement of PLWHA

HOPE CAN LIE WITHIN YOU: RABI SULEIMAN’S STORY

Forty-year-old Rabi Suleiman lives in Koko Besse local government area, Kebbi State, Nigeria. She is married without children. Rabi, who now lives with her third husband, recalls that her ordeal with illness and social ostracism began in 2009. Rabi’s three marriages were the result of her inability to conceive, and a continuous search for a partner with whom she could successfully bear children. In the course of her multiple marriages, she contracted HIV and tested positive on April 16, 2009. Rabi believes she got the HIV infection from her second husband.

Weakened by continuous infections and emaciated beyond recognition, Rabi recalls that she was abandoned, equated to animal status, and locked up in a hut meant for cattle at her family home. Her meals were pushed to her through a door-opening by relatives who refused to look her in the face.

Today, Rabi has a new story to tell. With the assistance of the ProACT project outreach team, Rabi was enrolled in the USAID-supported ProACT antiretroviral (ART) program in the General Hospital, Koko, late in 2009. She says her traumatic experience with sickness, stigma, and ostracism is now history. “I am happy; I am confident of who I am now. Now I can speak publicly about my status.” Transcending her initial status of rejection and abandonment, Rabi is once more a respected member of her community. With her support, two individuals were recently counseled, tested, and enrolled at the Koko General Hospital facility, Kebbi State, where she now works as a peer counselor.

Rabi urges, “Know your status because if you don’t, you could be at risk. HIV is never the end. Your attitude toward your medication determines your attitude toward your health. A lot can be said about you and to you, but it’s in your best interest not to worry about it. I am happy and can do everything any other human being can do. I have a shop at home, I go to the market, and I have a lot of friends. I always advise HIV-infected individuals to take their medication regularly and to try to free their minds of worry.”
3.2 Encouraging Support Groups

Before they can become fully involved in care and support programs, PLWHA need to come to terms with the reality of the disease. Support groups have proven to be an important means of guiding PLWHA through the initial shock and fear and helping them to rebuild their lives. These groups bring people together to share experiences and knowledge. When they are most effective, they lead to empowered clients who are able proactively to care for themselves and their families. Support groups can offer a wide range of services to their members: health education, reinforcement for adherence to treatment, counseling, psychosocial support, family-life education, and prevention of opportunistic and secondary HIV infections. They can promote economic empowerment, including income-generating activities.

ProACT-supported PLWHA groups have actively educated themselves by collaborating with trained health care workers and have been involved in creating awareness within their communities. They have collaborated with local NGOs and community leaders on expanding HIV prevention initiatives. They have successfully mobilized food, clothes, and other supplies, as well as funds, from community members, business groups, government agencies, and donor organizations. They have used these resources to assist indigent members and their families; to set up and grow several income-generating activities; and to offer education, medical care, and transportation to members in need.

As they gain experience and influence, the challenge for these groups is to scale up their activities while remaining sustainable beyond whatever initial funding they receive. In many instances, this leads them to become legally registered as NGOs that are able to mobilize funds from donors, other community members, and business organizations to implement effective and sustainable HIV/AIDS and TB mitigation programs. An important step is to develop strong financial monitoring and utilization systems so that they can grow their resources and make an even larger contribution to their communities over time.
3.3 Engaging PLWHA as Service Providers

Some of the challenges to effective delivery of HIV-related services in Nigeria are inadequate human resources for health (HRH), weak referral systems, and stigma and discrimination. PLWHA are a special group of people in the fight against HIV and AIDS. They have the experience of living with the disease, and when properly supported and motivated, they can offer care and support to others in similar situations. Enlisting PLWHA as service providers can help alleviate the challenges of inadequate HRH, stigma, and discrimination. PLWHA are key stakeholders, and when their capacity is built and they are adequately mobilized, they can be a critically important resource in HIV care, treatment, and support programs. (See box below.)

In the ProACT project, PLWHA have contributed to the project as lay counselors and supporters of provider-initiated counseling and testing (PITC). They have helped to promote C&T, counseled individuals of all ages at health facilities, and offered critical care and support services including the administration of life-saving medications to parents, children, and families. PITC supporters facilitate diagnosis and access to HIV-related services at a variety of health service delivery points. Other roles PLWHA have played on the ProACT project include the following:

- HIV/AIDS support group facilitators
- Treatment supporters
- Community home-based care providers
- OVC service providers
- Adherence counselors
- Facilitators of trainings
- Trackers of defaulters and patients lost to follow-up
- Participants in community health promotion activities
- Providers of escort services for inter- and intrafacility linkages
- Agents of change in HIV prevention and in stigma- and discrimination-reduction efforts in the community

3.4 Reducing Stigma and Discrimination

Stigma is an unfavorable attitude of disapproval or reproach directed toward an individual or group. Discrimination is an action or behavior in which an individual or group is treated with partiality or prejudice. Both stigma (attitudes) and discrimination (actions)
are common in relation to HIV/AIDS in many communities. Apart from the emotional harm to individual PLWHA and their families, stigma and discrimination have had profound effects on the course of the epidemic. The fear of negative community reaction may prevent a person from getting tested to learn his or her HIV status, admitting that he or she is HIV-positive, or seeking services. Action to fight stigma and discrimination is required at individual, community, and policy levels. You can play an important role by providing accurate information to gatekeepers and opinion leaders—such as influential faith-based community groups—by partnering with PLWHA and by helping to strengthen the leadership and management capacity of PLWHA groups.

MSH has contributed greatly to the reduction of stigma through the following community interventions:

- The use of the PITC option, instead of voluntary CCT or the Heart to Heart Center (an HIV services center). It was observed in the past that anybody seen entering the Heart to Heart Center was stigmatized, but the PITC option that MSH is using is more effective and less stigmatizing. We have different service points where clients can go and access HIV testing and counseling without being noticed by an outsider.
- MSH has encouraged service integration in all sites. By not limiting people to only HIV testing and counseling services, HIV clients receive services at the same site where other services are also delivered, and HIV patients’ folders are kept together with other patients’ folders, thereby reducing stigma.
- MSH has facilitated formation of support groups in all supported sites. These groups have encouraged people to share their HIV status with others, which reduces stigma.
- Involving community leaders in the care of PLWHA and participatory approaches to education communities and delivering care also help to reduce stigma.
- In Adamawa State, MSH facilitated male involvement and couple C&T activities with support from religious and traditional community leaders. Different advocacy visits were paid to community leaders to de-stigmatize HIV/AIDS issues at meeting places and to encourage access to HIV services in facilities for men and couples. At the end of year two of the activity, client retention increased by about 30 percent, and more people accessed the services as couples than before. This innovation reduced both self stigma and community stigma.

3.5 Making Community-Based Care and Support Initiatives More Gender-Responsive

We define gender as a social construct that refers to the different roles men and women play because of the way their society is organized. Gender is expressed in the relations between the sexes and assumptions about “appropriate” behaviors that arise from these roles. Attitudes and expectations related to gender are learned and can change from generation to generation, from culture to culture, and from one social, ethnic, or racial group to another within the same culture.
A gender perspective takes into account gender roles, social and economic relationships and needs, access to resources, and other constraints and opportunities imposed on both men and women by society or culture, age, religion, and/or ethnicity.

Women and men may have interests, needs, and priorities that are not always fulfilled by their gender roles, but those of us who are working on HIV/AIDS and TB projects have seen many examples of women and men as partners in progress—bringing their different roles, relationships, needs, perspectives, and interests together to improve services.

No one can deny that in Nigeria, a long tradition of male dominance has given women unequal access to health services and has disempowered women to make decisions about their own health. It is also clear, however, that women’s opportunities, status, and participation cannot be improved without involving men in the process. (See box left.)

**INCREASED AWARENESS AMONG MEN LEADS MORE WOMEN TO PMTCT**

Prevention of mother-to-child transmission (PMTCT) services at Argungu Hospital in Kebbi State were recording a low uptake of ARV prophylaxis by HIV-positive mothers because they had to get permission from their husbands.

The Emir, with support from MSH, mobilized 700 chiefs to attend a one-day orientation on the benefits and process of PMTCT.

The 6 months that followed recorded no noticeable increase in the number of women accessing PMTCT services, but instead, the hospital noted a marked increase in number of men accessing HIV testing and counseling.

After first the 6 months, however, the number of women accessing PMTCT services increased significantly, which the hospital attributed to better spousal support once the men understood and appreciated the benefits of PMTCT.
STEP 4. BUILDING COMMUNITY CAPACITY TO LEAD AND MANAGE

“There is little chance of improving people’s standard of living and overall quality of life in a sustainable way without their collaborative participation in the planning process. This requires community capacity-building leading to empowerment.”

Capacity is the “ways and means to do what has to be done.” Community capacity-building aims to develop the skills, knowledge, confidence, and competence to work together for positive change. Strong leadership and efficient management of community initiatives is recognized by the government, NGOs, and other stakeholders as an essential component in community development.

4.1 Building Community Capacity

Without a generous supply of confidence and competence, no community can succeed in bringing about changes that will improve the quality of the lives of its inhabitants. As community organizations, individual men and women, traditional and religious leaders, and leaders of community groups develop new skills, they come to realize that they can change their situation, participate more fully in society, and influence decisions that affect them.

Members of your community can develop the capacity to bring about changes in HIV/AIDS and TB services. They can use their new knowledge, skills, and competence to identify and grasp opportunities for progress in the struggle against these diseases.

Increased capacity can also mean increased motivation to work together to provide services to PLWHA and their families. In a motivated community, you will find organizations, physical resources, leadership, and structures ready to participate in a common effort. Community leaders will be able to mobilize economic and financial resources and establish enabling policies and systems to sustain successful initiatives.

The following principles have proved successful in community capacity-building in MSH-supported areas.

- Build on the existing strengths, talents, competencies, and skills within the community as the starting point for development.
- Be driven by the community’s priorities.
- Design programs of benefit to the wider community as well as to the direct beneficiaries.
- Empower people to act on behalf of their community.
- Learn from best practices in other communities.
- Strengthen existing networks and support the establishment of new ones where they do not exist.
4.2 What Activities Are Most Appropriate for Building Community Capacity?

Because of the different contexts in which community capacity-building can be carried out, many varied activities can contribute to the effort. What matters is not so much the volume or variety of activities as the extent to which those activities combine encouragement with practical assistance, help community members to recognize that they can do important things for themselves, and help them to help each other.

The most appropriate activities are those that encourage and reward the ongoing participation and involvement of community leaders and potential leaders. Here are some you may want to undertake:

- Working directly with members of the community on a project that they consider high priority
- Helping them to identify and deal with challenges that affect them as members of that community
- Helping to develop structures that enable them to cooperate with each other and with organizations in the wider geographic area
- Providing advice and support for the participatory evaluation of projects
- Nurturing networking and the sharing of experiences as part of the learning process
- Enabling groups to consolidate and build upon existing skills

The mechanisms for carrying out these activities might include the following:

- Providing formal and/or informal training and information on topics of interest to participants
- Providing advice and support on assessing group needs and priorities and then planning and implementing projects to meet those needs and priorities
- Helping to develop transferrable skills such as teamwork and problem solving
- Developing people’s capacity to organize structures, systems, and practices within their communities
- Enabling community members to facilitate productive meetings and make compelling presentations
- Strengthening people’s ability to work within structures outside their groups by coaching in negotiation, conflict management, and advocacy
- Providing mentoring and supportive supervision
STEP 5. USING COMMUNITY MONITORING AND EVALUATION (DATA-DRIVEN DECISION-MAKING)

Community monitoring and evaluation (CME) is an ongoing process through which communities measure the quantity and quality of health and social services. Community members and other stakeholders track the progress of health initiatives to ensure that the services provided are meeting desired objectives. This presupposes that stakeholders are conversant with the health challenges facing their communities and are leading the planning and implementation of HIV/AIDS and TB mitigation activities.

CME is not simply a mechanism for collecting data about the performance of health initiatives. It is also a process designed to strengthen relationships between community members and leaders. Knowing the facts about the quantity and quality of HIV/AIDS and TB services will empower community members to own, support, and improve these services. In coming to decisions about what indicators to measure, relevant stakeholders need to identify the issues of most importance to the community and agree on what to do with the feedback information.

The more common situation, however, is that organizations and groups external to the community have predesigned their interventions and have received funding to implement and monitor these programs. The challenge, therefore, is for these implementing groups to establish a link between their project objectives and the community’s priority needs. This link requires mutual awareness, trust, and the ability of community leaders to convince these stakeholders to buy into the community’s agenda.
STEPS FOR SETTING UP CME SYSTEMS

Step 1. Building Trust with the Community and Identifying Issues for Monitoring

Building a relationship of trust with the community is essential for securing its commitment, which in turn is necessary to ensure the sustainability of the system. Identifying the issues that matter most to the community is also essential so that programs are focused on achieving objectives of highest priority. This initial engagement and assessment should ensure that the process you develop is pitched at the right level and fully inclusive. It is important to seek out and speak directly to the most vulnerable and least powerful members of the community such as women, children, or people with disabilities, so that everyone’s priorities are represented. Focus group discussions are useful at this stage.

Step 2. Identifying and Engaging Stakeholders

Create a stakeholder map to identify those responsible for delivering the priority activities and outputs that need to be monitored. Community stakeholders here include, but are not limited to, local government officials and councilors, traditional leaders, women’s groups, youth groups, and FBOs. There is evidence that CME is more effective when government is engaged throughout the process. Establish strategic engagement with organizations that have influence with government officials, access to information, good campaigning skills, links to the media, expertise on the HIV/AIDS issue, or technical skills in conducting research.

For more information and resources on identifying and engaging stakeholders, please refer to the Overseas Development Institute’s Stakeholder Analysis web page at http://www.odi.org.uk/rapid/Tools/Toolkits/Communication/Stakeholder_analysis.html.

Step 3. Establishing a Baseline Using Selected Indicators

Before beginning to collect evidence, it is essential to establish the units of analysis for the indicators, the indicators, and the baseline:

- **Unit of analysis**: Decide, for example, whether evidence be collected about individuals, families (households), specific groups within the community (e.g., older women) or about the entire community.

- **Indicators**: Determine what will actually be measured. For example, as part of a community intervention to reduce mortality in children, communities may focus on tracking the following water and sanitation provision indicators:
  - Incidence of diarrhea
  - Availability of clean water
  - Distance from nearest water source
  - Time spent at borehole or in queue at water source
  - Number of boreholes in a zone.
Baseline: Measure your selected indicators before activities begin. Primary research or existing information, such as census data and government household surveys, may be the source of your baseline data. Establishing a baseline is one of the most important monitoring and evaluation tasks. Without a baseline, teams cannot track their progress, determine whether activities are going according to plan, or measure the extent to which they have achieved their results. Without a baseline, it is difficult to correctly implement a CME plan. Gathering baseline data allows for two things:

- A baseline provides information you can use to set targets and goals for the results you hope to achieve by implementing your activity or program. It might tell you the targets are too ambitious, or not ambitious enough, and prompt you to make adjustments to the plan.
- A baseline provides the starting point for tracking changes in the indicators over the life of a project. Why track changes in indicators? The indicators are linked to the immediate results (output) and the longer term results (outcomes) that you will want to monitor and achieve. Changes over time in the indicator values show whether the results are going up, going down, or staying the same. In turn, this measurement tells you whether planned activities and strategies are working as planned.

Step 4. Collecting the Data

To collect the data, you can choose to use quantitative methods such as household surveys, qualitative methods such as focus group discussions, or a mix of the two. For instance, a survey could help establish whether people's perceptions about the length of time spent waiting at the primary health centers has improved. Alternatively, you could also ask community monitors to stand by a small health post one day a month and simply record how long people wait.

To the extent possible, evidence must be representative of the entire community. It is not possible to speak to everyone in a community, but it is important to gather evidence from people with different levels of education, with varied backgrounds and experiences, and from different locations. Sample size is also important, since the larger the group is that you collect information from, the more of the community will be represented.

Research activities must also be open and transparent, people must participate willingly, and information must be kept confidential. These imperatives reinforce the importance of building a relationship of trust with the community. Involving communities in the analysis of the results is also fundamental to maintaining community support and sustaining progress.
Step 5. Using the Results for Decision-Making

Monitoring and evaluating progress and sharing results and recommendations are essential. Efforts to encourage community participation are also critical. Forging partnerships with government at the local levels and with research institutions can help facilitate implementation of community recommendations. It is important to stimulate the community’s interest in using data to drive decision-making, which will help ensure that solutions are evidence-based and cost-effective. From time to time, the communities need to take an active role in generating data, conducting basic analysis, and utilizing this data.

THE LAST WORD

PLWHA could be us, our spouses, our children, our friends, our neighbors, or someone totally unknown to us but known to another. We know that ARVs are not the panacea to healthy living for PLWHA, but effective care and support services, including the positive living services, go a long way in restoring broken down systems and a return to normal life. We understand psychosocial care will alleviate stress, nutritional services will promote healthy tissues, medical care will prevent and treat opportunistic infections, and income-generating activities will avail financial resources needed for the family. Because HIV is a chronic infection, providing these services within the community promotes adherence and improves quality and quantity of life.

May you today become selfless and begin to actively look out for those with HIV/AIDS, may you love and educate them, and may you connect them to care and support services within your community. Each extra day they live will bring joy to your life — together against AIDS!
Eboso support group member, nursing aide & volunteer Amina Ahmed talking with colleague in Bida General Hospital, Niger State (a ProACT supported HIV Comprehensive Care and Treatment Center).
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