

THE CEDPA TRAINING MANUAL SERIES

# HOME CARE FOR PLWHA: THE POWER OF OUR COMMUNITY



Integrating Reproductive Health  
and HIV/AIDS for NGOs, FBOs & CBOs  
Vol. III



ENABLING CHANGE FOR WOMEN'S  
REPRODUCTIVE HEALTH



THE CENTRE FOR DEVELOPMENT  
AND POPULATION ACTIVITIES

# **Home Care for People Living with HIV/AIDS: The Power of Our Community**

**Integrating Reproductive Health and HIV/AIDS for  
Non-Governmental Organizations, Faith-Based  
Organizations and Community-Based Organizations**

**Volume III**

**cedpa**

# Home Care for People Living with HIV/AIDS: The Power of Our Community

**Authors** Kathy Callahan, MA  
Laurette Cucuzza, MPH



**The Centre for Development  
and Population Activities**



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## Abbreviations

<b>ABC</b>	Abstinence, Be Faithful, and Condom Use
<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ARV</b>	Antiretroviral
<b>AUSAID</b>	Australia Agency for International Development
<b>CEDPA</b>	The Centre for Development and Population Activities
<b>CBO</b>	Community-Based Organization
<b>ENABLE</b>	Enabling Change for Women’s Reproductive Health
<b>FBO</b>	Faith-Based Organization
<b>FP</b>	Family Planning
<b>GIPA</b>	Greater Involvement of Persons Living with HIV/AIDS
<b>HIV</b>	Human Immunodeficiency Virus
<b>IEC</b>	Information, Education, and Communication
<b>IDU</b>	Injecting Drug User
<b>IGA</b>	Income Generating Activities
<b>ICPD</b>	International Conference on Population and Development
<b>MSM</b>	Men Who Have Sex with Men
<b>MTCT</b>	Mother-to-Child Transmission
<b>NGO</b>	Non-Governmental Organization
<b>ORS</b>	Oral Rehydration Solution
<b>OVC</b>	Orphans and Vulnerable Children
<b>PLWHA</b>	People Living with HIV/AIDS
<b>RH</b>	Reproductive Health
<b>RTI</b>	Reproductive Tract Infection
<b>STI</b>	Sexually Transmitted Infection

<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on AIDS
<b>UNGASS</b>	United Nations General Assembly Special Session on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>VCT</b>	Voluntary Counseling and Testing
<b>WHO</b>	World Health Organization

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The Enabling Change for Women's Reproductive Health (ENABLE) project works to strengthen women's capabilities for informed and autonomous decision making to prevent unintended pregnancy and improve reproductive health. Begun in 1998, ENABLE seeks to increase the capacity of non-governmental organization (NGO) networks to expand reproductive health services and to promote a supportive environment for women's decision making.

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Laurette Cucuzza  
Advisor, RH/HIV/AIDS Integration

Kathleen Callahan  
Consultant

CEDPA/Washington, DC

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## Overview

The HIV/AIDS pandemic has created a crisis of unprecedented proportion that greatly impacts society as a whole, especially women and their reproductive health. Communities everywhere are struggling to respond. It is our hope that this manual will help communities find the strength to address this crisis.

The International Conference on Population and Development (ICPD) held in Cairo in 1994 was a watershed in the field of reproductive health (RH). In Cairo, the thinking about population and development underwent a major change: from a focus on demographic goals to a greater recognition of the interrelation of population, sustainable development, and economic growth, and to advances in the education, economic status, and empowerment of women. Women's groups, non-governmental organizations (NGOs), faith-based organizations (FBOs), community-based organizations (CBOs), and other members of civil society pressed for a new, holistic interpretation of reproductive health that focused on the individual's needs and desires and the interdependence of individuals and their communities.

Given the call to action from Cairo, CEDPA's ENABLE Project was designed "to strengthen women's capabilities for informed and autonomous decision making to prevent unintended pregnancy and improve reproductive health." Through partner NGO networks, women would have greater access to high-quality, *integrated* reproductive health services and an enabling environment would be promoted.

In a strategic response to the HIV/AIDS pandemic, ENABLE has developed a series of manuals entitled "Integrating Reproductive Health and HIV/AIDS for NGOs, FBOs, and CBOs." Each volume addresses various facets of the pandemic and the issues of sexuality underlying both family planning (FP) and HIV transmission. Priority areas include: (1) integrating HIV/AIDS education, prevention, and care and support activities into ongoing programming; and (2) building capacity in NGO partner programs, networks, and communities affected by the destabilizing effects of the HIV/AIDS pandemic.

Communities that have been hard hit by HIV/AIDS need to be supported in their response to the crisis. Families and community groups that are caring for people living with HIV/AIDS and orphans and vulnerable children often need basic information on HIV/AIDS to keep themselves safe and to help those in their care stay healthy and emotionally positive for as long as possible. This training manual provides the necessary information, as well as tapping into the strength of the community and empowering participants to action. This manual offers people living with HIV/AIDS, orphans and vulnerable children, families, and community members knowledge about healthy living with the virus, about care and support, and about death and dying. Community members are urged to visualize their regions protected against the ravages of HIV/AIDS and to work together to find solutions to the impact of HIV/AIDS on their spheres of influence and action.

# A Note on Greater Involvement of Persons Living with HIV/AIDS in Home and Community-Based Care<sup>1</sup>

In Paris in 1994, the representatives of 42 countries signed a declaration supporting the greater involvement of people living with or affected by HIV/AIDS (GIPA) as an imperative, ethical, and effective response to the HIV pandemic.

## Defining GIPA<sup>2</sup>

At its most basic, GIPA means two important things—

- Recognizing the important contribution people living with or affected by HIV/AIDS can make in the response to the epidemic
- Creating space within society for people living with HIV/AIDS involvement and active participation in all aspects of that response

This contribution can be made at all levels, from the individual to the organizational, and in all sectors from the social and cultural to the economic and political. In particular, the Paris Declaration emphasizes the role of networks of people living with HIV/AIDS and community-based organizations (CBOs).

Community- and home-based care are often undertaken with the assumption that people living with HIV/AIDS and orphans and vulnerable children are passive recipients of care and support services. But studies have shown that their involvement can enhance those services, and at the same time provide benefits for the NGOs, CBOs, people living with HIV/AIDS, and orphans and vulnerable children. There are four levels of involvement of people living with HIV/AIDS in community and home care programs—

- **Access**—Using the care and support services of NGOs and CBOs
- **Inclusion**—Working as support staff or volunteers, providing peer outreach or home visits
- **Participation**—Providing HIV/AIDS services, either as volunteers or staff, using their experience and training
- **Greater Involvement**—Designing services and managing organizations, often engaging in advocacy activities and public speaking

Their meaningful involvement strengthens NGOs and CBOs by improving providers' attitudes and understanding of issues affecting people living with HIV/AIDS, and by creating a more supportive environment. There is often a greater integration of HIV/AIDS advocacy into the

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<sup>1</sup> Gilborn, Laelia. *Meaningful PLWHA Involvement; A Part of the Solution for Home and Community Care*. (Washington, DC: HORIZONS/Population Council, 2003).

<sup>2</sup> UNAIDS. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. (Geneva: UNAIDS, 2002). <http://www.unaids.org/publications/documents/persons/gipa-8.doc>.

work of NGOs and CBOs. Care and prevention activities become more effective by improving perceptions and by putting a human face on the epidemic, thus building synergy between prevention and care and support. It also increases the credibility of the organizations with beneficiaries, donors, and other stakeholders.

There are also challenges when involving people living with HIV/AIDS in service provision. These include disruption of services due to illness and death of a person living with HIV/AIDS, the attendant costs of providing health and life insurance, and increased training costs due to turnover. Organizations also have to beware of “tokenism” or superficial involvement of people living with HIV/AIDS, and the occasional tension that may arise between HIV positive and HIV negative employees. One challenge that many face in care and support is that it can be difficult emotionally for an asymptomatic HIV positive person to work with a person in the final stages of AIDS. NGOs/CBOs also need to be sensitive to gender-specific needs, including the reproductive goals and care burden for women.

The benefits to people living with HIV/AIDS are very important when they are meaningfully involved in care and support programs. Many experience improved psychological and physical health, reduced isolation through peer contact, better access to care, increased knowledge of HIV/AIDS, access to treatment, information on safer sex, better acceptance of their HIV status both by self and family, and increased self-esteem. They also often derive material benefits and paid employment.

Studies have shown other wider benefits from involving people living with HIV/AIDS and orphans and vulnerable children in care and support efforts.<sup>3</sup> In Uganda, some areas have experienced greater acceptance at the community level when they are seen to be thriving and active in their own and other’s care, thereby reducing stigma. People living with HIV/AIDS have even become role models in the community for their proactive positive living and planning for the future of their families. This has also increased the demand for voluntary counseling and testing (VCT) and access to care and support services.

There are several key elements that have been identified for creating a supportive environment for people living with HIV/AIDS involvement—

- Non-discriminatory staff attitudes, policies, and procedures
- Psychological support
- Avoiding tokenism by building skills of people living with HIV/AIDS—
  - personal empowerment
  - communication and presentation skills
  - HIV/AIDS knowledge
  - knowledge of the legal aspects of HIV/AIDS

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<sup>3</sup>These findings were drawn from a HORIZONS study funded by USAID entitled, *A Modified Approach to Support for AIDS-Affected Children in Uganda*. Principal investigators were Rebecca Nyonyintono, Makerere University, and Laelia Gilborn at HORIZONS, Population Council.

- skills for organizing and conducting policy dialogue<sup>4</sup>
- Material support
- Gender- and sexuality-sensitive services and opportunities for participation

Any organization or group developing home or community care services should keep these ideas in mind and in practice.

## **A Note on Caring for the Caregivers**

Experience has shown that to effectively fight the HIV/AIDS pandemic, communities need to work together and utilize their resources wisely. One of the greatest resources are those people willing and motivated to care for others who are ill and affected by HIV/AIDS. Caregivers may be family members, volunteers, or health and social workers, but they are on the front line in dealing with the epidemic and they need to be cared for themselves and supported in their work, lest they become overwhelmed by the burden of grief and despair.

Any home-based care program should provide for the needs of its caregivers, by building in support systems for them. These may be as simple as creating opportunities for caregivers to talk with one another to share their experiences, as in a weekly meeting or a “buddy system” (pairing up home-care givers). Other possibilities include respite care for family members caring for people living with HIV/AIDS or orphans and other vulnerable children, day care centers, regular vacation time built into volunteer and professional caregiver schedules, and regular visits with a psychologist to protect the caregiver’s mental health. The type of support given will depend on the resources available in the community, but it is crucial to provide support in order to keep caregivers from “burning out.”

## **Methodology**

Several training methodologies are utilized in this curriculum in order to add variety to sessions and to engage all types of adult learners—

- Demonstration
- Discussion
- Brainstorming
- Small group work
- Role-play
- Presentation/lecture
- Guest speakers

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<sup>4</sup> Ibid.

## Evaluation

It is important to get an idea of participants' level of knowledge about HIV/AIDS and home care before the training starts in order to evaluate how much they learn from it. Evaluations also inform the instructors of participants' baseline knowledge, experience, background, and expectations. During the registration process on the first morning of the workshop, give each participant a copy of the questionnaire "What We Know about Home Care for People Living with HIV/AIDS" (see the Appendix page I-376 for instruction and forms). The same questionnaire will be distributed during the evaluation session at the end of the workshop. You can then compare the two to determine what was learned and areas that need to be strengthened or followed up.

At the end of each day, participants will fill out three color-coded cards. On green cards, they will write one thing they have learned today. On pink cards they will write one thing about which they need more explanation. On yellow cards they will write one suggestion for improvement for the facilitator(s). Volunteers from among the participants will collect and summarize the cards, giving feedback to the group the following morning. The training team will meet each day to evaluate the day's work, plan and modify the program as necessary. A final workshop evaluation will be conducted with participants at the end of the workshop (see the "Workshop Final Evaluation" in the Appendix page I-382).

## Learning Objectives

**By the end of Section One, *The Many Aspects of Care*, participants will be able to—**

1. Describe at least five categories of needs of people living with HIV/AIDS and orphans and vulnerable children and possible community interventions to meet those needs
2. Discuss the importance of psychological health of people living with HIV/AIDS and describe some of the issues around VCT and disclosure of status to partners and children, including potential partner violence
3. Identify activities that pose a risk of HIV transmission and at least five examples of ways to prevent HIV infection among caregivers
4. List at least five positive behaviors and hygienic measures in the home that can help people living with HIV/AIDS to live longer, healthier lives
5. Describe symptoms of common illnesses, suggest strategies for managing them in the home, and identify those that require medical attention
6. Depending on the circumstances, discuss where to obtain World Health Organization (WHO) approved oral rehydration solution (ORS) packets or demonstrate the correct method to make ORS and to use a thermometer
7. Describe issues of particular importance to women in the community and home-based care
8. Describe special issues surrounding pregnancy and breastfeeding for HIV positive women

9. Demonstrate at least two ways to help people living with HIV/AIDS and their families to obtain and understand instructions from health care workers
10. Define “antiretroviral therapy” and list at least two benefits and two risks
11. List strategies for helping a person living with HIV/AIDS to prepare to die with dignity and for helping orphans and vulnerable children to heal psychologically and emotionally after the loss of their parent(s)
12. Identify psychological, physical, medical, social, material, and other supports and resources for people living with HIV/AIDS and orphans and vulnerable children in the local community

**By the end of Section Two, *The Basics of HIV/AIDS*, participants should be able to—**

13. Name three ways HIV can be transmitted and three ways to prevent transmission
14. Describe the stages of HIV progression in the body and define related terms

**By the end of Section Three, *Harnessing the Power of the Community*, participants should be able to—**

15. Create an action plan and affirm the participant’s commitment for providing support for people living with HIV/AIDS and orphans and vulnerable children in the community and for each other
16. Describe community responses to past challenges and visualize a successful community response to HIV/AIDS

## How to Use This Manual

In recognition of the volume of material included in this manual, and considering the different audiences, settings, and circumstances (especially those surrounding people living with HIV/AIDS and orphans and vulnerable children and their caregivers), the manual is designed and organized for flexibility. Prototype-training schedules have been provided, however, alternative exercises and sections have been included for the trainer to choose from depending on the participants’ background. It is important that the caregivers/participants know the basics of HIV/AIDS, including how HIV is transmitted and how to prevent further transmission, in order to protect themselves and reduce stigma. If the participants do not already know this information, the trainer should begin with activities from Section Two, *The Basics of HIV/AIDS*, which offers these basic facts. The trainers will need to evaluate the participant’s knowledge of HIV/AIDS and which areas specifically they lack knowledge in and add the appropriate activities from Section Two. CEDPA has produced an entire series of HIV/AIDS manuals, of which this is just one. If possible, it is recommended that participants attend a training based on Volume I, *Family Planning Plus: HIV/AIDS Basics for NGOs and Family Planning Program Managers* prior to this training. Section Three, *Harnessing the Power of the Community*, consists of activities aimed at mobilizing the community as a whole. If the participants express interest in the care of people living with HIV/AIDS in a broader context and would like to take further action in their community, these activities might be more appropriate.

**The four-day training** provided is based on the activities and topics only in Section One, *The Many Aspects of Care*. These are directed more specifically to aspects of care, both mental and physical. The manual is meant to be used within a community that is confronting the issues of care and support for people living with HIV/AIDS and orphans and vulnerable children. There should be 15 to 20 participants, from the same community, who are motivated and in positions within that community to make/support positive change in dealing with HIV/AIDS. Family members who are actively caring for a person living with HIV/AIDS, community groups involved in home care, and community leaders that can mobilize and influence the community to take on this work would be ideal participants for this training.

**The two-day training** is a refresher course for caregivers, with only the core competencies of care included (see example page IIX). This could also be used to give caregivers who cannot spare a full four days a quick overview of the most important aspects of care and to introduce them to resources available to them in the community. These activities can be modified or shortened depending on the facilitators' and participants' needs.

**A five-day training** can be utilized if the participants are able to attend for this length of period. In this case, the trainers should evaluate their competency in the subjects that will be presented and discuss with participants what they would like to learn. Section Two or Section Three can be added depending on the outcome. Prototype schedules can be found at the beginning of each Section.

Many programs, however, do not conduct the two to five-day trainings exactly as presented in this manual. Instead, trainers use the manual as a model and design their own home-based care training depending on the needs of the participants and the reality of the clients and community members they serve. Alternatively, sections of this manual can be used independently, to give specific skills to home care teams and family caregivers, or to empower a person living with HIV/AIDS and their support groups. Facilitators should feel free to adapt the sessions to meet the needs of the specific audience with whom they are working and design a realistic schedule. Also, in cases where there is difficulty in convening a group workshop, the manual can be used to develop easy-to-use resources for already scheduled meetings and other situations.

Remember, it is important to have full participation of people living with HIV/AIDS as equal partners in all HIV/AIDS activities, so it is assumed that wherever possible, they will be included as participants and facilitators in this workshop. Including people living with HIV/AIDS as active agents in the sessions can be very powerful, as other participants and facilitators can benefit from their insights and experiences.

*Home Care for People Living with HIV/AIDS: The Power of Our Community* is Volume III of a series of manuals entitled, *Integrating Reproductive Health and HIV/AIDS for Non-Governmental Organizations, Faith-Based Organizations and Community-Based Organizations*. The other two manuals, *Volume I—Family Planning Plus: HIV/AIDS Basics for Non-Governmental Organizations and Family Planning Program Managers* and *Volume II—Faith Community Responses to HIV/AIDS*, are important resource materials for trainers who may want to refer to them for more information in dealing with diverse target groups with different skill levels.

## Sample Four-Day Caregiver Care and Support Training

Schedule	Day One	Day Two	Day Three	Day Four
	<b>Registration</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>
<b>Session</b>	<b>The Power of Our Community</b> Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	<b>Medical Support for People Living with HIV/AIDS (cont.)</b> Common Illnesses Role-Play <i>1 hour 45 minutes</i>	<b>Nutritional Needs for People Living with HIV/AIDS and Their Families</b> We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	<b>Preparing for Goodbye</b> Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> <b>Seeking Medical Support from a Professional Service Provider</b> Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	<b>Social Support for People Living with HIV/AIDS and Their Families</b> Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
<b>Lunch</b>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
<b>Session</b>	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	<b>Psychological Support for People Living with HIV/AIDS and Their Families</b> People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	<b>Closing</b> Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	<b>The Life Tree</b> Life Tree <i>1 hour 30 minutes</i> <b>Medical Support for People Living with HIV/AIDS</b> Common Illnesses Role-Play <i>1 hour</i>	<b>Physical Support for People Living with HIV/AIDS and Their Families</b> Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
<b>Evaluation</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Total Time</b>	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

## Sample Two-Day Refresher Training for Caregivers— Core Competencies

Schedule	Day One	Day Two
	<b>Registration</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>
<b>Session</b>	Introductions and Workshop Structure <i>1 hour 30 minutes</i>	Common Illnesses of People Living with HIV/AIDS <i>2 hours</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Breathe in Life Transmission Facts What's the Fluid? Where's the Door? Prevention Facts <i>2 hours 10 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i>
<b>Lunch</b>	<i>1 hour</i>	<i>1 hour</i>
<b>Session</b>	Condom Carousel Condom Demonstrations <i>1 hour 20 minutes</i>	Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i> Antiretrovirals <i>30 minutes</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Caring for People Living with HIV/AIDS in the Home <i>1 hour</i> Nutrition <i>1 hour</i>	Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
<b>Evaluation</b>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Total Time</b>	<i>9 hours 15 minutes</i>	<i>8 hours 30 minutes</i>

## Sample Five-Day Training for Caregivers: Sections 1 and 2

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	<b>Registration</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>
<b>Session</b>	<b>Transmission and Prevention of HIV/AIDS</b> Myths and Facts <i>1 hour</i> Transmission Facts <i>30 minutes</i>	<b>The Power of Our Community</b> Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	<b>Medical Support for People Living with HIV/AIDS (cont.)</b> Common Illnesses Role-Play <i>1 hour 45 minutes</i>	<b>Nutritional Needs for People Living with HIV/AIDS and Their Families</b> We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	<b>Preparing for Goodbye</b> Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	What's the Fluid? Where's the Door? <i>30 minutes</i> Prevention of HIV <i>30 minutes</i> Condom Carousel <i>30 minutes</i>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> <b>Seeking Medical Support from a Professional Service Provider</b> Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	<b>Social Support for People Living with HIV/AIDS and Their Families</b> Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
<b>Lunch</b>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
<b>Session</b>	Condom Demonstration <i>1 hour</i> <b>The Immune System and HIV</b> Elephants and Lions Game <i>15 minutes</i>	<b>The Life Tree</b> Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	<b>Psychological Support for People Living with HIV/AIDS and Their Families</b> People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	<b>Closing</b> Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Disease Progression Diagram <i>1 hour</i>	<b>Medical Support for People Living with HIV/AIDS</b> Common Illnesses Role-Play <i>1 hour 30 minutes</i>	<b>Physical Support for People Living with HIV/AIDS and Their Families</b> Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
<b>Eval</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Total</b>	<i>7 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>

## Sample Five-Day Training for Caregivers: Sections 1 and 3

Schedule	Day One	Day Two	Day Three	Day Four	Day Five
	<b>Registration</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>
<b>Session</b>	<b>The Power of Our Community</b> Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	<b>Medical Support for People Living with HIV/AIDS (cont.)</b> Common Illnesses Role-Play <i>1 hour 45 minutes</i>	<b>Nutritional Needs for People Living with HIV/AIDS</b> We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	<b>Preparing for Goodbye</b> Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>	Merging the Community Maps <i>30 minutes</i> <b>Action Planning for Our Community</b> Story with a Gap <i>1 hour 30 minutes</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> <b>Seeking Medical Support from a Professional Service Provider</b> Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	<b>Social Support for People Living with HIV/AIDS and Their Families</b> Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>	Group Action Plan <i>1 hour</i>
<b>Lunch</b>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
<b>Session</b>	<b>The Life Tree</b> Life Tree <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	<b>Psychological Support for People Living with HIV/AIDS and Their Families</b> People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	<b>Creating Our Community Vision Statement</b> Developing My Own Vision Statement <i>15 minutes</i> Creating Our Community Vision <i>1 hour 30 minutes</i>	<b>Closing</b> Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	<b>Medical Support for People Living with HIV/AIDS</b> Common Illnesses Role-Play <i>1 hour 30 minutes</i>	<b>Physical Support for People Living with HIV/AIDS and Their Families</b> Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	<b>Community Mapping</b> Creation of Community Maps <i>1 hour 15 minutes</i>	
<b>Eval</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Total</b>	<i>8 hours 15 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>8 hours 15 minutes</i>	<i>7 hours 15 minutes</i>

## **Building a Training Team**

Ideally, to facilitate the five-day prototype training, using all the activities in the manual, you should build a team of at least three facilitators. Team building is a process. Facilitators should meet to familiarize themselves with the content and discuss it, to choose sessions that each will facilitate and prepare, and to determine appropriate participants. It is important to have a variety of skills among the facilitators, in order to respond to the needs and questions of participants. It is also important to have a daily evaluation with facilitators in order to address concerns, assess progress, and to make any modifications that may be needed in the training.

The facilitator for the technical sessions needs substantial knowledge and experience in HIV/AIDS, perhaps a health or medical professional. Another should have a solid background in counseling or social work, either a trained social worker or other professional counselor, for facilitation of the psychosocial sessions. And finally, someone with experience in community mobilization, perhaps from a local NGO or an activist who is living with HIV/AIDS, would be useful for sessions on community response and action planning. Of course, you may be able to find one person that has two or more of these skills. It is still a good idea to have three or more facilitators to share the sessions, as this is quite a long and intense workshop. Each facilitator should be a skilled presenter and trainer.

### **Important Things to Remember when Presenting this Training Course**

When giving this training course, it is important to be aware of the emotional impact on participants and facilitators. Although the manual is focused on finding the strength within the community to deal with HIV/AIDS with hope and commitment, many of the sessions will be painful and emotionally challenging. Everyone should feel that they are in an environment where they are supported and can explore issues and feelings safely. There should be respect for each other and assurance that all information that is shared will be confidential.

Participants and facilitators may be HIV positive and may experience severe emotional reactions during the course of the training. Even if they are not positive, these sessions may bring up very difficult feelings. It is crucial to be sensitive and supportive to all and understanding of those whose behavior is out of the norm.

Due to the intensity of the subject matter of this workshop, it is recommended that the participants and facilitators take a recreational break of some kind on the third or fourth evening of the workshop. For example, go on some kind of outing together, or have a festive dinner together with dancing, entertainment or games, to release tension and stress and facilitate bonding of the group.

Given the strong feelings and emotions that the process of this training may bring up, not necessarily at the time of the training, it is important for both facilitators and participants to identify someone to whom they can turn in the future to provide support. This training will lay the foundation for the support that caregivers will need to give to each other, as caring for people living with HIV/AIDS and orphans and vulnerable children can be very emotionally draining and burnout is common.

Those participants who commit to continuing this work in the community in the future will need to have regular opportunities to support each other; any program providing these services needs to build in support for caregivers.<sup>5</sup>

Also, as facilitators it is important to remember that our words have power and positive words can reframe the way we, and our communities, think about HIV/AIDS. Positive, non-judgmental messages, both in verbal and non-verbal gestures, can combat stigma and discrimination. Please refer to the “Guidelines for Communicating about HIV/AIDS” on page 1-17 before presenting this training.

## How the Manual Is Organized

The manual is divided into three sections and 15 chapters, each chapter dealing with a specific content area. Prototype schedules are provided at the end of this section as a guide. (There are also large sections of this manual that are reference materials, both in “Handouts” and “Trainer Resources,” which can be photocopied for distribution to participants. Because of the volume, you may need to budget extra funds for photocopies.)

Each chapter may contain—

**Key Questions.** This section allows you to see at a glance what major questions will be addressed in the chapter.

**Introduction.** This section introduces the major theme of the chapter content and orients the facilitator to the overall lesson plan.

**Objectives.** The objectives set the learning goals for the sessions in specific, clear, and measurable terms. They can be used to focus your pre-test/post-test material and to orient the participants to the focus of the sessions.

**Sample Session Design.** The sample lesson plan contains the time required, the content, the methodology used, materials needed and a way to evaluate the participants’ learning. It helps the facilitator to determine whether the content is appropriate for the audience and to make sure that everything is prepared for the session.

**Important Terms.** This section contains definitions of key words that are necessary for comprehension of the session content. You may want to use them as handouts for participants to help them learn new terms, and then keep as a reference.

**Activities and Handouts.** This section contains all of the activities included in the sample lesson plan. Each activity has the learning objectives and step-by-step directions on how to conduct the session. Any handouts needed are included after the activity.

**Note to Trainers.** Denoted by a “notebook” graphic, these contain tips or helpful hints based on experience for facilitators, on how to teach the session, and extra resources that can be used for the session.

**Tools for Trainers.** The “Tools for Trainers” contain helpful examples or materials that trainers can use in sessions and can be adapted by the trainer to fit various audiences.

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<sup>5</sup> UNICEF, World Vision, Save the Children (USA) Malawi, and the Ministry of Women, Youth, and Community Services of Malawi. *Starting from Strengths, Community Care for Orphaned Children*. (Malawi: UNICEF, 1998).

## References

- Cook, R. Michele. *Starting from Strengths, Community Care for Orphaned Children: A Training Manual Supporting the Community Care of Vulnerable Orphans: Facilitators Guide*. (Victoria, BC and Malawi: University of Victoria, Unit for Research and Education on the Convention on the Rights of the Child, School of Child and Youth Care, Canada, and Chancellor College, Department of Psychology, 1998).
- Gilborn, Laelia. *Meaningful PLWHA Involvement; A Part of the Solution for Home and Community Care*. (Washington, DC: HORIZONS/Population Council, 2003).
- UNAIDS. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. (Geneva: UNAIDS, 2002).  
<http://www.unaids.org/publications/documents/persons/gipa-8.doc>.

## Training Schedule: Section 1

Schedule	Day One	Day Two	Day Three	Day Four
	<b>Registration</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>	<b>Recap</b> <i>30 minutes</i>
<b>Session</b>	<b>The Power of Our Community</b> Introductions, Goals, and Objectives Workshop Structure <i>1 hour 30 minutes</i>	<b>Medical Support for People Living with HIV/AIDS (cont.)</b> Common Illnesses Role-Play <i>1 hour 45 minutes</i>	<b>Nutritional Needs for People Living with HIV/AIDS and Their Families</b> We Are What We Eat <i>1 hour</i> Nutritional Needs for People Living with HIV/AIDS <i>1 hour</i>	<b>Preparing for Goodbye</b> Supporting People Living with HIV/AIDS <i>1 hour 30 minutes</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	Breathe in Life, Breathe Out Trouble The Power of Our Community <i>1 hour 30 minutes</i>	Oral Rehydration Solution and Thermometer Use <i>1 hour</i> <b>Seeking Medical Support from a Professional Service Provider</b> Special Medical Concerns for People Living with HIV/AIDS <i>1 hour</i>	<b>Social Support for People Living with HIV/AIDS and Their Families</b> Small Groups on Social Issues <i>1 hour</i> Plenary on Social Issues <i>1 hour 30 minutes</i>	Supporting Orphans <i>1 hour 30 minutes</i>
<b>Lunch</b>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>	<i>1 hour</i>
<b>Session</b>	Review from Section Two Review of HIV Transmission, Prevention, and Disease Progression <i>1 hour 30 minutes</i>	Strategies for Dealing with Health Professionals <i>45 minutes</i> Antiretrovirals <i>30 minutes</i>	<b>Psychological Support for People Living with HIV/AIDS and Their Families</b> People Living with HIV/AIDS Vignettes <i>1 hour 45 minutes</i>	<b>Closing</b> Evaluation <i>1 hour</i> String Spider Web and Closing Ceremony <i>1 hour</i>
<b>Break</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Session</b>	<b>The Life Tree</b> Life Tree <i>1 hour 30 minutes</i> <b>Medical Support for People Living with HIV/AIDS</b> Common Illnesses Role-Play <i>1 hour</i>	<b>Physical Support for People Living with HIV/AIDS and Their Families</b> Caring for People Living with HIV/AIDS in the Home <i>1 hour 30 minutes</i>	<i>The previous session can be emotional. Trainers may want to have a counselor present and use the afternoon session for this purpose.</i>	
<b>Evaluation</b>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>	<i>15 minutes</i>
<b>Total Time</b>	<i>8 hours 45 minutes</i>	<i>8 hours 45 minutes</i>	<i>8 hours 30 minutes</i>	<i>6 hours 45 minutes</i>