Module 12 Community Linkages and Adolescent Involvement

Session 12.1: The Importance of Facility-Community Linkages
Session 12.2: Creating a Community Resource Directory
Session 12.3: Adolescent Participation and Peer Education Programs

Learning Objectives

After completing this module, participants will be able to:

- Discuss common challenges to creating strong facility-community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
- Describe community-based support services that ALHIV and their caregivers may need
- Create a community resource directory for adolescent clients and caregivers
- Describe the rationale behind meaningful adolescent involvement and describe effective strategies of involving adolescents in service delivery
- Understand the key components of implementing a successful Adolescent Peer Education program
Session 12.1  The Importance of Facility-Community Linkages

Session Objectives

After completing this session, participants will be able to:

• Discuss common challenges to creating strong facility-community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
• Describe community-based support services that ALHIV and their caregivers may need

Improving Facility-Community Linkages

Challenges to establishing facility-community linkages

Some key challenges to establishing facility-community linkages include:

• Health workers may not be aware of community-based services or there may be no mechanism to exchange information or to formalize two-way referrals.
• Community organizations and leaders may not be aware of adolescent HIV services at the health facility.
• Teachers may not be familiar with HIV or the needs of ALHIV.
• Community organizations and leaders may not trust facility-based services or they may prefer traditional medicine/healing.
• There may not be any community services specifically for ALHIV.
• Adolescents may get treated poorly when they go to the health facility and this type of information spreads among members of the community.
• Service delivery may be fragmented, uncoordinated, and/or not youth-friendly.
• It may cost a lot of money to get from the community to the health facility (transportation costs).
Strategies to improve facility-community linkages

Strategies to improve facility-community linkages and to develop a more coordinated and collaborative approach to ALHIV service delivery include:

- Learn what community organizations and services are available in the areas where adolescent clients live (and where they go to school or work). Make an appointment and go to these organizations. Meet with the staff to find out what services they offer, to discuss the services offered at your facility, and to set up formal or informal “two-way” referral systems. This means that the health facility can refer adolescents to the community organization and the community organization can refer adolescent clients to the health facility. Invite representatives of the organization to visit the health facility for an informal meeting or a formal tour and “open house.”

- Facilitate regular (for example, monthly or quarterly) meetings that include health facility managers and staff, the staff of community-based youth groups, Adolescent Peer Educators, PLHIV associations, community health workers, school teachers/headmasters, teachers, and others. The meetings should aim to share insights and information about the special needs of ALHIV, about the services available at health facilities and in the community, and about how to facilitate interagency linkages and referrals.

- Meet with community leaders to talk with them about ALHIV and the importance of HIV care and treatment services. Also try to clarify common myths about HIV, ALHIV, and ARVs.

- Participate in community meetings and community gatherings to discuss HIV, ALHIV, and HIV care and treatment.

- Train/orient existing community-based Peer Educators, youth group members and leaders, and community health workers to identify adolescents in the community and refer them for HIV testing and care and treatment. They can also be trained to provide basic adherence and psychosocial support to ALHIV and their caregivers, and to follow up with clients who have missed appointments.

- Start support groups for adolescents of different ages/stages at the health facility or in the community. Invite community health workers and youth outreach workers to the support group meetings to provide guidance and information. See Module 5 for more information on setting up and leading support groups.

- Involve young community members openly living with HIV in strengthening facility-community linkages; for example, by starting an Adolescent Peer Education program (see Session 12.3).
Community Support Needs of ALHIV

Examples of common support needs of ALHIV, their caregivers, and families include:

- ALHIV support groups (including support groups for different ages/stages of adolescence) and associations
- Disclosure support (for both caregivers and adolescents)
- Nutritional and food support
- Spiritual guidance and support
- Transportation to get to the clinic
- Education and counseling for caregivers and family members
- Social grants
- Grants to purchase supplies, such as soap, school supplies, school uniforms, condoms, etc.
- Support for child-headed households, orphans, and vulnerable children
- Access to formal and non-formal education, including vocational training (for example, help with school fees/tuition) and life skills training
- Job preparation and placement
- Income-generating activities and savings and loan programs
- Home-based care
- Home-based adherence support
- Home-based infant feeding support
- Legal advice and support
- Others…

Continuum of care

Remember: no single person or organization can provide all of the services and support ALHIV and their families need. We must work together to provide a continuum of ongoing care and support within the health facility, in the community, and at home.
Session 12.2 Creating a Community Resource Directory

Session Objective
After completing this session, participants will be able to:
• Create a community resource directory for adolescent clients and caregivers

Creating a Community Resource Directory
In order to provide effective referrals, health workers need to be up-to-date on the community services available to young people and ALHIV.

• A good way of knowing where to refer clients is for each health facility to develop and regularly update a community resource directory (see Appendix 12A: Community Resource Directory Template). This makes it easier to refer clients to needed services.

• Each facility should have an up-to-date community resource directory and established, formal two-way referral systems to and from these organizations and services. The resource directory should include days/times services are offered, fees, documentation required at the initial visit, address, phone number, contact person, etc. The community resource directory should be posted in the clinic waiting room and should also be available in all of the examination and counseling rooms for easy reference.

• Health workers can also work together with youth (for example, Adolescent Peer Educators) to map available resources in the community for ALHIV and their families. They can then post this map in the clinic and/or give photocopies of the map to clients.

• Resource directories need to be updated regularly to keep up with changes in personnel, addresses, phone numbers, etc. It is a good idea for one person to be responsible for keeping up to date with these changes and adjusting the directory accordingly.

Exercise 1: Creating a Community Resource Directory: Small group work and large group discussion

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<thead>
<tr>
<th>Purpose</th>
<th>To provide an opportunity for participants to brainstorm and create their own resource directory</th>
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</table>

Refer to Appendix 12A: Community Resource Directory Template.
Session 12.3 Adolescent Participation and Peer Education Programs

Session Objectives
After completing this session, participants will be able to:
• Describe the rationale behind meaningful adolescent involvement and describe effective strategies of involving adolescents in service delivery
• Understand the key components of implementing a successful Adolescent Peer Education program

Adolescent Involvement
The meaningful involvement of PLHIV and affected communities in service delivery contributes powerfully to the HIV response by supporting people to draw on their own experiences to increase the effectiveness and appropriateness of services. PLHIV participation in all aspects of HIV programs is critical to ensure that services are designed and implemented to meet client needs.

Two important mechanisms to formally involve adolescent clients in service planning, implementation, and evaluation are:
• The engagement of ALHIV as Adolescent Peer Educators
• The establishment of ALHIV consumer (or community or client) advisory boards (CABs)

Both are discussed below.

Adolescent Peer Educators
Adolescent Peer Educators can complement the work of health workers and they play an important role in improving client adherence and service quality. Adolescent peer education offers many benefits to HIV care and treatment programs, including:

A safe environment:
• People trust others in similar situations. Adolescent Peer Educators provide ALHIV with the opportunity to discuss their personal circumstances in a safe environment, with someone who can relate to their situation.

Improved retention in care and adherence to treatment:
• Adolescent Peer Educators can support clients’ retention in care and adherence to treatment because they are likely to have a deep understanding of the challenges faced by ALHIV as well as practical solutions to those challenges.
• Youth involvement and the availability of Adolescent Peer Educators often make HIV care and treatment services more attractive to adolescents, thus improving their retention in care.
**Improved linkages:**
- Adolescent Peer Educators can draw on their own knowledge and experiences to help other ALHIV navigate health facilities and to strengthen linkages between the clinic and community-based services.

**Increased positive living:**
- Building on their own experiences, Adolescent Peer Educators can serve as role models to encourage positive living and positive prevention.
- Peer Educator Programs can empower and create positive changes in the lives of the Adolescent Peer Educators themselves, they can help decrease stigma and discrimination against ALHIV in the community, and they can encourage other adolescents in the community to access HIV services.

**Improved service quality:**
- Adolescent Peer Educators can help programs become more youth-friendly. They can also help identify and address program barriers to reaching young people.
- Adolescent Peer Educators are in a unique position to contribute to quality assurance activities, making suggestions based on their own experiences as clients in the program and based on feedback solicited from their peers.
- Adolescent Peer Educators can make services more accessible to youth by helping to plan and facilitate peer support groups and activities, including art, drama, music, sports, and other youth-friendly activities.

**Increased community participation and advocacy:**
- Adolescent Peer Educators can play a role in community mobilization by serving as positive role models, by decreasing stigma, and by increasing support for ALHIV.

**Job opportunities:**
- The training and work experience that comes with the Adolescent Peer Educator job prepares adolescents for future job opportunities in the formal economic sector.

**Increased access to services:**
- When young people such as Adolescent Peer Educators conduct outreach and advocacy work in their communities, more adolescents are reached with information about clinical services.
- Adolescent Peer Educators can play a role in identifying and reaching most-at-risk adolescents in their communities.

**A closer sense of connection for adolescent clients:**
- Young people are a vital source of information about youth needs.
- Programs that utilize youth staff tend to address young clients’ needs and concerns more sensitively and accurately than programs that do not.
- Adolescent Peer Educators may hear of client challenges or successes that have not come to the attention of other team members.
- Young people often speak the “same language” and Adolescent Peer Educators can help explain things in terms and language that their peers will understand (instead of using, for example, explaining things using formal or clinical language).
Client/Consumer/Community Advisory Boards (CABs)

Some health care programs may be interested in establishing a formal mechanism to facilitate feedback from clients through the establishment of a CAB (client/consumer/community advisory board). CABs are autonomous bodies that advise the clinic on service quality and gaps in care. They also make recommendations on how to improve service provision. CABs:

- Include 5–20 members. 7–9 is typical, most or all of whom are clients or caregivers. Members should represent a wide range of the clients served by the clinic.
- Typically meet every other week at first and monthly once established.
- Have a direct line of communication with clinic management. Typically, a clinic manager attends every meeting.
- Are guided by a set of by-laws developed by members and approved by the clinic they advise.

Avoid Tokenism

Adolescents should be recognized, integrated, and supported as the vital human resource they are. Tokenism is NOT the same as partnership or meaningful involvement and participation. Examples of tokenism include:

- Having youth present but with no clear role, training, support, or supervision. Both CAB members and Adolescent Peer Educators need training before they can fully contribute in their new roles. They also need ongoing support and supervision to continue to develop their skills and capacity.
- Asking youth their opinions but not taking these opinions seriously or incorporating them into program decisions or planning.
- Assigning tasks to youth that adults do not want to do, like filing or cleaning.
Ensure Expectations Are Appropriate

Remember: health facilities should always use a developmental approach when involving adolescents in program delivery:

- Keep expectations and assigned responsibilities and tasks realistic. Expectations should always match adolescents’ developmental capacity and responsibilities should always be appropriate for their age and ability. For example, an Adolescent Peer Educator should not be expected to provide professional-level counseling or mental health screening and management.

- Provide follow-up training and ongoing mentoring and supervision. If Adolescent Peer Educators are not well trained, this will compromise the quality and effectiveness of their work. Adolescent Peer Educators also need ongoing support, mentoring, and supervision. They need an experienced supervisor to:
  - Observe their work frequently at first and regularly thereafter (for example, weekly progressing to monthly) and to provide constructive feedback. The supervisor should observe both one-to-one interactions as well as those in a support group setting.
  - Provide a listening ear. As an ALHIV, it can be difficult to separate yourself and your issues from those of your clients. The death of a client can be a particularly difficult time during which Adolescent Peer Educators may need extra support.
  - Answer questions.
  - Not “look over their shoulder,” as this can undermine their self-confidence and the confidence of clients in their work.

- It is important to make the boundaries very clear to Adolescent Peer Educators and CAB members, and to enforce them in a transparent way. Make sure that the program has explicit policies and rules for addressing what is appropriate and inappropriate behavior and make sure that Adolescent Peer Educators are appropriately supervised and supported to adhere to these policies.
Key Steps to Implementing a Facility-based Adolescent Peer Education Program

Before implementing an Adolescent Peer Education program, it is important to consider how Adolescent Peer Educators will function within the existing program framework. In other words, how will Adolescent Peer Educators assist other adolescent clients and how will they become part of the multidisciplinary team as a whole? Neglecting to consider these factors can result in unclear job descriptions, mismatched expectations, poor peer performance, and, ultimately, compromised client service.

Table 12.1: Key steps to implement an effective Adolescent Peer Educator Program

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>1.</td>
<td>Conduct a participatory situational analysis and needs assessment: Ask colleagues, adolescent clients, and caregivers how youth are currently involved, how they could be involved in the future, and how they are involved in planning, implementing, and evaluating services at other organizations.</td>
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<td>2.</td>
<td>Engage stakeholders in participatory program design: Ask adolescents and their caregivers how they would like the peer involvement project structured. What should the Adolescent Peer Educators do? How should they be trained and managed? See Appendix 12B: Template for Adolescent Peer Educator Job Description.</td>
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<td>3.</td>
<td>Define program indicators, set targets, and develop tools: Indicators and targets include: “To train 12 Adolescent Peer Educators by April 1, 2012” or “To engage 6 Adolescent Peer Educators by May 1, 2012.” Tools might include supervisory tools, job descriptions (see Appendix 12B), personal criteria, etc.</td>
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<td>4.</td>
<td>Develop a detailed budget and workplan: This budget and workplan should include the cost and activities involved in recruiting, training, and engaging Adolescent Peer Educators.</td>
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<td>5.</td>
<td>Recruit Adolescent Peer Educators, based on selection criteria (see below for examples).</td>
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<td>6.</td>
<td>Adapt or develop an Adolescent Peer Educator training curriculum.</td>
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<td>7.</td>
<td>Train Adolescent Peer Educators. (Note: A useful, publically available curriculum exists to train Adolescent Peer Educators: Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators. See Appendix 12C and the “Resources” section at the beginning of this module for further information.)</td>
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<td>8.</td>
<td>Engage health facility teams to roll out peer education activities.</td>
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<td>9.</td>
<td>Provide ongoing support, supervision, and mentoring to Adolescent Peer Educators.</td>
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<td>10.</td>
<td>Continuously monitor, evaluate, and adjust the program.</td>
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Peer Educator Selection, Roles, and Responsibilities

A sample job description for Adolescent Peer Educators is included in Appendix 12B: Template for Adolescent Peer Educator Job Description.

Sample selection criteria for Adolescent Peer Educators

Some suggested selected criteria for Peer Educators include:

- Is an older adolescent
- Is living positively with HIV
- Is adherent to care and medications
- Has an open-minded and non-judgmental attitude (for example, is respectful and tolerant of different perspectives, cultural backgrounds, and lifestyles)
- Has basic literacy and numeracy skills
- Has good interpersonal and oral communication skills
- Is committed to working with other ALHIV
- Demonstrates self-confidence
- Has the ability to be self-disciplined and to work both independently and as part of a team
- Has the availability to work at the clinic (in a way that does not conflict with school or work attendance)
- Represents the age, ethnicity, socio-economic status, gender, language preference/abilities, and other characteristics of adolescent clients at the clinic
- Other qualifications identified by the health facility and/or suggested by young people

For additional information on setting up and managing Peer Education programs and on training Adolescent Peer Educators, see Appendix 12C: Resources for Peer Education Programs and CABs.

For more information on starting or planning a peer support group, see Appendix 5B: Starting/Planning a Peer Support Group. For more information on facilitating a peer support group, see Appendix 5C: Facilitating A Peer Support Group.
Module 12: Key Points

- Linkages to community resources and support are important to help ALHIV and their caregivers get the services and support they need across the continuum of HIV care.
- There are many ways to strengthen facility-community linkages, including organizing informal and formal meetings with community and youth group leaders; orienting community organizations and staff/volunteers working with youth on the needs of ALHIV; and developing a strong two-way referral system between the health facility and community organizations working with PLHIV, ALHIV, and youth in general.
- Health workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and should maintain a directory of these services to facilitate the making of referrals. This directory should then be shared with community organizations so that they also have a current list of the community- and health facility-based services for adolescents.
- PLHIV participation in all aspects of HIV programs is critical to ensure that programs are designed and implemented to meet client needs.
- Two important ways of including adolescents are through Adolescent Peer Education programs and through CABs.
- As ALHIV and service recipients themselves, Adolescent Peer Educators can give meaningful feedback to health care programs, offering insights into the best ways to retain young people in care and support their adherence to treatment.
- Adolescent peer education can be a powerful approach to improving the youth-friendliness and quality of adolescent HIV care and treatment services. However, such programs require careful planning, clear objectives, regular supervision, and good communication.
## Appendix 12A: Community Resource Directory Template

DISTRICT NAME: ___________________________  FACILITY NAME: ___________________________  DATE: ___________________________

<table>
<thead>
<tr>
<th>NAME OF ORGANIZATION</th>
<th>SERVICES PROVIDED FOR YOUTH/FAMILIES</th>
<th>GEOGRAPHIC AREAS COVERED</th>
<th>CONTACT PERSON</th>
<th>PHONE NUMBER AND ADDRESS</th>
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* “Other” could include, for example, hours of opening, fees, documentation needed at the initial visit, information about how to get there (transportation, bus line, directions if difficult to find), etc.
Appendix 12B: Template for Adolescent Peer Educator Job Description

SAMPLE Adolescent Peer Educator Job description

Adolescent Peer Educators are expected to (fill in/adapt as needed):

- Participate as active members of the multidisciplinary care team in the clinic, including attending required meetings and trainings
- Openly disclose their HIV-status to clients
- Help conduct/co-facilitate support groups and other psychosocial support activities for ALHIV (and caregivers/family members, when needed)
- Conduct peer education sessions with ALHIV and provide support on the following topics:
  - Basic information about HIV and HIV care and treatment
  - Retention in HIV care
  - Adherence to HIV treatment
  - Disclosure
  - Basic emotional and psychosocial support
  - Positive living and positive prevention
  - Safer sex
  - Others, as decided by the program
- Help ALHIV with referrals within the health facility
- Help link ALHIV with needed community support services
- Be positive living and adherence role models to other ALHIV
- Act as a link between adolescent clients and the multidisciplinary care team
- Keep basic records and compile monthly reports

Expectations and time requirements for Adolescent Peer Educators (fill in/adapt as needed):

- Once selected, Adolescent Peer Educators will be expected to serve at least 1 year in their position.
- Adolescent Peer Educators are expected to attend and participate in the initial 10-day basic Adolescent Peer Education training.
- Adolescent Peer Educators will be expected to work at the clinic at least 2–3 days per week.
- Adolescent Peer Educators may, as needed, be expected to attend meetings or refresher trainings on weekends or during holidays — estimated to be (fill in) days per month/year.

Supervision and reporting lines:
Adolescent Peer Educators will report to and be supervised by (fill in).

Incentives:
Adolescent Peer Educators are volunteers, but they will receive the following incentives, supplies, and stipends: (fill in).
Appendix 12C: Resources for Peer Education Programs and CABs

ICAP. (2011). *Positive voices, positive choices: A comprehensive training curriculum for Adolescent Peer Educators.* This easy-to-use, youth-friendly curriculum was designed to train Adolescent Peer Educators to become active members of multidisciplinary HIV care teams in health facilities.

The training course consists of a Trainer Manual and an illustrated Participant Manual containing 15 Modules that can be adapted to a range of country, program, and organizational settings and that can be used to start, scale-up, or improve the involvement of ALHIV as Adolescent Peer Educators. Available at: http://www.columbia-icap.org/resources/peresources/index.html

ICAP. (2011). *Comprehensive peer educator training curriculum. Version 2.0.* To share lessons learned and experiences more widely, ICAP developed and has recently updated per the new WHO guidelines a set of generic Peer Educator materials that can be adapted by organizations and implementing partners wishing to start or scale-up peer education programs.

Training content areas were selected to prepare adult Peer Educators for integration into the multidisciplinary HIV care team and to provide added support in key areas of PMTCT and HIV care and treatment service delivery. The curriculum contains 15 basic and 4 advanced Modules. Both Manuals can easily be adapted to specific country and program contexts.

The training curriculum consists of 3 components:
1. Trainer Manual, which is highly participatory, easy to follow, and contains step-by-step instructions for facilitators.
2. Participant Manual, which includes key information and illustrations to engage participants and improve learning. The Participant Manual can also be used as a reference for Peer Educators after the training.
3. Implementation Manual, which is meant to guide Ministries of Health, PLHIV Associations, or NGOs initiating or expanding facility-based Peer Education programs. It provides practical advice on planning, managing, and monitoring Peer Education programs. The appendices of the Manual also include a number of generic tools that can be adapted.

Available at: http://cumc.columbia.edu/dept/icap/resources/peresources/PE.html

FHI. (2005). *Youth peer education toolkit.* The Youth Peer Education Toolkit is a group of resources designed to help program managers and master trainers of Peer Educators. Collectively, these tools are meant to help develop and maintain effective Peer Education programs. The 5 parts of the toolkit are based on research and evidence from the field, as well as local examples and experiences. They are designed to be adapted locally as needed. The toolkit was the result of collaboration between the United Nations Population Fund (UNFPA) and Family Health International. It was produced for the Youth Peer Education Network (Y-PEER), a project coordinated by UNFPA.
The 5 parts of the toolkit are:
1. Training of Trainers Manual
2. Standards for Peer Education Programs
3. Theatre-Based Techniques for Youth Peer Education
4. Performance Improvement
5. Assessing the Quality of Youth Peer Education Programs

Available at: http://www.fhi.org/en/Youth/YouthNet/Publications/peeredtoolkit/index.htm

IMPAACT. (2007). IMPAACT community advisory board (ICAB) training curriculum: Trainer manual. Although the ICAB training curriculum is designed to provide training and support to CAB members responsible for advising research and clinical trials, the first module of the curriculum includes content on how to develop a CAB mission statement, identify goals, determine CAB structure, and develop standard operating procedures. Available at: https://impaactgroup.org/icab-trainer-manual
References
