Children, Adolescents & HIV

A simple toolkit for community health workers and peer supporters

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Paediatric AIDS Treatment for Africa
www.teampata.org

one to one children's fund
rebuilding lives

UKaid
from the British people

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Acronyms

AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescents living with HIV
ANC	Antenatal care
ANECCA	African Network of Care for Children Affected by HIV/AIDS
ART	Antiretroviral therapy
ARV	Antiretroviral
BIPAI	Baylor International Pediatric AIDS Initiative
CCAPA	Coalition for Children Affected by AIDS
CDC	Centers for Disease Control
CHAI	Clinton Health Access Initiative
CHW	Community health worker
CRS	Catholic Relief Services
ECD	Early childhood development
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
EP	Expert Patient
FHI	Family Health International
HIV	Human immunodeficiency virus
HTC	HIV testing and counselling
IATT	Interagency Task Team on the Prevention and Treatment of HIV infection in Pregnant Women, Mothers, and Children
IMC	Infant male circumcision
JSI	John Snow, International
K4Health	Knowledge for Health
LTFU	Loss to follow-up
MELYCABA	Monitoring, Evaluation & Learning Initiative for Young Children Affected by HIV and AIDS
MUAC	Mid-upper arm circumference
NGO	Non-governmental organisation
PATA	Paediatric AIDS Treatment for Africa
PEPFAR	President’s Emergency Program for AIDS Relief
PEP	Post-exposure prophylaxis
PIH	Partners in Health
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission of HIV
PPD	Postpartum depression
PS	Peer supporter
PSS	Psychosocial support
REPSSI	Regional Psychosocial Support Initiative
S2S	South to South
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TAC	Treatment Action Campaign
TB	Tuberculosis
USAID	US Agency for International Development
WHO	World Health Organization
YPLHIV	Young people living with HIV

Foreword

Daniella Mark,
PATA Executive Director

Children and adolescents in sub-Saharan Africa infected with human immunodeficiency virus (HIV) have poor access to quality care, and the severe shortage of healthcare workers is one of the major barriers. Overburdened health teams are unable to offer the child- and adolescent-friendly services and psychosocial support that are needed to realise integrated and comprehensive care.

Despite strides forward, many mothers, children and adolescents are still not receiving the care they need. Up to 28% of mothers who enrol in antenatal care (ANC) are lost to follow-up (LTFU) prior to delivery, while as many as eight of every ten are lost at six months postpartum. While 3.2 million children under the age of 15 years are living with HIV today — 91% in sub-Saharan Africa — only 24% are receiving antiretroviral therapy (ART). Children living with HIV are one-third less likely to receive ART compared to adults. Without ART, half of the children living with HIV will die before their second birthday, and 80% before their fifth. The unprecedented numbers of adolescents (10–19 years old) living with HIV brings with it novel challenges, and healthcare workers and communities are struggling to provide support that meets the needs of this vulnerable population

Paediatric AIDS Treatment for Africa (PATA) and One to One Children's Fund have worked together to address the specific needs of children and adolescents with HIV since 2007 through the Expert Patient (EP) Programme. Over the past eight years, the programme aimed to improve the quality of HIV treatment and care for children living with HIV across sub-Saharan Africa, providing additional human resource capacity to 48 health facilities across 13 countries and reaching 23,769 children in care.

word

Emma Bell,
One to One Children's Fund Executive Director

Today the EP Programme improves access to and quality of ART for HIV-positive infants, children and adolescents in 16 clinics in Zambia and Zimbabwe. On 1 April 2015, PATA and One to One Children's Fund launched Project REACH, a new programme model which engages adolescents living with HIV (ALHIV) and young people living with HIV (YPLHIV) age 18–24 years, as peer supporters (PSs) to improve the quality of services for their paediatric and adolescent peers in five priority countries.

Through this work, PATA and One to One Children's Fund identified how valuable a simple toolkit would be for community health workers (CHWs). Despite the many job aids, resources and materials available to support specific aspects of HIV treatment and care, most are not comprehensive, do not focus on childhood and adolescents in enough detail, and are inaccessible to CHWs and PSs who may not have the requisite literacy levels or educational grounding. It was with this in mind that the two organisations, with support from UK Aid, developed this resource. The toolkit provides the latest HIV guidance and information needed for CHWs and PSs to support children and adolescents living with HIV.

Together with these brave and committed community members, the global HIV community may turn the tide of the disease, safeguarding our children and improving healthcare systems and community wellbeing.

Emma Bell

Daniella Mark
Executive Director, PATA

Emma Bell
Executive Director, One to One Children's Fund

Introduction

Community Health Workers and Peer Supporters: Part of the Healthcare Team

CHWs and PSs are generally members of a community who provide certain kinds of basic healthcare to members of their community. Although different organisations and programmes may call them by different names (EPs, Accompagnateurs, amongst others) all play a special role in healthcare, as they are part of both the community and the clinic team. CHWs help clinics to deal with a shortage of staff and resources by carrying out practical tasks, which helps clinics to run more efficiently. These tasks include helping to count pills in the pharmacy, providing childcare for young patients visiting the clinic, or visiting homes and supporting adolescents and caregivers of children living with HIV to adopt healthy lifestyles. CHWs form part of the clinic healthcare team — they are involved in treatment support, attend team meetings, and take part in decision-making where appropriate. When CHWs are part of the healthcare team, clinics can offer more services to patients. Overall, CHWs play a very important role in encouraging patients to take good care of themselves and continue to follow their treatment. They can reach people in their homes and communities in a way that doctors and nurses at the clinics often cannot. CHWs and PSs are a central link between the clinic and the community, representing the needs and concerns of people living with HIV (PLHIV) at the clinic.

Throughout this toolkit, we refer to the term CHW generally, with the understanding that peer supporters can and should use the same information in their daily practice.

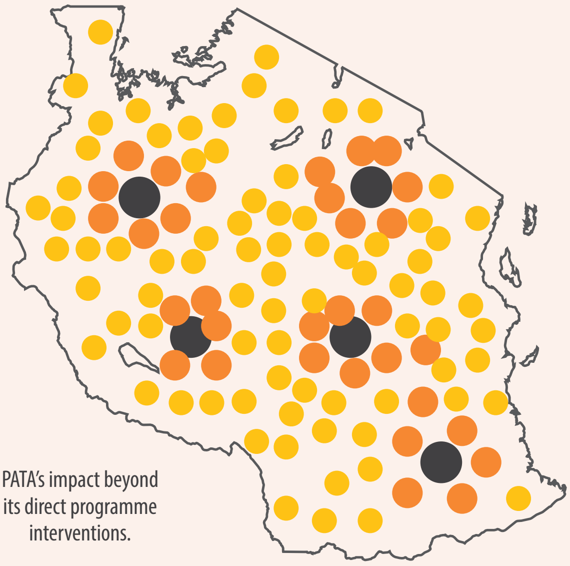
PATA and One to One Children's Fund: Expert Patients & Peer Supporters

Through the Expert Patient Programme (2007–14) and Project REACH (beginning 2015), PATA and One to One Children's Fund have worked closely with two specific types of CHWs: **Expert Patients (EPs)** and **Peer Supporters (PSs)**.

EPs are people living with or affected by HIV themselves, so they are experts in what it means to deal with HIV treatment and care. They have personally battled issues of disclosure and stigma, come to terms with the need for treatment adherence and they continue to work through their fears around living with a chronic disease. They and act as role models for positive living. The EP support model has been linked to better adherence to treatment, improved health outcomes, reduced stigma and fewer patients who stop treatment. Similarly, PSs are youth and adolescents who themselves are living with HIV, making them ideally placed to support other young people facing the same challenges.

The PATA effect

PATA's impact on paediatric and adolescent HIV care is felt far beyond the physical boundaries of its projects and programmes. PATA works with a network of committed healthcare workers and clinics throughout sub-Saharan Africa, providing them with access to leading experts and evidence-based resources, guidelines and tools to improve the paediatric and adolescent HIV care they are able to provide. These healthcare workers come together to form 'communities of practice,' sharing experiences and innovations, and supporting each other's continued improvement. The impact of the support, education and skills building they receive from PATA and their colleagues in the PATA network is felt throughout their clinics and communities in a ripple effect.



PATA's impact beyond its direct programme interventions.

PATA and One to One Children's Fund: Strengthening CHWs and PSs

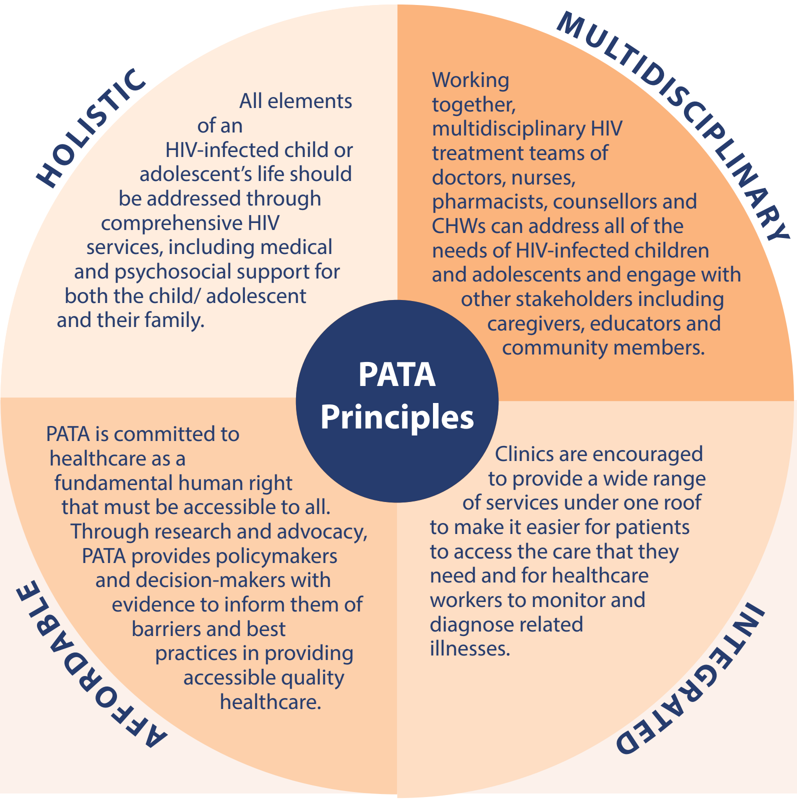
PATA works to ensure that children and adolescents living with HIV in sub-Saharan Africa have access to comprehensive, high-quality health services, including ART. We do this by working closely with healthcare teams of doctors, nurses, pharmacists, counsellors, CHWs and PSs who provide treatment and care to children and adolescents living with HIV and their families. CHWs are a key part of these healthcare teams, so PATA programmes resource, educate, support and guide them. PATA's work is child- and adolescent-focused, meaning that all of our projects and programmes aim to improve the lives of children and adolescents living with HIV.

The PATA EP Programme, in partnership with One to One Children's Fund, was started in 2007 and Project REACH in 2015 to improve the quality of care for HIV-infected children and adolescents and to involve PLHIV in the clinic as key members of treatment teams.

In order to meet the different and specific needs of each clinic, PATA does not specify the roles that EPs or PSs must fill in each clinic and/or community; instead, EPs focus broadly on practical and supportive activities in and outside of the clinic that improve identification, treatment and care of HIV-infected children and adolescents. Within this framework, it is left to each clinic to determine the activities that would be most helpful in improving care for HIV-infected children and adolescents at their facility and then apply for admission into and support from the EP Programme or Project REACH. Each clinic is responsible for recruiting, training, supervising and mentoring their EPs and PSs.

EPs and PSs are managed in accordance with the PATA EP Programme and Project REACH Handbooks, which are adopted by each clinic on admission to the applicable programme. Each EP, PS, EP Supervisor and PS Supervisor must read the handbook, understand and sign a memorandum of understanding, and ensure that EPs, PSs and their supervisors are provided with and adhere to the relevant Code of Conduct, which sets out the expectations of each of these role players.

While the EP Programme and Project REACH are specific initiatives of PATA and One to One Children's Fund, CHWs throughout the region are requesting similar information and skill building to effectively perform their important activities and play an active role in their clinics and communities. Throughout this toolkit, we refer to the term CHWs generally, with the understanding that peer supporters and expert patients can and should use the same information in their daily practice.



HOLISTIC

All elements of an HIV-infected child or adolescent's life should be addressed through comprehensive HIV services, including medical and psychosocial support for both the child/ adolescent and their family.

MULTIDISCIPLINARY

Working together, multidisciplinary HIV treatment teams of doctors, nurses, pharmacists, counsellors and CHWs can address all of the needs of HIV-infected children and adolescents and engage with other stakeholders including caregivers, educators and community members.

AFFORDABLE

PATA is committed to healthcare as a fundamental human right that must be accessible to all. Through research and advocacy, PATA provides policymakers and decision-makers with evidence to inform them of barriers and best practices in providing accessible quality healthcare.

INTEGRATED

Clinics are encouraged to provide a wide range of services under one roof to make it easier for patients to access the care that they need and for healthcare workers to monitor and diagnose related illnesses.

The PATA principles

All of PATA's work, including the EP Programme and Project REACH, is guided by a set of core principles. PATA works to ensure that all frontline healthcare workers provide high-quality HIV care that is holistic, multidisciplinary, integrated and affordable.

PATA's family-centred approach to care

While children and adolescents living with HIV are the main focus of PATA's programmes, HIV has an impact on the entire family unit. Where children are living with HIV, it is more likely that other members of the family also have the virus. However, the impact of HIV is experienced by the entire family, regardless of their HIV status. For example, having an infant with HIV can mean that caregivers have to stay home to take care of them when they are sick. When caregivers cannot work, they are not able to give their children the food they need. In general, the whole family can become more socially and economically vulnerable. A family-centred approach takes into account how HIV affects the whole family.

Since issues facing a family can be so broad, it's unlikely that one person or programme will be able to meet all of its different needs; however, a family-centred programme should always have strong communication between people in different support roles and good referral systems in place. CHWs can help caregivers to know what resources are available and how to support their HIV-infected child or adolescent in the best way possible.

Target patient groups for PATA's work

While CHWs may provide a voice for PLHIV in the healthcare system and support all groups of HIV-infected patients in care, PATA emphasises the work that CHWs do with four main target patient groups:

Pregnant and Breastfeeding Women: Pregnant and breastfeeding women who are HIV-infected need to take special precautions and be cared for in specific ways to make sure that they do not pass HIV on to their infants.

Infants and Children: Children living with HIV have unique needs in treatment and care, and must be provided with child-friendly services.

Adolescents: Young people age 1019 years face many changes during this transition from childhood to adulthood. To live a healthy and fulfilled life, their specific needs and rights should be provided for in the context of their healthcare.

Caregivers: Parents and other caregivers who look after HIV-infected children and adolescents — many of whom are HIV-infected themselves — need information and support too, to make sure they are best equipped to help the children and adolescents in their care.

Each of these groups has a different set of needs and concerns when it comes to clinical care, treatment and psychosocial support. The different parts of the toolkit highlight specific things you should think about for each of these patient groups. The chart on the next page highlights a few key interventions for these target patient groups.

Following your clinic's protocols

Each clinic operates in a different context and with different challenges and considerations that need to be taken into account. The information provided in this toolkit is a general set of guidelines, and may not be a good fit for all settings. It is important that you are up to date on your own clinic's protocols, and that you follow those protocols if they differ from what is mentioned here. You can learn more about your clinic's protocols by talking with your supervisor.

This toolkit does NOT replace other training

This toolkit provides practical tools and information that you can use to better do your job as a CHW, but it is not meant to replace other kinds of training you may need. You should use this toolkit in conversation with your supervisor and ask for additional help as you need it.

Key interventions for target patient groups

Some interventions are common across all of PATA's target groups, and others are specific to one or more groups. This is not a comprehensive list of all interventions, rather a look at some of the most common and important interventions for each group.

HIV testing and counselling and (HTC), enrolment in prevention of mother-to-child transmission (PMTCT) programmes and initiation of ART

Regular ANC and facility-assisted birth or home birth attendant trained in PMTCT

Treatment literacy, adherence counselling and adherence counselling and support

Ongoing ART and monitoring for mother

Breastfeeding education and support

Follow-up and monitoring of all HIV-infected mothers and HIV-exposed infants

Mother-to-mother support groups

Promote positive living

Promote male involvement and HTC for partners

Early infant diagnosis and high-yield paediatric HIV testing

Infant male circumcision (IMC)

Child-friendly adherence counselling and support

Recommend HTC for siblings

Initiation and monitoring of ART

Growth and nutrition monitoring

Assess and refer for Early Childhood Development (ECD) support services and ensure school enrolment

Age appropriate disclosure to child — full disclosure prior to adolescence

Sexual and reproductive health (SRH) education and services

Treatment literacy and adolescent-friendly adherence counselling and support

Adolescent-friendly services

Ongoing ART monitoring

Special services for adolescents who are pregnant and referred for PMTCT

Assistance and support in preparing for transition from paediatric into adult HIV care

Peer support through support groups and/or teen clubs

Promote positive living

Referrals to psychosocial and neurocognitive support services where required

ART and ongoing ART monitoring (if HIV-infected)

Treatment literacy for caregivers

Caregiver support groups

Promote livelihood strengthening opportunities

Promote positive living

How to Use the Toolkit

This toolkit is for use by CHWs working with children and adolescents living with HIV throughout sub-Saharan Africa. It is designed as a simple self-study learning guide with concrete examples to help you to be as effective as possible in your work. The aim is for you to be able to practice your skills in a real-world setting so that you have to take very little time away from your important work with patients. The toolkit does not include everything that a CHW should know, but provides the highlights and points out resources for further learning.

The toolkit is divided into five sections:

SECTION 1 — Effective CHWs and PSs: Information to help you to communicate well with different patient groups and the wider community, and to make positive choices, draw boundaries, and relieve stress.

SECTION 2 — Understanding HIV & AIDS: Information on what HIV is, how it is transmitted, how it can be prevented, its progression, with specific information on each of the four target patient groups.

SECTION 3 — Treatment and Care: Information to help you to provide adherence counselling, basic triage in clinics, tracking and tracing of those defaulting treatment, and nutritional and educational support.

SECTION 4 — Psychosocial Support: Information to help you to lead support groups, encourage and support disclosure, promote positive living, and educate caregivers on effective childcare strategies.

SECTION 5 — Community Outreach & Referrals: Information to help you to provide health education, promote health services, combat stigma and discrimination, and undertake advocacy, as well as ways for you to map existing resources in your community and link your patients to those resources.

In each section you will find information about the topic, as well as:

Be Aware: Things in the main text we want to call to your attention.

Key Concepts: Important information for you to know and understand.

Tools to Use: Practical tools and techniques for you to use in a particular setting.

Put it in Context: Questions for you about how a topic is dealt with in different country and clinic contexts.

Exercises: Questions and exercises to test your knowledge and understanding (answers included).

Further Reading: Links to other resources that may provide additional or more in-depth coverage of a specific topic in case you want to learn more.

A note to supervisors

CHW supervisors have a particularly difficult job: you are responsible for helping CHWs to do their jobs as best as they can, often without the necessary time or resources to help CHWs as much as they need.

This toolkit is designed as a resource and self-study guide for CHWs. At the end of each section there are a series of exercises that the CHW should complete to make sure they understand the main points.

CHWs can receive a certificate of completion upon successful completion of all exercises. To judge this, you should discuss each section's exercises and their solutions with them. Some questions do not have a specific answer, but are more about talking through the issue and sharing with you how they would approach the problem. When you are satisfied that the CHWs have completed the exercises and understand the content of the toolkit, you can issue them with the certificate of completion signed by you and another member of the clinic staff (the certificate is found in Annex 2:).

Section 1:

Effective Community Health Workers & Peer Supporters

Section 1.1: Role of Community Health Workers and Peer Supporters

CHWs play a very important role in supporting the health, care and wellbeing of children and adolescents living with HIV and their families. Depending on the setting, CHWs are referred to by different names, such as PSs, EPs, peer educators, patient advocates, accompagnateurs, or other titles. They can work within the clinic or out in the community, wherever there is a need for their help. Clinic staff work with CHWs to define exactly what is most important for each CHW to do. Some activities that CHWs often support include:

What's your role?

In every clinic and community, CHWs play different roles. The toolkit talks about many of the possible activities that CHWs may be asked to do, but depending on your clinic's resources and other staff, you may do some of the activities mentioned in this toolkit and not others. Talk with your supervisor while you're using this toolkit to make sure you know which activities you are expected to take on.

- **Clinic administration and healthcare worker support:** In the clinic, CHWs can play many roles — you many manage clinic triage, do filing, welcome patients for clinic visits, act as an interpreter, assist in the pharmacy or provide directly observed ART administration. Specific tasks that you may do to help children and adolescents in the clinic include supervising children in play areas, recording children's weight and height, and helping to make the clinic child- and adolescent-friendly and their experience a positive one. CHWs can help children, adolescents and their families to understand all of the different services available to them at the clinic and the links between these services, such as PMTCT, ANC, under-5 clinics, adolescent days and other and treatment and care services.

- **Counselling:** Dealing with an illness like HIV can be frightening, especially for children and adolescents. CHWs can play many roles in counselling, from acting as peer counsellors and leading support groups, to supporting caregivers who are learning about their own HIV status or disclosing to a child. As CHWs often understand what it is like to live with HIV in the community, you can build strong, trusting relationships with children, adolescents and their caregivers, encouraging them to share feelings, concerns and experiences, and directing them to specialised help when they need it. CHWs can also map out the psychosocial support and counselling needs of households, helping clinic staff to know which patients are facing new challenges and in need of additional support.

- **Education:** In the clinic, CHWs may conduct training sessions on nutrition, treatment adherence, infant feeding, PMTCT, disclosure and other topics. They can serve as role models to encourage positive living and healthy behaviours among patients. In the community, CHWs often visit patients' homes to provide education about the need for HIV testing and treatment, explain different aspects of treatment in simple terms that are easily understood, follow up with patients who have stopped coming to the clinic for treatment, provide gardening demonstrations, conduct community education that can help to decrease stigma and discrimination, and encourage community members to access HIV services. Since CHWs come from the communities surrounding the clinic themselves, they can provide an important link to community-based services, such as nutrition support and home-based care.

- **Advocacy:** CHWs often see, hear and understand more about what patients need and are struggling with than other members of the clinic team. Because of this, CHWs can play an important role in advocating for the needs of patients, acting as the voice for patients in clinics and beyond.

Regardless of the role that CHWs play, clinics should provide an orientation for new CHWs. You will need to know how you will be supported by the clinic staff, what you need to do to maintain your own personal safety in the workplace (hand-washing, gloves, etc.) as well as safety while in the community (encountering inappropriate behaviour, violence, etc.). You should also receive training on basic infection control, orientation to the clinic layout and an explanation of the role of clinic staff, and record keeping. If you don't receive training or information on these topics, you should ask your supervisor to discuss each of them with you.

Record keeping and reporting

Each clinic will have a different set of policies and procedures for record keeping and reporting. Your supervisor should provide you with a basic overview of what information you need to collect from patients in clinic and/or their home, as well as specific forms that you should use in different situations.

Generally, records are important because they can help us to:

- Remember things.
- Plan activities.
- See what we've done and accomplished.
- See what we can do better.
- Report to other people (like a supervisor) what we've done.
- See what the gaps are so we can fill them.
- Change the patient's plan as needed.

As a CHW, you may be asked by your supervisor to complete your own weekly or monthly report showing:

- Your activities (for example, how many support groups you've led).
- How many people you have reached through these activities (for example, how many adolescents you've counselled).
- Successes you may have had and ways you have solved problems that could be used by other CHWs.
- Challenges you may have faced and any refresher training you may need.
- Any expenses you have incurred (for example, transportation).

These reports help to show your supervisor what you've achieved and highlight areas in which you may need more support. They will help you and your supervisor to plan for the next week or month. They may also help you to follow up on specific patients from month to month. Sometimes, these reports help to show how effective CHWs can be when all of the reports are combined across your programme country.

What data do you need to collect?

You should talk with your supervisor to find out exactly what information you are expected to collect, and learn about any forms that your clinic uses to collect data.

Urgent issues need urgent attention

If an issue needs urgent attention, you should report it to your supervisor or the appropriate referral person immediately — you should not wait until your next report is due.

Understanding the CHW Code of Conduct

Each clinic should have a Code of Conduct for CHWs to sign to make sure that everyone knows what is expected. A sample Code of Conduct from PATA and One to One Children's Fund EP and REACH programmes is included in Annex 1, but some of the most important things to remember are:

- Confidentiality must be maintained at all times. Nothing that a CHW sees or hears about patients during their work may be discussed or spoken about outside of the clinic.
- CHWs must be careful not to take advantage of their position or cross inappropriate boundaries with patients. For example, sexual relationships with, or taking money from patients is not acceptable.
- Reliability and punctuality are important for CHWs. If you are unable to be present or on time for work, you will need to know whom to contact as well as how this will affect your allocated leave.
- Respectful, tactful and courteous behaviour towards other staff and patients is expected at all times.
- Honesty and trustworthiness are essential for all CHWs — there will be low tolerance of bribery or corruption.

Section 1.2: Communication Skills

A successful CHW is able to communicate well with patients. CHWs interactions with patients can greatly influence their decisions to seek and remain in care. How you approach and talk with children, adolescents and their caregivers can change the way that they think about HIV, its treatment and the clinic, and whether they continue to take their medication and come to clinic visits. Your role is to build trust with patients, find out what their needs and concerns are through active listening and asking open-ended questions, and support their decision-making with accurate information, compassion and advice.

Effective communication skills also help you to speak with patients and other members of your community so that they feel comfortable and can share their concerns with you. Knowing how to ask good questions and listen to people's answers lets you help and support your patients. People need to know that you will keep everything that they tell you confidential if they are going to open up to and share with you.

How to build trust through effective communication

Being a CHW does not mean telling people what you think they should do, or being the one with all of the answers. Instead, you should try to really understand people's problems and help them to work out themselves, with your compassion and support, the different ways they might deal with these problems. Here are seven basic skills that are practiced by good communicators:

1. **Keep things confidential:** Keeping something that a patient tells you confidential — whether they are a child, adolescent or adult — means that you do not share it with anyone else, even their caregiver. When a patient knows they can rely on you to keep the things they tell you confidential, they will trust you and speak more freely with you.

2. **Show empathy:** One of the most important things that CHWs can do to encourage trust is to try to put themselves in the shoes of their patients and imagine how they may be feeling. This is called empathy — the ability to recognise and acknowledge the feelings of others. Empathy isn't the same as feeling pity or sympathy for people (feeling sorry for them). Empathy is about understanding another person's feelings, and will help you to show true compassion. Empathy can help to encourage people to talk more about what is bothering them because they feel understood and supported. Being empathetic can be hard emotionally because it opens you up to feeling the other person's feelings — in the next section we will discuss things you can do to take care of yourself.

Children have the right to be heard

"Children have a right to information being presented in such a way to take account of their linguistic and communication needs."

— 1989 *UN Convention on the Rights of the Child.*

When children are dealing with serious illness like HIV, it can be a traumatic period of time for them with lots of fear and anxiety. Your words, actions and expressions all send messages to a child. Communicating with children takes different skills — they are not just little adults, they have different needs that require different responses. You need to learn to talk to them in language that they understand, and give them information that is appropriate for their age and level of development.

What does confidentiality look like?

Some examples of privacy and confidentiality include:

- Not talking about one patient with another patient.
- Not telling caregivers what their children or adolescents say in private discussions.
- Not telling teachers what children in their care may have shared with you.
- Not gossiping with other CHWs or clinic staff about patients except in team meetings, referrals or appropriate feedback.

There are, however, certain times when you should not keep information that a child or adolescent tells you confidential. If you are ever worried that a child or adolescent will come to harm, you must make sure to tell your supervisor immediately.

Communicating with children through touch

Touch is an infant's first language — it can give comfort and a sense of security and assurance before words are understood. Touch can build a strong relationship into childhood and adolescence, and this non-verbal communication will often lead to more open verbal communication.

It is important to be aware, however, that touch can also be misused. You should make sure to only use appropriate forms of touch with children and adolescents, and to have the caregiver's approval before hugging or cuddling a child.

Children are sensitive

Children especially react to the attitudes and feelings of those around them. You should do your best to keep your feelings of frustration, anxiety or worry out of your words and body language, and help caregivers to do the same.

3. **Don't judge:** CHWs must be respectful of different points of view, different spiritual beliefs, and different attitudes. You should be aware of your own attitudes and beliefs, and not let them interfere with providing the care that all patients deserve. Avoid judging words like 'right,' 'wrong,' 'bad,' 'good,' and 'enough.' You want to try to build the confidence of patients and give them support by focusing on their experience and the choices open to them in the future, not what they are doing 'right' or 'wrong'.

4. **Communicate without words:** What you 'say' when you are not talking is also important in building trust and making people feel comfortable with you. Your non-verbal signals (how your voice sounds, what position your body is in, for example) tell patients what you are thinking or feeling underneath your words. Children especially respond strongly to our tone of voice, body language and other forms of non-verbal communication. You should take care to send the right message by:

    - Making eye contact.
    - Facing the person to whom you are listening.
    - Being relaxed and open with your posture.
    - Nodding your head.
    - Leaning forward.
    - Smiling, when appropriate.
    - Focusing on the person you are talking to, rather than looking at your watch, the clock, or anything else.
    - Turning your mobile phone off.

5. **Reflect:** To show someone that you have been listening and check if you really understand them, you can repeat back or summarise what they have said, or say it back in a slightly different way. For example, if the patient says "I am scared that someone will find out that I have HIV" you could say "It seems like you are nervous about people knowing your status. Let's talk about that some more."

Reflect

Reflecting back what someone has said shows that you really understand what they are saying. Some helpful phrases you can use to reflect include:

6. **Listen actively:** To show the person you are talking to that you are really listening to and hearing what they are saying, you should practise active listening. Active listeners do the following:

    - Show the person you are listening by saying things like "ok" or "mmm hmmm."
    - Listen to the content of what the person is saying — are there themes or patterns that are being repeated?
    - Listen to how they are saying it — do they seem worried, angry or shy for example?
    - Allow the person to express their emotions — for example if they are crying, allow them time to cry.
    - Keep distractions to a minimum and find a private place to talk.
    - Don't do other tasks while listening.
    - Don't interrupt.
    - Ask questions or gently probe if you would like more information.

7. **Ask open-ended questions:** Open-ended questions are questions such as "Tell me about…" or "What is it like when…" that start discussions, while closed questions are questions such as "Did you do…" or "Did you want…" that can only get a one word or short answer. Asking open-ended questions gives you the chance to hear more about people's fears, concerns and motivations, and better understand what lies behind them.

closed questions	open-ended questions
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you relieve stress or anger?
Did your partner get tested?	How would you feel about asking your partner to get tested?
Do you want to have children in the future?	How do you feel about having a bigger family?
Do you have someone you can talk with about taking your medicines?	Tell me more about the people you have disclosed to and how they could help you remember to take your medicines.
Do you know how to prevent transmission of HIV to your infant?	Can you tell me what you understand about ways you can protect your infant from HIV?
Do you exclusively breastfeed the infant?	Can you tell me about what you fed the infant yesterday?

Asking open-ended questions

Closed questions will only get you a short answer. To get more information, make sure you are asking open-ended questions, like the ones above.

— Information in this section is adapted in part from Catholic Relief Services (CRS), *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi*, 2011.

Communicating effectively with target patient groups

CHWs need to communicate effectively with children and adolescents living with HIV as well as their families. Communication starts from the first time you have contact, and continues throughout the treatment process. For each of the target patient groups, there are different issues that you should consider and best ways of communicating.

Communicating with pregnant and breastfeeding women

Pregnant and breastfeeding women must understand the risks associated with passing HIV on to their infants, and how they can prevent the spread of the disease. Your role is to help them to know their own status and make decisions regarding their treatment that will reduce as much as possible the risk of passing HIV on to their infants.

Many pregnant women may not even know that they have HIV, and feelings of guilt or shame or fear of disclosing to their partner may keep them from getting tested. They should be helped to understand why they should get tested, that passing HIV on to their infant can be prevented, and that both mother and infant can stay healthy if they know early enough and take the right precautions, including getting treatment.

Principles for communicating with children

Depending on the age of the child, you may communicate differently and use different tools to help them to open up. However, there are some basic principles that you should use when communicating with children of all ages:

- **Honesty:** You should be careful not to lie to a child. It can add to a child's anxiety if they find out, but also destroy the child's trust in you. Keep your communication short and simple but always truthful.
- **Respect:** Do not ignore, dismiss or judge a child's viewpoints or feelings. You should give children the space to express their feelings, even if you don't agree with these feelings or they are uncomfortable to discuss.
- **Participation:** Children should be involved in their own care, be encouraged to learn about their illness, and be supported to make decisions where appropriate. You should always speak with the child, and not to the child.

Communicating with children

It is important to talk to children about their health and HIV, even though it can be difficult. We find it hard to communicate effectively with children for a number of reasons:

- **We use the wrong words:** If we use adult language to explain things to children, they will not really understand what we are trying to tell them. We need to use language that is at the appropriate level for the child.

- **We assume children can't understand:** When we assume that children are too young to understand complicated things, we may communicate with caregivers only. The truth is, children can understand a lot more than we give them credit for if it is communicated at their level.

- **We want to protect them:** It is natural for adults to want to protect children from all worries, but this can sometimes make the situation worse. Children can often sense if something is not right, and may start to imagine realities that are worse than the truth. Children are resilient if they have loving, attentive caregivers to support them.

To best communicate with a child, you should build a trusting relationship from the beginning of a visit. Starting a visit with a warm greeting and a discussion about an easy, non-threatening topic can help to get the conversation going. Depending on the age of the child, different ways of interacting work best. Some young children might need their caregivers present to feel more secure. Very young children don't always have the language or awareness to express their feelings in words. With them, it is better to use non-verbal tools like drawing and playing.

Many children find it easier to talk about things that are not related to their illness. Sometimes telling stories or doing role plays about something unrelated will actually show you a lot about what they are thinking and feeling about the illness too. You might notice specific themes that come out, such as fear of others finding out their HIV status and rejection and concerns about their own health or the health of their caregivers. Although not all children feel the same about their illnesses, some feelings are common. Denial is often a first reaction, and children may tell themselves that everything is fine and that nothing has changed. Anger is another common response, including self-anger and self-blame, or anger directed at other people they might feel are responsible. Once you understand what children are thinking and feeling, you can help their caregivers communicate with them effectively and provide them with the support that they need.

Feeling cards or pictures can help children to learn new words to describe and understand their feelings. Draw faces on a piece of paper (or ask the child to draw faces) that show anger, fear, sadness, happiness and other feelings. Talk with the child about the faces, asking them about the sorts of situations that could make children experience the feelings.

Role-play and drama let children pretend to be someone else and act out situations that they might otherwise not be comfortable talking about. You can ask them questions about the characters they are playing, and take note of feelings and ideas that come up.

Drawing helps children to express themselves without having to use words. You should encourage the child to use crayons, pens, pencils or whatever materials you have available to draw something related to what you want to talk to them about, e.g. what makes them angry. Use open-ended questions to ask them about the drawing, checking your understanding with them as you go. The drawing can form the basis for your conversation.

Storytelling helps children to talk about themselves in a non-threatening way, and can help you support them to solve a problem. You can use a story with made-up characters or animals to convey a message to the child. Afterwards, ask the child to talk about what happened in the story, and link it to the child's experience where appropriate. You can also encourage children to tell their own stories by asking a question like "Tell me a story about a boy who was feeling very angry."

Tools for communicating with children

There are many tools that you can use to communicate with children, especially those who are too young to express themselves well in words. Caregivers should also be encouraged to use these tools with their children.

— adapted from Regional Psychosocial Support Initiative (REPSSI), *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Communicating with a child

What works?

Get down to the child's eye level: Let the child see your eyes and read your intentions.

Speak softly and directly to the child: Children respond better when you address them rather than just the caregiver.

Smile and play : A smiling face makes a big difference and will help to improve your interaction with the child. Remember that for young children, play is very important. If they leave the visit laughing, they will look forward to coming back.

Be honest: Telling the child the truth will build confidence for future clinic visits and develop a relationship built on trust.

Allow and respect normal emotions: Sadness and crying are okay and so is anger – be patient with the child.

Start with the least invasive activity: If you need to examine a child who is anxious, keep the child on the caregiver's lap as much as possible and don't start with painful or invasive activities such as ear examinations or blood draws.

Offer the child choices: Choices provide a sense of control. Let the child choose whether you measure their height or weight first, or whether to have juice or water with medication.

Engage with the child: Talk about things of interest to the child, such as school, friends or hobbies.

Support the caregiver/child relationship: Caregivers are experts on the children in their care, so involve and engage them as you look to understand the child.

Adapted from PATA's "Child-friendly Clinician" poster

What doesn't?

Avoid comparing the child to others: Each child is an individual with unique strengths and weaknesses. Comparing a child with others who are adhering well for instance will do more to damage self-esteem than motivate. Children do the best they can, and making them feel inadequate will not help build a good relationship.

Be mindful when you touch the child: Physical affection may build connection, and you might need to examine the child for medical reasons, but the child should never be made to feel uncomfortable and touch should always be respectful of the child as owner of his or her own body.

Don't forget the child is in the room: If you want to have a private conversation with the caregiver, make a separate time or create a separate space. This is especially important when discussing disclosure. Children always understand more than we think.

Don't pity: Children need love, support and care, but not pity.

Don't treat older children like infants: Treat the child appropriately for their age and respect their level of understanding and maturity.

Respect children's different upbringings: Approaches to child rearing and discipline differ by family, and there are many ways to raise children that will lead to good results. As long as caregivers meet the needs of the children in their care, and treat them with love and respect, don't judge caregiver styles that differ from your own background.

Don't use your position to build fear in the child: We know that children often feel fear and anxiety when attending clinic visits and interacting with healthcare workers. Helping the child to feel comfortable at the clinic and in your interactions will build trust and confidence.

Communicating with adolescents

Adolescents are a special patient group and have unique communication needs. They are no longer children but not yet adults, and they need high-quality care and support at this critical time. Some of the concerns that adolescents living with HIV might have include:

- Fear of disclosing their HIV status, and dealing with stigma and discrimination from family and friends.
- Issues related to losing their parents or caregivers, such as living on their own or taking care of younger siblings.
- How HIV might impact their physical appearance.
- Dealing with dating, relationships, safe sex options, and reproductive choices.
- Issues of HIV status at school and unwanted disclosure.

The period of adolescence is long and filled with many changes — a child at age 10 years thinks and behaves very differently than he or she will at age 18 years. Here are some communication principles that are common across the adolescent years:

- **Trust:** Trust is very important when working with adolescents. Adolescents tend to take time to build trust with healthcare workers, and these trusting relationships are critical to adolescents' outcomes and wellbeing. When adolescents feel supported, they are able to develop their own inner resources including strong personal identity, purpose in life, independence, responsibility, and the ability to overcome challenging times. You should never lie to an adolescent, or you will lose their trust.

- **Confidentiality:** You should explain confidentiality and its limits — if an adolescent tells you something that is confidential it should remain confidential, but there may be situations where it is necessary to involve a caregiver, such as if the adolescent threatens to harm themselves or others. If an issue arises that you think would be important to discuss with a caregiver, ask permission from the adolescent first wherever possible, and only go to the caregiver without that permission in an urgent situation.

- **Participation:** Getting the adolescent involved in conversations and decisions as much as possible will build their trust and make communication more effective. Ask for their ideas, give them feedback, encourage questions and explain processes wherever possible. Be approachable, and allow the adolescent to educate you about themselves, asking them things like, "Have I understood what you are saying?"

Tips for fostering good communication with adolescents

- Consider each adolescent as an individual and take the time to understand him or her.
- Be direct and use clear, jargon-free language.
- Avoid giving direct or unrequested advice.
- Encourage their own ability to take responsibility for decisions.
- Use an interactive, participatory style of communication.
- Give feedback and ask for ideas.
- Encourage questions and explain processes.
- Accept the adolescent and avoid being judgemental.

— adapted from African Network for Care of Children Affected by HIV/AIDS (ANECCA), *Handbook on Paediatric AIDS in Africa*, 2011.

You should work to build a relationship with the adolescent, rather than just the caregiver. Make sure to take an interest in the adolescent and not just their illness, and build a solid relationship before starting to talk about the hardest topics. Adolescents may resist authority figures, so you should be non-judgemental and avoid telling them what to do. Your role is to listen to and support them to make the best decisions possible for themselves. It is still important, however, to involve the caregiver in your work, especially to help to improve the communication between the adolescent and their caregiver. Caregivers may need support in learning how to talk with adolescents in ways that are not undermining. Caregivers who have spent so much of their lives trying to increase the chances of their children's survival might have a particularly hard time letting them have the space they need to grow up and make their own decisions.

General characteristics of adolescent development

Age	Emotional Development	Cognitive Development	Relationship with Peers	Relationship with Family
Early Adolescence (10 –13 years)	• Wide mood swings • Intense feelings • Low impulse control	• Concrete thinking • Little ability to anticipate long-term consequences of their actions • Literal interpretation of ideas	• Increased importance and intensity of peer relationships	• Need for privacy
Mid Adolescence (14–16 years)	• Sense of invulnerability • Risk-taking behaviour peaks	• Able to conceptualise abstract ideas such as love, justice, truth and spirituality	• Peak of peer conformity • Increased sexual relations	• Peak of parental conflict • Rejection of parental values
Late Adolescence (17–19 years)	• Sense of responsibility for one's health and wellbeing • Increasing sense of vulnerability • Able to think of others and suppress own needs • Less risk-taking	• Formal operational thought and improved decision-making • Increased understanding of the possible consequences of various actions • Ability to understand and set limits • Can understand other's thoughts and feelings	• Peers decrease in importance • Begin to develop mutually supportive, mature, intimate relationships	• Improved communication • More acceptance of parental values

— adapted from ANECCA, *Handbook on Paediatric AIDS in Africa*, 2011.

Communicating with Caregivers

It is very important for CHWs to help strengthen the relationship and communication between caregivers and children or adolescents, as this will make treatment and care easier and more effective. The younger the child, the more dependent they are on their caregivers. CHWs should help caregivers in their role of supporting the child or adolescents.

Caregivers face a few common issues that you can help them to deal with, including:

- Incorrect information and beliefs about HIV and AIDS.
- Denial of their own HIV status.
- Feelings of responsibility for the child or adolescent's infection.
- Feelings connected with disclosing his/her own HIV status.
- Anxiety about their own morbidity and future plans for their children.
- Financial concerns.
- Concerns about disclosing a child's status to the child or the broader community.

When you communicate with caregivers, you should remember that they may also be living with HIV, and may have the added burden of their own illness. Helping a caregiver to deal with issues related to their own illness may be important in order to support them in caring for their children or adolescents.

Caregivers of adolescents need special support to help them to communicate well. Strong levels of communication between caregivers and adolescents help to improve the choices adolescents make about their treatment and health. Although adolescents may want to meet with CHWs and healthcare workers on their own without caregivers, it is still important to remember that they need the support of their caregivers as trusted allies.

Helping caregivers learn from each other

You may find that a caregiver is burdened with their own HIV disease and its effects, which impacts the support they are able to offer the child. CHWs can help to organise one-on-one meetings or support groups between caregivers they are working with to break down isolation, and create support between those in similar situations. As caregivers hear stories from other caregivers about disclosing HIV status to their children and helping them to manage their illness, they may be better equipped to support their own children. You can also use these support groups to teach caregivers more about looking after themselves and their children.

Confidentiality is key

All target patient groups may be sensitive about the subject of their HIV status. Some people may even be afraid to seek or treatment for fear that others may find out and judge them. CHWs must keep all patient information confidential and not share it with patients' family or community members. Assure patients that their treatment and care information might be discussed among clinic staff, but would not be shared beyond those who need to know in order to provide care and support. Respecting the patient's privacy is very important to building trust and encouraging them to open up to you.

Section 1.3: Taking care of yourself

As a CHW, you form an important part of the support network for children and adolescents living with HIV and their caregivers. You are there for them in many ways, listening to their stories, concerns and worries. Especially when times are tough, it is easy for a CHW to take on too much, making their patients' problems their own, sympathising and worrying along with them. When you see patients having an especially hard time, you may wish you could do more to help.

It is important to remember that if you do not take care of yourself both mentally and physically, you won't be able to help anyone else well. Knowing the boundaries of what you can and can't help with as a CHW and living positively yourself will help you to take good care of yourself.

Knowing the role of CHWs and setting boundaries

While it is natural to want to help your patients to solve all of their problems, it is important to know when an issue falls outside of your role as a CHW. When we set boundaries, we protect ourselves by knowing when we should say no. We need to understand that it is not selfish to draw lines around what we can and cannot do. It is in fact a very important way that you can take care of yourself and make sure that you stay healthy and can help others in the future.

When you first become a CHW, you should discuss with your supervisor and other clinic staff what role you are expected to play. You should have a clear understanding of what tasks you are responsible for, and what tasks are outside of your responsibility. One CHW's responsibilities may be very different from another's, depending on the needs of a clinic or community.

Once you know what your role is, you should begin to set boundaries. This could include things like telling patients when you are and are not available to them — working in the same community in which you live can mean people feel able to reach you any time of the day, which can be emotionally and physically exhausting. Another way you can set boundaries around your role is to know what other resources are available to them. CHWs are only one part of a larger network of carers — you cannot help your patients with everything by yourself. You need to be able to tell patients what your role is, what they can go to the clinic for, and when they need to be referred elsewhere for help (see Section 5 for more information on referral networks).

Peer support groups for adolescents

Adolescents need a balance between structure and freedom to express their feelings and gain stability. While some of the tools you use with younger children, like role play, can also be useful, adolescents often prefer to talk about issues in a group of others their own age.

Peer support groups bring together adolescents of a similar age who are going through similar issues — dealing with disclosure, perhaps loss of loved ones and difficulties with treatment, amongst others. Support groups and teen clubs can be especially helpful for adolescents, as they offer the opportunity to exchange views and experiences, and can break the isolation that adolescents living with HIV may face. The clubs can include activities like sport, drama, arts and crafts, as well as train adolescents to become peer counsellors, supporters or educators themselves.

Emotional and psychological self-care

Stress is a physical and emotional response to a new or difficult situation. Certain situations are more stressful than others, and a small amount of stress is completely normal in life. Being a CHW is a very stressful role. As you try to help patients through their difficult times it is easy to take their stress yourself. If you are constantly stressed in your role as a CHW, you may start to feel like you have no energy or become sick more often, as stress weakens your body's immune system, and you may not be able to fight off illness or recover as quickly. If you are exposed to stress over a long period of time, you can 'burn out', which means to feel exhausted, depressed and disinterested in work that used to be fulfilling for you.

You can feel stress in a number of different ways:

- **Physical** — for example, tiredness and exhaustion.
- **Emotional** — for example, anxiety, depression and mood changes.
- **Cognitive** — for example, poor concentration.
- **Behavioural** — for example, missing work frequently and decreased work effectiveness and productivity.
- **Spiritual** — for example, increased or decreased interest in religion.

People cope with stress in very different ways — what is stressful for one person may not be as stressful for another. In the same way that you advise your patients to look after themselves and find help and support, you yourself need to find ways of dealing with stress that work for you. Some ways of managing stress that some people find helpful are outlined on the next page:

Stress and fatigue checklist

This fatigue checklist can help you to assess how well you are coping with the everyday stress of your job. If you answer 'always' or 'often' to some of the questions, talk with your supervisor about what you can change to help you to deal better with stress and be healthier.

-adapted from AIDS Response, *Train the Trainers Manual: A guide to setting up a Care for Carers Program*, 2011.

	Always	Often	Sometimes	Never
Do you feel moody and have a hard time getting up in the morning?				
Do you have trouble remembering things and concentrating?				
Do you find yourself wanting to avoid being with people?				
Are you more impatient, irritable, nervous, angry or anxious than normal?				
Do you have little energy or find it hard to stay awake?				
Do you feel like you have the flu, or have frequent headaches, fevers, or swollen glands?				
Are you less active than you were before?				

- **Talking and sharing experiences:** A CHW support group, activity, meeting or network can be a great way to share your experience with people who are in the same situation as you. Other clinic staff might also understand what you are going through. Debriefing, or talking through your work with your supervisor, is another way you can share your experiences and lighten your burden.

- **Time away from your responsibilities:** You need time to yourself, away from your work as a CHW. You should not be available to your patients all of the time. If patients come to you when you are not working, you should try to encourage them to visit the clinic or a carer that is working, or come back to you when you are next working. You need to take time off to relax and do things for yourself, so that you have the energy that you need to help your patients when you are working.

- **Physical activity:** Walking, sports or other physical activities reduce stress by helping you to clear your head and letting off feel-good brain chemicals called endorphins.

- **Breathing or meditation exercises:** Deep breathing helps to release stress, processing the feelings that you experience on a daily basis. Meditation also helps you to relax just by taking time out during your day to breathe deeply and sit in stillness for a few moments, whenever you can.

- **Prayer or other spiritual outlets:** Your religion might also be an outlet for you to talk about your feelings and get support to relieve the stress you may be feeling. Other spiritual outlets could include spending time in nature, meditation, or simply being present in the moment.

Fingerholds

Fingerholds are one tool you can use to cope with strong emotions. When we are in a crisis, we may experience a rush of emotions and feelings. We sometimes try to ignore our feelings and they can later come out as a headache, sore shoulders or stiff neck for example. This exercise is used in the Indonesian culture to release and balance strong emotions. It doesn't change the reality of the situation you are in, but it can change how you respond to the situation, so that you are not controlled or overwhelmed by the emotion.

To do this exercise, hold a finger of your opposite hand for 2–5 minutes, breathing deeply, until you feel a steady, rhythmic pulse. This helps to move blocked energy and bring a sense of balance and harmony to your body. When you breathe in, acknowledge the feelings and emotions you are holding inside yourself, letting them go as you breathe out. Each finger relates to a different emotion. You can hold each finger in turn at the start or end of the day to clear the emotions, or only hold one finger as you feel the need.

— adapted from AIDS Response, *Train the Trainers Manual: A guide to setting up a Care for Carers Program*, 2011.

Feeling like you are a part of a larger team can be very helpful in dealing with stress and anxiety. One of the most important relationships you can build is with your supervisor. Supervisors are there to give you support as you do your job, and to help you to find additional help if you need it. You should have a regular meeting scheduled with your supervisor to debrief, or talk through, what you have seen and heard, how you are coping, and what you need to do your job well. Your supervisor should also make sure you feel part of the team — having a good relationship with others on your team can be very helpful when you need to talk or share with others. If you are new to the healthcare team or don't know the other people well, talk with your supervisor about taking time to do some team-building activities together.

Physical self-care

In addition to taking care of yourself emotionally, it is also very important to take care of yourself physically to be the best CHW you can be. Many CHWs are living with HIV themselves, and if they are sick or weak they cannot take good care of others. You need to follow the same advice that you give your patients about positive, healthily living:

- **Eat well:** The food that you eat plays an important role in your health and energy. Eating nutritious, good food is the most basic way to care for your health and wellbeing and ultimately, to be a better carer. Eat a balanced diet of foods from all of the food groups; eat regularly and enough; take supplemental vitamins; and avoid drugs and alcohol (see Section 3 for more information on nutrition).

- **Exercise:** Physical activity isn't only good for your emotional wellbeing, it also helps your body to stay strong and healthy.

- **Avoid opportunistic infections:** CHWs are exposed to more infections than other people, as you may often be in contact people who have illnesses such as Tuberculosis (TB) that can be highly contagious. If you are living with HIV, your immune system may not be as able to fight off these infections, so you should be careful. While you wouldn't turn away from helping someone who is sick, it is important that you take care to protect yourself well. Wear masks and gloves when they are needed and available, and avoid contact with bodily fluids if possible (see Section 3 for more information on opportunistic infections).

- **Be aware of other risks:** Since you often work in the community and visit patients in their homes, CHWs can face more risks than other health workers, including crime, assault, and even rape. You need to make sure you do what you can to protect yourself — don't go to places where you feel unsafe, and if there are places or people in the community that make you feel uncomfortable, speak with your supervisor about what you can do to avoid them or get support for these visits such as another CHW to do these visits with you.

Deep breathing as stress relief

One of the human body's natural stress management solutions is deep breathing. When we are feeling stressed or anxious, our body's natural reaction is to breathe quickly and not very deeply. If we want to relax, all we need to do is make a conscious effort to slow down our breathing and take deeper, longer breaths. By doing this, we turn off the 'fight-or-flight' stress response and activate our body's natural 'rest and digest' relaxation response. This reduces your stress hormones as well as reduces your heart rate and blood pressure. Here are two exercises that you can use to easily relieve stress on a daily basis:

Exercise 1: Deep Breathing

1. Start by exhaling all of the air out of your lungs through your mouth.
2. Close your mouth (and keep it closed for the rest of the exercise).
3. Breathe in through your nose while slowly counting "1–2–3–4" to yourself silently in your head.
4. Then slowly breathe the air out through your nose for another silent count of "1–2–3–4".
5. Repeat steps 3 and 4 above three more times so that in total you are taking four slow, deep breaths.

Tip: *When you are doing your deep breathing exercises, make sure that your belly is expanding and filling up with air (not just your chest). Put one hand on your belly while you do your breathing exercises to make sure you are doing this.*

Exercise 2: Left Nostril Breathing

1. Start by exhaling all of the air out of your lungs through your mouth.
2. Close your mouth and use the thumb on your right hand to cover your right nostril (keep your mouth and right nostril closed for the rest of the exercise).
3. Breathe in through your left nostril while slowly counting "1–2–3–4" to yourself silently in your head.
4. Then slowly breathe the air out through your left nostril for another silent count of "1–2–3–4".
5. Repeat steps 3 and 4 above three more times to that in total you are taking four slow, deep breaths through your left nostril.

Tip: *Left nostril breathing activates the part of your nervous system which helps our bodies slow down and relax. If you are feeling tired and want more energy, you can do the same exercise breathing through your right nostril instead (this has the opposite effect and stimulates the body).*

Laughter as stress relief

Research has shown that laughter lowers the level of stress hormones in our blood and brings more oxygen into the body which has many benefits. Laughter also helps to create a positive mental state when you are facing stressful situations.

Exercise 1: Breathing and Laughing

1. Start by exhaling all of the air out of your lungs through your mouth.
2. Close your mouth.
3. Take a slow, deep breath in through your nose, and then let out the air by slowly exhaling through your nose. Repeat this step two more times.
4. Take a slow deep breath in through your nose, and then let out the air by exhaling while laughing with your mouth open and saying "ha-ha-ha-ha-ha" out loud. Repeat this step two more times.

Exercise 2: Laughing Doing Something You Don't Enjoy

You can choose to laugh at any moment, even if there is nothing funny to laugh at. One useful technique to relieve stress is to laugh while doing something you find to be boring or stressful. For example, laugh while you are cleaning or washing your clothes, or before doing something that you are afraid of doing. This will make it easier for you to enjoy these otherwise boring or stressful situations and improve your mood.

Tip: *To get the full health benefits of laughter, make sure that you are laughing from deep in your belly and with your whole body and not just your face.*

Exercises for Section 1: Effective Community Health Workers and Peer Supporters

Key take away messages:

- **Communication that is supportive and non-judgmental is key to effectively interacting with patients, especially children and adolescents.**
- **Effective self-care means you are better able to be a positive role model and provide care and support.**

Questions:

1. With another CHW, role play a conversation about a topic (such as breastfeeding, disclosing your status to your child, talking to a child about taking their medicines, or talking to an adolescent about sexual health). Take turns being the CHW and the patient, and use active listening, asking open-ended questions, good body language, and other skills during your conversation. Rate each other on how well you did after the role play, making suggestions about what might have made the patient open up more.

2. Have a group discussion with other CHWs about how you communicate with children using different tools in the clinic or during a home visit (drawing, role play, storytelling, feeling cards, play, etc.). Talk with your supervisor to make a plan to use some of these tools during your next home visits — decide which children you will work with and what issues you want to try to address. Report back to your supervisor after you've used the tools.

3. Talk with your supervisor about how you are feeling. Are you tired? Anxious? Worried? How does this affect the work that you do? How much of it is caused by your work, and how much from things outside of work? Together come up with a plan of how you can feel better and be more effective at work and home — it might include time in your day to talk with other CHWs about an especially difficult issue you might be facing, taking a few moments every day to meditate or pray, or coming up with better ways to draw boundaries.

Further reading on being an effective CHW or PS

Want to learn more? The resources below served as references for the information presented in this section, and are a great source for more in-depth information on the topics covered here. For even more resources, see Annex 3.

Roles and responsibilities of CHWs

- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.
- Partners in Health (PIH), *Accompagnateur's Handbook*, 2012.
- South African National Department of Health, *Psychosocial Support for Children and Adolescents Infected and Affected by HIV*, 2012.

Communication skills

- AIDSTAR-One, *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*, 2014.
- ANECCA, *Handbook on Paediatric AIDS in Africa*, 2011.
- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi*, 2011.
- International HIV/AIDS Alliance, *A Parrot on you Shoulder: A guide to working with orphans and vulnerable children*, 2004.
- International HIV/AIDS Alliance, *Good Practice Guide: Family-Centred HIV programming for children*, 2012.
- PIH, *Accompagnateur's Handbook*, 2012.
- REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.
- REPSSI, *Psychosocial Care and Support for Young Children and Infants in the Time of HIV and AIDS — A Resource for Programming*, 2007.

Basic self-care for CHWs

- AIDS Response, *Train the Trainers Manual: A guide for setting up a care for carers programme*, 2011.
- PIH, *Accompagnateur's Handbook*, 2012.
- World Health Organization (WHO, *Flipchart for Patient Education: HIV Prevention Education and Care*, 2006.

Ideas and strategies for stress relief include:

- Antares Foundation offers resources and guidance on stress management, www.antaresfoundation.org.
- Headington Institute offers free online training and resources to support humanitarian workers with issues around stress, burnout, and resilience, amongst others, www.headington-institute.org.

Section 2:

Understanding HIV & AIDS

Section 2.1: HIV Basics

HIV (human immunodeficiency virus) is a virus that multiplies in the body and destroys the immune system. People can have HIV for years without showing any signs or symptoms, but they can still pass the virus to others. In the body, the virus enters vital immune cells, a kind of white blood cell, called CD4 cells (sometimes called 'T-cells'). CD4 cells are the part of the immune system that keeps you strong and helps you to fight off disease.

If HIV multiplies in the body, CD4 cells are reduced and the body becomes too weak to fight back. The person becomes tired, weak and sick, getting illnesses and opportunistic infections that take advantage of a weak body to make you sick, like TB or hepatitis (see Section 3 for more information about opportunistic infections). When the immune system becomes too weak and the person becomes very sick with an illness, or their CD4 count drops below a certain level, they have developed AIDS.

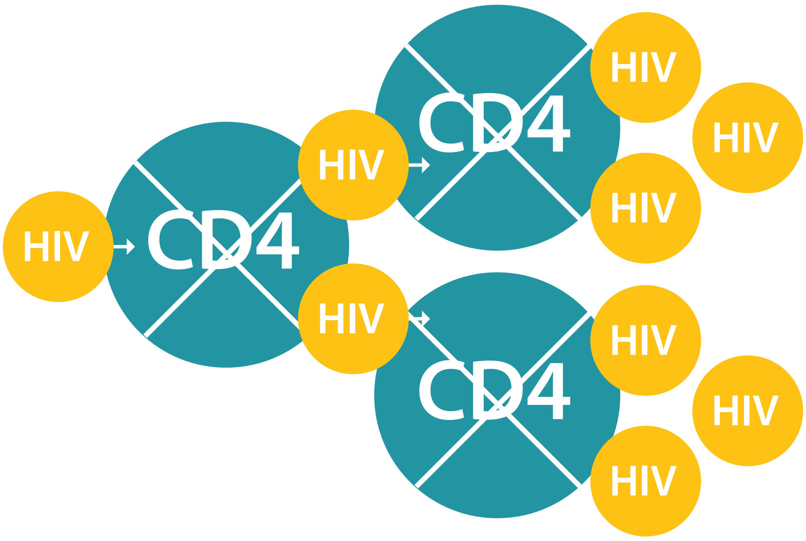
What is a CD4 count and why Is it important?

A CD4 test is a laboratory or point of care test that counts the number of CD4 cells in a blood sample to see how much HIV has attacked the system. If the CD4 count is low, it means the body's immune system weak. The higher the CD4 count the better. An increased CD4 count is also a way that you can tell if ART is working.

How HIV works

CD4 cells control your immune system and help to fight off disease. When HIV enters the body, it invades CD4 cells, copying itself and destroying the cell in the process. The more HIV attacks CD4 cells, the more it is able to multiply. The fewer CD4 cells your body has, the less able it is to fight off illness.

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.



Disease progression: From HIV to AIDS

There are 4 stages of the progression of the disease from HIV to AIDS:

1. **Asymptomatic HIV infection:** The virus enters the body but the person doesn't have any major symptoms and feels healthy. This stage could last for years and is dangerous because if a person does not know they have HIV they could easily pass it on to others. In children, this stage is usually much shorter, and they become sicker more quickly.

2. **Early symptoms of HIV infection:** A person might still feel healthy most of the time, but may start to lose weight and get sick more often (for example, respiratory or skin infections) as their immune system gets weaker.

3. **Symptomatic HIV infection, or AIDS:** The amount of virus in the body rises and the CD4 count drops, showing that the body's immune system is being attacked and destroyed. When this happens, the person's body is unable to fight off germs and they might develop opportunistic infections (see Section 3 for more information on opportunistic infections) and be unable to get rid of them.

4. **Late-stage AIDS:** As the body's immune system is destroyed, the body gets weaker and weaker, and the person become even sicker. If not treated, the person could die.

You cannot tell if a person has HIV just by looking at them. Some people may have HIV for years without experiencing any symptoms, but can still have the virus and pass it on to others. A person only knows whether they have been infected with HIV by getting an HIV test.

Medical male circumcision as an HIV preventative measure

Medical male circumcision is when a trained health professional surgically removes the foreskin — the retractable fold of tissue that covers the head of the penis — which is highly susceptible to HIV infection. It has been shown to reduce the risk of female-to-male sexual transmission of HIV by approximately 60%. Circumcision alone can't prevent HIV, however. It is still very important for partners to know their HIV status, correctly use condoms every time they have sex, and get tested and treated for any sexually transmitted infections to most effectively protect against spreading HIV.

— adapted from WHO, *Fact Sheet: Medical Male Circumcision in Preventing HIV.*

HIV progression in infants and children

Because infants' and children's immune systems are not yet fully developed, the progression from HIV to AIDS can happen much faster for them. They may get the same common childhood illnesses as HIV-negative children, but may not be able to fight these infections as well. Because of this, there are different treatment guidelines for children than there are for adults. The WHO recommends that all children under five years old be treated with ART regardless of how sick they are, but make sure to learn and follow your clinic's protocols related to HIV treatment.

Adolescents with HIV

Adolescents can either get HIV in the womb or as infants from their mothers, or through their own behaviour (such as sexual activity or drug use). CHWs should take into account the way that an adolescent contracted HIV when making decisions on how best to provide support, as adolescents who were born with or contracted HIV early on may require different approaches to those who contracted it later in life.

Section 2.2: How HIV is spread

Anyone can get HIV. HIV lives in blood, semen, vaginal fluids, and breastmilk, so the virus can pass from one person's body to another through any of these activities:

- **Sex:** HIV can be transmitted through sex — including oral, vaginal and anal sex — with someone who has HIV. This includes sex between men and women and between men and men.
- **From mother to child:** HIV can be transmitted from an HIV-infected mother to her infant through pregnancy, childbirth, and breastfeeding.
- **Bleeding or open wounds:** If an HIV-positive person has an open wound or is bleeding and you get that blood into your body, you can get HIV.
- **Sharing needles or razors:** If you share a needle or razor blade with someone who has HIV, you can get HIV.
- **Blood transfusions:** More rarely, you could get HIV from a blood transfusion at the hospital, but that is very unlikely because blood is now checked for HIV before it is used for transfusions

Post-exposure prophylaxis (PEP)

Violence against women (physical, sexual and emotional) increases their vulnerability to HIV. If someone has been sexually assaulted, one tool they can use to prevent HIV is to take PEP. PEP is a strong course of ART that can be taken just after exposure to HIV to prevent the person from getting HIV. It must be taken as soon as possible, no later than 72 hours after exposure. It is not 100% effective, so it is not a substitute for other prevention tools like condoms, but it can be used in an emergency. Find out what the protocols are in your clinic, and if and where PEP is available in your area. If you know a person has been sexually assaulted, help them to get to the nearest clinic as soon as possible to get access.

I can be cured from HIV if I have sex with a virgin".

Having sex with a virgin CANNOT cure HIV.

"I can get HIV from being around people who are HIV+".

HIV CANNOT be transmitted by hugging, living with, sitting next to, shaking hands with, kissing, eating with or sharing food or eating utensils with someone who has HIV.

"I have HIV, my life is over".

Your life is NOT over! If you get treatment and take care of yourself, you can live a long and productive life.

"Traditional medicine can cure HIV".

Traditional healers and holy water CANNOT cure HIV.

"If I'm getting treatment, I can't spread HIV".

Treatment CANNOT completely cure HIV. You must still practice safe sex to make sure you do'nt pass the virus on.

"I can get HIV from mosquitos".

HIV CANNOT be transmitted by having contact with animals, or being bitten by a mosquito.

HIV myths

There are MANY myths about how HIV can be spread, these are just a few. Make sure that you know exactly how HIV is spread so you can help the community to combat stigma and make sure your patients aren't discriminated against.

— adapted from information found at
AIDS Foundation South Africa, www.aids.org.za.

Section 2.3: How HIV Can Be Prevented

Testing and knowing your status

One of the best ways to prevent the spread of HIV is for people to get tested and know whether they are HIV-positive or negative. When people know their HIV status, they can learn how to protect themselves if they do not have HIV or control their disease and avoid giving it to others if they do. It is a simple test, and there are counsellors and CHWs available to help people to understand what it means when they find out the results of their test.

When someone first contracts HIV there is a 'window period' where the person has the virus but it might not show up in a test yet. If a person has been exposed to HIV and tests HIV-negative, they should get tested again to be sure — if they have not been exposed to HIV again during that window period and they test HIV-negative again, then they are assumed to be HIV free. You should encourage people to practice safe sex even if they test HIV-negative, and to get tested regularly.

Many people don't want to get tested for HIV. They may not know that HIV can be treated, and that if they have the disease and find out early that they can still live a happy, long life if they take their ART and manage their illness well. Some people are also worried that their partners, family and friends might treat them poorly if they have HIV, so they choose not to get tested. Some people are even concerned that their partners, family and friends might assume they have HIV if they go for an HIV test. These are normal fears. Even though people often feel they have good reasons for not getting tested, it is the CHW's job to encourage them to find out their status and provide support when they do. It is especially important that pregnant women, infants, children and adolescents get tested.

Women and HIV

Women are more vulnerable than men to getting HIV, for many biological, social and cultural reasons. Young women are especially vulnerable. All pregnant women should be tested for HIV, as they could pass the virus to their infants during pregnancy, birth or breastfeeding.

HIV testing protocols

What are your clinic's specific protocols for HIV testing? Check with your supervisor to find out what tests are available and what guidelines you should follow, particularly for early infant HIV diagnosis.

Antibody vs. viral load HIV tests

There are two different ways of testing whether someone has HIV: an antibody or a viral load test.

Antibody tests detect HIV antibodies in the blood, i.e. whether a person's immune system is reacting to HIV. They are much easier to do, can be done at nearly every clinic and some community settings, and you can get results quickly. However, they are not as accurate as viral load tests because they don't test for the virus itself, just whether the person's body is reacting to HIV. There are times when an antibody test can have a false negative result, i.e. when the test says the person does not have HIV, but this is not true. This can happen in the first few weeks when someone gets HIV and their immune system is not yet reacting to HIV. There are times when an antibody test can have a false positive result, i.e. when the test says the person does have HIV, but this is not true. This can happen in infants under 18 months old whose mothers have HIV, because young infants have not yet developed their own antibodies and are still carrying their mother's.

Viral load tests measure how much of the virus is in a person's blood. While they are much more accurate and have less chance of a false positive or negative, they are also more expensive and require more specialised testing equipment that isn't available at all clinics. In those cases, a sample would need to be sent to a laboratory where they can conduct the test, which takes longer.

PMTCT

Most HIV infections in children are from mother-to-child transmission, where the virus is passed from a mother who has HIV to her infant during pregnancy, birth or breastfeeding. With the right medical care and support however, the risk of a mother passing HIV to her infant can be reduced.

PMTCT is a set of treatments and behaviours that help to reduce the risk of a infant getting HIV from its mother. HIV-positive pregnant women must take daily ART to stop the virus from being passed to the unborn infant. The highest risk of transmission occurs during labour and delivery, so it is best for women to deliver their infants in health centres where possible or in the presence of a qualified birth attendant who is trained in PMTC. Health centre staff can help to reduce the length of labour and to make sure the mother receives the necessary drugs during labour to reduce the risk of transmission further. During breastfeeding, mothers should continue to take ART and breastfeed exclusively (see Section 3 for more information on safe infant feeding practices).

Sexual and reproductive health education

Adolescents, whether or not they have HIV, are at an age where they are able to understand and make decisions about their sexual and reproductive health. For adolescents living with HIV, it is even more important that they have the information they need to make smart choices to keep themselves healthy and prevent the spread of HIV. Regardless of whether they got HIV from their mother or later, it is very important that adolescents feel supported and not judged for their actions. To keep themselves healthy, both HIV-positive and HIV-negative adolescents should be helped to understand:

- How delaying sex is the most effective way of preventing the spread of HIV.
- The importance of knowing and disclosing HIV status to potential partners.
- How to use condoms correctly.
- How circumcision can reduce the spread of HIV.
- Why reducing partners can help to limit HIV transmission.
- Why it is important to be careful not to contract STIs.
- Family planning options.

It is very important that this information is presented to adolescents in a non-judgemental way. Adolescents have the right to information and services that will help them to make healthy informed decisions and that will support them whatever their HIV status. CHWs can support adolescents to make responsible decisions about their sexual activity and reproduction.

About 90% of HIV infections in children are passed from mother to child.

— UNICEF, 2015.

Clinic-specific PMTCT protocols

A combination of ART, safe feeding practices and follow-up testing help to make sure that an infant has the lowest risk possible of getting HIV from its mother.

Talk with your supervisor and familiarise yourself with your clinic's protocols and national guidelines around prevention and treatment for mothers and infants so that you can provide your patients with the latest information.

Exercises for Section 2: Understanding HIV & AIDS

Key take away messages:

- **HIV is a virus that is passed from person to person in a number of different ways.**
- **PMTCT is one of the most important interventions to prevent the spread of HIV.**

Questions:

1. Name four ways that HIV is transmitted.
2. Describe how HIV affects the immune system.
3. Name three ways HIV can be prevented.
4. In your clinic, what are three things that should happen during PMTCT?

FOR SUPERVISORS: Answers

1. HIV is transmitted through infected fluids, such as semen, vaginal fluids, birthing fluids, breastmilk, or through contact with another person's blood stream.
2. HIV affects the immune system by entering the blood stream, attaching to and destroying CD4 cells, weakening the immune system.
3. HIV can be prevented by abstinence, correct condom use, being faithful to one's uninfected partner, and PMTCT. It is important to get tested and understand sexual and reproductive health to know your HIV status make the right choices to prevent the spread of HIV.
4. This is clinic specific, but generally during PMTCT, the mother should be tested, given prenatal care, take ART, deliver in a clinic or hospital or with a qualified birth attendant, infant should be given ART, infant should be tested in the first few weeks and again regularly until 18 months. Discuss your clinic-specific processes or national guidelines together.

Further reading about HIV & AIDS

Want to learn more? The resources below served as references for the information presented in this section, and are a great source for more in-depth information on the topics covered here. For even more resources, see Annex 3.

- ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.
- Avert, *HIV Transmission & Testing, www.avert.org.*
- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi*, 2011.
- Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), *Issue Brief: Pediatric HIV & AIDS*, 2013.
- PIH, *Accompagnateur's Handbook*, 2012.
- Treatment Action Campaign (TAC), *HIV in Our Lives*, 2007.
- WHO, *Flipchart for Patient Education: HIV Prevention Education and Care*, 2006.

Section 3:

Treatment & Care

Section 3.1: HIV Treatment

HIV treatment and care is the medical treatment, clinical care, information and support that PLHIV receive at clinics, hospitals and other health centres. Clinical treatment and care includes everything from the initial testing for HIV, to treating HIV with antiretrovirals (ARVs) and testing for and treating opportunistic infections like TB and malaria and will be covered in this section. CHWs form an important part of the clinic team in many heath facilities (see Section 4 for information on psychosocial support).

The clinic team

CHWs work as part of a team of people that are all responsible for different parts of a patient's treatment and care. We can call the clinic team 'multi-disciplinary' when it is made up of a mix of different professionals and healthcare workers who each have different knowledge, skills and strengths that they can use to support patients. The clinic team that you work with could include some or all of the following people:

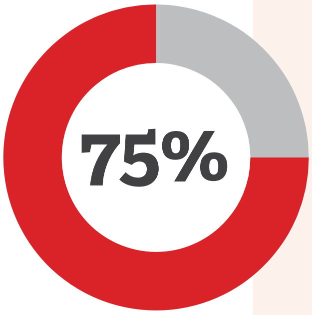
- **Clinicians and doctors** check on patients' health and make treatment and care plans for them. They assess if a patient needs to be on ART and if so, which drugs they should take.
- **Nurses** can also check on the patients' health and make treatment and care plans for them. They can also assess if a patient needs to be on ART and if so, which drugs they should take. Nurses often perform intake and history-taking activities when the patient comes to the clinic, take blood samples, weigh infants and give immunisations, and may provide PMTCT, adherence and other types of counselling and positive living support.
- **Pharmacists and pharmacy technicians** give patients medicines and information on how to take them.
- **Counsellors, social workers,** and sometimes psychologists, provide HTC and counsel patients on adherence, positive living, disclosure and other issues. They may also help when a patient feels depressed, anxious, hopeless or is thinking about suicide by providing referrals to other supportive services in the community.
- **CHWs, PSs and peer educators** can provide 'real life' advice and psychosocial support to patients, to help them with adherence and disclosure. They can do this through support groups or one-on-one sessions. They can talk to patients about HIV treatment and care in understandable terms and educate them about HIV, ART and nutrition. They can look after children in the clinic and work in communities, helping to find patients who need treatment and care.
- **Other clinic staff,** including lab technicians, phlebotomists, data clerks/information officers, administrators or other staff may exist at your clinic.
- **Community-based workers and organisations** may provide psychosocial support, material support, home-based care, and nutritional support in patients' homes and communities, and help to stop stigma and discrimination.
- **Faith-based organisations and spiritual leaders** can provide support and counselling to patients and their families and may even provide direct support services in the community. They can help to stop stigma and discrimination and encourage people to attend clinics.
- **Family members, partners and friends** can help by accepting the person's HIV status and providing support for them to live positively, go to clinic visits, take prescribed medication, and practice safe sex. They can also serve as home-based care providers.
- **Patients** themselves can be educated and informed and actively participate in their own care.

The different people in a clinic team need to work together, communicate with one another, and respect each other's contribution to improving the health and wellbeing of the patient. If one or more people from the team are excluded or not listened to, the patient may not get the quality of care that they deserve. It is important that clinic teams plan ways to work together, such as by meeting regularly to talk about the clinic and specific patients' treatment and care.

— adapted from CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.

Challenges of clinical treatment and care for pregnant and breastfeeding women, infants, children and adolescents

Treatment and care can be especially challenging for pregnant and breastfeeding women, infants, children and adolescents. Pregnant women are less likely to get the treatment and care that they need, either because they don't know they are living with HIV or for many other reasons. They need to be encouraged to test for HIV and start treatment as early as possible to reduce the risk of passing HIV to their infants.



Finding infants and children with HIV as early as possible is one of the most important ways that we can help to reduce the impact of HIV. All children born in clinics or hospitals should be tested, as well as any children coming to the clinic for routine maternal, newborn and child health services, such as check-ups and immunisations. It is also important to find infants and children born at home and who have not come to the clinic for check-ups or immunisations so that they too can be tested for HIV.

Caring for and treating infants, children and adolescents is difficult, as they are not just little adults. Adults can sometimes live many years with HIV before they get sick, but children are not as strong and get sick much more quickly once infected with HIV. Infants rely on adults to bring them in to clinics for treatment, and this is hard when caregivers themselves are sick, unaware of their own HIV status or don't want to test because they are worried about stigma and discrimination. Although it is sometimes difficult to find infants, children and adolescents that need treatment and care, it is very important for CHWs to help to do this because with ART and healthy living, infants, children and adolescents can live long, healthy lives and grow up to be healthy adults.

6 days	An infant should first be tested for HIV at the six day postnatal visit.
6 weeks	At six weeks, the infant should be retested for HIV.
18 months	At 18 months (or six months after breastfeeding finishes) the infant should again be retested for HIV.

— WHO *ARV Guidelines*, 2013.

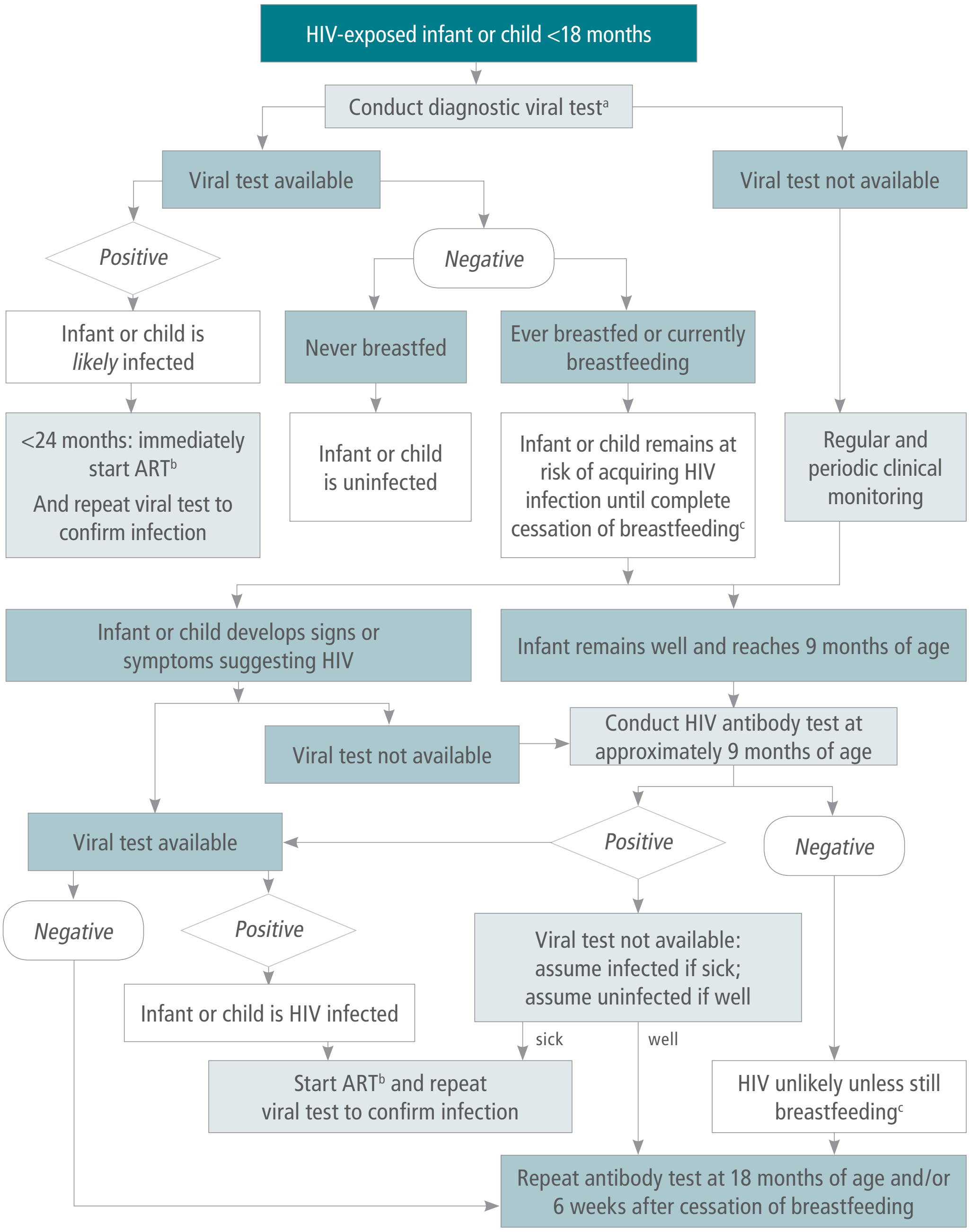
Treating HIV-positive infants with ARVs within the first 12 weeks of life can reduce their risk of dying by 75%.

— UNAIDS, *The Gap Report*, 2014.

Early infant diagnosis clearly saves lives. Without treatment, a third of HIV-positive children will die before their first birthday, and half before their second.

Early infant diagnosis challenges

Although finding out early whether infants have HIV is so important to their survival, antibody tests don't tell if an infant is infected. These tests are only useful if the infant is one or more years old (and in some places over 18 months). Younger infants need a viral load test, which measures the amount of the virus in the blood. A viral load test is more accurate but it can't be done at all clinics and takes longer to get results.



[a] For newborns, test first at or around birth or at the first postnatal visit (usually 4–6 weeks). See also Table 5.1 on infant diagnosis.

[b] Start ART, if indicated, without delay. At the same time, retest to confirm infection.

[c] The risk of HIV transmission remains as long as breastfeeding continues.

Infant and child testing and treatment algorithms

The flow diagram above is a tool that you and the clinicians can use when working with infants and children who have been exposed to HIV. Each box asks a question, and based on the answer, points you to the next step and suggested action.

— Table from: WHO, *Antiretroviral therapy for HIV infection in infants and children: Towards universal access. Recommendations for a public health approach*, 2010.

Your role as a CHW in clinical treatment and care

As a CHW, you can encourage community members to come to the clinic for testing and treatment early and to continue to come to clinic visits. Some of the specific roles that CHWs may play include

- **Encouraging HIV testing:** Knowing her HIV status can help a mother not to pass HIV to her infant, as well as adolescents from passing the virus to sexual partners. CHWs come into contact with people in communities and can encourage pregnant women and adolescents who don't know their status to get tested at the clinic. CHWs can also encourage women with children to bring their children to the clinic to get tested, and for couples and partners to get tested and go for counselling together.

- **Recording patient information and doing assessments:** In the clinic, CHWs help doctors, nurses and pharmacists by recording patient information, like height and weight, and conducting nutritional assessments. This information is given to doctors, nurses, and pharmacists to help them to quickly provide the right care to patients visiting the clinic (see Section 1 for more information on record keeping).

- **Encouraging adherence to medication:** Once a person has been diagnosed with HIV, it is very important for them to take their medication as prescribed. Both in the clinic and during home visits, CHWs help to make sure that patients are taking their medication as often and in the way that they are supposed to, and that caregivers are helping their children to take their medication correctly (see Section 3.2 for more information on adherence).

- **First line of screening/ identification of opportunistic infections:** PLHIV, especially children, are at risk for developing what are called 'opportunistic infections.' These are sicknesses that PLHIV are more likely to get because their immune systems are weak. If these infections are not caught early and treated, PLHIV can get sick very quickly, and possibly even die (see below for more information).

Watch infants for signs of illness

Even the most common sicknesses, like diarrhoea, malaria or pneumonia, can be dangerous for children, and need to be treated quickly. When an infant has HIV, it is even more important to get treatment fast, as these illnesses can become life threatening very quickly. Some basic signs of illness that you should look for:

- Low weight or not growing (see Section 3.1)
- Fever over 37.5°C
- Severe diarrhoea
- Fast or difficult breathing
- A cough that lasts for more than a month
- White spots on the inside of the mouth (thrush)
- Infections and skin rashes that don't heal
- Swollen glands
- Sores and cracks around the mouth

— adapted from Hesperian, *Helping Children Live with HIV*, 2013.

- **Providing nutritional support:** HIV-positive patients, especially pregnant and breastfeeding women, children and adolescents need to be especially careful about their nutrition and make sure that they are getting plenty of nutritious food and supplements as needed (see Section 3.1 for more information on nutrition).

- **Providing childcare and ECD support:** In clinics, CHWs are often asked to look after children while they are visiting the clinic for appointments or accompanying their caregivers. This is a good opportunity to interact with children in a way that helps them to develop and to identify any developmental delays that they might have. In the home, you can help caregivers with ideas of how to support child development and identify any delays. You can also help families to find and access other support services in the community that they might need (see Section 4 for more information about ECD).

- **Other general tasks:** You may be asked to take on a number of other tasks that are traditionally the role of other clinic staff in order to free them up to spend more time on clinical work. Some examples include helping to count pills in the pharmacy or collecting patient files. You may also be asked to act as an interpreter, and receive patients in the waiting area.

Recognising opportunistic infections

As CHWs, you may be in contact with patients more regularly than clinic staff. Because of this, you are best placed to notice early signs and symptoms that may show that a patient has an opportunistic infection. If you notice any, you can encourage the person to come to the clinic and get checked as soon as possible. Some of the illnesses and their major symptoms you should look out for include:

- **TB** is one of the most common opportunistic infections. It most often affects the lungs, but it can also affect other areas. Usually, people with TB have a bad cough that doesn't go away, fever, and lose weight. TB can be easily transmitted from person to person, so if you suspect a patient has TB they should visit the clinic immediately and be screened and treated according to national protocols.
- **Malaria** causes high fever and weakness. It is especially dangerous for pregnant women, as it can cause anaemia, so patients you suspect to have malaria should be referred to the clinic right away. It is passed to people by mosquitoes, so you should encourage all patients to use bed nets treated with insecticide to help prevent malaria.
- **Pneumonia** is an infection of the lungs that can develop quickly. It causes coughing, weakness, shortness of breath and may cause death if it's not treated.
- **Meningitis** is a deadly disease of the brain. It is more rare and hard to detect, but one of its signs is that it can cause very bad headaches.
- **STIs** can cause infected sores in the genital area of both men and women, unusual discharge, or sometimes have no symptoms. They are easy to spread through sexual activity and need to be treated right away.
- **Bad diarrhoea,** or diarrhoea that lasts more than a few days, can cause dehydration and weight loss. It is especially dangerous if the person also has a fever. You should refer the patient to the clinic right away.
- **Vomiting** is often a sign of other problems, especially if there is also fever and it doesn't go away after a few days, as this may cause dehydration. You should refer the patient to the clinic.
- **Skin problems,** like rashes, shingles, warts, or sore lesions, can be caused from fungus and be very uncomfortable.
- **Oral sores** are also very common among PLHIV and can be very painful.
- **Developmental delays** in children can be a sign that children are getting more ill.

— adapted from CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi*, 2011 and ANECCA, *Handbook on Paediatric AIDs in Africa*, 2011.

Section 3.2: Nutritional Support and Education

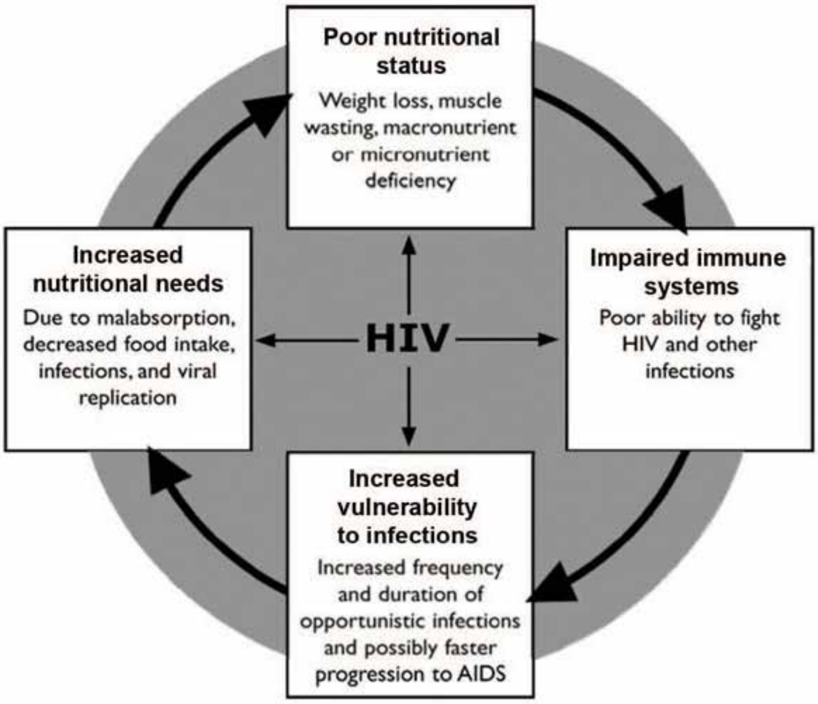
PLHIV should take very good care of themselves in order to stay healthy. They should take their medications, adopt safe sexual practices and have access to good nutrition in order to do this. CHWs can help people in their communities to live healthy lives through teaching them how important good nutrition is, how to prepare and eat healthy foods, and how to feed their infants and children according to WHO guidelines.

Nutritional needs and challenges

It is well known that PLHIV need to pay special attention to their nutrition — how much they eat, what they eat and how often they eat — in order to stay healthy. Healthy food strengthens the body to fight infections, prevents weight loss, and helps medicines to be absorbed into the body. Even if they do not feel sick, PLHIV need energy and nutritious food to fight the virus and stay healthy. If a patient is malnourished, it is much more likely that they will develop opportunistic infections or other illnesses.

HIV, pregnancy and nutrition

Ensuring that women who are living with HIV receive nutritional support and education before and during pregnancy is closely linked to these women having healthy infants. If a woman thinks she might become pregnant, she should take good care to eat healthily even before she becomes pregnant in order to give her infant the best start possible.



Vicious cycle of HIV and poor nutrition

HIV can contribute to poor nutrition. Poor nutrition can lower the amount of food that your body can absorb, leading to malnutrition. If you are malnourished, your body is weak, which makes it even harder more difficult to fight off illnesses, and you are more likely to get sick. Once you become sick, your HIV can get worse, creating a vicious cycle.

- diagram from OpenLearnWork's Health Education and Training (HEAT) program, at www.open.edu.

Pregnant and breastfeeding women, infants, children and adolescents should pay special attention to their nutrition. Pregnant and breastfeeding women are not just eating for themselves, but also for their unborn infant. Infants' and children's minds and bodies develop quickly in the first few years of life, and eating the right foods to feed that development is very important. Children living with HIV need even more food to stay healthy as their little bodies are working hard to fight HIV, and need the extra energy to keep up the fight. Medicines for HIV also work better when children and adolescents have enough to eat and a balanced diet.

Children living with HIV are at an especially high risk of malnutrition, which can cause a number of serious growth problems. This is because children living with HIV:

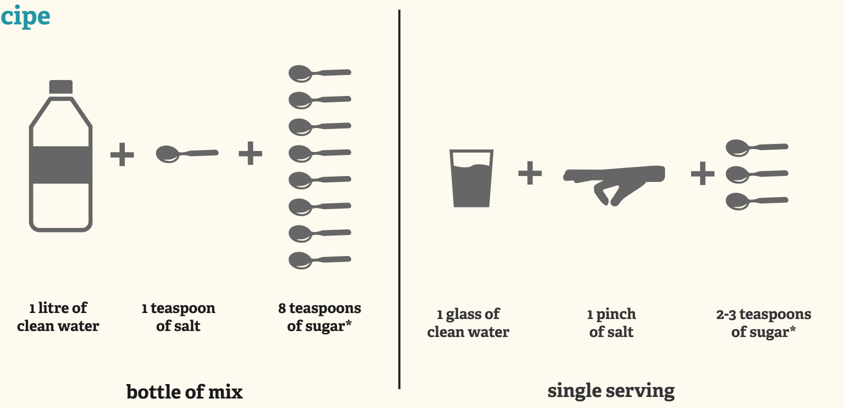
- **Need more energy:** Children living with HIV need more energy to fight HIV as well as keep up with normal growth and childhood activity.
- **Don't absorb nutrients well:** Children living with HIV taking ART are at risk of not getting the nutrients they need from food because the drugs can interfere with how the food is absorbed into their systems.
- **Suffer from chronic diarrhoea:** This is a common side effect of ART.
- **Lose their appetite:** This is because of common ART side effects such as fatigue, depression, loss of sleep and pain.

Many families affected by HIV find it hard to eat enough healthy food or provide it for their children, even when they know that they should. When caregivers are sick due to their HIV, they may not be able to work or earn enough to buy healthy food for themselves and their children, or to farm, fish or prepare food for their families. HIV can make people nauseous or have sores in their mouths, which may make them not want to eat. ARVs can make people lose their appetite or make food taste different. People who are depressed or tired from living with the virus also may not feel like eating.

CAUTION!

It is important that patients do NOT stop taking ARVs if they are experiencing any of these side effects. Rather, they should discuss them with a doctor or nurse.

Oral rehydration mix recipe



* You can use cereal, such as ground maize meal or rice cereal, instead of sugar. If you use cereal, cook the mix for a few minutes before you serve it.

Oral rehydration for infants and children

If an infant or child has bad diarrhoea or vomiting, they can very quickly become dehydrated. One of the most effective ways of helping children is to give them a simple salt and sugar mix to drink that helps them to rehydrate.

— adapted from Hesperian, *Where There is No Doctor*, 2013.

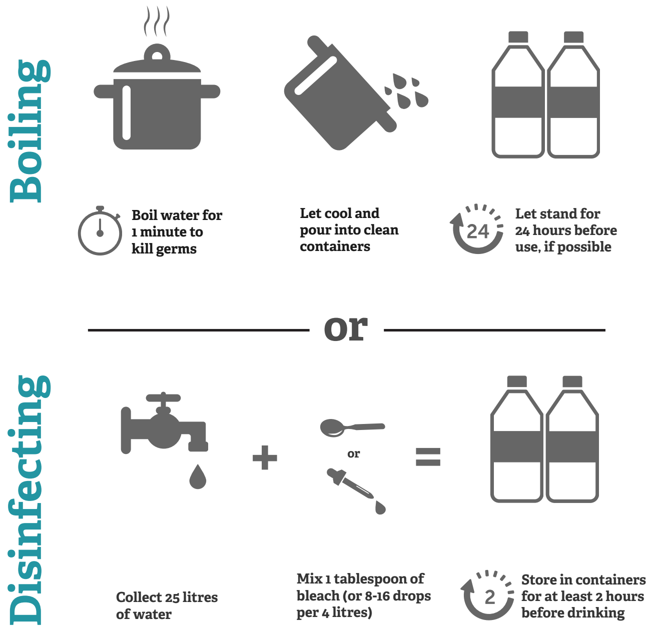
Food storage, preparation and hygiene

Food can be infected with germs that make people sick. These germs can cause many illnesses, including diarrhoea, vomiting and worms. Children whose bodies are already weak from HIV can get very sick very quickly. People increase the risk of getting sick when they don't properly clean, store and prepare foods. Healthy children, adolescents and adults can usually fight off minor illnesses, but the bodies of those living with HIV aren't as strong to fight off germs. CHWs can help families to understand the risk of not keeping germs out of food, and teach them how to store and prepare food in the right way to avoid making their children sick.

To avoid getting germs in food, CHWs should encourage people to:

- Wash their hands often, especially before preparing and/or eating food.
- Keep animals away from food to keep them from spreading their germs to food.
- Cook all food well to make sure any germs that might be in it are killed, including reheating leftover food to kill any germs that may be in it from storage.
- Wash and peel vegetables and fruit to make sure that any germs on the outside don't get ingested.
- Avoid spoiled food that looks or smells bad.

Clean water is one of the most important ways to keep families healthy when preparing food. You can't tell that water is safe to drink by the way it looks — even water that looks clean can contain harmful germs, worms and other dangerous things. Unless they know for certain that water is safe, patients should always boil water before it is used for drinking or preparing food, including infant formula if it is being used. Water can also be treated with chlorine to make sure that it is safe to drink. Water also needs to be stored and served properly to keep it clean.



Encouraging children to wash their hands

It is very important for children to wash their hands to stay healthy. A few tips:

- It is important to wash hands before eating, and after using the toilet.
- You need to wash children's hand for them when they are small, and keep helping them until they are big enough to reach and use the water and soap.
- You should use clean, treated water whenever you can.
- If you don't have soap, you can use ash or sand.
- It is best to use moving water (from a tap or pitcher) to rinse hands.

Water storage

Stored water can get germs in it when someone touches it with dirty hands, dips a dirty cup or other object in it, pours it into a dirty cup or other vessel, and when dirt or dust gets into it. To keep water from becoming unsafe:

- Wash your hands before collecting and carrying water.
- Clean the containers that you use to carry and store water.
- Carry water in a covered container.
- Keep water containers off the floor and away from animals.
- When you pour water out, do not touch the mouth of the container with your hands.
- Clean all cups used for drinking.
- Treat only the water you need for a day or two, so it does not sit too long

— adapted from Hesperian, *Helping Children Live with HIV*, 2013.

Nutritional guidelines and recommendations

Food groups and general nutrition

All adults, children and adolescents need to eat food from all three food groups to stay healthy. A food group is a collection of foods that are similarly nourishing. For infants six months and younger, breastmilk is the only food they should get, so it is important that nursing mothers eat as well as they can.

3 Food Groups

Try to eat three meals a day with food from each of these food groups to make sure your diet is balanced and healthy.

Body-building foods (proteins) Examples include dairy (milk, yoghurt, cheese),beans, soya, peanuts, eggs, meat, fish, and chicken

Vitamin-rich foods (fruits and vegetables) All fruits and vegetables, especially green leafy vegetables, and orange and yellow fruit

Energy-giving foods (carbohydrates & fats) Examples include maize, millet, rice, potatoes, sugar (in moderation), and oil

— adpated from TAC, *HIV in our Lives*, 2007.

Exclusive breastfeeding

Exclusive breastfeeding is when a mother only gives a child breastmilk and no other liquids or solids, not even water, for the first six months of a child's life (with the exception of drops or syrups of vitamins, mineral supplements or medicines given by a healthcare worker). WHO recommends exclusive breastfeeding as best for infants whose mothers are on full ART.

Mixed feeding

Mixed feeding is feeding an infant breastmilk as well as other milk (including commercial formula or home prepared milk), foods or liquids before the age of 6 months. Mixed feeding is NOT recommended, as it increases the risk of passing on HIV to the infant.

Infant feeding

Exclusive breastfeeding is proven to be the safest and most nutritious way for a mother to feed her child, regardless of whether she is living with HIV or not.

If there is HIV in breastmilk, there is a risk of HIV being passed on to the infant. To make breastfeeding as safe as possible for the infant, the aim is to reduce the amount of virus in the breastmilk. In order to do this, the mother should start ART early in her pregnancy so that she can be on treatment for as long as possible, and she should feed her infant breastmilk only (exclusively breastfeed) until her infant is six months old. This is because if a infant is exclusively breastfed, the breastmilk will form a protective lining in the infant's gut, and the virus will not easily pass through to the infant. It is very important that the HIV-positive mother does NOT mix breastmilk with formula or food before six months of age because this may damage the gut lining and put the infant at more risk of getting HIV. This is called 'mixed feeding'. Mixed feeding is the most likely way of passing on HIV during breastfeeding.

Mothers can also protect their infants by:

- Eating as well as possible and keeping healthy.
- Taking ARVs as prescribed.
- Ensuring infant is given ARVs as prescribed from birth.
- Taking infant for HIV testing as soon as possible after birth.
- Using a good breastfeeding position to prevent cracked nipples and breast infections, and treating any problems that do emerge quickly.
- If a mother cannot exclusively breastfeed for six months, she should exclusively breastfeed for as long as possible before switching to exclusive replacement milk feeding.
- Using condoms during sex to prevent STIs, which can make the virus stronger and more easily passed on to the infant.

> “Mothers known to be HIV-infected and who are on full ART should **exclusively breastfeed their infants for the first 6 months** of life, introducing appropriate complementary foods thereafter, and **continue breastfeeding for the first 12 months of life.**”
>
> *- WHO, 2013*

Breastfeeding is not always easy for mothers. It can take time and requires support for both the infant and the mother to make it work, but given how important it has been shown to be for a child’s health and for preventing HIV, it is very important to make sure that mothers get the help they need. Breastfeeding support groups have been shown to greatly increase the chances that women will be able to successfully breastfeed. Women should also be encouraged to visit the clinic for help if breastfeeding is painful or difficult — if a mother living with HIV has cracked or bleeding nipples, it can increase the chances of passing on HIV to her infant, and can also reduce the chances that she will continue breastfeeding.

After six months, a mother should continue to breastfeed and introduce complementary foods until she gradually stops breastfeeding at 12 months or sooner if necessary. When a mother wants to stop breastfeeding, it is best for her to stop gradually over one month. The easiest way to do this is for the mother to drop one feed over a few days, then another until all feeds have been stopped. This will prevent any breast problems and be easier for both her and her infant.

Complementary feeding

Complementary feeding refers to any food, whether in liquid, solid or semi-solid form, given to an infant after the age of 6 months as part of the transitional process during which an infant learns to eat food appropriate for their developmental stage, while continuing to breastfeed or being fed with commercial infant formula.

Complimentary feeding: what and how much?

Here are some ideas that you can share with caregivers about what and how much food young children should be getting each day, in addition to breastmilk.

— adapted from South to South (S2S), *Nutritional Support from Birth through Adolescence*, 2009.

Age	Types of foods	Consistency	Number of meals/ snacks	Amount an average child usually eats
6–8 months	Offer puréed or mashed, semi-solid foods Start with foods rich in iron such as boiled egg yolk, mashed, cooked or dried beans, chicken livers, boneless mashed fish, peanut butter, fortified maize meal porridge, mashed sweet potatoes, mashed potatoes, pumpkin, and avocado	Avoid foods that may cause choking Test for temperature	2–3 small meals per day	1/4 cup per meal
9–11 months	Same as above, plus: Offer chopped foods such as chicken, mince, liver, yoghurt, stiff porridge, soft cooked vegetables, and soft fruits	Include foods infants can pick up (finger foods)	3–4 small meals per day	1/2 cup per meal
12–23 months	Same as above, plus: Offer chopped or mashed foods such as fish, chicken livers, dried beans, masonja, pounded peanuts, porridge, pumpkin, sweet potatoes, and fruits without skin	All	5 small meals per day	1 cup per meal

If a mother is too sick to breastfeed, cannot breastfeed for other reasons, or chooses not to breastfeed, she should talk with someone at the clinic to get the best advice possible about safely feeding her infant. CHWs can help mothers or caregivers understand how to:

- Buy or access enough replacement milk to feed the infant for six months.
- Prepare replacement milk exactly as directed on the tin or by a healthcare worker.
- Sterilise feeding cups, bottles and teats each time they are used (cups are easier to keep clean).
- Use only clean, boiled and cooled water to mix replacement milk.
- Throw away any leftover milk that isn't used within an hour.

ARV policies differ by country

What is the policy in your country for how long mothers living with HIV should receive ARVs? WHO recommends that all pregnant and breastfeeding women living with HIV start taking ARVs when they are first diagnosed, and continue for the rest of their lives, but some countries only continue ARVs until a week after stopping breastfeeding.

Key messages to share with caregivers about infant feeding:

- Breastmilk is healthy, available and free, and helps to prevent infants from getting illnesses like diarrhoea and respiratory problems that can be very serious. Breastmilk is the only food infants need until they are six months old.
- Women should try to continue breastfeeding for at least six months.
- From six months, the infant needs to have other foods as well as breastmilk in order to get the nutrition he or she needs to grow well. Mothers or caregivers should meet with a healthcare worker to talk about safely preparing other foods for the infant from 6 months.
- The infant can continue to have breastmilk and other foods until the mother stops breastfeeding completely. WHO recommends that mothers living with HIV breastfeed for two years or more, but check with your supervisor to find out what local guidelines recommend.
- If the infant is tested and found to be HIV-infected, the mother should keep breastfeeding for as long as possible to give the infant all of the benefits of breastmilk.
- Women should watch out for breast problems (cracking, sore nipples, strange discharge from nipples, pain, infections, amongst others) and go to the clinic right away if this happens.

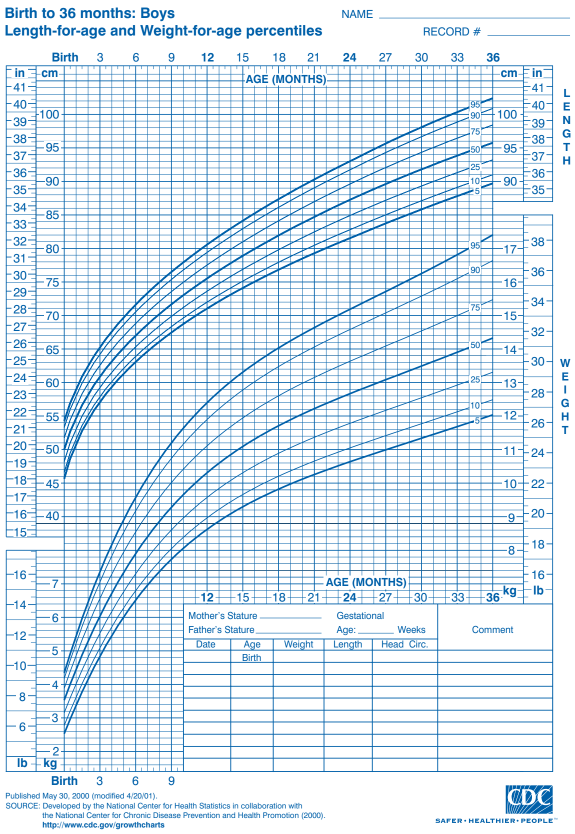
Assessing nutrition and monitoring growth

Standard measures are used to check how well a child is nourished and growing. Children who are doing well should gain weight and grow at an expected rate. Growth problems in children living with HIV are often an indicator that the illness is getting worse, so any problems should be taken very seriously.

To monitor how well infants and children are growing, certain measurements need to be taken regularly. Looked at together, height, weight and head circumference measurements can show how well a child is developing, and raise alarm bells if the child's growth is not on track. A child's measurements can be taken at the clinic or at a home visit. The measurements should be plotted on a growth curve, and any changes in the growth patterns noted. Check with your supervisor to find out which growth chart you should use — you should use your country's standard government growth chart.

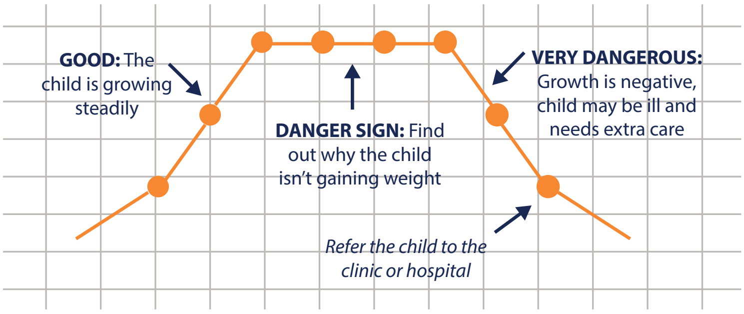
Growth charts

A child's height, weight and head circumference are plotted on a growth chart like the one below. There are separate charts for girls and boys, and they show the average rates of growth over time.



Interpreting growth charts, and danger signs

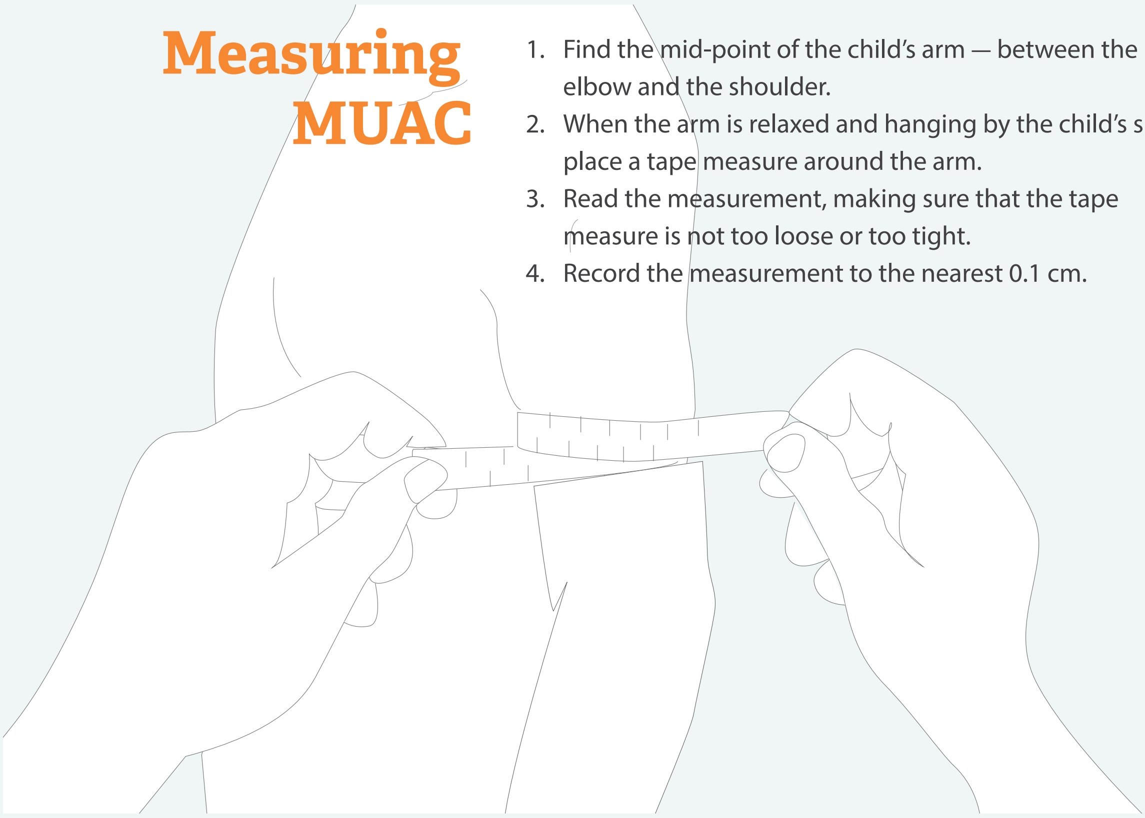
Once a child's height, weight and head circumference have been plotted on the appropriate growth chart, one can start to see how their growth compares to previous visits. Watch the direction of the curve to understand how well the child is growing. In a child who is 'failing to thrive,' or whose growth is faltering, the curve will not follow the expected lines according to the standard measures. When a child's height or weight is not following the expected line, it indicates a possible risk and the child should be referred to the clinic to find the cause. The chart below explains this.



— WHO boy's growth chart (L) and chart (R) adapted from S2S, *Nutritional Support from Birth through Adolescence*, 2009.

Measuring MUAC

1. Find the mid-point of the child's arm — between the elbow and the shoulder.
2. When the arm is relaxed and hanging by the child's side, place a tape measure around the arm.
3. Read the measurement, making sure that the tape measure is not too loose or too tight.
4. Record the measurement to the nearest 0.1 cm.



— adapted from S2S, *Nutritional Support from Birth through Adolescence*, 2009.

Another quick and useful way to check the nutritional status of a child during a home visit is by measuring the mid-upper arm circumference (MUAC). While not part of routine growth monitoring, measuring MUAC on children from 6–60 months of age can be a useful tool to quickly identify severe malnutrition. If a child's MUAC is less than 11.5 cm, they are considered to be severely malnourished and at a much higher risk of death. MUAC is a very useful tool for screening in the community — if you take the measurements and see that a child is malnourished, you should refer them to the clinic immediately.

If you cannot weigh a child, there may be other ways to assess a child's wellbeing. You can look at the child during a visit and take note of what you see. If the child appears thin, unusually short, has dull hair and eyes, is tired or has little energy, they might not be not getting enough or the right foods to eat. These observations aren't as accurate as standardised measurement, but they may provide you with the clues that you need to refer the child for further assessment. You can also do a structured nutritional assessment interview with the family to find out whether there is enough access to food in the house, and what are the family's eating habits, food choices and activity patterns.

Cognitive growth can also be an indicator of health and development (see Section 4.2 for more information on child and adolescent development).

Helping families to improve nutrition

CHWs can help children, adolescents and their caregivers to eat more healthily in several ways.

- **Educating families and promoting healthy eating:** Sometimes adults don't realise how much the food they choose to eat influences their and their children's health. CHWs can see how people are eating during home visits, and educate them about basic nutrition and the importance of healthy living.

- **Linking patients to nutrition support programmes:** For children and adolescents who are malnourished, there are often programmes that can help to provide additional and high-energy food when needed. These types of programmes include:
    - » Clinic-based nutritional programmes.
    - » School feeding programmes.

- **Social grants:** You should be familiar with any social grants available and refer patients to them when needed.

- **Helping families to start community or kitchen gardens:** Caregivers do not always have enough money to buy the food that they need for their families, especially if they themselves are sick. Community or kitchen gardens are one way that families, even in urban environments, can start to grow additional nutritious food to add to their diet. If the gardens get big enough, they might even be able to sell some of the food to buy other food. The gardens usually use household waste to fertilise the plants and scrap materials to build the garden, so there is little cost to setting one up other than the seeds.

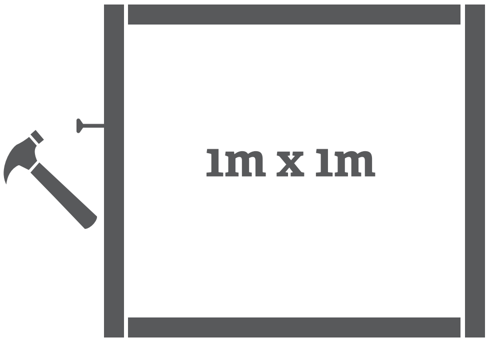
Nutritional assessment client interview

For older children, adolescents and adults, a useful tool to identify nutritional problems is a comprehensive nutritional assessment. Some of the questions you can ask include the following:

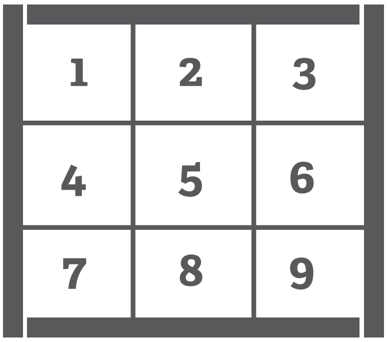
How many meals do you eat on a typical day? When there is meat, does everyone get a share? Did everyone in the household eat (meat, fruits & vegetables, dairy, fats) yesterday? If not, why not?	These questions can help you to know if there is enough food in the household. You can make recommendations on how the family can stretch their food budget (for example, use more beans and less meat), and identify families who may need referral to nutritional programmes if these are available.
How much and what did you and your child eat and drink yesterday? Who usually buys or produces the food that you eat? Who prepares the food you eat?	These questions can help you to know what nutritional education the family might need to eat more healthily, what resources you can suggest to them, and who you should target for specific messages.
What activities does your child do? Have you noticed any changes in play or activity?	By noticing changes in activity patterns, you might get a better idea about the child's health and illness, and whether or not the child's food intake is adequate to support activity levels.
What are you feeding your child? How do you feed your child? What problems have you had?	These questions tell you if caregivers are exclusively breastfeeding, and allow you to communicate the recommendation that mixed feeding not start before six months.

— adapted from S2S, *Nutritional Support from Birth through Adolescence*, 2009.

M^2 Gardening

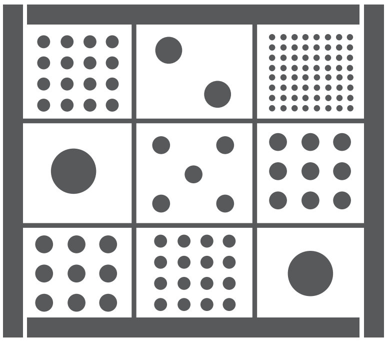


Step 1: Build a 1m x1m enclosure using wood, scrap metal, or bricks.

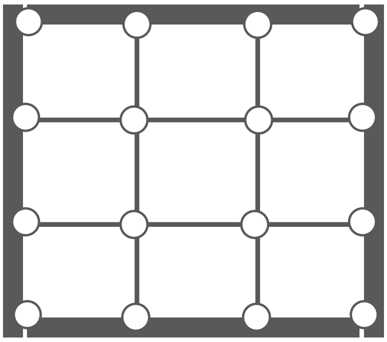


Step 2: Divide the box into 9 squares of the same size, using card, wood metal, or other materials.

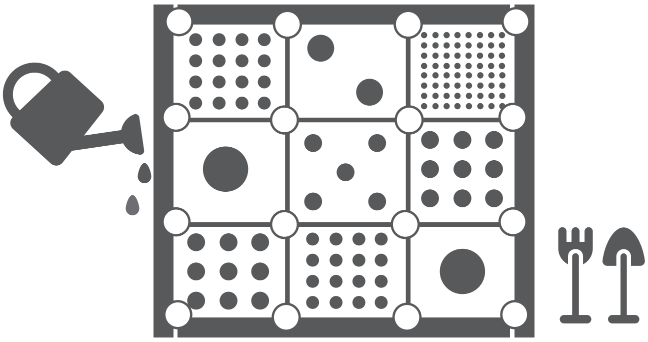
You can fit more small vegetables like carrots in one square than you can large vegetables such as cabbage!



Step 3: Fill the box with compost (very rich soil) 15cm high and plant your seeds, making sure to space them out.



Step 4: Plant herbs like onions, garlic and chives in the corners to keep away insects and other pests.



You should always think about what people in your community like to eat and encourage them to plant those foods – it is no use planting vegetables that the family isn't interested in eating or can't sell! You should also make sure to recommend a method that works in the patient's particular situation – an urban setting might need a different type of garden than a rural household, and different families might have access

M^2 Gardening

One type of community or kitchen garden that is popular in a many settings is the container garden. It uses wood, metal, tyres, boxes or other materials to create a box where you can grow plants even when you don't have access to land. It uses household waste that has been composted as the soil in which to grow the plants, and requires less water.

— adapted from Small Projects Foundation, *M^2 Gardening (Square Meter Gardening)*, ND.

Section 3.3: Adherence

Unfortunately a cure for HIV has not yet been found. Once someone is infected with the virus, it remains in the body forever. However, we have come a long way, and today PLHIV can live long and happy lives if they are getting the treatment they need.

ARVs, the drugs used to treat HIV, are a group of different drugs that all work to keep the virus from multiplying and killing CD4 cells, which are an important part of the body's immune system. As long as ARVs are taken correctly every day, they will suppress the HIV virus so that the person taking them will stay strong and healthy.

CHWs play a very important role in all stages of HIV treatment and adherence. Many of the stages of treatment take place outside the formal clinic environment, in patients' homes and communities. As members of the community, you are regularly interacting with your patients and their caregivers, and can play an important role in making sure that treatment is adhered to and any issues are referred to the clinic for follow-up. Your role as a CHW includes:

- Providing PLHIV with information about ARVs.
- Helping patients to take their ARVs correctly.
- Ensuring that any side effects are reported to the clinic.
- Monitoring a patient's overall health between clinic appointments.

Common ARV drugs

Clinic staff will prescribe different drugs and combinations of drugs depending on what is available and what is best for the patient. Some of the common drug names that you might hear are Zidouvine (AZT), Lamivudine (3TC), Combivir or Duovir (a combination of AZT and 3TC), Suavudine (d4T), didanosine (ddI), Nevirapine (NVP), Abacavir (ABC), Tenofovir (TDC), Efavirenz (EFV), Nelfinavir, Lopinavir/Ritonavir (Kaletra), Indavir (IDV), Triomune/T30, Coviro (L30 and LS30). Many PLHIV also take Cotrimoxazole, also known as Bactrim, an antibiotic that can help to fight off opportunistic infections.

— adapted from
PIH, *Accompagnateur's Handbook*, 2012.

Treatment options

Depending on the country, not everyone who has HIV will necessarily start taking ARVs right away. In some countries, PLHIV only start taking ARVs when their CD4 cell count drops below a certain level. A person living with HIV should get their CD4 count tested regularly. You can't tell if a person needs ART just by looking at them — they need to be checked to see what their CD4 count is. A person may look healthy and still need to be on ARVs.

At the least, however, all pregnant and breastfeeding women living with HIV and children under 5 years should start taking ARVs as soon as possible, no matter what their CD4 count is. Pregnant and breastfeeding women living with HIV should start taking ARVs as soon as they know they are pregnant in order to reduce the risk of passing HIV to their unborn infant.

To treat HIV, people take several drugs every day. Depending on what drugs are available or used at your clinic, patients may take several different pills or a combination of ARVs in one or two different pills. Each of the drugs works in a different way to stop the virus, so they are each important and must be taken.

Traditional medicines

While some traditional medicines may help people to feel better, they do not actually treat the illness and are not a replacement for ART. Some of them, in fact, may interact with ART and make the drugs less effective.

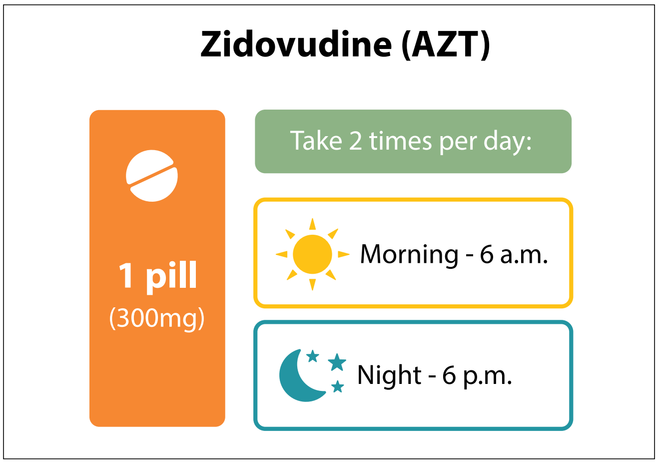
ART adherence counselling and preparation

As patients start ART, they should feel ready and willing to commit to treatment. To help them, CHWs should spend time with them to make sure that they understand the basics of HIV/AIDS, ARVs and how they work, the importance of adherence and what is required, and possible side effects. It is also important that patients are prepared for the psychological aspect of dealing with the virus for the rest of their lives (see Section 4 for more information on psychosocial support). Depending on a child or adolescent's developmental stage, CHWs work with caregivers children and/or adolescents. It is very important that issues around stigma and discrimination be discussed. Treatment is much more likely to be successful if the child or adolescent has the support that they need and openness around treatment in the home. It is best for people who are starting ART to take part in group education and support as well as one-on-one counselling sessions if possible to understand the importance of treatment and talk about barriers to adherence and how to address them.

ART adherence[1]

Once children, adolescents and pregnant and breastfeeding women living with HIV start ARVs, they should keep taking the right drugs, at the right dose, at the right time, in the right way. This is called ***adherence***. It also means that patients go to their clinic appointments, get their lab tests done and refill their prescriptions as required. Patients need the right information and support to make sure that they can adhere, and children need the support of their caregivers to adhere. Making sure that patients correctly take their ARVs is one of the most important roles that CHWs can play.

It can be very hard to take pills every day at the same time. However, if a patient keeps starting and stopping their ARVs or misses doses, HIV can begin to multiply again and kill CD4 cells. The HIV in the body will also become stronger and better able to fight off the drugs that are treating the virus. This is called ***drug resistance,*** and it means that the ARVs will not work as well as they should in the future, which is very dangerous.



Treatment buddies

A treatment buddy is someone who gives someone living with HIV support to take their ARVs. While they don't give medical advice, they can help to motivate and encourage a patient, or help them to decide when to go to the clinic for side effects or other issues. This sort of peer support has been shown to make ART adherence much more likely. As a CHW, you can be a treatment buddy for someone, or you can help to match them up with someone in a similar situation through the clinic or a support group. Treatment buddies are particularly helpful for adolescents, who may be more willing to talk with a peer or friend.

Different treatment dosages for infants and children

There are special kinds of ARVs and dosages for infants and children, which are based on weight. Be aware that infants and children receive different dosages of ARVs than adults. Their dosages are based on their weight, which needs to be reviewed regularly to make sure they are getting the right dose. Children should never get adult ARVs unless a doctor or nurse prescribes it Children usually respond very well to ART, sometimes better than adults, and can get better quickly if they take their drugs in the right way.

Treatment cards

When patients start ARVs, clinic staff may give them treatment cards that show special instructions for taking ARVs, such as taking them with food or on an empty stomach, in the morning or at night, and how many times to take them.

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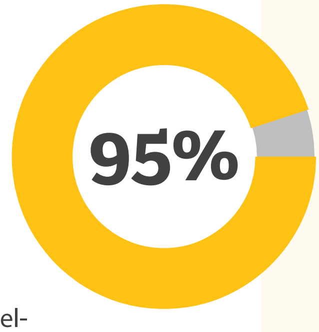
[1] information in this section is adapted from PIH, *Accompagnateur's Handbook*, 2012.

Measuring adherence

One way that clinics and CHWs help patients to track and monitor their adherence is through a simple pill count. To do a pill count, patients bring any pills they have remaining with them to the clinic (or you can check them during a home visit), and with the right chart you can check to see what their adherence percentage is. If you don't already have a pill chart, you could work with your supervisor to develop one for your clinic. A sample pill count chart is included below.



Pill counts and adherence

In the clinic or home, you can measure how well patients are adhering to their ART.

Use the formula below to calculate a patient's adherence, or use a pill chart like the example here to quickly see how a patient is doing.

$$\frac{\text{\# of pills taken}}{\text{\# of pills prescribed}} \times 100 = \text{\% adherence}$$

Note that this pill count is specifically made for a pill being taken once a day for 30 days - if a patient has a different treatment regime the pill count card will be different.

Pill Count Card

30 days prescribed

1 pill per day

28 days (4 weeks) since last visit

Number of pills remaining	Adherence (percentage)
-2	114%
-1	111%
0	107%
1	104%
2	100%
3	96%
4	93%
5	89%
6	86%
7	82%
8	79%
9	75%
10	71%
11	68%
12	64%
13	61%
14	57%

— adapted from Baylor International tool.

At least 95% adherence to ARVs is needed to avoid treatment failure and drug resistance.

In general, all or almost all of ARV doses need to be taken for the drugs to be effective. Adherence less than 80% almost always fails, and drug resistance can develop with only a few missed doses each month. This is especially dangerous in children, as there are even fewer drugs options for them.

Pill fatigue

Taking pills every day can become tiresome. This is especially true for children and adolescents who have taken ARVs for their whole lives. Doctors call this 'pill fatigue.' If you think this may be the reason that a patient is not adhering to ART, you can suggest that they talk with clinic staff about their medications. It may be possible to change medications to a pill that only needs to be taken once a day, doesn't need to be taken at the same time or with food, or has fewer side effects. Any one of these factors could be enough to help a person to start taking their ARVs again.

— adapted from aidsmap and Right to care/Dr. Levine, *Adolescents with HIV*, PATA presentation .

Children and ART

It is especially hard for children to take ARVs: the pills can be difficult to swallow; the syrups can be bad tasting; the amount, timing and whether the drugs should be taken with or without food can be hard for caregivers to keep track of; and side effects can make children feel sick. The dosage for children also changes regularly as they grow up, as it is based on their height and weight, so they need to go regularly to the clinic. Their caregivers need to help them to make sure they are taking their drugs every day at the right time, and are getting the check-ups they need at the clinic. This is especially hard if the caregiver is also sick. When children need ART, it is important to make sure that they have a caregiver available who understands the treatment and will be able to help them to continue treatment until they can take care of themselves.

Check dosage changes carefully

Remember that the correct dosage for children's ARVs is based on height and weight. Infants and children grow very quickly compared to adults, so it is important that they get weighed and measured regularly at the clinic. This will ensure that they are taking the right amount of the drugs to keep them healthy.

Find out about treatment in care in your clinic and community

To best help the patients you work with, you should get to know as much as you can about the treatment protocols and support available in your clinic and community. Some questions you can ask your supervisor include:

- What tools does the clinic have to help PLHIV to be prepared as they start ART?
- Does the clinic have a treatment buddy system, support groups, education or counselling?
- Are there materials about HIV treatment that the clinic gives out to new patients and/or their caregivers?
- What is the CD4 cell count when patients are eligible to start ART in the country?
- How often do patients need to visit the clinic to have their CD4 cell count tested if they are not on ARVs?
- What ART regimen is used most in the clinic?
- How many pills must people take?
- What are the names of the ARVs most frequently used?
- Does the clinic use treatment cards?
- How is treatment measured in the clinic — are pills counted in the pharmacy, or are patients asked to self-report?

General rules for giving medication to children and adolescents:

- Begin by telling the truth.
- Involve children in their care; even small children can be involved in their care through play therapy.
- Tell the child that he or she is going to learn a new skill. Remind him or her that other skills have been learned in the past, like skipping, dressing and eating.
- Do not bargain or bribe the child to take medication. Bargains or bribes will likely cause the child to take medication to earn a reward rather than because it is a habit, an expected part of growing up, and good for their health.
- Do not mix with food or otherwise try to 'trick' the child.
- Do not threaten or punish.

Strategies for giving medicine to babies and toddlers (under 2 years)

- Use a syringe or small soft dropper. Ensure that it is clearly marked with date, time, and dosage of medication.
- Sit the baby on your lap, keep the head slightly tilted but firmly towards your body so that it does not move.
- Gently close the child's mouth with your hand on the chin, until the child has swallowed. You can demonstrate this to a mother or caregiver on a doll.
- Speak softly to the child throughout.
- Reassure the child, perhaps with a cuddle, after giving the medication.
- Offer some water or juice if recommended by the clinic.

Strategies for giving medicines to children (2-12 years)

- Get the child's 'buy in' and ask him or her to help you to prepare the medication according to developmental age.
- Connect taking the medicine with a positive effect on his or her health, being strong, able to do activities, etc.
- Do not ask children if they want to take the medication.
- Do not mix with food, especially favourite food.
- Never show anger toward the child for refusing to take the medicine.
- Speak softly to the child.
- Reassure the child after giving the medication and offer praise.
- Let the child choose water or juice afterward.
- Use reward charts to show how well a child is doing taking their medicine.

Strategies for giving medicine to adolescents

- Make adolescents responsible for their medication with support from an adult.
- Get them to document when they take their medication, i.e. they should self-report.
- Ensure that they understand why their medication is so important.
- Ensure support from appropriate adults (for example, school teacher, school nurse).
- Encourage disclosure to those who are trusted and significant in the adolescent's life (for example, best friend, youth group leader).
- Connect them to an adolescent support group and/or treatment buddy.
- Help them to become confident in taking their ART and to maintain a positive attitude toward their treatment.

Missing a dose:

- If a child misses a dose, there is a four-hour window in which the dose can be given (for twice daily medication). Do not give two doses together.
- Help the child to find ways of remembering to take medication.
- If a child vomits, repeat the doseafter two hours.
- If a child if feeling unwell, encourage them to take the medication despite feeling unwell. Give praise afterwards.

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

Adherence and adolescents

There are many reasons why adolescents might fall out of treatment. For many, ARVs simply don't fit in with their lifestyle — it may be hard to remember to take them every day or the medication might make them feel sick. For others, it may be the stigma associated with taking pills. Some adolescents might feel sad or even depressed about their HIV status, and taking ART might remind them of the disease. For some, poor adherence may be an act of asserting independence from adults. Understanding why an adolescent is not taking their medication is important in order to be able to help and support them in the right way

Identifying treatment failure

In some cases, the treatment that children, adolescents and pregnant and breastfeeding women living with HIV take will not work properly. As discussed earlier, if ARVs aren't adhered to, the HIV might become resistant to the drugs being taken and continue to destroy CD4 cells. There may also be other reasons that a patient's HIV could become resistant to the ARVs they are taking. When resistance happens, patients will start to become sick again. CHWs are well placed to be able to identify early on when treatment might be failing, to notify doctors or nurses in the clinic, and encourage patients to go to the clinic as soon as possible. Once treatment failure has been confirmed, the doctor or nurse might change the ARVs that a patient is taking in order to try to fight the virus with another drug. CHWs can then help patients to correctly adhere to the new treatment.

Tracking and tracing those who default treatment

If a patient isn't taking, or stops taking their ARVs (called non-adherence), they can quickly become sick and the virus can become immune to the drugs. As CHWs spend much of their time in the community, you are often better able to identify those who are defaulting treatment, find and invite them to come back to the clinic, and encourage them to start treatment again. It can be very difficult to adhere to ART, and those who default treatment should not be judged or blamed for their poor adherence or concerns. Rather, you should encourage them to come back into care, try to understand the difficulties they are facing, and find a way for them to address these challenges.

Infants, children and adolescents sometimes have more difficulty than adults taking their medications for a number of reasons. The chart on the previous page includes some guidelines, tips and tools you can use to help your patients to make sure they are adhering to their ARVs.

Transitioning adolescents to adult care

In many countries, children and adolescents are cared for in a separate paediatric or adolescent clinic on a separate day or by separate healthcare workers. The move ('transition') for adolescents from a paediatric or adolescent to an adult setting can be a challenging time and needs to be managed carefully. Adolescents should be involved in the planning of this transition as much as possible. Specific staff in the adult clinic should be identified and introduced to the adolescent, and joint discussions held with both new and old healthcare workers and the adolescent, to address any questions they may have and to ensure continuity of care. Adolescents who have successfully made the transition can act as role models and guides to others who are transitioning.

— adapted from ANECCA, *Handbook on Paediatric AIDS in Africa*, 2011.

Side effects of ART

One of the hardest parts of taking ARVs can be dealing with their side effects. A side effect is a bad reaction to the medicine in the body — it can be expected or unexpected, mild or severe.

There are a number of side effects that patients might experience that will disappear after a few weeks of starting ART. However, patients should continue to take the drugs regardless of these side effects. Some side effects are mild and will go away by themselves, while some are more serious and might cause the doctor or nurse to switch the patient's drugs. If a child, adolescent or adult has any of the severe reactions mentioned below, it is very important that you help them to get to a clinic or hospital immediately, as some reactions can be severe enough to cause death. A patient should never decide to stop taking all or some of the drugs themselves.

Patients need help to recognise side effects and decide which are serious and which will pass. You should encourage patients to visit the clinic when necessary. Make sure to ask patients every time you see them if they are having any of the side effects below.

Urgent side effects — go to the nearest clinic or hospital immediately!	**Non-urgent side effects — go to the clinic within one week**
Difficulty breathing Trouble swallowing Swollen eyes or tongue Blisters or sores Vomiting (continuing for several days) Rash (itching, severe or broken skin) Abdominal pain Yellow eyes or palms (jaundice) Fever	Mild nausea/vomiting Headache Diarrhoea Rash or skin issues (minor) Tiredness Nervousness or anxiety Trouble sleeping or nightmares Numbness or tingling in feet Muscle pain Loss of appetite Night sweats

For non-urgent side effects, CHWs help patients and caregivers to understand, prepare for and manage their side effects. Some of the most common side effects include the following:

Common side effects	Advice CHWs can give
Mild nausea and vomiting	• Usually disappears after 2–4 weeks. • Better if patients take ARVs with food, but stay away from greasy, fatty or spicy foods. • Eat small meals more often. • Drink lots of clean, boiled water, weak tea, lemon water or rehydration salts to avoid dehydration. • Visit the clinic if a fever is present, vomiting continues for several days, the patient can't drink anything, or has severe stomach pains.
Headache	• Usually disappears after 2–4 weeks. • Rest in a quiet, dark room. • Put a cold cloth over face and eyes. • Don't drink strong tea or coffee. • Visit the clinic if it doesn't go away with paracetamol, a fever is present, or there is vomiting, blurry vision or convulsions.
Diarrhoea	• Usually disappears after 2–4 weeks. • Eat small meals more often. • Eat soft foods (for example, rice, bananas) and stay away from greasy, fatty or spicy foods. • Drink lots of clean, boiled water, weak tea, lemon water, or rehydration salts to avoid dehydration. • Visit the clinic if there is blood or mucous in the diarrhoea, a fever is present, if diarrhoea occurs more than 4–5 times in a day or for 5 or more days in a row, or if the person loses more than 2 kg.
Rash or skin issues	• Keep skin clean and dry. • Only use mild soaps. • Drink a lot of clean, boiled water to keep skin healthy. • Visit the clinic if the itching is severe, skin is peeling, looks infected (for example, has pus), is blistering, or has open sores; also visit the clinic if the patient has a fever or if the rash is in the eyes or mouth. • If taking the drug Neverapine, visit the clinic if there is any kind of rash.
Tiredness	• Avoid alcohol and drugs. • Do light exercise (for example, take a walk). • Eat lots of fruit and vegetables; get lots of iron. • Take multivitamins. • Try to get enough sleep at night and rest during the day if needed. • Visit the clinic if there is alcohol dependence or abuse or the patient may be depressed.
Trouble sleeping or nightmares	• Usually disappears after 2–4 weeks (most common with patients taking Efavirenz). • Take pills at bedtime. • Avoid heavy meal before bedtime. • Avoid alcohol. • Avoid food or drink with sugar or caffeine before going to bed. • Talk about feelings and worries with CHW, friends or family members. • Visit the clinic if they are depressed and/or suicidal.
Numbness or tingling in feet	• Wear loose socks and shoes to protect the feet. • Check feet to make sure there are no infections or open sores. • Keep feet uncovered when in bed. • Soak feet in warm water and massage them if this helps. • Keep feet up when possible. • Don't walk too much at one time; take regular breaks. • Eat healthy foods and take multivitamins daily. • See a doctor or nurse if the patient can't walk, is in pain, or is weak. • Visit the clinic if the symptoms are not getting better; the doctor or nurse may be able to decrease the dose.

Know when to get the patient to the clinic

Many of these side effects are not serious and will disappear on their own, but you should help patients to decide if they should go to the clinic to be checked. Remember, patients should never stop taking their ARVs because of side effects unless they are advised to do so by a doctor or nurse. If they do, they may increase their risk of becoming sick.

Exercises for Section 3: Treatment & Care

Key take away messages:

- **Treatment is life saving.**
- **Positive treatment outcomes rely on adherence to treatment and retention in care.**

Questions:

1. During the course of your day, visit at least one patient who is new to ARV treatment. Explain to them the tools used in your clinic — show them examples of the treatment cards, describe why adherence is so important and how it is measured, and give advice about giving medicines to children.

2. Conduct a pill count in one household and report the results back to your supervisor. If the patient isn't adhering to ART, present your suggestions about what might help the patient to get back on track. If they are adhering, present any risks that you see that might make them not adhere in the future, and what you might do to help them keep taking the medicine.

3. Conduct an interview with a family with young children during a home visit to assess their nutritional status and food security situation. You can use tools like asking them to remember what they have eaten and drank in the last 24 hours or what and how they are feeding the children. If you think they need nutritional support, make suggestions based on their needs — for example, help them to set up a community garden, get the mother support for breastfeeding or give suggestions on what kinds of food they can give older infants for complementary feeding, or refer them to more specialised services if they need them.

Further reading about HIV treatment and care

Want to learn more? The resources below served as references for the information presented in this section, and are a great source for more in-depth information on the topics covered here. For even more, see Annex 3.

- TAC, *HIV in Our Lives*, 2007.
- AIDSTAR-One, *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*, 2014.
- S2S, *Psychosocial & Adherence Counseling Support Training Toolkit,* 2010.
- Treatment Action Campaign (TAC), *HIV, Pregnancy & Your Choices: A fact sheet for parents to be*, 2011.
- TAC, *Pregnancy in our Lives*, 2010.
- AIDSTAR-One, *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*, 2014.
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- International HIV/AIDS Alliance, *Community Engagement for Antiretroviral treatment: A training manual*, 2006.
- International HIV/AIDS Alliance, *Young Children and HIV: Strengthening family and community support,* 2006.
- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.
- UNAIDS, *Handbook on access to HIV/AIDS-related Treatment: A collection of information, tools and resources for NGOs, CBOs and PLWHA groups*, 2003.
- PIH, *Accompagnateur's Handbook*, 2012.
- Avert, *HIV and Breastfeeding, www.avert.org.*
- Avert, *HIV Opportunistic Infections, www.avert.org.*
- S2S, *Paediatric HIV Care and Treatment: A Toolkit for South African Healthcare Workers*, 2010.
- WHO, *Consolidated Guidelines of the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection*, 2013.
- WHO, *Flipchart for Patient Education: HIV Prevention Education and Care*, 2006.

Section 4:

Psychosocial Support

Section 4.1: Including Psychosocial Support in Treatment and Care

Medical care is very important for those living with HIV. Without it, they are more likely to become sick and pass the infection on to other people. However, HIV is a disease that also has a big impact on the psychological and social wellbeing of children, adolescents, families and communities. PLHIV need more than just medical care to stay healthy and well. They also need support to deal with how they are feeling, how their family and community may react to them, and how to deal with these emotions. We call this type of non-medical care psychosocial support (PSS). When people receive this care and support, they have the strength to better deal with the challenges of living with HIV.

Psychosocial support works best when it is included in all aspects of healthcare. It is often easier to focus on clinical needs at the expense of psychological and social needs, as many people fear talking about sensitive issues such as sex, illness, death and relationships. However, it is important to remember that HIV is not just a medical condition. Children, adolescents and their caregivers should feel emotionally and socially supported in all parts of their life — at school, in the community and at the clinic. It has been shown that integrating PSS into clinical care helps patients to take more responsibility for their own treatment, and improves their adherence.

The definition of psychosocial

The term 'psychosocial' is a combination of two words:

- **Psychological:** The mind and how it works (the feelings, emotions, thoughts, understanding, attitudes and beliefs that an individual has).
- **Social:** The personal relationships that we have with other people and how we relate to the world around us.

We link the two ideas together to show the important relationship between them — an individual's state of mind as well as their larger social world — and the wellbeing of the patient.

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

What causes psychosocial problems in HIV-affected and infected children and adolescents?

There are a number of factors that can cause psychological and social problems for children and adolescents living with or affected by HIV at the individual, family and community level.

At the individual level:	At the family level:	At the community level:
Poor parenting	Illness in multiple family members	Lack of knowledge of HIV
Separation from brothers and sisters	Poverty	Lack of knowledge of children and adolescents' needs
Chronic illness	Stigma and discrimination by family members	Poverty
Death or sickness of a caregiver	Loss of family members	Stigma and discrimination
Loss of home and instability	Dysfunctional relationships (abuse, substance abuse, domestic violence)	Over-stretched communities from increasing numbers of orphans and vulnerable children
Death and grief	Child-headed households	Negative peer influence
	Elderly caregivers	

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

When children and adolescents are at the clinic, it is an opportunity to make sure that their psychosocial needs are being met. You and the clinic staff can assess how they are doing emotionally, and note whether they might need additional support. In the same way, when you visit patients' homes, you can get a sense of how children, adolescents and their caregivers are coping emotionally and provide them with encouragement, or connect them with other resources to meet their particular needs. By integrating PSS into clinical care at your clinic, you can help more children, adolescents and their families to deal with their emotional and social needs.

Stigma and discrimination

Stigma and discrimination are still among the most common psychosocial challenges faced by children and adolescents.

- ***Stigma*** is when someone is labelled in a negative way because of a particular quality or circumstance, such as being HIV-positive. People who are stigmatised are seen as being different, and blamed for that difference.

- ***Discrimination*** is stigma in action. Discrimination means that someone is treated differently, denied rights or opportunities, or even abused psychologically or physically.

CHWs can help to build a trusting relationship with their patients by letting them know that you do not judge or blame them for their HIV status or the decisions they make around it. You can also help to reduce stigma and discrimination in your community by educating people about HIV and dispelling myths and rumours about HIV.

Physical symptoms:
- Pain
- Fatigue
- Generally not feeling well

Behavioural symptoms:
- Restlessness
- Hyperactivity
- Withdrawal and self-neglect
- Aggressiveness
- Sleep problems
- Acting out
- Rule breaking or lawlessness
- Drug or alcohol abuse
- Sexual promiscuity

Emotional symptoms:
- Irritability
- Depression
- Sadness
- Mood changes
- Anxiety
- Fear
- Anger
- Temper tantrums
- Suicidal tendencies

Cognitive symptoms:
- Inability to concentrate
- Poor development or regression on milestones
- Forgetfulness or poor memory
- Confusion
- Poor academic performance

Social symptoms:
- Social withdrawal and isolation
- Antisocial behaviour

Psychiatric symptoms:
- Confusion
- Forgetfulness
- Disorientation
- Memory loss
- Personality changes
- Anxiety
- Agitation
- Hallucinations
- Delusions
- Mood disorders

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009 and REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment,* 2008.

Children's PSS needs:

Children need love, support, reassurance and acceptance, as well as a sense of belonging, to thrive and cope with life's difficulties. Children affected by HIV are often especially vulnerable to emotional distress. This distress can come from many sources — the illness itself, loss of loved ones, stigma and discrimination leading to isolation or abandonment, low self-esteem, and feelings of guilt and despair. Psychosocial issues can materialise in many ways.

CHW's role in PSS

CHWs are uniquely able to help caregivers, children and adolescents to deal with these issues, as you are trusted members of both the community and clinic environment, who may have faced some of the same challenges yourselves. CHWs living with HIV understand what their patients are going through in a way that people not living with HIV cannot. The caring and understanding relationships that you build with your patients, and the encouragement you give them, are the most important and powerful forms of PSS you can give to children, adolescents and caregivers dealing with HIV. Specifically, CHWs can:

- **Act as role models for positive living.** CHWs living with HIV in particular can be great role models for patients, showing them that it is possible to follow their drug regimens, live positively, and discourage stigma and discrimination.
- **Encourage patients to disclose their status to trusted individuals,** such as spiritual or religious leaders, as well as close family and/or friends who will listen without judgement and help to relieve the burden of dealing with the illness alone.
- **Help families to deal with age-appropriate disclosure,** helping them to decide when and how to disclose a child's HIV status, as this can be a worrying time for caregivers. CHWs can provide families with the necessary tools and guidance to disclose to children at the most appropriate time and in the best way (see Section 4.1 for more information on disclosure).
- **Provide caregivers with resources on ECD,** and hold age-appropriate playgroups (see Section 1.2 and Section 4.3 for more information on the importance of play for children).
- **Assess a child's psychosocial state,** and help caregivers to develop an effective care plan to support children to be as independent and high functioning as possible.
- **Encourage patients to get the help they need,** which could include joining support groups where they can connect and share experiences with other PLHIV, or playgroups for children. Family therapy can support relationships and communication and improve the patient's family environment. You might also refer patients to counsellors or psychologists where these are available if they need more specialised help (see Section 5.2 for more information on referrals).

While PSS can include a wide variety of interventions, two of the most common issues that CHWs address with families are disclosure and ECD. When and how to disclose HIV status to a child is a challenge that CHWs can help to address. CHWs can also help caregivers to understand children's development, and to learn to create an environment where children have the opportunity to grow and meet the goals of each stage of development in a positive, healthy way. This section will provide you with tips and tools to help in these two areas.

Postpartum depression:

Postpartum (or postnatal) depression (PPD) is a serious illness that women sometimes suffer from after giving birth. Mothers with PPD might feel sad or cry all the time, be anxious or irritable, feel exhausted, have no energy, or pull back from normal social interaction. PPD can affect the care that the mother is able to give her infant — when a mother feels depressed or anxious she might find it difficult to take care of her child. PPD can also make it hard for the mother to bond with her infant in some cases.

You should be on the lookout for signs of PPD in all new mothers, but especially mothers with HIV — these mothers may be at increased risk of PPD as they have extra stress and worry around whether the virus has been passed on to the infant, and they may be concerned about how to get the right care and treatment for the infant if needed. If a mother has PPD, these worries can seem impossible to deal with. PPD usually shows up within the first eight weeks after the infant is born, but can develop up to a year later. Mothers who have PPD will probably not know why they are feeling so unhappy and unable to cope. If you think a mother might have PPD, make sure to help them to get to the clinic to talk to a healthcare worker urgently.

PMTCT PSYCHOSOCIAL ASSESSMENT GUIDE AND RECORDING FORM (to be used with all pregnant and postpartum women after testing positive for HIV)

Client's Name: ______________________________ Client's File# ______________

COPING

1. What feelings or concerns do you have, now that you know your HIV status?	
2. Can you tell me how things have been going since you learned your HIV status?	

FAMILY, CHILDREN, AND PARTNER

3. Who lives with you at home? *Counsel on family-testing, care and treatment*	Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship: Name: Age: Relationship:
4. For the children who live with you, can you tell me if each has been tested for HIV and their status? *Counsel on HIV testing for all children, even if they seem well, and importance of early care and treatment for HIV infected children*	Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No Name: Age: Tested: Yes/No/? Result: pos/neg If positive, in care and tx: Yes/No
5. Has your partner been tested for HIV? *Counsel on partner testing and discordance*	Yes No Don't know
5a. If yes, what was the result?	Positive Negative Don't know If positive, in care and treatment? Yes No Don't know
5b. If no, do you think he would be willing to come for an HIV test?	Yes No Don't know

DISCLOSURE

6. Have you disclosed your HIV status to anyone? *Follow up on pre-test counselling. Counsel on full and partial disclosure*	Yes No
6a. If yes, to whom? What was their reaction?	
6b. If no, how do you feel about disclosing to someone you trust? What support do you need?	

SUPPORT SYSTEM

7. Who can you go to for emotional support? *Counsel on importance of social support*	
8. Do you belong to a community organization, support group, or religious group? *Refer to support group, if needed*	Yes No Name and location of organization or group:
8a. Would you be willing to join a support group at this clinic (if applicable)? *Give information about the support group*	Yes No
9. How will you remember when to come back to the clinic for your appointments? Is there someone who can help you? *Counsel on adherence to care*	
10. How will you remember to take your medicines? Is there someone who can help you? *Counsel on adherence to medicines*	

Psychosocial assessment

Before a CHW can help a family to deal with a child or adolescent's specific psychosocial needs, you first need to understand a family's strengths, coping abilities and vulnerabilities. To do this, you may conduct a psychosocial assessment during home visits. A psychosocial assessment could include the living arrangements, who is part of a family and its background, the levels of employment of adults in the family, what role religion plays in the family, how involved and supportive extended family is, whether the family has the basic life necessities, and the family's overall strengths, capacities and resources. The assessment tool here is just one example of questions you could ask to help you understand a patient's PSS needs.

— adapted from S2S, *Psychosocial and Adherence Counseling Support Training Toolkit*, 2010.

SUPPORT SYSTEM continued

11. Who will help you take care of the baby and give the baby medicines? *Counsel on importance of bringing baby back often and adherence to care and medications*	Name(s) and relationship(s):
11a. If you cannot bring the baby back to the clinic, who else will be able to bring the baby?	Name and relationship:
12. Would it be ok if we call you (or someone you trust) if you miss an appointment at the clinic?	Yes No Phone number: Own phone or other's?:
13. Have you experienced or do you fear discrimination or violence? *Counsel and refer for more support*	Yes No Details:
13a. If you experience stigma, discrimination, or violence, or if you are afraid, what do you think you will do? *Counsel on available support services, including at the clinic*	
14. Do you have a regular source of income or do you receive help, such as social grants, food parcels, or others? *Counsel and refer to social worker and community-level support*	Yes No Sources of income/support: Receiving social grant? Yes No

PLANS FOR HER OWN AND BABY'S CARE

15. What are you going to do to stay well during and after your pregnancy and to reduce the chance that your baby will be HIV infected? *Counsel on PMTCT during and after pregnancy including ARVs/ART*	
16. How do you plan to feed your baby? Do you have any questions or concerns? *Counsel on infant feeding choices, safer infant feeding*	Exclusive breastfeeding Exclusive formula Not sure Final infant feeding choice:
17. What do you think are the most important things you can do to care for your new baby? *Counsel on care for HIV exposed infants, including ARVs and testing at 6 weeks, and on bringing the baby back often for all clinic appointments*	

QUESTIONS, SUMMARY, AND NEXT STEPS

18. What other questions or concerns do you want to discuss today?	
19. *Summarize the session and review immediate plans and next steps, including the next clinic visit date*	Note next steps here and in the space below:

Additional notes:

Referrals made:

Date of next counselling session/clinic appointment: ______

Lay counsellor's signature: ______ Date: ______

Section 4.2: Disclosure to Children

We use the word disclosure to talk about the process that a person goes through to tell others that they are living with HIV. It can be a difficult process for people to decide if they want to tell others, as disclosure may lead to stigma and discrimination based on misunderstandings about the disease.

When we talk about disclosing to children, we are referring to the process of telling a child that they are living with HIV. This can be an incredibly difficult thing for caregivers to do, and CHWs can help them to navigate the disclosure process, supporting them to communicate in the right way with the child so that he or she comes to understand the meaning of the illness.

Challenges of disclosure

Telling a child about their HIV status can be frightening for a caregiver. HIV is a serious illness that could cause death if not treated. It is not an easy concept to explain, especially to a young child. How the child contracted HIV is especially difficult for many families to talk about, as it may be related to sex, which is a taboo topic to discuss in many households. Caregivers also want to protect their children as long as they can to make sure they have a happy childhood, and may not see the value in possibly upsetting them by disclosing to them. They may also blame themselves or feel guilty about their child's HIV status.

To make things more difficult, if the caregiver is HIV-positive themselves, they may not have disclosed their own status to their community for fear of stigma and discrimination. Caregivers may need to be supported to deal with their own fears around disclosure before they can confidently disclose to their children.

For children and adolescents who are aware of their status, CHWs can help them to identify which trusted individuals they could disclose to, and help them to find the support they might need through religious organisations, counsellors, supporters at school or other networks.

What is a good age for disclosure?

Disclosure is a process that may start as early as two or three years of age (or whenever the child starts asking questions about their health), and continues as they become older and better able to understand more details about their illness. What one tells a five-year old will be very different from the much more detailed and specific information one might give to a 12 year old. The ideal age for full disclosure is usually around 8 –11 years, depending on if the child is ready developmentally. The later the child is told about their illness, the harder it will be for them to accept it.

— adapted from S2S, *Disclosure Process for Children and Adolescents Living with HIV: Practical Guide*, 2009.

Benefits of disclosure

Despite being difficult to do, there are many benefits to telling a child about their status. It is important for caregivers to disclose to children because disclosure:

- **Improves adherence and treatment outcomes:** When children know their HIV status, they can be involved in their own healthcare, and will be more likely to live positively and adhere to ART.
- **Builds trust:** Disclosing to a child shows them that you trust and respect them.
- **Builds relationships:** By avoiding secrecy and lies we can help families to build stronger relationships. For a child to find out they are HIV-positive from someone other than their caregiver can seriously harm the trust relationship.
- **Children can cope better:** Giving children accurate information helps them to handle any stigma and discrimination in the community.
- **Families can plan together:** Once children know their status, families can plan together for the future.
- **Allows for informed choices:** Adolescents can make informed choices about sexuality and sex.
- **Dispels fears:** Children often know more than we think or give them credit for. They tend to know when something is being hidden from them, which can lead them to imagine a secret worse than the reality.
- **Increases hope:** Disclosure provides opportunities for sharing positive messages with a child.
- **Improves access to healthcare:** It is easier for caregivers to ensure that children have consistent care when they can be taken to clinic visits openly and medications can be named and explained.

If caregivers do not disclose to their children, the child could become depressed, feel bad about themselves for feeling or looking sick, refuse to take drugs, discover their HIV status from someone other than their caregivers, lose trust and confidence in their caregivers, and be confused by mixed messages.

Partial disclosure refers to telling a child only some information about their illness, for example, that they are sick and must take medicine. With partial disclosure, the term 'HIV' isn't yet shared with the child. This approach is often used with young children who may not be able to grasp the full meaning of their illness.

Full disclosure means naming and giving more HIV-related details, for example, how it is transmitted and how the child might have contracted it. Caregivers must decide when full disclosure is possible. An important sign that full disclosure should be considered is when the child starts asking specific questions about their illness—for example, how did they get sick — and no longer seems to be happy with the answers you are giving them.

— adapted from S2S resources, including *Disclosure Process for Children and Adolescents Living with HIV: Practical Guide,* 2009 and ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

CHW role in disclosure

The caregiver is responsible for disclosing to a child. As CHWs, you play an important role in helping caregivers to have the courage, confidence and capacity to disclose to a child. As we've discussed, building a trusting and honest relationship with both the caregiver and the child is one of the most important things you can do. By avoiding judgment and understanding the caregiver's fears and concerns, you can help them to understand why they should disclose to the child and are prepared with the tools to disclose in a sensitive and appropriate way.

Disclosure is a gradual process that takes place over time; it is not a once-off event. Caregivers can decide to fully disclose to a child, or provide partial information as the child is ready (partial disclosure). There is no clear process of how or when a caregiver should disclose. There are many different options, and the path chosen needs to be right for the caregiver and their situation. You should be careful not to force them into disclosure — caregivers need to be ready in order to handle the questions and concerns the child will have. Instead, you should talk about the benefits of disclosure and help to address any concerns they have so that they are encouraged to disclose.

Phases of disclosure to children

Many caregivers go though different stages in the process of preparing themselves to disclose to a child. It can be useful for CHWs to understand these phases when talking with caregivers about disclosure.

— adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Phases of disclosure to children

Secretive phase

Caregivers may want to keep the child's diagnosis to themselves.

Usually right after the child's diagnosis, caregivers may only tell a few people, like a partner, close friend or family member. The only people who know the child's status in this phase are the healthcare workers in the child's care and the caregiver herself. At this stage, thinking about disclosure causes anxiety and denial.

Exploratory phase

Caregivers may tell a person who is close to them to test their reaction.

Caregivers answer other people's questions about things like clinic visits with vague replies and false explanations, such as that the child is sick with something else. They will give their children incorrect but believable explanations for clinic vists, but they will begin to undersand and accept the need for disclosure at some distant point in the future.

Prepatory phase

Caregivers are now ready to disclose to a wider group.

Caregivers may also now be intrested in hearing about the experience of other caregivers and children. They begin to think more concretely about ways they might disclose to the child, although they still may not have made a definite decision to do so.

Disclosure phase

Caregivers take steps to disclose to their child.

If the child confronts them, they try their best to give clear answers. A lot of preparation needs to take place in this phase. The healthcare worker can help the caregivers decide which is the best approach for disclosure to a particular child, based on the child's age, developmental stage, and level of maturity. There is no blueprint for disclosure, but there are some important general principles.

Preparing caregivers for disclosure

CHWs play an important role in explaining to caregivers why disclosure to the child is important, and what can happen if they are not told by their caregivers and find out another way.

Once caregivers are ready to disclose to their children, CHWs can help them to prepare for the disclosure by:

- **Reviewing disclosure guidelines:** Review the guidelines on disclosure below with the caregiver.
- **Talking about fears:** Ask the caregiver to share how he or she might disclose the child's HIV status, and talk about what will be helpful and what won't. Caregivers should be encouraged to think of hopeful messages that they can share with the child.
- **Practicing disclosure:** Encourage the caregiver to practice the disclosure conversations with you or someone they trust.
- **Planning for questions:** Help the caregiver to anticipate questions they might be asked by the child and think through how they might respond to these questions.

It is important that CHWs remind caregivers to be led by the child's questions and reactions as they decide how much information to share at a certain time. As mentioned earlier, disclosure is a gradual process, and caregivers do not need to tell a child everything at once. Caregivers should always keep what they say simple, clear, and honest.

Basic guidelines when disclosing to a child

CHWs can help caregivers to keep these points in mind when preparing to disclose to a child:

- Make sure you are in a quiet place without any interruptions.
- Consider the personality of the particular child and the situation they are in.
- Remember there is no blueprint that covers all children or situations. The individual child's needs and the nature of the relationship between the child and the caregiver should be taken into account.
- You should use language that is right for the child's level of development, education and readiness.
- Create a situation where the child will feel free to ask questions. Try not to avoid questions that the child may ask.
- Make sure that disclosure is part of an ongoing conversation.
- Emphasise that HIV is a common illness, like asthma and diabetes. It is not curable, but it can be treated and is not a death sentence.
- If you do not know the answer to all of a child's questions, try to find the answers and come back to them.

— adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Guidelines for disclosing to different age groups

Giving information to preschool children (under six)

- Emphasis should be on the child's health and illness.
- Disclosure of HIV status will generally be delayed until later.
- Give information in response to the child's questions ("why does the doctor take my blood?") or reactions (refusing to cooperate with the doctor).
- Give explanations that answer questions - don't add unnecessary details.
- Use play activities (for example, doctor-doctor or dolls) to allow the child to communicate any concerns or express feelings indirectly.
- Tell young children about germs in general.
- Young children need reassurance and comfort, and to know that doctors and medicine can help them to feel better.

Giving information to primary school children

- Give more detailed information with concrete examples.
- If a child asks for more information (such as, "what's the germ called?" or "how did the germ get in my body?") give short, clear answers.
- Stop when the child seems satisfied. They can always ask for more information later when they are ready.
- Help the child deal with possible stigma.
- Reassure the child that they can ask further questions or express more concerns.
- Focus on general health and hygiene (eat well, keep clean, look after their teeth, and rest).

Giving information to adolescents

- You should give accurate and more detailed information in response to questions or to add to information given earlier.
- You should give realistic information about health status.
- Different ways to live meaningfully with HIV is often of more concern to adolescents than the actual mode of transmission.
- Assuring them that their status and what they say to you is confidential is very important.
- Normal teenage striving for independence may make the response to disclosure more complicated (for example, adherence may decline).
- Issues of possible disclosure to others should be discussed. The adolescent should make their own decisions about this.
- Assurance of support and willingness to help should be given without seeming intrusive.

Different age groups need different information

Depending on age, different levels of detail and language should be used to talk about HIV. You should always be honest with a child, but they may not yet need to know or be ready to hear detail about the disease.

– adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment,* 2008.

During disclosure

Some caregivers may prefer that a CHW is with them during the process of disclosure to their child. You should make sure the caregiver knows that whatever happens during the session will stay confidential, and that you will be there to provide ongoing support as needed. You can initiate disclosure during a visit to the clinic, or in the child's home.

- Make sure you have plenty of time and won't be interrupted or have to rush off.
- Assess the child's knowledge about why they come to the clinic and why they take medication, and also what they have already been told.
- Create a safe space and allow the child and caregiver to share feelings openly.
- Be prepared to deal with emotions like denial, fear, bitterness, grief and pain, and to handle outbursts and tears from the child and even the caregiver. Allow them to move through the process at their own pace.

Some questions you might be asked:	Possible answers and considerations:
How did I get HIV?	"Let's talk (or read) about the way children can get HIV and then talk about how you got it"
Do you have it?	"Yes, I have it too just like you. I am also taking medicines and looking after my health." Or "No, I do not have HIV, but I am going to be with you every step of the way, supporting you."
Where did you get it from?	You could say "This is a private matter and I am not ready to talk about it," or be more open and say to an older child "I got HIV through sex. When you are older, we will talk more about this. When you are ready to have sex, you should speak to me or a doctor, nurse, counsellor or CHW first so that we can teach you how to keep yourself and your partner safe."
Why must I take medication? Can I stop taking medicine?	"The medications stops HIV from multiplying, which will help you to stay strong and well." "You will need to take medicines until the doctors find other ways of helping your body live with HIV."
Will I be sick forever?	"There is no cure yet. HIV will live in your body forever, but this does not mean you will feel sick. You can live with HIV like any other disease. We need to help your body to stay strong so that you will feel well most or all of the time. You can take medicine, visit the clinic, eat healthy foods and keep a positive attitude. Remember, we will always love and support you."
Will I die?	(The feeling behind this question is fear and confusion. It is very important to respond appropriately.) "Death is a scary thought for us all, but if you take this medication properly there is no reason why you should not live as long as anybody else. There are also special doctors and scientists who are looking to find other ways of fighting HIV, but for now we have this medicine which will help you to live a long and healthy life".
Who can I tell?	(This is something caregivers might need to consider before the disclosure sessions.) "Having HIV is not a bad or shameful thing, but it can be a private thing. You can talk to me, your father, mother, nurses, counsellors and other children at the clinic (add trusted others the caregiver feels comfortable supporting disclosure to)." Help your child to feel free to talk to you at any time about any unkindness they may experience themselves or witness someone else experiencing. Ask your child about ideas of what he or she would like to say or do to respond to unkindness. Make sure your child knows that you are there to give love and support. You could say: "Not everyone understands about HIV. It is better to talk to people who understand and know the facts. When people don't understand, they get scared. Scared people sometimes say hurtful things. Who would you like to tell and why? What do you want them to know? We might be able to tell them together."

Questions and answers that caregivers might face during disclosure

Caregivers should think through the questions they might face from the child during and in the period after disclosure and how they could respond to these questions. A few questions that they might expect and some ideas for responses are below — you can go through these with the caregiver prior to the disclosure discussions.

— adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Post-disclosure follow-up

In the same way that they prepared for disclosure, caregivers should plan how they will respond to and support the child in the period following disclosure. CHWs can play an important role in this period as well. You can:

- **Continue to build strong relationships with the child and family:** The same CHW should try to work with the same family to make sure there is consistency and connection built.

- **Support caregivers to deal with emotions:** It is normal for children to have many different kinds of reactions to disclosure — anger, sadness, denial, shock, or a combination of these and other feelings. CHWs should encourage caregivers to pay attention to how the child is feeling, encouraging the child to talk about how they are feeling and why.

- **Encourage hope and a positive outlook:** Learning about one's HIV status can be very difficult and cause some children to develop low self-esteem and a negative outlook on life. You can help the child to draw on their own inner strength as well as support from caregivers, community and friends to improve self-perception and outlook on life. You can also help children to explore talents like song, dance, and drama that can be tapped into to enhance the child's self-esteem. Encourage children to think about the future by discussing their hopes and dreams.

- **Encourage healthy living:** Talk about personal hygiene, sexuality, self-awareness, stress management and modelling healthy living yourself.

- **Refer caregivers or children for additional support if needed:** If caregivers face reactions or situations that they find hard to manage alone, they should know about additional support options that are available to them. CHWs can help to identify families that may need additional help and refer them for assistance (see Section 5.2 for more information on referral networks).

- **Encourage involvement in support groups:** It can be very helpful for caregivers to have others in the same situation to talk to while they are going through the disclosure process. CHWs can help caregivers to find and take part in these support groups. Similarly, children can also benefit from spending time with other HIV-positive children who understand what they might be feeling.

- **Continue to provide information:** The need for information doesn't stop when a child finds out about their status; rather, they will have more questions and concerns over time. CHWs, clinic staff and caregivers should be a source of accurate, up-to-date information for children, and be available to them whenever they have questions.

Section 4.3: Child Development

Supporting child development is part of holistic, family-centred care. When we look at a child's ongoing process of growth, we need to provide them with the opportunities and support to reach their full potential.

Each child is different, developing emotionally, socially, intellectually and physically at their own pace. There are, however, some major developmental milestones that children should reach at around the same time. Understanding these stages of development can help you to interact with children in age-appropriate ways and help caregivers to give children the right kind of support to encourage their development. Since HIV can sometimes cause delays in development, caregivers also need to know how to identify developmental problems and where to go for help and support.

CHWs' role in child development

CHWs often interact more with families in clinics, homes and the community than other healthcare workers. This means that you may have more opportunities to observe children, formally and informally, to assess their development, and raise any concerns you have with healthcare workers. To do this, you need to be aware of what is expected of children at different ages and stages of normal development, and know to whom in the community you can refer children if you suspect developmental delays.

In addition to observing and assessing children's development in the home, CHWs play an important role in strengthening families' abilities to support growth and development. When caregivers understand different stages of child development, and how to interact with children in age-appropriate ways, they are better equipped to help children to meet their developmental milestones.

In clinics, CHWs are often in charge of creating or looking after child-friendly spaces and interacting with children in a targeted way. This can range from playing age-appropriate games with children while they are waiting for their clinic appointments, to leading more formal ECD activities and helping caregivers to learn about child development.

Holistic child development

"Holistic child development is the ongoing process of growth that starts from the moment children are conceived and continues until they reach adulthood. It includes the intellectual, emotional, spiritual, social and physical development of children, and is concerned with helping them to reach their greatest possible potential."

Developmental milestones

Developmental milestones are the skills children gain as they grow and play. All children should reach these milestones at roughly the same time if they are developing normally.

— REPSSI, *Psychosocial care and support for young children in the time of HIV and AIDS*, pg. 13, 2007.

Developmental delays

When a child is less developed, mentally or physically, than what is expected for his or her age, we say that they have developmental delays. These delays can range from mild to severe, and may require specialist attention to help the child get back on track.

— adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Stages of development

While each child develops emotionally, socially, intellectually and physically at their own pace, there are well-defined stages of development that each child should pass, and generally in the same order. These stages cover all aspects of a child's life.

Motor (gross and fine) skills

Movements that are carried out when the brain, nervous system, and muscles work together to complete a task, such as rolling over, crawling, picking up small objects or holding a spoon. Some examples of motor skills milestones are below:

by the age of 1 month

An infant should be able to:	• Turn their head towards a hand that is stroking their cheek or mouth. • Bring both hands towards their mouth. • Turn towards familiar voices and sounds. • Suckle the breast and touch it with their hands.
Advice for caregivers:	• Make skin-to-skin contact and breastfeed within one hour of birth. • Support the infant's head when you hold the infant upright. • Massage and cuddle the infant often. • Always handle the infant gently, even when you're tired or upset. • Breastfeed frequently and on demand. • Always safely disposed the infant's faeces and wash your hands with soap and water or a substitute, such as ash and water, after changing the infant. • Talk, read, and sing to the child as much as possible. • Give consistent love and affection. • Visit a trained healthcare worker with the infant during the first week and again six weeks after birth.
Warning signs to watch for:	• Poor suckling at the breast or refusing to suckle. • Little movement of the arms and legs. • Little or no reaction to loud sounds or bright lights. • Crying for long periods for no apparent reason. • Vomiting and diarrhoea, which can lead to dehydration.

by the age of 6 months

An infant should be able to:	• Raise the head and chest when lying on their stomach. • Reach for dangling objects. • Grasp and shake objects. • Roll both ways. • Sit with support. • Explore objects with hands and mouth. • Begin to imitate sounds and facial expressions. • Respond to their own name and to familiar faces.
Advice for caregivers:	• Lay the infant on a clean, flat, safe surface so they can move freely and reach for objects. • Continue to hold and cuddle the infant every day, giving consistent love and affection. • Prop or hold the infant in a secure positoin so they can see what is happening nearby. • Continue to breastfeed on demand day and night, and strt adding other foods (two to three meals a day, starting at six months, three to four meals a day from nine months). • Talk, read, or sing to the child as often as possible, not only when they are hungry or getting ready to sleep.
Warning signs to watch for:	• Stiffness or difficulty moving limbs. • Constant moving of the head (this might indicate an ear infection, which could lead to deafness if not treated). • Little or no response to sounds, familiar faces, or the breast. • Refusing the breast or other foods.

by the age of 12 months

An infant should be able to:	• Sit without support. • Crawl on hands and knees and pull themselves up to stand. • Take steps holding on to support. • Try to imitate words and sounds and respond to simple requests. • Enjoy playing and clapping. • Repeat sounds and gestures for attention. • Pick things up with thumb and one finger. • Start holding objects such as a spoon and cup and attempt self-feeding.
Advice for caregivers:	• Point to objects and name them; play with, talk, sing, and read to the child frequently. • Use mealtimes and other family activities to encourage interaction with all family members. • Give consistent affection and be responsive both when the child is happy and when upset. • If the child is developing slowly or has a physical disability, focus on the child's abilities and give extra stimulation and interaction. • Do not leave a child in one position for many hours. • Make the area as safe as possible to prevent accidents, and keep dangerous objects, such as sharp objects, plastic bags, and small items a child can choke on, out of the child's reach. • Continue to breastfeed and ensure that the child has had enough food and a variety of family foods. • Help the child experiment with spoon and cup feeding. • Make sure the child's immunisations are up to date and that she or he receives all recommended doses of nutrient supplements. • Keep the child's hands clean and begin teaching the child to wash them with soap.
Warning signs to watch for:	• Does not make sounds in response to others. • Does not look at objects that move. • Listlessness and lack of response to the caregiver. • Lack of appetite or refusal of food.

by the age of 2 years

A child should be able to:	• Walk, climb, and run. • Point to objects or pictures when they are named (for example nose, eyes, or ears). • Say several words together (from about 15 months). • Follow simple instructions. • Scribble if given a pencil or crayon. • Enjoy simple stories or songs. • Imitate the behaviours of others. • Begin to eat by themselves.
Advice for caregivers:	• Read to and sing or play games with the child. • Teach the child to avoid dangerous objects. • Talk to the child normally - do not use baby talk. • Continue to breastfeed and ensure the child has enough food and a variety of family foods. • Make sure the child is fully immunised. • Encourage, but do not force, the child to eat. • Provide simple rules and set reasonable expectations. • Praise the child's achievements, provide reassurance when the child is afraid and continue to give consistent affection every day.
Warning signs to watch for:	• Lack of response to others. • Difficulty keeping balance while walking. • Injuries and unexpected changes in behaviour (especially if the child has been cared for by others). • Lack of appetite.

by the age of 3 years

A child should be able to:	• Walk, run, kick and jump easily. • Recognise and identify common objects and pictures by pointing. • Make sentences of two or three words. • Say their own name and age. • Name colours. • Understand numbers. • Use make-believe objects in play. • Feed themselves. • Express affection.
Advice for caregivers:	• Read and look at books with the child and talk about the pictures. • Tell the child stories and teach rhymes and songs. • Give the child their own bowl or plate of food. • Continue to encourage the child to eat, giving the child as much time as they need. • Help the child learn to dress, use the toilet or latrine and wash their hands with soap and water or a substitute (such as ash and water) after defecating and before touching food and eating. • Listen to and answer all the child’s questions. • Encourage creative play, building and drawing. • Give the child simple tasks, such as putting toys back in their place, to build responsibility. • Limit television watching and ensure that violent shows are not viewed. • Acknowledge and encourage positive behaviour and set clear limits. • Provide consistent affection every day. • If available, enrol the child in an early learning (play) activity with other children.
Warning signs to watch for:	• Loss of interest in playing. • Frequent falling. • Difficulty manipulating small objects. • Failure to understand simple messages. • Inability to speak using several words. • Little or no interest in food.

by the age of 5 years

A child should be able to:	• Move in a coordinated way. • Speak in sentences and use many different words. • Understand opposites (for example, fat and thin, tall and short). • Play with other children. • Dress without help. • Answer simple questions • Count 5-10 objects. • Wash their own hands.
Advice for caregivers:	• Listen to the child. • Interact frequently with the child. • Read and tell stories. • Encourage the child (both girls and boys) to play and explore. • Listen to and answer all the child’s questions, have conversations (with both girls and boys). • Encourage creative play, building, and drawing. • Limit television watching and ensure that violent shows are not viewed. • Acknowledge and encourage positive behaviour and set clear and consistent limits. • Provide consistent affection every day. • Enrol the child (both girls and boys) in an early learning (play) programme that helps to prepare the child for school.
Warning signs to watch for:	• Fear, anger or violence when playing with other children, which could be signs of emotional problems or abuse.

by the age of 8 years

A child 's:	• Physical development proceeds more gradually and steadily than in the early years. • Muscle mass increases, and small and large motor skills improve. • Ability to understand and communicate abstract and complex ideas has begun. • Span of attention increases, and they can focus on the past and future as well as the present. • Learning capacity is expanding and they are learning to read, write, and do problem solving in a school environment. • Friends and interactions with their peer groups are increasingly important. • Interest in friendships include enjoying time with their peer group and turning to peers for information. • Self-control improves, and understanding of more complex emotions increases.
Advice for caregivers:	• Be a good role model, equally for girls and boys. • Encourage your child to express feelings and beliefs and to solve problems. • Recognise and support your child's strengths and skills as well as limitations. • Spend time with your child and talk and listen to them. • Find activities you can do together that will make your child feel successful, secure, and loved. • Facilitate and support your child's playtime with friends and in extra-curricular school activities. • Acknowledge and encourage positive behaviour and set clear and consistent limits. • Show interest and become involved in your child's school - remember that the child's caregivers are a child's first and most important teachers.
Warning signs to watch for:	• Difficulties making and keeping friends and participating in group activities. • Avoiding a task or challenge without trying, or showing signs of helplessness. • Trouble communicating needs, thoughts, and emotions. • Trouble focusing on tasks, understanding, and completing schoolwork. • Excessive aggression or shyness with friends and family.

— Table on this and previous pages adapted from UNICEF, *Facts for Life,* 2010.

Language

The process that children go through, from cooing to babbling, to learning sounds and patterns, to being able to express themselves with increasingly complex words and phrases. Typical language development stages are detailed here:

Language development stages

Typical language development usually follows a standard pattern:

• 6–8 weeks	cooing
• 8–10 months	babbling
• 12 months	first words
• Age 2 years	two-word phrases
• Age 2 years	200 words
• Age 6 years	15,000 words

Talking and interacting with a child helps to develop their language skills. Caregivers are encouraged to use adult language with children, rather than infant talk, to build their vocabulary.

– adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

Cognitive function

The mental abilities related to knowledge, attention, memory, judgment, evaluation, problem solving and decision-making. The stages of normal cognitive development are listed below:

Stages of cognitive development

Swiss developmental psychologist, Jean Piaget, developed one of the most widely used theories of the development of how children think. He believed that children think differently to adults, and that the way a child thinks changes as they grow older. These stages are biological, meaning that if a child is developing correctly, they should go through the stages at roughly the same time as other children. These four stages of cognitive (thinking) development are:

- **Sensorimotor stage (0–2 years old):** Infants start to learn about the world around them, mostly through trial and error, developing basic thinking skills like relating movements with actions/ behaviours, learning how to mimic other people, and eventually starting to play make-believe.

- **Pre-operational stage (2–7 years old):** The child starts to use their imagination and intuition, explaining or arguing their point of view with words, and exploring their surroundings. They are focused mainly on themselves and can't yet see the world through someone else's eyes, and can only focus on one part of a problem at a time.

- **Concrete operational stage (7–11 years old):** There is a major change in children's thinking during this stage. The child is now mature enough to think logically and apply rules to physical objects, start to make sense of directions and instructions, associate consequences with actions, and start to empathise with others. However, they can't yet reason in abstract terms (imagine how something might change based on their actions).

- **Formal operational stage (11–15 or 20 years old):** The child or adolescent can manipulate ideas in their mind, like doing maths calculations, think creatively, or imagine the outcomes of certain actions. They can think critically about their actions and understand that actions have consequences.

Theories like this can help CHWs and caregivers to learn how children understand the world, and help us to use the best tools possible to communicate with children about difficult subjects like HIV.

— adapted from ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

Social and emotional skills

This refers to the way that a child experiences, expresses, understands and regulates their emotions, transitions from one activity to another, and cooperates and interacts with others. A child's temperament (for example, shy or outgoing) is generally determined by genetics and early attachments formed with caregivers.

Developmental stages from birth to adolescence

Stage 1: Trust vs Mistrust

Birth to 18 months

Babies learn and grow very quickly at this stage. They need to learn to trust. The relationship that they have with their primary caregiver (usually the mother) forms the basis of their sense of security and ability to trust for the rest of their lives. It is the time in which they learn to trust the world and experience it as a safe and caring place. Children cannot deliberately misbehave at this age. Their behaviour is merely their way of communicating their needs and discomforts. A baby can never have too much love or affection.

Stage 2: Autonomy vs Dependence

18 months to 3 years

Children of this age are learning to be independent. They assert their emotional separateness by asserting their wishes. They begin to learn to do things for themselves. They also learn to get along with their peers. They do not want to be controlled and continually test the power of "NO". Although it can be very trying to caregivers, children's negativity and wilfulness should not be interpreted as naughtiness or stubborn behaviour. It is part of the child's natural and healthy attempt to achieve autonomy.

Caregiver's role:

Our primary task as caregivers is to provide a secure and safe environment in which language and social skills can be acquired and developed. We need to have realistic expectations of the child and allow them to make mistakes. NO's should be kept to a minimum. Caregivers can best help their children at this stage by avoiding direct orders and encouraging cooperation through giving them appropriate choices. It is also helpful to acknowledge and accept children's feelings while at the same time limiting unacceptable behaviour. This is the beginning of the separation process that continues throughout life.

Stage 3: Initiative vs Guilt

3 to 6 years

This stage is marked by an overwhelming drive to play and explore. Children of this age need to express their creativity and feel competent. They are learning to master the world around them. They experience a great deal of intellectual growth, and become more involved with the world around them. They are also learning to have better control of their bodies. They need to engage in lots of physical play.

Caregiver's role:

Our primary task as caregivers of children at this stage of their lives is to encourage their attempts to try new things. Encourage them to show initiative. Believe in their ability to succeed. The focus should be on building self-esteem. They should be allowed to fail and to try again. Any mistakes they make at this stage are good opportunities for learning. At the same time, children of this age begin to become aware of the process of socialisation. They realise the need to cooperate and know when they are not being cooperative.

Stage 4: Industry vs Inferiority

6 to 12 years

The world expands for children of this age through their interactions with peers and teachers. They learn by doing. They become more and more capable intellectually. They learn values through what they experience at home.

Caregiver's role:

Caregivers should show that they trust their children. They should be given increased responsibility, but within reason. Friendships and activities outside of the home should be encouraged.

Stage 5: Identity vs Identity Confusion

13 to 21 years

Adolescents are looking for a sense of identity. Although they are preoccupied with themselves, they also have an awareness of the social world around them. Their peer group is very important. Their sexuality awakens. This results in dramatic hormonal and physical changes and powerful feelings, which can cause anxiety. Although they are becoming physically mature, they are not yet emotionally mature. They often struggle for their independence.

Caregiver's role:

Caregivers need to start granting teenagers autonomy, while still providing the emotional care. In many countries, there is a very real conflict between allowing independence and being careful about children's safety. Caregivers need to provide guidance, but teenagers need to do things for themselves.

Social and emotional developmental stages and caregiver's role

Development happens differently for every child, but there are some common milestones that should be reached at around the same age.

— adapted from REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

Identifying developmental delays

Children living with HIV need to be seen first and foremost as children, and shouldn't be defined by their illness. Caregivers should encourage normal development wherever possible, but be aware that these children may experience developmental delays.

HIV can both directly and indirectly affect a child's development. Children who are sick and suffer from malnutrition when they are young are often behind when it comes to physical growth, but HIV can also affect their cognitive development. Some research has shown that children who receive ART and stay on their treatment are less likely to have severe developmental delays, which is another reason to make sure that children are adhering to their ART regimen.

To identify developmental delays, you should first be familiar with the normal stages of development. Formal and informal assessments can also be used to determine if a child is behind developmentally.

If you suspect that a child is developmentally delayed, you should talk with your clinic team about the best course of action for the child. If the delays are severe, the child might need to be referred to others who can better support him or her. If delays are more minor, there may be simple things that caregivers can do at home to help them to catch up. You can help families to understand their options and develop a plan to help the child.

An estimated 40–60% of children living with HIV have some developmental delays

Studies have shown that developmental delays are common among children born with HIV. Starting ART early can improve or even reverse the course of neurological impairment in many children.

— adapted from S2S, *Paediatric HIV Care and Treatment Toolkit*, 2010.

Checklist for assessing and recognising delayed development

To assess and recognise delayed development in children, you should start by gathering as much information as you can about a child's history. The more information you can gather, the more you will be able to decide what kind of intervention a child might need. You should talk to both caregivers and other sources of information (with caregivers' permission), such as teachers, friends, community members and healthcare workers who have interacted with the child and his or her family. It is important to gather information from a variety of sources in order to get the most accurate information. Questions you should ask include the following:

Pre-birth and birthing risk factors: It is important to understand whether a child experienced any risk factors before and during birth. Ask the caregiver about:

- ☐ The mother's medical and mental state (including substance abuse) during pregnancy.
- ☐ Any physical trauma that the mother or child experienced during pregnancy.
- ☐ Any infections (for example, bacterial or viral) that the mother or child experienced during pregnancy.
- ☐ Birth trauma experienced by the mother or child.
- ☐ Any post-birth medical conditions in the child.
- ☐ Nutritional status and medical history: To get a sense of how a child is developing physically, you should look at their growth chart and talk to healthcare workers about any medical issues they may have had.

Developmental milestones: Is the child developing according to the typical physical, emotional, and social developmental milestones? (see Section 4.3 for a list of typical child development milestones.) You can ask caregivers questions such as:

- ☐ Describe your child's 'firsts'. At what age did your child first smile, crawl, walk and talk?
- ☐ Do you think your child is generally happy or sad?
- ☐ Is your child able to recognise when you are feeling sad or happy?
- ☐ Does your child make good eye contact with you and others?

History of social, emotional and behavioural problems: To gather this information, you can ask caregivers and others questions such as:

- ☐ When did the child's behaviour first concern you? Who noticed?
- ☐ Tell me about the child's emotional reactions.
- ☐ Have you ever felt that there is something different about the child?
- ☐ Does the child have friends? Does the child spend a lot of time alone?

Social, emotional and behavioural problems: You should observe the following in the child:

- ☐ What do you observe about the child? Notice their walk, facial expressions and prevailing mood.
- ☐ How is the child adjusting to the clinic setting?
- ☐ Does the child show any unusual behaviour (for example, hyperactivity or inactivity, physical aggression, violates rules and norms)?
- ☐ Caregiver-child interactions (for example, how does child handle separation from caregiver?)
- ☐ What do you feel from the child? Is the child projecting any emotions, such as anger or anxiety?

Educational history: Talk with teachers to get a sense of how a child has performed in school, specifically looking at issues like:

- ☐ Behaviour in the classroom.
- ☐ Ability to concentrate.
- ☐ Academic progress.
- ☐ Acquisition of skills.

From these questions, you can begin to learn whether a child might have a developmental delay, whether the child needs additional services at or outside of school, and whether the child may need counselling or other therapy. You can also share with caregivers some ideas about what can be done at home to help a child to develop.

Encouraging child development

In the clinic, CHWs can provide child-friendly spaces and support that incorporates games and activities that encourage child development.

During home visits, CHWs can educate caregivers on age-appropriate activities and child development milestones. You can be a great resource for caregivers on how they can interact and play with their children in ways that will encourage development. This can be especially important for caregivers who are worried about and dealing with their own health and finding it hard to connect with their children.

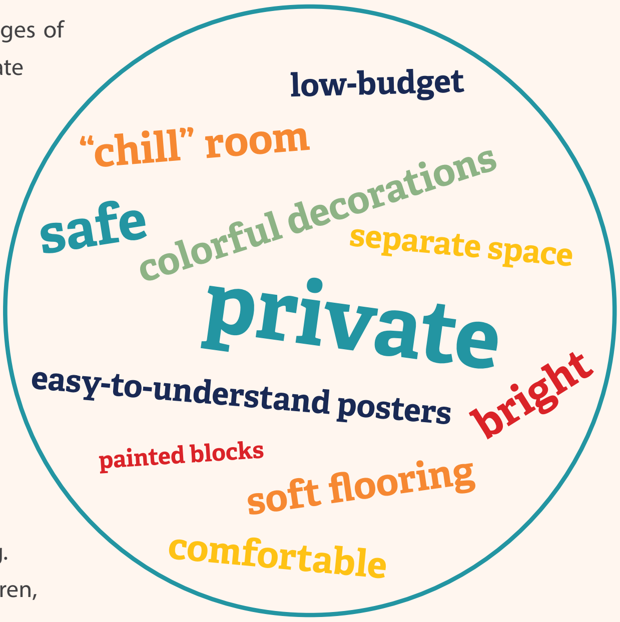
In both settings, CHWs can assess progress towards milestones and overall child development. When problems are identified, CHWs should refer children for full assessments. In instances of significant developmental delays, CHWs can help to observe and monitor progress towards goals.

Child- and adolescent-friendly clinics

Clinics can be a scary place for children to visit. Clinics are encouraged to create a child-friendly environment that is welcoming to children and that encourages their development.

Where possible, clinics should have separate days for different ages of children, where staff can focus on age-appropriate activities and create opportunities for children of similar ages to meet and engage. Ideally, children and adolescents should have a separate space that can be set up to meet their different needs. Where this isn't possible, a corner of the waiting room can be set aside for children, decorated in bright colours and appealing decorations. Local materials and inexpensive décor like painted crates for child-sized furniture, colourful curtains and signs can be used to brighten up a space and make it more welcoming to a child. Soft flooring, like rugs or blankets, can help children to be more comfortable.

For adolescents, it is ideal to have a more private 'chill room' that can also be used for peer education sessions and information sharing. Easy to read and understand information posters can help children, adolescents and their caregivers to remember important health messages. All of these elements can come together to create a space that is welcoming to children and adolescents, and that can help caregivers to better understand how to actively engage with their children at home.



— adapted from PATA, *Child-friendly Clinic Initiative Guidelines.*

The importance of play

Play is a broad term that refers to many different kinds of activities. One of the main ways that children develop is through play. Many adults think that play is just about having fun, making noise or being messy. Often adults don't understand how important play is. Play is how children explore, develop and practice skills, gain social understanding, and generally develop a sense of wellbeing. When caregivers play with children, they help children to feel loved, safe and encouraged.

There are three main types of play that children engage in:

- **Sensorimotor play** is when children use one or more of their five senses (touch, taste, sight, hearing or smell) and body movements (for example, pulling, pushing, crawling and balancing) to learn about the world.

- **Symbolic play** is when children use make-believe or pretend games to develop their thoughts, creativity and imagination and explore different roles.

- **Games with other children** teach a child to cooperate and work together successfully with others.

When infants or children are sick with HIV or their caregivers are too weak from the disease, they might not have as many opportunities to play. CHWs can help caregivers to understand the importance of play, and give them ideas of how to play with their children to encourage development. Many children with sick caregivers have had to take on bigger roles in their family. They might be responsible for looking after their younger brothers and sisters, doing many household chores, or other things that their peers aren't responsible for. While this can help a child to feel like they have some control and input into a situation where so much is out of their control, it may also mean that they are expected to do things that are beyond their ability and that take them away from age-appropriate activities that help them to develop, like play.

Exercises for Section 4: Psychosocial Support

Key take away messages:

- **Positive treatment outcomes rely on addressing the holistic needs of the child, caregiver and family.**
- **Disclosure is a lengthy process, not a one-time event, that should be done by a caregiver with support from healthcare workers if needed, and take into account the age and development level of the child or adolescent.**

Questions:

1. Study three different children of different ages, either at the clinic or during a home visit, and take note of whether they are meeting the physical and cognitive development milestones appropriate for their age. Take notes and share them with your supervisor. If you think there may be a problem, mention it to your supervisor and encourage the caregiver to bring the child to the clinic.

2. Work with your supervisor to develop a plan for a family who is thinking about disclosing to a child. You should practice the conversation you would have with the caregiver, and how you would help him or her to prepare for the disclosure conversation, taking into account how old the child is and how much they already know about their illness. Reflect on your own experiences learning about your HIV status, and how you shared the information with those around you.

3. Conduct a psychosocial assessment with one family during a home visit or in the clinic. Present your findings back to your supervisor along with a plan to address any areas that worry you (referring for counselling, scheduling extra visits, linking them to a treatment buddy or support group, etc.)

Further reading about psychosocial support

Want to learn more? The resources below served as references for the information presented in this section, and are a great source for more in-depth information on the topics covered here. For even more, see Annex 3.

General Psychosocial Support

- AIDSTAR-One, *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*, 2014.
- ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.
- Avert, *Emotional Needs and Support, www.avert.org.*
- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.
- International HIV/AIDS Alliance, *Psychosocial Support: Resources for communities working with orphans and vulnerable children*, 2003.
- International HIV/AIDS Alliance, *Young Children and HIV: Strengthening family and community support,* 2006.
- REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.
- REPSSI, *Psychosocial Care and Support for Young Children and Infants in the Time of HIV and AIDS — A Resource for Programming*, 2007.
- S2S, *Psychosocial & Adherence Counseling Support Training Toolkit,* 2010.

Disclosure to Children

- AIDSTAR-One, *Pediatric Disclosure Materials*, www.aidstar-one.com.
- REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.
- REPSSI, *Psychosocial Care and Support for Young Children and Infants in the Time of HIV and AIDS — A Resource for Programming*, 2007.
- REPSSI, *Supporting Young Carers: Programme Guidelines for Households in which Young People are Caring for Other Household Members*, 2007.
- S2S, *Disclosure Process for Children and Adolescents Living with HIV: A Practical Guide,* 2010.

Child Development

- International HIV/AIDS Alliance, *Young Children and HIV: Strengthening family and community support*, 2006.
- Monitoring, Evaluation & Learning Initiative for Young Children Affected by HIV and AIDS (MELYCABA), various assessments and tools related to child development, melycaba.com.
- S2S, *Nutritional Support from Birth through Adolescence,* 2010.
- S2S, Paediatric HIV Care and Treatment: A Toolkit for South African Healthcare Workers, 2010.
- UNICEF, *Facts for Life: How Children Develop*, 2010.
- WHO, *Health for the World's Adolescents: A second chance in the second decade*, 2014.

Section 5:

Community Outreach & Referrals

Section 5.1: Community Outreach and Referral Basics

HIV has a big impact on communities and families. Some of these effects can include:

- Loss of wages and resources due to illness and clinic visits.
- Poverty because of healthcare costs and lost wages.
- Increased number of orphans to care for.
- Stigma and discrimination.
- Children can't attend school because they are caring for sick relatives or have to work.
- Teachers are sick or need to take care of relatives who are sick.
- Community healthcare systems are overstretched.

CHWs are an important part of the larger community response to HIV. While some of your work may take place in a clinic, some of your time is spent out in the community. CHWs have two important ways of working with the community:

- **CHWs work directly with pregnant women, children and adolescents living with HIV** and their caregivers to prevent the spread of HIV, and ensure/ encourage treatment for those affected.

- **CHWs work with the wider community** to raise awareness and change attitudes and perceptions to make life better for those living with HIV. CHWs also educate the community about HIV and how it can be prevented.

Both roles are important and deserve attention.

CHWs' direct engagement with patients and caregivers

Unlike traditional healthcare workers, many CHWs spend much of their time conducting home visits and interacting with their patients in the community. Because of this, you are best placed to:

- Take note of any side effects or opportunistic infections that patients may be experiencing and encourage them to go to the clinic for assessment and treatment as needed.
- Find patients who have missed or stopped attending clinic visits and encourage them to return.
- Observe and assess the home environment and make the necessary referrals and linkages to community networks and services available.

Section 1, Section 3 and Section 4 include tools that CHWs can use for this kind of direct engagement with patients.

Wider community engagement and education

In addition to your direct work with patients, you can also play a very important role within the larger community.

CHWs are key to preventing HIV from spreading in communities. You can do this by carrying out HIV education and more general health promotion, where you teach people about what HIV is and how it is spread. When CHWs educate the community about HIV, this helps people to understand the truth about the illness and stop myths and misunderstandings about the disease. When people are better informed about HIV, it can help to reduce the stigma and discrimination that children and adolescents living with HIV may face.

You can also make sure to target certain groups of people who may not be in care and who would benefit from treatment. You can encourage pregnant women to be tested as early as possible in their pregnancy so that they can prevent passing HIV on to their infants and support children and adolescents to be tested. CHWs are trusted members of the community, so you can more easily gain access to target groups and earn their trust.

Dealing with stigma

As discussed in Section 4, stigma is when someone is labelled in a negative way because of a particular quality or circumstance, such as being HIV-positive. People who are stigmatised are seen as being different, and blamed for that difference. Often, people stigmatise other people because they don't have the right information and/or because they are afraid.

Stigma prevents good access to HIV prevention, treatment and care services for many reasons. For example:

- Stigma stops people from getting an HIV test because they fear the result.
- Stigma makes it hard for PLHIV to tell their partners, family and friends their test results.
- Stigma makes it hard for caregivers to disclose to their children.
- Stigma stops PLHIV from accessing treatment, care and community support services because they feel they have to hide their status.
- Stigma discourages pregnant women from taking ARVs or accessing other PMTCT services.
- Stigma prevents people from caring for PLHIV.

Children and adolescents especially need help to deal with stigma and any unfair treatment they may receive because of it. While it is important that they have people that they trust and can talk to, it is also important that they understand that they might not choose to talk about their status with everyone, as not everyone will be supportive. Depending on the child's age, you should help caregivers to talk with their children about whom they can trust and openly talk with about HIV. Helping children and adolescents to join support groups, camps and other spaces where they can freely talk about HIV with their peers is also very helpful in dealing with stigma.

— adapted from PIH, *Accompagnateur's Handbook,* 2012 and Hesperian, *Helping Children Live with HIV*, 2013.

Section 5.2: Community Engagement and Education

Health promotion and education techniques

Before you get started with health promotion and education, you should carefully plan the messages you want to share. First, think about who you want to target with your health education messages. Next, decide how you are going to conduct the sessions. How CHWs educate people in the community about HIV and healthy living is as important as what information is shared. If you choose the right way of sharing information, people will really understand your messages and you will more likely inspire them to choose healthy behaviours. You should choose your approach based on the resources you have available to you. The table on the next page shows some different techniques and suggests what might work best in different situations.

You should also think about issues like when would be best to hold the session in order to get the most participation from the target audience, where you will hold it, and how many people you would want to attend to have the most impact (a larger group is not always better — smaller groups may mean more open conversation). You will also need to think about how you will let people know about your session in advance.

It is important to think about what learning materials you might need in order to get your message across. It is very useful to have a number of visual teaching and learning aids that you can use when you are doing health promotion in the community. These can help you to:

- Encourage people to be interested in the topic and curious to know more.
- Simplify complex ideas.
- Assist people to remember your message.

When the session is over, it is important to look back and take note of what worked and what didn’t. Ask those who attended to give you their feedback. You can also talk through the session with your supervisor, and make a plan for what you might change for the next session.

Facts, not opinions

It is important that all of the information you share with the community is based on facts. If you are unsure of something, it is always better to consult with your supervisor to make sure you have the right information, or you might risk spreading the wrong information. The information you share should not include your personal judgements of particular groups of people or their behaviours. Your sessions should always be respectful and engaging to make sure that you are building trust within the community.

Type of teaching method	Advantages	Disadvantages
Lecture Typically formal presentation of information by a trainer so that participants can listen, observe and understand the concept, principle or procedures being presented. The trainer usually does most of the talking to transfer a large amount of information to learners in a fairly short time.	One trainer can communicate with a large number of participants at the same time A lot of content can be covered in a fairly short time Time spent on topics can easily be controlled The trainer has control over the content	If overused without participant's interaction, can easily lead to boredom One-way communication Can't address individual participants' needs Participants are passive recipients of information Pace of lecture does not suit all participants It may be difficult to achieve effective learning
Discussion Participants share information, ideas and experiences during a session facilitated by a trainer.	Participants can develop self-confidence and communication skills Gives an opportunity for self-expression and self-development Helps the trainer to define his/her role as a guide, and not a leader Offers opportunities for participants to practice facilitation techniques and to take on different roles, such as group leader	Requires lots of preparation to be effective Can be time-consuming Trainer must be a strong facilitator to keep participants on track Participants with strong personalities may dominate the discussion Some may feel shy or intimidated and may not contribute
Demonstration A trainer visually explains facts, concepts and procedures.	Visuals have a greater impact on learners, improve engagement and increase interest An interactive approach allows for immediate correction of error	Time-consuming and expensive Not suitable for large groups
Brainstorming A facilitator asks a question and guides participants to think of as many ideas or solutions to a problem as they can. Emphasis is first on free expression of ideas without criticism. The list is then analysed and evaluated.	Everyone has an opportunity to contribute Enables problem solving in groups and generates many ideas quickly Helps to stimulate creativity and imagination Encourages open-mindedness Helps to build individual and group confidence by finding solutions within the group itself Can help to generate solutions that were not seen before	Time-consuming Ideas suggested are limited by the experiences of group members Some group members may dominate, others may withdraw
Role play An unrehearsed acting out of a real life situation by participants to understand the experience of someone else.	Participants are given the opportunity to understand how others might feel, think and act Participants are encouraged to express their own feelings and attitudes Can be used with all groups regardless of their standard of education A real life situation is created in a non-threatening atmosphere, which lets participants try out new approaches or behaviours and practice handling difficult situations Helps to develop empathy	Tends to over-simply complex situations Some participants may feel inhibited Role play can be psychologically harmful if actors are not debriefed following the intensive role play Outcomes can be unpredictable
Peer education A strategy where the learner teaches fellow learners. In the context of HIV education, includes sessions where those living positively with the virus are able to share their experiences with others as role models.	Participants can relate to the 'trainer' better The trainer is personally familiar with the issues	If not well organised may inhibit effective learning

Advantages and disadvantages of different types of education techniques

The above table shows several different techniques you might use in community education. You should think about the audience, the message you want to get across and the resources you have available when deciding which technique to use.

— adapted from CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi*, 2011.

Section 5.3: Community Resources and Referrals

CHWs are not alone in supporting their patients to have the highest quality of life possible. You are only one person, and cannot be expected to be able to meet all of a patient's needs. There are going to be times where a patient needs support that you can't give them. As mentioned in Section 3, you are part of a multidisciplinary team that together can help a patient through many issues. There are also other resources in the wider community that you can refer patients to for specific issues.

Organisations that work together in this manner make up a referral network that can help PLHIV to:

- Access needed services more quickly.
- Improve their quality of life.
- Actively participate in decisions that impact their lives.

Referral networks

A referral is when you assess the needs of your patient or their caregiver and understand that you cannot provide the help needed. You then direct them to another service provider who can provide the support they need. This could mean sending them to another person in your clinic, to another clinic, to an outside organisation, or to an informal community resource. All of the organisations that work together to provide comprehensive treatment and care services to a patient are called a referral network. When a referral is made, it should also include follow-up when possible to make sure that patients have connected with the referral point and are receiving the services they need.

Mapping community resources and referral networks — focusing on what you have

CHWs are often the first person that a patient turns to for help, so it is important that you provide them with information about where they can get the help they need.

It is easy to focus on the challenges of getting your patients the help they need. However, there are probably already a number of formal and informal resources that provide services that your patients could access. These might include:

- HTC centres.
- Clinics and hospitals for treatment and care.
- Associations of PLHIV and support groups.
- Psychosocial support and counselling services.
- Faith-based organisations.
- Nutritional and breastfeeding support.
- Child development organisations.
- Organisations providing help to orphans and vulnerable children
- Social welfare programs.
- Other informal support mechanisms such as school support, early childhood and educare centres, teachers and peers.

A good place to start is to work with community members or other CHWs to map out the resources that are available in your area. This way, you will become familiar with what services exist, and can direct your patients to them as they need. This can also help to identify service gaps, which CHWs can use as a basis for their patient advocacy.

Keep in mind that the community resources you identify don't have to be formal organisations or networks. Be open to informal and non-traditional community resources that you could draw upon.

Community resource mapping

One way for you to get a sense of the help and support available for children, adolescents and adults living with HIV is to map all of the formal and informal organisations working to provide treatment, care and support in your community. You should focus on what your community has to offer. If you think creatively, you'll be surprised at how many resources already exist!

A map doesn't have to be a difficult thing to draw — it can be very simple, and you can use whatever materials you have on hand. Together, you and your peers should brainstorm all of the organisations, groups and individuals who provide services in your community. You can then think about who already benefits from each of the services, why some people or groups aren't benefiting, and where there may be gaps.

Community resource diagram exercise

The exercise on the next two pages is just one example of how you could conduct a community resource mapping exercise. You can specifically adapt it to look at the needs of children with HIV. Children themselves should be a part of the conversation. The exercise can also be adapted to look at adolescent health issues.

— adapted from International HIV/AIDS Alliance, *Building Blocks in Practice: Participatory tools to improve the development of care and support for orphans and vulnerable children*, 2004.

Community resource diagram

Aim	- The aim of this tool is to identify resources and services that are relevant to a project. These can include: – Resources and services children use at the moment – Existing resources and services that could benefit children but which children do not use at the moment – New resources and services that the community can provide or services and resources that would need to come from outside the community.
Time needed	- Minimum one and a half hours.
Good practice	When making this diagram, it is important that: - Community members focus on resources and services for children - Facilitators recognise that children have a lot to offer. Children use different resources from adults, and will have a clear idea of the resources they use, and also of resources they would like to use - The facilitator is clear about the task at each stage of the diagram-making process - There is plenty of time, since making a diagram can be time-consuming, particularly with very large groups.
Materials needed	- Suitable drawing materials.
Notes and paper copies to be made	- Paper copies: Community resource diagrams. These should include: – All the resources and services children use at the moment – Existing resources and services that could benefit children but which children do not use at the moment – New resources and services that the community can provide or services and resources that would need to come from outside the community. Where necessary, give a written description of symbols used.

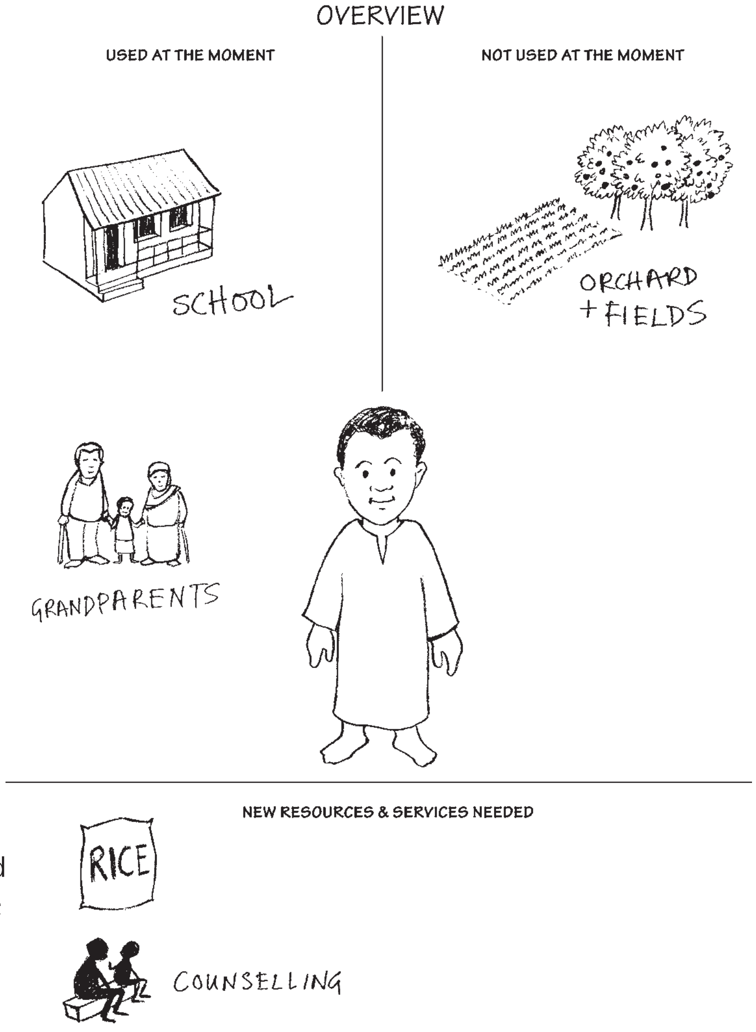
How you do it

- Explain that this is the first meeting at which community members will be looking at resources and services. Explain that at future meetings community members will be exploring resources and services in much greater detail.
- At this meeting community members will be looking at the different kinds of resources and services which orphans and vulnerable children use or could use. These include land-based resources and services, building-based resources and services, human resources and other resources and services. For clarification of the resources and services go through each of the four types asking for examples (see below with suggestions of examples):

1. **Land-based resources:** fields, gardens, woods, sources of wild food
2. **Building-based resources:** school, clinic, church, NGO
3. **Human resources:** grandparents, aunts, uncles
4. **Other resources:** those resources that do not fit into any of the categories above: football pitch, choir.

- Divide the group into four smaller groups.
- Ask each group to draw a child in the middle of their paper.
- To the left of the child, each group should draw, with symbols, all the resources and services which children use at the moment.
- To the right of the child, each group should draw, with symbols, all the resources and services which could benefit children but which children do not use at the moment. Each group should also discuss whether any new services are needed to support orphans and vulnerable children.
- Beneath the child, each group should draw any new resources or services that may be needed. These can be resources that the community could provide or resources which need to come from outside the community.
- Ask each group to present its drawing to the other groups and have a general discussion on the work done. The facilitator should sum up the information that has been gained, from all the drawings created.
- If the drawings have been done on the ground, ask a volunteer from each group if he or she can make a paper copy of the drawing.
- Give the drawings to the community member appointed to look after drawings.
- Discuss and agree how those present will find out from community members who have not attended the meeting today whether they agree or disagree with the ideas that were discussed or if they have new ideas to add. Any additional ideas can be included in the action plan.
- Thank everyone for their hard work and involvement. Arrange the date and time of the next meeting.

Below is an example of a community resource diagram. This diagram is to guide facilitators when they are explaining to community members how to make a community resource diagram. It is not necessary to show this diagram to community members. Their diagrams may look very different to this one.



Worked example of a community resource diagram (not completed)

COMMUNITY REFERRAL DIRECTORY TEMPLATE

District Name: ______________________ Clinic Name ______________________ Date ____________

NAME OF ORGANIZATION	SERVICES PROVIDED	COMMUNITIES/AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS
1.				
2.				
3.				
4.				
5.				
6.				
7.				

Creating a community referral directory

If your clinic or community doesn't already have one, it may be useful to create a community referral directory from your community mapping exercises similar to the one above (although you should feel free to change it). It can include the names and contact information for both formal organisations that you could refer patients to, as well as informal networks and individuals.

— adapted from S2S, *Psychosocial & Adherence Counseling Support Training Toolkit*, 2010 .

Record keeping for effective referrals

When patients are receiving support from a number of different people and organisations, it is important that everyone involved knows what others are doing. The best way to keep everyone up-to-date is to keep complete records that can be shared.

Your clinic will have forms that you are required to complete; you should become familiar with them. These could be forms for you to complete when you conduct home visits, when you are assisting in the clinic, when you are leading support groups or health education sessions, or any other records. It is very important that you learn how you are expected to fill out the forms, and that you complete them on time and turn them in to your clinic supervisor. Without complete forms, your patients run the risk of not getting the right treatment, care and support.

Confidentiality is very important when keeping patient records. You should closely follow the record-keeping systems set up by the clinic, and never share patient information with those who do not have a right to this information. When you are working outside of the clinic, you should make sure that your records are kept in a safe place and transported with care to the clinic as soon as possible where they can be stored safely.

Exercises for Section 5: Community Outreach & Referrals

Key take away messages:

- **It is very important to know what services are available to be able to link patients to additional support.**
- **CHWs are the key link between the patient, clinic, and community.**

Questions

1. Conduct a community resource mapping exercise to find out what nutritional support programmes are available in your community. Think about programmes that offer education on food and nutrition, supplemental feeding programmes for malnourished children, help with breastfeeding or community gardens, or other programmes. Use the information you gather to create a referrals reference sheet. Visit at least two of the support service providers to learn more about how they help patients, and what information they need to know in a referral to more easily help patients. You can use this list the next time you are working with a family who needs more nutritional support than you can provide. (This exercise can be done with other support services instead).

2. Develop a plan to lead one session in the community to explain the basics of HIV transmission, prevention and treatment, using the information provided in this manual, and present it to your supervisor. Decide first who the target audience is (pregnant women, adolescents, church groups, savings group, etc.), what the main things are that you want them to leave knowing, develop visual aids (draw pictures, use props) to illustrate the information, and choose the best type of training to meet the needs of the target audience.

Further reading about community outreach and referrals

Want to learn more? The resources below served as references for the information presented in this section, and are a great source for more in-depth information on the topics covered here. For even more, see Annex 3.

Community Engagement and Education

- International HIV/AIDS Alliance, *Community Engagement for Antiretroviral treatment: A training manual*, 2006.
- International HIV/AIDS Alliance, *Toolkit: Understanding and challenging HIV stigma*, 2007.
- JSI Research & Training Institute, Inc., *Community HIV Counselling and Testing: A handbook on Participatory Needs Assessment,* 2008.
- PIH, *Accompagnateur's Handbook*, 2012.

Community Resources and Referrals

- CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.
- Family Health International (FHI), *Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings,* 2005.
- UNAIDS, *Handbook on access to HIV/AIDS-related Treatment: A collection of information, tools and resources for NGOs, CBOs and PLWHA groups*, 2003.

Annexes

ANNEX 1: Sample Code of Conduct

CHW and Peer Supporter Code of Conduct

This code of conduct provides guidance CHWs and PSs (collectively referred to as CHWs throughout the remainder of this document) in their conduct within the clinic and community they serve.

a. Scope of role

A CHW is a lay health worker who assists with less technical tasks in the clinic or performs community outreach. CHWs report directly to a CHW Supervisor.

b. Core ethical values and standards required of CHWs and PSs:

i. **Respect for persons:** CHWs should respect patients as persons, and acknowledge their intrinsic worth, dignity, and value.
ii. **Best interests of wellbeing:** CHWs should not harm or act against the best interests of patients, even when the interests of the latter conflict with their own self-interest.
iii. **Human rights:** CHWs should recognise the human rights of all individuals.
iv. **Autonomy:** CHWs should honour the right of patients to self-determination and to make their own informed choices, and to live their lives by their own beliefs, values and preferences.
v. **Integrity:** CHWs should incorporate these core ethical values and standards as the foundation of their professional conduct.
vi. **Truthfulness:** CHWs should regard the truth and truthfulness as the basis of trust in their professional relationships with patients and colleagues.
vii. **Confidentiality:** CHWs should treat personal or private information as confidential in professional relationships with patients — unless overriding reasons confer a moral or legal right to disclosure.
viii. **Compassion:** CHWs should be sensitive to, and empathise with, the individual and social needs of their patients and seek to create mechanisms for providing comfort and support where appropriate and possible.
ix. **Tolerance:** CHWs should respect the rights of people to have different beliefs, as these may arise from personal, religious or cultural convictions.
x. **Boundaries:** CHWs should not have sexual relationships with patients or take money from patients.
xi. **Punctuality:** CHWs should be punctual and reliable in their duties.
xii. **Self-care:** CHWs should make sure to take care of their own wellbeing and inform their supervisor if they are unwell.
xiii. **Role models:** CHWs are expected to act as role models to their patients and communities.

ANNEX 2: Certificate of Completion

The certificate on the next page should be awarded by a supervisor once the CHW has completed all of the exercises in this toolkit and demonstrates an understanding of the key take away messages in each section. The certificate demonstrates completion and dedication to improving as a CHW. It does not represent a formal training certificate, as the self-study guide is not an accredited training.

Certificate of Completion

This certificate is proudly presented to

____

for completion of the exercises in the PATA and One to One Children’s Fund Community Health Workers’ toolkit.

The person named above has demonstrated a commitment to improving his/her understanding of the role of Community Health Workers and key issues related to children, adolescents, and HIV.

____
Date

____
Supervisor’s Signature

____
Supervisor’s Name

ANNEX 3: Resources and Further Reading

The resources below served as references for this toolkit, and include practical tools that you can use to become a better CHW, as well as theory and learning behind the work that you do. Some are general resources on children, adolescents and HIV, and others are specific to a certain topic mentioned in the toolkit. You can find all of the resources online if you have access to the internet — each listing has the web address where you can go to download or read the information.

Documents

AIDS Response, *Train the Trainers Manual: A guide for setting up a care for carers programme*, 2011.

AIDSTAR-ONE, *Disclosure materials for children and adolescents, www.aidstar-one.com.*

AIDSTAR-One, *Improving the lives of PLHIV through WASH: A training manual.*

AIDSTAR-ONE, *Mother-infant health cards.*

AIDSTAR-One, *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*, 2014.

ANECCA, *Handbook on Paediatric AIDS in Africa*, 2011.

ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum,* 2009.

ANECCA, *Psychosocial Care and Counseling for HIV-Infected Children and Adolescents: A Training Curriculum*, 2009.

Avert, *Emotional Needs and Support, www.avert.org.*

Avert, *HIV and AIDS Treatment & Care, www.avert.org.*

Avert, *HIV and Breastfeeding, www.avert.org.*

Avert, *HIV Opportunistic Infections, www.avert.org.*

Avert, *HIV Transmission & Testing, www.avert.org.*

Avert, *HIV and Nutrition, www.avert.org.*

CRS, *Peer Education in HIV/AIDS Prevention, Care, Treatment & Support: A Comprehensive Training Course for Expert Clients in Malawi,* 2011.

EGPAF, *Issue Brief: Pediatric HIV & AIDS*, 2013.

FHI, *Establishing Referral Networks for Comprehensive HIV Care in Low-Resource Settings,* 2005.

Hesperian, *Helping Children Live with HIV*, 2013.

Hesperian, *Where There is No Doctor,* 1977, 1992, 2013.

Hesperian, *Where Women Have No Doctor: A health guide for women*, 1977, 2014.

International HIV/AIDS Alliance, *A Parrot on your Shoulder: A guide to working with orphans and vulnerable children,* 2004.

International HIV/AIDS Alliance, *Building Blocks in Practice: Participatory tools to improve the development of care and support for orphans and vulnerable children*, 2004.

International HIV/AIDS Alliance, *Community Engagement for Antiretroviral treatment: A training manual*, 2006.

International HIV/AIDS Alliance, *Family-centered HIV Good Practice Guide*, 2012.

International HIV/AIDS Alliance, *Good Practice Guide: Family-Centred HIV programming for children*, 2012.

International HIV/AIDS Alliance, *Health and Nutrition: Resources for communities working with orphans and vulnerable children*, 2003.

International HIV/AIDS Alliance, *Psychosocial Support: Resources for communities working with orphans and vulnerable children*, 2003.

International HIV/AIDS Alliance, *Toolkit: Understanding and challenging HIV stigma*, 2007.

International HIV/AIDS Alliance, *Young Children and HIV: Strengthening family and community support*, 2006.

John Snow International (JSI) Research & Training Institute, Inc., *Community HIV Counselling and Testing: A handbook on Participatory Needs Assessment,* 2008.

PIH, *Accompagnateur's Handbook*, 2012.

REPSSI, *Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment*, 2008.

REPSSI, *Psychosocial Care and Support for Young Children and Infants in the Time of HIV and AIDS — A Resource for Programming*, 2007.

REPSSI, *Supporting Young Carers: Programme Guidelines for Households in which Young People are Caring for Other Household Members*, 2007.

South African National Department of Health, *Psychosocial Support for Children and Adolescents Infected and Affected by HIV,* 2012.

S2S, *Disclosure Process for Children and Adolescents Living with HIV: A Practical Guide,* 2010.

S2S, *How to Keep Healthy,* 2010.

S2S, *Knowing About Myself,* 2010.

S2S, *Living a Life of Health,* 2010.

S2S, *Nutritional Support from Birth through Adolescence,* 2010.

S2S, *Paediatric HIV Care and Treatment: A Toolkit for South African Healthcare Workers,* 2010.

S2S, *Psychosocial & Adherence Counseling Support Training Toolkit,* 2010.

TAC, *HIV, Pregnancy & Your Choices: A fact sheet for parents to be*, 2011.

TAC, *HIV in Our Lives,* 2007.

TAC, *HIV and Nutrition,* 2008.

TAC, *Pregnancy in our Lives*, 2010.

TAC, *Talk About Nutrition: Nutrition Fact Sheet,* 2005.

UNAIDS, *Handbook on access to HIV/AIDS-related Treatment: A collection of information, tools and resources for NGOs, CBOs and PLWHA groups*, 2003.

UNICEF, *Facts for Life: How Children Develop*, 2010.

WHO, *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection,* 2013.

WHO, *Flipchart for Patient Education: HIV Prevention Education and Care*, 2006.

WHO, *Guidelines for an Integrated Approach to the Nutritional care of HIV-infected children (6 months –14 years)*, 2005.

WHO, *Health for the World's Adolescents: A second chance in the second decade*, 2014.

General resource websites

1000 Days, www.thousanddays.org
1,000 Days promotes action and investment to improve nutrition for mothers and children in the 1,000 days from a woman's pregnancy through her child's 2nd birthday, when better nutrition can have a life-changing impact on a child's future and help break the cycle of poverty.

ANECCA, anecca.org
ANECCA has written a number of very useful publications that are available for download from its website, including the *Handbook on Paediatric AIDS in Africa* (2013), and the *Comprehensive Paediatric HIV Care Training Manual* (2007), both in English and French.

AIDSTAR-ONE, www.aidstar-one.com
An initiative of USAID, AIDSTAR-ONE houses a huge library of HIV resources that you can draw from. A number of key documents are included in the preceding list.

AVERT: Averting HIV and AIDS, www.avert.org
AVERT is a global resource for HIV and AIDS education and information, with easy-to-read fact sheets on just about anything related to HIV and AIDS, advice and support on living positively with HIV, and targeted resources for teachers, caregivers, and youth.

Baylor International Pediatric AIDS Initiative (BIPAI), www.bipai.org
BIPAI has a wealth of resources specifically focused on paediatric HIV and AIDS, including the BIPAI Toolkit, a how-to manual for care and treatment of children with HIV/AIDS in low-resource settings.

Centers for Disease Control (CDC), www.cdc.gov
While many of the CDC's resources are more focused at healthcare providers in formal clinic settings, the CDC's resource list includes some prevention, care, and treatment resources that might be of use to you as a CHW. You should always talk with your supervisor about how international guidelines are implemented in your country and clinic.

Clinton Health Access Initiative (CHAI), www.clintonhealthaccess.org
CHAI works to scale up ART internationally, especially amongst children. Their website houses information about their work and some resources and tools on ART scale-up.

The Coalition for Children Affected by AIDS (CCABA), www.ccaba.org
CCABA works to bring funders and experts together to advocate for the best policy, research and programs for children affected by AIDS. Their website hosts a few resources that may be useful, including *Palliative Care at Home for Young Children in Africa* and the *Healthy Parents, Healthy Children, Healthy Families* brochure that you can adapt and give to community members and patients.

EGPAF, www.pedaids.org
A leader in the field of paediatric HIV research, EGPAF have some useful documents on their website, particularly their *fact sheets* that give an overview of key parts of the HIV response.

Hesperian Health Guides, hesperian.org
The writers of *Where There Is No Doctor* have a number of other titles as well, including many mentioned in this toolkit. Some of the books are available as downloadable resources for free on their website. They also have a very useful HealthWiki page with links to resources from other organisations.

ICAP at Columbia University (ICAP), icap.columbia.edu
ICAP works globally to improve the health of families and communities. On their site, ICAP has some great resources for CHWs, including *Adolescent HIV Care and Treatment: A Training Curriculum for Multidisciplinary Healthcare Teams* (2011), *Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators* (2011), and a *Comprehensive Peer Educator Training Curriculum* (ND).

Interagency Task Team on the Prevention and Treatment of HIV infection in Pregnant Women, Mothers, and Children (IATT), www.emtct-iatt.org
The IATT has resources to help with the elimination of mother-to-child transmission. These include publications like *Why I Take My Medicine* (2012), a book about disclosure written for children in Namibia.

International HIV/AIDS Alliance, www.aidsalliance.org
Tackling the HIV epidemic at the community level for over 20 years, the International HIV/AIDS Alliance has a large number of resources and tools. Two toolkits in specific will be useful for CHWs: the *Sexuality and Life-Skills Toolkit,* and *Feel! Think! Act!*, a toolkit of ideas of how to work with young people to think about and take action to improve SRH.

Knowledge for Health (K4Health), www.k4health.org
K4Health has compiled collections of carefully selected health resources for you to draw on in 10 different topics. Specifically interesting for you may be the ALHIV toolkit, a list of resources that look at issues around prevention, care and treatment from the perspective of adolescents.

MELYCABA, melycaba.com
MELYCABA links to some useful tools and resources on its site to help people working with ECD better understand ECD, make assessments of child development, parenting capacity and organizational development, and learn how best to design and evaluate interventions for children.

PIH, www.pih.org
PIH uses a CHW approach to implement their health programs, and their Knowledge Center on their website includes a number of useful tools for CHWs, including the *Accompagnateur's Handbook* (2012), which includes lots of great resources that you can use without lots of technology ('accompagnateur' is the name PIH uses for CHWs).

Prevention Resources for People Living with HIV, www.plhivpreventionresources.org
A website created by PEPFAR in collaboration with the CDC, USAID, and the US Department of Defense that houses thousands of resources on preventing HIV, positive physical and mental living, and the involvement of PLHIV in all aspects of prevention, care, and treatment.

REPSSI, www.repssi.org
This South African-based organisation works for psychosocial wellbeing for all children, including those living with HIV. They have many practical tools on their website, from Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment, (2008) to Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment (2008).

UNICEF, www.unicef.org
UNICEF's resources includes information around children and adolescents and HIV. One resource you might find useful is *HIV and adolescents: Guidance for HTC for ALHIV,* 2013.

Women, Children and HIV: Resources for prevention and treatment, womenchildrenhiv.org
A comprehensive resource library managed by the University of California — San Francisco. Organized by topic area, resource type, target audience, countries and regions, and languages, it also houses an online training course specifically on PMTCT in low-resource settings that you might find useful for further study.

WHO, www.who.int
While many of the WHO's resources are more focused at healthcare providers in formal clinic settings, the WHO's resource list includes official HIV Guideline documents that might be of use to you as a CHW. You should always talk with your supervisor about how international guidelines are implemented in your country and clinic.

Icons in the toolkit have been adapted from flaticon.com

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