THE MEMORY WORK TRAINER'S MANUAL

supporting families affected by HIV and AIDS

NACWOLA

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The memory work trainer's manual: supporting families affected by HIV and AIDS

This manual has emerged from experience of memory work in Africa. It is intended as a template that can be adapted for use in different settings. It is a work in progress. Your feedback will help us to improve the manual.
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Contents

Preface

Memory work is a community-led approach to encourage families to communicate openly about HIV. It helps parents look at how to disclose their HIV status to their children, record important information in ‘memory books’, and plan for the future.

Barnardo’s (UK) began working with memory books in the 1990s with African families affected by HIV and AIDS in the UK. Since then, memory work has come a long way. NACWOLA (the National Community of Women Living with HIV and AIDS) in Uganda, Save the Children Uganda and CLS Development Services have contributed significantly to its development. These organisations worked to develop the approach so that it could be used on a larger scale, and to widen it from its initial focus on producing memory books.

This manual has emerged from the International Memory Project, funded by Comic Relief, through which Healthink Worldwide and NACWOLA have introduced NACWOLA’s pioneering approach to other organisations in Africa.

The memory work approach is designed to evolve, responding to the changing needs and circumstances of communities – for example, the increasing access to antiretroviral therapy. However, the focus of memory work on disclosing of HIV status and improving communication between parents and children remains key in an environment where people are living longer with HIV.

Members of NACWOLA perform a song about HIV and AIDS

Introduction for the trainer

The Memory Work Trainer's Manual guides trainers through a course to support parents, guardians and carers affected by HIV and AIDS, by helping them to:

- share information, hopes and fears with their children
- strengthen each child's sense of identity and belonging
- plan for the future care of their children.

Many parents who have completed the course feel empowered to overcome the fear of disclosing their HIV status. This starts a process of breaking down 'walls of silence'. Experience shows that when children learn the truth about HIV and AIDS and can share in their family's problems, they start to face up to the future. Trusted with the truth, it is generally less frightening for them than if parents tell them very little, leaving them to worry alone.

Who are the manual and course for?

The manual is written to support trainers with all levels of experience, but all will need some basic HIV and AIDS training and/or knowledge. It guides trainers through a course that is designed to be delivered to:

- parents and other family members living with HIV and AIDS
- future guardians of children affected by HIV and AIDS
- community workers and volunteers working with children and families affected by HIV and AIDS.

It can be delivered to people with varying levels of education, but the trainer will need to adapt it to suit the local cultural context and reality. All participants will have the common aim of wanting to prepare for their children's futures, safeguarding as far as possible their children's emotional, physical and financial wellbeing.

Because the course is relevant to an increasingly wide group of people involved in providing support to children, it is important for the trainer to note that not all participants will be living with HIV themselves.

The manual can also be adapted to train future trainers to deliver the course.

The manual draws significantly on the experiences and ideas of NACWOLA trainers and trainees, as well as those of Healthlink Worldwide and others. We see it as a living document that can be adapted and improved over time, informed by our growing experience.

Aims

The aims of the course are to:

- improve understanding of child development and explore children's differing needs at different stages
- explore parenting styles and promote an understanding of positive relationships between parent and child
- explore issues of disclosing HIV status
- help parents prepare their children for the impact of separation and loss
- help parents, guardians and carers prepare and plan for their children's futures, and explore how children and teenagers can participate in these processes
- explore aspects of new family relationships
- improve understanding of the purpose and benefits of making a memory book

- explore how to make a memory book
- improve understanding of key legal issues involved in safeguarding children's futures
- help parents, guardians and carers plan a way to make the most of their learning after the end of the course.

How to deliver the course

The course consists of 12 modules. Ideally you will be able to cover all the modules. However, the course has been designed to be flexible so that if there is not enough time, or you decide as a group that you do not need particular modules, it is possible to drop some of them. Module 1, the introductory session, guides you and your participants on how to prioritise and negotiate which modules to cover. Modules 1 and 12 are essential and should not be dropped.

As you go though the manual you will see that each module has a consistent structure, shown in the box below, to help you plan the session:

Structure of the modules

Trainer's introduction
This includes:

- the approximate length of each module
- the aims of each session or module
- the key learning outcomes.

Trainer's preparation

- Module plan – this guides you on how much time to spend on each topic. These are suggested times only and can be adapted to your group's needs. Before each session, please add refreshment and meal breaks to the module plan that you show to the participants. These should be added at intervals that suit your course's circumstances.
- Materials you will need – this tells you what extra materials are required for the session. Use whatever materials are appropriate and available to you. These may include overheads, flipcharts or other presentation materials. For the purpose of this manual, we have marked certain sections for use on an overhead or a flipchart, but you can adapt this as necessary. Whichever method you use, please ensure that you prepare appropriately before the session.
- Trainer's notes – these are briefing notes for you for information and to help you plan the session. The notes are placed at the end of relevant modules but do not appear for every module. These notes are for you, the trainer, and should not be delivered directly to participants.

Trainer's guidance
Under this heading we have set out the content of the module that you will cover with participants. We offer guidance on how to tackle each topic and activity, and key points to bring out in discussion to help participants get the most from the course.

The modules are designed to give you some flexibility as you deliver them. We have given suggested times for each activity so that, if time is short, you can choose to focus on one or two activities that best meet the needs of your participants and leave the others out. Groups may need more or less time, depending on their levels of learning, experience and knowledge.

Size of the group

We recommend that you deliver the course to groups of 12 to 16 participants. This is a good number to enable discussion and encourage everyone to take part.

Length of the course

The full course is intended to run over seven to eight days. If, together with the group, you decide to leave out a module, you can change the timing of the course accordingly.

A field visit could also be included in the training workshop, for example, to an organisation carrying out memory work in the local area, or to a family that has been using the approach. Extra time needs to be allowed for this and as trainer you will need to make a preparatory visit before the course starts. You may also wish to add in an extra day for looking at the practical aspects of implementing memory work.

The approach of the course

The course will best work for you and the participants if you encourage a **participative approach**. This means that you should encourage everyone in the group to actively participate and contribute to discussions and activities. Gently encourage them to reflect and share with each other their personal experience and knowledge and how they are affected by the different issues. Participants are more likely to be open if they feel they will not be judged, and will be listened to with respect. Encourage these attitudes in the group. Say that if participants want to challenge what a member of the group says, it must be clear they challenge the view and not the person.

Guidance on how to be a good trainer or facilitator is outlined in *Tips for Trainers* on page 10. Read it carefully. Note those points you already do and keep doing them. Recognise your areas for development and think about how you can improve on them for this course.

Pre-planning

We recommend you plan well in advance. **Go through the manual weeks before the course starts**, to help you absorb and reflect on some of the issues and to arrange for support where necessary. You will need to make practical arrangements such as finding an appropriate venue, organising meals, copying handouts and getting flipcharts, an overhead projector and video player if available.

Think about the people you are preparing the course for. Consider how you can adapt some of the activities to make them fit the particular local context. Can you do anything to make the content and activities more relevant and stimulating for your group? Consider the difficulties and challenges that might arise among the group you will be working with and how you would address them.

The more time you spend preparing for the course, and refreshing your memory about each module the day before you deliver it, the more confident you will feel, and the more you will encourage participants to take part and get the most from the course.

Practical preparation for the course

The materials and equipment you will need for every module are:

- flipchart, marker pens and sticky tack or drawing pins
- overhead projector, screen and transparencies or flipchart paper or any other appropriate material available to you. You will find the content of overheads/flipcharts clearly marked in each module
- pens for participants.

Extra materials or equipment you will need are listed under the **Trainer's preparation** heading in the modules.

Prepare name badges for the participants and yourself, and ensure that all participants know where to find facilities such as the toilets.

Complementary resources

Some key resources complement the manual to help you deliver the course effectively. These include:

- *The Memory Book for Africa* (revised ed 2000), which includes guidance on how to use and make a memory book and a memory basket, and is available in a range of African languages.s
- *NACWOLA Guide to Legal Information for Parents Living with HIV/AIDS in Uganda*, which gives guidance that can be adapted to the circumstances of different countries. Topics include legal protection for children, writing a will and securing property rights, all of which are vital parts of memory work.
- **Videos,** including some or all of the following:
  Everyone's Child (Media for Development Trust, Zimbabwe, 1996, colour, English, 85 mins): to support Module 6
  Beyond Survival (TILLA – Association of Women Living with HIV, Ethiopia, 1997, colour, 25 mins): to support Module 5
  A River of Hope (Healthlink Worldwide et al, 2003, colour, English, 44 mins): To support Module 10
  Neria (Media for Development Trust, Zimbabwe, 1990, English, Portuguese and Swahili, 103 mins): to support Module 11.

Please see Appendix 1: Key course materials (page 123) for more information.

Emotional content and demands on the trainer

The nature of the course presents you with some particular challenges. Many of the issues you will cover are complex and can be difficult to talk about. You are likely to address family relationships, parent-child relationships and sexual relationships and practices. These areas are sensitive at the best of times and will be particularly so during the course.

You need to be aware of your own feelings and the feelings in the group. Be prepared to take a break if people get too upset and tell participants it is fine to leave the session for a while if they need to. Make sure there is a place where participants can go if they become very emotional. If possible, arrange for someone who can listen to them.

Although honesty and openness are encouraged throughout the course, it is important not to force this on participants. The most you can expect is for people to be ready to ask themselves difficult questions about their own attitudes and behaviour, and those of the important people in their lives.

Tips for trainers

If you already do all the things on the list, you are a wonderful trainer. Most of us do some of these things, but not all of them. Tick those points you already do and keep doing them. Think carefully about the points you do not do yet and prioritise the ones you think you can start to do most easily. You will find you can tick more as you gain experience.

Prepare well for the course

- Be well organised and plan in advance. This includes practicalities like photocopying handouts, preparing overheads and flipcharts (or other presentation aids you are using), checking all equipment, having all supporting resources and facilities ready on time, checking the suitability of the venue, and arranging appropriate meal and break times and menus.
- Always plan to arrive at the venue well before the participants to ensure the room is ready and to sort out any problems so you can start the session on time.
- Use this manual flexibly and adapt it to fit local circumstances and the needs of the particular group. Each group will be different.

Be participative

- Be a good listener and respond to the needs that participants express.
- Be sensitive to the needs and emotions of individuals and groups.
- Make all participants feel safe, respected and valued.
- Encourage everyone to take part. Give quiet people a chance to speak. Tell people who speak too much that the group need to hear other people's thoughts too.
- Motivate and inspire people.
- Ask people to help when appropriate.

Help people to get the most from the course content

- Provide guidance and leadership. For example, make sure the agreed content of modules is followed. This will only happen if you keep time effectively and move people on when necessary.
- Be flexible, so that you can include important issues as they arise, while recognising the importance of keeping to the timetable.
- Know the course well so you can link: activities to learning points; topics to people's individual needs; and themes between sessions.
- Draw out the important points from participants' contributions and summarise them to the group.
- Be thought-provoking and challenge people to think.
- Admit when you do not know something. Participants will generally appreciate your honesty.
- Be ready to tell participants where they can get help and support after the course ends.

Deal with differences

- Appreciate that participants have had a range of experiences and are likely to be at different starting points. Their levels of engagement and the pace at which they move will also differ. Be ready to explain things more than once and to summarise points.
- Be prepared to manage tensions and conflict, for example, by making clear what is and is not relevant and appropriate to the course. Ask individuals to sort out their differences at another time if necessary.

Good luck!

Key words and phrases used in the manual

As you go through the manual you will see words and phrases that might be unfamiliar or need clarifying. Here is a list of key words and phrases to help you.

1. Related to training

Befriender: a person who acts as a friend or helper.

Brainstorming: to share everything that comes to people's mind about an issue or topic.

Communication: the two-way giving and receiving of information and ideas.

Pair: group of two people.

Participant: someone who actively takes part or joins in.

Participative (or participatory): describes an approach that encourages everyone to actively take part or join in.

Small group: a group of three or four people.

2. Related to memory work

Disclosure: revealing private information or the truth about a secret.

Family tree: a diagram that shows how people are related and from whom they are descended.

Memory book: a written record of family and individual history, important facts, memories, hopes and messages. They can be written by parents or guardians with or for children, or they can be written by children themselves.

Memory work: Memory work is a community-led approach to communicating about HIV in the family. It addresses a variety of issues including:

- improving communication between guardians and parents living with HIV and their children
- disclosing HIV status
- imparting other important information
- planning for legal guardianship and inheritance (succession planning)
- writing important family history in a memory book.

A variety of activities take place around these main pillars.

NACWOLA: National Community of Women Living with HIV and AIDS in Uganda.

People affected by HIV and AIDS: includes PLHA (see below) as well as people not living with HIV or AIDS themselves, but who are otherwise affected by their impacts.

PLHA: People living with HIV and AIDS.

Role-play: to act out real-life situations, playing the role of certain characters.

MODULE 1

Introduction to the course

Trainer's introduction

Please do not miss out this module, or any section of it, as it is essential to the smooth running of the course. It welcomes participants and sets course objectives, and it guides the group to have realistic expectations of what they will gain from the course. A good introduction can encourage enthusiasm and openness to learning among participants. These attitudes help to make it a constructive experience for everyone.

Approximate length of module 2 hours 10 mins

Aims

The aims of this module are to:
- introduce the trainer(s) and participants
- make a group agreement
- present the aims of the course
- introduce key learning outcomes
- discuss expectations and negotiate areas to be covered
- clarify the agreed course content.

Key learning outcomes

By the end of this session participants will:
- have introduced themselves to other participants
- understand the group agreement for the course
- understand the aims of the course
- know the key learning outcomes they are working towards
- have discussed expectations and negotiated areas to be covered
- have an overview of the agreed content of the course.

Trainer's preparation

Module plan (with suggested times)

- Introductions – **55 minutes to 1 hour 5 minutes**
- Presenting the aims of the course – **10 minutes**
- Introducing key learning outcomes – **10 minutes**
- Expectations of the course and negotiating areas to be covered – **45 minutes**
- Reflection – **10 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 1
Overhead/flipchart 2: The aims of the course
Overhead/flipchart 3: Key learning outcomes from the course

Trainer's guidance

Introduction

Welcome the group and introduce yourself. Briefly tell the group something about your professional background and how it is relevant to the course. Do not spend more than two or three minutes on this.

One of your jobs is to put the group at ease. At this point simply say that the group has gathered to look at positive ways to plan for their children's futures and that you look forward to working with everyone so that they can get as much as possible from the course.

Next, inform the group of the following points:

- Practical arrangements including location of toilets, meal and refreshment break arrangements, and any evacuation or emergency procedures.
- Ask participants to let you know either now or at the first break if they have any special needs such as hearing or sight impairments that need to be taken into account.

Activity 1 Getting to know each other

Suggested time: 30-40 minutes depending on the size of your group

Below, there are two ways you can use to help participants to get to know each other. Select the activity you prefer.

Explain to the group that the aim of this first activity is to get to know each other.

Option 1

1. Ask everyone in the group to divide into pairs, with someone he or she has never met before or does not know well.

2. Tell the pairs to take turns to interview their partner for three minutes. Ask them to be ready to introduce their partner to the whole group, providing the following information:

- the name by which they want to be called during the course
- where they come from
- why they are on the course
- anything interesting they would like the group to know about themselves.

3. Ask participants to volunteer to feed back. Tell them they have only two minutes each. Make a note of what participants want to be called as this might be different from the name on their name badges.

4. Thank each person after they have finished introducing their partner. Ask who would like to go next. Use eye contact to encourage and help people to take part.

5. Thank everyone again and state that you hope and expect that you will all get to know each other, to trust each other and to work well as a group.

Option 2

1. Tell participants you are going to ask them to introduce themselves by telling the group the name they want to be called and three interesting things about their lives. Give them three minutes to prepare, saying they will be given two minutes each to speak to the group.

2. Ask participants for feedback. Make a note of what participants want to be called as this may be different from the name on their badges.

3. Thank each person after they have finished introducing themselves. Ask who would

like to go next. Use eye contact to encourage and help people to take part.

4. Thank everyone again and state that you hope and expect that you will all get to know each other, to trust each other and to work well as a group.

After the introductions the next step is to go through the topics to be covered in this module and how the session is structured.

Overhead/flipchart 1: Outline of Module 1
Please use the list in the module plan on page 13, but without the suggested times.

Activity 2 Making a group agreement

Suggested time: 20 minutes

Explain that it is important for you as trainer to encourage people to discuss issues and share ideas safely and openly. Say that to do this the group needs to agree to a set of rules that promote an atmosphere of respect towards all members of the group. These rules will make up the group agreement. They will guide what behaviour is acceptable in the group and what is not, and help the course to run smoothly. The group agreement will be particularly valuable as you look at sensitive issues in later modules.

1. Ask participants to think of rules that should make up the group agreement. Encourage everyone to participate in the discussion. It is important to recognise that rules are most likely to be followed if they come from the group.
2. Record participants' ideas on the flipchart. You may need to ask participants to explain what they mean by some of their suggestions.
3. Look at the list of rules below. You may need to prompt the group if any of these points are left out.
4. After 10 minutes, take a further 10 minutes to guide participants to decide on the rules they want in the group agreement.
5. Ask the group to make sure they and others keep to the agreed rules. This will encourage a sense of responsibility in the group.

Keep the flipchart and write up the group agreement clearly on a new flipchart paper during a break or at the end of the day. Keep the group agreement on display throughout the course to remind participants what they have agreed. As trainer, lead by example and make sure you keep to the rules. For instance, always arrive on time, be well prepared and do not interrupt when someone is speaking.

Rules within the group agreement should include:

Respect each other
Treat participants the way you would like them to treat you. Avoid judging other people's thoughts and feelings. We are all different and have different ways of looking at the world. People's contributions must be listened to and valued. If we disagree with what someone has said, we should not challenge the person, but the person's view.

Be open and honest
Say what you think, without fear of being laughed at or being judged.

Be confidential
Agree among everyone that what people say on the course is confidential. Never talk about people's personal issues or identify participants by name outside the group.

This rule must be strictly followed, otherwise participants may not speak freely. It is important everyone understands this.

Actively listen to each other

Agree to listen to each other without interrupting. Only one person should speak at a time. The group should recognise that it is the trainer's responsibility to move people on when appropriate, to give other participants time to talk.

Be a good time-keeper

Agree to all arrive on time at the start of the day, and after meal and refreshment breaks. The group should recognise that it is the trainer's responsibility to keep participants to allocated times for exercises and activities.

Presenting the aims of the course

Allow 10 minutes for this part of the module. Explain to the group that at this stage it is important for them to have an outline of the modules that make up the course. Tell them the modules are linked and one builds on the learning of another. Say to them that later in this module they will have an opportunity to discuss whether they need all the modules, so it is important to understand what each module covers before making that decision.

Overhead/flipchart 2: The aims of the course are to:

- improve understanding of child development and to explore children's needs at different stages
- explore parenting styles and promote an understanding of positive relationships between parent and child
- explore communication skills
- explore the issues around disclosing HIV and AIDS status
- help participants prepare their children for the impact of separation and loss
- help participants prepare for their children's futures
- explore how children can participate in planning their own futures
- explore aspects of new family relationships
- improve understanding of the purpose and benefits of making a memory book
- explore how to make a memory book
- improve understanding of key legal issues involved in safeguarding their children's futures
- help participants plan how to take forward what they have learned after the end of the course

Go through each point on the overhead/flipchart carefully. Be ready to answer questions about what each module contains.

Introducing the key learning outcomes

Allow 10 minutes for this part of the module. Explain that you will now go through what participants can hope to learn during the course. It is important to link this back to the course content. Obviously if the group decides to leave out a module, it will have an effect on the learning they will gain from this course.

Overhead/flipchart 3: Key learning outcomes of the course

By the end of the course participants will have a better understanding of:

- why planning for their children's future is important (an outcome of the whole course)
- children's needs at different stages of development (Module 2)
- the importance of positive relationships between parent and child (Module 3)
- communication skills, including why and how to communicate more openly with children (Module 4)
- the importance of being open and honest with their families (Module 5)
- how to prepare their children to cope with loss and separation (Module 6)
- how to start planning for their children's future (Module 7)
- how to help their children participate in planning their own future (Module 8)
- how to prepare for changes in family relationships (Module 9)
- making a memory book (Module 10)
- where to get practical help and support (Module 10)
- how to make a legal will and appoint guardians for their children (Module 11)
- ending the course (Module 12) – this module must not be dropped

Tell the group that the modules complement each other and points covered in one may be developed in another. It is useful to remind participants of this when they are frustrated about having to finish something and move on.

At this point you could read out the following quote on memory work training, that shows how memory work affects people's lives. First, explain that NACWOLA is a women's organisation in Uganda that led the way in developing memory work.

> "Before I joined NACWOLA I used to have a lot of fears and worry a lot about the children and about my life span. Now I lead a normal life like anyone else. Now I have confidence." Woman living with HIV in Pallisa, Uganda

Expectations of the course and negotiating areas to be covered

As trainer you need to guide Activity 3 (below) very carefully. It is your role to ensure that people's expectations are realistic and that, by the end of this session, participants understand what they can and cannot expect from the workshop. Participants often come to workshops with huge expectations that can never all be met. It is better to be honest about this, than to try to fit individuals' needs into a course that has not been designed for the purpose.

If appropriate, say that a follow-up workshop might cover some of the issues at a later stage and that you will provide details of sources of support, information and further opportunities at the end of the workshop. Emphasise that you will try to meet their hopes and expectations as far as possible within the planned course.

Allow five minutes for this introduction.

Activity 3 Balancing expectations with what is possible to achieve on the course

Suggested time: 40 minutes

Explain that the aim of this activity is to help people think about what they want from the course and recognise what is realistic.

1. Ask participants to divide into groups of three or four and organise themselves so they can talk without hearing the other groups. This will help them to concentrate. Give each group flipchart paper and a pen.

2. Tell the groups they have 10 minutes to discuss the following questions:

- What am I here for?
- What would I like to get out of the course?

Ask them to divide the flipchart in two and give one part the heading ‘Expectations’ and the other part the heading ‘Concerns and fears’. Ask them to list responses under these two headings.

3. Next, get one person from each group to take three minutes to share their flipchart with the whole group. Then allow a few minutes for questions and comments from other participants. As you go through, make it clear what can be covered and what is unrealistic. Say it is rarely possible to meet all expectations. Reasons why an expectation might be unrealistic include:

- there is not enough time
- the course is just not designed to look at that issue
- the issue is so specific that it would not benefit the whole group to look at it.

Allow 20 minutes for feedback and discussion.

4. As the discussion progresses it may become clear that some of the participants’ wishes do not match up with what the course offers. This is the time to refer back to the list of modules and their broad learning outcomes. If participants really do not want to cover a particular module or say they already know that subject area, then you can agree with the group to drop this module from the course. But make sure that everyone, including the quiet participants, has had their say. You could compromise: say that certain named people need not attend particular modules if they believe it is covering old ground, but that the module will be run for everyone else.

You can remind participants that the content of the course has been developed building on practical experience from over 10 years. It follows a logical path through issues that parents have found give them support, and that one session builds on another.

5. Spend five minutes clarifying what has been agreed as the content of the course.

6. Thank everyone at the end of the discussion and assure them that the course will aim to provide appropriate support to their needs and wishes.

In a break, write on flipchart paper the agreed modules that will make up the content of the course. Keep this on display throughout the course where everyone can see it.

Reflection

Tell the group that at the end of each module you will spend 10 minutes or more reflecting on it. This is a chance for people to share how they feel, to discuss what they think about the way the day has gone and any suggestions they might have about the handling of the next module.

At the end of this first introductory session you should:

- summarise what the group has covered (allow five minutes for this)
- ask for comments or questions
- thank the group for their hard work and say that you look forward to working with them on the next module

MODULE 2

What we need to know about child development

Trainer's introduction

This module looks at what it means to be a child and the different development stages children go through up to the age of 18. It explores what children's needs are at these different stages and encourages participants to think about how they might meet these needs.

In this module one of your roles as trainer is to emphasise the value of participants' existing knowledge and experience. In this session build on this know-how and help participants understand how their responsibilities as parents, guardians or carers might change.

Approximate length of module: 2 hours 20 mins

Aims

The aims of the module are to:

- enable participants to explore their understanding of what a child is and how children develop
- improve participants' understanding of children's development and how children's needs differ at each development stage
- help participants think about how to meet their own children's needs more closely by being open with them.

Key learning outcomes

By the end of this session participants will:

- have a better understanding of what a child is and how children develop
- know more about children's development stages and children's changing needs at each stage
- have an improved understanding of how to meet their own children's needs more closely
- recognise that each child is unique: they rarely fit precisely into the stages of development covered in the module, which are given as a general guide only.

Trainer's preparation

Module plan (with suggested times)

- Exploring our understanding of what a child is – **35 minutes**
- Understanding children's development and how children's needs differ at each development stage – **55 minutes**
- Recognising your children's needs and being open with them – **35 minutes**
- Reflection – **15 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 2
Overhead/flipchart 2: The law relating to children

Trainer's notes

The trainer's notes at the end of this module (page 25) will give you useful background on child development and will help you bring out learning points during the session and guide you to answer participants' questions.

Trainer's guidance

Introduction

Start the session by saying that you are going to look at the ways children develop as they grow up and how their needs change. Tell the group that with parents and guardians among them, they have a lot of very useful experience to draw upon and share with each other. Explain that by the end of the session, they will be able to use all the contributions that participants make and the new information the module will give them. They will feel more confident about dealing with children's needs and the problems and difficulties that children face.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 2
Please use the list in the module plan on page 19, but without the suggested times.

Exploring our understanding of what a child is

Activity 1 Looking at participants' understanding of what a child is

Suggested time: 35 minutes

Explain that the aim of the activity is to explore participants' understanding of what a child is. This activity will draw on their own experience.

1. Start with a brainstorm in the whole group on the word 'child'. Write this word on a flipchart and ask participants to call out thoughts, words and phrases that come to mind. Write all responses on the flipchart. Make sure you include everyone. Participants can say more than one thing. Allow about five minutes for this.
2. Go through what is on the flipchart. Point out that some of the differences between what the participants have said might be because they are thinking of children at different ages. For instance, the words we associate with a baby will be very different from those associated with a child of 6 or 16 years.
3. Bring out the following points. Explain that as parents, guardians and carers they are concerned about the safety and protection of all their children. How they approach difficult topics such as HIV will be different depending on the age of the child and the child's ability to understand. Say that HIV makes it necessary to talk with children, including the very young, about complex and serious issues that you may not normally discuss with them. These might be issues to do with sex, serious illness or death. Subjects like these need to be handled very carefully in a way the child can understand and begin to accept.

Spend about 10 minutes on this. End by summarising that the group has shown that how we think about children depends upon their age and stage of development.

Follow up this activity by showing participants what the legal definition of a child is in their country. Before the course begins, make sure that you have prepared an overhead/flipchart like the one below, adapted to the law of the country in which you are working. NACWOLA's *Guide to legal information for parents living with HIV/AIDS in Uganda* provides helpful information – see page 123, Appendix 1: Key course materials for more details.

Overhead/flipchart 2: The law relating to children
This is an example from Uganda that you can adapt – replace the words in brackets with the relevant information for the country in which you are working.

Under the law of [Uganda] a child is a boy or girl from birth up to the age of [18].

It is not legally permitted for anyone to have sex with a child [under 18], and a child [under 18] cannot be legally married.

Go through the points of the law carefully and, taking around 15 minutes, facilitate a group discussion on the topic. Point out that there are usually important differences between the laws of the country and local customs and practices among different tribes and clans. For example, in some areas female children may be promised in marriage or married at a much younger age than the official law recognises. Ask the group about local beliefs and practices relating to sexual activity, marriage and childbearing. Note also that teenagers sometimes become pregnant. This creates new relationships for the young person and changes the way parents interact with their children.

This discussion may bring up sensitive issues and opinions that participants might not agree on. You may need to remind participants of the group agreement and that they need to listen without judging the person speaking. If necessary, they may challenge the view, but not the person.

Tell the group that when parents and carers are talking with, or making plans for, their children, it is very important for them to be clear with the child which laws or practices affect them.

Finally, ask participants if they have any comments or questions.

Understanding children's development and how children's needs differ at each development stage

Please make sure you have read the trainer's notes (page 25) before you tackle this key topic. It will help you facilitate the discussion and add to what participants already know.

Introduce this topic by explaining that the group will build on the first activity by looking more closely at children at different ages or stages of development. By sharing what the group knows and adding to it, participants will have a better awareness of how children's needs differ at different ages. One of your roles as trainer is to build the confidence of parents and guardians.

Activity 2 Looking at children's stages of development

Suggested time: 55 minutes

Explain that the aim of this activity is to help participants look back at their own feelings and levels of understanding as a child, and how these changed as they grew up, so that they can try to imagine how children – their own and those of others – feel now.

1. Divide the group into three smaller groups and explain that each will consider children of a different age group: 0-6; 7-12; and 13-18. Ask participants to decide which group is most relevant to them based on their children's ages. Make sure that each group includes someone who can write the main discussion points on flipchart paper.

2. Ask the groups to take 15 minutes to think about the behaviour and understanding they expect from children in their given age group. Ask participants to think of themselves as children at those ages and about how their own children behave. Acknowledge that the age ranges are very broad and there will be great differences in expected behaviour within. Nonetheless, ask the groups to try to identify:

- the main characteristics of children in that age group
- the key issues for parents who need to impart something of importance to children in that age group.

Ask the groups to record the main characteristics and key points on the flipchart paper, before a representative feeds back to the whole group.

3. Give each group five minutes to feed back.

4. Allow another five minutes for whole group comments and discussion. Introduce the idea that things will be different in an unsettled and uncertain environment, and discuss how this may affect the behaviour of children.

This is a potentially emotional activity. As trainer you need to be aware that some parents and carers may find it difficult to talk and think about their children if they do not expect to be alive to share these development stages with them. Some parents and carers may have children who are living with HIV and might have strong feelings about how they may or may not develop. These participants might feel that parents with HIV-negative children cannot fully understand what they are going through. Others may have children who have already died.

For these reasons it is important to remain sensitive to how participants are reacting. Be especially sensitive when you ask people to contribute. Do not force anyone to speak. Participants may not be able to speak, but they may wish to listen. Take a break for a few minutes if participants become upset.

We recommend you summarise the behaviours and differences between the age groups in the following presentation. Make sure you have read the trainer's notes (page 25) thoroughly in your preparation for the module. If possible, relate relevant points back to what the group representatives have said. Be ready to answer questions.

Presentation

Allow 15 minutes for this. Before you start, say that the boundaries between the different stages are very flexible. They are given for broad guidance only. Each child is unique and development along this scale varies according to the child, and social and cultural influences. Children might be intellectually and physically mature, but emotionally young for their years.

0-6 years

In the first year of life a baby's world revolves around the loving care of its mother (or someone else who becomes a consistent primary carer).

From one to three years, a toddler begins to explore its surroundings and widen its relationships to include other very familiar figures such as its father or grandmother, brothers and sisters. The toddler begins to develop a sense of independence.

From birth to three years there is very little understanding of time, or the fact that people who go away might or might not come back.

Between the age of four and six years, intellectual, physical and social skills develop rapidly. These children tend to play with other children. Independence increases and they begin to make sense of the world.

Children at this stage increasingly understand rules of behaviour and begin to understand the concept of time.

This age group tends to rely on the family, particularly the primary carer, for security. Explain gently that children can thrive with anyone who provides consistent loving care, someone they can trust and come back to. A person other than the birth mother can also enable the child to develop into a well-balanced, happy young adult.

7-12 years

This is a stage where development is generally not as fast as in the other age ranges described here.

Children continue to build their intellectual, physical and social skills. This is a time for improving their competence in each of these areas.

Children begin to have much wider contact with people outside the family, building links in the community and school. Independence increases.

At this stage adults other than the parents become more influential in the children's lives: for example, teachers or people they admire.

Children of the same age can be a major source of self-esteem.

Children at this age can have a basic understanding of time, illness and death.

13-18 years

This is a stage where development speeds up again.

The changes of puberty often bring a sense of uncertainty about what type of adult they might be.

Teenagers often push away from their family and authority figures as they test their independence.

It is well known that this can be a difficult time for parents and carers: the young person can reject ideas and advice at one moment, and be very calm and accepting the next.

Some teenagers find it difficult to concentrate. Some might be anxious about the future and find it hard to plan.

It is important for parents and carers to be firm and predictable during this period.

When parents and carers have something important to say, they should choose their time carefully, looking for a time when the teenager is going through a calm and receptive period.

Be ready to answer questions at the end of your presentation. Allow five minutes for this.

Recognising your children's needs and being open with them

Introduce the next activity. Explain that now the group has covered some of the characteristics of children at different development stages, it is important to consider how to recognise their needs. One of the ways to do this is by being open with them.

Activity 3 Exploring the impact that keeping secrets has on children

Suggested time: 35 minutes

Explain that the aim of this activity is to consider the possible impacts that keeping secrets or withholding information might have on children.

1. Explain that this is a whole group exercise. Ask participants to reflect on their childhood to remember if changes happened in their family that they were aware of, but were not told about by their parents and carers. Encourage them to ask themselves:
  - How did I feel about it at the time?
  - How do I feel about it now?
  - What does this teach me about being parents and carers?
  - What support would I have liked at the time?

Allow five minutes for this.

2. Next ask if anyone would like to share any of these experiences and their feelings about them, or what they have learned from them. Please note this is only appropriate if participants choose to do so. Otherwise, individual reflection is enough. If anyone volunteers, give them five minutes to speak.

3. Now ask participants to take five minutes and consider individually what it would feel like to be one of their own children who is worried about his or her parent's health.

4. Divide participants into three smaller groups. Give them five minutes to discuss the signs that show a child is ready or anxious to receive more information. Then choose someone from each group to summarise the main signs their group has identified. When all groups have contributed (taking no more than 10 minutes in total) make sure the following points have been brought out. Signs that a child is ready for information include:
  - asking questions
  - sleeping badly and having nightmares
  - withdrawing from other people into their own world.

5. Close the activity by telling participants that Module 5 deals with disclosing HIV status to children and looks at these issues in more detail.

Reflection

Activity 4 Reflecting on the module and sharing key learning points

Suggested time: 15 minutes

Explain that the aim of this activity is to share their thoughts on the module and what they have learned.

1. Ask the group to work in pairs and share with each other:
  - what they thought about the content of the session
  - what ideas or thoughts they are taking away from it
  - how they feel about the structure of the day
  - whether they felt included and able to take part.

Allow five minutes for this.

2. End the session by asking three or four participants to share their views on the module and what they have learned. Ask for suggestions to improve the module if people are critical. Allow five to 10 minutes for this.

Close the module by thanking the group for their hard work and say that you are looking forward to working with them on the next module.

MODULE 2 – Trainer's Notes

In preparing for Module 2, you will first need to familiarise yourself with the broad **stages of child development**. Please refer to the information in the presentation on pages 22-23.

These notes provide a general introduction to the significance of separation and loss, and how they may affect children at different stages of development.

The significance of separation and loss

Separation and loss are distressing and may affect how children develop emotionally. Research across cultures shows that separation and loss are likely to be most distressing for children under six and particularly in the 0-3 age group. There are two peak phases of sensitivity in this age range. These are at six to seven months, when the baby's attachments have just developed, and between 12 and 18 months, as they begin to explore their surroundings and rely on a loving and secure base (generally the mother) to return to.

If the mother is no longer there, young children, who have limited understanding of language, may believe their mother no longer loves them and that they are somehow to blame for her disappearance. It is essential to try to make up for this lack of understanding by giving the child a photograph, a tape recording of the mother's voice or an article of her clothing to keep the child's memory alive.

The following points are generally true for children at all stages of development. Try to bring out these points in discussion during the module:

- The more stable and less tense the relationship is before separation or loss, the better the child may cope. However, this should not be confused with never letting the child out of your sight. Separation and loss in these circumstances will be even more traumatic.
- There is good evidence that well-prepared short trial separations help the child cope with later separation and loss, and enable the child to become more self-sufficient.
- If a child has multiple attachments, for example, to a carer such as an aunt, grandmother or father as well as the mother, this can help to make the total absence of the mother less stressful. This is particularly true if the child stays in the home environment or other setting she or he knows well.

Research also shows that:

- Losing a primary carer in childhood may not necessarily have lasting effects on the person. Individuals can show resilience to adverse events and circumstances.
- Healthy emotional development is more likely when parents have prepared well to arrange lasting, loving care, and strengthened their own relationships with their children, so that they feel confident they were loved before they experience loss.

MODULE 3

Parenting styles and parent-child relationships

Trainer's introduction

This module looks at different parenting styles and ideas of how to encourage good parent-child relationships. It also explores what it means to be a parent living with HIV and AIDS. The module continues the approach of building upon participants' existing knowledge, valuing their experience and increasing their confidence.

Approximate length of module 2 hours 20 minutes

Aims

The aims of this module are to:

- explore what it means to be a parent, and the impact of HIV and AIDS upon parenting responsibilities
- consider different parenting styles and factors that lead to better parent-child relationships.

Key learning outcomes

By the end of this session participants will:

- have a better understanding of what it means to be a parent, and the impact of HIV and AIDS upon parenting responsibilities
- have an awareness of parenting styles and factors that lead to better parent-child relationships.

Trainer's preparation

Module plan (with suggested times)

- Looking at what it means to be a parent, and the impact of HIV and AIDS upon parenting responsibilities – **50 minutes**
- Exploring parenting styles and factors that lead to better parent-child relationships – **1 hour 20 minutes**
- Reflection – **10 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 3

Overhead/flipchart 2: How might changes in family circumstances related to HIV and AIDS affect parenting?

Overhead/flipchart 3: Parenting styles

Trainer's guidance

Introduction

Explain to participants that the purpose of this module is to give them an opportunity to explore what it means to be a parent, the different styles of parenting and to look at ways to strengthen relationships with their children.

Remind participants that they all have relevant experience they can share with each other. Encourage the group to offer examples of their experience in different parenting situations. Emphasise that there are many different ways to bring up children and there is no single correct way. By sharing ideas and learning from each other, and what the module offers, each participant can examine her or his own parenting style and might find some things they want to do differently in the future.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 3
Please use the list in the module plan on page 27, but without the suggested times.

Looking at what it means to be a parent, and the impact of HIV and AIDS on parenting responsibilities

Activity 1 Looking at what it means to be a parent

Suggested time: 15 minutes

Explain that the aim of this activity is to explore what it means to be a parent. Before you begin, tell participants that there are no right or wrong answers. Everyone's ideas and opinions are useful and will help the group have a good discussion.

1. Brainstorm with the whole group on their ideas of what parenting is. Write up all their responses on a flipchart.
2. Make a definition of a parent with the group. Offer a definition you have prepared before the course. Put the ideas together and agree on a working definition of a parent with the group. Allow five minutes for this.

Activity 2 Looking at the issues faced by parents and carers affected by HIV and AIDS

Suggested time: 35 minutes

Explain that the aim of this activity is to explore how changes in family circumstances related to HIV and AIDS could affect parenting.

1. Ask participants to divide into pairs and discuss the questions on the overhead/flipchart 2 below. Tell them they will have 20 minutes before you ask them to report back to the whole group with the three most important points from their discussion.

Overhead/flipchart 2: How might changes in family circumstances related to HIV and AIDS affect parenting?

- If a parent dies when children are young, does he or she remain a parent?
- How might a parent who has died still have some influence on family members, particularly children?

- Guardians or foster carers may become the people with legal responsibility for a child – can they become parents and carers for the child too?
- In families where there is more than one wife, do the mothers only parent their own children, or do they have parenting responsibilities for the father's other children? What problems might come up? What might be the benefits?
- If a parent with HIV becomes too ill to do everything for the children, who else can share the parenting?
- What might happen if a step-parent (and maybe step-brothers and/or step-sisters) joins the family? How do you choose which parents should set out the rules of the household and style of living? What problems might come up?

2. Ask the pairs to come together as a large group. Ask each pair to explain the three most important points from their discussion to the rest of the group.
3. Record the points on a flipchart. Summarise the most important points and ask for questions or comments from the group. Allow 15 minutes for this.

Exploring parenting styles and factors that lead to better parent-child relationships

Introduce this topic by saying that you will build on participants' experiences of parenting, and consider different parenting styles and the factors that lead to better parent-child relationships.

Activity 3 Exploring parenting styles and factors that lead to better parent-child relationships

Suggested time: 55 minutes

Explain that the aim of this activity is to give the group an opportunity to discuss different approaches to parenting and share their experiences.

Stress that, because there are many ways of parenting, participants will not necessarily agree with each other about everything. There is nothing wrong with this and it is to be expected. Also, parents and carers in the group will face some similar and some different challenges. Remind parents and carers of the group agreement and that they should not be judgmental. Say that listening to different opinions will help them think through their own values and styles of parenting.

1. Divide participants into three or four smaller groups. Give them 20 minutes to discuss the points on the overhead/flipchart. Give them flipchart paper and pens, and ask them to summarise the main ideas coming out of their discussion.

Overhead/flipchart 3: Parenting styles

- When you think of a parenting style that helps children, what do you think of?
- When you think of a parenting style that does not help children, what do you think of?
- Look at this list and think of the ways of tackling each point that work best for you:
    - giving children safety and protection
    - giving children physical contact and comfort
    - giving children emotional support
    - disciplining children
    - communicating in front of, and with, children
    - trusting and handing over responsibility to children
    - being a responsible parent.

As trainer you could add more parenting issues that might be appropriate for the group. Be aware of local practices and circumstances.

2. Display the flipchart papers on the wall and ask everyone to look at what the others have written. If it helps people, you could read out the points on the flipcharts yourself. Ask the group for comments. Ask the following questions to help the discussion:

- Are there any similarities in what the groups came up with?
- What are some of the differences?
- Are there any surprises?
- Has anything changed in the way you parent since becoming HIV positive?

Allow 10 minutes for this discussion.

3. Now ask the participants to return to their small groups. Give them 10 minutes to identify three to five factors they think are most important to good parenting.

4. Ask one person from each group to take three minutes to report back with the points that their group selected. Ask the whole group for comments or questions and see if they can agree on the three to five most important factors that lead to good parenting and better relationships with children. Make sure that the discussion covers the following points:

- It is important to be consistent and fair in whatever parenting style you choose. This means being as secure and predictable for your children as you can be, for example, in the way you give love and comfort, in the way you protect and care for them, in the way you reward and discipline them. (Note that you are not telling the group what to do as a parent, only how to do what they think is best.)
- It is important to try to listen to what your children say and give them time to express their hopes and fears. Be honest with your children. (This is a suggestion based on research and practice in childcare.)

Hopefully the group will be able to identify some points of agreement. However, if participants cannot agree on five points, say that this does not matter, because we all view parenting from different perspectives. Generally, parents and carers try do what they think is best for their children. Allow 15 minutes for feedback and discussion.

5. To close the discussion, you could read out the following words from an evaluation of a NACWOLA memory work project in Uganda.

> “The [memory work] project has had an extensive impact on the relationship between NACWOLA women living with HIV and AIDS and their children. This is evident from the ease expressed by mothers in talking about their status, and how free children are about their parents’ and carers’ lives and the plans they hold.”

Say that some of the issues raised by this activity might feed into the discussions in Module 9 on developing new relationships.

Activity 4 Looking at participants’ own experiences of families and parenting

Suggested time: 25 minutes

Explain that the aim of this exercise is for participants to reflect on, and draw lessons from, their own experiences.

1. Divide participants into groups of three to four people. Ask the groups to focus on their own childhood homes and upbringing, and use their experiences to role-play an imagined scenario. Each person should take on a different role: for example, of wife, husband, daughter, uncle. Give them five minutes to prepare their role-play.

2. Ask each group to perform their role-play to the main group, taking no more than three minutes each.

3. After each role-play, invite discussion of the different parenting styles demonstrated.

To finish, as trainer you should remind the group that there is no one style of parenting that is ‘best’.

Reflection

Activity 5 Reflecting on the module

Suggested time: 10 minutes

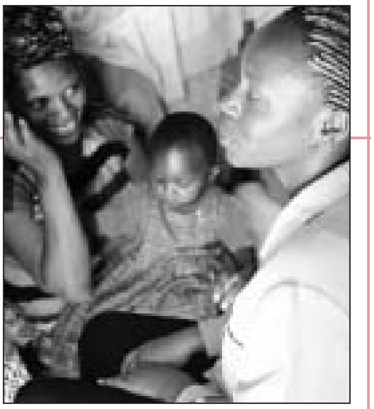
1. Say that the module has focused on ways we might change being a parent. Give participants a quiet moment for individual reflection to think about positive things that stand out for them about being a parent.

2. Then give participants five minutes to consider:
   - what they found most helpful in the session
   - what content they would have liked on this topic, but did not get.

3. Ask for three volunteers to feed back. Record their responses on flipchart paper. Thank them for their input and say their comments will help you improve the content of the course to meet participants' needs more closely. Allow five minutes for this part of the exercise.

Close the session by thanking participants for their feedback and say you look forward to working with them on the next module. Wish them well in their parenting and planning for their children.

MODULE 4



Improving communication between parents/carers/ guardians and children

Trainer's introduction

This module looks at communication skills and helping parents, carers and guardians to communicate more effectively with children of all ages. The module builds basic skills in preparation for Module 5, which addresses the important issue of disclosing HIV status to children. You may need to be clear about the importance of learning the skills of communication first before applying them to the topic of disclosure.

Approximate length of module: 2 hours 25 minutes

Aims

The aims of this module are to:

- provide an understanding of what communication is
- help participants learn about effective communication and practise key communication skills
- explore how to communicate effectively with children of different ages.

Key learning outcomes

By the end of this session participants will:

- have an understanding of what effective communication is
- have practised key communication skills
- have an awareness of how to communicate effectively with children of different ages.

Trainer's preparation

Module plan (with suggested times)

- Understanding what communication is – **30 minutes**
- Learning about effective communication and practising key communication skills – **40 minutes**
- Exploring how to communicate effectively with children of different ages – **1 hour.**
- Reflection – **15 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 4
Overhead/flipchart 2: Exploring listening skills
Overhead/flipchart 3: Communicating with children
Handout 1: Communicating with children
Handout 2: Better communication

Trainer's guidance

Introduction

Some of the activities in this module cover similar topics in different ways, such as activities 1 and 4. You will need to choose the activities you think best meet the needs of your group.

Begin the module by explaining to participants that the purpose is to learn how to be a good communicator. Say they will practise some general skills that will help them communicate better with children of all ages. Explain that this module links closely with Module 5, which looks at how a parent, guardian or other person may disclose his or her HIV status to a child. The group needs to learn the skills of good communication first before applying them to disclosing their HIV status. Be clear that this module will not cover disclosure itself.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 4
Please use the list in the module plan on page 33, but without the suggested times.

Understanding what communication is

Activity 1 What is communication and what gets in the way of good communication?

Suggested time: 30 minutes

Explain that the aim of the first activity is to help participants to develop a better understanding of communication.

1. First, ask participants to spend three minutes talking with the person next to them, to try to define the word 'communication'. Ask them to come up with their own definition in 15 words or less.

2. Ask each pair to give their definition to the group. Write key words on the flipchart. Allow 10 minutes for this.

3. After everyone has fed back, discuss the ideas with the whole group for about five minutes. Emphasise the words and ideas that fit with the guidance in this module. Have a definition of your own ready to share with the group. It might be something like this: *Communication is the two-way giving and receiving of information and ideas.* Explain that good communication suggests a shared understanding of each other's ideas and meanings.

4. Next, write the following question on the flipchart: *Why do people often misunderstand each other when they speak?* Ask the participants to consider the question for a few moments and then have an open discussion for 10 minutes. Write people's suggestions underneath the heading.

Add the following points, if the discussion does not include them:

- people tend to make assumptions about what the other person thinks or wants
- they do not listen carefully
- they are so eager to make their own point they do not give the other person space to communicate
- they do not check they have been understood.

Bring the discussion to a close by emphasising that there are no right or wrong answers. The point of the exercise is that often we do not communicate as well as we think we do. This might be because we think communicating is more about talking than listening.

Ask participants to remember these points and reflect on them the next time they speak to a child. Ask them to imagine what it might be like for a child to speak with an adult, perhaps drawing on their own childhood experiences.

Learning about effective communication and practising key communication skills

Activity 2 Role-plays to develop listening skills

Suggested time: 20 minutes

Explain to the group that this activity aims to help participants understand the importance of listening and developing listening skills.

1. Ask the group to divide themselves into pairs and to sit facing each other.

2. Explain that each person will take turns to play the role of speaker and listener. For three minutes, the first speaker should talk as naturally as possible about something important to them. The topic is not significant, but it should be something that the listener can relate to.

3. When the time is up, swap roles for another three minutes.

4. When each pair has played both roles, ask them to discuss the experience for five minutes. Prompt the discussion with questions from the overhead/flipchart below.

Overhead/flipchart 2: Exploring listening skills

- What was it like to be the listener?
- What was it like to be the speaker?
- Did the listener's behaviour seem rude?
- Did the listener appear interested?
- Did the listener appear bored?
- Did they really listen?
- Did they pick up on any issues, seek clarification or request more details?
- Did they respond appropriately and sensitively to any difficult issues that came up?
- How well did the speakers feel listened to?

5. Bring everyone back together and ask for volunteers to share anything they found difficult about listening or anything they noticed about their own listening behaviour. Allow five minutes for this.

6. Ask participants what lessons they can take away from this activity. Some of the lessons might be:
   - active listening is hard work
   - it is easier to interrupt the speaker than to keep quiet and really listen
   - if you lack the right words to explain yourself, this can lead to misunderstanding
   - if you are avoiding saying certain things, this could affect the honesty of everything you say – your listener may notice this
   - you need to use appropriate words to help your listener understand you.

Allow five minutes for summing up.

Activity 3 Identifying the skills and qualities of a good communicator

Suggested time: 20 minutes

Explain that the aim of this activity is to explore the skills and qualities needed to communicate effectively.

1. Give participants five minutes to think by themselves about someone they think is a good communicator – *not* their mother, father or partner. It could be someone from

school or in the community. Tell them they will not be asked to name the person.

Ask participants to identify what it is that makes them think of this person as a good communicator. You might need to suggest a few ideas to the group to start them off, such as: Do they show interest in what you say? Do they speak warmly to you? If you think they listen well to you, why do you think this? Do they, for example, check that they have understood you?

2. Bring together the whole group to brainstorm the skills that people need to communicate effectively. Record their answers on a flipchart. As participants feed back, it may become clear that they see a good communicator as a person who speaks clearly and confidently and is interesting. Discuss their feedback and make sure the following skills are also included in the discussion:

- active listening, which involves listening carefully without interrupting, and showing you are taking in information by nodding, using appropriate facial expressions and vocal encouragements
- questioning when appropriate to check that you have understood
- giving feedback or responding to the other person when appropriate
- carefully observing how the other person is reacting to what you say.

Allow 15 minutes for feedback and discussion. Close the activity by clearly emphasising that one of the most important and difficult skills in communication is listening.

Exploring how to communicate effectively with children of different ages

Activity 4 Exploring how to communicate with children of different ages

Suggested time: 45 minutes

Explain that the aim of this activity is to explore and address the challenges of communicating with children of different ages.

1. Ask participants to divide themselves into small groups and give them 10 minutes to discuss what prevents good communication between parents and children. Encourage each group to consider how this will differ according to the age of the children. Tell them you will need one volunteer from each small group to take two minutes to feed back the main ideas to the large group.

2. Record the main points from each group's feedback on a flipchart. These ideas might include the parent or the child not listening, the age of the child (they might be too young to understand), or an inappropriate time or place chosen for the discussion. Record the feedback.

3. Ask people to return to their groups and give each group two different problems to consider that came out of the discussion. Ask them to spend five minutes discussing possible solutions and support to help overcome these difficulties.

4. Bring everyone back together and ask each group to feed back in two minutes. Record their responses on a flipchart. Participants are likely to offer practical and realistic suggestions. However, be ready to go through the additional points on the overhead/flipchart below. Allow 10 minutes for discussion of the overhead.

Overhead/flipchart 3: Communicating with children

- Prepare well and, if you can, practise what you want to say with another adult first. Remember, put equal effort into communicating whether the child is a boy or a girl.
- Find a setting where you will not be interrupted and where the child feels relaxed.
- Use appropriate language for the age of the child. The younger the child, the simpler the language should be.

- Keep your ideas clear and separate. Break them down into pieces that are easy to understand.
- Do not try to cover too much information at once.
- For younger children who can talk, it helps to put what you want to say in the form of a story.
- Check what the children have understood by asking them to tell you in their own words what they think you have said.
- Check that you understand the child's responses and questions by saying something like "Let me see if I've got this right…", then say in a simple way what you think they have told you or asked you. You will need to be patient and listen carefully to what the child says.
- Be aware of how the child reacts to what you say. If he or she gets restless, stops speaking, looks away a lot or seems distressed, it is time to stop.
- Be aware that some teenagers may not be as emotionally or intellectually mature as they look. Teenagers often feel confused about the present and the future. Teenagers, as well as youger children, need to be treated sensitively.
- Younger teenagers tend to respond better to questions that give options for possible answers. For example: "Would you like this … or that … to happen?" Older teenagers tend to be able to cope with open questions such as: "What would you like to happen?"
- Remember to use your listening skills.
- Finally, remember children have a need and a right to know about:
  - personal and family history
  - relatives, clan and origins
  - information about managing the home, land, animals and so on
  - family property and inheritance (including wills)
  - guardianship arrangements: who will advise and protect them
  - arrangements for their education.

The information above also forms *Handout 1: Communicating with children* (see page 39). Give a copy of this to each participant after discussing the information.

Activity 5 Looking at questioning skills

Suggested time: 15 minutes

Explain that this activity uses a presentation and a handout to increase the group's awareness of the importance of questioning. Say you will show how to ask questions that are appropriate and sensitive to different situations.

1. Start by covering the reasons why people need to ask questions. These include:
   - to find out what someone already knows
   - to gain information
   - to help encourage thinking, reflection and seeing things from different viewpoints.

2. Explain that there are two types of questions:
   - **Closed questions**, which often receive a 'yes' or 'no' response, or a short, often one-word, answer. For example: "Have you attended a workshop before?" or "How many children do you have?"
   - **Open questions**, which give people more choice of how to answer, in their own words and in more detail. For example: "What do you know about HIV?" or "How do you feel about telling children about HIV?"

3. Next give each participant a copy of *Handout 2: Better communication* (see page 40). Take 10 minutes to go through it, showing participants the questions they should ask themselves before they try to communicate something important or to question other people.

4. Close the session by asking the group if they have any questions for you.

Reflection

Activity 6 Reflecting on the module

Suggested time: 15 minutes

Tell participants that it is time to bring the module to a close by sharing key learning points with each other.

1. Ask the group to work in pairs for five minutes to talk about how useful they found the session. Ask them to be ready to say what ideas or thoughts they are taking away with them.

2. Invite three or four participants to share what they have learned and their thoughts on how the module was delivered. Give them two to three minutes each.

3. Close the session by summarising the module, using the following points:
   - Communication is a two-way process that involves both giving and receiving ideas and information.
   - Poor communication results from not listening properly, from jumping to conclusions too quickly or making judgments without enough information.
   - It is easier to be a good talker than a good listener.
   - Listening is essential to good communication and we all need to improve our listening skills.
   - It is important to create an appropriate atmosphere for communication, especially about sensitive issues like those related to HIV and AIDS.
   - Effective communication does not happen easily or automatically. It is important for all of us to try to improve our communication with those close to us.
   - You need to take many points into consideration when communicating with children.
   - Children are able to give useful and important feedback.

Finally, thank participants for their input and participation, and say you look forward to working with them on the next module.

Handout 1: Communicating with children

- Prepare well and, if you can, practise what you want to say with another adult first. Remember, put equal effort into communicating whether the child is a boy or a girl.
- Find a setting where you will not be interrupted and where the child feels relaxed.
- Use appropriate language for the age of the child. The younger the child, the simpler the language should be.
- Keep your ideas clear and separate. Break them down into pieces that are easy to understand.
- Do not try to cover too much information at once.
- For younger children who can talk, it helps to put what you want to say in the form of a story.
- Check what the children have understood by asking them to tell you in their own words what they think you have said.
- Check that you understand the child's responses and questions by saying something like "Let me see if I've got this right…", then say in a simple way what you think they have told you or asked you. You will need to be patient and listen carefully to what the child says.
- Be aware of how the child reacts to what you say. If he or she gets restless, stops speaking, looks away a lot or seems distressed, it is time to stop.
- Be aware that some teenagers may not be as emotionally or intellectually mature as they look. Teenagers often feel confused about the present and the future. Teenagers, as well as youger children, need to be treated sensitively.
- Younger teenagers tend to respond better to questions that give options for possible answers. For example: "Would you like this … or that … to happen?" Older teenagers tend to be able to cope with open questions such as: "What would you like to happen?"
- Remember to use your listening skills.
- Finally, remember children have a need and a right to know about:
    - personal and family history
    - relatives, clan and origins
    - information about managing the home, land, animals and so on
    - family property and inheritance (including wills)
    - guardianship arrangements: who will advise and protect them
    - arrangements for their education.

Handout 2: Better communication

How often do you stop to think about whether you could be a better communicator?

Look at these questions. They will help you reflect on your own communication skills, so you can prepare how to say something important to an adult or a child.

1. **Who** am I communicating with?
Who are the listeners?
What do I know about them – their characteristics, interests, views, prejudices?
How can I adapt the way I say something so that they can understand it?

2. **Why** am I communicating?
What is my purpose?
What response do I want?
What do I hope to achieve by this communication?

3. **What** do I need to say?
What does the listener already know?
What does she or he need to know?
What is appropriate for children of different ages?
What is appropriate for family members and non-family members?

4. **How** should I communicate?
How can I best achieve my purpose?
What method should I use – should I simply say what I need to say or, perhaps for young children, put it in the form of a story or even a drawing?
In what order should I make my points?
What language, words and tone should I use?
What is appropriate for children of different ages?

5. **When** is the best time for this communication to take place?
Will I have time to finish what I need to say?
What should I do to prepare?

6. **Where** will I communicate?
Do I need somewhere private?
Is somewhere else suitable if it is not possible at home?
Who else should be nearby for support?

7. Will I remember that I must **listen** as well as speak?
How will I check that my listener has understood me?
How will I encourage my listener to ask questions?
How will I support my listener if he or she becomes upset?
How will I sense when a child has reached her or his limit and it is time to stop?

MODULE 5

Disclosing HIV status

Trainer's introduction

This module looks at helping people to disclose (tell others about) their HIV status. It guides participants who are personally affected by HIV and AIDS to prepare for disclosure and to decide who needs to know their status. The focus is on parents/guardians telling children but it will help participants to reveal their HIV status and other sensitive issues to adults too.

Remember that some participants may not be living with HIV themselves. This module will help them understand how children might be told about their parent's, guardian's or friend's HIV status. These participants will then be in a position to give support to the child.

Approximate length of module 3 hours 25 minutes to 3 hours 45 minutes

Aims

The aims of this module are to:

- provide an understanding of what HIV disclosure means
- explore the implications of deciding to disclose or not to disclose HIV status
- help participants prepare for disclosure of HIV status and other sensitive issues.

Key learning outcomes

By the end of this session participants will:

- have an understanding of what HIV disclosure means
- have an understanding of the implications of disclosing or not disclosing HIV status
- have prepared for, and practised, disclosing HIV status
- have an awareness of the impact of disclosure upon others.

Trainer's preparation

Module plan (with suggested times)

- Looking at what disclosure means and who needs to know – **1 hour 10 minutes**
- Understanding the implications of disclosing or not disclosing HIV status – **40 minutes**
- Preparing for disclosure of HIV status and other sensitive issues – **1 hour 15 minutes to 1 hour 35 minutes**
- Reflection – **10 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 5
Overhead/flipchart 2: Who needs to know?
Overhead/flipchart 3: Difficult and easy people to tell
Handout 1: Difficult and easy people to tell
Handout 2: Some key points about disclosing to children
Handout 3: Disclosure role-plays
Video: *Beyond Survival* (optional) see Appendix 1: Key course materials, page 123
TV & video player

Trainer's notes

Please make sure you read the trainer's notes at the end of this module (page 53). They give you useful background on HIV disclosure issues and ways to prepare for disclosure.

Trainer's guidance

Introduction

Before you start the session, be aware that this module may touch upon some vulnerable feelings in the group. You will need to be sensitive to how participants are reacting. Do not force anyone to disclose information. This is a personal decision for each individual. This point is very important, because of the possible consequences of disclosure. Please also remember that you should not assume that all participants are living with HIV; the module can also guide participants to address disclosure issues in the communities where they will be implementing memory work.

Start by explaining that the purpose of this module is to explore aspects of disclosing HIV status. Say that together you will look at what disclosure means, who needs to be told and how to prepare to tell people. Explain that the focus will be on how to tell children in an appropriate and sensitive way, but what participants learn in the session can be used for disclosing to adults too. Emphasise that **no one will be forced or persuaded to give information about themselves** in the session. Remind all participants about the group agreement and stress the importance of confidentiality.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 5
Please use the list in the module plan on page 41, but without the suggested times.

Looking at what disclosure means and who needs to know

Start by explaining that disclosure means being open and revealing the truth about a secret. Say that in this training course when we speak about disclosing we are talking about something very personal and sensitive. In the context of this group, it means talking openly about HIV and AIDS in the family. Encourage participants to think of disclosure as ongoing, rather than a single act of communication with another person or child.

Also say that disclosure can happen accidentally, for example, if a child overhears an adult conversation. When disclosure happens this way, the message has not been prepared appropriately for the child. This might cause worry and distress. Say that whenever possible, it is important to manage disclosure carefully and sensitively.

Activity 1 Exploring who needs to know about a person's HIV status

Suggested time: 35 minutes

Explain that the aim of this activity is to explore who needs to know about a person's HIV status.

1. Divide the participants into three groups. Tell them they will have 15 minutes to discuss the questions on the following overhead/flipchart, after which one person from each group will feed back to the whole group.

Overhead/flipchart 2: Who needs to know?

- Who needs to know about HIV and AIDS in the family?
- What do different people need to know?
- How do you think family and friends will react?
- How will it affect employment, relationships (especially marriage) and social life?

2. Bring everyone back to the whole group. Give each group representative five minutes to report the main points of their discussion. Ask the group for comments and questions.

3. Summarise the main points of the discussion and make sure the following points are brought out:

- There are some people who need to know about HIV and AIDS in the family: for example, the children of the person disclosing. But the person disclosing does not have to disclose to everyone.
- When a person does disclose her or his status to someone, she or he does not have to tell that person everything related to it.
- If a person chooses not to tell certain people, she or he may need to be prepared to answer awkward questions. This may also be the case when people find out a person's HIV status another way.

Activity 2 Deciding who needs to know and how easy or difficult it will be to tell them

Suggested time: 30 minutes

Before you start this activity please note that it could be very painful and upsetting for some participants. Emphasise that it is designed to help participants to think about the issues together and to learn from each other. Make it clear that if anyone does not wish to discuss their personal situation in the group, they do not have to. Say some individuals may wish to think about their own situation elsewhere or with support, for example, with a counsellor.

If participants living with HIV feel uncomfortable doing the activity with people who are not, you could ask the participants not living with HIV to form their own group and *imagine* who they would need to tell and the difficulties involved. Alternatively, you could mix the groups let the participants support each other, whatever their HIV status.

Encourage everyone to participate as far as they want to. This might be simpy listening to others in the group talking about how they have faced similar challenges to their own.

Explain that the aim of this activity is to help each person consider who needs to know about their HIV status and who will be easy or difficult to tell.

1. Divide participants into groups of three. At least one person in each group needs to be able to write. Tell them they will not share what they write with the whole group. They will discuss only in the small groups for this activity.

2. Give them 10 minutes to discuss and make a list of all the people (children and adults) they need to tell about their HIV status.

3. Display overhead/flipchart 3 – *Difficult and easy people to tell* (see page 44) and give each participant a copy of Handout 1, which contains the same chart (see page 50).

4. Ask the participants to put the names of people on their list into the appropriate squares. Provide some examples like the following: Auntie Jean might fit in the 'difficult, but less important to tell' box, sister Anna might go in the 'easy and important to tell' box, son Ahmed might go in the 'difficult and important to tell' box.

As you say these names write them in the squares on the overhead/flipchart and give some examples of why each person might be easy or difficult to tell. For example, Auntie Jean might not be very good at listening. Sister Anna might be a sympathetic person who gives good advice. Son Ahmed might be someone you need to prepare carefully to tell – you might need to practise with a supportive adult beforehand.

Give the group 10 minutes to fill in their boxes.

Overhead/flipchart 3: Difficult and easy people to tell

Difficult and important to tell	**Easy and important to tell**
Difficult, but less important to tell	**Easy, but less important to tell**

5. Ask each small group to discuss the following questions among themselves, with each person taking five minutes:
    - What makes it hard for you to talk to the people in the ‘difficult and important’ box?
    - Who is it difficult for – the people in the box or the person doing the telling?
    - What might make talking to these people easier?
    - Where or whom might you get support from?

Say that as each person talks, the people listening should not give the speaker their opinion of what to do. Instead, they should ask encouraging questions to help the speaker think about it. For example: “Tell me more…”, “Can you explain that some more…”, “What else could you do?”

6. Finally, ask participants to help each other in their groups to plan how they can use the people in the ‘easy and important’ box to help them to talk to the people in the ‘difficult and important’ box. Allow five minutes for this.

Understanding the implications of disclosing or not disclosing HIV status

Introduce this topic by explaining that it is important to realise that whether a person chooses to disclose his or her HIV status or not, the decision will have consequences. The following activity will help the group to examine what the positive and negative effects of the decision might be.

Activity 3 Exploring the possible consequences of disclosing HIV status to children and other family members

Suggested time: 40 minutes

Explain that the aim of this activity is to explore the possible consequences of disclosing HIV status to children and other family members. The activity also explores sources of support for the person disclosing.

Please note that, depending upon the priorities of the group, you may wish to focus just on children or to consider families as a whole.

1. Ask participants to divide themselves into four small groups.
2. Ask two groups to think about the possible advantages of a person disclosing their HIV status to her or his children and family. Ask the other two groups to think about the possible disadvantages. Give them 10 minutes to do this.
3. After their discussions, ask all the groups to take five minutes to consider sources of coping and support that might be available to them. Ask them to have one person from each group to be ready to give feedback.
4. Bring the groups back together and ask the volunteers from each group to feed back some of the points that came out of their discussions, taking two minutes each.
5. Finally, ask for comments from the whole group. Summarise the main points and make sure the following points are covered:

Some advantages of disclosing:

To adults

- There is no worry about being found out and having to keep up pretence.
- It is easier to get medical treatment and support.
- It is easier to negotiate safe sex.

To children

- Being open helps parents and children to support and trust each other.
- Children will be less vulnerable to being hurt by rumours from outsiders.
- It makes it possible to plan for children’s future in good time and the children can take part in planning for their own futures.
- Parents find that after they have faced this issue with their children, they are free to talk about many other things. They usually start listening to and understanding each other better.
- Children have time to ask questions, and find out about their family and background.
- Older children can begin to take on family responsibilities.
- Although children cannot be protected from the pain of losing a parent, they are better prepared and the shock will be less.

Some disadvantages of *not* disclosing:

To adults

- It often involves being untruthful, which can be stressful.
- Awkward questions may need to be answered.
- The person might be afraid of being seen at clinics and AIDS support centres, and may miss the treatment and the support he or she needs.

- It is harder to negotiate safe sex.

To children

- It makes it very difficult to prepare children for the loss and change they will have to face.
- Children might feel disgrace and stigma. This can lead to low confidence.
- Children cannot be involved in making plans they agree with.
- It will not be so easy to pass on important information and skills to children.

Highlight any good ideas that participants contribute for sources of support. Make a distinction between emotional support from friends and family, and practical support, for example, from clinics and AIDS support centres. Stress that if someone decides to disclose their HIV status, they will need support and should think about where to find this before they disclose.

At this point you could read out the following words from NACWOLA mothers in Pallisa, Uganda:

> "Under the memory project, I got the strength for telling my children my status."
>
> "I would advise other mothers to disclose their status. This gives confidence and people can then associate with others. It removes their fear and clears stigma. It opens you to other people."

Preparing for disclosure of HIV status and other sensitive issues

Please be aware of how participants are reacting and allow people to leave the room if they need to. Explain to participants that after a person has made the decision to disclose, it is important to prepare how to do it. The activities will help the group think about preparation and give them an opportunity to practise, through role-plays, how they could approach disclosure and how they might answer questions.

Activity 4 Exploring how to tell a child that a parent is living with HIV

Suggested time: 40 minutes

Explain that the aim of this activity is to explore how to tell a child or children that a parent is living with HIV.

1. Ask participants to divide themselves into small groups, according to the age of their children or a child they want to focus on. For example, groups could consider children in the following age ranges: 4-6; 7-12; 13-18.
2. Ask each group to discuss how to disclose HIV status to children of the age group they have selected. What factors would they need to consider? Which words would be appropriate to use? Tell them they have 15 minutes, after which you will ask for volunteers from each group to feed back.
3. Bring everyone back to the whole group and ask for the feedback. Be prepared for participants to be upset and unable to say very much. Allow five minutes for all the feedback.

Next, make the presentation on the following page. It contains key information, so make sure you have prepared it well.

Presentation

Some key points for a person disclosing HIV status to children

Preparing

- Be clear about what you want to say and what the child needs to know.
- Break this down into smaller pieces that can be given to the child one at a time. For children aged four to six, it helps to put the information in the form of a story. For older children who can read, you could prepare a letter to start the process. The child can read it at a quiet time and think about it before you speak together.
- Make sure the information you give is appropriate to the child's level of understanding.
- Practise what you want to say with an adult you can trust before you disclose.
- Think about the signs your child shows when they are upset and be ready to stop if you see these signs. Some children feel more comfortable talking to another adult outside the immediate family. This might – but not always – be true for children between the ages of 7 and 12, who often admire other adults in their lives such as uncles, aunts and teachers. You will need to be able to trust and feel comfortable with such a person before you share this responsibility with them.
- Think of the questions they might ask and think through your possible answers.
- It helps if you have already started thinking about plans for the future so you can reassure your children they will not be left alone.
- When you know what you want to say, be ready for the right time to say it: for example, when your child raises the subject of illness or has AIDS lessons at school. Make sure both you and the child are calm and that you will not be interrupted before you begin.

Telling

- Decide what to begin with and do not talk for too long.
- Be clear and ready to summarise the important points.
- Be honest and calm.
- One way to start is to talk about illness generally, then about your own personal illness, and then HIV and AIDS in the family.
- Stop if your child shows signs of distress, becomes quiet, looks away or changes the subject. Comfort the child.
- Be ready to answer questions like: "How did you get it?", "Have I got it?" and "When will you die?"
- Be ready for shock, anger, blame and denial. Remember, these reactions will pass with time.

Give participants *Handout 2*, page 51.

Next, you could read out the following story. It is a real example of how a mother told her son about her HIV status and the negative and positive effects the disclosure had.

> Carla had attended a Memory Project training. Afterwards she decided to disclose her status to her 19-year-old son. She started by teaching her son about the facts, myths and misconceptions about HIV and AIDS. Then she took him out and after spending a wonderful day together she said: "There is something that has been bothering me and I did not know how to tell you. I am HIV positive…" The boy was extremely shocked. Soon after, his school grades began to drop and he isolated himself.
>
> The boy was given counselling and with time he accepted the situation. He has now become supportive and has joined a youth group that uses theatre and music to sensitise the community on HIV and AIDS.

You could then read out the words of a Ugandan lady who describes how she disclosed her status to her older daughter:

> "I used the techniques I acquired from NACWOLA and initiated a conversation with my elder daughter one evening at home. I cracked a joke about death and gave options of types of death, for example, an accident or HIV, for her to choose if it were possible for one to make a choice. She suggested HIV, because she urged that according to the knowledge she got from her school, someone with HIV could stay alive for many years until it developed into AIDS, unlike an accident. My daughter's response gave me an entry point to disclose my HIV status.
>
> "Following on from this conversation, I said: 'My daughter, do you remember my conversation and jokes about the options of death we talked about?' My daughter answered in a relaxed mood: 'Yes.' I then told her: 'I have HIV!' She responded: 'Mama nga tulabye!', meaning 'Mummy, it is a pity to us!' I saw her emotionally touched, but I tried to comfort and counsel her. Since then she has taken the responsibility for me and her sisters. She has become supportive and I equally feel relieved."

Close this activity by saying that the person disclosing must be ready to deal with the effect of what is said upon the child and to be loving and supportive. The person disclosing will also need emotional support.

Activity 5 Disclosure role-plays

Suggested time: 30 to 50 minutes

See the note below about preparing your own role-play situations based on the specific needs of the group. If you decide to do this, you will need to prepare well before you do this module.

Explain that the aim of this exercise is to give every participant the chance to ask and answer difficult questions about HIV disclosure. Say that this will be done through role-plays in small groups. Reassure participants they will not have to perform role-plays in front of the whole group.

1. Divide participants into small groups of three people. Say that each group will be given a situation with a mother and child talking. Ask participants to decide who in each group will take the roles of the mother and child and who will be the observer. Make sure each group has enough space to work without disturbing the others.
2. Give each group a role-play handout (see below). If there are more than four groups you can give the same role-play to more than one group.
3. Give the groups three minutes to read the information on their handout and tell them they have five minutes for their role-play. Encourage participants to use what they learned from the previous activity to guide how they disclose in the role-play.

Sample role-plays

Four sample role-plays, which are based on NACWOLA training and experiences, are presented in Handout 3, page 52. All except one are scenarios involving a mother and a child. It would help your group to learn if you could develop other role-plays, based on what you have heard in the stories of your participants. If you decide to do this, you must get permission from people to use their stories in this way (without names, so other participants and groups do not know which story belongs to which person).

4. At the end of the role-plays, give participants 10 minutes to discuss the following questions in their groups:

- What happened during the role-play?
- Was it realistic?
- What feelings came to the surface?
- What have you learned from the experience?
- How could you use the experience in your own situation?

5. Bring everyone back together to share ideas and highlight key learning points. Ask the people playing the role of mother whether they remembered to use some of the learning points from the previous activity and if so, which they found most useful. If they forgot to do this, ask them to think now about which ones they could have used. Allow 10 minutes for this.

6. If you have enough time, repeat the role-playing until everyone has had a chance to experience being the mother, the child and the observer. You can use the same role-play or change it each time. Remember to build in the extra time for doing this.

7. At the end of the discussion, ask everyone to leave their roles behind, by saying their own name and that they are not the character they were role-playing.

Reflection

Activity 6 Reflecting on the module

Suggested time: 10 minutes

Tell participants that the module is coming to a close and that this activity provides an opportunity to share any anxieties and key learning points in an informal way. Say that this is a way to unwind after what has been an intense session at times.

1. Tell the group that you are going to ask them to walk around the room or the compound, at a speed that is comfortable for them. Every now and then you will ask them to stop and have a chat with a friend.

2. Ask participants to move any chairs or mats to the edge of the room.

3. Ask participants to walk slowly, this way and that, until you call out: “Stop!”

4. When you call “Stop!” ask them to stand still, look around and find someone they would like to talk to. Ask them to make their way to that person or group of people.

5. Ask participants to talk to each other about the session. What do they feel about it? What were the most important issues for them? What did they learn?

6. After two minutes, tell them all to walk on again. They can walk on alone or with the person they have been talking to.

7. Ask them to stop again and repeat the process until everyone has talked to at least two other people.

Bring the module to a close. Thank participants for their contributions and for being open about these difficult issues. Say that you are looking forward to seeing them at the next session.

Handout 1: Difficult and easy people to tell

Difficult and important to tell	**Easy and important to tell**
Difficult, but less important to tell	**Easy, but less important to tell**

Handout 2: Some key points about disclosing to children

Preparing

- Be clear about what you want to say and what the child needs to know.
- Break this down into smaller pieces that can be given to the child one at a time. For children aged four to six, it helps to put the information in the form of a story. For older children who can read, you could prepare a letter to start the process. The child can read it at a quiet time and think about it before you speak together.
- Make sure the information you give is appropriate to the child's level of understanding.
- Practise what you want to say with an adult you can trust before you disclose.
- Think about the signs your child shows when they are upset and be ready to stop if you see these signs. Some children feel more comfortable talking to another adult outside the immediate family. This might – but not always – be true for children between the ages of 7 and 12, who often admire other adults in their lives such as uncles, aunts and teachers. You will need to be able to trust and feel comfortable with such a person before you share this responsibility with them.
- Think of the questions they might ask and think through your possible answers.
- It helps if you have already started thinking about plans for the future, so you can reassure your children they will not be left alone.
- When you know what you want to say, be ready for the right time to say it: for example, when your child raises the subject of illness or has AIDS lessons at school. Make sure both you and the child are calm and that you will not be interrupted before you begin.

Telling

- Decide what to begin with and do not talk for too long.
- Be clear and ready to summarise the important points.
- Be honest and calm.
- One way to start is to talk about illness generally, then about your own personal illness, and then HIV and AIDS in the family.
- Stop if your child shows signs of distress, becomes quiet, looks away or changes the subject. Comfort the child.
- Be ready to answer questions like: “How did you get it?”, “Have I got it?” and “When will you die?”
- Be ready for shock, anger, blame and denial. Remember, these reactions will pass with time.

Handout 3: Disclosure role-plays

Role-play 1

MOTHER: You are a widow, 45 years old and you have two teenage sons. You have been very tired and ill in recent weeks. Just when you need more help, your younger boy, aged 14, has become very quiet and spends a lot of time away from home.

SON: You are not sure what is going on at home. You feel you cannot ask questions and it is easier to stay out of the way with your friends. One day your mother looks really ill and you burst out with the question: "What exactly is wrong with you, mum?"

Mother: What do you say?

Son: How do you react?

Role-play 2

MOTHER: You have four children aged 13, 12, 9 and 6 years. Your two sisters have come round, because they know you are not well. Your young sister has taken the children into the compound, leaving you alone with your older sister. You want to ask for help but you don't know how to start.

MOTHER'S OLDER SISTER: You have guessed your sister is HIV positive and you think it is time she told her two older children.

Mother: How can you let your sister know you need help?

Sister: How can you raise the subject?

Role-play 3

MOTHER: Your husband recently died. You know he had AIDS, but so far you have managed to keep this secret from your relations and your children who are aged 15, 7 and 3. But now you have heard there are rumours going round the neighbourhood.

OLDEST CHILD: When you went back to school after the funeral, people were staring at you and you felt they were talking behind your back. You guess it is about your father, but your mother keeps avoiding the subject.

Mother: What do you want to tell your children? What do you need to do and say?

Oldest child: What do you want to ask your mother?

Role-play 4

MOTHER: You have been getting more and more tired. Cooking, cleaning and fetching water are too much for you to manage on your own. You want your eldest daughter, aged 16, to organise the other five children to share the work. You have not disclosed your status to your daughter, because she is at the stage of being a difficult teenager.

OLDEST DAUGHTER: You feel your mother is expecting too much from you, but she doesn't treat you as an equal. So why should you take responsibility for getting the younger children to help out?

Mother: What can you do to get your daughter on your side?

Daughter: What do you want your mother to say or do?

MODULE 5 – Trainer's notes

Guidance on disclosure of HIV status

These notes will help you understand the issues and deliver the module effectively. In particular they support activities 3 and 4. Please read the notes carefully so you can offer additional learning points and facilitate discussion with the group throughout the module.

You may wish to use the video *Beyond Survival* at the beginning of this module to aid disussion (see Appendix 1: Key course materials on page 123).

Disclosure

Many parents have already struggled to disclose their HIV status to their children, families and communities. Some were the first people in their community to speak out about their HIV status. They have given courage to other parents to do the same and talk openly to their children. Many NACWOLA women say that when they work out how to say the words, a weight is lifted and they feel freer to get on with their lives.

Why disclose?

Many people try to keep their HIV status hidden, because they are afraid of what will happen to them or their family if the truth comes out. However, when people hide their HIV status it can cause many problems:

- It takes a lot of mental energy, always being worried about being found out, waiting for awkward questions.
- It often involves being untruthful, which over time can cause problems.
- It makes it difficult to get medical treatment or support, for fear of being seen in a clinic or AIDS support centre.
- It makes it impossible to prepare children for the loss and changes they will have to face.
- It makes it harder to negotiate safe sex.

Talking to children

The notes below are adapted from Gerard Egan's book *The Skilled Helper* (1997/2001). This book was written to support professional staff working with families and individuals facing loss, separation or other major life changes. We have also added experiences and ideas from NACWOLA women.

For many parents, disclosing to their family is one of the worst things they face in relation to their HIV status. Unfortunately, because of the shortage of health workers, counsellors and other skilled helpers, most parents have to manage on their own. But if possible, it is important that people are assisted to prepare for this challenge. Knowing something about the different stages of disclosure and the skills required will help parents get started and stay on track.

1. Preparation: 'Preparing the ground'

Just as the ground has to be prepared before planting crops, parents and carers must prepare for the time when they will speak to their children about their HIV status. They will need to think about:

- WHY they need to talk to their child/children
- WHAT they need to tell their child/children
- WHERE they can talk with their child/children

- WHEN is the best time to talk to their child/children – there will never be a perfect time for this, just a time that is good enough.

Good reasons for disclosing to children, according to NACWOLA women:

- Being open helps parents and children to support and trust each other.
- Children get correct information directly from their parents.
- Children are less vulnerable to being hurt by rumours from outsiders.
- It makes it possible to plan for the children in good time.
- Children can be involved in making plans they agree with.
- Parents find that after they have faced this issue with their children, they are free to talk about many other things. They usually begin listening to, and understanding, each other better.
- Parents have time to pass on important information and skills to their children.
- Children have time to ask questions, find out about their family and their background.
- Older children can begin to take on family responsibilities.
- Although children cannot be protected from the pain of losing a parent, they are better prepared and the shock is less.

Talking to children who do not want to listen – tips from NACWOLA women:

There is never a perfect time for a parent to talk to her or his children about HIV in the family and some children will resist. This can make an already difficult and painful task even harder. Depending on the ages of the children, the suggestions below might help:

- Be clear about what you need to say.
- Break it down into small pieces of information that can be given to the child one at a time.
- Decide what to start with. Do not talk for too long.
- Make sure the information is appropriate to the child's level of understanding.
- Decide how to tell essential sensitive information to those individuals who really need to know it. For example, this could be by leaving written information for each child that includes facts important for that child (for instance, about the child's father). Or you could write a letter to go with the memory book, to be held by a trusted friend until the child is older.
- If the child is young, it may help to put the pieces of information into a story.
- If the child is older and can read, it might help to start with a letter. This gives the child the opportunity to read and digest the information at a quiet time.
- If older children in the family know about the situation, they might be able to help tell younger children.
- Sometimes a child will feel more comfortable talking to another adult, someone outside the immediate family.
- Watch the child's body language as you speak. Be ready to stop if the child has had enough.

2. Telling children

Egan (1997/2001) describes three steps that parents or helpers need to take. These steps are given below with notes to outline the skills and attitudes required by parents or helpers who plan to talk to children about HIV and AIDS in the family.

Step 1: Exploring (telling the story)

At this stage, the parent or carer will tell his or her story, talk about the problem and what is on his or her mind. He or she tells it in his or her own way and own time.
To tell the situation as it is, the parent will need to be:

- clear – able to explain in words that the children will understand
- honest – not afraid to say difficult things
- aware of good timing – know the right moment to begin, go slowly enough for the children to take in the information, and give them a chance to check what they do not understand
- calm – this helps the children not to panic when they receive information
- child-centred – keep to what the children need to know. Do not give unecessary detail or blame others
- understanding – be aware of how the children are feeling and give them comfort or a break to recover from immediate shock or distress
- supported – is there a reliable friend or relative who could support you to tell the story? Or is there someone who could give comfort and practical support? For example, he or she could prepare food while the family discusses their situation.
- focused – be able to summarise the most important points
- patient – be ready to go over the story as many times as necessary.

Step 2: Understanding (options and alternatives)

At this stage the parent or carer tries to make it easy for the children to ask questions. The children need to be able to ask how this problem might affect them and what they can do about it. This could be a family brainstorming session. Everyone could be allowed to ask and say whatever they think, no matter how impossible or difficult their questions and ideas might be.

To give the children a chance to question and come up with ideas, the parent or helper will also need to:

- listen – hear and react to what the children have to say
- reflect back – make sure the children know their ideas and fears have been heard – for example, you could say: “Let me get this right, what you are saying is…”
- ask the right questions – help the children be clear about what they are trying to say
- challenge – to not let false ideas or hurtful comments slip by
- encourage discussion – make it easy for all the children to join in with their ideas
- build on ideas – let children see that their views are respected and their suggestions can become part of the solution.

How to start talking to children: some ideas from NACWOLA women

- Talk first to a reliable friend or relative, and practise saying the words.
- Discuss with this friend when and how you can start to talk to your children.
- Listen to your children and find out what they already know about HIV and AIDS.
- Watch out for ‘entry points’ that you can build on, for example, times when your child raises the subject of illness, AIDS lessons at school, radio programmes and so on. You may be surprised at how much they already know.
- Do not overload children with too much information and in general do not tell the whole story at one time. This will be too much for most children.
- It is better to start slowly, talk about sickness generally and build up to your own personal health and, finally, to HIV and AIDS in the family.
- Pick a quiet time to talk, without strangers in the house or possible interruptions.
- Give simple and appropriate answers, using simple, everyday language.
- Choose a time when your own health is okay and when you feel calm.
- Be prepared for shock, anger, blame and denial (these reactions will pass with time).
- You might find your children have already guessed. They might be relieved to hear the truth from you.

- Be ready to answer awkward questions like: "How did you get it?", "Have I got it?", "When will you die?"
- It helps if you have already started to make plans for the future, so you can reassure your children they will not be left alone.
- Be prepared to have this discussion many times. Children will absorb the information bit by bit. They will come back for more detail as they come to terms with the facts.

Step 3: Taking action (planning)

At this stage the parent (or carer) and children need to slow down and think about the situation. Together, wherever possible, they will consider different possibilities and work out the best plan in the circumstances.

The plan needs to be:

- realistic – something possible to achieve, which will meet agreed needs
- manageable – not too complicated and only involving people who will definitely be able to help when the time comes
- ready in time – in place before a crisis happens
- achievable – even if the plan does not cover everything, the people concerned need to feel secure that what has been arranged will work.

To come up with useful plans, parents or carers will need to:

- be realistic – do not raise hopes of a perfect solution which does not exist
- be strong – help the children accept what is happening
- be firm – set time limits to work towards a good plan
- be fair – take everyone's fears and wishes into account
- keep going – reach decisions while there is still time to put plans into action
- involve and update the children at all stages.

MODULE 6

Helping children cope with separation, loss and grief

Trainer's introduction

This module looks at supportive ways in which parents can talk to their children about separation and loss, and prepare them to cope. It gives guidance on how to help relieve children's grief, and helps guardians and other carers to communicate sensitively when talking about these important topics with children. Here we build on Module 5 by developing the idea of the importance of planning communication.

Approximate length of module: 2 hours 30 minutes (up to 3 hours 40 minutes including the video)

Aims

The aims of this module are to:

- provide an understanding of the impact of separation and loss
- help participants prepare children and others for separation and loss
- help participants understand the importance of planning for separation and loss.

Key learning outcomes

By the end of this session participants will:

- have an understanding of separation and loss
- have explored death and dying
- have an increased understanding of children's fears of death
- have looked at ways to prepare children to cope with separation and loss, and have recognised the importance of planning.

Trainer's preparation

Module plan (with suggested times)

- Understanding separation and loss – **45 minutes**
- Exploring death and dying – **40 minutes**
- Looking at children's fears of death and ways of preparing them to cope with separation and loss – **45 minutes or up to 2 hours including the video**
- Reflection – **15 minutes**

Materials you will need

Video: *Everyone's Child* (85 mins), if available – see Appendix 1: Key course materials (page 123).
TV & video player
Overhead/flipchart 1: Outline of Module 6
Overhead/flipchart 2: Exploring the death of someone important to you

Trainer's guidance

Introduction

Please note that this session deals with very emotional issues. It might be necessary to take extra short breaks between activities.

Explain that the purpose of this module is to explore separation and loss. Say that together you will look at the meaning of separation and loss, the impact of death and dying, and ways to plan and prepare children to cope. Remind the group that we have all survived separation and loss and these experiences will help us think about this subject, whether we are living with HIV or not. Ask participants to support each other through the module. Say that if any participants have recently experienced a death, it is fine for them to observe quietly and join in wherever they feel able.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 6
Please use the list in the module plan on page 57, but without the suggested times.

Understanding separation and loss

Activity 1 What do separation and loss mean to you?

Suggested time: 20 minutes

Explain that in this activity participants will look at what separation and loss mean to them. By looking at different views from the group this can help increase our awareness of the different ways that people are affected by separation and loss.

1. Ask participants to brainstorm the difference between separation and loss. Record their responses on a flipchart. Allow five minutes for this.

2. Summarise the main points of the brainstorm. If participants have not made any distinction, explain that:

- **Separation can be long or short.** For example: when a husband goes away to work for part of the year; when the children are sent to stay with a friend or relative, because their mother is ill.
- **Loss means forever.** A phase of your life is over, for example, when you leave school or when someone important to you dies.

Allow five minutes for summary and discussion.

3. Next, brainstorm with the group what separation and loss mean to them. Record their responses on the flipchart. Take five minutes to do this.

4. Summarise the main points of the brainstorm. Make sure you bring out the following:

- **Separation** generally leads to anxiety about what is going to happen, a mixture of hopes and fears.
- **Loss** means the change is final. Thoughts and feelings might include shock, confusion, denial, hurt, loneliness, hopelessness, guilt, anxiety, anger and feelings of "why me?"

Allow five minutes for summary and discussion.

Activity 2 Exploring the impact of separation and loss and our experiences of coping

Suggested time: 25 minutes

Explain that the aim of this activity is to explore the possible impacts of separation and loss and to look at experiences of coping.

1. Ask participants to work in pairs. Tell them they will have 10 minutes to share with each other an experience of separation or loss. Emphasise that they do not have to talk about a death. Say that if they choose to talk about a death, **they should not discuss the death of someone important to them.** Suggest some ideas to get people started, for example:

- first day at school
- leaving school
- moving home
- getting married
- leaving a job.

As trainer, think of your group and try to add ideas that might be particularly relevant to them and their local context.

2. Next ask the group to stay in pairs to discuss:

- what was difficult about the loss they have chosen to talk about
- any positive outcomes of the experience in the longer term
- what helped them cope.

Give them 10 minutes to do this.

3. Bring everyone together in the whole group and ask for volunteers to feed back the main points of their discussion. Bring out the following points:

- What feelings did people experience?
- Was any loss or separation *completely* negative or were there positive aspects?
- What has helped people cope? Make sure the discussion includes having someone to share your feelings and thoughts with, and note how time can often heal.
- What was positive about it in the longer term?

Allow five minutes for this.

4. Ask participants to reflect individually on the discussion and remember what helped people cope.

Exploring death and dying

Be sensitive to how participants feel: some may want to listen rather than join in.

Activity 3 How do we feel about death?

Suggested time: 40 minutes

Explain the aim of this activity is to explore feelings about death.

1. Ask participants to sit alone for a few moments and think of a death that was significant to them when they were younger.

Overhead/flipchart 2: Exploring the death of someone important to you

- What did you feel like at the time of the death?
- What were the attitudes of the people around you?
- How did you cope and who did you get support from, if anyone?
- How did you find out about the death?
- Is there anything you would have liked to be different about the way you found out about the death?
- What would have made it less painful or shocking?

Ask participants to consider the points individually for five minutes.

2. Ask participants to work in small groups and discuss these questions for 10 minutes. Ask each group to choose one person to feed back the main points to the whole group.

3. Next bring everyone back together. Ask the representative for each group to feed back, taking two minutes each. Record their answers on the flipchart.

4. Take 10 minutes to summarise the main points. Ask participants how the exercise could guide us to plan for the future.

5. Bring the activity to a close by emphasising the importance of planning for the future as a key part of memory work. Remind participants that the course will help parents living with HIV to plan memory books, the subject of Module 10. These memory books will keep alive in their children's minds the memory of them and the important things that the children will need to remember about their background. Explain to participants who are future guardians and carers that this activity helps them to be sensitive to the child's need to remember and talk about loved ones they have lost and where they come from, as well following through parents' plans for the child's future.

Looking at children's fears of death and ways of preparing them to cope with separation and loss

Please note this topic is likely to make participants feel sad and possibly angry. Do not force individuals to participate in discussion. They may want to be passive and just listen. But be ready to answer any questions that the activity raises.

Activity 4 Looking at the emotional impact of loss and separation caused by HIV and AIDS on children, and ways to meet their needs

Suggested time: up to 2 hours if you are watching the video;
45 minutes if you make the presentation instead

If possible, show the video as it gives more impact and support than the presentation.

Option 1. The video *Everyone's Child*

1. Decide before the session whether you are going to show all of the video (85 minutes) or select parts. Explain to the group that the video covers the emotional and practical impacts of HIV and AIDS on children's lives. It also shows the supporting roles that community members can play.

2. Ask the group to watch the video and think about issues to discuss or questions to ask after it has finished.

3. When it has finished, gently start a discussion about it. Ask if it has given the group any ideas about preparing for the futures of their children. Be ready to answer any questions and allow 30 minutes for discussion. Give people time to reflect, compose themselves and think of questions.

Option 2. Presentation

Explain to the group that you are going to give a short presentation to help them understand the impact of separation and loss caused by HIV and AIDS on children, and to look at ways to meet children's needs. Ask the group to think about the points as they listen and decide which are most important. Ask them to be ready to discuss how these points might help parents prepare to meet the needs of their children in the future.

Take about 15 minutes to give the following presentation, having prepared well beforehand.

Presentation

1. The impact of separation and loss

Separation

Separation makes children feel anxious. The younger the child and the less they understand the reason for the separation, the more anxious they might feel. This is known as separation anxiety, which has three main stages:

protest – an outward expression of what they are feeling, for example, in the form of anger, fear, or not understanding
hopelessness – the child becomes calmer, but seems sad and does not react much to comforting
detachment – if the separation continues for a long time, the child begins to respond to people again, but treats everyone the same. The child needs to re-learn how to relate to someone special.
However, remember each child is unique. Children may feel different levels of anxiety and they may not go through all three of these stages.

Loss

When children experience loss (in this context we are mainly talking about death), they may react with:
shock – for example, feeling numb
confusion – for example, not being able to do even simple things
denial – for example, searching for the person who has died, behaving as if they are still alive
hurt – this includes feeling sad and empty and longing for the person who has died
loneliness
hopelessness – for example, feeling helpless and unable to bring the dead person back; coming to realising they have gone forever
guilt – for example, thinking they did not do enough for the person when they were alive, or for having angry thoughts or feelings about them. Very young children who do not understand why a person has died sometimes feel they are to blame
anxiety – for example, worrying about the future and increased responsibilities
anger and thoughts of "why me?" – this can range from being irritable towards friends and family to angry outbursts to God or fate, nurses, doctors or even the person who has died.

It is best not to think of these reactions as stages. They can happen in a different order or come back again after being worked through once. With time, the child learns to **acknowledge** and then **accept** what has happened. The child can then start to reorganise his or her life, with others to help.

2. Meeting children's needs

It is important to be clear about children's emotional and physical needs. These all have to be planned for while the parent is still alive and while the child can be included in planning their futures.

Emotional needs: remind participants that earlier modules, particularly Module 2 on child growth and development, covered some of these needs at different ages. Remind the group of the following points:

- Children need to know in good time about their parent's HIV status.
- It is important to strengthen the relationship between parent and child before the loss occurs to make them feel loved and trusted.

Cont. next page

- Allow the child to find out more about the parent’s life and experiences. This encourages a sense of belonging and helps open the way for communication.
- It is important not to cling to the child, and to involve other family members or friends. This will encourage independence.
- If possible, parents should try to identify someone they can trust to provide consistent loving care for the future. When they have made an arrangement, the child should be involved in the planning. Children will recover better if they can stay with the same primary carer after losing a parent, until they become young adults. This avoids coping with more separations.
- Support can also come from many sources in the community if it is planned ahead. This might include other people who are familiar with the child, such as relatives, friends, teachers and local members of the church.
- Before and after loss, a child will need to be comforted and listened to. He or she should be encouraged to express his or her feelings. It is also important to validate what the child feels. Validation means acknowledging that the child is having the feelings he or she is describing. Try not to say that things will get better or that time will heal, as this approach does not meet the child’s immediate needs. Validation is about acknowledging this is how the child feels right now.
- It is important to keep brothers and sisters together if possible. Research shows that they can provide emotional support to each other from early ages, as young as three or four.

Physical needs

- The child will need to have somewhere to live and someone who will care for her or him physically, looking after her or his health and education.
- Again, the community can help support these children, and local church and AIDS support centres may be able to provide practical, and possibly financial, help.

After the presentation, gently start a discussion about what the group has learned and whether it has given them any ideas to prepare for the future of their children. Be ready to answer any questions. Allow 30 minutes for discussion. Give people time to reflect, compose themselves and think of questions.

Reflection

You will need to be aware of participants’ feelings in this last activity. Be ready to comfort anyone who is very upset.

Draw the session to a close. Acknowledge that the module has probably been emotionally tiring for everyone.

Activity 5 Reflecting on the module

Suggested time: 15 minutes

Explain that the aim of this activity is for participants to reflect on what they have done in this module and to share key learning points with each other. Say that they can do this quietly with another person, but if anyone wants to speak to the whole group they are welcome to do so.

1. Ask participants to turn to the person sitting next to them and say how they would like to be remembered. Allow five minutes for this.
2. Ask each person to share with the same person how they are feeling and what they have learned from this session. Allow five minutes for this.
3. After five minutes, say that if anyone would like to share their thoughts with the rest of the group they are welcome to do so.
4. Close the module. Thank participants for their contributions and say you are looking forward to working with them on the next module. Remind participants that the next session builds on this one. It focuses on planning for more positive futures.

Make sure that everyone is feeling calm by the time they leave the session. An extra refreshment break to encourage people to talk among themselves might help participants to feel better before leaving.

MODULE 6 – Trainer’s notes

Five stages of loss and bereavement

(Taken from *On Death and Dying* by Elizabeth Kubler-Ross, September 1992)

1. DENIAL AND ISOLATION

This is characterised by statements such as “No, not me, it cannot be true”. For example, on receiving an HIV-positive diagnosis, a person may say: “No, it cannot be true – the hospital must have got the results mixed up.” She or he may ask for further tests to be carried out in the hope that the initial diagnosis was wrong.

Denial is used by almost all people, not only during the first stages of illness, but also later on from time to time. Very often, people can consider the possibility of their own death for a while, but then have to put these thoughts away in order to continue with life. Denial functions as a buffer after unexpected shocking news. It allows the person to collect her or himself and mobilise other defences. Denial is usually a temporary defence and will soon be replaced by a partial acceptance. The need for denial exists in all people at the end of a person's life. The need comes and goes and the sensitive listener will acknowledge this and allow the person his or her defences without making him or her aware of the contradictions.

To summarise: the person's first reaction maybe a temporary state of shock from which she or he recuperates gradually. When the initial feeling of numbness begins to disappear, and the person can collect her or himself again, the usual response is “No, it cannot be me”. The person will gradually drop his/her denial and use less radical defence mechanisms.

2. ANGER

When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. It is characterised by questions such as “why me?” This stage can be very difficult to cope with for family and others surrounding the person. The anger can be displaced in all directions, projected on to the environment at different times. For example, if the reaction is “The doctors are no good, they are not experienced, they do not care,” the visiting family may be received in an unfriendly manner, making the meeting a painful event. They, in turn, may either respond with grief, guilt or shame, or even avoid future visits, which only increases the person's discomfort or anger.

A person who is given attention and time will soon reduce his or her angry demands. She or he will know that she or he is a valuable human being, and one that is cared for. Often, we do not think of the reasons why a person is angry and take it personally, when it has little to do with the person who has become the target of our anger. In this situation, it is important to understand and not to judge the person.

3. BARGAINING

Bargaining involves entering into some sort of an agreement which may postpone the inevitable happening. For example, “If God has decided to take me from this earth, and He's not responding to my angry pleas, then maybe He'll be more favourable if I ask Him nicely.” The patient feels that he or she may be rewarded for good behaviour. Bargaining includes an implicit promise that the patient will not ask for more if this one postponement is granted. Most bargains are made with God and are usually kept a secret or mentioned ‘between the lines’. Psychologically, promises may be associated with quiet guilt. It is therefore important to take such remarks seriously. It may be useful to find out if the person really does feel guilty for not attending church more regularly or whatever it is, or if there are deeper unconscious hostile wishes which have led to such guilt. According to Kubler-Ross, none of her patients ‘kept their promise’. In other words, they are like the children who say, “I will never fight my sister again if you let me go.”

4. DEPRESSION

When the terminally ill person can no longer deny his or her illness, and begins to get weaker, this numbness and anger will soon be replaced with a sense of great loss. Kubler-Ross suggests that we often tend to forget the preparatory grief that the terminally ill patient has to undergo in order to prepare him or herself for his or her final separation from this world. Kubler-Ross differentiates between two kinds of depression: reactive and preparatory.

Reactive depression: In this case the cause of the depression needs to be found, and some of the unrealistic guilt or shame that often accompanies the depression needs to be alleviated. This may involve dealing with practical matters and helping the reorganisation of the person's household, e.g. making fostering or adoption arrangements for children. Very often, the person’s depression will be lifted quickly after these vital issues have been taken care of.

Preparatory depression: This type of depression is one that does not occur as a result of something that has happened in the past but is taking into account impending losses. At this stage the patient should not be encouraged to always look on the sunny side of things as this would mean that he or she would not be thinking about his or her impending death. In being allowed to express sorrow, he or she will find that final acceptance is much easier.

This second type of depression is usually a silent one, with little need for words. It is often approached better with a touch of the hand or a silent sitting together. There can also be a discrepancy between the patient's wish and readiness to die and the expectation of those in his or her environment to fight to live. It is this that causes the greatest grief and turmoil for terminally ill people.

5. ACCEPTANCE

If the person has had enough time or has been given some help in working through the previous stages, she or he will reach a stage of acceptance. She or he will be tired, and in most cases, quite weak. She or he will also have a need to doze off or to sleep often and at brief intervals. There is a gradually increasing need to extend the hours of sleep, very similarly to that of the new born child, but in reverse order. Acceptance is almost void of feelings. It is as if the pain has gone, the struggle is over and there comes a time for 'the final rest before a long journey', as one person put it. This is also the time when the family needs more help, understanding and support than the dying person him or herself.

Communication then become more non-verbal than verbal. Moments of silence may be the most meaningful kind of communication at this time. We may just let him or her know that it is all right to say nothing when the important things are taken care of and it is only a question of time until she or he can close her or his eyes forever. The dying person, while accepting his or her impending death, still maintains hope.

The phases of loss

1. Shock

This presents itself in a variety of ways, such as sleeplessness, yawning and tiredness, loss of appetite, ‘dreamlike’ behaviour, and an inability to concentrate, make decisions or absorb information.

You can HELP by: comforting and, above all, listening. Do practical tasks. Be available and supportive, but not intrusive. Do not chatter: this can be very annoying as some people have a low tolerance to noise at this time. Provide drinks and light food but do not force the person to eat. Gently encourage her or him to undertake tasks such as funeral arrangements, telling others and so on. This will help the person to come to terms with the loss.

2. Denial

This often presents itself as an inability to talk about the situation and indeed some people continue to plan and live as if the dead person were still alive. Enquirers are often told "I'm fine", are dismissed or are forced to change the subject. It is not unusual for people in this phase to adopt phrases or even characteristics of the dead person. There will be an inability to cry, as this acknowledges the loss. During this phase, hyperactivity and anxiety are common.

You can HELP by: being there or not being there – depending on the person's wishes; actively listening. Although it takes courage, do not be afraid to talk about the dead person.

3. Yearning/pining

There will be feelings of being alone. There may be frequent bouts of crying at thoughts or objects that give reminders of the dead person. This process should not be interfered with, as it is a good sign that the loss is no longer being denied. The loss will feel increasingly real and with it will be a wish for the dead person to return and fill the void. Some people imagine they have heard the dead person. During this phase, which can last for months, people change their minds frequently – wanting to be alone, not wanting to be alone, wanting to be alone, and so on.

You can HELP by: being there or not being there, as the person wishes. Go through photos and openly talk of the dead person. Avoid platitudes such as "He's at peace now", "She had a good life", and so on.

Unless you have had a similar experience avoid phrases such as "I know how you feel". Be tolerant. Do not hurry to sort out clothes and belongings, but should someone want to do this do not stop them either. Some people feel they have to do it straight away. Allow them to weep, although you may find this uncomfortable.

4. Anger, guilt, apathy and bargaining

This is a strange mixture of emotions and people can become very frightened by them. They can feel nothing one minute and suddenly become angry either with the dead person for leaving them or those around for not helping properly. This can result in guilty feelings or regretful expressions such as "If only I had done this." There is often both anger and apathy towards making a new life, and even doing the basics like cleaning or preparing meals. Feelings of low self-esteem are often evident.

You can HELP by: being supportive. Accept the anger, although it can be profound and sometimes very damaging to a relationship. Be comforting and give hope. It is also useful to express positively what the person did for the dead person. Do not press him or her to eat but try to tempt him or her with small titbits.

5. Acceptance

This occurs for some people. It is a very gradual process and the length of time it takes can be governed by many things, such as how the person died, whether the relationship was good or bad, and previous bereavement experiences. As acceptance occurs, it often presents itself as a growing awareness of others, the ability to laugh again, appreciation of growing things and feelings of warmth for those who have been supportive. People often start to be more sociable. The 'bad' as well as the 'good' attributes of the dead person will be remembered and acknowledged. There will be increased feelings of self-confidence and self-esteem.

You can HELP by: encouraging and giving positive feedback. Be available, comforting and supportive when mistakes are made.

MODULE 7

Planning for your children's futures

Trainer's introduction

This module helps participants consider possible care options for their children after a parent or parents have died. It looks at important factors to take into account and encourages participants to compare the advantages and disadvantages of their options. It is a key module for participants who are parents living with HIV. It is also useful to future guardians and carers who will learn about the factors that parents consider when making these important decisions. The module may also enable participants to support other parents, guardians and carers to plan for the future.

Approximate length of module: 2 hours 5 minutes

Aims

The aims of this module are to:

- help participants consider what factors are most important to parents in choosing care for their children
- explore the different care options for children
- help participants prepare for planning their care arrangements.

Key learning outcomes

By the end of this session participants will:

- have explored criteria for choosing someone to care for children
- have considered different care options and the pros and cons of each
- have looked at how to plan for care options for children
- recognise that different people will have different priorities when choosing care options
- recognise that although parents might choose one carer, that person will need support from others.

Trainer's preparation

Module plan (with suggested times)

- Looking at what is important to parents in arranging the future care of their children – **40 minutes**
- Exploring different care options for children – **1 hour 15 minutes**
- Reflection – **10 minutes**

Materials you will need

Cards for Activity 1: see preparation material, page 71
Overhead/flipchart 1: Outline of Module 7
Overhead/flipchart 2: Looking at care options

Trainer's guidance

Introduction

The activities in this module will help participants explore factors they think are most important in deciding the future care of children of all ages. Care issues and options will vary according to the age of the child because their characteristics and needs are different.

Introduce the module by explaining that its purpose is to help each participant explore what factors are most important to parents when they think about future care options for their children. Say that the session will help them explore the advantages and disadvantages of the different options. It will also help them think about planning their chosen option.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 7
Please use the list in the module plan on page 67, but without the suggested times.

Remind the group that together you looked at stages of child development and children's changing characteristics and needs in Module 2. It may be very helpful to briefly remind the group of the main points of that session. Ask them to keep in mind the different needs of their own children at different ages when doing the following activities.

Activity 1 Looking at what is important to parents in arranging the future care of their children

Suggested time: 40 minutes

See page 71 for instructions on how to make and present the cards for this activity.

Explain that the aim of this activity is to help participants think about what characteristics and qualities parents would look for in a carer or family to look after a young child or teenager.

1. Divide participants into groups of three and give them a full set of the cards you have prepared beforehand. Explain that each card has a different personal quality or characteristic written on it. Ask each group to to place the cards into three columns headed important, very important and not important, acording to the importance they attach to the quality of the characteristic on each card in a future carer for their child or children. Ask them to come to some agreement if possible. Give them 15 minutes to do this.
2. Next ask participants to walk around to see how the other groups have placed the cards. Give them 10 minutes to do this.
3. Take 10 minutes to discuss how participants found the exercise and summarise the main points. What was easy and challenging about placing the cards? How might the way participants placed the cards affect how or who they choose to look after their child or children? Emphasise there is no one right choice.

Make sure you bring out the following points in your summary:

- It is important to think how each child would deal with a new carer or family situation where there are different rules from those they are used to.
- One way to address this is for a parent to look for a guardian or carer with similar ideas to their own about what is important and appropriate for children of different ages. This is why some parents prefer friends, rather than family, to look after their children.

- Think about how to prepare children for these changes. (This will also be looked at in future modules.)
- It is helpful to make frequent visits to the future carers, or to encourage the children to stay with them from time to time, so that they can get used to them.

Exploring different care options for children

Activity 2 Looking at care options

Suggested time: 1 hour 15 minutes

Explain that the aim of this activity is to help participants identify possible care options, looking at the advantages and disadvantages of each, to help them guide their planning.

1. To begin the activity write the word 'child' on the flipchart paper and ask the whole group to brainstorm for 10 minutes which people might be suitable carers for their children. Say they can include groups of people, such as the family or local support organisations, as well as individuals. Then write the word 'teenager' on the flipchart paper and repeat the activity.

2. Take about five minutes to go through both lists. Tell the group the options might be different for children of different ages and will also depend upon parents' preferences. Add some options to the list if the group has not suggested them. These might include: member of the extended family, friend's family, legal guardian, foster parent, children's home, child-headed family.

3. Ask participants to choose which option they would like to work on, and to form a group with two or three others who wish to think about the same option in more depth. It could be an option they prefer or one they have not thought much about yet. Encourage participants who will be guardians or carers in the future to choose an option they want to find out more about, and ask them to try put themselves in the place of a parent living with HIV facing this challenge. If too many people choose the same option, direct the participants so that all of the different options are all addressed.

4. Give the participants 15 minutes to think about the *advantages* of the care option they are considering. To guide them, ask them to look at the points on the overhead/flipchart below.

Overhead/flipchart 2: Looking at care options

Advantages – would the carer you are thinking about offer the following things to children?

- familiarity, feeling comfortable and 'at home'
- education
- housing/accommodation/space
- health
- religious and spiritual input
- meeting social needs
- means of dealing with bereavement
- stability and compatibility with existing family circumstances
- understanding of HIV and parents' views on disclosure.

Add your own factors that you think are important.

Now try to answer these questions:

- Do you have the resources (social and financial) to care for the child or teenager?
- Have you disclosed your HIV status to the carer(s)?
- Is your child living with HIV and does your intended carer know?
- What extra support will your child need if he or she is living with HIV?
- Does the child get on with this person or family?
- Do you think your child would like to live with this carer?
- Would your children be able to stay together with this carer?

4. Now ask the small groups to consider the *disadvantages* of their option for 10 minutes. Say that this is important, as any option will bring difficulties and challenges. Ask participants to discuss what they could do about these.

5. Inform participants that the next step is to share ideas in order to learn from each other. Ask each group to work with the other groups in turn, until all groups have worked with each other. Ask the groups to share the main points of their discussions to explore how different solutions might support each other. For example, if one participant felt that a neighbour might be able to help supervising a child at play or meal times, this might support another group's option of giving an older sibling (the main carer) time to study, shop or socialise. Give five minutes for each two-group discussion.

6. When all the groups have had five minutes together, ask everyone to come back to the whole group and share the key points of their discussions. Allowing 15 minutes for this. Guide the discussion by asking the following questions:

- What sorts of advantages and disadvantages came up for different care options?
- What issues and considerations came up for children of different age groups: 0-6; 7-12; and 13-18?
- What have participants learned to help choose a carer?
- What practical steps can they take to help prepare for the care of children?
- Say that it is important to think carefully about arranging support for children who are HIV positive. This does not mean the children could not live with the carer they have in mind; it just means that they will need more support and access to treatment. A self-support group for people living with HIV and AIDS might be helpful for them too.

7. Close the activity by saying that you hope it has helped the group to consider some options they had not thought of before. Say that it is important to consider how a range of different people can contribute to the care of their child or children. This helps to take the pressure off just one carer and will better meet a child's different needs.

Reflection

Activity 3 Reflecting on the module

Suggested time: 10 minutes

Explain that the aim of this activity is to draw the module to a close, help participants reflect on what they have done in this session and share key learning points with each other.

1. Give the group five minutes to work in pairs and discuss how they found the module. Ask them to think about what ideas or thoughts they are taking from the module. How do they feel about the way in which the day was structured and facilitated?

2. End the activity with three or four participants sharing what they have learned and their feelings about the day. Allow five minutes for this.

Close the module by thanking participants for their contribution. Tell the group that the modules that follow will guide them to take these issues forward. Say you look forward to working with the group in the next module.

Trainer's preparation material for Module 7

Cards for Activity 1

Make a copy of the table below, and cut it up so that each box makes a separate card. Gather the cards into packs before the session. Make sure there are enough packs to give one pack to each small group of three participants. To each pack, add three blank cards to allow participants to add their own ideas.

Trustworthy	Parents in paid work	Similar approach to bringing up children or teenagers
Have teenage son/daughter	A married family	Have time and energy for the children
A stable family (one without too much stress and turmoil)	Good discipline	Patience
Loving	Enough money	Their children go to the same school
Religious and go to the same church as you	Close family relationship	Have child of same age as yours
Your child or teenager is familiar with the family	Has family gatherings – the extended family is actively involved	Live close by
Show affection to their children	Caring	Their children are well behaved
A family active in the village or town	Both parents are living at home	A family with several children of their own
They value education	Welcoming	Open-minded
Traditional		

MODULE 8

Involving children in planning for their futures

Trainer's introduction

This module helps participants explore how to actively involve their children in planning their futures. The activities encourage participants to try to put themselves in the place of children of different ages, from young children to teenagers. It helps the group improve their awareness of children's changing needs and desires at different ages, and learn how adults and children can work together. The session is relevant to parents living with HIV as well as future guardians and carers, who will also need to understand and talk with children at some stage about future plans.

Approximate length of module 2 hours 30 minutes

Aims

The aims of this module are to:

- help participants understand the viewpoints of children of different ages
- show that children base their decisions on different factors from adults, and this will affect how to involve them in planning
- enable parents and carers to involve children in planning for their futures.

Key learning outcomes

By the end of this session participants will:

- have a greater understanding of children's viewpoints at different ages
- understand that children base their decisions on different factors from adults and how this might affect involving them in planning
- understand that children are likely to focus on their immediate needs rather than think far into the future
- recognise that all children have something important to contribute if they can be involved appropriately
- be aware that as adults, parents and carers keep the responsibility to decide which wishes and requests from children are reasonable and which decisions they should take themselves.

Trainer's preparation

Module plan (with suggested times)

- Understanding children's viewpoints at different ages – **35 minutes**
- Looking at how children use different factors from adults to make decisions – **50 minutes**
- Dealing with difficulties when planning with children – **45 minutes**
- Reflection – **10 minutes**

Materials you will need

Activity cards you prepared for Module 7
Overhead/flipchart 1: Outline of Module 8
Handout 1: Being prepared to deal with difficulties when planning with children

Trainer's guidance

Introduction

Introduce the module by explaining that its purpose is to help participants involve children appropriately in planning for their futures. Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 8
Please use the list in the module plan on page 73, but without the suggested times.

Remind the group that together you looked at stages of child development and children's changing characteristics and needs in Module 2. You also covered ways to communicate effectively with children of different ages in Module 4. Briefly remind the group of key points from those sessions. You will need to read modules 2 and 4 again in preparation for this module, so that this information is fresh in your mind.

Explain that young children and teenagers are usually able to participate in planning their futures. Even very young children between four and six years will be able to express likes and dislikes. From these ages to 18, children and teenagers may play an increasing part in working with parents or carers to plan what will happen to them. How much they take part will depend on their age and maturity, as well as the quality of the relationship. It is important to stress that each child is individual and different, and that their specific needs and wishes must be considered.

Ask parents to keep in mind the ages and different needs of their own children. They should also think about what does and does not work when they speak to their children about important things.

Understanding the viewpoints of children of different ages

Explain that it is important for participants, whether they are parents or not, to try to put themselves in the place of a child. They can use what they know about children to try to see things from their viewpoint. This will help them understand a child's contributions and think of ways to empower them to take part in planning for the future.

Activity 1 – Seeing things from a child's viewpoint

Suggested time: 35 minutes

Explain that the aim of this exercise is to encourage participants to put themselves in the place of children of different ages, to try to understand a child's viewpoint.

1. Tell the group they are going to try to put themselves in the place of a child of a particular age. Divide participants into three small groups. Give each group a different age: 6, 10 or 14.
2. Ask each group to pretend that they are children of the age they have been given and that they have to go to the local shop to buy lunch for a school trip. Tell them how much money they have to do this. As trainer, adapt this exercise to make it relevant to the

local context and the group you are working with. Work out what amount of money is appropriate locally. You will need to prepare this before the module.

3. Give each group 10 minutes to make a list of what they might buy at the shop. Ask them to choose one person to feed back to the larger group.

4. Next bring everyone back to the whole group. Give each group representative two minutes to read out their list.

5. Discuss the differences between the lists and what they suggest. Bring out the fact that the younger children or more immature older children are more likely to think about what they want right now, rather than what might be good for them. Generally, they do not think about planning for the future. For example, young children might buy sweet things, while older children might hold back some of the money to spend on something else.

Emphasise that every child is different and participants need to take the likes and dislikes of each child into account when making a decision about their future. Allow 10 minutes for discussion and summary.

Looking at how children use different factors from adults to make decisions

Activity 2 Using role-play to explore how children make decisions

Suggested time: 50 minutes

Explain that the aim of this activity is to help participants explore how children choose factors that make sense to them to make decisions about their future. For this activity you need the cards you made for Module 7 (see page 71).

Children can easily decide what food they like or which games they want to play. However, it might be more difficult for both younger and older children to think about their future and their future needs. So it is important for parents and carers to consider how to decide which of the children's wishes and requests are reasonable and which decisions they should take as parents.

1. Ask participants to form small groups. Say that you are going to ask them to prioritise the cards as they did in the previous module, but this time they will do so while imagining that they are seven years old. Give participants 10 minutes to do this.

2. Next, give the group 10 minutes to:
   - discuss the differences between how they graded the cards as seven-year-olds and how they graded the cards as adults in the last module
   - consider how the list might be sorted if they made the decisions as an adult together with their seven-year-old. What points of agreement and disagreement might there be?
   - be ready to report back to the whole group.

3. Ask the groups to volunteer brief feedback to everyone. Allow five minutes for discussion. Make sure participants pay attention to some of the things that are important to a seven-year-old. Ask them to think about how they could achieve a balance between what is important to the child and what can be done to meet their wishes, and an adult's understanding of the realities of the situation and what needs to be done.

4. Repeat the exercise from the viewpoint of a 16-year-old. Allow another 25 minutes for this.

Dealing with difficulties when planning with children

Activity 3 Looking at ways to deal with difficulties when planning with children

Suggested time: 45 minutes

Explain that the aim of this activity is to consider how to deal constructively with the difficulties and challenges that might arise when planning with children and teenagers of different ages.

1. Ask participants to divide themselves into groups of three or four, and take 10 minutes to consider what difficulties they expect to face when they try to plan future care with children. Be aware that participants living with HIV might raise different issues from other group members, because they might forsee planning sessions affected by shared sadness and other emotions. Ask the groups to choose a representative to be ready to feed back the main points of their discussion.

2. Ask each small group to take two minutes to feed back to the whole group. Record their points on a flipchart.

3. Ask the whole group to discuss:

- what might help overcome the difficulties and challenges in the way parents and carers understand and communicate with children
- what friends, family and other people could do to help with the difficulties identified
- possible sources of support for parents.

Record responses on the flipchart. Take five minutes to summarise the discussion.

4. Go through the points below, which also formHandout 1 (see page 78). Allow 20 minutes for this part of the activity. Say that the points draw on learning from earlier modules.

Being prepared to deal with difficulties when planning with children

- Choose a time when the child is calm and responsive and you will not be interrupted.
- Know what point of planning you want to discuss and that it is a realistic possibility. Do not try to cover too much at once.
- Actively listen and reflect back the main points. Make sure the child knows you are taking in what she or he says, and what she or he thinks is important.
- Be honest. Do not make promises you cannot keep. Be prepared to say gently that a wish is not realistic, giving a reason. Be ready to say: “I can’t give you an answer right now, but we’ll talk again when I find out what is possible.”
- Try to fulfill the child’s wishes whenever possible. Be ready to explain why you need to do something differently from what the child suggests.
- Offer choices of what is possible to younger children and younger teenagers. Try not to ask them open-ended questions such as: “Who would you like to live with?”
- Older and more mature teenagers are often frustrated, because they think parents and carers continue to treat them like children and do not give them responsibility. They might have a clear idea of who they get on with and what they want to do. With teenagers like this you can ask open-ended questions that show that you are ready to trust them. But be careful, because you are talking about emotional concerns and teenagers may begin to feel overwhelmed as the discussion continues.
- Be ready to comfort children of any age if they become distressed.
- If a child of any age gets angry or confrontational, try not to get angry yourself. If possible, try not to interrupt and do not raise your voice. Frustration comes partly out of not feeling heard, so let the child say what she or he wants to say. Speak calmly and try to explain your view. Be ready to stop and say that you both need to take time to think, and that you will talk at another time.

- Some children might find it helpful to talk to someone you both respect and trust, either on their own or with you. This can defuse anger and allow the child to say difficult things she or he might otherwise avoid saying.
- Remember to explore all the possible local options for support to help plan and to provide future support for your children. These include friends and family, the local church, teachers, community groups and AIDS support groups.
- Finally, remember that as a parent and carer you have to make the final decision. If you are a parent living with HIV, you are responsible for arranging a secure plan for the future of your child. If you are a guardian or carer, you will be responsible for looking after the child and carrying out the plans her or his parent(s) made, as well as making other decisions that arise from everyday life.

After you have finished presenting these points, give Handout 1 to each participant.

You could close this activity by reading out the following words, from a lady who involved her children in planning for the future:

> "Choice for the caretaker was made together with my first-born, based on the existing good relationship between my family and the person she selected."

Reflection

Activity 4 Reflecting on the module

Suggested time: 10 minutes

Explain that the aim of this activity is to help participants reflect on what they have done in this module and to share key learning points with each other.

1. Ask the group to work in pairs and talk about what they have learned from this module. What ideas or thoughts are they are taking from it? Give them five minutes to do this.
2. End the activity with three or four participants sharing what they have learned. Allow five minutes for this.

Close the module by saying you hope the participants feel better prepared to start talking to children about planning their futures. Thank the group and say you are looking forward to working with them on the next module.

Handout 1

Being prepared to deal with difficulties when planning with children

- Choose a time when the child is calm and responsive and you will not be interrupted.
- Know what point of planning you want to discuss and that it is a realistic possibility. Do not try to cover too much at once.
- Actively listen and reflect back the main points. Make sure the child knows you are taking in what she or he says, and what she or he thinks is important.
- Be honest. Do not make promises you cannot keep. Be prepared to say gently that a wish is not realistic, giving a reason. Be ready to say: “I can’t give you an answer right now, but we’ll talk again when I find out what is possible.”
- Try to fulfill the child’s wishes whenever possible. Be ready to explain why you need to do something differently from what the child suggests.
- Offer choices of what is possible to younger children and younger teenagers. Try not to ask them open-ended questions such as: “Who would you like to live with?”
- Older and more mature teenagers are often frustrated, because they think parents and carers continue to treat them like children and do not give them responsibility. They might have a clear idea of who they get on with and what they want to do. With teenagers like this you can ask open-ended questions and show that you are ready to trust them. But be careful, because you are talking about emotional concerns and teenagers may begin to feel overwhelmed as the discussion continues.
- Be ready to comfort children of any age if they become distressed.
- If a child of any age gets angry or confrontational, try not to get angry yourself. If possible, try not to interrupt and do not raise your voice. Frustration comes partly out of not feeling heard, so let the child say what she or he wants to say. Speak calmly and try to explain your view. Be ready to stop and say that you both need to take time to think, and you that will talk at another time.
- Some children might find it helpful to talk to someone you both respect and trust, either on their own or with you. This can defuse anger and allow the child to say difficult things she or he might otherwise avoid saying.
- Remember to explore all the possible local options for support to help plan and to provide future support for your children. These include friends and family, the local church, teachers, community groups and AIDS support groups.
- Finally, remember that as a parent and carer you have to make the final decision. If you are a parent living with HIV, you are responsible for arranging a secure plan for the future of your child. If you are a guardian or carer, you will be responsible for looking after the child and carrying out the plans her or his parent(s) made, as well as making other decisions that arise from everyday life.

MODULE 9

Preparing for new family or care relationships

Trainer's introduction

This module guides participants to think about preparing for new family or care relationships, so that they are easier for everyone involved. The focus is mainly on the new person joining a family or care arrangement. This might be a child, a partner or an adult. The module looks at both positive and negative aspects of the change. It will be useful for parents living with HIV and other participants too, such as future guardians, foster carers and community carers (who might support families or work in children's homes or hostels).

Approximate length of module 3 hours 10 minutes

Aims

The aims of this module are to:

- provide an understanding of the effect of making assumptions about others
- explore the challenges newcomers face when they join a family or home
- look at the impact of newcomers upon the existing family or home
- explore how new adult partners can prepare for forming a new family together
- look at ways to make emotional space for a newcomer in the family or home.

Key learning outcomes

By the end of this session participants will:

- have an improved understanding of the impact of making assumptions about others
- be aware of the challenges faced by newcomers – particularly bereaved children – and their needs, when they join a family or care arrangement
- have explored the impact of newcomers upon existing families or homes
- have an improved understanding of how new parents and carers can prepare for forming a new family or group together
- have explored ways to make emotional space for newcomers in the family or home
- understand the importance of planning for change.

Trainer's preparation

Module plan (with suggested times)

- Understanding the effect of making assumptions about others – **30 minutes**
- Exploring the challenges newcomers face when they join a family or home – **45 minutes**
- Looking at the impact of newcomers on the existing family or home – **30 minutes**
- Exploring how new adult partners can prepare for forming a new family together – **40 minutes**
- Making emotional space for newcomers in the family or home – **35 minutes**
- Reflection – **10 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 9

Trainer's notes

Please make sure you read the trainer's notes at the end of this module (page 87). They give you useful background on making relationships easier for new family groups.

Trainer's guidance

Before you start this module, make sure you know about local customs so you can guide discussions in appropriate ways for the local context. For example, in the local area is it common practice for widows or widowers to live with their new partner and their family?

Introduction

Start by explaining to participants that the purpose of this module is to explore how to make new family or care relationships easier for everyone involved. The focus is on the children or adults joining a new family, but the session also looks at the impact on members of an existing family or group, such as a children's home, who receive a new child into the existing arrangement. Tell the participants that the module encourages them to identify the possible positive impacts, as well as discussing possible difficulties.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 9
Please use the list in the module plan on page 79, but without the suggested times.

Understanding the effect of making assumptions about others

Activity 1 Looking at the impact of making assumptions about others

Suggested time: 30 minutes

Explain that the aim of this activity is to help participants recognise the impact of making assumptions about people and the importance of keeping an open mind to find out what people are really like.

1. With the whole group, brainstorm the assumptions the community makes about people living with HIV and AIDS. Record what participants say on a flipchart. Allow five minutes for this. Remember that in brainstorms there are no rights or wrongs. Accept all responses and do not discuss at this stage.

2. Next, ask the group, particularly participants living with HIV, to brainstorm what they know about HIV and AIDS. Record what they say on a new flipchart. Allow five minutes for this.

3. Show the group both sheets of flipchart paper. Ask the group:
   - What are the differences between the two lists?
   - Why are they different?

Record the main points of the discussion on another flipchart. Allow 10 minutes for this.

4. Ask the group what they have learned from this activity. Make sure you bring out the following as you summarise the main points:
   - When we first meet people we often make assumptions. This means we are making judgments, even if we are not aware of this.
   - Sometimes we form opinions too quickly. It is better to keep an open mind until we have more facts and experience on which to base our opinion.

- Fear of the unknown often makes us think the worst.
- It is dangerous to base conclusions on what other people think rather than on reality.
- It takes time, trust and understanding to find out what a person is really like.

Allow 10 minutes for discussion and summary.

5. Close the activity by saying that it is useful for participants to remember these points as we go through the module, and when they are making plans for their children's future.

Exploring the challenges newcomers face when they join a family or home

Activity 2 Using role-play to understand the challenges faced by newcomers to a family or home

Suggested time: 45 minutes

Explain that the aim of this activity is to increase participants' awareness of the challenges newcomers face when they join a family or home. Say that it will use role-play to show participants what it feels like to be on the outside of an existing family or group trying to get in, and what it is like to be a close-knit group trying to keep someone out.

Please note that this can be a powerful exercise. It can raise uncomfortable issues about hostility to outsiders. It may bring back memories of hostility experienced by the participants. Be ready to deal with this. Do not force people to participate.

1. Find a space where everyone can move around.

2. Divide participants into groups of six or seven people.

3. Ask for a volunteer from each group to play the role of outsiders who try to get into the existing family or home. The others in each group will be family members or residents of the home. Take the outsiders out of the room to explain their role in the exercise (step 4 below). They should wait outside until the others have been briefed (step 5).

4. **Instructions for outsiders:** Tell the outsiders that their role is to find a way to get into the family or home circle. Ask them to think of a story or imagine a reason why they are so desperate to join them. Maybe they are a homeless orphan, a distant relative who is sick or a child of the new partner in the household. Tell them to walk round the group circle and try to find a way in. Is there someone sympathetic who will listen to their sad story? Is there someone physically weak who they can push out of the way? Can they sneak in when the group is busy talking to each other?

5. **Instructions for family group members:** Tell them their role is to try to keep the outsider away and outside the family or home. They could each decide to be different people within the family – for example, mother, father, grandparent, teenager or child. The group might decide some members will present strong physical barriers and others will present tough emotional barriers. Ask members of each group to link arms and form a tight circle. Each circle represents a family or home. Explain that each family will be approached by an outsider who is desperate to be allowed in, and who the group is determined to keep out.

Allow 10 minutes to go through the instructions and organise everyone.

6. Bring the outsiders into the room or compound. Remind them they can use every possible way to break through, including begging for mercy, looking for a weak link in the circle or pushing their way through. If necessary, as trainer, help the outsiders think of different ways to break through the emotional and physical barriers. Remind group members and outsiders to be aware of how they feel while the struggle is going on.

7. Stop the exercise after five minutes or sooner if all the outsiders have broken through.

Ask each family and outsider to talk together about their feelings and how this applies to real-life situations of someone new joining a family or home. Allow five minutes for this.

8. Bring everyone back together to share ideas from the smaller groups. Guide the discussion with some of the following questions:

- Why did the family or home refuse to help the outsider? What do they fear?
- What does it feel like to keep out someone you know is suffering?
- What made it possible for the outsider to break into the circle?
- How did group members feel about the outsider when he or she was inside the circle?
- How did group members feel if they succeeded in keeping the outsider out?
- Were group members united in their action?
- Were the outsider's opinions listened to?
- What did it feel like to be a group member who wanted to let the outsider in?
- What was it like to be the outsider and to be kept out?
- What was it like to have to beg for help?
- What was it like not to be understood?
- Why did people despise or fear the outsider?
- What was it like to finally get into the family or home?
- Did the outsider feel he or she could settle within the family or home after this hard beginning?
- Was there someone in the group who understood the outsider?
- Why was that person different to others in the group?

Allow 15 minutes for feedback and discussion.

It is useful to keep your own list of other useful questions and ideas that come out of different groups, as you gain experience delivering this course.

9. At the end of the discussion it is essential to 'de-role'. Ask participants to look out of the room or compound to the furthest point they can see. Tell them to fix on one point and, in their mind, throw the unpleasant and hostile feelings from the role to that faraway point. Next ask participants to bring their eyes back into the room, look around at each other then speak to two or three people near them, each person saying:

- "I am not …............. [the outsider/the unfriendly family member or resident of the home]."
- "I am …………….….... [own name]"
- "The thing I like best about myself is …………….......”

Allow five minutes for this.

10. After de-roling, encourage general discussion for five minutes. You could ask the following questions:

- What are the learning points from the exercise?
- Do you think families or existing groups, such as residents in a home, will join together in their efforts to keep outsiders out?
- Do you think more powerful family or home members will dominate weaker ones?
- Will the children be listened to?
- How would you treat an outsider?

11. Take five minutes to close the activity by bringing out the following points:

- It is not fair to expect incoming children to make all the effort to fit into a new family or home.
- The new child's feelings and emotions need to be considered.
- If a family or home does not welcome or understand a bereaved child, the child will have a hard time fitting in. She or he will probably disrupt the new household or home.
- The family or home taking in the child will need to adapt. The family or home members should be prepared to play a role in making the new child feel welcomed and valued.

- Experienced parents or carers might feel they know exactly what to do. But as guardians, foster parents or community carers they are starting again with a child who has his or her own character, opinions, needs and life experiences.
- It is important to emphasise the positive aspects of newcomers to the family or home. These might include the newcomer being a new friend for the children, bringing new skills and interests, and being able to take a share of the workload.
- It is important to think about all of these points when planning a care arrangement.

Looking at the impact of newcomers on the existing family or home

Activity 3 Looking at the impact of newcomers in the family

Suggested time: 30 minutes

Explain that the aim of this activity is to consider the impact of newcomers – adults and children – on a family, and to think about preparing both the existing children and the new child or children, for these changes.

1. Divide participants into four smaller groups. Explain that two groups will work separately on one set of questions for 10 minutes and the other two groups on another set of questions. Each group should choose someone to feed back in no more than two minutes.

Ask groups 1 and 2 to work on:

- how a child might react if a stepfather or stepmother moves in
- how we could make it easier for the children to accept him or her.

Ask groups 3 and 4 to work on:

- how a child might react in a new family, for example, a guardian's family, a foster carer's family or a children's home
- how we could make the new child feel welcome
- What existing parents or carers could do to assist this process.

2. Next, bring the groups together to share some of the ideas and main points from the small groups, allowing 10 minutes for feedback. Ask members of groups 1 and 2 to go first, then ask members of groups 3 and 4 to feed back. Invite the whole group to discuss and make sure you bring out the following points:

New partners and step-parents

- When a new partner or step-parent joins a family, the family rules and ways of doing things might need to change. It is helpful to involve children in discussion before the change. This helps prepare them before the new person arrives.
- It is helpful to explain why a new partner or step-parent is coming. Reasons might include the following: the mother or father needs adult companionship and love as well as love from their children; the new partner might bring more security for the family and extra income. It is important to explain that the new partner will not change the parent's existing love for their child.

New children

- It is natural for children to feel jealous, afraid and possessive before a new child joins the family. These feelings need to be discussed openly with parents before the new child arrives. Similarly, children in a home may feel some resentment to a new child and carers should do as much as possible to prepare them.
- In a new family all the children will compete for the parents' attention, but the new child will carry an extra burden of grief and feel the strangeness of adapting to change. In a home, where the attention that can be given to each child might be less than in a family, the existing children might become jealous of a new child who takes away some of the housemother's attention. Carers should try to reassure the existing children as much as possible while supporting the new child to settle in.

- You can encourage children to see the positive side of a new member of the family or home and try to welcome the newcomer (see Activity 1).

Allow 10 minutes for discussion.

3. Finally, remind participants that when dealing with these issues, it is good to put into practice the learning and skills the course has covered so far. The learning on communication is particularly important. Ask participants to reflect on:
   - what they have learned about listening to children
   - what adults can do to make sure that all children involved are treated fairly
   - how the incoming children can be helped to talk constructively about grief, the loss of parents and fear of an unknown future.

Close the activity by saying that counselling from a support group can help children understand and cope with loss of a parent, and with being in a new family or home.

Exploring how new adult partners can prepare for forming a new family together

Activity 4 Looking at important factors new partners should discuss as they prepare to form a new family

Suggested time: 40 minutes

Explain that this activity aims to help participants consider what issues parents might need to discuss and agree before they start living together as new partners and families. This may be particularly important to participants living with HIV. It will also increase understanding of the situations that some children experience. Ask group members to imagine themselves in these situations so that they can contribute to the activity.

1. Tell the group to divide themselves into groups of three or four. Ask each group to take 15 minutes to consider what would be important to discuss if a new partner was preparing to move in with another adult and his or her family. Inform each group that they should choose a representative to feed back two key points from their discussion.

2. Bring everyone back to the whole group and ask for feedback from each group. Give each group's representative three minutes to share their two points, then invite the whole group to discuss. Allow 15 minutes for this.

3. Summarise the main points of the discussion and make sure that the following are among the important points for new partners to discuss:
   - What they have both experienced, so there are fewer misunderstandings and secrets.
   - The implications of one or more family members living with HIV. It is important to be honest about this subject.
   - How they approach parenting, their expectations for their children, the standards they set; and methods of discipline they use. Parents will quickly become anxious or angry if they do not agree with the way their new partner relates to their children.
   - What to do if the children are rude or disobedient. Who will take charge? Can they punish each other's children? What do they need to think about in these situations?
   - Money. Who will pay for what? What if there is not enough money?
   - Relatives and other important people who spend time with the family. Do they know who will help and who might cause trouble? For example, in a situation where the mother has died, will her relatives continue to come and go as if she was still alive? Or will the deceased father's brothers continue to behave as if they are in charge of the household?
   - When and what they will tell their children about the new relationship?
   - What should children call the new partner, for example, Uncle or Dad, Auntie or Mum?

- What do you do with reminders of the person who has died, for example, wedding photographs or clothes? Remember, it is important for the children to keep alive memories of the parent they have lost.
- What could everyone do to try to make the situation less difficult?

Allow 10 minutes for the summary.

Making emotional space for newcomers in the family or home

Activity 5 Looking at ways to give bereaved children or adults space to grieve

Suggested time: 35 minutes

Explain that the aim of this activity is to consider ways to make emotional space for new parents and children, so that they can grieve in their own way.

1. Divide the group into small groups. Share the questions below among the groups, giving them two each. Give them 10 minutes to discuss their two questions. Divide the questions appropriately: for example, if the group includes community carers or participants who work in children's homes or hostels, give them questions relating to carers. Some questions may be given to more than one group.

- How can new partners make time and space to deal with their own needs and the potentially competing needs of the children? Will there be times when each parent needs to give attention to their own children?
- In a busy household, how will the two parents find time to be together? Who else could help?
- What can parents do to help their children to start bonding with a new parent? Can each parent find ways to help and praise the children of the other parent?
- How can parents or carers help children talk about their dead parent?
- How can parents or carers help children keep good memories alive?
- How can parents or carers make family or home arrangements feel safe for new children?
- How can parents or carers help the 'old' children not feel pushed out or overwhelmed by newcomers?

Ask the small groups to choose one person to be ready to feed back their main points.

2. Next, bring everyone back together. Ask each group to feed back in two minutes. Record their points on a flipchart. Allow time for discussion and questions when all the groups have presented. Give 15 minutes for this part of the activity.

3. Summarise the main points and add the following if they have not been covered:

- It is better for adults and children to be open about loss.
- Help children to feel safe and able to talk about the parent or parents they have lost.
- Don't ignore or try to get rid of memories of a parent, wife or husband – for example, by throwing away photographs.
- Talking to children about important events might not be part of family tradition, but this might be a good time to break old patterns. The children will benefit. Find ways to explain the changes to come. Involve children in discussing how they can deal with change. You could use a memory book to help the child share memories of the parent who has died (see next module).
- Remember to use the support of friends and family so you can make time to talk to each other as new partners or to talk to your children.

Allow 10 minutes for this.

Reflection

Activity 6 Reflecting on the module

Suggested time: 10 minutes

Explain that the aim of this last activity is to help participants reflect on what they have done in this module and share key learning points with each other.

1. Ask the group to work in pairs for five minutes and talk about how they found the module. Ask them to be ready to feed back the key points they have learned and what they are taking away with them.
2. Ask three or four participants to share their reflections about the module and what they have learned.
3. Draw the module to a close by reminding participants that parents cannot do everything. But if they invest time, planning, sensitivity and careful words in the early stages of new relationships, they may help to avoid long-lasting problems for the whole family.

Thank the group for their hard work. Say that you hope their learning from this module has helped them feel better prepared to plan for the future. Add that you look forward to working with them on the next module.

MODULE 9 – Trainer's notes

Please read this information carefully. You will find that some of the information has already been highlighted as key points to bring out in the summaries at the end of activities. Try to contribute additional points you feel are important from these notes to help facilitate discussion.

Many parents who attend this course are widows or widowers. Others might have been left to cope alone by former partners. Some will have already made new relationships.

When parents find new partners it raises some important issues. For example, how can a mother begin to talk to her children about her needs for companionship, love and support, particularly if the children's father has recently died? How will the children react if they feel that a new parent is interfering in their lives? New relationships are involved when families take in a new partner and/or the children of relatives or friends who have died.

There are many hopes and fears to deal with and all these situations create challenges. How will 'new' and 'old' children get on with each other? How might these relationships change over time? How will the money be stretched to meet the new family's needs? How will parents deal with the needs of bereaved children if they are tired, ill and worried about the future? New family members come with their own life experience, and resentment, jealousy and anger can easily get out of control. There will probably be more pressure on everyone.

Many of the points about the changes that bereaved children face are also relevant to community carers in children's homes or hostels, as well as parents.

Preparing for changes

Participants need to think about the different ways someone coming in might disrupt – and benefit – the family.

Emotional space

In many cases, adults will already have suffered the death of their former partner and children will have lost a parent. In general, it is better to be open about such loss and to create space for children to feel safe to deal with their loss in a more positive way. It is not helpful to ignore or try to get rid of the memories of a loved one.

Although talking with children about important events may not be part of family tradition, this might be an opportunity to break with old patterns. It is important to find ways of explaining changes to come and to involve children in discussing how to deal with these changes.

Physical space

If one partner is moving into the other partner's home, how will they feel? How will it feel for all the different children involved?

Participants should consider any of the following questions that are appropriate in their context:

- Are there wedding photos in the house?
- Do the father's clothes still hang in the cupboard?
- Do the mother's relatives come and go as if she were still there?
- Do the father's brothers behave as if they are in charge of the household?
- Would people still use their old married name after the new marriage?

Participants should also consider the practical steps they could take to make newcomers feel welcome. The following questions may help:

- Could the children choose some of the family photos for their memory books?
- Could important pictures or possessions be moved to places where they are easy to see, if the children approve?
- Is there someone who would be glad to have, for example, the late husband's clothes? Would the children like to choose something to keep, which will help them remember their father or mother?
- If there is space, can things be moved around so that the new partner will not move into the old bedroom or the same bed?
- Can all the children help to decide where they will sleep and where their belongings will be kept?
- Is there space for 'new' children to put out some of their photos and special possessions?
- Everyone has to be prepared to make changes. Children will adapt better if they are given a chance to question and offer their own ideas about practical arrangements.

New children in the family

(These notes can be adapted and integrated into the module activities to be relevant to parents and carers alike.)

Children need emotional and physical space. They need to understand how the family works and the new carer needs to explain family rules to them. They need to feel safe, wanted and welcome.

It is not fair to expect incoming children to make all the changes to fit in with their new family. Their feelings, ideas and emotions need to be considered. Their possessions and skills need to find a place in their new home. The family taking the children in will also need to change.

Experienced parents might feel they 'know it all', but as birth parents to their own children they had time to grow into a parenting role. As guardians or foster parents they are starting again, with children who already have their own characters, opinions, habits, needs and life experiences. It is not possible, or reasonable, to expect any child to quickly accept major changes and to adapt easily into a new family – especially if the child has been through extreme shock and loss.

If a family does not try to welcome or understand bereaved children, the children will have a much harder time, and will probably disrupt the new household. It is important for every member of the household to know that they have a role to play in helping the new child or children to feel safe and welcome. This means that families need to prepare themselves. Parents need to involve existing children in working out how to help new children feel both welcome and valued. The positive aspects of newcomers in the family should be emphasised – for example the new child could offer new friendship for the children, bring new skills and interests to the household, and share the family workload.

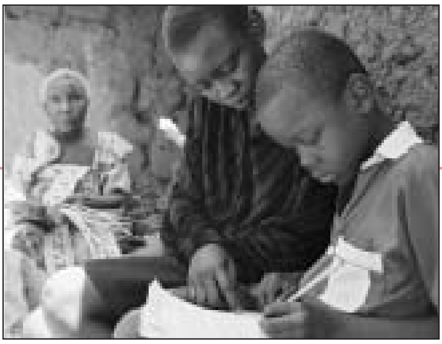
Relationships between children

(These notes can be adapted and integrated into the module activities to be relevant to parents and carers alike.)

Parents should expect to see jealousy, fear and possessiveness when children from the outside join an existing family. Both sets of children will compete for parental attention, but the new children carry an extra burden of grief, separation and change.

Parents cannot do everything. But an investment of time, planning, sensitivity and careful words in the early stages may help to avoid long-lasting problems for the whole family.

MODULE 10



Making a memory book

Trainer's introduction

This module introduces the idea of a memory book and provides guidelines on how to make one. We have suggested you split the module into two sessions to avoid rushing. The first session covers the purpose and possible content of a memory book. The second shows how to start planning and making one. The module is useful to parents living with HIV who want to make their own memory book, and is highly relevant to future guardians, community workers and carers who can provide support and guidance to help others create a lasting record for their children.

Approximate length of module: 2 hours 10 minutes (Part 1) plus 3 hours 50 minutes (Part 2)

Aims

Both parts of this module aim to:

- provide an understanding of the purpose of a memory book
- explore where to get support to make a memory book
- think about what a memory book might contain
- help participants start planning a memory book
- help participants start writing a memory book

Key learning outcomes

By the end of this module participants will:

- have improved their understanding of the purpose of a memory book
- recognise a memory book as part of a range of memory work activities that combine to meet children's needs
- recognise the importance of open and appropriate communication within families to prepare for the future
- have explored possible sources of support
- have an increased understanding of the value of recording histories and experiences, and of recording important information in a child-friendly way
- know how to plan and make a memory book

Trainer's preparation

Module plan (with suggested times)

Part 1

- Understanding the purpose and context of a memory book – **30 minutes**
- Thinking about starting a memory book and sources of support – **30 minutes**
- Thinking about what parents and children might want to include in a memory book – **1 hour to 1 hour 10 minutes**

Part 2

- Watching and discussing the video *A River of Hope* – **1 hour 30 minutes**
- Helping participants to start planning their memory books – **30 minutes**
- Helping participants to start writing their memory books – **1 hour 40 minutes**
- Reflection – **10 minutes**

Materials you will need

Copies of the *Memory Book for Africa* (see Appendix 1: Key course materials, page 123)
Four sets of sample pages of completed memory books and magazines, if available
Examples of different books and files that can be used to make a memory book
Video: *A River of Hope* (see Appendix 1: Key course materials, page 123)
One mango tree outline for each participant (page 124). Enough copies of family trees and maps to allow one for each child of each participant (page 125-6).
Overhead/flipchart 1: Outline of Part 1, Module 10
Overhead/flipchart 2: Preparing yourself to start a memory book
Overhead/flipchart 3: Outline of Part 2, Module 10
Overhead/flipchart 4: Sources of help and information

Trainer's notes

Please make sure you read the trainer's notes at the end of this module (page 101). They give you useful background on making memory books.

Trainer's guidance

Before you start this module please be aware that participants may become sad and emotional at times. Give them space to observe without speaking and to participate when they are ready.

Part 1

Introduction

Start the module by explaining to participants that it will be split into two parts. The first part looks at the purpose and importance of a memory book and how it fits into memory work. It explores what a memory book might contain. In the second part, participants will plan and start making their memory books.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Part 1, Module 10
Please use the list in the Module plan on page 89, but without the suggested times.

Remind the group of the group agreement at the start of the course. Say that the module is likely to contain confidential information and that all participants have agreed not to share outside the group what they hear about others on the course.

Understanding the purpose and context of a memory book

Activity 1 Trainer's presentation on memory books

Suggested time: 30 minutes

Please use the trainer's notes (page 101) and the *Memory Book for Africa* to plan this presentation. As you talk to the group, explain about memory books as if it is the first time they have heard about it. This will help you include all the important points and avoid making assumptions about what participants might already know.

Explain that the aim of this activity is to introduce the idea of a memory book and see how it fits into what participants have learned about memory work so far.

You can use the following presentation as a framework. Add extra information from the trainer's notes (page 101), or from your own knowledge of the local area.

Presentation

An introduction to memory books

All participants know that one of the outcomes of the course is to learn how to make a memory book. It is easy to think the memory book is the main purpose of the course. But everything we have learned together in all the other modules about disclosing HIV status, understanding and communicating with children, and planning for the future, is just as important. The memory book is one part of a whole package.

What is a memory book and why make one?

A memory book is a written record of:

- historical facts about the family
- parents' beliefs and traditions
- parents' hopes for their children's future
- warm memories and messages for the children.

If parents die when children are young, important memories fade away. Children risk growing up without understanding who they are. A memory book provides a way to help parents, family and friends save vital information for the children as they grow up. A memory book cannot protect children from loss and separation, but it can help them understand the past, know that the parent(s) they have lost loved them, and be stronger to face the future. it will give them a sense of belonging.

Also, making a memory book helps parents think about their whole life, including the happy times. The children see that there is more to their family life than HIV and AIDS. Children can also write their own memory books which may be important, for example, for a child who has been orphaned.

There are different ways of making a memory book, which we will look at in Part 2. NACWOLA uses a ready-made book that people can fill in. Other groups have made books from recycled materials (see page 99).

The history of the memory book

Memory books for people affected by HIV and AIDS were first made in England in 1993 by African parents who thought they would die while their children were young. The children were growing up in a foreign country and they risked losing contact with their origins. These parents left their children a legacy of wise words, precious memories and standards to live by.

Since then memory books have been made by many more people. The idea is relevant to people of different cultures and backgrounds. People who cannot write can be helped to make a memory book. In Africa, NACWOLA in Uganda has led the way in spreading the idea of the memory book.

What to include in a memory book

Every memory book is different. Each person includes what he or she thinks his or her children should know. But it is important to remember that the focus is not on death and sadness. The aim is to help children understand who they are, and to give them information to make the best of the future.

Memory books may include:

- information about both parents and the early life of each child – experience shows these are the most important pages in a memory book
- parents' beliefs, ideals and hopes for their children's future

Cont. next page

- traditions and special events of your family and clan
- memories of happy times and jokes
- words of favourite songs, hymns or poems
- knowledge about cooking, cultivation or caring for animals
- details of how to contact close relatives and friends
- a family tree and maps marking important places to the family.

Where to get support to start making a memory book

Anyone who has known the child, the family or the home area might be able to provide stories, information and memories. Others might be able to give practical advice and support and be willing to act as carers, legal guardians or befrienders. All these people can be recorded in the memory book, to inform the children and to provide support while making the book.

If one parent has already died, it is important to collect information about them to put in the memory book.

People who can help with memories and information about a partner include:

- friends from school, work or the community
- religious or community leaders
- health workers, youth club and activity leaders
- family and clan members.

Sources of personal support include:

- self-help groups or HIV and AIDS support groups
- professionals such as health workers, social workers and counsellors
- local religious groups.

Sources of help for planning for the future care of children include:

- self-help groups
- health professionals, social workers and counsellors
- religious and community leaders
- lawyers
- local organisations that work with children
- family and community elders
- PLHA support network for children who are HIV-positive.

Sources of help for older children who live alone

Appoint a legal guardian or befriender. These might include:

- neighbours or parents of school friends
- relatives or friends
- community elders, leaders or other respected community members.

Sometimes older children become reponsible for younger brothers and sisters as well as themselves. These young people need extra support from neighbours, friends, relatives and the community. The children heading households may also find that if their parents have not written a memory book, they need help to write one for themselves and their brothers and sisters. These young people carry a lot of responsibility, and need sensitive practical and emotional support.

Here you could read out the words of two children heading households alone:

> "Our training at NACWOLA has changed the way I treat my younger sister. Before, I used to make her work hard all the time. Now I understand why she gets angry or upset. She needs time to play with her friends." Teenage girl living alone with her younger sister in Uganda.
>
> "I have hope for the future, because NACWOLA is building my capacity for the future to enable me to help my siblings. I have hope that NACWOLA will give me the parental love that I have missed and protect me from apathy in the community." Boy heading household in Uganda.

Next, you could read the following words of a community worker who received memory book training and went on to support others:

> "After receiving training in memory book writing, I trained women in the community to write memory books. A 30-year-old lawyer returned to Uganda from overseas. I suspected the man had HIV. I approached him and explained the importance of writing a memory book and a will with him. The man wrote the memory book and the will before he died. After his death, the memory book and will were retrieved and this avoided inheritance problems." COBAP community worker, Uganda

Continue the presentation by showing the group different examples of memory books that others have made. If this is not possible make sure you can show the example of the memory book you have made yourself (see the guidelines in the trainer's notes on page 103). Allow 10 minutes for participants to look at memory books.

Also introduce the idea of a memory basket or box. Explain that this is a container that holds special objects to keep memories alive and remind children of daily life. The objects are not usually worth much money, but have sentimental value. They could include small domestic objects, favourite books, photographs and other small possessions that belonged to family members. If it is possible to include a tape recording of the parent's voice or perhaps the parent and child together, this can be a very precious possession.

Close the presentation by saying that the module will enable participants to explore these ideas and issues in greater depth. Each participant will be able to relate these issues to how they want to plan, and what they would want to include in, a memory book.

End this part of the module by emphasising that a memory book is just one part of the memory work process. The aim of memory work as a whole is to:

- open communication in the family
- make plans for the future
- build each child's sense of identity and self-worth
- help children think to the difficult future and prepare them to cope in the best way
- make sure children have important information about their family and background
- make sure children know who they can trust.

Thinking about starting a memory book and sources of support

Activity 2 Preparing to start a memory book

Suggested time: 30 minutes

Explain that the aim of this activity is to help participants think about whether they are ready to begin work on a memory book, and where they might get support. Ask participants who are not living with HIV to try put themselves in the place of a parent planning a memory book for their children.

1. Ask the participants to work in small groups of four or five people and to consider the following questions for 10 minutes. Ask them to be ready to volunteer feedback.

Overhead/flipchart 2: Preparing to start a memory book

- How will you feel about creating a memory book?
- When should you start working on your memory book?
- What can you do with difficult or sensitive information?
- Who can you ask for support?

2. Next ask for each group to report back the main points of their discussions in five minutes. Summarise these points. Be sensitive if any participants are upset. Make sure you cover the following points:

- Remind the group that it is important to make memory books while the training is fresh in their minds. Say that it is also important to be able to support their children emotionally while making the books.
- There are no rules about when children can be trusted with family secrets. Each family and child is different. It might be better to think about how each child might react to difficult or sensitive information.
- Often children react well when they are trusted with the truth about problems in the family. But if you disclose information that has a negative effect and, for example, children become distressed or react against new responsibilities, be prepared to organise support for yourself and the child. This might be through counselling provided by an HIV and AIDS support group or a community or religious organisation, or just having a valued friend who can listen to you both.
- Remind the group of sources of support you covered in the presentation. At this point you can add other ideas from the trainer's notes (page 101) or from your own knowledge of the local area.

Thinking about what parents and children might want to include in a memory book

Activity 3 What would you want to put in a memory book about yourself?

Suggested time: 30-40 minutes

Explain that the aim of this activity is to give participants a chance to think about the kind of information and memories they want to give their children about themselves. Say that parents can change their minds and put different things in their books from what they say in this activity. This is just to give them a start. Ask participants who are not living with HIV to try to put themselves in the place of a parent planning a memory book for their children.

1. Ask participants to think individually about what they would like to include in a memory book about themselves. If participants can write, ask them to make some notes. You could put people who cannot write in pairs or small groups with others who can. Write down the ideas on separate pieces of paper for each person in the group.

Give participants 10 minutes to do this by themselves, or 20 minutes if they are working in pairs or small groups.

2. Next, bring everyone back to the whole group. Allow 10 minutes to discuss how participants found the experience of thinking about things to go in the memory book:

- What difficulties did they experience?
- Can they imagine themselves working on this at home?
- Who would they want to share making a memory book with, if anyone?

3. Summarise the main points and bring out the following:

- If participants cannot write, they could ask for the help of a trusted friend or relative. Or they could go to an HIV and AIDS support group to ask for help.

- If they want to share the experience of making the book, children can find this very positive. It could be an experience they will remember and value in later life. Many parents think: "Why am I just writing this down? Why don't I talk to my children about this as well?" Many children become curious and actively involved in making the memory book. This gives them the chance to talk about the content of the book and other, often sensitive, topics. Children's questions can lead to more open discussions about family situations.

Allow 10 minutes for this.

Activity 4 Thinking about receiving information as a child

Suggested time: 30 minutes

Explain that the aim of this activity is to help participants reflect on their past and their upbringing. This will help each person to think about how they were treated as a child and how important information was passed on to them. This will guide them to consider what information children might want and how to pass it on in a positive way.

1. In the whole group, ask participants to think for two minutes about how their family life was organised and how they learned important information when they were children.

2. Ask participants to brainstorm for five minutes the following questions:
   - How did you learn about family history, rules and traditions?
   - Who was in charge of different aspects of family life?

Record the ideas on a flipchart.

3. Next, divide participants into groups of five or six people. Ask them to think about their family life today and discuss the following question:
   - How and why have things changed from your own childhood days and experiences?

Allow five minutes for this.

4. Ask the groups to continue the discussion for another five minutes to consider:
   - How can you help children to know who they are, where they belong and who they can trust in the future?

5. After five minutes ask for the groups to volunteer feedback. Record the key points on the flipchart. Summarise the discussion and bring out the following points:
   - Making a memory book encourages parents to think about the information children need and want for the future.
   - Making the memory book together with children means the book will contain what they want as well as what you want.

Allow 10 minutes for this.

Bring the first part of the module to a close. Say that in the second part participants will start to plan and make their own memory books. Remind participants to bring something that feels emotionally precious to them to the next session.

Part 2 – Making memory books

Introduction

Please note the first activity in this part of the module involves playing a video. You will also need to discuss the video following guidance provided in the booklet that goes with it. You will therefore need to obtain the video and booklet, and organise the video player and TV. You will need to watch the video and familiarise yourself with the booklet before the session.

Because you will be training others to make memory books, it is important to practice making one for yourself. This experience will give you confidence and may enable you to give practical tips to participants.

Start Part 2 by explaining that it carries on directly from Part 1. In this session the group will learn how to plan and start a memory book. It is useful to repeat how this module is relevant to parents living with HIV and carers alike as stated in the introduction to Part 1.

Go through the topics to be covered in this part of the module and how it is structured.

Overhead/flipchart 3: Outline of Part 2, Module 10
Please use the list in the module plan on page 89, but without the suggested times.

Before you start the activities, remind the participants about the group agreement and confidentiality.

Watching and discussing the video *A River of Hope*

Activity 5 Video – *A River of Hope*

Suggested time: 1 hour 30 minutes hours for video and discussion

Participants may become upset during this video. Be prepared for some members of the group to stay quiet during the discussion.

Explain that the aim of this activity is to give insight into a number of issues, such as talking to children about memory books, how they can benefit from having one, and seeing children as carers.

1. Show the video (44 minutes).
2. Discuss the video using the guidance in the booklet that goes with the video. Allow approximately 45 minutes for discussion.

Helping participants to start planning their memory books

Activity 6 Planning a memory book

Suggested time: 30 minutes

Explain that the aim of this activity is to help participants think about who holds information that is appropriate for their memory book, and who might support them to make the book and prepare for the future. Ask them to think back to the presentation in Part 1 of the module for ideas. Be prepared to remind the group of the key points. Remind those participants who are not living with HIV to try to put themselves in the place of a parent planning a memory book for a child.

1. Give a copy of the mango tree outline to each participant (see Appendix 1, page 124). Explain that the purpose of the exercise is to think about people or organisations in the community, not just family members, who can help. Ask the group to think about how different people can help with the different pieces of work they need to do for the children. By the end of the exercise, participants should have filled in the leaves of the tree with names of people or organisations that could provide information or support them in a particular way, either to write the book or prepare for the future.
2. Ask the participants to form small groups. Say that the groups will be sharing personal information, so they need to feel comfortable with the other people in their group. Make sure at least one person in each group can write. If some people prefer to work on their own or in pairs, that's fine.
3. Ask participants to think as widely as possible about one or more of the following questions. Say they need not name names, but to think of the kinds of organisations or people that may help. Ask them to start filling in leaves on their mango tree when they have

thought carefully about the questions. Tell them they have 20 minutes to fill in some leaves. Allow five minutes for this introduction and to go through the overhead/flipchart below.

Overhead/flipchart 4: Sources of help and information

- Who has knowledge of the family history? For example, who has memories of a parent who has already passed away, or stories about individual children that can go into the memory book?
- Who can parents rely on for personal support while creating a memory book?
- Who can help parents work out safe plans for their children?
- Who could be asked to act as guardian or to befriend older children when parents have passed away?

As the groups work, go round and look at participants' ideas. Be ready to help people think and make suggestions of useful organisations if anyone is having difficulties.

4. Ask participants to try identify someone, or think how to find someone, who could be their main helper in making a memory book. Allow five minutes for this.

5. Bring the activity to a close by saying that the mango tree does not have to be full. Also, parents do not have to follow up all the ideas they have put down. This activity is just to get people thinking about sources of support beyond the immediate family circle and to learn from other people's ideas. Be ready to share good ideas about organisations from participants' mango trees. Do not mention any person's name, only organisations. Do not break confidentiality. Allow five minutes for summing up.

Helping participants to start writing their memory books

Activity 7 Starting to write a memory book

Suggested time: 1 hour 40 minutes

Please read *Memory Book for Africa* thoroughly before this activity and the trainer's notes (page 101). They will give you lots of ideas and information to guide participants.

Explain that the aim of this activity is to help participants begin to write their books and start tackling some complicated topics in a supportive environment. Remind those participants not living with HIV to try to put themselves in the place of a parent starting to write a memory book for a child.

1. Allow 20 minutes for the following introduction. Start by again showing participants the memory book you prepared and any other examples of memory books you have borrowed. This will give the group ideas for their own memory books. The sort of topics to cover include those in the presentation you gave in Activity 1 (page 91) – be ready to remind the group of these. Suggestions for content that other families have found very useful include:

- a title for the book
- who the book belongs to
- full names of the writer
- the story of the family
- facts about family members
- the family home
- the birth of the child/children
- how they got their name
- when they were a baby
- the first time they...
- their school days and growing up
- their interests and activities
- parent's favourite memories of them
- hopes for the child's future
- childhood
- growing up and adult life
- interests and activities
- likes and dislikes
- special memories
- beliefs and thoughts on life
- health
- life today
- names and addresses of people important to the family, for example, banker, lawyer, minister or trusted friend
- dates and information about other important events and people

Cont. next page

- important people in the child's life
- information about the child's health
- mother and/or father
- certificates, bank books, property deeds or a will
- any special memories or messages for the child.

It is important here to say the memory book (or box/basket) should not be used to store legal documents, because the books are for children. It is also vital to say that the memory book is not a legal document, and therefore a will should be made separately. The next module covers making a will. Also, remind participants of the following:

- Often parents do not have photographs of their children. A way to overcome this is to use photographs of babies and children from magazines. Parents should not pretend that the picture is of their own child. They can write something like: "This picture reminds me of you as a baby" or "This is how you looked the first day you went to school."
- By using photographs, pictures from magazines or drawings as well as writing, parents can make the book look more attractive and encourage the child to read it. Pictures can also be used to depict a story.
- Parents who cannot write easily can ask for help from a friend, relative (perhaps their own children) or community worker.
- It is best to write a memory book as if you are talking to the child, using 'I' and 'you'. For example "I remember when you..." This makes the book feel more personal for the child.

Finally, tell the group there is no right or wrong way to write a memory book. The parents decide the content and you as the trainer are offering ideas to start people off. Each parent should choose to include what feels right for them and their child.

2. Next, say it is time to start working on the memory books. Ask participants to divide themselves into the same small groups as the previous activity, where they should feel comfortable talking about personal information.

3. Ask each group to choose one of the easy topics, such as: 'Where I grew up' or 'My school days'. Tell participants that there is no fixed order in writing a memory book. It is like a jigsaw. If you like, you can start with the easy pieces first. Ask the groups to talk about what they want to say first and then to start writing down their ideas. Remind participants that they are practising producing a memory book. They are learning by doing. They are not expected to produce a perfect page for a memory book. Ask them to work in groups for about 30 minutes.

4. Bring everyone back to the whole group to discuss:

- how it feels so far
- whether it is better to make one memory book for the whole family to share, or a book for each child
- the problems and benefits of both the above options.

Allow 10 minutes for discussion.

4. Next, share the following advice from parents who have made memory books:

- First write the general pages about family history, clan, your experiences of growing up and family trees. If possible, photocopy these for each child.
- Next, write pages for each child about their birth and early development, likes and dislikes, experiences growing up, and special messages and hopes from the parent.
- Then write a summary about brothers and sisters. Be clear about parentage if they have different fathers. Make a copy of the summary for each child's book.

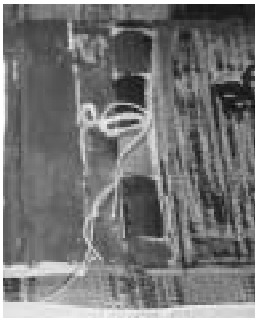
Finally, say that these are suggestions from people who have faced similar issues. Participants do not have to do it this way, if they have their own clear idea of how they want to tackle making a memory book. Allow five minutes for this discussion.

5. Next, ask the group to go back to the same small groups. This time ask them to discuss one of the more complicated topics before writing something down. Give them 15 minutes.

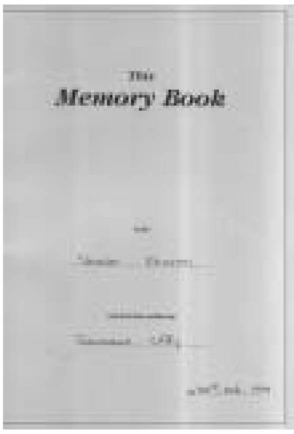
6. Next, ask the groups to discuss the following questions. Give them 20 minutes:
    - Should we be talking to our children about the sort of information we have been writing down?
    - How much do they already know about these things?
    - Does the age of children matter?
    - How can we explain the memory book ideas to our children?
    - How might the children themselves contribute to the memory book?
    - Is this a good way to encourage discussion about the family situation?
7. Ask for feedback from each group. Record the main points on a flipchart. Make sure the following points are highlighted:
    - Difficult or sensitive information, such as details about the cause of death of a parent or break up of a marriage, need not be included in the memory book. One solution is to put a short note in the memory book and leave a letter with a trusted friend until the children are old enough to read it. Make a note in the book about who holds the letter.
    - Ask participants to think back to the Module 4 to help them plan how they will explain the idea of the memory book and what it contains.
    - Many parents say it helps open discussion and understanding if children know that parents are making a memory book and can join in. Allow 10 minutes for discussion.
8. Finally, remind the group that the memory book cannot be written in a day. Parents should not delay the task, but start as soon as possible – before they begin having health problems and while the training is still fresh in their minds. Say also that some people find writing difficult and people might be struggling with illness or painful emotions. These people could ask a friend or older child to help by jotting down what they say.

9. You can pass on ideas from people who have made low-cost memory books. These tips include using pieces of stiff cardboard, cut to the size needed for covers. These can be painted or covered with pictures from magazines to make them attractive. The inside pages can be made from recycled paper. If photographs are not available, pictures can be cut from magazines or newspapers or the parent can draw pictures of the home, family members or simple maps. A thread of string or thick colourful twine can be used through the holes to bind pages and covers, and tie it all tidily together. Participants who are not parents themselves can use this information to support other parents to produce memory books.

Low-cost memory books



Binding of a low-cost memory book



NACWOLA memory book

10. Finally, close the activity by thanking the group for their hard work. Say you hope they have plenty of ideas and feel confident about making a memory book.

Reflection

Activity 8 Closing the session on memory books

Suggested time: 10 minutes

1. Ask participants to talk to a partner about:
    - how to make good use of the people named on the mango tree
    - how to make time and space to carry on with individual memory books
    - how and where to keep their memory books.

Allow five minutes for this.

2. End the module by asking whether anyone would like to share their thoughts with the group. Allow five minutes for this.

Close the module by thanking the participants for their contribution to the day. Say it has been hard work, but you hope they feel prepared to work on their own memory books away from the course. Emphasise that memory books need to be made while parents (or guardians) still have some strength, and can support the children emotionally. Encourage them to get started as soon as possible.

Wish the participants good luck. Say that you look forward to working with them in the next module.

MODULE 10 – Trainer's notes

Please be aware that many parents living with HIV may have high expectations of a memory book as they start the training course. However, a memory book will never be the solution to people's problems. It is a tool to help parents start some important work for the futures of their children. Remember also that the memory book is one part of a whole package.

Encourage parents to look outside the family for support from people in the community, professionals and organisations: they should not feel defeated if there is no relative or neighbour to support them. Add your own ideas to those below, including details about local self-help and other support organisations.

Preparation

- Read the *Memory Book for Africa* carefully so you feel confident to talk about it and answer questions.
- A good guideline to follow as a trainer is to be able to do yourself what you ask participants to do. So, practise writing a memory book for yourself. This will remind you of the pain and pleasure of remembering the past, the difficulty of finding the right words to describe sensitive facts and what to do when you lack accurate information. You do not have to show your personal details to anyone else. This activity is to help you tune into the feelings of people who are being asked to share personal information.
- Before the course, make an example memory book to show participants. This book should be about an imaginary person. You can include drawings or pictures from magazines rather than photographs of people who might be identified. This takes time and thought, but your efforts will be rewarded.

Possible sources of support for families

1. Anyone who has known the child, the family or the home area might have stories, information and memories for the memory book. If one parent has already died, it is important to collect information about him or her.

People who might be appropriate to ask for support include:

- school teachers
- school friends
- parents of school friends
- religious leaders
- members of a religious congregation
- youth club or activity leaders
- sports group leaders and colleagues
- health workers
- community leaders
- employers
- friends from work
- neighbours
- brothers and sisters
- distant relatives
- older members of the community
- clan members.

2. Sources of personal support include:

- a local self-help or HIV and AIDS support group like NACWOLA
- religious leaders or members of a familiar congregation
- local non-governmental organisations

- professionals – for example, health workers, social workers or counsellors, who may provide support directly or advice about where to get support
- older, respected members of the community.

3. Others who could help make plans for the future care of children include:
   - members of self-help or other HIV and AIDS support groups like NACWOLA
   - PLHA groups that provide support and advice for children living with HIV
   - health professionals, social workers, counsellors
   - religious or community leaders
   - lawyers, especially local and/or women's legal services
   - non-governmental organisations that work with children – some of these have school fee schemes, for example
   - family elders and senior members of the village.

4. Legal guardians or befrienders for older children who live alone include:
   - neighbours or former neighbours who already know the children
   - parents of school friends
   - relatives or friends, even if they live somewhere else
   - community elders, leaders of support groups or other respected local people who may be willing to oversee older children who live alone.

Benefits of a memory book

- It helps parents think about their whole life, including the happy times and not just present difficulties.
- It helps children see that there is more to their family life than HIV and AIDS.
- Parents begin to think about all the important information children might need or want. The memory book gives them an easy way to start writing it down.
- Communication between children and parents becomes more open and richer. When parents start thinking about memory books, they ask themselves: "Why am I just writing this down? Why don't I talk about this with my children?"
- Many children become curious about, and actively involved with their memory book. They are interested to see parents writing and collecting photos and information. This gives parents the chance to address different, often sensitive topics with them. Children's questions often lead to more open discussion about family situations.
- Children can support parents who have difficulty writing by collecting information and/or writing down a parent's words. In this way a memory book can become a family project.
- Filling in family trees and asking children to name people who are important to the family is a way of checking that children understand the family ties and community networks. This means that they will know which people could help them in the future.
- Many parents are thankful to have a place to write down their hopes for their children's futures. The memory book gives them a way to express these or carry them forward.
- The memory book sections that cover family beliefs and traditions give parents an opening to talk or write about subjects they might have left unsaid.
- The family becomes better informed about their current situation, sources of support and options for the future.
- The family becomes more informed about HIV and AIDS, and its implications.
- Firm plans can be made for uncertain futures. For example, parents can arrange guardians and how to legally deal with property and assets. This ensures improved care and better protection of children. This often increases confidence and makes everyone feel better at a difficult time.
- The more open people are, the more they are able to access support and reduce

their isolation.
- Making a memory book usually has a therapeutic effect. Making the book together is rewarding, because everyone can be involved and they can see the outcome.
- Everyone is better prepared for changes to come.

Challenges to consider and be ready to handle

- There may be secret and sensitive family information parents do not know how to explain. For example, children in the same family might have different fathers.
- Explaining the illness and death of another parent, or talking about a parent's own illness, will probably bring out powerful emotions that seem overwhelming to begin with. These might include distress, anger and fear.
- Parents with many children may not have the resources or time to produce a book for each child.
- If there are no photos and little information available about the past, parents can feel inadequate.
- Most parents are keen to start, but it can be difficult to keep working on the memory book without support. How can you help people to achieve their plans? Could an informal parent support group be formed by participants? What other sources of support are there?
- What can you suggest to support parents who cannot read or write, both during and after the course? How can you make sure these parents do not feel inadequate?
- Many parents want to know when children are old enough to be entrusted with family secrets. You must be ready to say that every child and situation is different; there are no rules about this. Try to help parents imagine the effect of giving information to particular people. For example, what effect would revealing their HIV status have upon different children and how does this influence how they would communicate it?
- What support can be given to parents who are worried about the negative outcomes that being open may bring?
- How can you prepare parents to support children who might become very distressed and frightened, or those who react against taking on new responsibilities? Note that many parents report that their children react well when they are trusted with the truth about problems in the family.
- What can you suggest to parents who have no one to name as guardians or supporters for their children? How are they going to deal with this, both in the memory book and in discussions with their children?
- Be prepared to help participants deal with disappointment that the memory book is not a magic solution.
- Think about what you can suggest to parents who cannot afford the material to make a memory book.

Making the memory book

- Remind the parents and other carers on the course that the memory book is a practical tool to guide thinking and planning for the future.
- Remind participants about confidentiality and group rules. What they hear on the course is personal and private. It should never be repeated outside the room. This is true of all the training, but the memory book sessions are particularly sensitive.
- When participants need to talk about things that are usually kept private within the family, make sure they are in a small group where they feel comfortable to talk openly. This applies both to the parents themselves and the carers on the course, who you will ask to try put themselves in the place of parents living with HIV.
- Sometimes people go into details that they might regret afterwards. Be ready to help them stop if you think they are going too far.
- Provide some local magazines or newspapers with pictures of babies and children

that can be used by parents who have no photos.
- If you are aware of participants who have difficulty writing, try to find trustworthy volunteers to help with these sessions. It is important that at the end of the module, everyone has something written down. At least make sure every group includes some individuals who can write.
- When it is time to begin writing, start with a relatively easy, descriptive heading, for example, 'Where I grew up' or 'My schooldays'. More emotional and complex topics can follow when people feel more confident.
- In the training session there will only be time to write a few lines about a few topics.

Memory basket or box

Encourage participants, as they make their memory books, to collect small domestic objects, favourite books, photos and other small possessions that belonged to family members. These are not usually valuable in monetary terms, but are everyday items that help to keep memories alive and remind children of daily family life. They can put these things in a memory basket or box for their children's futures. In Uganda some parents use specially woven baskets and others decorate tin trunks in which to store their family treasures.

Follow-up

If possible, organise a follow-up session to check on progress and give support. Give people a date to work towards for their memory books and action plans. Remember that in reality most parents will be working alone after the workshop. It is important to guide them to make realistic plans about how, when and where they will carry on their memory work.

MODULE 11

Legal guardianship and making a will

Trainer's introduction

This module aims to increase participants' awareness of their legal rights and responsibilities. It provides information on how the law can help parents legally protect their children and make sure the children are provided for after they are gone. This is an important module for all participants. It gives parents living with HIV information that will help them know their rights and plan for their children's futures. It also helps carers to know the parents', guardians' and childrens' rights and to support others.

Because of differences in national and customary laws, it is not possible to provide a generic guide that will fit the circumstances of every country. However, this module can be used as a starting point for exploring some of the issues with participants and raising awareness among them of the importance of understanding their rights and making a will.

We strongly encourage you to identify a local expert to help you run this session (see Trainer's guidance, page 106). This person should have a good understanding of international and national law relating to making wills, property rights, marriage rights, women's rights, parents' and guardians' rights and responsibilities, and children's rights for the country in which you are working.

Length of module: 5 hours, including video

(This can be shorter if you show only selected parts of the video rather than the whole film.)

Aims

The aims of this module are to:

- make participants aware of the importance of understanding parents' and guardians' rights in law and the responsibilities that go with them, and children's rights
- increase participants' understanding of parents', guardians' and childrens' rights in the law
- increase participants' awareness of local services that can help in legal matters.

Key learning outcomes

By the end of this session participants will:

- be aware of the importance of understanding legal rights and have an understanding of relevant laws and the legal rights of parents, children and guardians
- understand the importance of making a will, and have a basic understanding of how to prepare to make one
- be better informed about the legal services and information services that are available locally, and how to use them.

Trainer's preparation

Module plan (with suggested times)

- Introducing the topic – **5 minutes**
- Legal rights and responsibilities **– 3 hours 30 minutes (whole video)**
- Making a will – **45 minutes**
- Where to go for information and support **– 30 minutes**
- Reflection **– 15 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 11
Handout 1: A local alternative (appropriate to your region) to the *Guide to legal information for parents living with HIV/AIDS in Uganda* (see Appendix 1: Key course materials, page 123). This should be provided or prepared by the legal resource person and is not included in this manual.
Handout 2: Will form, drawn up by the legal resource person and trainer
Handout 3: Local sources of information and support, drawn up by the legal resource person and trainer
Video: *Neria* (see Appendix 1: Key course materials, page 123)
TV and video player

Trainer's guidance

Introduction

It is very important to read the trainer's notes for this module (page 114). These suggest background reading to help you prepare.

Before the module starts, you are strongly encouraged to identify a legal resource person. We recommend you work with a support person from your country's branch of FIDA (the International Federation of Woman's Lawyers). FIDA teaches women their rights and obligations under the law through attorney volunteers, and translates laws from complicated legal terms into everyday language and then into local languages. FIDA also trains community-level paralegals.

If there is no FIDA representative available, try to find a legal person who has experience working with community groups, non-governmental organisations, or government institutions such as the police or social services. They should also understand the aims of the course and feel positive about taking part.

You will need to brief the outside speaker carefully about his or her role and responsibilities, the background of the participants, and the aims and key activities within the module. If you intend to use legal documents as resource materials, you will need to work with this person before the session to simplify these documents and if possible translate them into the local language, use everyday terms, and address any particular needs of participants might have.

Introducing the topic

At the beginning of the module, introduce the legal expert to the group. Then explain that this module is important, because information from many countries shows that often people, particularly women, are not aware of their legal rights. Many people do not make a will and so it is unclear in law who the deceased person intended to leave their money, land and property to, or who they would have appointed to look after their children. This situation arises, firstly, because there is often a spoken (oral) rather than written tradition of stating last wishes. When the information is not legally recorded, this system is sometimes abused and people and children lose what is rightfully theirs. Secondly, sometimes people are confused about how to sort out traditional ways of dealing with these issues from their legal rights. And thirdly, many people do not make a will because they are not aware of the legal protection it gives, or it seems too complicated a process and they do not know how to get help to make one.

Say this session will help all participants to learn about their rights and how to find help to make a will, to protect the futures of their children. Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 11
Please use the list in the module plan on page 106, but without the suggested times.

Legal rights and responsibilities

Activity 1 Looking at the issues, using the video *Neria*

Suggested time: 2 hours 30 minutes (less if you do not show all of the video)

We have provided an outline of the story in the *Neria* video to help you prepare for this session. If you have access to the internet you could go to www.mfdi.org (Media for Development website) for additional information.

Video outline
Patrick and Neria are a married couple in Zimbabwe who have worked hard together to build a comfortable home and life with their son and daughter in the city. Their loving partnership ends suddenly with the death of Patrick in a road accident. Patrick did not leave a will and Neria's life is turned upside down, as Patrick's brother Phineas takes their car, bank book, furniture and house. Phineas, using tradition to suit his needs, leaves his brother's family high and dry. At first Neria watches helplessly. But when Phineas takes her children, Neria takes action. Her friend encourages her to seek legal help and Neria learns that law and tradition can both be on her side, as she fights for her rights in the community court.

You will need to watch the video before the module. As it is quite long, decide beforehand whether you want to show all or only parts of the film, which runs for 103 minutes in total. If you choose to run selected parts there will be more time for discussion points.

Before the session it would also be helpful to write a short handout for participants that records some of the learning points from the video, particularly about possible problems and how to get legal advice and help.

Introduce the activity by saying that you will watch and discuss the video together. Explain that the aim of this activity is to improve participants' understanding of the importance of making practical and legal plans, and knowing and fighting for rights. Say that the activity is useful to all participants, whether they are parents living with HIV or carers supporting other parents. It provides a starting point for people to relate their own needs to the issues raised in the video and begin the process of getting help.

Ask participants to make a note of questions. If they are using too much time in the activity to ask detailed questions, tell them they have to move on, but that they can follow up these points with the legal expert or yourself in the break.

Play the video and stop it at certain points that you have identified beforehand so that the participants can reflect on and discuss the key issues.

We have suggested points for pausing the video for discussion. You may want to add others. There will probably not be enough time to discuss all of these points so choose the ones you think are most relevant to your participants' needs. You will have planned up to two hours for this part of the activity. A common problem is running out of time for the later discussion points: make sure you manage the time carefully to allow the group to adequately cover each of the key points you have chosen.

Suggested points for pausing the video for discussion:

- After Scene 7, when the family is driving back to Patrick's mother's village. **Discuss** the nature of the relationships between the different family members.
- After Scene 9, in the bar in the village, when the brothers are watching the band and talking about the death of a friend. **Discuss** how the men react to the news that the deceased man left a will when he died.
- After Scene 18, following Patrick's death, Phineas takes money and a bank book from his dead brother's wardrobe. **Discuss** what the participants feel as they watch this happening. What do they think of Phineas's actions?
- After Scene 22, in which the family is discussing the inheritance ceremony. **Discuss** the different opinions the family has on carrying out the ceremony. How is tradition affecting what is done?
- After Scene 25, when Neria is talking with her work colleagues about Phineas taking her property. **Discuss** the reactions and opinions of Neria's colleagues. Do the participants agree with any of the points they make? Can they think of examples from their own communities that back up what is being said?
- After Scene 26, when Connie, Neria's friend, is advising Neria to talk to a lawyer. **Discuss** what the participants feel about Connie's advice. What do they think they would do in Neria's situation?
- After Scene 29, when Neria confronts Phineas about taking away her children. **Discuss** what Phineas says about having respect for ancestors and about curses. Do they think it is fair or appropriate of him to say this?
- After Scene 32, when Neria visits the lawyer. **Discuss** what the lawyer tells her. Are any of the participants surprised about the strength of Neria's position, according to the lawyer?
- After Scene 34, in which Neria goes to court (for the first time). **Discuss** the outcome of the case and Phineas's reaction.
- After Scene 36, when Phineas goes to court as plaintiff in protest. **Discuss** what he says to the court, how Neria reacts to his statements and the outcome of this second case. How do the participants feel about it? Do they find her case encouraging?
- After the final Scene 37, in which Neria takes part in a ceremony to choose another husband. **Discuss** what participants feel about the choice she makes and her statement: "I have my own life to live."

Allow about two hours for this part of the activity.

After the video

At the end of the video, you can ask participants if their opinions about writing wills have changed at all, and if so, how and why. Or have a general discussion about the issues raised along less structured lines. Summarise the main points and emphasise the importance of making a will. Allow 30 minutes for this.

Activity 2 Looking at participants' rights

Suggested time: 1 hour

For this activity you will need to provide a set of guidelines of key information on legal rights for parents, children and guardians, including local laws of succession (who benefits from the property and money of the person who has died) and the importance of a will. This is Handout 1. Firstly, you will need to contact local relevant organisations (see Appendix 2: Legal resources and contacts, page 127) to find out if there is a legal guide for the country in which you are working that is similar document to the *Guide to legal information for partners living with HIV/AIDS in Uganda* (see Appendix 1: Key course materials, page 123).

If no local guide is available, ask your legal resource person to prepare a handout for participants on local legal rights for people living with HIV and AIDS, adapting the information in the *Guide to legal information for partners living with HIV/AIDS in Uganda* to the local legal context. Ask your legal resource person to explain the key points in the handout clearly, step by step. Be ready to answer questions and help participants understand the difference between traditional ways and rights under the law. Ask participants to continue their discussion at the break if they use too much time on questions that are not helpful to the rest of the group.

1. Introduce the activity by saying that the legal resource person will spend the next hour helping the group understand the legal rights of parents, children and guardians, and how to prepare legally for the future of children. Encourage the group to ask questions after each point. Say it is important to understand — so if something is not clear, participants should not hesitate to ask for further explanation.
2. Give each participant a copy of Handout 1 to keep for their own reference.
3. Close the activity by summarising the main points and the importance of knowing your legal rights.

Making a will

Explain to participants why it is important to make a will. Say that it is helpful to make practical arrangements as early as possible – for the guardianship of children, leaving your land, property, money to the people you choose; settling your debts; payment of school fees; funeral costs and so on. Explain that, although it can be painful to think about these things, making plans can reduce worry in the future. A legally recognised will can prevent family arguments and allow children to inherit what is legally left to them. If the group watched the video *Neria* you can link back to the participants' discussion in Activity 1.
Allow 10 minutes for this introduction.

Activity 3 How to write a will

Suggested time: 45 minutes

For this activity you will need to read the trainer's notes (page 114) carefully beforehand, and be prepared to explain what makes a will legal. You will also need to check with your legal resource person that the will form in Handout 2 (page 111) is legal for the country in which are working. If it is not, you will need to change the form with his or her help before the module.

1. Ask the group for ideas on what a will is and what makes it legal. Record comments on a flipchart. After five minutes, explain what a will is and how it will need to be written to make it legal for the country in which you are working. Ask your legal helper to explain further, if there are questions.
2. Allow 15 minutes to go through the key points you have taken from the trainer's notes (page 114) and summarise points on the flipchart as you speak.
3. Give each participant a copy of Handout 2 (page 111). This is an adapted version of FIDA Uganda's will form, which you might have changed further with the help of your legal helper. Go through the form step by step with participants. Encourage your legal

helper to answer questions too. You can suggest that people make notes about how they would like to fill in the form, but that they will need to think carefully before making the final decisions about what they will actually write in each part of the will form. Allow 30 minutes for this.

Where to go for information and support

Activity 4 Looking at where participants can go for advice

Suggested time: 30 minutes

Before the module you will need to ask your legal resource person and others for the names of useful local organisations that participants can contact to obtain information and support about their legal rights and making a will. We have provided information for some countries in Appendix 2: Legal resources and contacts (page 127). To provide detailed information from your country that meets your participants' needs and includes local contacts, you will need to do some research and preparation beforehand. This activity provides vital support that helps motivate people to tackle what may feel like an unpleasant task.

1. Give out Handout 3: the list you have prepared of names, addresses and other contact details of useful local organisations and people.
2. Explain that you understand that some people might feel they need more information and support before sorting out the legal aspects of the futures of the children and writing a will, or helping others do these things.
3. Ask the participants to look at Handout 3, and then go through it with them. Be ready to answer questions.

Reflection

Activity 5 Reflecting on the module

Suggested time: 15 minutes

Explain that the aim of the activity is for participants to reflect on what they have done in the module and to share key learning points with each other. Say that they can do this quietly with another person, but if anyone wants to speak to the whole group they are welcome to do so.

1. Ask participants to turn to the person sitting next to them and say what ideas or thoughts they are taking away, how they are feeling and what they have learned. Allow 10 minutes for this.
2. Next, say that if anyone would like to share their thoughts with the rest of the group, they are welcome to do so.

Close the module. Thank participants for their contributions and say you are looking forward to working with them on the next and final module.

Handout 2: will form

THE LAST WILL OF

Name:

Physical and postal addresses:

Date:

Make this will and revoke any former wills made by me.

I have made this will voluntarily while of sound mind.

Father's name:
Mother's name:
Grandparents' names (maternal and paternal):

My clan is:
My tribe is:
My religion is:

Date of birth:
Place of birth:
Home district:

Delete as applicable:
I am not married/married/widowed/divorced/separated from my husband/wife.

Answer this section if you are legally married:

The names of my husband/wife:
In the case of a man who has more than one wife, please provide all relevant names.

Date and place of marriage:
In the case of a man who has more than one wife, please provide details of all weddings.

Delete as applicable:
I am divorced/separated from my wife/husband named.

Details of all of my children:
Provide name, sex, date of birth, and names of mother and father for each child.

These are my dependants:
(These should be relatives or other people whom you would like to provide for in your will.)
Provide full name, relationship and full addresses for all dependants.

I have chosen my son/daughter/grandchild/brother/sister/other (delete as applicable) **to be my heir/heiress:**
Provide full name, relationship and full address.

I appoint the following person/people to be guardian(s) of my young children:
Provide full names and addresses for all.

I own the following property:
Provide name, particulars and locations for each property.

I give my property to the following:
Provide full name, relationship and particulars for each property.
(Note: If your spouse and children are living in your principal residence, do not include your home and household property among the property to be distributed.)

I want my property to be distributed by my executors as follows:
Provide any special conditions for distributing your property.

The property I have given to my children below the age of 21 years will not be distributed to them immediately. It will be dealt with as follows:
If applicable, leave guidelines for spouse, executors or your children's guardians on how you wish them to maintain the property for the children until they are of age.

I am employed by:
Provide name and address of employer and your position.

I have the following bank account(s):
Provide account number(s), type(s) of account, your bank(s)/branch(es).

I have a shareholding/interest in the following business(es):

Provide names and addresses of business(es)/company/companies and percentage(s) of any shareholding/interest and insurance policy you own.

I have the following creditors and/or debtors:

Provide creditors' name(s) and address(es) and amount(s) owing.

Provide debtors' name(s) and address(es) and amount(s) owing.

I wish to be buried at:

Provide full details of location.

Any other information/wishes related to your funeral ceremony or any other matter not previously mentioned:

Declaration

I have made this will while of sound mind.

Name:

Date:

Signature/thumb print:

Witnesses

For each witness, provide full name, postal and residential addresses, and occupation.

Signature/Thumb:

Date:

MODULE 11 – Trainer's notes

When preparing this module, you might need to consult relevant national and international documents – for example, the **UN Convention on the Rights of the Child** (1989 – www.uncrc.info), the **African Charter on the Rights and Welfare of the Child** (1990 – www.africaninstitute.org/eng/afSystem/child/afcharter.php), Kenya's **Children's Act No. 8** (2001).

Legal rights

NACWOLA has developed a local guide called *Guide to legal information for parents living with HIV/AIDS in Uganda* (see Appendix 1, page 123 for details). This booklet includes detailed information on Ugandan property law, marriage and guardianship. We suggest that, if all your workshop participants come from the same country, you could work with the legal resource person to locate existing similar material from your region, or to develop material for your participants.

Acknowledgement: all legal information in NACWOLA's *Guide to legal information for parents living with HIV/AIDS in Uganda* was provided by Emma Ssali Namuli (lawyer and legal advisor to NACWOLA in 2002). Additional legal information has been provided by Dorah Kwikriza, NACWOLA's legal advisor as of 2003.

Wills

The following notes use information from:

- *AIDS Action*, issue 41 (Healthlink Worldwide, London, UK, 1998) – see http://aidsaction.info/aa/aa41.html#Will.
- *Writing a valid will* by MC Mukoyogo, published by AMREF, PO Box 2773, Dar-es-Salaam, Tanzania (cited in *AIDS Action*, 41, 1998).
- *A guide to making a will*, developed by FIDA Uganda.

Please note that these are only guidelines and may need to be adapted for use in your country. However, they will be useful to share with your participants, to raise awareness of the importance of producing a will and to get them thinking about developing their own wills.

What is a will?

A will is a written document that makes clear what a person wishes to happen after their death regarding the distribution and maintenance of property or the rights, duties and responsibilities of certain individuals or groups. Making a will is easy – easier than many people think.

The following is adapted from guidelines developed in Tanzania in response to a growing number of women and children being left unprovided for (*Writing a valid will* by MC Mukoyogo, in *AIDS Action*, 1998).

A will must be made in accordance with local law, although the principles are similar everywhere. A will can:

- ensure property, land and valuables are passed on to the people that the will-maker would like to receive them
- make clear who has custody of children and, if there is no partner, appoint suitable guardians
- identify the person(s) who will ensure the will is acted upon (trustees or executors)
- provide instructions for the will-maker's funeral.

To be valid, a will must be:

- written in permanent ink or typed (this requirement may differ from country to country)
- signed by the person and clearly dated (note that a thumb print may suffice in some countries if the will-maker is not able to sign)
- witnessed by persons present at the same time as signing and dating the will. Those who will benefit from the will should not be witnesses. The number of witnesses required depends on the country.
- written when the person is of sound mind and has not been forced to do so by someone else.

Another requirement might be that a legal will must include any surviving husband, wife, children or relative who depends wholly or partly on the will-maker for basic needs. (This is the case in Uganda, for example.)

A will must be written according to the requirements of your country's current law of inheritance and succession in your country. The following example shows the information that a legal will should contain in Uganda:

- the name and address of the person making the will
- the date the will is made; the legal will is the one with the most recent date
- the age of the will-maker; this is to ensure that the will-maker is legally capable of writing a will
- name(s) of wife or wives (if any); the term wife or wives in law applies only to those women who are legally married under customary, religious or civil law
- name of husband (if any)
- name(s) of child/children (if any)
- names of relatives that the will-maker has been providing for and that the will-maker wishes to continue providing for even after death
- property/properties owned by the will-maker; this may include land, livestock, crops, household items, business items and shares in a company or partnership
- the way the property will be distributed, ie how much, and to whom
- the name(s) of the person(s) who will distribute the property and who will ensure all wishes in the will are followed exactly as they are written (the 'executor' of the will); this person may be the surviving husband or wife, a trusted relative or friend.
- signatures or thumb prints of the will-maker
- signatures of two witnesses; these must not be people who are being left property in the will.

There are other wishes that a will-maker may include in a will in Uganda, such as:

- guardian(s) who will look after any children who are less than 18 years old or still going to school
- salary entitlements due to the will-maker and related benefits under existing employment
- details of bank accounts held.

A will-maker (in Uganda) who cannot write a will personally can obtain a will form, ask a trusted person to fill it in, then sign it or make a thumbprint, or request the person to write down their wishes and sign the document or make a thumbprint.

Language: A will does not have to be written in English – it can be in any language as long as it is made by the will-maker or a trusted friend and understood by the will-maker.

Changing the will: Part or all of a will can be changed if the will-maker acquires more property, marries or remarries. The will with the most recent date will be taken as the recognised will.

Keeping the will safe: A will must be kept safe and with a trusted person or organisation. FIDA (Uganda) recommends keeping it with a bank, lawyer, husband or wife, trusted friend or religious institution. It is important to make at least two copies and leave the will with more than one trusted person, who must open it soon after the will-maker has passed away in order to avoid confusion and failure to observe his or her wishes.

FIDA Uganda's will form (adapted) – see Handout 2, page 111

Tell participants that people filling in the form (Handout 2) are asked to remember the following (paraphrased from the original):

- It is important for you to sign your will at the bottom of each page and also on the final page. The will should be signed in the presence of at least two witnesses who SHOULD NOT have been left any property in your will. The witnesses need not read the will since they are only meant to witness your signature. All witnesses should be over 21 years of age. You and these witnesses should also sign your will in each other's presence.

MODULE 12

Closing the course

Trainer's introduction

This module is essential. Participants should not feel they can leave the course before this session. The course has been about preparing for an ending. It is therefore vital that the course also closes in a way that is as prepared and positive as possible. Do not drop this module or any section of it.

Approximate length of module 2 hours 10 minutes

Aims

The aims of this module are to:
- encourage participants to think about their support needs
- help participants plan how they will continue their memory work for their own family or how they will support others to do so
- plan how they will complete their memory books, if they are parents living with HIV
- bring the course to an end and allow the group to say their farewells

Key learning outcomes

By the end of this session participants will:
- have a clearer idea of their individual support needs
- have started to plan how they will continue their memory work for their own family or support others to do so
- have planned how they will complete their memory books, if they are parents living with HIV
- have experienced a positive end to the course, said goodbye to the group and made appropriate links for the future.

Trainer's preparation

Module plan (with suggested times)
- Thinking about individual support needs – **45 minutes**
- Planning how to continue memory work and complete a memory book – **40 minutes**
- Closing the course and saying goodbye to the group – **45 minutes**

Materials you will need

Overhead/flipchart 1: Outline of Module 12
Overhead/flipchart 2: Reflecting on the course
Handout 1: Action plan

Trainer's guidance

Introduction

Be aware that on the last day, groups are often anxious to get home. This can lead to a lack of focus. Because of this, it is very important that you end this module at the time you agree at the start of the day. Keep enough time for this important final module. People should not start leaving before it is over.

Introduce the last module by saying that all of the group has worked together for a week and you have shared an important experience. It is important to acknowledge this and end properly. This last module is therefore important for all participants whether they are parents living with HIV or other carers.

Go through the topics to be covered in the module and how it is structured.

Overhead/flipchart 1: Outline of Module 12
Please use the list in the module plan on page 117, but without the suggested times.

Thinking about individual support needs

Introduce this topic by saying that as participants think about the support they already have and the support they need, they might agree to keep in touch with each other. They could meet and review their plans. Say that each individual's situation is different and no one should feel they must do this. Support may happen spontaneously between some participants, but often on courses it does not develop between everyone. This is fine.

Activity 1 Thinking about support needs

Suggested time: 45 minutes

Explain that the aim of this activity is to help participants think about the support they need and how they might get it. Ask members of the group who are future guardians or other carers to try to place themselves in the position of people living with HIV, as they participate.

1. Ask participants to split into small groups. Give them 10 minutes to discuss what support means to them. Start by asking if are they looking for people who know them, people to cry with and/or people to laugh with. Are they looking for people with particular expertise? Sometimes people need practical support, like looking after children, shopping or help with housework. Practical and emotional support are both necessary.
2. Next, ask participants to stay in the same groups and consider what support each member of the group wants. Give them 10 minutes to do this.
3. Then ask them to consider who might be able to provide them with different kinds of support. Ask each group to choose one person to be ready to feed back to the whole group after five minutes.
4. Ask the representative from each group to feed back, taking two minutes each. Record the main points on the flipchart under two headings: 'Types of support' and 'Sources of support'. Allow 10 minutes for this.
5. Summarise the main points from the feedback and discussion. Emphasise both emotional and practical needs, and ideas for sources of support – particularly those outside the family. Encourage participants to explore many sources of support, not just one. As trainer you may need to remind them of the sources of support they discussed in Module 10. Prepare to give this information by reading the trainer's notes (page 101) for Module 10 before the session.

Close the activity by asking the group to think about how the course participants might support each other.

Planning how to continue memory work and complete a memory book

Introduce this topic by saying that together you will look at a special way of planning that could help participants take their ideas forward after the course. The method is called action planning. Explain that this activity is relevant to parents living with HIV, who can use it to plan to write their memory books and plan for their children's future.

Activity 2 Action planning

Suggested time: 40 minutes

Explain that the aim of this activity is to help each participant to use action planning to make good use of what they have learned on the course. Say that an action planning approach helps us look at what we want to do and compare this with the resources we have to do it. This helps us recognise when we need support and to look for it, so we can achieve what we want to do. We might achieve it in the way we first thought of, or in an alternative way with help.

1. Give each person a copy of Handout 1: Action plan (see page 122). Ask participants to work alone for about 10 minutes to think about:
    - three things they would like to do within the next six weeks to carry on the memory work they have learned about on the course
    - the support they need to achieve what they want to do
    - two things that could make their plans difficult.
2. Next, ask people to work in pairs to share their plans. Tell them not to write anything on the action plan yet. Give participants 10 minutes for discussion, to give each other ideas for support, and to think of ways to help with the difficulties if possible.
3. Ask participants to fill in their action plan. Make sure one of each pair can write and help those who cannot. Tell them they have 10 minutes to do this.
4. Finally, bring everyone back to the whole group. Ask if anyone would like to share their plan. Ask if the main challenges they have identified relate to themselves, to other individuals, to their family, community or another person or group of people. This encourages people to think on different levels about what they and others can do to help. Allow 10 minutes for discussion and again be ready to give examples of support if the group runs out of ideas.

Closing the course and saying goodbye to the group

Activity 3 Closing the course

Suggested time: 30 minutes

It is important you record participants' feedback during this activity on the flipchart. It provides valuable information that will help you or your organisation plan future courses. It will guide you to improve the training material and any supporting material you have used. It is also important for funding organisations to know what participants have gained from attending the workshop. This may help you to obtain funding for similar or related training in the future.

As you hear the feedback, do not be defensive or judgmental; try to be open. If you disagree with some of what the participants say, it is important that you do not show this.

Explain that the aim of this activity is to formally bring the course to an end and encourage reflection. Say you want the group to express their honest thoughts and feelings about the whole course. Ask for ideas for improvement to help you plan better courses in the future. Emphasise that anything they share is confidential. Say that you will not name them if their feedback is shared outside the group – for example, with other trainers or with your organisation. Allow five minutes to introduce the activity.

1. Ask participants to split into small groups. Each group should discuss the questions below for 10 minutes. Ask each group to choose one person to feed back their main points to the whole group.

Overhead/flipchart 2: Reflecting on the course

- What are the most important things you have learned during the workshop?
- What areas or issues would you like to spend more time on?
- Can you do anything to spend more time on these issues after the course?
- What skills have you developed?
- What strengths have you identified: in yourself; among participants in the group; in your families; in your community?
- What support is available to take forward ideas from the workshop?
- What have you most enjoyed about the workshop?
- If you had an opportunity to attend a similar workshop again, what would you change next time?

2. Next bring, everyone back together and ask the volunteers to report the main points from their group's discussion, taking two minutes each. Ask each one to report on just one or two questions they choose from the list. Make sure that all the questions are eventually covered. If there is time, link the group's reflections with the expectations recorded on the flipchart in Activity 3 of Module 1 (page 17). You should have met many of the expectations by now. Allow 15 minutes for this part of the activity.

3. Thank the group for their feedback. Say that you hope they have learned a lot from the course and that they will carry on the good work they have started. Also say that their feedback will help you develop a better course for future participants.

Activity 4 Closing the group

Suggested time: 15 minutes

Please be aware that at the end of the course participants might feel a sense of loss. This is because of high levels of involvement and the knowledge that being together as one group is coming to an end. For some participants this course may be the first time they have felt safe and comfortable talking about such personal and sensitive issues with others. These people might feel a particularly strong loss. As the trainer, you have a responsibility to set aside time to discuss endings. You are not responsible for the feelings of participants, but you need to be sensitive to their emotions and aware of their needs at this time. No one should leave the workshop feeling too distressed.

Explain that the aim of this activity is to bring the time of working together as a group to an end. Say that, because of the sensitivity of the issues discussed on the course and the sometimes emotional time that participants have spent working closely together, it is important to 'close' the group.

1. Ask participants to stay in the whole group and have an open discussion on the questions below. Ask people to share their thoughts and feelings on:

- how they feel about working as a group
- how it feels to be a member of this particular group
- what they have learned from this experience.

After everyone has had a chance to contribute, say that, although you expect that some group members will stay in touch with and support each other, the group itself no longer exists. Allow 10 minutes for this.

2. Remind participants of the confidentiality rule that everyone agreed at the start of the course. Say that this remains important. Even when the course is over, participants are not free to share any information inappropriately. They should not use people's names if they talk about any of the issues raised during the course.

3. Remind everyone of the action plans they have written, and that these plans provide a positive and forward-looking focus for each participant. Encourage the group to take these plans forward.

4. Finish by thanking all participants for their contributions and hard work, and say that you have enjoyed working with them. Wish the parents living with HIV well with their families, their memory work and their memory books, and wish the future guardians and other carers well for their work supporting others.

Handout 1: Action plan

Personal contract

A. Three things I would like to do within the next ___ weeks

1.

2.

3.

B. Support – what do I need to help me to achieve what I want to do?

1.

2.

3.

4.

5.

6.

C. Difficulties – what things will make what I want to do difficult?

1.

2.

3.

4.

5.

6.

Appendix 1: Key course materials

Books and booklets

Memory Book for Africa

CLS Development Services/National Community of Women Living with HIV/AIDS in Uganda (NACWOLA), 2000, 24 pages
Available from: Teaching Aids at Low Cost (TALC), PO Box 49, St Albans, Herts AL1 5TX, UK
Fax: +44 1727 846 852 Email: info@talcuk.org Web: www.talcuk.org
Or from: NACWOLA, PO Box 70574, Kampala, Uganda
Fax: +256 41 510528 Email: nacwola@infocom.co.ug

Guide to legal information for parents living with HIV/AIDS in Uganda

Emma Ssali Namuli/National Community of Women Living with HIV/AIDS in Uganda (NACWOLA), 1996
Available from: NACWOLA, PO Box 70574, Kampala, Uganda
Fax: +256 41 510528 Email: nacwola@infocom.co.ug

Videos

Everyone's Child

Media for Development Trust, 1996, colour, 85 mins, English
Available from: Media for Development Trust, PO Box 6755, Harare, Zimbabwe
Fax: +263 4 729 066 Email: mfdvrc@pci.co.zw Web: www.mfdi.org

A River of Hope

Healthlink Worldwide, 2003, colour, 44 mins, English; comes with a booklet video guide.
Available from: Healthlink Worldwide, 56-64 Leonard Street, London EC2A 4JX, UK
Fax: +44 20 7549 0241 Email: info@healthlink.org.uk Web: www.healthlink.org.uk

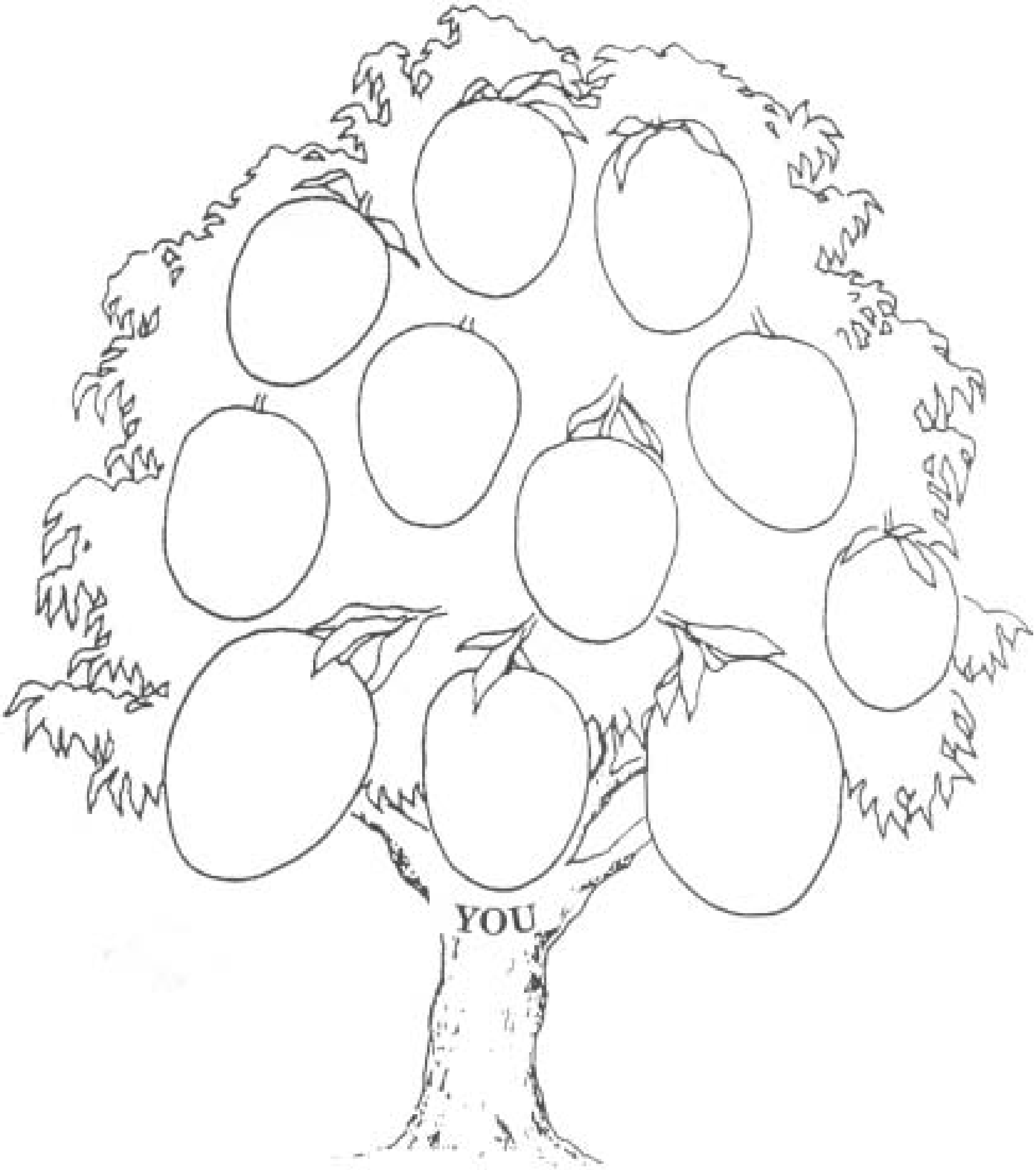
Neria

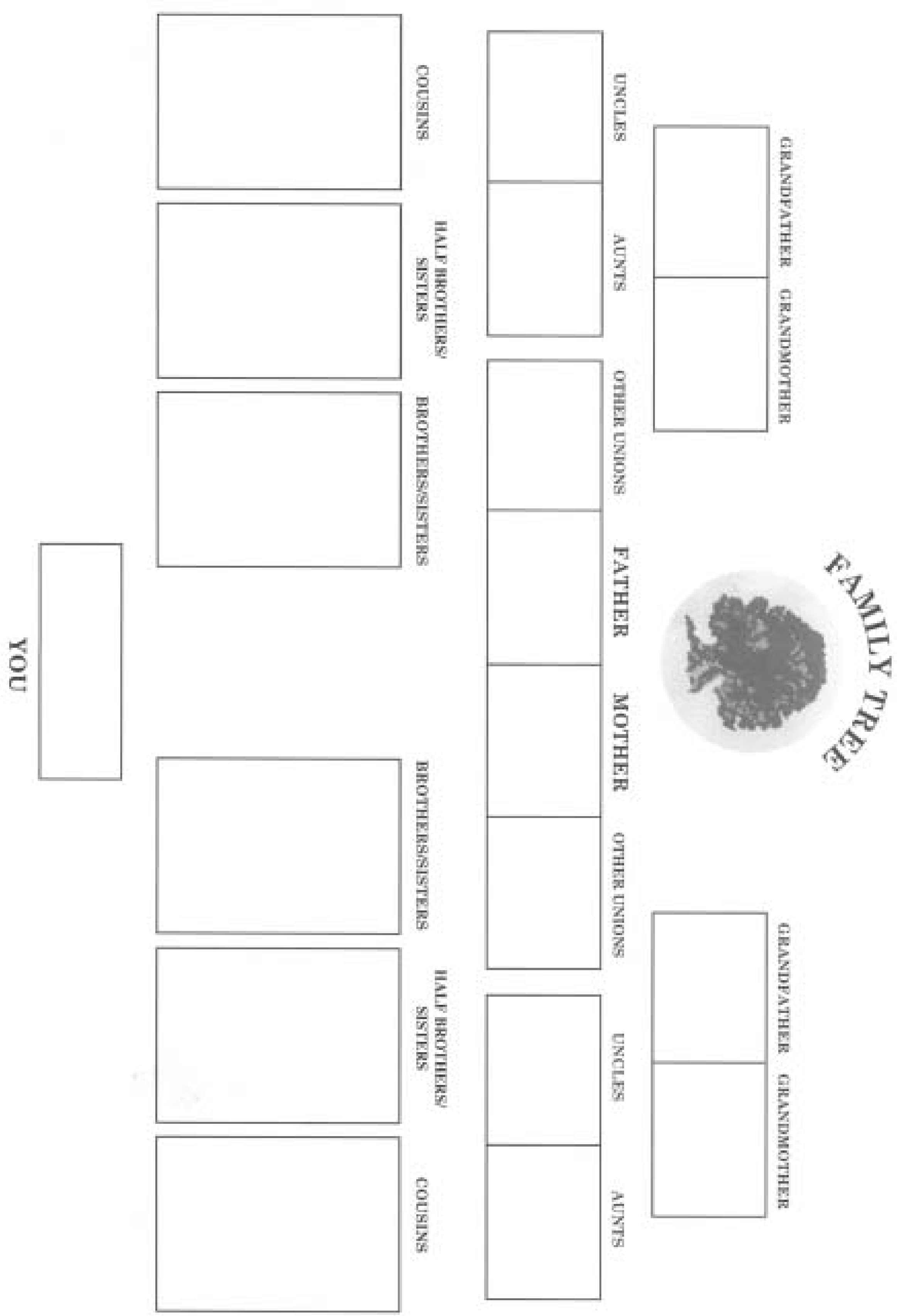
Media for Development Trust, 1990, colour, 103 mins, English
Available from: Media for Development Trust, PO Box 6755, Harare, Zimbabwe
Fax: +263 4 729 066 Email: mfdvrc@pci.co.zw Web: www.mfdi.org

Beyond Survival

TILLA – Association of Women Living with HIV, 1997, colour, 25 mins, English and Amharic
Available from: TILLA – Association of Women Living with HIV, PO Box 1041, Awassa, Ethiopia
Fax: +251 6202900 Email: tilawlwh@telecom.net.et

Important people in your life




FAMILY TREE
GRANDFATHER
GRANDMOTHER
UNCLES
AUNTS
OTHER UNIONS
FATHER
MOTHER
OTHER UNIONS
GRANDFATHER
GRANDMOTHER
UNCLES
AUNTS
COUSINS
HALF BROTHERS/ SISTERS
BROTHERS/SISTERS
BROTHERS/SISTERS
HALF BROTHERS/ SISTERS
COUSINS
YOU

MAP OF AFRICA

© CLS Development Services

Appendix 2: Legal contacts and resources

Tanzania

Organisations

KWIECO (Kilimanjaro Women's Information Exchange and Consultancy Organisation)
PO Box 376, Moshi, Tanzania
Tel: +255 27 2751121
Email: kwieco@africaonline.co.tz

Envirocare Kilimanjaro
Moshi, Kilimanjaro, Tanzania
Tel: +255 27 2754659

Legal and Human Rights Centre
Contact: Ms Hellen Kijo Bisimba
PO Box 75254, Tulyer House, Ocean Road, Dar-es-Salaam, Tanzania
Tel: +255 22 277 3048 Email: lhrctz@raha.com

Tanzania Media Women's Association
PO Box 8981, Dar-es-Salaam, Tanzania
Fax/Tel: +255 22 2115 278 Email: tamwa@raha.co or info@tamwa.org

Resources

Children in need of special protection measures: a Tanzanian study
Suleman Sumra and Judith Ennew
UNICEF Tanzania, 1999, 395 pages
Available from: United Nations Children Fund (UNICEF), PO Box 4076, Dar-es-Salaam, Tanzania
Email: daressalaam@unicef.org

Ethiopia

Organisations

Ethiopian Women Lawyers Association (EWLA)
Association established by women lawyers to advocate for the rights of women, particularly the disadvantaged ones.
Fax: +251 1 523946 Tel: +251 1 507774 Email: ewla@ethionet.et

Forum for Street Children Ethiopia (FSCE)
Runs various programmes on child protection and advocates for the implementation of child rights in the country.
Tel: +251 1 534722/524294 Email: fsce@ethionet.et

African Child Policy Forum (ACPF)
Established to provide a forum for dialogue, give a voice to children, and carry out child rights advocacy.
Fax: +251 1 513420 Tel: +251 1 528407/09/10 Email: info@africanchildforum.org

Women Lawyers Association
Tigist Enyew, PO Box 970, Assawa, Southern Ethiopia
Fax: +251 6 206109 Tel:+ 251 6 204800 Email: tegenyew@yahoo.com

Kenya

Organisations

Federation of Women Lawyers (FIDA)

Advocates for human rights especially of women and girl children.
PO Box 46324, 00100 Nairobi, Kenya
Tel: +254 020 3870444 Email: info@fida.co.ke

Coalition on Violence Against Women

Aims to promote the rights of women.
PO Box 46516, 00100 Nairobi, Kenya
Tel: +254 020 3874357/8 Email: info@covaw.or.ke

African Network for the Prevention and Protection Against Child Abuse and Neglect (ANPPCAN) Kenya Chapter

Improves the welfare of children and enhances opportunities for the development of their full potential by offering services to targeted groups of children and their families.
PO Box 46516, 00100 Nairobi, Kenya
Tel: +254 020 2722835 Fax: +254 020 2723104 Email: admin@anppcankenya.co.ke
Web: www.anppckenya.co.ke

Kenya Alliance for Advancement of Children (KAACR)

Aims to develop a culture that respects human rights, the rule of law, gender sensitivity and accords equal opportunity to all.
PO Box 73637, 00200 Nairobi, Kenya
Tel:[+254 020 445056/7 Email: kaacr@kaacr.com or infor@kaacr.com

Your Voices Centre

Provides legal and counselling services and also educates key target groups regarding their legal rights and issues.
PO Box 19743-00200 Nairobi, Kenya
Tel:[?] 240901/0733777559/ 0720407604 Email: jmbuguah@yahoo.com

Resources

The Children Act Cap 586 Laws of Kenya

Government of Kenya
The act addresses the rights a child is entitled to and the role of the government and parents in protecting these rights. It also sets out the general roles and responsibilities of parents in ensuring the wellbeing of the child.
Available from: Department of Children's Services, Ministry of Home Affairs, PO Box 46205, 00100 Nairobi, Kenya
Tel: +254 020 228411 Email: childk@nbnet.co.ke

National Programme guidelines on orphans and other children made vulnerable by HIV and AIDS

Government of Kenya
The guidelines are intended to assist in programming for orphans and other children made vulnerable by HIV and AIDS and in effectively responding to the effects of the pandemic on such children as well as discouraging harmful practices in Kenya.
Available from: Department of Children's Services, Ministry of Home Affairs, PO Box 46205, 00100 Nairobi, Kenya
Tel: +254 020 228411 Email: childk@nbnet.co.ke
and National AIDS Control Council (NACC), Office of the President, PO Box 61307 Nairobi, Kenya

Guidelines on child rights and child protection for police officers

African Network for the prevention and Protection Against Child Abuse and Neglect, 2001

A resource for police officers on the Children's Act 2001, for use in cases concerning children. The guidelines are also intended to enhance police officers' understanding of the provisions of the Children's Act, the African Charter on the Rights and Welfare of the Child and the United Nations Convention on the Rights of the Child, and finally to enhance service delivery to children within the Kenyan Juvenile Justice Systems.

Available from: African Network for the prevention and Protection Against Child Abuse and Neglect (ANPPCAN), PO Box 46516, 00100 Nairobi, Kenya
Tel: +254 020 2722835 Fax: +254 020 2723104 Email: admin@anppcankenya.co.ke
Web: www.anppckenya.co.ke

The HIV and AIDS Prevention and Control Bill, 2003

Government of Kenya, 2003

This Bill provides for measures for the prevention, management and control of HIV and AIDS. It also provides for the protection and promotion of public health and for the appropriate treatment, counselling, support and care of persons infected or at risk of HIV and AIDS infection, and for other connected purposes.

Available from: Office of the Attorney General, PO Box 30520, Nairobi, Kenya

Appendix 3: Resources

Child growth and development

Books and reports

Facts for life: child growth and development
UNITED NATIONS CHILDREN'S FUND (UNICEF)
Cairo: UNICEF, 2002, 215p

A comprehensive guide giving parents and other caregivers the information they need to save and improve children's lives. It also includes a section on child development and early learning which describes what children need to develop socially, emotionally, physically and intellectually.

Available from: United Nations Publications (AFRO, EMRO and EURO) Sales and Marketing Section, Bureau E-4, CH-1211 Geneva 10 Switzerland
Fax: +41 22 917 0027 Email: unpubli@unog.ch Web: https://unp.un.org/
Free online: www.unicef.org/ffl/ www.unicef.org/ffl/pdf/factsforlife-en-full.pdf [PDF, 1900Kb]
www.unicef.org/ffl/text/factsforlife-en.txt

HIV/AIDS and early childhood [Coordinators' Notebook No 26 whole issue]
BARTLETT, Kathy and ZIMANYI, Louise (eds)
December 2002

Contains articles examining the particular experience of the very young child and the social, psychosocial and nutritional impact on their lives in AIDS-affected communities.

Available from: Consultative Group on Early Childhood Care and Development (EGCCD), Ryerson University, School of Early Childhood Education, 350 Victoria Street, Toronto, Ontario M5B 2K3, Canada
Fax: +1 416 979 5239 Email: info@ecdgroup.com Web: www.ecdgroup.com
Free online: www.ecdgroup.com/pdfs/CN26withphotos.pdf

Communication skills

Guidelines for counselling children who are infected with HIV or affected by HIV and AIDS [HIV Counselling Series No 7]
SOUTHERN AFRICAN AIDS TRAINING PROGRAMME (SAT)
Harare: SAT, 2003, 33 pages

This booklet provides guidance for counsellors working with children who are infected or affected by HIV and AIDS, including how to communicate with them about sensitive issues such as sex, illness and death, and how to identify their needs and provide appropriate support. It covers drawing, storytelling, drama and play, as well as personal and professional challenges that arise for counsellors regarding personal, gender, cultural, traditional and religious issues; confidentiality; and advocacy.

Available from: Southern Africa AIDS Training Programme (SAT), 3 Luck Street, PO Box 390, Kopje, Harare, Zimbabwe. Fax: +263 4 752 609 Email: info@satregional.org Web: www.satregional.org

HIV and AIDS affect all children
Soul City Institute for Health and Development Communications
Houghton: Soul City, 2003, 45 pages

Written in plain English, with some difficult words translated into Zulu, Xhosa, Sotho and Afrikaans, this book explains the different ways that HIV and AIDS can affect children. It is useful for parents, families and anyone who works with children – teachers, carers, health and community workers.

Available from: Soul City Institute for Health and Development Communications, PO Box 1290, Houghton 2041, South Africa. Fax: +27 11 643 6253 Email: soulcity@soulcity.org.za
Web: www.soulcity.org.za

Getting started

Getting the basics (2nd ed) (Parents... let's talk: talking to our children about growing up. Book 3)

KABISWA, David, KYEDZA, Godfrey and KABUNGA, Paul Kato
Kampala: AIDS Care Education and Training (ACET), February 2001

Addresses problems that parents may have particularly in talking about sexuality with their children. It includes tasks for parents and other adults to complete.

Available from: ACET Uganda, PO Box 9710, Kampala, Uganda
Fax: +44 256 41 267826 Email: acet@afsat.com or acet-uganda@maf.org

HIV/AIDS counselling for children

Uganda Network of AIDS Service Organisations (UNASO) (UNASO Best Practice Series, Vol 1, Issue 2)
Kampala: UNASO, Sept 2000

Provides a useful summary of the issues around counselling children affected by HIV and AIDS, such as the need to develop a rapport with children, issues around disclosure of HIV status to children and indicators that children may be suffering distress or are in difficult circumstances.

Available from: UNASO, Block 10 Plot 264, Nakulabye-Balintuma Rd, PO Box 27346, Kampala, Uganda
Fax: +256 041 530277 Email: unaso@africaonline.co.ug Web: www.unaso.or.ug/index.htm

Manual: psycho-social support of orphans

MADRIN, Kurt Basel: Terre Des Hommes

A tool for trainers to train concerned community members to assist distressed children, and to facilitate their interventions on the level of awareness, knowledge, skills and behaviour in relation to orphans. Its stated objective is to enhance the capacity of adults to listen and talk to orphans and children of terminally ill parents, and to understand their situation and their needs.

Available from: Terre Des Hommes Switzerland, Attention of Kurt Madrin, Laufenstr 12, Postfach 4018, Basel, Switzerland
Fax: +41 61 338 9139 Email: k.madorin@terredeshommes.ch Web: www.terredeshommes.ch
Free online: www.terredeshommes.ch/humuliza/pdf/manual.pdf [PDF]
www.terredeshommes.ch/humuliza/manual/manual_titel.html [HTML]

Activity pack: a resource pack for those working with children affected by parental illness

PAEDIATRIC AIDS RESOURCE CENTRE (PARC)
Edinburgh: PARC, 1997, 150 pages

This pack aims to help children understand their parent's illness and to help parents tell them more about their situation and future care in the best possible way.

Available from: Barnardo's, Tanners Lane, Barkingside, Ilford, Essex G6 1QG, UK
Fax: +44 20 8498 7801 Email: Jo.Barnes@barnardos.org.uk Web: www.barnardos.org.uk

Involving children in planning

Children changing their world: understanding and evaluating children's participation in development

HART, Jason *et al*
Surrey, UK: Plan International, June 2004

A report pulling together evidence of the impact of children's participation in development projects, drawing on literature, interviews with project staff and engagement with children and young people involved in participatory projects. The impacts are mapped under personal, family, community and institutional 'realms of impact'.

Available from: Plan International, Chobam House, Christchurch Way, Woking, Surrey GU21 6JG, UK
Fax: +44 1483 756505 Email: info@plan-international.org Web: www.plan-international.org

Exploring the field of listening to and consulting with young children

CLARK, Alison, MCQUAIL, Susan and MOSS, Peter (Research Report 445)
London: Department for Education and Skills (DFES), July 2003

A review of how to consult with children under five years old in the UK, with a focus on views and experiences of education and child-care. Examines methodologies and approaches used in research and consultation, including those used when listening to practitioners and parents, and tools that are open to young children with special needs.

Available from: Department for Education and Skills Publications, PO Box 5050, Sherwood Park, Annesley, Nottingham NG15 ODJ, UK
Fax: +44 845 6033360 Email: dfes@prolog.uk.com Web: www.dfes.gov.uk/publications
Free online: www.dfes.gov.uk/research/data/uploadfiles/RR445.pdf

So you want to consult with children? A toolkit of good practice

INTERNATIONAL SAVE THE CHILDREN ALLIANCE
London: International Save the Children Alliance, Nov 2003

A flexible toolkit for people who want to involve children of all ages in discussion about issues that affect them. It does not list practical activities but makes suggestions of what can to be done to ensure that children feel their opinions have been heard and respected.

Available from: International Save the Children Alliance, 2nd floor Cambridge House,
100 Cambridge Street, London W6 0LE, UK
Fax: +44 20 8237 8000 Email: info@save-children-alliance.org Web: www.savethechildren.net
Free online: www.savethechildren.net/alliance/resources/childconsult_toolkit_final.pdf [English]
www.savethechildren.net/alliance_fr/resources/French_So_You_Want_to_Consult.pdf [French]
www.savethechildren.net/alliance_sp/resources/Spanish_So_You_Want_to_Consult.pdf [Spanish]

Memory work

Memory work

Medicus Mundi Schweiz Bulletin No 97 (Whole issue)
Basel: Medicus Mundi Schweiz, June 2005

Articles describe the evolution of memory books and memory work; NACWOLA's experiences in Uganda; scaling up memory work; and related projects and tools such as hero books and the Ten Million Memories Project.

Available from: Medicus Mundi Schweiz, Murbacherstrasse 34, Postfach CH-4013 Basel, Switzerland
Tel: +41 061 383 18 10 Email: info@medicusmundi.ch Web: www.medicusmundi.ch
Free online: www.medicusmundi.ch/bulletin/bulletin97.htm

Starting to do memory work: a guide to the stages of implementation [draft]

WARD, Nicola
London: Healthlink Worldwide, 2006, 24 pages

This brief guide is based on the experience of the National Community of Women Living with HIV/AIDS (NACWOLA) and initial experiences of the International Memory Project. It will be useful for non-governmental organisations and community-based organisations interested in starting memory work.

Available from: Healthlink Worldwide, 56-64 Leonard St, London EC2A 4JX, UK
Fax: +44 20 7549 0241 Email: info@healthlink.org Web: www.healthlink.org.uk

Breaking the silence: memory books and succession planning. The experience of NACWOLA and Save the Children UK in Uganda

WITTER, Sophie
London: Save the Children UK, 2004

This report highlights the work of the National Community of Women Living with HIV/AIDS (NACWOLA) in Uganda and Save the Children UK in supporting parents and children to develop memory work. It outlines the successes and challenges of memory books and succession planning in Uganda, looking at the impact of the project on families, and NACWOLA's organisational development.

Available from: Save the Children (SCF) UK c/o NBN International, Estover Road, Plymouth
PL6 7PY, UK
Fax: +44 1752 202333 Email: orders@nbninternational.com Web: www.savethechildren.org.uk

Special issue on children in the context of HIV/AIDS [whole issue]

AIDS Bulletin 13(2) July 2004

This special issue of AIDS Bulletin includes five articles about memory work, and several others on orphans and vulnerable children and psychosocial support.

Available from: Medical Research Council of South Africa, Corporate Communications, PO Box 19070, Tygerberg 7505, South Africa . Fax: +27 21 938 0395 Email: michelle.galloway@mrc.ac.za
Web: www.mrc.ac.za
Free online: www.mrc.ac.za/aids/june2004/contents.htm

Memory boxes and the psycho-social needs of children: trainer's manual

Sinomlando Centre for Oral History and Memory Work in Africa (SINOMLANDO)
Pietermaritzburg: Sinomlando, School of Theology, University of KwaZulu-Natal, South Africa, 2003, 35 pages

This manual describes a training curriculum designed to give community workers and volunteers a basic understanding of the psychosocial needs of vulnerable children, and basic skills in 'memory box' methodology. It is based on a four-day, 12-session workshop and covers child development, bereavement, loss, stigma, counselling skills and making memory boxes.

Available from: Sinomlando Centre for Oral History and Memory Work in Africa, School of Religion and Theology, University of KwaZulu-Natal, Private Bag X01, Scottsville 3209, South Africa
Fax: +27 33 260 5858 Email: denis@ukzn.ac.za Web: www.hs.unp.ac.za/theology/sinomlando/
Free online: www.hs.unp.ac.za/theology/sinomlando/MAN%20MB%205%20(Trainers)%20REV3.pdf

Boxes and remembering in the time of AIDS

MORGAN, J. in: AIDS Bulletin 10(2), July 2001

Jonathan Morgan, a writer and therapist, writes about his experience of establishing the Memory Box Project in South Africa. Motivated by the resolve to educate himself about the issues of HIV and AIDS, Morgan invited a group of HIV-positive women at the AIDS Counselling, Care and Training (ACCT) in Soweto to begin such a project.

Available from: Medical Research Council of South Africa, Corporate Communications,
PO Box 19070, Tygerberg 7505, South Africa
Fax: +27 21 938 0395 Email: michelle.galloway@mrc.ac.za Web: www.mrc.ac.za

Parenting

ChildrenFIRST: a journal on issues affecting children and their carers

DESMOND, Cosmas (ed)
ChildrenFIRST Vol 5 No 38 (Whole issue), August 2001, 40 pages

This issue of ChildrenFIRST is devoted to a workshop on family support held in Cape Town in June 2001. The workshop intended to share knowledge and experiences of working with families in different social and cultural contexts. The issue contains articles on the importance of male involvement in early childhood development (ECD) and a useful list of ECD suppliers and family support resources.

Available from: Children First, Room 67, Diakonia Centre, 20 St Andrews Street, Durban 4001, South Africa. Fax: +27 31 307 3405 Email: office@childrenfirst.org.za Web: www.childrenfirst.org.za
Free online: www.childrenfirst.org.za/shownews?mode=cats&setref=2731

Know yourself (2nd ed) (Parents… let's talk: talking to our children about growing up. Book 3)

KABISWA, David, KYEDZA, Godfrey and KABUNGA, Paul Kato
Kampala: AIDS Care Education and Training (ACET), February 2001, 32 pages

Guides an adult through the process of knowing themselves so that they can help a child or young person learn about themselves. Helps adults look at what they went through as young people, acknowledging their hopes, fears and expectations for their children.

Available from: AIDS Care Education and Training (ACET Uganda) PO Box 9710, Kampala, Uganda
Fax: +44 256 41 267826 Email: acet@afsat.com or acet-uganda@maf.org

Participatory facilitation techniques

100 ways to energize groups: games to use in workshops, meetings and the community

INTERNATIONAL HIV/AIDS ALLIANCE
Brighton: International HIV/AIDS Alliance, 2002

A compilation of icebreakers and games that can be used by anyone working with groups of people, whether in a workshop, meeting or community setting. Games can help people to get to know each other, increase energy or enthusiasm levels, encourage team building, or make people think creatively about an issue.

Available from: International HIV/AIDS Alliance Queensberry House, 104-106 Queens Road, Brighton BN1 3XF, UK
Fax: +44 1273 718 901 Email: publications@aidsalliance or Web: www.aidsalliance.org
Available free online: http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ene0502_Energiser_guide_eng.pdf [English]
http://synkronweb.aidsalliance.org/graphics/secretariat/publications/enf0602_Energiser_guide_fr.pdf [French]
http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ens0602_Energiser_guide_sp.pdf [Spanish]

Participatory workshops: a sourcebook of 21 sets of ideas and activities

CHAMBERS, Robert
London, UK and Sterling, USA: Earthscan Publications Ltd, 2002

Presents 21 sets of ideas, activities and tips to those who work with others on participatory learning and change. It will be useful to facilitators, trainers and others. Covers topics such as getting started, seating, forming groups, managing large numbers, helping each other learn, analysis and feedback, evaluation and ending, coping with mistakes and difficulties.

Available from: Earthscan/James & James, 8-12 Camden High Street, London NW1 0JH, UK
Fax: +44 20 7387 8998 Email: orders@earthscan.co.uk Web: www.earthscan.co.uk

Training for transformation: a handbook for community workers (Book 4)

HOPE, A and TIMMEL, S
St Albans, UK: TALC, 1999, 294 pages

Book 4 of this series is a practical and accessible work book for community development workers which focuses on the environment, gender, racism, multi-cultural understanding and building participatory governance. The book is divided into easy-to-follow modules, which can be covered in any order.

Available from: Teaching-aids At Low Cost (TALC), PO Box 49, St Albans, Herts AL1 5TX, UK
Fax: +44 1727 846 852 Email: info@talcuk.org Web: www.talcuk.org

Participatory learning and action: a trainer's guide

PRETTY, Jules N. *et al* (IIED Participatory Methodology Series)
London: International Institute for Environment and Development, 1995

Provides a comprehensive background to the principles of adult learning, focuses on the facilitation skills necessary for effective training, and describes group dynamics and how to build interdisciplinary teams. It summarises the principles of participatory learning and action, describes in detail the process of training, both in the workshop and in the field, and suggests how to organise workshops.

Available from: Earthprint Ltd, PO Box 119, Stevenage, Herts SG1 4TP, UK
Fax: +44 1438 748 844 Email: enquire@earthprint.com or customerservices@earthprint.com
Web: www.earthprint.com

Programme tools, approaches and research

10MMP (Ten Million Memories Project) website

http://web.uct.ac.za/depts/cgc/Jonathan/index.htm

This website describes the activities of the Ten Million Memories Project. It includes useful tools such as guidelines for creating memory books, tracing books and body maps and wills. It is planned to put a hero book manual on the site. It also has links to research and other information resources related to the project and its partners.

AIDSMAP: information on HIV and AIDS website

National AIDS Manual (NAM)
www.aidsmap.com

This website includes information on antiretroviral treatment and care, living with HIV, preventing HIV, basic information on the disease and the epidemic, and a database of organisations. Although there is a slight bias towards information relevant to people in developed countries, particularly to do with treatment options, many of the information resources will be useful in and, are tailored to, resource-poor settings.

Orphans and other vulnerable children support toolkit website

INTERNATIONAL HIV/AIDS ALLIANCE and FAMILY HEALTH INTERNATIONAL
www.ovcsupport.net/sw505.asp

This is a collection of information and tools for supporting orphans and other vulnerable children living in a world with HIV and AIDS. It covers a wide range of subject areas, including running a programme, health and nutrition, education, psychosocial support, economic strengthening, living environments and children’s rights. It contains a wide range of useful resources on the different topic areas. There is also a section on early childhood development.

Psychosocial support portal website

REGIONAL PSYCHOSOCIAL SUPPORT INITIATIVE (REPSSI)
www.repssi.org/portal.htm

The psychosocial support portal contains links to documents produced by and with REPSSI. These include: reports of programme acitivites; manuals, guides and toolkits; country responses to children and HIV/AIDS; training manuals; research papers; and information about training and education.

Children Affected by AIDS (CABA) online forum

SYNERGY PROJECT
www.synergyaids.com/Caba/cabaindex.asp

A discussion forum established by the US Agency for International Development (USAID) to facilitate vital discussion and information exchange on efforts to mitigate the impact of HIV and AIDS on children, families and communities. USAID and the Synergy Project, which hosts the forum, encourage all to participate. Areas covered include: global HIV and AIDS, women, children and youth, tuberculosis and HIV and AIDS, donors, Africa, newly independent states, Asia and the near east, Latin America and the Caribbean.
To subscribe (free), email Elizabeth Berard: cabaforum@s-3.com

Responding to children affected by HIV and AIDS: using external support to strengthen community initiative and motivation

WEAVER, Richard (Tearfund HIV/AIDS briefing paper 3)
Middlesex: Tearfund, October 2004

Maintains that substantive international action on HIV and AIDS is not translating into effective responses for those worst affected by the epidemic, particularly children. Instead, it is community-based organisations and community initiatives which are most successful in reaching out to these children, often without external funding.

Available from: Tearfund, 100 Church Road, Teddington, Middlesex TW11 8QE, UK
Fax: +44 20 8237 8000 Email: enquiry@tearfund.org Web: www.tearfund.org
Free online: http://tilz.tearfund.org/webdocs/Website/Campaigning/Policy%20and%20research/AIDS_briefing_3_children_final.pdf

A last resort: the growing concern about children in residential care

INTERNATIONAL SAVE THE CHILDREN ALLIANCE
London: International Save the
Children Alliance, June 2003, 18 pages
Free online: www.savethechildren.net/alliance/resources/last_res.pdf

This paper sets out the International Save the Children Alliance's position on the residential care of children and highlights concerns about its growing use. It draws attention to an area that has largely been ignored as a rights issue for international attention and action.

Available from: International Save the Children Alliance, 2nd floor, Cambridge House,
100 Cambridge Street, London W6 0LE, UK
Fax: +44 20 8237 8000 Email: info@save-children-alliance.org Web: www.savethechildren.net

Building blocks: Africa-wide briefing notes. Resources for communities working with orphans and vulnerable children

INTERNATIONAL HIV/AIDS ALLIANCE
Brighton: International HIV/AIDS Alliance, January 2003

A set of seven booklets designed to support programme design and practice at the community level around children made vulnerable or orphaned by HIV or AIDS in Africa. The resources are all locally adaptable and are based on the experience of The International HIV/AIDS Alliance, its partners and other organisations. The six booklets are: Overview; Psychosocial support; Health and nutrition; Economic strengthening; Education; Social inclusion; and Older carers.

Available from: International HIV/AIDS Alliance Queensberry House, 104-106 Queens Road,
Brighton BN1 3XF, UK
Fax: +44 1273 718 901 Email: publications@aidsalliance.org Web: www.aidsalliance.org
Free online: www.aidsalliance.org/sw9170.asp

Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia

NYBLADE, Laura *et al* International Center for Research on Women, 2003

This report explores the causes and consequences of HIV and AIDS-related stigma in sub-Saharan Africa. It also discusses how people living with HIV react to stigma, and how they and their families and friends develop strategies to cope with stigma. Recommendations include the need to provide safe spaces to discuss values and beliefs about sex, morality and death, to find a common language to talk about stigma, and to ensure a contextually appropriate and ethically responsible role for people living with HIV.

Available from: International Center for Research on Women (ICRW), 1717 Massachusetts Avenue NW,
Suite 302, Washington DC 20036, USA. Fax: +1 202 797 0020 Email: info@icrw.org
Web: www.icrw.org
Free online: www.icrw.org/docs/stigmareport093003.pdf

Education and HIV/AIDS: a sourcebook of HIV/AIDS prevention programmes

WORLD BANK Education Team. Washington DC: World Bank, 2003

Education sectors of affected countries are playing an increasingly important role in the fight against HIV and AIDS. This sourcebook aims to support efforts by countries to strengthen the role of the education sector in the prevention of HIV and AIDS.

Available from: Education Advisory Service, World Bank, 1818 High Street NW, Washington DC
20433, USA
Fax: +1 202 614 5000 Email: eservice@worldbank.org Web: www.worldbank.org/education
Free online: www.schoolsandhealth.org/Sourcebook/sourcebook-complete.pdf [English]

Forgotten families: older people as carers of orphans and vulnerable children

HELPAGE INTERNATIONAL and INTERNATIONAL HIV/AIDS ALLIANCE
London: HelpAge International and Brighton International HIV/AIDS Alliance, 2003

This policy report examines the economic, social and emotional problems experienced by older carers, orphans and vulnerable children through case studies of community responses in Africa and Asia. It concludes with recommendations for action by national governments, international development institutions, non-governmental and community-based organisations.

Available from: HelpAge International, PO Box 32832, London N1 9UZ, UK
Fax: +44 20 7713 7993 Web: www.helpage.org
or from: International HIV/AIDS Alliance, Queensberry House, 104-106 Queens Road, Brighton BN1 3XF, UK
Fax: +44 1273 718 901 Email: publications@aidsalliance.org Web: www.aidsalliance.org
Free online: www.helpage.org/images/pdfs/HIVAIDS/ForgottenFamiliesReport.pdf

Policies for orphans and vulnerable children: a framework for moving forward

SMART, Rose
Washington DC: United States Agency for International Development (USAID), July 2003, 28 pages

A summary of the global orphans and vulnerable children (OVC) situation, and current policy responses. It is meant for individuals with strategic decision-making responsibilties for HIV and AIDS programmes. It defines what is meant by OVC and outlines existing policy frameworks in responding to OVC including international and national instruments.

Available from: POLICY Project, Futures Group International, 1050 17th Street NW, Suite 1000, Washington DC 20036, USA
Fax: +1 202 775 9694 Email: policyinfo@tfgi.com Web: www.policyproject.com
Free online: www.policyproject.com/pubs/generalreport/OVC_Policies.pdf

Succession planning in Uganda: early outreach for AIDS-affected children and their families

POPULATION COUNCIL
Washington DC: Population Council/Horizons, 2003

This summary paper describes and discusses a survey into the effects and outcomes of a succession planning programme. It discusses the background, context and methodology of the survey, before presenting the key findings.

Available from: Population Council, 4301 Connecticut Avenue NW, Suite 280, Washington DC 20009, USA. Fax: +1 202 237 8410 Web: www.popcouncil.org
Free online: www.popcouncil.org/pdfs/horizons/orphanssum.pdf

Children and HIV and AIDS: child-centred approaches to HIV and AIDS in Kenya

Kenya AIDS NGOs Consortium (KANCO) (Partner Vol 7 No 2 (Whole issue))
Nairobi: KANCO, September 2002, 8 pages
Available from: Kenya AIDS NGOs Consortium (KANCO) PO Box 69866, 00400 Nairobi Kenya
Fax: +254 20 271 4837 Email: kenaids@iconnect.co.ke Web: www.kanco.org

Games for adolescent reproductive health: an international handbook

PROGRAM FOR APPROPRIATE TECHNOLOGY IN HEALTH (PATH)
Washington DC: PATH, 2002

This handbook outlines how games can be used to provide young people with information and skills about sex and sexuality to protect them from HIV, other sexually transmitted infections, AIDS, unwanted pregnancy, abortion, rape, and emotional and physical violence.

Free online: www.path.org/files/gamesbook.pdf

Orphans and other children made vulnerable by HIV/AIDS: principles and operational guidelines for programming

INTERNATIONAL FEDERATION OF RED CROSS AND RED CRESCENT SOCIETIES (IFRC)
Geneva: IFRC, 2002, 35 pages

Provides guidelines and practical suggestions on how National Red Cross and Red Crescent Societies may help communities and families to strengthen their traditional coping mechanisms and meet the challenge of addressing the needs of orphans and other children made vulnerable by HIV and AIDS.

Available from: Administration Department, International Federation of Red Cross and Red Crescent Societies, PO Box 372, 1211 Geneva 19, Switzerland
Fax: +41 (22) 733 0395 Email: jeanine.guidera@ifrc.org Web: www.ifrc.org

Care for orphans, children affected by HIV/AIDS and other vulnerable children: a strategic framework

FAMILY HEALTH INTERNATIONAL (FHI)
Washington DC: FHI, 2001

Family Health International's strategic framework for setting priorities and developing responsive care and support programmes for orphans, children affected by HIV and AIDS and other vulnerable children. It describes projects in three countries.

Available from: Family Health International (FHI) Institute for HIV/AIDS, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201 USA
Fax: +1 703 516 9781 Email: publications@fhi.org or aidspubs@fhi.org (for HIV/AIDS-related materials) Web: www.fhi.org/en/HIVAIDS/index.htm
Free online: www.fhi.org/NR/rdonlyres/e7tlfsxscaediyd3udgnttghmzp3jks4bzrnjqujncru4nyoi7cfrcuqstrj7djufcu5gfvw3mm3ko/ovcstrategy.pdf

Child needs assessment tool kit: a tool kit for collecting information your organization needs for designing programs to help young children in areas heavily impacted by the HIV/AIDS epidemic (version 2)

TASK FORCE FOR CHILD SURVIVAL AND DEVELOPMENT
Decatur: Task Force for Child Survival and Development, December 2001, 269 pages.

The Task Force for Child Survival and Development was commissioned by the World Bank's Early Child Development Team to develop an assessment tool to help programmes address issues and the needs of young families and their children. The toolkit was designed to access the needs of young children (under 8 years old) in communities heavily affected by the HIV and AIDS pandemic.

Available from: The Task Force for Child Survival and Development, 750 Commerce Drive, Suite 400, Decatur, Georgia 30030, USA
Fax: +1 404 371 9098 Email: mrogers@taskforce.org or info@taskforce.org or ecd@worldbank.org
Web: www.taskforce.org
Free online: www.taskforce.org/pdf/AIDSkit.pdf

Expanding and strengthening community action: a study of ways to scale up community mobilization interventions to mitigate the effect of HIV/AIDS on children and families

PHIRI, Stanley Ngalazu, FOSTER, Geoff and NZIMA, Masauso
Washington DC: USAID, March 2001

The purpose of this study is to make a series of recommendations on how to scale up effective, sustainable community mobilisation and capacity-building interventions to mitigate the effects of AIDS on children and families in the countries most seriously affected by the pandemic. Recommendations for change are made in two main areas: programmatic methods and approaches; and global, regional, and national efforts to develop and implement effective strategies.

Available from: United States Agency for International Development (USAID), Development Experience Clearinghouse (DEC), 8403 Colesville Road, Suite 210, Silver Spring, MD 20910, USA
Fax: +1 301 588 7787 Email: docorder@dec.cdie.org Web: www.dec.org
Free online: www.dec.org/pdf_docs/PNACL778.pdf

Investing in our future: psychosocial support for children affected by HIV/AIDS: a case study in Zimbabwe and the United Republic of Tanzania

FOX, Susan (UNAIDS Best Practice Collection: UNAIDS Case Study Doc No: UNAIDS/01.47)
Geneva: UNAIDS, 2001, 75 pages

This study is intended for people who are concerned about, and working with, families affected by HIV and AIDS. Providing examples of successful interventions being undertaken by organisations in Zimbabwe and Tanzania, the report shares experiences of essential psychosocial support to children who are infected and affected by HIV and AIDS to stimulate new awareness of needs and to open new doors for action.

Available from: Joint United Nations Programme on HIV/AIDS (UNAIDS), V Building, Office 102, 20 Avenue Appia, 1211 Geneva 27, Switzerland
Fax: +41 22 791 4187 Email: unaids@unaids.org Web: www.unaids.org
Free online: www.unaids.org/html/pub/publications/irc-pub02/jc606-invfuture_en_pdf.pdf [English]
www.unaids.org/html/pub/publications/irc-pub02/jc606-invfuture_fr_pdf.pdf [French]

Learning to live: monitoring and evaluating HIV/AIDS programmes for young people

WEBB, Douglas and ELLIOT, Lyn
London: Save The Children Foundation, 2000, 219 pages

This handbook looks at the basics of monitoring and evaluation through the examples of Save the Children projects internationally. It deals with all stages of planning, monitoring and evaluation for project design and in particular participatory methods, which it identifies as most appropriate to interventions with young people.

Available from: Save the Children (SCF) UK c/o NBN International, Plymbridge House, Estover Road, Plymouth PL6 7PY, UK
Fax: +44 1752 202333 Email: orders@nbninternational.com or Web: www.savethechildren.org.uk or orders@plymbridge.com or www.nbninternational.com
Free online: www.savethechildren.org.uk/temp/scuk/cache/cmsattach/211_learning2livecond.pdf

Separation and loss

Telling our stories: children deal with loss, grief and transition

SIMMONDS, Felly Nkweto
[no date]

This is the product of a psycho-social project in Zambia with a group of orphaned and vulnerable children. It contains the children's own stories of how they have coped with bereavement and loss, and caring for dying or ill parents.

Available from: Care International Zambia, PO Box 36238, Plot 10799/10800 Dedan Kimathi Road, Kamwala, Lusaka, Zambia
Web: http://carezambia.org
Free online: www.synergyaids.com/caba/documents/telling%20our%20stories.pdf

Care for children infected and those affected by HIV/AIDS: a handbook for community health workers

SAVE THE CHILDREN UK
Kampala: Save the Children UK, 2003 91 pages

This handbook looks at ways to improve the provision of care and support to children infected or affected by HIV and AIDS. It provides basic information on HIV and AIDS, and assists carers in providing home-based care and counselling.

Available from: Save the Children UK, PO Box 1124, Kampala, Uganda
Fax: +256 41 230096 Email: scfukuga@imnl.com Web: www.savethechildren.org.uk
Free online:
www.savethechildren.org.uk/scuk_cache/scuk/cache/cmsattach/1099_HIVCareHandbook.pdf

Building resiliency among children affected by HIV/AIDS

MALLMAN, Silke-Andrea
Windhoek, Namibia: Catholic AIDS Action, 2002

A practical guide for caregivers and teachers consisting of a collection of ideas, theories, tasks and exercises to help people understand the behaviour and feelings of children affected by HIV and AIDS. The handbook provides practical advice on how to support children who have experienced loss and death in order to help them to cope.

Available from: Catholic Aids Action, PO Box 11525, Windhoek, Namibia
Fax: +264 61 276364 Email: info@caa.org.na Web: www.caa.org.na

Caring for ourselves in order to care for others: conference handbook

CATHOLIC AIDS ACTION (Caring for ourselves in order to care for others conference, Windhoek, Namibia 27-30 June 2001.)
Windhoek, Namibia: Catholic AIDS Action, 2001

It presents various coping methods, inspirational words and suggestions on dealing with the stress and grief of caring for people living with HIV and AIDS.

Available from: Catholic Aids Action PO Box 11525, Windhoek, Namibia
Fax: +264 61 276364 Email: info@caa.org.na Web: www.caa.org.na

Counselling guidelines on disclosure of HIV status

SOUTHERN AFRICAN AIDS TRAINING PROGRAMME (SAT) (HIV Counselling Series No 1)
Harare: SAT, 2000 15 pages

This booklet describes the importance of disclosure for people who are living with HIV. It covers the basics of effective counselling in the context of dealing with issues around disclosure.

Available from: Southern Africa AIDS Training Programme (SAT), 3 Luck Street, PO Box 390, Kopje, Harare, Zimbabwe
Fax: +263 4 752 609 Email: info@satregional.org Web: www.satregional.org

Source

Key list

» www.asksource.info

This list of resources was compiled by Source International Information Support Centre.
Key lists on many other subjects are available at www.asksource.info.
Healthlink Worldwide is a partner in Source.

Healthlink Worldwide, 56-64 Leonard Street, London EC2A 4JX, UK

www.healthlink.org.uk