



**Breaking the silence:
Memory Books and succession planning -
the experience of
NACWOLA and Save the Children UK in Uganda**

**Breaking the silence:
Memory Books and succession planning -
the experience of
NACWOLA and Save the Children UK in Uganda**

Sophie Witter



Save the Children UK is a member of the International Save the Children Alliance, the world's leading independent children's organisation, with members in 29 countries and operational in more than 100.

Save the Children works with children and their communities to provide practical assistance and, by influencing policy and public opinion, bring about positive change for children.

Published by
Save the Children
1 St John's Lane
Farringdon
London EC 1M 4BL
United Kingdom

© The Save the Children UK 2004
Registered Charity No. 213890

All rights reserved, copy or transmission of this publication may be made without written permission, except under the terms set out below.

This publication is copyright, but may be reproduced by any method without fee or prior permission, provided it is not for resale. Copying for resale requires prior permission from the publishers, and a fee may be payable.

Design and Layout: *Makau Ngola*

Contents

	Page
Acknowledgements	4
Abbreviations	5
Introduction	6
What is a Memory Book? What is it for?	7
The history of Memory Books in Uganda	9
Format of Memory Books	11
Costs of the Memory Project	12
Benefits for parents	13
Benefits for children	17
Benefits for NACWOLA	21
Benefits for the wider community	22
Constraints and issues raised during implementation	24
Links with other interventions	33
The impact of anti-retrovirals	33
Experiences from other countries in the region	34
Looking to the future: conclusions and lessons drawn	35
Other resources	36

Acknowledgements

Many thanks to all who have contributed to this booklet. They include:

- Children and parents in Kampala, Kasese and Arua
- NACWOLA staff and former staff in Kampala and in the districts, including Beatrice Were, Annet Biryetega and Rose Atibuni
- Save the Children staff and former staff, including David Maweje, Lucy Shillingi, Alfred Nimungu, James Acidri and Joshua Ainebyona
- Carol Lindsay-Smith in the UK
- Christiana Brown of Healthlink World Wide
- Staff of other NGOs in Uganda, including Beatrice Muwa of Plan, Grace Mayanja of World Vision and Betty Mwandha of TASO
- Staff of organisations implementing related projects elsewhere in Africa, including Catherine Ogolla of the Kenyan AIDS NGOs Consortium; Jennifer Inger of the Red Cross; and Jonathan Morgan of University of Cape Town, South Africa
- SC UK HIV/AIDS advisers, Doug Webb and Rena Geibel
- Alastair Penny for photographs

This piece of work was funded by the Dutch Government TMF funds, administered by the SC UK regional office in Nairobi

Abbreviations

AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-Retroviral
CBO	Community Based Organisation
CMS	Commercial Market Strategies
DHACs	District HIV/AIDS Committees
FIDA	The Federation of Women Lawyers
GoU	Government of Uganda
HIV	Human Immunodeficiency Virus
IMP	International Memory Project
INGO	International Non Governmental Organisation
LC	Local Council
MB	Memory Book
NACWOLA	National Community of Women Living with HIV/AIDS in Uganda
NGO	Non Governmental Organisation
OVC	Orphans and Vulnerable Children
PLWHAs	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PNFP	Private Not for Profit
PTC	Post Test Clubs
REPSSI	Regional Psychosocial Support Initiative
SC UK	Save the Children UK
SWAK	Society of Women and AIDS in Kenya
TASO	The AIDS Support Organisation
UAC	Uganda AIDS Commission
UGX	Uganda Shillings
UPE	Universal Primary Education
VCT	Voluntary Counseling and Testing

This booklet was written as part of Save the Children UK's institutional memory work in Uganda: looking to the experiences of the past 45 years' work, in order to bring out lessons for the future.

SC UK and NACWOLA wanted to document their joint work which led to development of the Memory Project for two reasons:

- it has been a very positive collaboration, and appears to have met a very real need in Uganda
- it is important to document the work so that others who are interested in adapting this approach are able to benefit fully from the experiences.

This booklet draws on the experiences of many people, including:

- parents and children in Kampala, Arua and Kasese who have participated in NACWOLA'S Memory Project and other forms of Memory Book work
- Save the Children and NACWOLA staff
- staff of other NGOs which are implementing similar projects in Uganda
- wider community members in project areas
- INGOs and other organisations across Africa that are using the NACWOLA model or developing their own versions of Memory Books or boxes

The original Memory Book ideas were developed in the UK in 1991/2* as a way of helping parents who were living with HIV/AIDS to document family history, traditions and important personal information for their children. These parents, many of whom originated from Africa, realised that if they did not live to see their children through to independence, the children were at risk of losing touch with their extended family.

The parents understood the importance of giving their children a sense of identity and making plans for their future care. But because most came from a tradition where children were excluded from important family discussions, they had not talked openly about their sero status, nor begun to prepare their children for the future.

They needed help to open up communications within the family and the Memory Book, originally a formula for recording facts, proved to be a tool for encouraging communication across the generations. In that sense its relevance is universal.

A Memory Book can be used in many ways. At its simplest, it is a book in which a parent or carer documents their memories of an individual child; his or her own background; and details of the child's parents and extended family.

** The original Memory Book was devised by Carol Lindsay Smith and Rory O'Brine and was first published by Barnardo's in 1992. In 1999 the original text was rewritten by CLS and a group of NACWOLA mothers and is now published by TALC UK under the title of Memory Book for Africa.*

In some families boxes or baskets, as well as books, have been used, to store important souvenirs. Children have also participated, either by helping their parents to fill in pages, or by making books of their own.

At NACWOLA, where the Memory Book ideas first took root in Uganda, it soon became clear that a lot more was or could be achieved than just producing a family scrap-book. For example, making a Memory Book could:

- encourage parents to disclose their HIV status to their children and/or to the wider community
- open up channels of general communication between parents and children, and so improve their relationship
- ensure that children understand their family's traditions and beliefs
- give parents an opportunity to state their hopes and advice for the future
- encourage a parent to make a will, so that the child's inheritance is more secure if the parent dies
- put children in touch with a 'lost' parent, such as a father, or the father's family
- help the parent to realise the importance of naming a guardian for their children and forge links between their children and the guardian
- encourage parents to plan for their children's future
- improve the self-image and self-esteem of HIV positive parents
- increase the child's knowledge of family assets and how to manage them
- increase the child's knowledge of HIV/AIDS and how to avoid infection
- help to raise awareness in the community and decrease stigma for people living with HIV/AIDS

As a result of the impact of the early Memory Book work, NACWOLA, with assistance of SC UK, decided to develop the Memory Project - a training programme for parents which would cover these and other related topics in more depth.

Experience shows that working with Memory Books or participating in the Memory Project is not solely applicable to families affected by HIV/AIDS, but should be integrated into programming to support orphans and vulnerable children, alongside other activities such as income generation, legal aid, psychosocial support, and improving access to education and health care.



The Memory Book is a tool for improved communication between the generations

In 1995, a retired social worker from the UK brought the Memory Book to Uganda. Out of many agencies which were shown the materials, NACWOLA (National Community of Women Living with HIV/AIDS) immediately recognised the potential value for its members, many of whom were struggling with how to talk openly with their children and prepare them for the future.

NACWOLA's then co-ordinator Beatrice Were was already campaigning to raise awareness of the crisis for children in families affected by Aids and she identified the Memory Book as a non-threatening intervention which could help parents to face their responsibilities. After successfully trying out the Memory Book with mothers in Kampala, NACWOLA approached Save the Children UK for technical support and funding in order to develop and extend the programme. Out of this partnership was born NACWOLA's Memory Project which has subsequently spread in various forms throughout Southern and Eastern Africa and to many other parts of the world.

The project objectives were to:

1. Relieve the mental stress of children affected by HIV/AIDS
2. Encourage dialogue between HIV-positive parents and their children
3. Reduce children's isolation when their parents die
4. Improve counselling for children
5. Strengthen family coping mechanisms
6. Improve children's understanding of their situation.

In 1997, a needs assessment was carried out in Kampala with adults and children, which revealed a demand for the project, especially by children. As a result, a one-week training of 30 trainers was carried out in Kampala. This led on to development of a training course of five days for mothers, focussing on:

1. Child growth and development
2. Parenting

3. Will-making
4. Communicating with children and family members
5. The Memory Book and how to use it
6. Preparation for separation
7. Disclosing one's status to the children

One child per family was also trained in a separate course for children covering:

- Child growth and development
- Communication
- Life skills
- Children's rights
- Caring for the sick
- HIV/AIDS & sex education

30 parents and children from each of the five divisions of Kampala were chosen to be trained in the first phase in 1997 (i.e. 150 in total). Afterwards, they were supported with home visits and counselling to go through the process of disclosure, making Memory Books and planning for the children's future.

After the pilot phase, which was positively evaluated, SC UK agreed to support its extension to other districts. In 1999, the Arua branch of NACWOLA was supported by SC UK to start activities. Since then, 10 members have been trained as trainers; 20 zonal facilitators have been trained; 232 parents have had training in Memory Book writing; and 70 youth have been trained in peer education and life skills.

SC UK later supported the establishment of NACWOLA branches in Kasese, after a needs assessment there in 2001. The aim in Kasese was to integrate the Memory Book work with the counselling and home care programmes, based in three hospitals in the district.

Other international organisations also supported Memory Book work in their project areas in other parts of Uganda. The AIDS Support Organisation (TASO) started working with NACWOLA in 2001, integrating Memory

Books into their support services for HIV-positive clients who have children, are literate and are interested in participating. Plan International has been supporting Memory Book work as part of their succession planning since 2000, working with post-test clubs in Luwero and Tororo. World Vision started working with NACWOLA in 2002, training home visitors in Luwero and Masaka to integrate Memory Book work into their succession planning component of the Orphans and Vulnerable Children (OVC) programme.

In 1999 Carol Lindsay Smith worked with a group of eight NACWOLA mothers to adapt the original text of the Memory Book, to make it more relevant for use in Africa. This version is called 'The Memory Book for Africa.' It has since been translated into Luganda, Swahili, Lukonjo, Lugbara and other local languages.

The Memory Project Training Programme went through several revisions and was produced in manual format in 2002. It is now being adapted into modular form by Healthlink World Wide as part of a scheme,

funded by Comic Relief, to disseminate the Memory Project ideas to other African countries. This programme is known as The International Memory Project (IMP).

Since its start in Arua, 386 Memory Books have been completed. Most of these were by women, though some are by men. About 75% of books which were given out were completed. Some parents died before they could complete them, and others dropped out. Most of those who completed them also disclosed their status, appointed guardians and drew up wills. In Kasese, 145 mothers have joined, with over 185 children. Of these, around 85 have fully completed the process. Children have been involved to varying degrees in the process of developing the books.

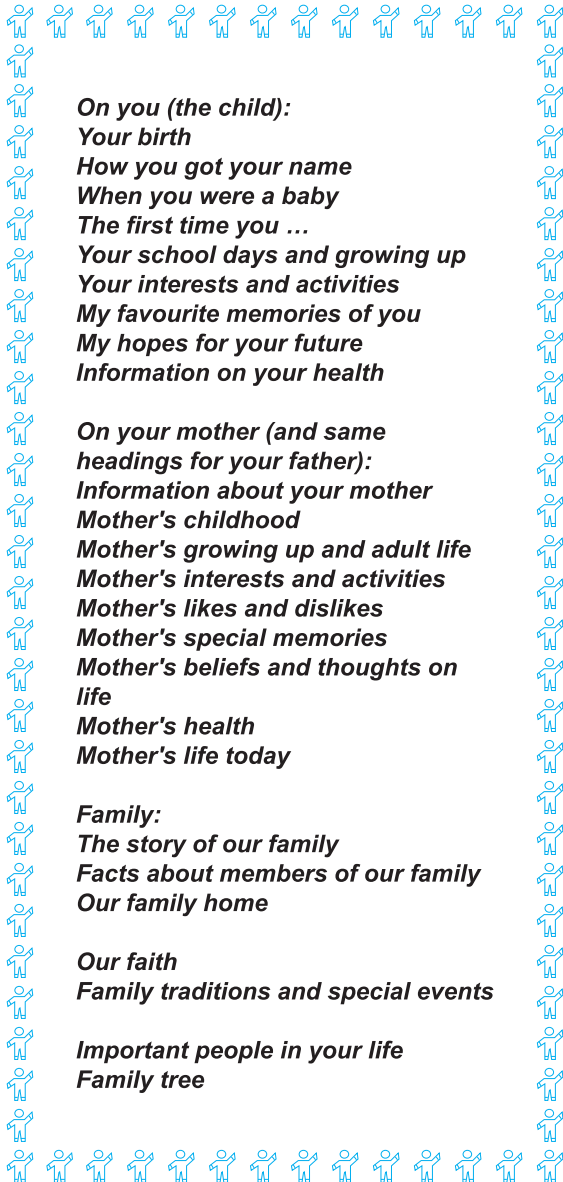
In total, about 20 districts of Uganda have had Memory Project training and are using the Memory Books. In some cases, NACWOLA is implementing, with external support. In other cases, they have provided training inputs.



Mothers support one another in completing the books

The Memory Book for Africa gives general advice on how to go about making a Memory Book and suggests topics which parents or carers may want to cover.

Examples of topics include:

- 
- On you (the child):**
 - Your birth**
 - How you got your name**
 - When you were a baby**
 - The first time you ...**
 - Your school days and growing up**
 - Your interests and activities**
 - My favourite memories of you**
 - My hopes for your future**
 - Information on your health**
 - On your mother (and same headings for your father):**
 - Information about your mother**
 - Mother's childhood**
 - Mother's growing up and adult life**
 - Mother's interests and activities**
 - Mother's likes and dislikes**
 - Mother's special memories**
 - Mother's beliefs and thoughts on life**
 - Mother's health**
 - Mother's life today**
 - Family:**
 - The story of our family**
 - Facts about members of our family**
 - Our family home**
 - Our faith**
 - Family traditions and special events**
 - Important people in your life**
 - Family tree**

Parents may not wish to fill in all of these topics, and may want additional space for some of them, so loose-leaf files are commonly used. Flexibility and durability are the key requirements.

It is important to stress that there is no fixed format for a Memory Book . People can be as creative and individual as they like. The important thing is to include what is significant to them and their children.

The main cost items for the implementing groups are:

- Training
- Community mobilisation
- Monitoring and support
Providing tools (the books, and any other materials required, such as pens, glue and assistance with photos).

For the families, the costs are:

- Time
- Books
- Any other materials, such as photos, glue etc., where these are not funded

NACWOLA estimates that it costs a family an average of 6,000 UGX (\$3) to complete one book. That cost includes a hardback exercise book, a pen and around 8 photos. Time costs are not included. Although it may seem small, many members are unable to meet these costs, particularly if they have many children.

The costs of training clearly depend on the venue and the distances which members are travelling. NACWOLA estimates the cost at \$60 per member, for the five day training. This estimate includes a small payment for the facilitators, the venue hire, materials, day allowances for food and accommodation, and travel costs. Plan International carry out a longer 10-day training and this costs \$50 per participant.

Follow-up and monitoring are very important. The process of disclosure and writing is emotional, and members usually require on-going counselling and peer support. This has not been costed, and will be very variable.

Where the support organisation is decentralised and members are close together, support can be provided at relatively little cost as part of other activities. The further afield the groups and more centralised the structure, the harder and more expensive the follow-up will be.



Support and follow-up are vital to Memory Book work

Carers (mostly, but not exclusively, mothers) have noted a number of benefits of the project for them.

Improved relationship with their children

The needs assessment prior to project implementation found that children were often the last to find out about their parent's illness. They were left to guess or hear from others. The Memory Book and the training have encouraged women to talk to their children about their sero-status.

I wouldn't have told the children without the Memory Book training. It was too hard. But now that I have done so, there is a big change. We have built confidence in each other. I encourage them. They encourage me. And we face life together.

Kasese mother

This has brought them closer, as the children get involved in caring for their parents and thinking about the future.

My attitude and treatment of my children has improved since they know my problems. Mostly we now take collective decisions about our life

Arua mother

These books have brought us closer to the children. We used to be distant.

But now there is improved communication between parents and children. The children are free to ask questions which they used not to be able to, and they now know lots more than they used to.

Kasese mother

I was one of the bad mothers. I used very bad language. But now I have really reduced on that.

Kampala mother

I used not to sit with the children or to listen. But now we are very close. The children say how much I have changed. We are a happy family – we share, laugh and talk, even if we don't have any supper. We love and support each other.

Kampala mother

It was found that it was very powerful, very emotional. It revealed a lot to all parties. For the first time, parents were looking at things from a child's point of view

*Carol Lindsay-Smith
Initiator of MB*



*Planning together
with your children*

Improved care and protection of children

Many mothers say that they used to be harsh and critical towards their children, but the Memory Project training course has taught them to respect children more and be kinder to them.

Similarly, in Kasese, women reported that where previously they would not have bothered to take a child to hospital (feeling that they were probably HIV-positive, and treating them was therefore a waste of time), they now take better care of their children.

Improved life skills for children

Parents felt that their children were better off than the children of HIV-negative parents, as they have been actively teaching them life skills, so that they can survive after their parents have died.

Improved planning for children

They have started to think about the children's future and make concrete plans with them for how they will survive.

Improved health

Many mothers felt that they would have died earlier without the emotional support of the project, as well as the greater care which their children had provided since they learned of their mother's condition.

There were things that I kept closely to myself and which affected me psychologically. It was a great relief to disclose. Since then, my children have given me all the care and attention that I need. They are aware of my vulnerability and are very helpful.

Kasese mother

I used to want to die, as everyone was talking about me. Now I am much more confident and at peace with myself and others

Kasese mother

Membership of NACWOLA and participation in the project also opened up benefits, in some areas, in the form of reduced treatment costs or access to subsidised drugs. (This was dependent on local funds, though, and not automatic.)

Participants also felt that they were better able to care for themselves and one another.

We are very different from other people living with AIDS. We know how to treat ourselves for opportunistic infections. We are also more open and so able to seek advice. Through meetings, we share information, which helps us to survive. We deal quickly with sicknesses and live longer.

Kasese father

Restored relationships with in-laws

In families affected by HIV/AIDS there is often a lot of recrimination, with blame laid for infection on the husband, by the wife, or on the wife, by the husband's family. Through the Memory Book process, many women stated that they had learned to lay that anger aside, and to seek improved relationships, for the sake of their children.

I used to have a poor relationship with my in-laws, who blamed me for the AIDS. But after the course, I learned to communicate with them, and we have resolved it.

Kampala mother

Positive living

For many women, positive living took on a real meaning in this project, as they were able to open up, to accept their status, and to move forward in a courageous way.

When I found I was positive, I was full of fear. I thought I would die tomorrow. But now I know that I am still strong, and that I am still useful. I am doing my best to plan for my children

Kampala mother

Improved confidence

They feel freed from fear and guilt, and are now empowered to speak to children and the wider community. The women have created drama groups to pass on messages. They have become counsellors to others.

The communication skills have also enabled me to improve my relationship with relatives and the wider community with whom I can now speak openly about HIV/AIDS
Arua mother

I used to deny the rumours to my children. But when I came back from training, I told them the truth. I had the morale and vigour to cope with HIV/AIDS.
NACWOLA member, Kasese

They also noted that their children are more confident and are able to pass on messages to other children.



Children can take positive messages to their peers

In our villages, we are now being called 'doctors' because people feel we are now versed with HIV/AIDS information
Kasese mother

Reduced isolation

Through the project and membership of NACWOLA, women are able to support one another and gain support from their children too. They no longer feel so alone.

In the Memory Project, I am part of a community of people living with HIV/AIDS
Arua Mother

The Memory Books are an entry point to look at our lives critically and develop family support systems.
Kasese mother

The zonal facilitators are able to mobilise community support for members and to link members with services (often accompanying them to hospital and back, for instance).

We have taken it upon ourselves to meet regularly to comfort one another and receive counselling, and we feel very happy
Kasese mother

Before we were all quiet, even in NACWOLA. We met, but went home with our problems unshared. Now we are able to discuss and to support one another.
Kampala mother

Improved benefits from counselling

The Memory Project training and process of making Memory Books has, according to counsellors in VCT centres, made their jobs much easier. It has reduced their clients' fear and made them much more able to talk through issues.

Before the Memory Book, it was very difficult to get information from clients. They never spoke about the death of their partners, for example. Now, they can speak about these things with the counsellor, and also with others, including their children.
Kasese counsellor

Increased knowledge of HIV/AIDS

Through the training, the knowledge of HIV/AIDS by participants has been greatly increased. They are now often treated as community resource persons, carrying out drama and other sensitisations, and giving advice to friends and neighbours on AIDS-related issues.

I have been exposed to several national and district HIV awareness workshops where I have learned a lot about AIDS management
Arua mother



The Memory Book process can help clients to open up to counsellors

Precious memories

For many of the children, especially those whose parents died young, their Memory Books are one of the main sources of memories of their parents. This is particularly valuable where both parents have died. Some books are partly filled by parents, and then completed by others, such as guardians and children, after their death.

In some cases, co-wives fill them out for children of another wife who has already died. They combine important factual information (such as where the family comes from, and what their customs are) with more personal thoughts about the parents and their recollections of and wishes for their children.

My father died when I was little and this book contains all the records we have and memories of him
Boy, aged 9

I have completed three books for my brother's orphans, and now want to do books for my own children (even though I am not positive). They are happy to know about their parents. Their favourite parts are the stories from their childhood.
Male guardian, Kasese

Although the books were initially conceived as being filled in by mothers or parents, in practice children have been involved, especially where parents are not confidently literate. This builds communication between parent and child, and should be encouraged.

The children love their books. They want to take them around with them. They write in them and add extra special memories of their own.
Kampala mother

Improved relationship with their parents

It was generally felt that before the project, parents had been harsh with their children. It is not clear why suggested a number of possibilities, including:

- the fact that they felt the children needed to be prepared for a hard life
- their ignorance of child development and lack of parenting skills
- their frustrations at their own condition

Our relationship with our step-mother is better since the project. She has a different way of looking at us, and at life. She is more open, more encouraging and more understanding.
Girl, aged 17, Kasese

Whatever the causes before, children felt that the relationship had improved as a result of the project. Mothers were more caring, and also more open. In response, children were able to take more responsibility in helping with family problems. Both children and parents noted that children now helped with family businesses and took greater care of their parents.

This project really broke the silence between parents and children. Before most parents' talk took the form of instruction or rebuke. They did not listen.
Plan coordinator

People who have done the Memory Books and gone public handle children differently. They know that children have rights and don't overwork them. They give them freedom of thinking and speaking. Their communication style is much improved, and they are more caring.
Kasese counsellor

Preparation for separation

Disclosure has also provided reassurance for children, who previously suspected what was happening, in many cases, but had not been directly informed.

Disclosure has eased children's stress, and created a sense of trust in the family unit. A spirit of support which was not there before has been built.
NACWOLA coordinator, Arua

At the same time, it is a vehicle which encourages parents to talk with children about their eventual death and to prepare them for life afterwards. This is of course a mixed experience. Nobody likes to think about death. However, if sensitively handled, it can reaffirm bonds and provide a strong basis for planning and positive living.

My children now know about HIV, death and separation. They do not like to talk about it though. They still fear it.
Kampala mother

Benefits to their parents

Children also recognised the benefits to their mothers, saying that they were more confident, that they now had a recognised role in the community, and in some cases had improved literacy skills as a result of the project. Many expressed pride in their mother.

Having a guardian

Almost every parent is able to identify a guardian, and children are usually consulted about which person they feel closest to. In more traditional areas, the guardian is most commonly a paternal uncle (who would traditionally have taken responsibility for his brother's children). In less traditional areas, such as cities, a member of the mother's family, such as her sister, or even a friend, may be chosen.

Greater knowledge of HIV/AIDS

Most children thought they had gained knowledge of HIV/AIDS and how to prevent it through the project. More importantly, they felt they were more likely to be motivated to follow the advice, given that they had witnessed parents dying of AIDS.



Both my mother and my father died of AIDS, so I feel the need to take care of myself. I do not go around with men.
Girl, aged 17, Kasese

Children can handle the truth, if it is conveyed sensitively

The level of awareness of children of the group is so high compared with other children. They have had practical experiences and have talked about their feelings with their parents.

They tell their friends about HIV/AIDS: what it is; how you get it; how you avoid it etc.

Kasese mother

Life skills

The Memory Books are also a vehicle for passing advice and guidelines from parents to children.

My mother cautions me to be honest and good mannered; to share what little I have with my younger siblings; to avoid premarital sex; and to take my education very seriously

Arua girl

Children have learned to report cases of men approaching them for sex, a thing that used not to happen. This was attributed to the live testimonies that women had made about HIV/AIDS.

NACWOLA member

Better knowledge of family assets

Children felt they had a better knowledge of the family assets as a result of the memory book process, in which parents document family assets and discuss them with their children. In some cases, children had become more involved in managing them too. In Pajulu, Arua, a boy reacted by planting trees around his family plot, so as to have a future income source for his school fees.

Greater knowledge of children's rights

Children in Arua noted that they had gained a greater awareness of children's rights. The evaluation of the work in Arua (see resources section) states that: 'the memory book has radically enlightened children about their rights. The children think about themselves as active members of society'.

Protecting property

Although the books are not legally binding in their own right, there is a tradition of respect for the dead, and where the deceased's wishes have been clearly laid out, it is hard for relatives or others to flout them.

Given the difficulty that many report in making wills (see below), the books can act as a de facto will in stating clearly the parent's wishes for their property and the care of their children after their death.

In Kasese, members reported that Memory Books are read during the funeral, so that all of the community is aware of their content, and that they are almost always respected.

The will is read out during the funeral and is highly respected. Whereas, if there is no will, clan heads decide how to allocate properties, and they tend to allocate to adults, rather than children.

SC project officer

Reduced stigma

Although stigma remains, most report that it has reduced, in part due to the project. The memory book activities and related campaigns by NACWOLA are said to have generated a positive reaction to positive people by the general community, compared with the previous negative one.

Stigma and discrimination is no longer so pronounced as it used to be before this intervention'

District Information Officer, Arua

The right to play and interact with other children has been improved. Our children used to be intimidated by others about our sero-positive status.

NACWOLA member, Kasese

Stigma levels are very low now. We talk openly about ourselves, so people can't gossip any more. Even those who are HIV-negative are joining our campaigns

Kasese mother

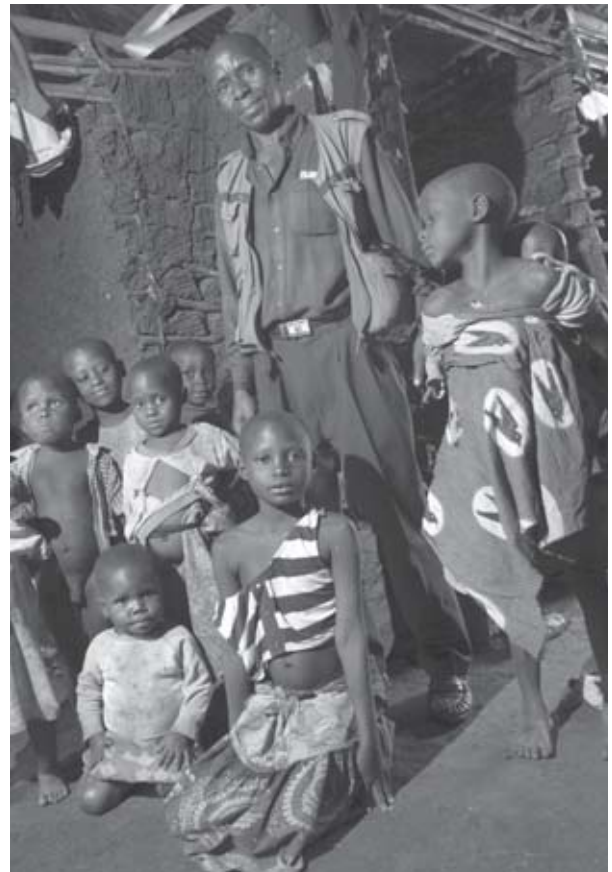
As a result, their children get more sympathetic treatment, including in schools, where fees may be waived or accepted late (rather than 'locking out' defaulters, as they would usually do).

Wider support structures

Children were often very lacking in knowledge of their extended family, especially on the father's side. This is exacerbated by separation and by the fact that children in the same family are often from different fathers.

After being involved in training and starting to document their experiences, many mothers were able to trace the children's paternal relatives and to forge links between them and the children. Many children said that they now had a better knowledge of their wider family, which provided hope for the future, if their mother and father died.

In Ugandan culture, the children are seen as belonging to their father's clan. If they lack knowledge of that clan, they are 'lost persons', without identity, so this aspect of the Memory Books is particularly valued by children.



Most orphans are taken in by family members, if they can manage it

Before the training, I was full of anger. I shouted and ranted at the children. Later, I realised that I had made them hate their father, so that they never visited his grave. I started to be more positive and supportive and to reduce my anger. The children now want to stay in touch with their relatives on the father's side, and the in-laws are happy to keep links with the children.

Kampala mother

NACWOLA has gained prominence and recognition, internationally and locally through its memory book work. This has helped it to gain funding from other organisations within Uganda and also internationally, so that it can support related work in other countries.

Nationally we are really well known and many have come here to see the work. It has put NACWOLA on the world map
NACWOLA member, Kampala

In the districts, this is reflected in, for example:

- increased membership
- an increased number of branches
- gaining a place on HIV/AIDS bodies, such as the DHACs (District HIV/AIDS Committees) and being included in the integrated AIDS workplan for the district
- gaining funding from district HIV/AIDS funds in Arua to extend the memory book work
- being invited regularly to talk at public meetings
- increased media citations
- being invited to carry out training in other areas

Because of the Memory Book project and its benefits, the membership of NACWOLA has increased considerably. Even people who are HIV-negative are interested in participating in the book writing... NACWOLA members are recognised and respected in the community and the community is willing to support functions of the organisation
NACWOLA members, Arua, in impact monitoring meeting

Indirectly, the prestige and experience gained in the memory project helped NACWOLA gain funding for its resource centre in Arua.

In Kasese, the formation of the NACWOLA branches came about due to the memory project, though they now play a wider role, including sensitising the community on HIV/AIDS issues.

It has raised the profile of NACWOLA in the district, and also of people living with HIV/AIDS. Before the launch in 2002, nobody in Kasese had ever heard a public statement by an HIV-positive person.
SC project officer, Kasese

Within NACWOLA, participation in the Memory Project has also raised the awareness and skill levels of members.

There is a marked difference between those in NACWOLA who participated in the Memory Book project and the ones who haven't. There is a greater openness and ability to communicate with children, as well as a more positive approach to HIV/AIDS by them and their children.
SC project officer, Arua



Memory Books can combine with other activities, such as income generation

The Memory Book project demonstrated that people with HIV, and women at that, can make a difference in their own lives. They are not just recipients, but someone who can play a role. It also demonstrated for the first time that people (HIV-positive or not) can talk about subjects like death or sex. Death, that great taboo, can be demystified.

*Beatrice Were
Former NACWOLA coordinator*

Contributing to general attitude changes is one of the main by-products of the project. As noted above, attitudes to HIV-positive people have changed for the good in most communities over the project's lifetime.

The image communities had of people living with AIDS has completely changed. There used to be lots of stigma. But now they are seen as similar to any other people.

SC project officer

Other attitude changes are also reported. In Save the Children's impact monitoring meetings in Arua and Kasese in 2003, a number of general benefits to the community were mentioned, though it is hard to ascribe these to any one element of the HIV/AIDS programmes there (which go beyond memory book work). These included:

- reduced HIV prevalence (from around 30% in 1998 to 5-10% in 2003)
- increased utilisation of voluntary counselling and testing

It is educating the community in forward planning, and reducing stigma. It also raised the status of women, who traditionally are not involved in family affairs. Now women are strengthened, and others appreciate it as the women are now better able to help their families.

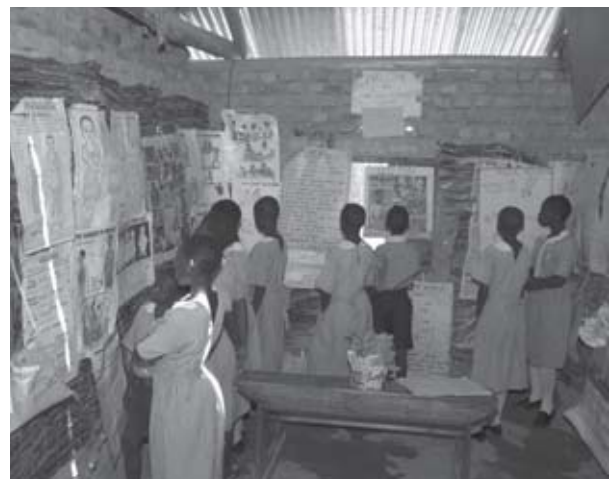
LC I chair, Kasese

- reduction in unwanted pregnancies
- increased school enrolment
- reduction in 'destructive habits' of the youth, such as 'mairungi' (cannabis) chewing
- preferential treatment for widows and orphans by LCs, compared with before.

For most of the clients who come to our office for VCT, when asked where they got the courage they normally refer to the influence of NACWOLA AIC trainer, Arua

In Kasese, institutions such as schools have taken up the AIDS messages passed by NACWOLA members and are actively promoting safe sex and uptake of services such as VCT. They are also adopting a more sympathetic attitude to children infected and affected by AIDS.

At the same time, the memory book work has reinforced the post-test clubs based in health centres with testing facilities. It has made them more active and attractive. The memory book trainees have been used to take messages into the communities, and have been a resource for other organisations (e.g. promoting condoms for CMS, a social marketing organisation, in Kasese).



Schools have joined the campaign to change attitudes

The local councils (LCs) are appreciative of the project, as they reduce disputes over property after parents die (disputes which the LCs would have to mediate) and make care arrangements for children smoother.

The memory book, with its emphasis on written documentation, is contributing to a general cultural shift away from oral record keeping. Just as people are starting to register their children and to get written land titles, so the idea of writing wills and writing memories is likely to grow over the foreseeable future, though it is still a very strange concept in rural communities at present.

The Memory Books help us to identify who will look after the children after death. They help us to protect properties when someone dies in the villages. They give clear plans for the LCs to follow. We don't need to make difficult judgements.
LCI chair, Kasese

Drop outs

Figures vary by project and area, but on average, a third of people who have been trained fail to complete their books, due to different factors, including illiteracy, ill health, death, poverty, fear of stigma, emotional stress and lack of time, confidence or access to information.

Time is a big constraint. The members need to work, so meetings often have low attendance. Survival needs come first.
SC project officer

Illiteracy

Illiteracy is a big constraint to a project involving writing. Although members can get support from one another, from outsiders or from their children, illiterate parents are much less likely to persevere with recording.

They have concerns about confidentiality and are also concerned that what is being written on their behalf may be different from what they are saying. Where resources are available, tape-recording is a solution. However, in rural Uganda, this was not practical.

I started a book for my youngest son, but it is hard. I am illiterate and rely on my nephew to help. He rarely has time and I have not completed yet
Kasese mother

Children who are not going to school are also less likely to appreciate and be able to benefit from books made for them. Although UPE (Universal Primary Education) is reducing the proportion of out-of-school children, illiteracy or low literacy of children is still a big problem.

One option for the adults is to combine the memory book with functional adult literacy training.

Another option, which was tried in Kasese, is to develop peer support by encouraging ‘veterans’ to link with new members. Illiterate parents were also encouraged to bring a ‘helper’ to the training (e.g. a family member who had agreed to help them with the writing). These measures will increase activity costs though.

Health

Despite the abolition of user fees in Uganda, accessing health care is still a big problem for the poor. Public health units usually lack the drugs which are needed for treating opportunistic infections.

Clients have to buy them from the private or private not-for-profit (PNFP) sectors. In some areas, grants allow subsidised access for HIV-positive patients, but funds are often insufficient, and even with the subsidy, treatment can be unaffordable.



Accessing drugs is still a big problem for the poor in Uganda

Factors limiting project coverage

The availability of funds for training and follow-up is of course a key limiting factor in project expansion. Another issue is the strength of the implementing partner and the existence of VCT centres which are able to host memory book activities. In the case of Kasese, for example, there were only three centres which were able and willing to get involved, which means that coverage is limited to less than half the district. In the case of Arua, NACWOLA's network outside the municipality was more limited, making it harder to support people who were trained in the rural areas.

Disclosure

Not all parents are willing to disclose their status to their children, even after training. In Arua, it was found that parents who had been open were more likely to complete their books.

It is however possible to write in secret and leave a written record, though many of the communication benefits will not be realised in that case.

Plan International also found that a substantial proportion – maybe 30% - of those who completed books had not been able to discuss the issues face-to-face with their children, but were leaving the books to be read after their death.

Of course, disclosure can also be mishandled, and can frighten and alienate a child. In one case, disclosure (prior to the training course) led the member's child to run away, and contact has never been resumed.

However, once they have gone through the initial fear and anger, children usually appreciate knowing the truth and are able to develop a stronger relationship with their parent.

Reasons for non-participation

Many more who might join and might write Memory Books exclude themselves because they are not willing to be publicly identified as HIV-positive. This appears to be particularly true of the middle class, who have jobs and official positions to lose, and also have less time to spare. Generally speaking, NACWOLA members are unemployed and relatively poor.

They tend to be widows with children (and often children of different fathers). They feel they have less to lose and more to gain (in particular, peer support and knowledge) by joining an organisation which effectively labels them as 'sufferers'.

People who join tend to be peasants – salaried people are too busy and have status to lose by being open. They are more likely to be women and to be sicker. This creates a bad impact, as people assume that only the poor get HIV/AIDS, or that only women are affected (and infecting)
Kasese counsellor

In some cases, being known to be positive or affected is an advantage, however – for example, where scholarships are restricted to AIDS orphans, or when treatment is available at subsidised rates from PNFP facilities for HIV-positive people. In these situations, there is a risk of people making false claims to be HIV-positive in order to secure benefits.

Getting information

Memory Books are usually written after one parent has died of AIDS. It is common that the husband is not open about his condition, does not prepare his wife for his death, and indeed keeps secrets from her about property. This is even more likely when there are several wives. In this case, women can struggle to fill in information about their children's father. Where they have children by different fathers, the problem is even greater.

Not all parents are in touch with their in-laws, and so collecting information on the other side of the family was not always easy. Some reported that their in-laws suspected them of collecting information for bewitching.

People in urban areas often face the greatest difficulties. In Kampala, for example, women may never have been legally married, and may have lived with someone from a different part of the country. They often lack even the most rudimentary information on their partner's background.

In some cases, guardians or step-mothers have to fill in information on both parents retrospectively. In this case, the task is doubly difficult. However, with commitment, many do manage it.

Finding a guardian

Some parents said that it was hard for them to find someone who was prepared to take on the guardianship of their child or children in the event of their death.

Even my own sister told me off that these days it is irresponsible for one to expect others to look after your child after you die'
Arua mother

In other cases, guardians themselves are HIV-positive, and may die before the parents. Others are willing and fit, but already overburdened with children. In some instances, the parents have made the oldest child guardian, and this can work, especially if they are supported after the parents' deaths.

Parents are sometimes unwilling to mention one person alone, fearing that others may not take responsibility for the children if they are not named. They choose to spread the risk by naming several 'important people'.

Some of the people trained in memory book writing are the guardians, who have already assumed responsibility for their relatives' children.

Difficulties in making a will

It is a cultural belief in Uganda that the act of making a will is an invitation to death. It therefore requires a lot of sensitisation to break this taboo. Another comment is: 'how can I make a will when I have so little property to leave?'

Cost is also an issue, even when using the simple version provided by FIDA (a women lawyers association). Typing and photocopying can cost up to \$15 per will. Where properties are scattered, the wills are more complex to draw up. (Few people have written land titles, so even describing locations can be difficult.)

In the groups visited, between 20 and 50% of those trained had made wills. In some areas, the Memory Books were regarded as equivalent to wills, and equally respected. However, there is no specific section in them on inheritance, and the books themselves have no legal status.

Costs of filling out books

Books which are sturdy enough to last and to which new sheets can be added are not cheap.

The books printed by SC UK in Kampala cost around \$15 per book. As the project went on, cheaper ones were substituted in the district, but these were more flimsy. Families also have to provide photographs. These costs are a deterrent for many.



Survival needs have to come first

Economic problems

The Memory Books do not address underlying economic problems, and many NACWOLA members felt that it was hard to visit households and not have anything concrete to offer to help with chronic poverty.

I make some home visits but it seems like a mockery to visit a colleague who is terminally ill empty-handed
NACWOLA member, Arua

Widows are generally expected to care for their children on their own. The most that widows can hope for from their in-laws is a supportive attitude and interest in their children. Financial support is rare. In the case of the children, economic problems mainly translate into concerns about education.

Most of us poor orphans go to school to spectate when other children are studying because we have neither books nor pens or pencils to write with... We are charged the same fees, expected to have uniform and chased away from school every time we default on any school requirement
Arua girl

In order to address the economic issues, Memory Books should ideally be combined with income generation measures. Plan International has tried this in Uganda but has had some problems with the capacity of its partners to implement IG components effectively.

Sustainability

NACWOLA members are volunteers, so they are expected to support project activities in their free time. Yet they have to make a living, and in many cases are not in good health themselves. This limits the amount of support and home-visiting that they are able to provide to others.

The evaluation carried out in Arua of the Memory Book project strongly recommended broadening community and other stakeholder involvement.

There is no magic bullet for sustainability, however. In Kasese, counsellors at testing centres were trained, so that they could promote memory book work through their day-to-day contact with clients. The counsellors themselves are semi-volunteers, though, and also lack funds to train and follow up new recruits.

The project is good but needs a lot of follow up. You have to keep up the momentum.
Kasese counsellor

It is also hard to organise peer support networks without outside funds for other activities. If women are coming together for handicrafts, or children coming together with some funding for leisure pursuits, they are enthusiastic. Without such organised activities, however, attendance tends to drop off rapidly.

Most of the funds for AIDS care activities in rural areas of Uganda are currently coming from the charitable and private not-for-profit sector. This limits long term sustainability. However, there are signs that funding through public channels will be increasing in the near future.

One issue we investigated was whether there was any mimicry from friends, relatives and neighbours – had any other families copied the memory book approach without being trained? It seems that this has not been the case. The skills and attitudes imparted by the training are considered to be critical by local partners.

This means that coverage in these districts has been relatively limited. However, in other places, according to Carol Lindsay-Smith, people have been inspired to fill out Memory Books on their own (guided by the ‘Memory Book for Africa’ booklet), without being part of a wider project.

We don't think it's possible to disclose without the training. People would lack the skills. Or, if they do disclose, they would do so in the wrong way.
Kasese counsellor

Involving men

The first needs assessment carried out in Kampala found that children wanted their fathers to be involved. This is important, but has not been easy.

Elites, most especially men, are stuck in the culture of silence that the Memory Project decampaigns
NACWOLA member, Arua

In Arua, most of the participants were women, which is not surprising given the mandate of NACWOLA. Other organisations, like TASO, which are not gender-biased, still found that men were less willing to participate than women.

In Kampala, all of the trainees were women, as they were all NACWOLA members. However, in the districts, training was carried out for members and non-members. For example, in Kasese, any Post-

Test Club member with children who was interested in joining was free to get involved. On average, up to 20% at most were men. Many men come for testing, but relatively few join the PTC, and even fewer the memory book group.

This poses a problem, especially in cultures where men usually control resources. Women are trying to plan for their children, but both the children and the family assets are at least nominally controlled by men. It is very important to address these legal and cultural gender issues, if the memory project is to be effective in its goal of sparing children additional trauma after the death of their parent.

Maybe that is why many women are not making wills. What would they put there? All of the resources, including the children, belong to the man's family. Unless we target men, we cannot achieve security for our children
Beatrice Were,
former NACWOLA coordinator



*Some men have got involved,
but they are in a minority*

In Arua, a men's equivalent to NACWOLA is being set up. Whether it will take up the memory book approach is yet to be seen.

Training capacity

NACWOLA has experienced a number of practical constraints in terms of training. These include:

- A shortage of trained trainers and the continuous loss of trainers through illness, death, and migration
- Delivering the training imposes heavy emotional toll, particularly on trainers who are themselves HIV-positive
- Many trainers are inexperienced in the training role, some probably having had only a ten-day training of trainers before embarking on such complex and emotionally charged topics
- Trainers are often working with participants who have very limited education and/or no previous experience of formal training
- In most areas there is a shortage of supplementary training resources and equipment and many trainers are working with minimal backup and supervision

Other issues

Rural-urban differences

Some key informants felt that the memory book work is easier to implement in rural areas. People are less busy with income-generating activities and more willing to spend the time. They are also less likely to be distanced from their in-laws. In rural areas, relationships with in-laws tend to be closer, because of proximity, compared with city families, where the wife may never have met her husband's family – and in extreme cases, does not even know which parts of the country they are living in.

The LCs in rural areas also appeared to be more appreciative of the project, seeing it as a way of spreading awareness, reducing stigma and preventing property disputes.

Language issues

Parents often feel more comfortable writing in their local language, but the emphasis in schools is on reading and writing in English. In some cases, parents get assistance so that they can write in English.

In others, parents have written a book in their local language and later translated it, at the request of their children. Some have also had to translate the books into the language of the father's clan, so that their children can share it with paternal relatives.

Polygamy

Polygamy is relatively common in Uganda, especially in Muslim communities and amongst businessmen. Wives in polygamous families are more likely to struggle to find information, including about co-wives, who have died or divorced, leaving behind children to be cared for. Suspicion about who infected whom can also be greater in this setting. Having said that, some very dedicated co-wives were found within the memory book participants: in one case, one lady is looking after 20 children, only 3 of which are hers. The rest belong to the six other ex-wives of her deceased husband.

Cause of infection

Disclosure may lead children to question how their mother was infected. Usually, they were infected by their husband, but it is considered to be culturally inappropriate to speak badly of your husband. Some members said that they made up tales, to cover the fact that their partner was promiscuous.

Although this is understandable (and fits with wanting to strengthen links with the father's family), it may give the wrong messages to the children about HIV/AIDS transmission and prevention.

Children's participation

Members in Arua and Kasese felt that children below 6 could not be involved in a meaningful way. Others commented that with the poor education system, even children in secondary school were not necessarily able to express themselves well in writing.

Even if there is an age below which written contributions cannot be expected, there is no minimum age for talking to children, telling them about life etc. Practical preparations can also be made early, such as encouraging a strong relationship with the intended guardian.



Children can get involved from an early age, in different ways

Children's reactions to disclosure vary greatly. Some members reported that younger children were less distressed than older children – perhaps because they had less comprehension of the concept of death.

The children initially blamed me for telling them sad news. But I persuaded them that it is better to face the bad news upfront. In any case, the children were already being taunted by other kids. Now they are OK about it.
Kasese mother

Children should also be encouraged to participate by illustrating their books, writing the personal sections and recording their own memories. In some cases, this has been done, and the books are kept up-to-date by children, who note their interests and activities as they grow up. In other areas, however, books are

rather rigidly formatted, and are seen as a formal record, rather than as a tool for communicating with and by children.

It is not enough to plan for them. They need to have hands on experience themselves. After all, they're going to take up adult responsibilities. Many of them are in fact already care-givers
TASO officer

Very few groups have any formal peer support network for the children, even though most recognise that this is important. This is partly for funding reasons, and partly because most children are in school. The potential to use children who have been trained in memory book work as mobilisers in the community has not been exploited.

Process, not just product

While the books themselves are treasured records, even more important is the process by which they are produced, including the growing self-confidence of the member, the ability to speak out openly about their status, the changed relationship with their children etc. It is therefore very important that projects are not judged mainly in terms of numbers of books 'completed'.

Someone who has been trained but who has not managed to finish their book (often due to lacking some pieces of information, for example) may still have gained most of the benefits of the process. Besides, filling them in should be regarded as a continuous process, with children adding more as they grow up.

New relationships

New relationships are a challenge. Many people are unwilling to disclose their status precisely because it would constrain their sexual activities, especially in smaller communities. Safe sex, though it is part of the course, is not widely understood, and access to condoms is limited in more remote areas.

In addition, many of the testing sites are in church-based health facilities, in some of which A (abstinence) and B (be faithful) are preached to the exclusion of C (condoms).

For those who do try to form new relationships, there is a demand for skills in breaking the news to their children. Children are naturally resistant, and in this society, have additional grounds for fear, as women, if they remarry, are often expected to leave their children in order to join their new husband's family. This element of the training course has been boosted in response to members' demands.

Multiple children

When there are several children in a family, there may be jealousy if only one child's book is being filled out. Mothers often do not have enough time or money to make books for all their children, or take a long time to complete all of them.

Despite that, the mothers and children we questioned had a strong preference for individual books, even though much of the information in siblings' books is shared.

Property grabbing

Despite the support for will-making within the project, property rights violations continue in the communities. Widows with daughters are particularly vulnerable, according to informants in Arua, as girls have no inheritance rights.

At Mvara, children from Oluko zone informed the evaluation team that some members of the community taunted them to die quickly so that their land can be grabbed
Arua evaluation

In other areas, such as Kasese, property grabbing is reported as being on the decline. This is in part due to the Memory Project, but also to wider community sensitisation and the intervention of

local counsellors, who are now active on behalf of widows and children.

Communication problems

Some parents found it hard to discuss sexuality, especially with adolescent children. This is an area which requires strengthening in the adults' training course.



Talking with teenage children about sexuality can be challenging

AIDS prevention messages

Given all the information that was being transmitted, some stakeholders expressed the concern that key messages about AIDS prevention might be lost. There has been no independent verification of the level of knowledge of members' children, but most believe that their children are better informed and more motivated to take care of themselves, having seen one or more parent die of AIDS.

Testing of children

The current policy in Uganda is not to test children for HIV/AIDS. The main issue is a fear that HIV-positive children will be discriminated against by carers and others. However, many members of NACWOLA and others involved in the memory book work have expressed a demand to test their children. They know that one or both parent is positive, and want to know the child's status, especially if they are falling ill frequently.

In Kampala, there are centres that will test children (and are able to offer ARVs), but in other areas, it is harder to get your child tested. As ARVs become more accessible, this policy will presumably be modified.

We wish that children could be tested. We believe in knowledge. It would help us to adequately care for children, as we do for ourselves. Often carers suspect, but they cannot be sure. If we knew, we would put more emphasis on life skills and the ability to manage their own health.
PTC chair, Kasese

Without testing of children, the whole issue of care of infected children cannot be addressed at community level. At present, all the focus for children and youth is on prevention. There are very few services for infected children outside Kampala.

Birth registration

Until recently, few children were registered at birth in Uganda, which made them more vulnerable to property grabbing later on (they have no written proof of their succession rights). Campaigns to increase birth registration are having some effect however.

Storage

Where should books be kept? If they are kept by the children, there is a risk of losing them. If they are kept by others, then confidentiality is lost. It seems that most books are kept at home and that very few have been lost or damaged in practice.

Turnover of leaders and trainers

In many areas workshop leaders and trainers are themselves PLWHA so inevitably the progress of the work is affected by high morbidity and mortality, though this will hopefully reduce as access to anti-retrovirals improves. Training courses should therefore be frequent which has financial implications.

There are also many requests for training of local counsellors, so that they can support people and mobilise communities in their areas. This is a good idea, but LCs are also affected by a high turnover.

Links with other interventions

As will have become apparent from the discussion of issues raised during implementation, the memory book approach is not a panacea. It will be most effective when linked to other interventions such as:

- Legal support
- Income generation activities
- Vocational training
- HIV/AIDS awareness raising activities
- Education support programmes
- Home-based care
- PMTCT and increased access to ARVs
- PLWHA support groups
- Counselling
- Nutrition support
- Improved access to health care, especially drugs
- Support for orphans and vulnerable children.

Different organisations in Uganda have integrated the memory book approach in different ways. SC UK linked it with counselling services in Kasese, for example, and with home-based care in Arua. In the case of Plan International, it was a part of Post-test Clubs in Luwero and Tororo. For World Vision, it is planned as a component of OVC programming, and for TASO as part of wider social support to clients.

All four organisations report positive impact but as there are few formal evaluations of these programmes, it is hard to say whether any approaches have been more effective than others. The memory book approach is complementary to so many HIV/AIDS interventions, that it can probably be integrated in many different and creative ways.

It should not be a stand-alone project, but needs to complement other activities. You cannot go into a 'virgin area' with no HIV activities and ask women to disclose. If community attitudes are too hostile, disclosure would be very risky for them. We need to change the culture
*Beatrice Were,
Former NACWOLA coordinator*

The impact of anti-retrovirals

ARVs are not yet widespread in Uganda, but it is assumed that they will become more so. This presents opportunities and challenges. For example:

- HIV-positive parents' lives can be prolonged, leading to increased security for their children
- They should be fitter and more able to spend time communicating with and caring for their children
- The fact of taking treatment is likely to publicise their status. Family members will need to be involved with supporting the taking of medicines
- On the other hand, treatment may lead to denial or delay ('I am not going to die; I don't need to talk to my children about these things, I don't need to find a guardian.')
- There is also an economic risk, unless drugs are totally free, that parents will liquidate assets to fund their treatment.

South Africa

The University of Cape Town has been working with HIV/AIDS support groups, helping PLWHAs to create 'memory boxes', using locally available materials, in which all manner of mementos can be placed.

The project also includes Memory Books (by parents), 'hero books' (books by children about themselves), and 'remembering books' (written by children after their parent's death). These techniques, and others, such as 'body mapping' are described on its website (see resources section). The focus of this project is on 'narrative therapy', in which people find empowering plots within their lives.

Zimbabwe

Since 2002, the Red Cross has been building Memory Books into its HIV/AIDS work in Zimbabwe. 'The project has more than met our hopes and expectations. The participants had opened up to their families and their children, and in some cases to the general community, about their health status. The children that I talked to were also very keen on the project. The project has succeeded in breaking down stigma and the participants now seem determined to fight for life but also to prepare for the future' (Red Cross representative, Zimbabwe). It now plans to extend the approach to other countries in the region.

Kenya

In 2001, NACWOLA trained 21 members of the Society of Women and AIDS in Kenya (SWAK). Since then, 230 PLWHA in other Kenyan NGOs have been trained by SWAK, many of them as trainers.

An experience-sharing workshop in November 2003 concluded that the MB approach was practical, acceptable and a strong instrument for fighting stigma in the community. It has succeeded in empowering children with coping skills, and enhancing communication and good relationships between children and parents.



*No child is too young: start telling them
the story of your life*

The memory book is primarily a tool for improving communication and building a strong sense of identity for the recipient, and as such is of universal relevance, for HIV-affected and non-HIV-affected households alike.

As ARVs become increasingly available, there is a risk that people will see the memory book approach as no longer relevant. That would be unfortunate, as the needs which it meets will continue to be very real. Specifically, it:

- Encourages parents to open up to their children and to listen to their fears and concerns. This tends to improve the relationship and improve the care received by children
- Encourages parents to plan for their children's future, including appointing guardians, making wills, and planning for their education
- Relieves parents of the burden of secrecy and the loneliness of suffering in silence
- Increases the coping strategies, knowledge and confidence of parents and children; and
- Fights stigma in the community and changes community attitudes to those infected or affected by HIV/AIDS.

The cost of this is estimated at \$60 per person trained (excluding follow-up and support costs, which are very variable).

Lessons

- Memory Books and related succession planning activities are effective and should be built into all programmes of support to PLWHA (As a parenting tool, they can in fact be integrated into any programmes for parents and children).
- They are inexpensive to implement, the main costs being training and follow-up/monitoring

- The main obstacles are poverty, illiteracy and poor health, which is why linkages need to be made to other support programmes
- Some children have been trained and have helped their parents or guardians to write the books and have become more involved in family discussions and decision making. This element should be further developed, through children's peer support groups and by encouraging children to be active in community mobilisation
- Peer support is vital to assist the parents who are struggling to finish their books and to carry out some of the other related activities, such as naming guardians and will making
- The issue of how to get more active participation from men is very important too
- There seems to be widespread satisfaction with the current format of the books
- Some elements of the training need strengthening, especially in relation to dealing with new relationships and communicating sex education issues to adolescents
- Community involvement should be encouraged from the start, by linking the programme with community leadership, CBOs, hospitals etc
- The process of opening up is very emotional and cannot be rushed. Therefore it makes sense to link it with counselling services, where these are available
- Experiences from other countries in Africa suggest that the memory book and related activities have wide resonance, and can be effective in many other contexts
- Innovation should be encouraged: there is no one right way to use this tool.

Other resources

- ‘The Memory Book for Africa’ gives detailed information on how, when, and why to make a memory book. It is available from TALC, PO Box 49, St. Albans, Herts AL1 5TX, UK. Email: talc@talkuk.org or via their website (www.talcuk.org).
- It is also available from NACWOLA in Kiswahili, Ateso and Luganda languages (PO Box 70574, Kampala; NACWOLA@infocom.co.ug), and from the Save the Children Uganda programme in Uganda in Lugbara and Lukonjo languages (PO Box 1124, Kampala; sciug@sciug.org)
- A shorter modular version of the training course is currently being developed by Healthlink World Wide as part of the forthcoming International Memory Project (email: c.brown@healthlink.org).
- A training manual for the Memory Box Project in South Africa is available from: www.uct.ac.za/depts/cssr/asru.html.
- A network of organisations interested in the Memory Book approach is being established under the auspices of REPSSI. For details, contact Jonathan Morgan on jonathan@10mmp.org.
- The evaluation of the Arua project (‘Final evaluation of the NACWOLA Memory Project in Arua district’, by Opolot, Aritua, Atibuni, Aseru and Acidri, Save the Children UK, 2000) is available from the SC in Uganda office (see address above).
- ‘Succession planning in Uganda: early outreach for AIDS-affected children and their families’, a study by Horizons/Population Council (2003), is available from horizons@pcdc.org.



Children can cope and can help one another



Save the Children
1 St John's Lane
Farringdon
London EC 1M 4BL
UK
[Http://www.savethechildren.org.uk](http://www.savethechildren.org.uk)

