



# Inspiring futures:

learning from memory work in Africa

**HEALTHLINK**  
WORLDWIDE

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The learning paper draws on the experience of Healthlink Worldwide's partner organisations implementing memory work in five sub-Saharan African countries through the International Memory Project – Ethiopia, Kenya, Tanzania, Uganda and Zimbabwe. We owe particular thanks to NACWOLA who pioneered the use of memory work approaches in Africa.

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# Introduction

This learning paper looks at experiences of applying memory work as part of broader strategies to mitigate the impact of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in five African countries: Ethiopia, Kenya, Tanzania, Uganda and Zimbabwe. The experiences occurred through the International Memory Project funded by Comic Relief, which started in 2004. The paper explores how six non-governmental organisations (NGOs) in sub-Saharan Africa established memory work as a key component of their community-based HIV programmes. It draws on the experiences of people living with HIV and AIDS (PLHIV), children and young people who participated in the initiative, partner organisations' own learning and analysis and the report from the end of project evaluation carried out at the start of 2009.

# Abbreviations

## List of abbreviations

<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>KANCO</b>	Kenya AIDS NGOs Consortium
<b>ART</b>	Antiretroviral Therapy	<b>KWIECO</b>	Kilimanjaro Women Information Exchange and Consultancy Organization
<b>ARV</b>	Antiretroviral	<b>MMAK</b>	Movement of Men against AIDS in Kenya
<b>CSO</b>	Civil society organisation	<b>NACWOLA</b>	National Community of Women living with HIV and AIDS
<b>FACT</b>	Family AIDS Caring Trust	<b>NGO</b>	Non-governmental organisation
<b>FGD</b>	Focus group discussion	<b>OVC</b>	Orphans and vulnerable children
<b>HAPCSO</b>	Hiwot HIV/AIDS Prevention, Care and Support Organisation	<b>PLHIV</b>	People living with HIV
<b>HIV</b>	Human Immunodeficiency Virus	<b>STI</b>	Sexually transmitted infection
<b>ICW</b>	The International Community of Women with HIV/AIDS	<b>VCT</b>	Voluntary counselling and testing
<b>IMP</b>	International Memory Project	<b>WOFAK</b>	Women fighting against AIDS in Kenya
<b>JeCCDO</b>	Jerusalem Children and Community Development Organisation		

# 1 Memory work and the International Memory Project

## How memory work began

Memory work was first developed by the children's charity Barnardo's<sup>1</sup> in the 1990's, as a response to help African families living in the UK who were affected by HIV and AIDS. Memory work is rooted in oral history approaches that value the transmission of knowledge between generations as a way of building cultural identity. This experience showed that memory work can play an important role in supporting families and communities to become more effective and responsive to the needs of their children.

In 1997, Barnardo's worked with the National Community of Women living with HIV (NACWOLA) in Uganda to adapt the approach to use with women living with HIV in Africa. Since then, memory work has expanded to countries in sub-Saharan Africa where it is increasingly employed as a response to help women, children and young people who are disproportionately affected by the HIV and AIDS epidemic.

## The International Memory Project

The International Memory Project (IMP) began in 2004 as an initiative between community organisations in five African countries: Ethiopia, Kenya, Tanzania, Uganda and Zimbabwe. The initiative, funded by Comic Relief, aimed to introduce and adapt NACWOLA's approach to memory work to help improve child, family and community coping strategies to HIV and AIDS in sub-Saharan Africa. IMP focuses on the use of memory work as a way to encourage families to communicate about HIV. By increasing communication in a safe environment, children are supported to develop increased understanding and resilience to the impact of HIV and AIDS on their lives. This, in turn, opens up opportunities for children to become more involved in planning for their future. Parents are also encouraged to share memories, family background and experiences to preserve their knowledge for future generations.

Memory work is centred on four main pillars:

- Improving communication between parents and other family members living with HIV and their children.
- Supporting parents to disclose their HIV status if that is their choice and other important health information.

- Succession planning, including writing a will and choosing guardians for children.
- Documenting important family history and information in a memory book.

Over the years, the IMP partners have developed a range of activities which support these pillars. Through these activities, parents and guardians receive training and support in: child development; improving communication with children; and making plans for the future.

Support groups enable parents, guardians and children to explore issues in a supportive environment and receive support from other people who are experiencing similar situations. Children are also involved in activities which aim to: increase their knowledge of HIV and AIDS; develop and strengthen life skills; and develop peer support groups. Activities with children use child-centred approaches, which ensure that they are appropriate for the child's stage of development.



Writing a Memory Book encourages families to share knowledge and experiences for generations.

<sup>1</sup> Barnardo's is one of the UK's leading charities with the vision that the lives of all children and young people should be free from poverty, abuse and discrimination. <http://www.barnardos.org.uk/index.htm>

Healthlink Worldwide has participated in the global response to HIV and AIDS for over 20 years and was already exploring issues when the opportunity to implement the International Memory Project arose.

### International Memory Project partners



National Community of Women living with HIV and AIDS (NACWOLA): Three HIV positive women in Uganda started NACWOLA in 1992. They wanted to unite women living with HIV and AIDS in Uganda, fight abuse, stigma and discrimination and restore their self-esteem and integrity. Now, in 2009, NACWOLA is a network of 40,000 women living with HIV with 25 different branches in Uganda, operating in 31 districts and using memory work in many of their programme areas.



Family AIDS Caring Trust (FACT) in Mutare, Zimbabwe: was established in 1988 in response to the growing HIV epidemic in Zimbabwe. Its services cover Manicaland in eastern Zimbabwe, with offices in Mutare, Rusape, Chipinge, Chiredzi and Nyanga. It offers a range of HIV-related services across the South East of Africa.



Women against AIDS in Kilimanjaro in Moshi, Tanzania (Kiwakkuki): began in 1990 with a small group of women working against HIV and AIDS in Kilimanjaro region in northern Tanzania. It now has both staff and volunteers working on programmes, which include information and education on HIV prevention, voluntary counselling and testing services, home-based care activities and OVC programmes.



The Kenya AIDS NGOs Consortium (KANCO) in Nairobi, Kenya: started in 1990 and is a leading national membership network of NGOs, community-based organisations, faith-based organisations, private sector organisations, and research institutions. KANCO has considerable experience of working on HIV and child-related issues and has been engaging at a policy level in Kenya around children's issues.



Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPCSO) in Addis Ababa, Ethiopia: Established in 1999, HAPCSO is an NGO whose work is focused in ten kebeles (sub-districts), located in the south-western outskirts of Addis Ababa. It provides home and community-based care to 8,000 PLHIV and their families as well as to more than 10,000 OVC with the help of more than 90 permanent staff and 600 volunteers.



Tilla association of women living with HIV in Awassa, (Tilla) Ethiopia: is an association of women living with HIV and AIDS working in southern Ethiopia. Tilla was established in 2002 and their main aim is to reduce the stigma and discrimination of women living with HIV in that region and to increase their livelihoods starting with their members who live in the community. It creates community awareness about HIV and AIDS, doing advocacy through the testimonies of members who are living with HIV and AIDS.



Healthlink Worldwide in London: is a UK-based international NGO, which aims to improve the health and well-being of disadvantaged and vulnerable communities in developing countries. Healthlink Worldwide works with over 50 partners worldwide, empowering less advantaged communities to voice their health needs and have those voices heard through effective communication and sharing of knowledge. Healthlink Worldwide has participated in the global response to HIV and AIDS for over 20 years and was already exploring issues when the opportunity to implement the International Memory Project arose.

## 2 What we have achieved and learned so far

In March 2009 the International Memory Project underwent an evaluation of its work over the project period. The evaluation was mainly qualitative and was led by two independent consultants, who worked directly with partner organisations, families and children to look at the impact of memory work. The methodology included focus group discussions (FGD) with parents, caregivers, children and young people, in-depth interviews with children, families, project staff and a range of stakeholders. All focus group activities were participatory and drew on child-centred techniques for those with children and young people.

Organising a multi-country evaluation is complex. Every effort was made to maximise the participation of children and young people. Timetabling sessions with children out of school hours and at the weekend helped to increase their participation. Good translation from local languages was also crucial. Ethical issues were considered at all stages of the evaluation, particularly when working with children and young people. Careful planning took place with partners fully briefing children and young people about the evaluation. Feedback was also given to children and young people after the evaluation about the key findings and next steps.

This section presents the findings from the evaluation about the achievements and learning at project and country level.

### 2.1 Project level

Since 2004, country partners have systematically integrated memory work into their HIV programmes. Each partner adapted the approach and applied it in different ways depending on their own organisational structure and local context.

Through this we have learnt that memory work needs to be rooted in existing HIV programmes and services, and is generally only effective when it works alongside other services which offer treatment, support to generate income and other health care provisions.

Integrating memory work has shown that it can increase communication in the family, reduce stigma and encourage openness in all sections of society. So far, the most significant impact has been on the well-being of parents, and the partners hope that this will bear dividends in the future as the parent-child relationships continue to improve.



Memory work helps families talk about family matters.

#### Impact on children

“I first took the training and then my children did the training. Their knowledge of HIV has increased and they can protect themselves. We have also been able to have discussions on family matters – it’s like an ice-breaker for the family and issues beyond HIV are discussed”.

(Father, FGD, Addis)

The main impact on children has been the start in increasing children’s participation in communication within the family. Their knowledge of HIV has also increased and children are learning not to stigmatise their parents and others who are living with HIV.

#### Increased participation of children in family life:

Children now feel that they are in a better position to take care of their parents.

We have learnt that in all five countries, memory work has led to children taking on increased caring responsibilities within the family, usually in relation to the parent living with HIV.

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We have learnt that communication about HIV at family and community level increases greatly and opens up opportunities to increase uptake and adherence to HIV treatment.

The disclosure of the parent's status has enabled children to become involved in the care of their parents. Closely linked to this is the role that children are taking in supporting their parent's adherence to antiretroviral drugs and other medication. Children remind their parents to take medication at set times, collect more medication for them when necessary and help prepare food for the parents and for the family.

“We not only remind them about their HIV medicine, but also about their TB medicine”.

(FGD discussion with children in Awassa, Ethiopia)

**Improved knowledge of HIV:** Children have learnt how to protect themselves from HIV transmission, particularly when caring for their HIV positive parents.

We have learnt that communication about HIV at family and community level increases greatly and opens up opportunities to increase uptake and adherence to HIV treatment, stimulating a more effective response to the HIV and AIDS epidemic.

“Now my child helps me to take medicines, and when I am not feeling well, the child understands and protects me”.

(Parent, Moshi, Tanzania).

**Access to peer support:** The children's clubs are valued as an opportunity for sharing experiences with other children and these appear to work best when meetings are regular with a structure of support for the children.

“I attended the NACWOLA children's training and I got life skills that included assertiveness, which has really helped me. As girls we are always challenged by boys and old men deceiving us – “something for something love”. One day I met a boy who told me he loved me and wanted to have sex with me, I never listened to him and he threatened to beat me.

I told my sister who cautioned him and reported the case to the local council defense official who warned him and he stopped bothering me”.

(A child from Luweero branch, Uganda)

In Moshi, Tanzania, for example, children met every month in a large centralised club where a variety of structured activities including life skills training were held.

“I could know my rights. I was able to meet and interact with other children and able to know myself importance”.

(Young girl, 16 yrs, Moshi)



Young people taking part in memory work also need good information on sexual and reproductive health.

There is a need to ensure that memory work can be experienced and monitored as a long-term initiative. In many situations, the activities may not pay dividends for several years, particularly when working with younger children.

### Impact on parents, families and communities

The biggest impact of memory work to date is seen in the lives of parents and guardians living with HIV. The training and ongoing support group activities have consistently increased the quality of life for parents.

**Enhanced positive living:** Very often, the training empowers the parent to disclose their HIV status within the family. This leads to more open communication, initially within the immediate family, but then also with the wider community. The ‘self stigma’ of many parents also decreases as a result of their involvement in memory work.

We have learnt that the initial phase of memory work has had a huge benefit on the well-being of PLHIV. After four years, impact on children can be observed but is likely to be a longer-term outcome of the work.

There is a need to ensure that memory work can be experienced and monitored as a long-term initiative. In many situations, the activities may not pay dividends for several years, particularly when working with younger children.

“Before this project, I had a lot of fear and stigma, but, since I joined, the fear has cleared and now I can present drama”.

(Focus group of parents in Uganda)



Sharing experiences through drama can help to reduce stigma and discrimination in the community.

### Partnerships in Tanzania supporting legal rights of women and children

In Tanzania, Kiwakkuki worked closely with Kilimanjaro Women Information Exchange and Consultancy Organization (KWIECO) to strengthen work around will writing and birth registration. Wills were initially written in memory books but as these have no legal status, parents have been encouraged to write proper wills. Kiwakkuki and KWIECO work closely with families and clan leaders, especially on issues of women inheriting property and land. In the rural areas, transport to Moshi for legal advice is an obstacle. As a result, KWIECO has decentralised its services and offers legal aid camps in three areas, linking with the gender and human rights committees at ward level. Kiwakkuki and KWIECO have found that many women living with HIV suffer from domestic violence which also needs to be addressed through this process. Kiwakkuki has negotiated for the penalty for the late registration of births to be waived for families affected by HIV.

‘Self-stigma’ is an important element in the reduction of stigma and discrimination at community-level. Memory work can play an important role in supporting people living with HIV to become more open about their status – initially within the family but also within the wider community.

**Strengthened links with the family:** Parents also value the increased knowledge and strengthened links with the wider family, emerging from memory work activities such as drawing of the family tree and planning for the future. This activity was particularly appreciated by parents but not as much by children at this stage. Some of the single mothers and widows involved in Tilla’s work began to share information about fathers, rather than hide it. As a result of these activities, parents reported feeling more secure about the future and were able to anticipate their children would be cared for in the future.

**Planning for the future:** One of the four pillars of memory work is succession planning, supporting parents and children to plan for the future together. This includes writing a will and choosing guardians for the children. This has proved to be a challenging component of the project

We have learnt that the component of memory work that looks at planning for the future, through writing wills, birth registration and choosing guardians for children, challenges issues relating to the rights of women and children.

across all the countries. Cultural beliefs that writing wills can cause death, was a major factor in slow uptake of this activity. Another barrier was that women and children have few rights to inherit property. Close partnerships with legal organisations have helped in some project sites and their involvement has helped to address legal issues more generally, such as inheritance rights of women. Birth registration is also essential for children to be able to secure rights and access services.

We have learnt that the component of memory work that looks at planning for the future, through writing wills, birth registration and choosing guardians for children, challenges issues relating to the rights of women and children. Most success has been experienced in this area when working closely with legal organisations.

#### Memory books: problems and practicalities

Although memory books are only one component of memory work, they are an easily understood and popular format. IMP partners encountered some practical issues over the four years:

- Low literacy environments: Memory books obviously demand a reasonable level of literacy by the parent. Where this did not exist, children or volunteers worked with the parent to write their memory book
- Using a set format: Some partners preferred to use a book with headings on each page to help parents structure their thinking. Other partners preferred to use a completely blank book and let parents devise their own headings and content.
- Storage and safe keeping: Once written, memory books become a valuable personal and family document. Keeping them safe in a high-poverty environment can be difficult. In Kenya, some memory books were lost in post-election violence (2009). Where possible and where permission is given, some partners are keeping copies of memory books.

## 2.2 Country level

### Memory work in Uganda

NACWOLA pioneered the use of memory work with women living with HIV in Uganda as a way to help women communicate about HIV with their children. They have continued to scale up their memory work nationally.

#### How NACWOLA approached memory work

The challenge for NACWOLA in the International Memory Project was to scale up their existing work to reach more of their members. From 2006 NACWOLA expanded memory work to five districts – Busia, Iganga, Luwero, Lira and Soroti. In these districts, new staff and volunteers were recruited and trained to implement memory work at community level. Now eleven other districts currently also include memory work in their activities. Most of NACWOLA's trainers are PLHIV, and there is a strong component of awareness-raising through drama and testimonies at community level. The memory book is used as a tool and a reference point to encourage parents to disclose their HIV status, fight stigma and discrimination and claim rights to health care, HIV treatment, and property. Staff encourage children through peer education techniques to reach out to their peers in school and in the neighbourhood.



Regular visits to families in their homes are vital for many who do not have easy access to other methods of support.

The majority of the NACWOLA, Uganda volunteer workforce has skills to apply memory work, which has greatly developed their self esteem and communication skills.

**Alex from Luwero, a mother trained in memory work under IMP**

“Earlier with the HIV diagnosis, I never felt comfortable discussing about HIV and AIDS issues. This did not matter where I was, whether in the community or place of work. It was all the same to me. Of course, I would attend secretly to my clinical appointments and NACWOLA meetings. As a God sent chance, I was lucky to have been one of the members selected to be trained in the memory project work. The training helped to break barriers to my openness/disclosure on HIV and AIDS issues. It was a total relief to break the silence. It seemed like unlocking a door.

Using communication skills I had acquired from the training, and the benefits of disclosure that we had shared, I thought I needed to think out of the box. I will never forget the day I shared with my headmistress (boss) about my HIV status, she was just amazingly supportive. She arranged for me so that the class timetable did not coincide with my clinic appointments. You can imagine how relieved I was.

I can only sing and praise the magic of disclosure. I am now a trainer in memory work after completing the Trainer of Trainers training. I am also active in community HIV and AIDS sensitisation. My secret life had turned me into a sad woman and a loner, yet with disclosure, I regained my freedom and happiness.”

**What NACWOLA has achieved and learnt**

Since they started using the approach, NACWOLA observed that when parents develop communication skills, they are able to disclose their HIV status to their children, involve them in key family decisions, and plan for the future of their children. This improves family and community relationships and helps to reduce stigma. In 2008, NACWOLA's advocacy at national level with the Uganda AIDS Commission and Ministry of Health was successful in getting memory work included in the national HIV and AIDS strategic plan.

The majority of the NACWOLA volunteer workforce has skills to apply memory work, which has greatly developed their self esteem and communication skills. NACWOLA has seen the value of supporting people living with HIV to disclose their status within their families and among their members. This process of empowerment means participants become central to NACWOLA's activities and become role models. Involving children in memory work activities has also become more important and supports improvement of family relations more quickly than if training focuses on parents and guardians.

**Challenges**

NACWOLA's long history of developing memory work has seen them cope with many challenges along their journey. Limited resources (and high inflation) means that it is difficult to respond to emerging issues that need an urgent response. NACWOLA has been innovative in working round this issue – instead of one learning visit NACWOLA was able to implement learning visits in five districts by getting parents to support each other. NACWOLA finds it difficult to cope with the very high demand from the beneficiaries for more memory work activities. Additionally, materials such as the training manual need to be reviewed to adapt to the changing nature of the HIV epidemic and incorporate a stronger rights-based component.

**Future plans**

In the future, NACWOLA would like to continue to train more PLHIV and other civil society organisations (CSOs) to use memory work and adapt work to the different challenges that emerge from the course of the HIV epidemic in Uganda. Many of NACWOLA's members and its beneficiaries have high expectations that the project will continue, but this

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As a result of memory work, FACT, Zimbabwe has observed some important changes in how both parents and children are responding to the impact of the HIV epidemic.

might not be possible unless NACWOLA can identify new funding sources and resources to continue to scale up its memory work. It also means people's new skills may not be used effectively in the future.

### Memory work in Zimbabwe

The experience of Family AIDS Caring Trust (FACT) in Zimbabwe demonstrates how memory work can function in difficult environments. FACT has focused on building community capacity to support memory work as a way to increase sustainability of the memory work approach.

#### How FACT approached memory work

FACT and Healthlink Worldwide previously worked on strengthening FACT's voluntary counselling and testing (VCT) programme. This highlighted the potential for memory work as a component of FACT's community work and FACT joined the group of partners to implement the International Memory Project. Memory work was integrated into FACT's Home Based Care and Orphans and Vulnerable Children programme. During this period of implementation, FACT also built relationships with the Ministry of Health, World Food Program, an NGO called Christian Care, and local churches.

#### What FACT has achieved and learnt

Over the past four years, FACT has worked in 14 sites throughout Manicaland. They have supported over 500 parents and guardians to develop communication skills and create succession plans, with over 450 memory books being written. Eighteen children's clubs have been set up. These groups use play therapy, drama, song and dance to increase children's awareness of sexual and reproductive health issues, and explore ways of coping with illness in the family. Children participated in a holiday camp and day outings, providing an opportunity to meet other children in similar situations. They valued these opportunities to have a break from their caring responsibilities.

As a result of memory work, FACT has observed some important changes in how both parents and children are

#### Case study: Tendai, Chisingwi support group member

“When I was nearly dying, the people who I was staying with brought me home to die. When I got here, there was only one hut and I really felt that this was my final resting place as it was dilapidated. The memory work training helped me accept my situation and be able to plan for my family. From the training, I began to develop a positive mentality to take care of my family, including my wife and three children. I now have a home for the family, my health is better and my children know my status. My wish now is to go back to the city and bring back the people who sent me to the rural areas to die so that they can see what progress I have made with my life.”

responding to the impact of the HIV epidemic. The most important changes that have taken place are increased communication about HIV between parents and children, children taking on more in terms of helping and caring for parents and guardians, and increased demand and uptake of VCT. There has also been a reduction of stigma more widely in the community and despite high costs and unavailability of antiretrovirals (ARVs), more people are willing to start treatment.

FACT's experience demonstrates the potential for developing memory work in difficult environments and the value of building community leadership. Improved community involvement in leadership and decision-making in activities develops community capacity and the ability to run activities independent of project staff. Involving local leadership, including church leaders, is another strong factor in supporting sustainability. Increasing children's involvement in planning and leading activities has also increased their self-esteem, enabled their concerns to be addressed, and

In areas where stigma and discrimination are high, partners plan to work with community groups in general...Just working with PLHIV support groups can sometimes perpetuate stigma, and partner organisations have recognised the potential of the approach for the whole community.

strengthened their ability to run activities with a minimum of support.

### Challenges faced

Since the inception of the project, FACT has implemented memory work in the context of a political and humanitarian crisis in Zimbabwe, characterised by political violence, high inflation, and food shortages. FACT's operating environment has been difficult. Vital referral services that enhance and support memory work no longer exist. The collapsing national health system means that few people can access antiretroviral therapy. The crisis has also made it more difficult to include children in project activities. Reaching children has been difficult at times, as schools have been shut. School fees and educational support remain a challenge.

FACT has been innovative in developing ways to continue their work at this time. As travel to project sites was sometimes restricted, FACT increased the training and support that they gave to community volunteers and support group members so that the work is not dependent on FACT staff. FACT has intensified children's participation and involvement in club activities to enable them to be able to organise themselves and carry out their own activities. FACT also encouraged memory work support group members to develop livelihood activities that would enable them to build assets, transfer skills to their children and provide occupational therapy for PLHIV.

### Future Plans

FACT intends to integrate livelihoods and economic strengthening work with memory work in order that people can access services that help them meet other needs. They have also identified that their approach to writing wills and making inheritance plans could be strengthened by engaging communities in awareness building on laws that protect them, particularly inheritance laws, such as issues of disinheritance among widows. The local leadership will be involved as gate-keepers to ensure enforcement of laws at community level. FACT also plans to train more community-based counsellors to provide ongoing support.

In areas where stigma and discrimination are high, partners plan to work with community groups in general – not just PLHIV support groups. Just working with PLHIV support groups can sometimes perpetuate stigma, and partners have recognised the potential of the approach for the whole community.

Memory work will need to adapt and change as Zimbabwe responds to its changing situation and the increasing availability of treatment in the country. With the world's lowest average age life expectancy, the need for memory work in Zimbabwe's future is huge. FACT has built a strong basis for memory work, which can play an important role in helping Zimbabweans respond to the challenges of HIV in their country in the future.



Memory work can help to strengthen the family.

The involvement of community-based organisations, faith-based organisations and NGOs has helped extend support to people involved in memory work in Tanzania.

## Memory work in Tanzania

Kiwakkuki used the strength of their community-based volunteer network to their advantage when developing memory work. It was able to work with young people to expand memory work. Through the International Memory Project, Kiwakkuki identified key advocacy issues, such as the right of women to inherit property, and started to stimulate community debate about these.



Writing wills helps to secure children's lives.

## How Kiwakkuki approached memory work

Kiwakkuki opted to integrate memory work into their existing HIV and AIDS services for orphans and vulnerable people. Over 600 adults and 240 children have participated in memory work so far. Kiwakkuki also worked closely with government hospitals and consultants to enable memory work beneficiaries to receive counselling, treatment and care. Kiwakkuki had already established a support group for PLHIV, called Centre of Hope, who were also involved with memory work from the beginning.

### Jacinta (ward leader) Pasua, Tanzania

“Since the Memory Book training, those infected know each other and are visiting and helping each other and exchanging information and views on HIV and AIDS on a regular basis. They have communicated with their children about their HIV and AIDS status, and also with their relatives. They now know their rights, such as the right to choose their leaders and to be chosen as leaders themselves, the right to be employed, to be respected, and to medical care and treatment.

Stigmatisation has been reduced by a high percentage in the ward. People now know it is okay to shake hands with infected persons and not become infected themselves. In our culture, there is a belief that if you write a will before you die, you can then die soon – now many, many people are writing wills.

I think the memory book work should be expanded. The training should not be limited only to those who are infected.”

Traditionally in Tanzania, adults and children are encouraged to show strength when faced with bereavement and this makes many people reluctant to tell children any family information.



Memory work helps to strengthening activities for children and young people.

### What Kiwakkuki has achieved and learnt

Kiwakkuki's memory work benefited from a range of partnerships they were able to develop. The involvement of community-based organisations, faith-based organisations and NGOs has helped extend support to people involved in memory work. Involving religious leaders and government officials in the project also supported the reduction of stigma. These groups now offer support instead of perpetuating stigma and discrimination. Kiwakkuki also learned that the tangible products of memory work can stimulate improved communication in the family by giving family members something to focus on.

Kiwakkuki put significant energy into supporting families to get the correct legal documentation to enable them to access government services and support the succession planning component of memory work. Without the correct birth registration, OVC cannot register for secondary school, receive government assistance, or register for free college tuition. Kiwakkuki has established an effective working partnership with a local legal organisation called KWIECO. There have been 180 birth registrations and 288 more are being processed. KWIECO have also completed and referred 160 wills.

### Challenges faced

Kiwakkuki faced many cultural challenges when implementing memory work. Traditionally, adults and children are encouraged to show strength when faced with bereavement and this makes many people reluctant to tell children any family information. There was also resistance to writing wills and planning for the future. Following memory work, women are now starting to register births, to make sure their children have legal status when they want to claim their rights, and are writing wills to make sure their children can get their rightful inheritance.

Kiwakkuki initially started memory work as a small pilot project in the Kilimanjaro area. There is increasing demand from local communities for Kiwakkuki to work across a wider geographical area, but they need to balance this demand with their own organisational capacity. Kiwakkuki are also dealing with local situations where high levels of poverty, urban migration and unemployment are a reality. In some of their project areas such as Pasua Kaloleni and Njero Moshi, there are high levels of sex work and drug use – and as a result, HIV infection continues to increase in these areas.

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More than 10,300 children in Kenya have been involved in activities and training which has included increasing their understanding about HIV and AIDS.

### Future Plans

Kiwakkuki will continue memory work and aims to increase the coverage of the programme. They also plan to develop increased community-based advocacy around birth registration and women's rights to property and inheritance. Kiwakkuki want to adapt the memory work approach to successfully reach vulnerable groups. For example, they would like to include more persons with disabilities in the programme. Having seen the value of memory work, Kiwakkuki will advocate to the national government to include memory work in the national strategy to fight HIV and AIDS.

### Memory work in Kenya

Memory work in Kenya was led by the Kenya AIDS NGO Consortium (KANCO). The work in Kenya took a different structure to the other countries, with KANCO making best use of its extensive membership structure to work with other organisations to introduce memory work.

### How KANCO approached memory work

With KANCO's strength coming from their membership structure, it was a natural decision to build the capacity of some of their members to implement memory work.

#### Eric, Nairobi

Eric attended the training for the MMAAK group. Though he had known his status for the last three years, he had not been able to disclose this to his 18 year old son. The son had noticed changes in his father, but his father had always avoided any discussion. After attending the MMAAK training, Eric decided he would disclose his HIV status to his son. He was surprised that his son had suspected this all along and just wanted a confirmation. The disclosure has changed the relationship between Eric and his son. They are writing a memory book together. Eric has received more support and the son accompanies him when he goes for medication. *"I cannot imagine what would have happened if I hadn't attended that training"* Eric says.

KANCO worked with many of its member organisations throughout the four years, providing training and support in all aspects of memory work. Member organisations involved included Movement of Men against AIDS in Kenya (MMAAK), Women fighting AIDS in Kenya (WOFAK), Maendaleo ya Wanawake, Kenya National Deaf HIV/AIDS Education Programme, Campaigners for an AIDS Free Society, and St John's Ambulance.

In order to build their own capacity to work effectively with children, KANCO chose to work more closely with a group of 15 families and monitor them more carefully. These families belong to an organisation called Triple A. KANCO also took a special role in supporting documentation of memory work in Kenya and in other countries.

### What KANCO has achieved and learnt

KANCO and its members are carrying out memory work with more than 15,000 families. More than 10,300 children have been involved in activities and training which has included increasing their understanding about HIV and AIDS. KANCO's own members have been key in making sure memory work reached more people.

Hope Valley Family Institute mainstreamed memory work in their psychosocial support programme for PLHIV. Maendeleo ya Wanawake has trained their community-based reproductive health service providers.

Realising that men are often not involved in memory work, KANCO made efforts to ensure that they were being reached in Kenya, working closely with MMAAK and WOFAK to implement this.

Involvement in IMP has opened up new opportunities for KANCO to work with other child and adolescent focused programmes in the country, such as Families Matter!, Child to Child Trust, and EDUCAIDS.<sup>2</sup> Sharing the experience of memory work in different forums, such as among the community leaders, policy makers, judiciary and the media, has increased demand in Kenya for training in memory work.

<sup>2</sup> EDUCAIDS – the Global Initiative on Education and HIV & AIDS. [http://portal.unesco.org/en/ev.php-URL\\_ID%3D36400&URL\\_DO%3DDO\\_TOPIC&URL\\_SECTION%3D201.html](http://portal.unesco.org/en/ev.php-URL_ID%3D36400&URL_DO%3DDO_TOPIC&URL_SECTION%3D201.html)

Preparing wills and succession plans has faced cultural resistance in Kenya, as they are perceived to be appropriate only when an individual is close to death. Women wishing to write wills face additional challenges.

KANCO and its partners' experiences of implementing memory work in a number of different situations have led to some important learning on different ways to implement memory work. Their experience shows that using existing community structures is the simplest and most cost-effective way to operate. Partners have conducted training within communities, using their facilities, and integrated follow-up meetings into ongoing group therapy meetings. KANCO and partners have also recognised the importance of children's participation. Involving children in memory work has speeded up the process of increasing communication and supported disclosure between parents and children.

### Challenges faced

KANCO and its partners have experienced challenges in adapting memory work with communities. Preparing wills and succession plans has faced cultural resistance as they are perceived to be appropriate only when an individual is close to death. Women wishing to write wills face additional challenges. Women are considered as men's property and unable to make or participate in decisions about the family future. These were some of the reasons behind KANCO trying to bring more men into memory work so that debates can start on these issues within communities.

As with many other partners, there has been an ongoing tension of people needing to prioritise meeting basic needs for food and income. Even writing a memory book sometimes demands the use of precious resources. When a family member is living away from home, they often want to travel back to find out information about their family background.

### Future Plans

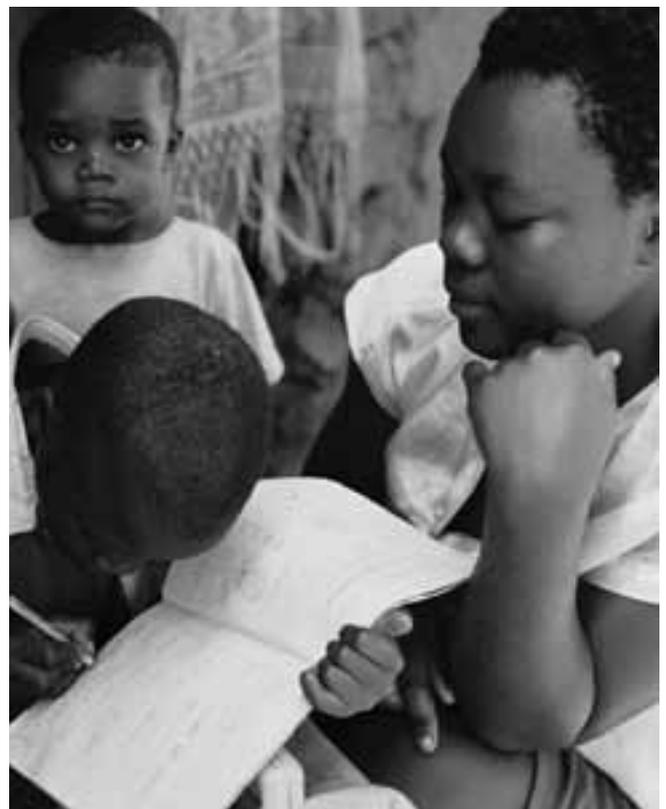
KANCO aims to strengthen its approach to memory work, training new organisations, mentoring more staff and reaching more vulnerable groups, including older care givers and child-headed households. This needs to be accompanied by increased resource mobilisation to support the range of organisations in Kenya who are working together on this initiative. KANCO also recognise that the existing memory work needs to be complemented with advocacy at a national and global level in order to get memory work included as a strategy within the Kenya National AIDS Strategic Plan and ensure that memory books carry legal status.

### Memory work in Ethiopia

HAPCSO, one of the two implementing partners in Ethiopia, was working in an urban area with a high level of HIV-related stigma and discrimination. Getting the support of the community has allowed memory work to flourish.

### How HAPCSO approached memory work

Memory work is part of the care and support component of HAPCSO's work, and is integrated into the Community and Home-Based Care and Orphans and Vulnerable Children Support Programmes. HAPCSO developed a range of strategies, including training direct and indirect beneficiaries, working with community-based organisations, and raising awareness. Community sensitisation activities were designed to respond to the high level of HIV-related



Positive parenting helps meet the needs of children.

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## Developing activities with children has become increasingly essential for HAPCSO, Ethiopia and is crucial in supporting the memory work that happens with parents and guardians.

stigma and discrimination in Ethiopia. These included community meetings and traditional coffee ceremonies, where the neighbourhood meets in one person's house to talk about issues over coffee. HAPCSO worked with over 30 leaders of idirs (community organisations) to ensure that the programme was accepted at community level. Memory work materials were translated into Amharic and 600 volunteer caregivers have been trained in the memory work approach.

### **Amognesh, Addis Ababa, Ethiopia**

"I am 45 years old and have three children, a girl aged 14 and two boys aged 12 and seven. Since the training, I have started on three memory books but I am illiterate, so the children are helping by writing the books. I have disclosed my status to the two eldest children, but not to the youngest. I have told the landlord and she doesn't stigmatise me. She treats me as a daughter and because of this no-one in the community treats me bad.

The training helped me to realise I can live positively. Before the training, I was worried about where my children will live after I die. After the training, I know they will have places to live. I do not want them to go live with their uncle. Since the training, I have been able to help my children learn how to live together here where we are.

Before the training, I thought like others in the community, that since I am positive I will die soon. Now I know I am not dying and can live normally for my children."

### **What HAPCSO has achieved and learnt**

HAPCSO implemented memory work in six kebeles: Arada, Addis Ketema, Bole, Nifasilk Lafto, Kolfe Keraneo and Yeka. As well as memory work training, HAPCSO held workshops with parents to help them develop skills to cope with stigma.

Support groups for PLHIV and a memory youth club were also set up for children. Over 200 children have taken part in the regular activities and retreats. HAPCSO realised that it could reach more people with memory work by working with others. They have worked with eight organisations and 16 local authorities to introduce and strengthen aspects of memory work.

HAPCSO's learning focuses on the importance of good awareness raising, community participation and efforts to reduce stigma and discrimination. Community involvement, particularly working closely with the idirs, has made it easier for the programme to be accepted by the local community and supported the reduction of stigma and discrimination. Developing activities with children has become increasingly essential for HAPCSO and is crucial in supporting the memory work that happens with parents and guardians. This has also been reinforced by the support to parents on developing positive parenting skills, helping parents understand the behaviour and communication needs of children.

### **Challenges faced**

Stigma and discrimination is the major challenge for HAPCSO, and it is particularly strong in the urban area where they work. It has also been challenging to get a good level of participation in activities from men. The demand for memory work is strong and HAPCSO have been limited to the number of people they can reach with the project budget available.

Low levels of literacy have also been a challenge. HAPCSO are trying to address this by involving care givers in supporting parents writing memory books. Care givers are very close to the people they look after, so most PLHIV will accept their help.

There is also an opportunity to integrate different approaches in memory work such as children's rights and sexual and reproductive health.

### Future Plans

HAPCSO plans to continue memory work and develop it further and will be looking for funding to support ongoing costs of staff salaries and volunteers. Their aim is to get what they are doing with memory work recognised and supported by the Government.

#### Case study, Hiwot, Awassa, Ethiopia

"After the death of my husband, none of his relatives showed interest in either helping or visiting us, which made me develop a negative attitude towards them. I even repeatedly told my children that it's only me, 'their mother', they have in this world. It took me many years to change my attitude. Once I took the training on memory work, I wrote the memory book for my children and then arranged for them to meet with their relatives from their father's side. It was after this that my children told me that now that they know their close relatives, they would be out of harm's way if they come to suffer the loss of their mother. I believe this gives others a very good lesson on the importance of memory work."

Tilla has for a long time used personal testimonies about HIV to raise awareness in communities in Southern Ethiopia. When they combined this with a memory work approach they found a very empowering process taking place within families and communities.

### How Tilla approached memory work

Tilla linked memory work to their growing programme supporting OVC, aiming to empower parents living with HIV and AIDS to communicate well with their children, and to help find better coping strategies to deal with HIV and AIDS. Since 2004, Tilla has established memory work in four zones and is in the process of scaling up the approach further. The Government is encouraging Tilla to include three more Woredas (administrative divisions) in the programme.

Tilla members give life testimonies in schools, churches, mosques and health centres. Memory support groups and memory drama groups are stronger because of IMP. Members are teaching the community using their practical life experiences through testimonies and drama sessions. Memory support groups are also setting up savings schemes for their children.

### What Tilla has achieved and learnt

Tilla has observed that HIV-positive parents have gained new skills in communicating with their children, storing important information, the importance of appointing guardians, and on how to approach will-writing.

They have also been able to work with other organisations to introduce memory work approaches to other communities. As secretary of the 'OVC network' in Awassa, Tilla has shared expertise on memory work and trained network member organisations. Of these, two organisations Jerusalem Children and Community Development Organisation (JeCCDO) and Shiny Day received funding and started implementing memory work.

Tilla's approach of combining memory work and sharing life testimonies has paid dividends in increasing communication about HIV and AIDS in families and communities. The sharing of experiences and testimonies is helpful to people who receive training in memory work and reduces stigma and discrimination. Support group meetings and sharing of experiences helps to strengthen memory work activities. People have changed their lifestyles and have more self-confidence and self-esteem than before. Tilla has found that in order for memory work to be a success, regular follow up and monitoring of activities are important.

### Challenges faced

In implementing memory work, Tilla has found high levels of stigma and discrimination, particularly in rural areas, and as a result a resistance to disclose HIV status even within the family. Tilla has also had to translate and adapt the memory work approach to the local languages in rural areas.

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From an early stage, documenting the learning from IMP was a priority. Healthlink Worldwide worked with partners to document case studies, supported partners to write articles, present at conferences, and organised a learning forum at the end of the project.

Although Tilla worked successfully with some local organisations, it would have liked to also work with others, but this proved difficult due to a lack of capacity and commitment of these groups.

### Future Plans

Tilla plans to strengthen memory work further and reach more people. A priority is to strengthen children's participation through exchange visits and life skills training. There is also an opportunity to integrate different approaches in memory work such as children's rights and sexual and reproductive health. Income generation activities are also a critical part of empowering parents and guardians. Tilla plans to participate in establishing a national memory work forum with HAPCSO and Save the Children UK in Ethiopia.

### Support to memory work from Healthlink Worldwide

Healthlink Worldwide had a central role in the International Memory Project from the beginning. Throughout the four year period, it has supported partners to develop programmes appropriate for their countries and locality. It also took the lead on fostering learning and interaction between all the partners.



Healthlink supports partner organisations with memory work training.

Healthlink Worldwide regularly receives many enquiries and interest from other existing partners about starting memory work in their own organisations, both in Africa and beyond.

### How Healthlink Worldwide approached memory work

Healthlink Worldwide was first involved in memory work through a project between 2000-2004 focusing on child-centred approaches to HIV and AIDS in East Africa. This project also included NACWOLA and KANCO, bringing together a group of organisations in East Africa to share expertise and learning on working with children. As a result of this work, Healthlink Worldwide was approached by NACWOLA and the International Community of Women with HIV/AIDS (ICW) to help in scaling up NACWOLA's approach to memory work to other organisations in Africa. Healthlink Worldwide worked with NACWOLA to identify the countries, partners and funding for the initiative, which saw the start of IMP.

### What Healthlink Worldwide has achieved and learnt

Healthlink Worldwide's role in the project was to support the delivery of the project, working closely with partners throughout the four years. Healthlink Worldwide developed a manual on memory work, which was used as the basis for training partners' staff on memory work. Support was also provided to partners on organisational development and project management tools, including a workshop on monitoring and evaluation relating to memory work and regular partner meetings to review progress and develop the initiative. At the start of International Memory Project, Healthlink Worldwide was also aware that few resources existed on memory work and that these could often be hard for other organisations to find and access. This led to six resource lists being developed and being made available through a CD-ROM launched at the International AIDS Conference in Toronto (2006).

From an early stage, documenting the learning from IMP was a priority. Healthlink Worldwide worked with partners to document case studies, supported partners to write articles, present at conferences, and organised a learning forum at the end of the project.

This was a major multi-country and multi-partner initiative. Healthlink Worldwide learned many lessons from working in this way. The importance of face-to-face communication emerged early on as vital to developing good relationships with and between partners. The interaction between the partners was always considered incredibly valuable by partners and by Healthlink Worldwide. However, it was often

difficult to maintain a high level of communication between partners outside the face-to-face meetings. Electronic media started to overcome some of the challenges but capacity and connectivity meant it was difficult to use these tools consistently.

### Challenges faced

The interaction between partners and the documentation of project progress has highlighted emerging and largely unforeseen issues that the partnership had to deal with. Some of these issues, such as working effectively with child-headed households and elderly carers, demand time and resources over the next few years to develop an appropriate and adequate response, as the resources available through IMP did not allow sufficient exploration of these issues.

### Future Plans

Healthlink Worldwide regularly receives many enquiries and interest from other existing partners about starting memory work in their own organisations, both in Africa and beyond. Healthlink Worldwide has already started work on a memory work pilot project in India with Child in Need Institute, adapting the existing materials and training for use in India. Healthlink Worldwide would like the opportunity to be able to explore the emerging issues in more depth and support organisations to adapt the approach for use with different groups and situations.

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The importance of face-to-face communication emerged early on as vital to developing good relationships with and between partner organisations.

**Dorcas, FACT staff member, Zimbabwe**

“I joined IMP at the start. At that time, stigma and discrimination levels in Mutare and its surrounding areas were high. Members of FACT’s support groups were the only ones in Mutare who gave testimonies about how they were coping with living with HIV and AIDS. But sometimes those giving testimonies had not disclosed their status to their families who would then hear these public testimonies. I found it very difficult at this stage to relate with PLHIV because I wouldn’t know what to say or how to help them.

Through IMP, I attended the master training at regional level on memory work. Most importantly, I met with NACWOLA women who had risen above stigma and discrimination. Their experiences helped me to understand better what PLHIV were going through and how to work with them to address stigma and discrimination. I learnt that what PLHIV were going through was often to do with self stigma and uncertainty about how to tell people around them, especially their children.

When I returned to Zimbabwe, I organised a ‘Training for Trainers’, with PLHIV being the majority of the participants. Working through the memory work manual was therapeutic both for me and the participants. Participants started disclosing their status freely and speaking openly about the negative attitude they had towards FACT staff and insecurity over their children’s future. My involvement in memory work and interaction with other partners at regional and national level has made me more able to understand issues affecting PLHIV. I have learnt about the importance of involving PLHIV. There has been meaningful involvement of PLHIV as trainers in FACT’s memory work, which has made implementation easier at community level and helped us reach more people. As the lead member of staff for memory work, I have trained staff in Plan International, Red Cross and FACT Rusape. I now want to explore some of the emerging issues, including supporting grandmothers who are carers and helping young people living with HIV.”

## 3 Emerging issues

A number of issues have emerged through the course of the evaluation and the partners' own reflections. These have relevance not only for the communities involved but also for other psychosocial support activities with children and HIV responses in general. Memory work and other similar psychosocial support activities are popular strategies in mitigating the impact of the HIV and AIDS epidemic on children. The evaluation of International Memory Project demonstrates that they are not a quick-fix solution and demand a high level of engagement and commitment to the children and family members involved.

**Children as carers:** As described earlier, many children assume greater caring responsibilities towards their parents as a result of involvement in memory work. The implications of this needs more exploration, particularly in terms of children's own needs and rights as carers. Many children also expressed the anxiety that they experienced following the parent's disclosure of their HIV status. Children showed worry about their ill or dying parent, concern about their own ability to care for them, and about their future when the parent has died. The anxiety they still feel for the future is clear, and the approach of memory work needs to invest more resources in child-centred approaches to support children during the period not only immediately after disclosure, but also further into the future. This is particularly important as many children were obviously experiencing stigma and discrimination from other children in school.

“My mum takes medicine at 10 o'clock at night and I may fall asleep before I remind her and she might also fall asleep and not take the medicine.”

(Boy 14 yrs, FGD, Addis)

**Memory work as a long-term process:** The evaluation and partners' own experiences demonstrate that memory work needs to be viewed as a long-term process. Many families have started a journey of discovery through memory work. The increased communication has already started to have a positive impact, but far more needs to be done to ensure that children are really benefitting from memory work and that memory work is responding to the changing needs of children as they grow up. There is no blueprint for memory work where one approach will meet all needs without any alteration now or in the future. The reality

shows that different approaches and activities are needed for adolescents, very young children and children who are themselves living with HIV. There is also a risk that if partners are not able to continue their engagement and support to children, memory work could have a negative impact on children's resilience.

**Meeting needs of vulnerable groups:** IMP has identified several vulnerable groups who need particular attention and focused strategies. Memory work as a tool to work with very young children (under 10 years) should also be explored further. This is due to the complexity of the issues and the need to find appropriate approaches to working with families with very young children. Another vulnerable group is child-headed households. There is some evidence in the evaluation and partners' programmes that child-headed households increase as a result of memory work because parents and children show this as a preference during succession planning. Child-headed households have particular psychosocial needs which will demand their own response. Children in child-headed households, for example, are recognised as being particularly vulnerable to child abuse.

**Supporting children through adolescence:** Depression among young people affected by HIV is emerging as a priority that needs to be addressed urgently. Older adolescents expressed a need for support around a number of issues, including sexuality, safety and their ability to bring up a family in future. Adolescents who are HIV positive have specific needs which are not being catered for at the moment and require specialist support.

“When I am in a depression and ask other people to help me, the help is very poor. Friends and family can't prevent my problems. I want to discuss them with a professional counsellor [but there is not one available].”

(Interview in Ethiopia)

### What makes memory work stronger?

The experience of IMP partners in adapting memory work to their own organisational structures and strategies and their own local contexts has highlighted the factors that can make memory work successful.

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Memory work cannot be carried out in isolation. One component where this is particularly important is succession planning. This has been most successful where partner organisations have worked closely with legal organisations.

**Meeting participants' basic needs:** A lack of basic needs is a problem for families participating in memory work. Many of those participating were experiencing hardship in food security, basic clothing, shelter, school fees and materials. There is significant demand from parents and many children for income-generating activities to help them address their basic needs. Many children taking part in the evaluation prioritised being able to attend school and perceived this as important for their future. Addressing the importance of meeting these basic needs alongside memory work would strengthen memory work in future.

“When the children come home from school, they have nothing to eat...so it's difficult to talk about doing memory work.”

(Project staff at Kiwakkuki)

**Working in partnership with other organisations and services:** Memory work cannot be carried out in isolation. One component where this is particularly important is succession planning. This has been most successful where partners have worked closely with legal organisations as described in the case study of Kiwakkuki and KWIECO. Their expertise has made it easier to work on birth registration, writing wills, and inheritance rights, contributing legal knowledge and advocacy skills to individual cases, and advising project staff.

**Integration into other programmes:** The experience of IMP is that memory work is strongest when it is integrated into a comprehensive package of care and support, either with an organisation's existing programmes or with other service providers. HAPCSO, Kiwakkuki, Tilla and FACT have integrated memory work into home-based care and OVC support programmes.

“Memory work is a very important component of the integrated approach because previously there wasn't this communication. You couldn't get children to talk about HIV. Memory work is like a conduit...When we put in memory work, it will strengthen aspects of the home-based care programme, and aspects of home-based care strengthen memory work.”

(FACT project staff, Zimbabwe)

#### International Memory Project – networking and learning

IMP was based around an informal network of seven partners, who met regularly throughout the project period to review progress and share learning. Partners valued being part of a larger regional network and key staff gained much from their wider exposure to different country contexts and with different types of organisations. Partners valued the early mentoring role that NACWOLA was able to play and particularly liked the meetings at regional level. A network of master trainers from these partners has been set up and has delivered training for other organisations starting memory work activities.

“We have gained learning from NACWOLA and it's been useful to see how far they have gone.”

(Kiwakkuki project staff)

## 4 Where next?

Memory work has been practiced in Africa for a number of years. NACWOLA started to work with the approach in the 1990's. It is now a widely known and practiced methodology although approaches and activities vary hugely.

**Adapting memory work for new contexts:** Adaptation also needs to take into account the use of memory work in non-literate situations. FACT takes an approach to the training which stresses the importance of verbally telling stories to children about their lives and puts less focus on the actual writing of the memory book. This approach would build on the oral tradition in African culture, which many people fear is being lost. Memory work could be a way of recreating these spaces and increasing young people's knowledge and understanding of their cultural heritage.

**Memory work in the era of universal access to treatment:** Since memory work was introduced as an approach within the HIV response, the availability of treatment has increased dramatically and has started to change the nature of the response to HIV and AIDS. Memory work still has a role in this changing context although during the evaluation, all partners emphasised that many people are still dying from AIDS. Memory work supports increasing effective access to treatment. Opening up communication in the family supports adherence and positive living. Memory work will need to adapt and include new themes around medication and adherence for PLHIV as is already starting to happen in some countries.

“Especially after ARVs, it has strengthened the memory work because parents are thinking ‘I have time to work more for my children’. It had helped a lot. Previously many of the members were bedridden, so it was difficult for me to help them to write a memory book and to think about it”.

(Tilla project staff, Ethiopia)

**Stronger and more structured support for children and young people:** A memory book is not and can never be enough for a child who may experience the chronic illness or death of a parent. This support also needs to be tailored for the needs of particular age groups or for children who have particular needs, such as child-headed households. Cultural norms remain an obstacle for the involvement of younger children (under 10-12 years) as many parents worry that younger children are not able to grasp the complexity of the issue or will be unable to maintain confidentiality if the parent desires this. The reality is that many parents were aware that younger children find out from siblings or indirectly from family conversation. Where younger children had been more involved in the parents' memory work, this had proved to be a positive experience.

Future memory work will also need to look at providing the necessary support for children in their roles as carers, while also supporting them to access education and social opportunities.

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Since memory work was introduced as an approach within the HIV response, the availability of treatment has increased dramatically and has started to change the nature of the response to HIV and AIDS.



Involving children in memory work at an early age improves their resilience.

# 5 Recommendations for practitioners and policymakers

## Recommendations for practitioners

Memory work is clearly a powerful way to support community-responses to HIV and AIDS. Embarking on memory work needs careful consideration and planning so that it fulfils its potential. Incomplete memory work without sufficient support structures in place may do more harm than good.

- Develop good linkages with other organisations to support components of memory work and to ensure the existence of strong referral systems. Partnerships with legal organisations are proving crucial.
- Increase activities and support for children participating in memory work. Giving children opportunities to be involved in leading and developing activities will make memory work stronger.
- Consider extending memory work to the whole community, not just families affected by HIV and AIDS.
- Learn from other areas where psychosocial support is practiced such as in situations of conflict.
- Ensure memory work participants can also access ways of having their basic needs met.

## Recommendations for policymakers

- Memory work needs long-term involvement with parents, children and communities to ensure that the initial positive impacts of memory work can be maintained until children reach adulthood. This will demand either long-term funding formats, which allow support over a 10 year period or longer, or a very low-cost approach which can be supported by communities themselves.
- Further research and evaluation needs to be carried out with existing memory work programmes over a minimum 10 year time period, to increase knowledge and understanding about the long-term impact.
- Children need to be placed at the centre of memory work, with a genuine commitment to facilitating their involvement and leadership of the work. Strengthening child-centred responses benefits the whole community.
- The experience of implementing memory work across five African countries shows that there is potential for social change but that the approach needs committed investment and support in a way that lays the foundations for the approach to flourish in future.
- Memory work does not work in isolation. Successful memory work is either integrated into other programmes such as home-based care, economic strengthening, orphan support or treatment provision or works closely alongside programmes that offer this support.







Memory work provides the tool to break through the barriers of discrimination and stigma caused by HIV and AIDS by building strong bridges of communication among children, family members and the wider community.

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