

Page of an Ethiopian memory book

Memory work: Learning from the Ugandan experience

Nicola Ward, Jacqueline Nabwire, Jacinta Magero & Annet Biryetega

Memory work is becoming a widespread community approach in the reduction of stigma and discrimination and planning for children's future in communities affected by AIDS, principally in Africa. The first memory project was started by the National Community of Women Living with HIV and AIDS in Uganda (NACWOLA) in 1997.¹ Their initial training for parents and children took place in 1998. At the time, the project targeted women living with HIV and AIDS and their children. However, after several years the decision was taken to include the fathers and husbands.

Memory work is a practical child-centred community-led approach that encourages families to communicate openly about HIV and AIDS.² It focuses on improving communication between guardians and parents living with HIV and their children; disclosing HIV status and other important information; succession planning and writing important family history in a memory book. A variety of activities take place around these four main pillars including training and peer support groups for parents, guardians and children. The memory book is a tool that is also used to facilitate the process. This book is a written record of family and individual history, important facts, memories, hopes and messages. It can be written by parents or guardians with or for children; or by children themselves.

NACWOLA's successful implementation of memory work is partly due to the fact that it is deeply rooted in the communities and also because the people who are imple-

menting the project feel a sense of ownership of the programme. The trainers and follow-up team are NACWOLA members – women living with HIV – who have been memory project beneficiaries and can therefore create strong bonds with other beneficiaries. Other trainer selection criteria include a minimum education qualification,

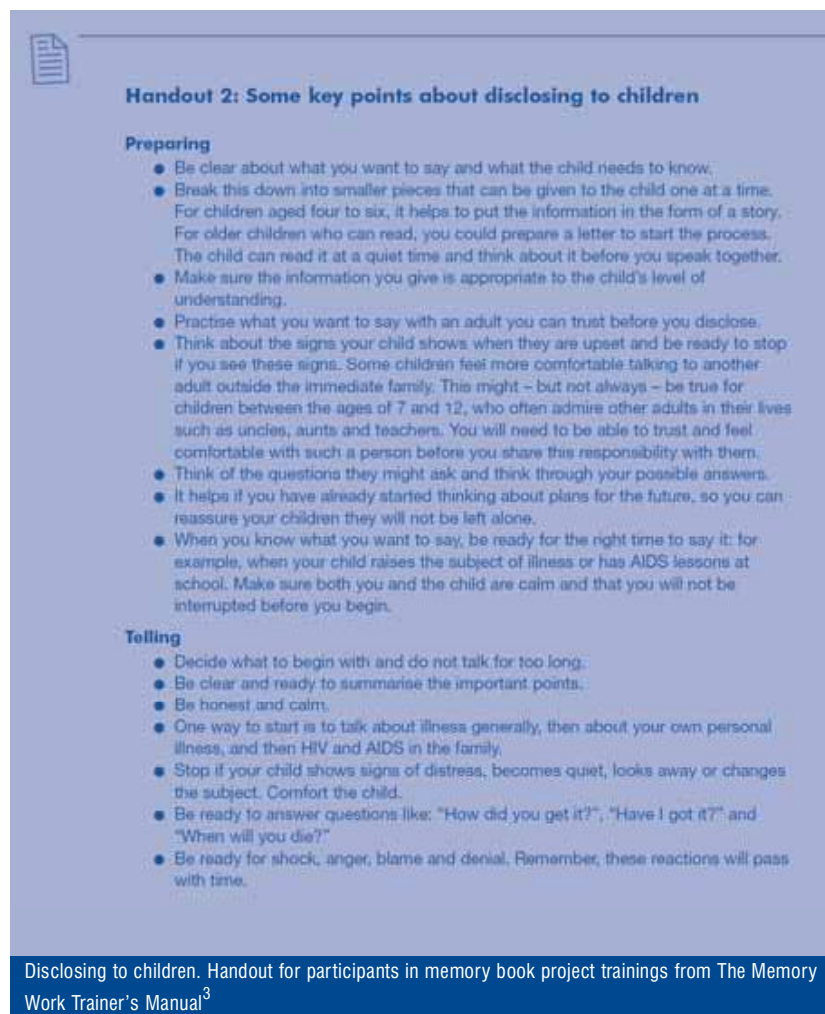
experience in writing a personal memory book and a disclosed HIV status to children or foster ones.

Those selected participate in a memory work training for trainers, which can last for 8 to 10 days. In 2005, a training manual was published to assist them in their work.³ Trainers have also benefited from other trainings, e.g. on home-based care, PMTCT, nutritional counselling, handling stigma and palliative care. NACWOLA has trained 141 memory work trainers since 1998. Some of these women have passed away while some are now staff or volunteers in HIV clinics and other AIDS service organizations in Uganda. Others are staff and volunteers

Opportunities for HIV prevention?

Memory work can be viewed as an entry point for HIV and AIDS work at the family level. It can be a good start for families to commence communication around HIV and AIDS issues, disclosure of HIV status to children and planning for the future. All these are fundamental issues critical for the success of HIV and AIDS programmes. In areas where memory work has taken place, there is evidence of increased demand for other HIV and AIDS programmes, from access to antiretroviral treatment, access to voluntary testing and counselling facilities and access to information concerning HIV prevention.

In the case of HIV prevention work, as more families start discussing important HIV and AIDS awareness issues at home, the raised awareness empowers children to access prevention information. As more families become involved in memory work, it becomes a community concern, and neighbours, other relatives and friends also become more aware of the situation and the need to become involved in prevention programmes.



Handout 2: Some key points about disclosing to children

Preparing

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

Telling

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

Disclosing to children. Handout for participants in memory book project trainings from The Memory Work Trainer's Manual³

in NACWOLA or resource persons at the district level where they assist in monitoring memory work.

Learning from experience

Participants in memory work go through a process of improving communication in the family setting with their children and planning for the future. The programme is flexible and allows for families to take different lengths of time to achieve improved communication. Between the training of the parents/guardians and the children, there is a three-month gap to allow parents time to disclose their status to their children, a pre-requisite before the children can participate in their training. Separate post-training support groups are established for the parents and children. This accords the children and the parents space and time to share experiences and improve communication.

Memory book clubs have been set up to support the parents in writing memory books. The memory work process is based on interpersonal interaction between the trainer, follow-up team and the communities in which they work. Participants are encouraged to share their own experiences of the challenges they faced while preparing to disclose their HIV status, facing stigma and discrimination and how they communicated with their children. The programme is cost-efficient because it reaches out to large numbers of individuals with minimum capital input. Another key factor behind its success is the commitment of the trainers.

Impact

The impact of the project is felt at the grassroots level and it starts with the participants in the programme who then share their experiences with others in the community. The following is a testimony

from a participant in the memory work project: *"I disclosed my HIV status to my son after going through a memory project training. My son now understands why I can't provide him with everything because we discuss family issues. When I gave him money to pay for his educational trip, he was so happy and told me that his teacher had told him that he can't afford a school trip because his parent died of AIDS-related illness".* (A parent from the Busia branch of NACWOLA)

Children who have benefited from the trainings have also become more supportive to their parents living with HIV: *"I saw the way my father was suffering before his death. I knew we would have nobody to care for us. However, my mother has been supportive. She told us she's HIV positive but she is still able to care for us. We always remind her to take ARV drugs",* a child from Luweero said. A child from Busia said: *"I am able to counsel my young brother and sister at home how to avoid early pregnancy, marriage, HIV/AIDS and I am a peer educator."*⁴

The project has expanded due to the ripple effect. Previous beneficiaries tell others about it hence creating an ever-increasing demand. Originally implemented in only one district, NACWOLA now has scaled up the memory work to cover five districts where it has branch offices, as part of the International Memory Project which started in 2004. Since then, some 150 parents and guardians and 150 children have been trained and commenced memory work. Children's peer support clubs have been established in all the five districts and they meet either during school holidays or on Saturdays. Issues discussed depend on the interests of the children and include topics around STI, HIV and AIDS awareness. The clubs are a safe space for sharing life experiences, developing a sense of self-confidence, raising self-esteem and increasing resilience.

Following the trainings with the parents and guardians, each participant receives a copy of a memory book and can request more copies depending on the number of children

they have per household. Since the start of the International Memory Project, 210 memory books have been completed or are in progress. Challenges encountered while compiling memory books include difficulty in getting family information on deceased husbands, and the issue of disclosure and the high levels of illiteracy in the rural areas. The children and literate mothers in the memory book clubs assist the illiterate parents to write memory books. Memory book guides have also been translated into three local languages to overcome some of the barriers.

Involving men

Through the process of learning from the years of experience in memory work, NACWOLA has modified the programme to include some new components. One of the most important changes is the inclusion of men in the programme. NACWOLA took a conscious decision to implement the memory project outside its core membership – women living with HIV – due to the high demand. It has now implemented memory projects together with other organizations working with men, notably Lumero, The AIDS Support Organisation (TASO), UWESO and Reach the Child Uganda.

There were various reasons for this change in approach. In the Ugandan culture, men head families and are, therefore, influential in family decision making. It is important to

Lessons learned

- A supportive family environment created through fathers' engagement in memory work builds psychosocial support, which is very important not only for the children, but also for the parents.
- A child-centred approach ensure that children are involved in planning for their future and a smooth take-over of the household tasks after the death of their parents.
- Memory book clubs for parents who are completing memory books can play an important role in offering peer support. The sharing of experiences assists parents to face the challenges and complete their memory book.

involve them so that they become an integral part of the memory work process and support the plans made for the children by their mothers. Including men in training workshops and group meetings opens up gender discussions. An example of such a discussion may be on why a female child may have to stop school to care for her ill mother when there is an older male child in the household. Finally, a supportive family environment created through fathers' engagement builds psychosocial support, which is very important not only for the children, but also for the parents.

Smooth take-over

Other changes in the approach of implementing the memory work project included developing a child-centred approach which involved children in planning for their future and home responsibilities for a smooth future take-over of the household tasks after the death of their parents. This led to the establishment of linkages with other organizations such as Heifer International to help parents set up income-generating activities. Thereafter children's clubs were set up and have now expanded into all memory project implementing districts in Uganda. The other benefit of children's clubs is that they can play the role of peer support groups. Memory book clubs for parents who are completing memory books have also started playing the role of support groups. The sharing of experiences assists parents to face the challenges and complete their memory book.

Refresher trainings are now carried out to enable beneficiaries and facilitators to share experiences and find ways of addressing challenges. It was recognized that due to the increase in numbers of orphans, the guardians and carers needed to be involved in the project so that the orphans are supported and could also benefit from the memory project. Community leaders are also involved and sensitized to enable them to support the implementation of the project.

The successful concept of memory work developed in Uganda by NACWOLA has

been borrowed and adapted in different countries in Africa. In the framework of the International Memory Project initiated by Healthlink Worldwide, memory work has also been introduced in Ethiopia, Tanzania and Zimbabwe and further expanded in Uganda and Kenya. NACWOLA plays an important role in this project. A mid-term evaluation of the International Memory Project including the Ugandan component is underway. The results are expected by the end of 2006. ■

In the next issue of Exchange, an example will be taken from Tanzania to see how organizations are adapting memory work to their own contexts.

Nicola Ward

Programme Manager Africa at Healthlink Worldwide, UK

Jacqueline Nabwire, Jacinta Magero & Annet Biryetega

Board Member, Member and National Coordinator of NACWOLA, Uganda

Correspondence:

Nicola Ward
Healthlink Worldwide
56-64 Leonard Street, London EC2A 4JX,
United Kingdom
Tel: +44 20 7549 0273
Fax: +44 20 7549 0241
E-mail: ward.n@healthlink.org.uk
Web: www.healthlink.org.uk/projects/hiv/imp.html and www.nacwola.com

1. See for instance J. Nabwire, *Sexual Health Exchange* No. 1, 2000 (www.kit.nl/iils/exchange_content/html/2000_1_uganda_memory_project.asp, and A. Biryetega, *MMS Bulletin*, No. 97, 2005 (www.medicusmundi.ch/mms/services/bulletin/bulletin200503/kap03/07biryetega.html)
2. *Starting to do memory work: A guide to the stages of implementation (draft)*. N. Ward, Healthlink Worldwide, 2005: www.healthlink.org.uk/PDFs/imp_stages_draft.pdf
3. *The Memory Work Trainer's Manual. Supporting families affected by HIV and AIDS*. NACWOLA/Healthlink Worldwide, 2005 (144 p.): www.healthlink.org.uk/PDFs/imp_manual.pdf. Hard copies are available free for CBOs and £20 a copy for international organizations.
4. *Policy Brief: Building children's resilience in a supportive environment: Reflecting on opportunities for Memory Work in HIV responses*. Healthlink Worldwide, 2006 (4 p): www.healthlink.org.uk/PDFs/memory_policy.pdf