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# Starting to do memory work: a guide to the stages of implementation

This guide is based on the experience of the National Community of Women Living with HIV and AIDS (NACWOLA) in Uganda and initial experiences of the International Memory Project

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Starting to do memory work: a guide to the stages of implementation. This guide is based on the experience of the National Community of Women Living with HIV and AIDS (NACWOLA) in Uganda and initial experiences of the International Memory Project (IMP)

This brief introduction to memory work describes the preconditions and factors that organisations and community groups wanting to start memory work need to consider at each stage of the process. It draws on the experience of a group of organisations across Africa who are part of a project led by the National Community of Women living with HIV and AIDS in Uganda and Healthlink Worldwide.

The stages are described in the context of a three year project. This does not necessarily mean that it takes three years to effectively implement memory work, but we believe that in any intervention, these stages are crucial.

What is memory work?

Memory work is a community approach to address fundamental issues around HIV communication in the family which 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.

What is a memory book?

A written record of family and individual history, important facts, memories, hopes and messages. A memory book has come to mean different things in different contexts. They can be written by parents or guardians with or for children. They can also be written by children themselves.

Year 1: Preparation, community awareness and beginning to implement

### **Phase 1: Setting the ground work for memory work implementation**

#### **a. Where should memory work take place and on what scale?**

If memory work has not taken place in a country before it may be best to carry out a pilot project in a specific community before scaling up the approach. This is important to carefully work through the different issues involved in memory work in the specific country context. Memory work involves some extremely sensitive issues around HIV that a community needs to be empowered to be able to work through. Communities where high levels of stigma and denial exist may need more sensitisation work around HIV before it is appropriate to start memory work. If piloting the approach with an intention to scale up the methodology across a district, region or country, it may be interesting to choose two or three different communities with different characteristics. If it

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is a pilot project the impact and community interest in the programme may be key to find out how appropriate memory work is in that specific country context.

Memory work can take place in a variety of settings rural or urban, and organisations have implemented memory work in both. Some of the criteria for choosing the location for where memory work will take place include the following:

- Where is the greatest need?
- Where can an impact be made?
- Where have the community identified key issues such as stigma and discrimination and disclosure as priorities to resolve?

If memory work has been introduced by a different organisation it is important to visit and find out what approaches have or haven't worked at the concept stage.

*Experience of Family AIDS Caring Trust (FACT) in Zimbabwe* (taken from first 6 monthly narrative report, Oct 2004/March 2005)

FACT decided to select four pilot sites for implementation of IMP, three in a rural setting and one in an urban setting. The aim was to compare experiences in rural and urban contexts. Communities from these sites participated in a needs assessment. Memory work is not a new concept in Zimbabwe and three community based organisations (CBOs) who have experience of memory work were approached to share their experiences and invited to FACT's training of trainers (ToT) workshop. The report comments that, "Networking with other organisations will go a long way in encouraging information sharing exchange of ideas and experiences, which will make the project effective and also enable more people to be reached."

### *Scaling up*

If Memory work has already been introduced and is now in a phase of being scaled up there are several considerations that need to be made. For further information see the article "Scaling up memory work: the challenges" p. 34 in *Medicus Mundi Bulletin*, no. 97, 2005. A practical guide to scaling up Memory work is also being developed.

### **Sensitisation phase:** *discovering community- level awareness*

The key for successful programme implementation is how the work starts. If the community are new to the concept of memory work it is important that discussions are held to analyse the level of interest. These can be with a range of key stakeholders eg. religious leaders, community leaders, traditional leaders, youth groups, people living with HIV including community groups for people living with HIV, children's groups and orphans, especially if there are any organised community groups for orphans. It could also be useful to hold general community meetings depending on the specific cultural context. It is necessary for the community to have identified the need for such a programme otherwise it will not be successful. When assessing the need for memory work a community work shop around HIV and AIDS awareness could be carried out to identify the challenges in the community and to identify different needs of the community in relation to HIV and AIDS issues. See the resources relating to participatory community assessments, AIDS Alliance publications

<http://ngosupport.aidsalliance.org/ngosupport/> especially useful is "Participatory Community Assessments for HIV/AIDS Prevention work" and resources in the Getting Started section of the AIDS Alliance OVC support tool kit.

<http://www.aidsalliance.org/sw4661.asp>. This is also an opportunity to talk about HIV prevention, care and support. As memory work can involve disclosure of HIV status, it is

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important to make sure that there are information and services to support the individuals and families involved.

An IMP partner in Ethiopia, Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPSCO) have “developed a community programme that works with community leaders (idirs) in their home based care programme and have developed a system whereby the idirs contribute money to care for the orphans in the community. This has raised the profile of the issue of caring for orphans in the community.” The Idirs are a key group for the introduction of memory work into the community, see p. 37 of “Scaling up memory work: the challenges” in the Medicus Mundi Bulletin no. 97 for further information.

### **b. Linkages at community and national level**

Early on in the programme it is important to make links with other organisations and groups who may be able to complement the memory work at a community level. For example NACWOLA have strong links with the AIDS Support Organisation (TASO) and members of NACWOLA then have access to TASO’s health clinics and can have access to anti retroviral therapy (ART) through TASO. They also link up with Heifer International and through them have been able to involve some of their members in the Heifer International income generation project with cows.

Before or after the community sensitisation phase it is important to share your ideas around memory work with key players at a national level including associations of people living with HIV and AIDS and the National AIDS Council.

### **c. Identification of key players and allies**

It is important to identify early on the allies and foes in the community for memory work and to identify community level support. An exercise to identify allies and foes, as is used in community level advocacy interventions, could be adapted, one such example has been produced by INTRAC. During community sensitisation meetings in Ethiopia TILLA association of women living with HIV and AIDS in Ethiopia (TILAA AWLH/A) became aware of the importance of involving men and fathers, child headed households and grandparents in their memory work programmes. It was noted that grandparents are often responsible for decisions in the household and can have a big impact on decisions regarding the children they may be caring for (Narrative bi-annual report from TILAA AWLH/A, Oct 2004 -March 2005). It was important for them to find ways of involving the grand parents for them to become allies of the memory work in order to consider the best interests of the children.

## **Phase 2: Management and implementation**

### **a. Management of memory work**

Care should be taken when deciding who will manage the programme at a national level and in the community who is going to work with the families involved in the programme. Within the International Memory Project, there are two key people who work in each partner organisation in their respective countries to manage the memory work programme (often, one full time, one part time). They have been trained in memory work approaches following “The Memory work trainer’s manual, supporting families affected by HIV and AIDS,” HLWW 2005. The two IMP officers train a network of community trainers who work with families in the community. It depends on the scale of

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the programme as to how this is organised. It may be that the two IMP officers have direct contact with training parents, guardians and carers in memory work especially if it is a small pilot project. In this case there may then be a need later on, as the programme expands, for a network of community officers/volunteers who can work with the families who are starting memory work. Different partner organisations have different structures and approaches to managing memory work in their organisations.

### *Points for consideration at the national level*

Who is responsible for the programme?

How will it be integrated into current programmes?

Who is going to be trained at a national level to be able to train community trainers?

Criteria developed by IMP partner organisations to select participants for the international ToT training of national Master trainers is as follows:

- Basic Literacy - in English and a local language (eg. Swahili, Amharic, Shona and Luganda)
- Good understanding of key concepts in memory work
- Reliable
- Graduate level or equivalent experience
- Basic computer literacy skills
- Previous experience in training other trainers (ie. ToT)
- HIV/AIDS experience including Orphans and Vulnerable Children (OVC) experience
- Staff (not volunteers)
- To be culturally sensitive to cultural issues of the communities where the programme will be implemented.

### *Points for consideration at a community level*

At a national level it is advisable that the people who are trained to lead the memory work programme are paid staff. At the community level of trainers this may be difficult for some implementing agencies and depends very much on the ethos of work within the organisation and the resources available. Issues around sustainability of the programme are key and should be considered early in the planning stages.

### *Criteria that may be considered for community level trainers:*

People who have basic counselling skills, who are reliable, who already have close relations at a community level with people living with HIV and AIDS and are members of the community. The criteria are not set in stone and will depend on how the organisation wants to implement the programme.

## **b. Implementation of memory work with parents, guardians, carers and children**

It is important that there is continual support for parents, guardians and carers to go through memory work at their own pace. There may be an initial training to introduce the different concepts of memory work but this needs to be followed up with regular group meetings where the issues are discussed in a supportive environment and individuals can discuss their own challenges and needs.

NACWOLA in Uganda is in a unique position as they are a member organisation of women living with HIV and AIDS and train their members in the districts to work with the

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families. The members are often parents, guardians or carers themselves and can apply memory work to their own family contexts before sharing with others in the community.

### *Training of parents, guardians and carers at community level (experience of NACWOLA)*

Critical issues in this training (as explained by Annet Biryetega, p.31 *Medicus Mundi* Bulletin, no. 97), “Enhancing communication skills to prepare parents and guardians to disclose their status to their children and later support them; understanding the needs of children at different stages; helping parents and guardians to understand inheritance rights and make secure plans for children and involving them and respecting their decision during planning; imparting skills of income generation, small loan schemes and savings; and supporting parents to write memory books for their children.

How to work with parents, guardians and carers living with HIV or/and caring for children affected by HIV and AIDS orphans?

Possible stages

- Identification of parents, guardians and carers who are interested in the programme through community counsellors, women’s groups, community groups etc.
- Group meeting with parents, guardians and carers
- Introduction of key pillars and concept of Memory project through initial training followed up by group meetings (frequency of dependent on community)
- Topics from “The Memory work trainer’s manual, supporting families affected by HIV and AIDS,” HLWW 2005 followed with parents/guardians

Other key components of memory work include the following:

- **Counselling:** It is key that parents and guardians and carers involved in memory work have access to some form of community support group or counselling. In NACWOLA this is achieved through NACWOLA members making home visits or through the Memory book clubs. Children’s clubs promotes peer support for children through child-to-child counselling, sharing experiences and testimonies to build resilience.
- **Memory book development:** One of the key activities that people have responded to very well is writing a memory book. The memory book provides a focus for family discussion around disclosure and related support. See “The Memory work trainer’s manual, supporting families affected by HIV and AIDS,” HLWW 2005 for more information.
- **Implementation of memory work with children:** Orphans and vulnerable children (OVCs) are the key focus of memory work. An underlining principle that runs through memory work is to use child centred approaches and to keep the interests of the child paramount at all times during implementation. NACWOLA carry out training with children at the community level as explained below.

### *Training of children at community level (NACWOLA experience)*

Critical issues in this training (as explained by Annet Biryetega, p.31 *Medicus Mundi* Bulletin, no. 97)

“Providing knowledge to help children get a deeper understanding of HIV prevention and care for the sick; helping children to understand their rights and responsibilities; helping bigger children to understand stages of child growth and needs of different stages to

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prepare them in case they have to look after their young siblings; empowering children with communication skills to enable them to open up to parents and care takers on difficult issues they experience; and life skills training". NACWOLA hold children's clubs following on from the training where children can share their experiences.

Some IMP partners have also started children's clubs eg. Women Against AIDS Kilimanjaro Region (Kiwakkuki) in Tanzania. Kiwakkuki works with large numbers of orphans and vulnerable children in the communities where they implement their programmes. They have integrated memory work into these programmes.

### Phase 3: Supporting review and reflection

At the start of memory work, it is also important to think about how to monitor and evaluate the impact of the project. This is for the benefit of everyone involved in the project from a woman living with HIV, her children, community leaders, and other interested organisations (and funders). The following mechanisms can help the project be 'valued' at all these levels, and support the different groups and stakeholders

#### a. Documentation and learning

Support may be needed in developing new techniques for documenting memory work. These could involve story telling techniques and can be linked into the monitoring and evaluation systems developed. HLWW is in the process of developing such techniques with partner organisations. Documentation of progress in memory work implementation is key to learn from the experiences and be able to analyse the progression of the project activities and the impact it is having on the community. Some approaches for enhancing documentation and learning include the following:

- **Memory work learning forum:** A Learning Forum is "an event that aims to provide a space and place for practitioners to share knowledge, skills, and experience and together begin to forge a community of practice that could help support the continued improvement of their work" (HLWW report of Learning Forum that took place for SIPAA programme in Lesotho, Feb. 2005). It is an ideal environment for participants to feel free to share their experiences of memory work (negative or positive) and to learn ways of overcoming challenges from each other. It creates a conducive learning environment for participants. It is important that people learn together how to address issues that may arise when implementing memory work otherwise the implementers at the community level can get very overworked and community members can put large expectations on their community volunteers. Solutions will need to be found that are appropriate to the specific context. Many needs may be identified by community volunteers that can not be addressed directly by the programme. It is necessary in these cases to ensure the programme is well linked to other programmes that can complement the work in different ways. HLWW has experience in running Learning Forums.
- **Partners meeting:** A partners meeting is an opportunity for sharing experiences possibly with a wider audience, it may also be an opportunity to invite other key stakeholders to participate and learn more about how the memory work has progressed. It could be an opportunity to learn about other memory work taking

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place in country or further a field. The nature of the partners meeting will depend on how the implementing organisation views it.

- **Community activities:** the following activities can support learning at community level and amongst people living with HIV. This can also be supported through interaction with others and visits to other groups implementing memory work in country or further a field.
  - Memory book clubs for parents, guardians or carers writing memory books and starting to share important information with their children – can be important to give support to each other. Such clubs can be used to discuss all of the memory work activities eg. Will writing, access to ART and income generation activities (IGAs)
  - Memory book clubs for children writing memory books – there may be situations where there are many children (possibly orphans) interested in writing their own memory books. A club environment can assist this activity and can be linked to recreational activities for children. This approach has been effective in Uganda.
  - Linkages with other organisations doing related work that can support the memory work eg. Access to ART, access to IGAs and access to health clinics

The above activities are important complementing activities for memory work to be successfully and fully implemented and may develop depending on the specific context, what is appropriate and possible for the implementing agency and the community response to the programme.

### **b. Monitoring and Evaluation**

As in any programme monitoring and evaluation is key. Different communities in varying cultural and religious contexts may react very differently to memory work implementation at a community level. It is important to capture and monitor the progress of memory work, to learn from and build this into the learning cycle within the programme implementation. Memory work is difficult to monitor as progress is linked to very individual experiences of parents, guardians, carers and children who are going through the process of memory work and coming to terms with personal and challenging issues around their life in the present and future. It is very challenging to have monitoring systems that respond to this effectively. IMP is developing a monitoring framework using the most significant change (MSC) approach based on story telling as a strong component. It is advisable to use quantitative techniques to record basic information eg. how many families are involved, how many participated in the trainings, how many memory books are being developed etc.. but to complement this with qualitative methods around story telling to really assess the progress. Community trainers, parents, guardians and the children are in the best position to monitor their own progress with memory work.

#### *Baseline survey*

It is important to monitor progress from a baseline. This can be linked to a situation analysis or needs assessment of a representative sample of communities before memory work implementation. Before implementing IMP a needs assessment of OVCs and PLWH/A particularly parents living with HIV and AIDS, guardians and carers of children affected by HIV and AIDS was carried out in the respective communities where IMP was going to be implemented. A range of issues were looked at including the

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needs of OVCs, parents living with HIV and AIDS, guardians and carers, issues around disclosure, levels of communication between parents and their children concerning HIV and AIDS issues, evidence of succession planning, levels of discrimination and stigma, what support is available for OVCs and if there were any groups, organisations or government bodies supporting OVCs in the community. The process involved interviews with parents living with HIV, guardians, carers and children. Individual case studies were also recorded as a way of gaining a more in depth understanding of the situation.

The needs assessment was used as a baseline survey for IMP in the respective countries. In Zimbabwe, FACT used the community sensitisation meetings as “a way of feeding back communities on the findings of the needs assessment survey and at the same time sensitising the communities on the implementation of the IMP programme”. In that way there was an important follow up from the initial baseline survey which built trust with the communities where the programme was to be implemented.

### *The Most Significant Change approach*

The Most Significant Change approach is being used with IMP partners to see how it might be used to monitor progress in memory work. (The Most Significant Change (MSC) Technique, A Guide to its use, Davies, R. and Dart, J, 2005 accessible electronically <http://www.mande.co.uk/docs/MSCGuide.pdf> )

“Most significant change is a participatory monitoring system that can deal with the unexpected. It draws meaning from actual events, rather than being based on indicators. The method involves systematically collecting stories which are then analysed, discussed and verified. The stories capture changes in the lives of “beneficiaries,” their colleagues and in the character of their participation. The method also helps to identify why change happens,” taken from a summary of the approach on the Health Exchange website, <http://www.healthcomms.org/comms/eval/le02.html>

Further information on use of this approach for memory work will be available in the coming months.

## Year 2 and 3: Consolidating work and moving into subsequent years of the project

### **Year 2 and 3**

In year 2 and 3 it is expected that the memory work would be firmly established in the pilot communities and there would be a focus on documenting the experiences and learning from them. Activities such as the development of memory books and will writing would be well developed. It may take sometime for these activities to be carried out by individual families depending on specific circumstances. New districts may also be identified for further expansion.