



**MMS Bulletin #97**

*Memory Work*

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***The origins (I): London, 1991***

**The memory book – and its close relations...**

Von Carol Lindsay Smith

*Memory book, memory box, memory store, memory suitcase ...these are all variations on a concept which together form the basis of the “Ten Million Memory Project“ (10MMP). The original memory book was produced in 1991 in direct response to the needs of African parents who had HIV/AIDS and who were living - and dying - in London, remote from their extended families. These parents were service users of Barnardo's “Positive Options”, an HIV-specific project set up to encourage parents to make plans for the future care of their children whom they were unlikely to see through to independence.*

Barnardo's is a large, voluntary child-care organisation providing a range of innovative services for children and young people who are amongst the most disadvantaged in the UK. In 1988, ahead of other voluntary and statutory child-care organisations, Barnardo's appointed a development officer to explore the numbers and circumstances of children who were directly and indirectly affected by HIV/AIDS. As a result, as well as explicit sexual health education programmes for children in their care, Barnardo's established projects aimed at helping HIV-positive parents to make secure plans for the future care of their children. The lead project was „Positive Options“ in Central London. Positive Options was a walk-in service for parents with HIV/AIDS with three clear aims: to help parents talk openly about HIV in the family; to support parents in preparing their children for the uncertain future, identifying guardians and making wills; and to encourage parents to strengthen their child's sense of identity by making individual memory books and by handing down family knowledge and practical skills.

When the Positive Options project opened in 1990 there was little knowledge in the UK about the numbers and circumstances of children who were infected or affected by AIDS. But after a year's work it was clear that many of the service users originated from sub-Saharan Africa and, because of distance, secrecy about their illness, political and economic factors, many of them were fearful about asking relatives back home to take care of their children. There was severe risk, therefore, that some of these children orphaned by AIDS would be marooned in the UK

care system, cut off from extended family and with no clear idea of their own identity. Potentially it was the worst possible outcome for children already devastated by the death of their parents.

## Give surviving children a clear sense of identity

This was the context in which the original memory book was devised. The aim was to give surviving children a clear sense of identity, including details of their personal history, family background and traditions together with parental guidance on how to face up to life, who to rely on, how to contact relatives - a written legacy of information which, in normal circumstances, would have been passed on to children orally by parents and senior relatives throughout their growing up years.

The memory book is a direct descendent of the life story book work which is often used in the UK and USA as a therapeutic way of facing children with painful realities about their early life. The theory is that if children know the truth and understand the reasons for their chaotic moves around the welfare circuit, they will have a better chance to finally come to rest within a substitute family.

Having seen life story books produce constructive outcomes for many shattered children, it seemed a logical step to turn the process upside down, to work out a format that would make it easy for parents to write their story, to tell their own truths and to impart their hopes and fears for their children's future.

Initially at Positive Options, we had asked parents to write or record their family history, adding personal information for each child. But this was an overwhelming task for many of the parents who were already in the late stages of illness or who were uneasy with reading and writing. Although they quickly latched on to the memory book concept, and were desperate to do the work, the parents wanted help to break the task into small 'bites'.

Service users, mainly Ugandans living in London, were involved at all stages of developing the memory book. Their questions and suggestions steered the process, first a list of headings to trigger ideas and memories. Later on, guidance notes were added to make it easier to get on with the work at home with their children. Later still parents asked for a child-friendly container so they could save small mementoes to remind their children of everyday life. The first attempt was the memory store, a colourful box with little drawers. (Latterly in Uganda we have encouraged parents to use much more durable tin boxes or traditional baskets, locally made, sometimes with the child's name woven into the design.)

It soon became clear that, as well as providing children with essential facts, the memory book work was intensely therapeutic for the parents who relished the opportunity to talk and write about happier times in their lives, revealing themselves not just as worn-down bodies with a terminal illness, but vivid individuals with a unique history, skills, achievements and aspirations for their children.

A third, even more important outcome of the memory book work, was that parents found themselves spontaneously opening up to friends, relatives and ultimately to their own children.

They asked themselves "Why am I writing this down without discussing it with my children? Why don't we do this together?" Gradually it became the norm, for parents, children and those they trusted to work together on the family history. This opened the way for children to ask questions, express fears and, in some cases, leading to open discussion of HIV in the family.

For the next four years memory book work bubbled away in the UK - in hospices, prisons, divorce-conciliation services as well as HIV agencies. It turned out to be adaptable to any setting where children were at risk of losing contact with one or both parents. Gradually too the ideas crossed frontiers, first within Europe and USA.

## “African people won't be interested...”

Eventually in 1995, the memory book reached Uganda. And here I have to add a personal note. I was invited to the wedding of one of the Positive Options social workers. Quite a few knowledgeable people advised me not to bother taking the memory book to Uganda "because African people have an oral tradition and they won't be interested in written records."

How glad I am not to have been intimidated. One of my earliest contacts was Beatrice Were, a courageous woman who helped to establish NACWOLA, the Community of Women Living with HIV/AIDS, and at that time was National Co-ordinator of this huge grassroots organisation, many of whose members lived openly with HIV, defying prejudice and physical threats. But despite their public openness, most of them struggled with the problem of disclosing to their own children and this inhibited planning for their future care.

As social workers, Beatrice and I were certain that children's capacity to survive family disaster would be increased by their being informed and involved in family issues and, conversely, their psychological and physical development would be undermined by secrecy and failure to plan for their future security.

Beatrice immediately realised the potential of the memory book to help parents face up to these painful tasks. With her enthusiasm, combined with the courage of NACWOLA members and the overarching support of the Ugandan government which was ahead of the world in encouraging openness about HIV/AIDS, the memory book found itself transplanted into very fertile territory.

From 1996 until 2003, I was privileged to have a close working relationship with Beatrice Were and many NACWOLA trainers and grassroots members who, with technical support from the Save the Children Fund and other non-governmental organisations, have built up the Memory Project Training Programme. As well as helping parents to record family history and pass on vital information on beliefs and traditions, the Memory Project gives practical help to parents on understanding their children's development needs, opening up communication within the

family including disclosure on HIV/AIDS, anticipating bereavement, planning future care and preparing children to cope despite loss and changes ahead. At all stages parents are encouraged to involve, inform and listen to their children.

Up to now hundreds of parents in Uganda have received training and, in addition, NACWOLA teams have taken the ideas to neighbouring countries and to HIV conferences and workshops in all corners of the world. Many participants say it has been a life-transforming experience, helping them to face up to their extreme problems and do the best they can within available time and resources. Numerous children also testify to the new experience of being trusted, listened to and fully involved in family decision making. Although unprovable, it is also widely believed that this level of transparency in the family about HIV/AIDS has a protective factor far more persuasive than any amount of AIDS education at school or exhortations on TV.

As the success of the memory book and Memory Project Training Programme spread, NACWOLA's small team of trainers and my own limited resources as a self-funded volunteer, were overstretched. Therefore Beatrice Were (on behalf of NACWOLA) and I decided to look for an umbrella organisation, to jointly seek serious funding to consolidate the training programme within Uganda and, if possible, to disseminate the ideas further afield. In 2002 Comic Relief agreed to fund a one-year feasibility study with a view to funding a three-year International Memory Project (IMP). With Health Link Worldwide grasping the umbrella, plans are moving forward for the programme to be rolled out in Tanzania, Ethiopia and Zimbabwe.

Meanwhile, all over Africa and in many other areas of the world, different forms of Memory Work are taking off. They are highly varied, each interpretation of the concept depending on the local capacity to be open about HIV, the availability of skills and resources, the experience and preferences of group leaders and, above all, the pressure of numbers which influences the depth at which the work can be done.

Whenever, wherever, however... it's good to realise that so many people living with the the pain and fears associated with HIV have been involved in developing these cheap, effective, simple ways of working which have meaning and value for us all. AIDS is not a prerequisite.

*\*Carol Lindsay Smith was Barnardo's development officer for HIV/AIDS services from 1989 - 1994, project leader of Positive Options from 1990 to 1992. She developed the memory book (1990) and the memory book for Africa (1999), and supported NACWOLA's development of the Memory Project Training Programme from 1995 to 2003. Contact: [cls.dev@lineone.net](mailto:cls.dev@lineone.net). First published in: AIDS Bulletin June/July 2004, Vol. 13, No.2*



## **Kontakt**

### **Deutschschweiz**

Medicus Mundi Schweiz  
Murbacherstrasse 34  
CH-4056 Basel  
Tel. +41 61 383 18 10  
info@medicusmundi.ch

### **Suisse romande**

Medicus Mundi Suisse  
Rue de Varembé I  
CH-1202 Genève  
Tél. +41 22 920 08 08  
contact@medicusmundi.ch

### **Bankverbindung**

Basler Kantonalbank, Aeschen, 4002 Basel  
Medicus Mundi Schweiz, 4056 Basel  
IBAN: CH40 0077 0016 0516 9903 5  
BIC: BKBBCHBBXXX