



**MMS Bulletin #97**

*Memory Work*

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**Origins (II): Experience of the National Community of Women Living with HIV and AIDS in Uganda (NACWOLA)**

**The Memory Project in Uganda**

Von Annet Biryetega

*The Memory Project is a set of activities that were designed by NACWOLA to address the critical need for HIV positive parents to prepare their children to cope positively with their situation, and to inculcate children with a spirit of care and support for their parents and to make secure plans for children in case parents die.*

The National Community of Women Living with HIV/AIDS (NACWOLA) started the Memory Project in Uganda in 1998. The idea of this project was conceived during psychosocial support meetings that were held to promote the objective of sharing testimonies and experiences based on the stigma and discrimination faced by the NACWOLA mothers and their children.

During this time Uganda was still battling to address issues of stigma and discrimination and NACWOLA women played a key role by going public about their HIV status. However when children received the news about the HIV status of their parents, they were traumatized, especially by community members who confronted them with statements such as “your mother is going to die of AIDS!” or “your mother has AIDS, the sickness of prostitutes”.

Subsequently this created guilt and self-stigma to the HIV positive mothers; therefore they decided to start the Memory Project to support their children to cope with the impact of HIV.

Since the pandemic started, the country has lost about one million people and this has contributed significantly to an estimated 2.3 Million orphans. Approximately 20% of the children in Uganda between the age of 6 and 17 years are orphans.

Many children who are orphaned are forced to live on the streets or under exploitative conditions of labour, sexual abuse, prostitution and other forms of abuse. Many of these children live in the child headed households where they have to fend for themselves and support their younger siblings.

The impact of parental death on children is complex. The child's mental health is affected; consequently intellectual development is stunted, and low self esteem and lack of hope for the future are resulting.

## The Memory Project

The Memory Project is one of the approaches that have registered tremendous results in providing psychosocial care and support for children affected and infected by HIV and AIDS.

The Memory Project aims to encouraging dialogue between HIV positive parents and their children; improving counselling for children; challenging the culture of silence about HIV/AIDS and sexuality; relieving the mental stress of children affected by HIV/AIDS; improving children's understanding of their situation; and strengthening family coping mechanisms.

The NACWOLA Memory Project was developed based on four pillars, namely:

- improving communication between HIV positive parents and their children
- disclosing HIV status and other important information
- succession planning
- writing important family history in a memory book.

The objectives of the Memory Project are enhanced through activities as follows:

**Parents' and Guardians' training:** The critical issues in this training are: 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.

**Children's training:** The critical issues in training children are: 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 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.

**Counselling:** This activity is carried out to support parents after they have disclosed their HIV status to their children. The children are taken through counselling sessions by other NACWOLA mothers. This is achieved through home visiting.

**Children's club and children's exchange visits:** The children's club promotes peer support for children through child-to-child counselling, sharing experiences and testimonies to build resilience.

**Income generating activities:** This activity facilitates the planning process, it entails training parents in skills for income generating activities and loan scheme management. The children are direct beneficiaries of the income generating activities but their parents are just care takers. The children identify the appropriate activities based on their existing skills and capacity.

**Vocational skills training:** This basically benefits children who have dropped out of schools due to failure to raise school fees. Most children heading families are beneficiaries of this activity.

**Writing memory books:** Parents or guardians write a book in which information is stored for their children to be used in future. The book contains information about the parents and the early life of each child, about beliefs, traditions, hopes for the future etc. The focus is not on death and disaster but on helping children understand who they are and giving them the right information to make the best of the future.

## Living without parents

In situations where parents are dead, the children are prepared to cope with life without parents. The testimonies of two children show how this can work:

*“My name is Ben. I am 16 years old. I am a total orphan, and my parents died of AIDS. I was ten years old by then. I became a destitute after the death of my parents because life had lost meaning. My two little brothers went away to live with a distant relative. My life only changed when I met NACWOLA women sensitizing in the community. I had gone there to steal something for survival but I was touched by the message of the women. I talked with the women and shared with them my experience, so they asked me to join the children's club for counselling. Consequently I benefited from the training of the Memory Project. My life has changed so much. I now live in our home. I brought my little brothers back and now I am the head of the family. I have been trained in skills of carpentry so I make stools and tables to sell. I earn income from car washing. My little brothers are in school and they are happy. NACWOLA mothers often visit us.”*

*“My name is Tukei Maureen. My father died of AIDS when I was young. I grew up with my mother who was a member of NACWOLA. I benefited from the Memory Project and I was empowered to head my family after the death of my mother. I grow crops for food on our piece of land. Sometimes I sell some food to get income. I was in senior two by the time my mother died now I am in senior six. I will go to university next year. Friends of NACWOLA women are now paying my school fees. My sister and I are happy and we have hope for a bright future.”*

## Bridging a communication gap

But there are situations where HIV positive parents are still living with their children; in this case the Memory Project creates a supportive environment between the parents and their children.

The project enables HIV positive parents to disclose their status to their children. This in turn creates a supportive environment for the HIV positive parents as their children understand the ill health of their parents and therefore show them care and love.

*“When I disclosed my HIV status to my bigger children, at first they were shocked, but I counselled them. Now they are my very good friends. They remind me about time to take my medication. My big daughter ever reminds me to cover my chest when the weather is cold.”* (Testimony by Christine Obuya)

HIV positive parents are relieved of stress after disclosing their HIV status to their children.

This project bridges the communication gap between parents and children, thus it enables parents to understand the problems and need of children and to support them through counselling.

*“We see a big change in our children after they have been taken through the Memory Project training. The children are now very free with us, they share with us their challenges and seek our guidance. The girls have started consulting us on issues of their reproductive health.”* (Statements made by NACWOLA mothers during follow up refresher training)

The project takes on a child-centered approach during planning for the future sustainability of the family. For instance HIV positive parents help their children to identify foster parents. Children are involved in activities that generate income for the family, so they become familiar with survival skills. Therefore bigger children are empowered to look after their young siblings.

The project helps parents and their children to prepare for bereavement with fewer traumas.

Memory book writing encourages HIV positive parents to record their own and their children's past lives, celebrating the good, loving memories. This builds a coping mechanism of positive attributes in children because they are not just reminded about the traumatizing stories of sickness and death.

*“My name is Mbabazi Jane. I am 17 years old. I have got two bothers and four sisters, and am the first born. My mother is living with HIV. She falls sick from time to time. I try to help her with house work and I read my memory book when I am bored. My mother had never told me facts about my late father, but when I read the book I discovered that my father was a medical doctor. I want to read hard and become a doctor so that I find a cure for AIDS. I want to encourage my mother to write down information about the origin of my sisters because our fathers were different.”* (Testimony)

The Memory Project encourages parents to write down the family history, traditions, beliefs and some other relevant information. These help to ensure that children have a clear sense of identity and belonging.

## Challenges

A lot has been said and done about this famous project but very little has been documented.

The Memory Project has registered good practices that have been recognized by other African countries, however NACWOLA has not yet built the capacity to enable all the members to access the services of the project.

The project entails dealing with very sensitive issues of disclosure of HIV status, death and bereavement, therefore it needs to be implemented by people who have got practical experience of the issues being addressed otherwise, if not well handled, it might become stressful to the beneficiaries.

The Memory Project has become very popular among people living with HIV/AIDS in Uganda. Building upon the successful experience of NACWOLA the module is being expanded and standardized as “International Memory Project” to benefit other African countries. To date Healthlink Worldwide UK is working in partnership with African countries, namely Uganda, Kenya, Tanzania, Ethiopia, Nigeria and Zimbabwe, to promote the best practices of the Memory Project.

Healthlink Worldwide UK have worked in partnership with NACWOLA to update the International Memory Project, to take on an inclusive approach that bridges the gaps that were identified by NACWOLA during the implementation of the original model. Issues that have been considered are:

- Involving widowers and guardians of children affected by HIV and AIDS;
- Bringing on board children who are heading families and looking after their younger siblings;
- Bringing on board children in special situations such as childrning living with HIV, disabled children, and very young children;
- Strengthening linkages with other organizations so as to achieve comprehensive support for children living with HIV; for instance getting these children onto antiretroviral treatment and treatment of opportunistic infections;
- Enhancing child counselling skills to all trainers of the International Memory Project;
- Helping parents and their children to smoothly deal with new relations without traumatizing children.

The International Memory Project manual is in the final stages and it will be translated into different African languages.

*\*Annet Biryetega is the National Coordinator of the National Community of Women living with HIV and AIDS (NACWOLA), Uganda. NACWOLA is an organization governed by women living with HIV and AIDS. Three HIV positive women started the organization; to date it has got a membership of over 40,000 women living with HIV and is operating in 25 districts of the country with a mission of promoting positive living for HIV positive women through psychosocial support, economic empowerment and access to essential services. Contact: nacwola@infocom.co.ug*



## **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 Varembe 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