



Girls sharing their memory books as part of the Memory Youth Club activities

Photo: KIWAKKUKI, 2006

## Scaling up memory work: the example of KIWAKKUKI in Tanzania

*Nicola Ward & Dafrosa Itemba*

**In the previous issue of Exchange, an article on memory work as introduced by NACWOLA in Uganda describes this approach to tackling core issues in HIV and AIDS around disclosure and communication in the family.<sup>1</sup> In the framework of the International Memory Project (IMP), with the support of Healthlink Worldwide, NACWOLA has been introducing its approach to four other African countries, notably Ethiopia, Tanzania, Kenya and Zimbabwe.<sup>2</sup> Scaling up has involved many challenges due to the wide range of different contexts, different types of implementing organizations and different cultures.<sup>3</sup> An example from Tanzania will be considered of how a partner organization involved in the IMP, KIWAKKUKI, has developed a memory project based on NACWOLA's experience and learning but adapted to its specific cultural and organizational context.**

According to Healthlink Worldwide, memory work is a practical, child-centred, community-led approach that encourages families to communicate openly about HIV. It is an approach to psychosocial support that nurtures an environment in which disclosing one's HIV status is possible. It is an important entry point to open up discussions around tackling stigma and discrimination. The overall purpose of memory work is to increase children's resilience. This approach requires sensitivity as it is often one that challenges cultural and traditional practices in the communities where the partner organizations are working.

KIWAKKUKI (Swahili acronym of Kilimanjaro's Women's Group Against AIDS) has a wide reaching prevention and care programme working in all six districts of Kilimanjaro region. The memory work

programme started as part of the IMP in October 2005 in Moshi District and is now being implemented in one other district. NACWOLA played a key role in the initial master training for all IMP partners and has also visited KIWAKKUKI to give technical support to develop their memory work programme. Some 43 staff and board members have participated in a training workshop run by KIWAKKUKI memory work trainers. In this way memory work has been integrated into KIWAKKUKI at an organizational level. The training has made it possible to find ways of integrating memory work programmatically to complement existing activities. A memory work officer oversees the process. This officer works closely with the voluntary counselling and testing (VCT) centre, and the home-based care, orphan support and prevention programmes.

### **Integrating memory work in existing programmes**

KIWAKKUKI clients in the home-based care programme and those who come for VCT are now being sensitized about memory work and encouraged to become involved. Children in existing KIWAKKUKI orphan and vulnerable children support programmes are involved in the memory work activities for children and youths and encouraged to write memory books. The KIWAKKUKI women's support groups assist the orphans living in their community. In Njoro for instance, the women's support group has collected money and paid school fees and bought stationery for these children, so they are now back in school.

Youth volunteers visit families in the community to encourage them to write memory books and become involved in memory work. Their support is recognised in part through small incentives, e.g. soap and a travel subsidy. Through the volunteers memory work has expanded very quickly to many families. So far, KIWAKKUKI has trained 260 parents and 50 guardians (including grandparents and carers) in memory work. Sixty parents living with HIV have disclosed their status amongst themselves, 20 of them to their children. Some 1170 memory books are in progress or have been completed, monitored by and

through the support of 20 volunteers. Six memory work training workshops for children have been carried out for a total of 180 children and youth. Of those trained, 110 now participate in a youth club.

## Overcoming cultural barriers

Fundamental activities that memory work encourages such as will writing, involving children in family decisions and planning, caring for people living with HIV and AIDS and protecting children's inheritance rights are not necessarily part of the culture of communities in Kilimanjaro as in many other communities in Africa and globally. KIWAKKUKI's strategy to address these issues is:

- *Involving key figures in the community* – By involving key figures, for example religious leaders, health workers and school teachers, the community has been encouraged to become involved. As a care-giver in Mjimpya, Kilimanjaro, explains: *“KIWAKKUKI was very wise when it began its memory work. It went to churches and mosques and got the support of religious leaders. When these leaders tell people that it is important to write a will and that it is important for the community to care for its members living with AIDS, it has an impact and people listen.”*
- *Creating a supportive environment* – By nurturing an environment where people care for others in the community, there

has been less discrimination or stigmatization of people living with HIV. Through implementing the memory programme KIWAKKUKI managed to dispel the myth that people who have AIDS symptoms are bewitched and need to see a witch doctor and has created an environment where people care for each other. A care-giver in Mjimpya explains: *“KIWAKKUKI taught people how to avoid contracting AIDS, how to care for people with AIDS, and about home-based care. There was a very positive attitude change in the community as a result of all this. People are no longer afraid to be in contact with people with AIDS. Before, they were even afraid to sit with someone who had AIDS. Now many people in the community are caring for relatives with AIDS.”*

- *Encouraging child participation* – By encouraging participation of children in decision making and learning about their family history the resilience of children affected by HIV and AIDS has been increased. A school teacher in Njoro, said: *“After my son received the memory book training, he started gathering photos of his father and he asked many questions to get to know about his father's history. Family members wanted to know why he was seeking photos of his father because it is not our custom or tradition to collect photos of people who have died. But he*

*was very anxious to know about his father and find photos of him. Now he asks me, ‘What would happen to us if you died?’ Through the memory books, my children are not only learning about the family and its history, but they are also coming to know about their future.”*

- *Encouraging community members to write wills* – Traditionally, the writing of a will is considered to pre-empt one's own death as explained by a hospital ward leader in Pasua: *“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.”*

Through programme integration of memory work, strong ownership of the programme by the beneficiaries and use of low-cost memory books, memory work has spread to many families. This has had a significant

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impact on stigmatization and discrimination in the community. These have reduced dramatically in a short period of time, as perceived by different community leaders and members who have been interviewed by an external consultant using the Most Significant Change approach.<sup>4</sup>

Challenges identified in memory work implementation include finding the balance between expanding the programme and reaching more people in the community, and providing quality follow-up support to those who have already received the training. Key questions include how to monitor those that have been trained to ensure that they are receiving the support they need after the training, and meet other expectations they may have such as education and housing for their children. Many will also need support to increase their ability to earn more income to leave their children in a better financial position. Related to this, increasing knowledge and demand for will

## Expanding memory work through children and youth

The story told by Samuel, a 15-year old orphan in Moshi who lives with his grandmother, gives a clear example of the potential for expanding memory work through working with children and youths. Samuel (not his real name) attended a two-week training programme for AIDS-orphaned children conducted by KIWAKKUKI in March 2005.

*“Since receiving the training, I joined the Memory Youth Club. I have also helped all 40 children from the orphanage write memory books. I have also helped five children in the village where I live with my grandmother to write memory books. I tell all the youth and children to be ‘open and free’, to tell others that their parents have HIV/AIDS and to ask for support. I tell them not to fear someone who has HIV/AIDS. I now try to get every youth in my school and in my village to go get tested. The only way I can get other children and youth to go for the test is if I go with them and get tested too. Community members in my village have changed their attitudes about people infected with HIV/AIDS. Many from the village have now gone for testing and a very high number have tested positive.”*



Learning about memory books in a memory work training for children

writing presents challenges in relation to how to provide the appropriate legal support to ensure the wills are legally valid, how to safeguard them and how to ensure property inheritance laws are kept for children.

### Innovative ways of working with children

KIWAKKUKI works with a large number of orphans and children affected by AIDS in its operating region. Early on in the implementation of memory work they started to form children's clubs in semi urban Moshi Municipality where the pilot project took place. They started with one small club but due to the demand from the ever increasing numbers of children, they adapted the idea of small support clubs for children and decided to have a larger Memory Youth Club where the children could meet and exchange experiences and take part in recreation activities. They now have two Memory Youth Clubs for over 200 children. These Memory Youth Clubs have proved invaluable for children to give peer support and increase children's resilience by making friends, sharing with one another and giving each other psychosocial support. In the clubs they start to look into ways they can write their own memory books guided by their guardians and carers.

Thirty of the youths from the Memory Youth Clubs are now leading other children's small groups. One outcome of the Memory Youth Clubs has been for a request for assistance to set up their own income-generating activity and for vocational training. KIWAKKUKI has responded by giving some of the children the opportunity to participate in a six-month programme in a vocational

training school in Moshi Municipality.

Children's clubs are a good forum for a child-to-child approach whereby children with similar experiences exchange information and console one another. Further, the children in the club are an inspiration for others in the community and are creating a demand for memory work by sensitizing the community around them about the project. For some children this had been the only outlet they have had to share their sometimes very painful and personal experiences in a safe environment.

### Key learning point

As depicted in this article, memory work has been integrated through all programme activities of KIWAKKUKI. Implementing memory work through the volunteer network is particularly key to the successful expansion in Kilimanjaro. KIWAKKUKI has integrated the aims of memory work into the culture of the communities where they are working. A key learning point from this is the ability to change community attitudes by working together with community and religious leaders and mobilizing the younger generations to take the lead in social and behavioural change. This is particularly

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relevant regarding the reduction of stigma and discrimination of people living with HIV and AIDS, future planning and will writing.

KIWAKKUKI has adapted NACWOLA's child-centred approach to memory work using a methodology that is suitable for the large numbers of children they work with through the Memory Youth Club and children's clubs. The experience of KIWAKKUKI is showing how memory work has strong benefits for the psychosocial support of orphans and vulnerable children affected by

AIDS. This is shown through the way the children and youths are changing attitudes of despair to ones of hope and strength for the future of the families and communities where they are growing up. ■

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1. N. Ward, Memory work: Learning from the Ugandan experience. *Exchange on HIV/AIDS, Sexuality and Gender*, No. 3, 2006, <http://www.exchange-magazine.info>
2. Five partner organizations in these countries are involved in this project: Family AIDS Caring Trust (FACT) in Zimbabwe; Hiwot HIV/AIDS prevention, care and support organization (HAPCSO) and TILLA association of women living with HIV and AIDS in Ethiopia; KIWAKKUKI in Tanzania; and Kenya AIDS NGOs Consortium (KANCO) in Kenya.
3. Some of the key challenges are discussed in N. Ward, Scaling up Memory Work: the challenges. Examples taken from Uganda, Ethiopia and the Philippines, *Bulletin of Medicus Mundi Switzerland*, No. 97, June 2005: <http://www.medicusmundi.ch/mms/services/bulletin/bulletin200503/kap03/08ward.html>
4. The research was carried out in August 2006 as part of the mid-term review for the IMP. The Most Significant Change (MSC) technique is an approach to monitoring based on story telling, which is currently being used by partners in the IMP to collect data on the impact of memory work in the communities where they are working. Evidence for this article has been drawn from the MSC stories collected by KIWAKKUKI.