

Building children's resilience in a supportive environment: Reflecting on opportunities for Memory work in HIV responses

MEMORY WORK AS A RESPONSE

Stigma and discrimination continue to undermine the fight against HIV and AIDS around the world. In 2000, Healthlink Worldwide began to support a unique home grown initiative called the **Memory Project** in Uganda. This has successfully challenged stigma and discrimination in households and communities by building strong bridges of communication among family members and strengthening community relationships and support networks.

The household and the wider community are where attitudes and responses to HIV and AIDS are formed and nurtured and where the physical and emotional suffering associated with the pandemic are experienced. Children are the most vulnerable in this environment. They may have family members living with HIV, may be living with HIV themselves or may be orphans.

Communication around HIV and AIDS at the household level is key to changing attitudes. There is an urgent need, therefore, for innovative, sustainable and effective approaches that have the potential to break through the barriers of discrimination and stigma at the household and community level and to ensure prevention, care and treatment programmes are reaching their full potential. Memory work provides an effective and sustainable approach that can be adapted to new environments, scaled up and integrated with national programmes to broaden and accelerate their impact.

WHAT IS THE PURPOSE OF MEMORY WORK?

Because of stigma, many parents and guardians find it difficult to talk with their children about HIV and AIDS. As a result families suffer in silence and isolation. For many children and family members, bereavement brings further stigma and discrimination from the wider community. The future for them is daunting, uncertain and difficult.

Memory work aims at breaking this cycle by improving communication in the household and fostering a supportive family environment for child growth and development. It is the starting point to address issues of discrimination and stigma and strengthen coping mechanisms.



Memory work helps children to cope with the impact of HIV on the family, understand what support and care is available and manage possible loss and separation. It empowers children to be part of planning for their own future.

Extract from a memory book, Ethiopia



Writing a memory book, Uganda

By strengthening child resilience and empowering children as decision makers within their families and in their lives, Memory work increases the agency of children for broader social transformation. It also paves the way for prevention and treatment programmes to be more successful.

"I feel a big load has been lifted from my shoulders. I'm able to make plans for my life I now have a renewed purpose in life, very soon I will be enrolling for treatment...I have opened to my family and I'm getting so much support from them."

Miriam, Zimbabwe

HOW DOES IT WORK?

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.¹

The Memory Book is the central tool in the memory work process and a starting point for communication in the household around issues such as family history, information concerning the parent or guardian's health, children's aspirations and childhood memories. All this is captured through illustration and writing. The process enables family members to voluntarily share important information in a supportive, structured and safe way.

"My child is very young and he doesn't know about my life and his father's too. I have got a chance to tell my internal feelings and secrets to my child."

Participant in Tilla's memory work programme in Ethiopia explains the impact writing the memory book had on her.

HEALTHLINK WORLDWIDE AND MEMORY WORK

The National Community of Women living with HIV/AIDS (NACWOLA) is a community-based organisation in Uganda that promotes positive living for women living with HIV and AIDS. NACWOLA is the pioneer of Memory work in Africa. Its initial Memory work training for parents, guardians and children took place in 1998 targeting women living with HIV and their children. Shortly after this, NACWOLA became a partner of Healthlink Worldwide and began working with other organisations on child-centred approaches to community responses to HIV.



Banner commemorating deceased NACWOLA members, Uganda

International Memory Project (IMP)

In 2004, Healthlink and NACWOLA developed a project to scale up NACWOLA's Memory work within Uganda and into four more countries in the region.

NACWOLA's **Memory Work Manual** was improved upon and developed as a trainer's manual suitable for different contexts. Regional partners were trained and introduced memory work into their own contexts, gaining significant practical experience at the community level.

Healthlink supports a small focused learning network of the partner organisations in IMP to share ideas and experiences and to learn from each other. In depth reflection and learning enhances the quality of Memory work.

"...by sharing experiences one feels they are part of a bigger picture in addressing issues affecting children."

Participant comments on Learning Network Meetings



Partners developing a monitoring framework, Zimbabwe

KEY FINDINGS FROM THE INTERNATIONAL MEMORY PROJECT

Scaling up Memory work makes it possible to evaluate its achievements and adaptability across different environments. Partners in the International Memory Project have reflected, analysed and shared key findings from their experiences. This process has been facilitated by using the Most Significant Change (MSC) technique. MSC is a qualitative approach to impact assessment based on a process of gathering and analysing stories of change at different levels.

The following key findings and quotations have been taken from over 60 stories collected from communities where partner organisations work.

► Memory Work has strengthened community responses.

Through empowering individuals and families in the Memory work process, the community response to HIV is strengthened. Memory work has a cascading effect - sharing encourages others to become involved. This strengthens coping mechanisms at the household and community level and builds peer support to challenge discrimination and stigma.

A mother from Luweero said: "I met colleagues with the similar problems without any hope at all, it was a relief knowing that I was not alone."

Participant, NACWOLA Memory programme, Uganda

A supportive environment is fostered as more people become involved in creating change at the community level.

► Stigma and discrimination are reduced.

Memory work, as an entry point into the community, challenges the social meanings which lead to discrimination. Disclosure is a powerful aspect of this process and one of the possible choices that people living with HIV can make to help them deal with the psychological and social circumstances of their situation. Some may limit their disclosure to family members while others may choose to extend it to the wider community. It is important that the manner in which disclosure takes place is empowering. Memory work, in itself, is a supportive process for disclosure to take place, empowering parents and guardians living with HIV to disclose to children in their care and to make plans for the future.

"Disclosure is the most significant change in my life because my close relatives understood my problem and they helped me in many different ways."

Dashash, Ethiopia

As a result, family and community members better understand, and become more sensitive to, the realities of people living with HIV. After suffering a great deal of discrimination from family members, Angela celebrates the positive response brought about through Memory work counselling.

"I'm accepted and loved, my family care and are supportive, it's like I have been given a new lease of life."

Angela, Zimbabwe

Memory work is a process that changes how an individual copes with and understands HIV and AIDS.

"I got lessons and improved my attitude towards HIV."

Abozenech, Ethiopia

It also draws in family and community members as support. By changing the attitudes of individuals, whole communities can change their attitude towards HIV and AIDS. Empowered through his disclosure, Yeshiwork speaks of how he was able to gain employment.

“I went to the HIV/AIDS Prevention and Control Office of the church and told them that I am HIV positive and have no way to generate income and nowhere to go. They wrote a letter to the church instructing them to help me as much as they can. The church hired me as a janitor. Now I am able to work, and generate an income that can cover the basic needs of me and my child.”

Yeshiwork, Ethiopia

► **Memory work has facilitated life skills among at least 2000 children.**

Memory work empowers children to be part of planning for their future. By writing Memory Books with their carers, they are encouraged to think about their future. Children are also encouraged to share their experiences with each other through child club activities. This strengthens peer support among children in the community. Through their participation, children learn ways to strengthen their resilience and coping strategies at home.

“I am able to guide my young brother and sister at home how to avoid early pregnancy, marriage, HIV/AIDS and I am a peer educator and attached to Butangasi primary young talk club where I provide counseling services to children living with HIV.”

Child participant, Uganda

► **Parents and carers have demonstrated increased empowerment living positively with HIV.**

“Memory work has helped me to stop blaming myself for things I cannot change.”

Miriam, Zimbabwe

By strengthening communication channels between adults and children, the Memory work process empowers parents with HIV to live powerfully and positively, directly impacting their lives and the lives of their children. Parents are encouraged to plan for their children's future with their children and to write wills to protect their children particularly in relation to property inheritance issues.

Through this empowering process, carers gain hope and courage to live positively.

“I had money that I had saved but because I had lost hope, I did not know what to do with the money... with the knowledge of immediate death. But when I attended the memory training, I got courage and I managed to buy a plot of land and I am currently putting up a house, I can now plan day and night. My hope was restored through the memory project training.”

Participant, Uganda

► **An enabling environment has been created for prevention and treatment programmes to take root.**

Memory work has provided a useful tool for engaging with local contexts. One key impact for partner organisations is their ability to successfully adapt the Memory work process to their environment. Initially, disclosure and establishing communication between adults and children was thought of as impossible due to cultural factors inherent in the various host countries.



A children's club, Kenya

“Because of the level of stigma and discrimination and the lack of communication, it seemed almost impossible to convince parents to do that, but is happening and parents are opening up to their children.”

Programme Manager, HAPSCO, Ethiopia

With the help of training, the Memory Work Manual and the Memory Book, partner organisations were able to make breakthroughs within their communities.

Partners have found this breakthrough so significant that they have mainstreamed Memory work into other organisational programmes.

► **Community-based organisations have achieved greater awareness of their capacity as change agents.**

Memory work practitioners facilitate a communication process at the household and community level. Memory work is adapted to suit the specific needs of the families and communities involved, progressing according to the speed with which each family is comfortable. Partner organisations as change agents are instrumental in establishing community ownership.

As well, capacity is developed. Individual staff members have gained personal exposure and knowledge from interactions with other organisations involved in progressive communication and support to orphans and vulnerable children.

“[We have] a global view of things instead of seeing the micro and being trapped in that.”

Programme Manager, HAPSCO, Ethiopia

They have also gained a range of transferable communication and adult education skills as facilitators, trainers and counsellors on the Memory work project.

“I gained a real insight into how to be a good trainer and how to communicate with people.”

IMP Training Officer, HAPSCO, Ethiopia

The transferable communication skills and deeper awareness of the impact of the pandemic on different dimensions of the community builds the knowledge assets of community-based organisations.

PARTNERS

The following organisations are participating in the International Memory Project (funded by Comic Relief in the UK). Healthlink Worldwide is also working with the Child in Need Institute in India to pilot Memory work in three states and with Save the Children UK in Ethiopia to expand its activities in this area.

Ethiopia: Tilla association of women living with HIV and AIDS (Tilla) is a community-based association which aims to reduce and mitigate the impact of HIV and AIDS on women, strengthening their coping mechanisms. Tilla's programmes include prevention and community awareness, home-based care and income generation.



Ethiopia: Hiwot HIV/AIDS Prevention, Care and Support Organisation (HAPCSO) implements a range of programmes including home-based care, income generation and orphan support targeting families, young people and health professionals.



Kenya: The Kenya AIDS NGOs consortium (KANCO) promotes leadership, solidarity and collaboration among its members for collective HIV and AIDS responses. It does this through facilitating networking and capacity building for its members.



Tanzania: Women against AIDS in Kilimanjaro (Kiwakkuki) is a prevention and care organisation. Kiwakkuki's activities include home-based care, orphan support, psychosocial support and voluntary counselling and testing. It works primarily for women and young people.



Uganda: The National Community of Women Living with HIV/AIDS (NACWOLA) promotes positive living for women living with HIV and AIDS through psychosocial support, economic empowerment and advocacy for essential services.



Zimbabwe: Family AIDS Caring Trust (FACT) is a Christian-based organisation working with communities, providing HIV prevention, care and support programmes in Zimbabwe and with other community-based organisations in Southern Africa to strengthen their capacity.



IMPLICATIONS

- ▶ Memory work must be embedded in local context. Then it is a powerful process to address the socio-economic and cultural factors which drive HIV and AIDS related stigma in the household and other environments most central to children's development.
- ▶ The combination of outcomes, which can be achieved with effective Memory work suggest that this psychosocial support is a useful component to support international efforts to achieve universal access to prevention, treatment and care.
- ▶ Memory work is an effective and sustainable way of scaling up psychosocial support in communities and strengthening community coping mechanisms. Mainstreaming the work into public sector health care and nutrition programmes could expand its impact.
- ▶ In building the communication capacity of beneficiaries, Memory work enables a community response to multidimensional poverty beyond the constraints of vertical projects.
- ▶ Memory work is adaptable to diverse cultural contexts. It offers insights to stigma and discrimination and provides culturally specific responses.
- ▶ Memory work offers a model of a communication process, which is concerned as much with social context as with individual behavioural outcomes and which approaches health and disease as social constructs.
- ▶ Memory work involves community-based organisations working in cooperation with other actors especially in the health and social welfare sectors. For the response to be effective, such community-based organisations need to be supported and strengthened as part of macro level strategies.

¹ Other definitions of memory work include:

"The deliberate setting up of a safe space in which to contain the telling of a life story," Jonathan Morgan, REPSSI, p.11 Bulletin 97, Medicus Mundi Schweiz.

"Memory work encourages dialogue between HIV positive parents and their children... challenging the culture of silence about HIV/AIDS and sexuality, relieving mental stress of children affected by HIV/AIDS... and strengthening family coping mechanisms," Annet Biryetega, NACWOLA, p.30 Bulletin 97, Medicus Mundi Schweiz.

HEALTHLINK WORLDWIDE

Healthlink Worldwide is a specialist communication and information organisation that collaborates with over 50 partnerships across 30 countries to address the social, cultural and economic aspects of vulnerability to poor health.

Healthlink Worldwide is able to coordinate and provide technical support for organisations who are interested in implementing Memory work. The support available draws on the practical experience and expertise of our partners in sub-Saharan Africa.