

# Making connections, improving health.

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# International Memory Project

## The Challenge

In 2007, some 12 million children in sub-Saharan Africa were estimated to have lost one or both parents to HIV and AIDS. An estimated 18 million children were living with HIV in the region.

Many parents don't take the test for HIV or reveal if they test positive because of fears over stigma. This prevents planning for the family's future, increases the children's despair over their parents' ill health and excludes them from taking on a carer's role.

## The Programme

The International Memory Project ran from 2004 to 2008. The network of six organisations in Uganda, Ethiopia, Tanzania, Kenya and Zimbabwe is still active.

Working in partnership with the other organisations in the network allows Healthlink Worldwide to play a role in helping to improve communication between guardians and parents living with HIV and their children, disclosing HIV status, succession planning and writing family history in a memory book.

The children received five days' memory work training. For children to be involved, a parent would usually have had memory work training and have disclosed their HIV status to their children. Following the training, the children were offered further support through children's clubs and youth groups. In Tanzania, sometimes children without parents were involved in memory work. These children, along with those from child-headed households or with sick parents who could not attend training, were supported by children's clubs, which were open to a wider group than just those who had received memory work training.

## The Achievements

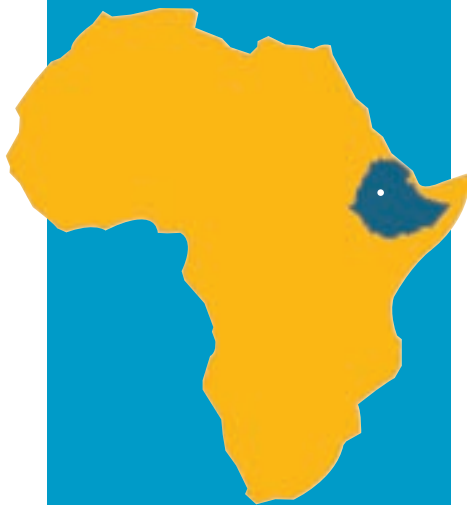
Children all said they were in a better position to take care of their parents' emotional and physical needs. This was the key result of the parent being able to disclose their condition to their children.

A total of 1,544 children and 2,499 parents received training.

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## Tewelde



Yeka sub-city,  
ETHIOPIA

# Case Study:

## Memory work in Ethiopia changes lives

**My name is Tewelde and I'm 17. I am a grade nine student and live in Yeka sub-city. My mother is HIV positive and my father died many years ago. Before I took the memory training I thought the [HIV] problem existed only in my family. It made me realise there are so many families affected and has given me friends whose parents also have the virus and with whom I can share my feelings.**

When my mother told me she was HIV positive, just before I took the training, I wept and thought I had no future with no one to take care of me. It affected my schoolwork too.

The training changed all that. I now meet regularly with other children from the training and share experiences. I can take care of my mother and help her write a memory book. I spend many hours with my mother and we have become much closer.

When I grow up, I now want to be a medical professional to help others who are in my position.

# Women with disabilities

## The Challenge

Discrimination against women with disabilities (WWD) is multi-layered. It occurs against women within disability groups, against those with disabilities within women's groups, and in mainstream society.

## The Programme

Realising the need for WWD to fight against discrimination for themselves, Healthlink Worldwide, in partnership with the Association of Women with Disabilities (AWWD), India, Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV), Bangladesh and Association of Women with Disabilities (AKASA) in Sri Lanka, developed a two-year programme which runs until the end of 2009. The programme primarily provides training on leadership and advocacy skills enabling WWD to understand their rights and giving them the confidence to mobilise WWD groups, organise similar training for others who, in turn, create groups of their own and do advocacy at their respective levels. This allows the programme to reach to community / grassroots where women are often neglected.

There have also been national level round table discussions in the three main partner countries on the needs and challenges faced by WWD, for which participants included civil society organisations, policymakers and women with disabilities themselves.

## The Achievements

At the start of the project regional training took place in India with 23 participants from nine countries which included India, Bangladesh, Sri Lanka, Nepal, Maldives, Pakistan, Bhutan, Azerbaijan and a male delegate from Afghanistan. It was followed by national trainings in India (22 participants), Bangladesh (25), Sri Lanka (24) and Nepal (22) which were organised and co-facilitated by the participants of the regional training along with main facilitators from Healthlink and AWWD. Similar trainings were conducted at district, provincial and divisional levels, which trained about 126 WWD in India, 85 in Sri Lanka and 86 in Bangladesh. Overall about 300 WWD at grassroots level were trained.

Women who received the training now have the skills and confidence to organise themselves locally and are also able to engage in advocacy with government and other stakeholder groups at different levels. These achievements came through the participatory way Healthlink Worldwide works with our partners, an approach which we consider one of our great strengths.



**Tabassum Ara**



**Kolkata,  
INDIA**

# Case Study:

## Tabassum's story

**My name is Tabassum Ara. I am one of seven children and was born in an urban slum in Kolkata in 1988.**

I always had problems seeing things which were far away but seven years ago my sight deteriorated rapidly. My father and one of my brothers also lost their vision during adolescence. When I had problems reading exam papers, I had to drop out of school as my teachers felt I could not study anymore.

Any chance of going back ended when my father's business - supplying materials for slippers to local shops - failed. I had to become a domestic help to help support my family financially.

Two years ago I met an AWWD project assistant and found out they were helping disabled women our area.

With her support I got my disability identity card, which allows me to get some benefits and money entitlements from the state. I took on the responsibility of identifying other disabled girls and helping them to get their cards, even though I suffered insults and lewd remarks from people in the street. Then I came to the leadership training organised by Healthlink and AWWD, which helped me to learn skills to ensure our rights.

Now I am more confident. I organise group meetings, accompany girls to hospital for check ups and make home visits. The girls' relatives would often ignore us and say that it was all pointless but we persevered and now people trust us. Would you believe that I organised four new groups in the past year?

My self esteem has increased and I hope to do a course in Braille at the National Institute for the Visually Impaired. My neighbours, relatives and friends treat me with respect and I want to bring more light to my own life and to others.

# Grandmothers caring for children orphaned by AIDS

## The Challenge

In some areas in Africa more than 80 per cent of children are orphaned, with HIV and AIDS the main cause. The burden of care falls increasingly on grandmothers.

Many grandmothers care for a dozen children or more, in conditions so cramped that some have to organise a “shift system” for sleeping. Often, they take in children who are not blood relatives. One woman is bringing up a child abandoned by the side of a railway. When asked how she would cope she replied, “I have 12 already, one more won’t make any difference. And if not me, then who?”

They struggle to feed and educate the children and face a lack of community support due to stigma over HIV and AIDS.

The children need counselling to deal with losing their parents, while the grandmothers worry who will take on the carer’s duties when they themselves die.

## The Programme

This is a new scheme being developed with partners who help to organise the grandmothers into groups with drop-in centres and saving schemes plus training in growing vegetables in their gardens. Healthlink Worldwide’s role has been to support the partners provide learning opportunities to groups of grandmothers, who are often neglected in HIV programming, building their confidence and ultimately, coping mechanisms.

## The Achievements

Through Healthlink Worldwide, grandmothers from Kenya and Ethiopia visited each other. They discussed the pleasures and challenges of their role and what they can learn from each other.



**Teresa  
Omoiju Oruku**



**Kisumu,  
KENYA**

# Case Study:

## Grandmothers learning through sharing

**Teresa Omoiju Oruku's five children all died of HIV and AIDS and she now cares for her 11 grandchildren. She is 50 years old and a former primary school teacher who has lived all her life in Kisumu, a rural part of Kenya.**

Teresa looked after her daughters when they were sick until they eventually died. As well as her own loss, it saddened her to see her grandchildren losing their parents. However, being a grandmother has changed her life, as the children left behind comfort her.

Like many grandmothers, Teresa has received little help from others. Sometimes, this has been due to stigma within the community towards families with HIV and AIDS, but often it is because the grandmothers are not aware of the support that they can receive. Also, it is rare for older people to be targeted effectively by aid and development agencies.

She was delighted to welcome the grandmothers from Ethiopia and to discover they had so much in common.

"We are happy and celebrating because having grandmothers visit from another country has never happened here and we can talk together about how to help our children."

# Thank you



The people who helped us make change happen in 2008-2009 were:

**ARCAN**

**Comic Relief**

**Department for International Development, UK**

**Johns Hopkins University**

**Lepra UK**

**Many individuals and organisations supported us. THANK YOU - we count on your generosity and commitment.**

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