

Healthlink Worldwide: Interview with Annet Biryetega, June 2004

Report by Niki Maniam, Healthlink Worldwide. This article appeared on the Healthlink Worldwide website, June 2004

NACWOLA's knowledge



Annet Biryetega, the National Coordinator for The National Community of Women Living with HIV/AIDS (NACWOLA) has been working with the organisation since 2001.

In 2004 she came to Healthlink Worldwide to share her knowledge and experience of helping children and their families who are living with or are affected by HIV/AIDS.

The Memory project – how it all began

The Memory project began in 1998 to support children who were facing the prospect of losing their HIV-positive parents. At the time a lot of support work was being organised for mothers within their communities, but there was no approach specifically aimed at helping children communicate with their parents about these life-changing events.

Anett Biryetega says: 'Children could hear NACWOLA mothers talking on the TV and radio about living with HIV, but their own mothers had said nothing. Other children watched their mothers and relatives fall sick and die, but nobody had talked to them about what was happening – it could be very traumatising for the children.'

'The NACWOLA women realised the importance of communicating with children to help them cope with their situation and this formed the basis of the Memory project. Mothers were trained with the skills to communicate about HIV and eventually disclose their positive status to their children. Developing these skills gives families time to talk about all the issues that come with having HIV in the family. It gives children the opportunity to plan ahead; it helps them find ways to cope while their parents are still living.'

A mother's skills

The Memory project centres on the skills of the mothers. These women are trained to support other mothers in their communities by organising and attending residential workshops. As knowledge and experiences are shared women and their families become empowered and can plan for a better future.

Anett explains: 'Mothers are the best counsellors for their children, more than any other person in the community. NACWOLA identify mothers who have the potential to train other mothers and in this way communication skills are passed through the community.'

'Another important aspect of the project is the documentation between the mother and her children,' continues Anett. 'This centres on the 'Memory book'. The book documents important family history and includes photos, stories, souvenirs and a

family tree. It is used to give children a sense of who they are, and includes details of the support they can receive when they lose a parent.'

How do you tell your children about your HIV status?

One of the challenges facing NACWOLA is deciding on the best time to tell children about their mother's (or father's) HIV-positive status. Anett says: 'We encourage mothers to disclose their status when their children are aged 12 or over; younger children may be too distressed by the news. It is a difficult situation; sometimes mothers do not survive until their children reach 12 years old. However support from NACWOLA through activities such as Memory books, or models of families being headed by older siblings all help to prepare younger children for the future.'

Bringing men on board

Another family issue is the lack of men involved in NACWOLA. 'Although primarily a women's organisation', says Annet, 'there are opportunities for men to become involved with our work. However, not many men will come forward and talk about the issues; they are in denial and often do not want to be open about their HIV status.' To counter this, NACWOLA organises seminars and targets community events at a male audience. 'Through dance, drama and music we speak to men about how to get themselves tested for HIV, where to find information and about family planning – all sorts of information that is good for the community. We also refer men to organisations that work with men such as TASO (The AIDS Support Organisation).'

Scaling up without losing out

Both governments and HIV/AIDS organisations are keen to uphold NACWOLA's Memory work. However, the attention NACWOLA generates is an issue. As Anett explains, 'We have bright ideas and plans but we are only a small organisation with mainly semi-skilled women, and we lack the capacity to put our ideas into practice. Larger organisations sometimes take our ideas and develop them but do not acknowledge NACWOLA's right to ownership of the projects.'

NACWOLA is planning, with the support of Healthlink Worldwide, to take its approach to other African countries. To do this Annet believes NACWOLA should be supported to work on a bigger scale. 'It is important for donors to help us to increase our capacity so we can carry on working, this can be through training – for documentation, counselling, even help with how to apply for funding!'

Anti-retroviral drugs – a help or a challenge?

With an estimated one million children expected to be orphaned by AIDS by 2010, the work of NACWOLA cannot be underestimated. Even with the arrival of long-awaited anti-retroviral treatments, which can greatly extend life expectancy, the work of NACWOLA is still vital. Anett explained: 'Women are taught that living with HIV/AIDS requires a holistic approach, including good nutrition, counselling, information about drugs and their side effects and an understanding of the context of these women's lives. Also, the work we do to help mothers communicate with their children is worthwhile even if parents live longer. The importance of passing on information about the reality of HIV cannot be understated.'