

# Raising awareness of HIV and AIDS in Southern Sudan

**Recognising the key role of older people as counsellors and carers**



Older women and men are caring for up to 60 per cent of orphans and vulnerable children in areas severely affected by HIV and AIDS.

## **Summary**

**Southern Sudan Older People's Organisation (SSOPO) has a long history of grassroots community response to the needs and rights of older women and men in Juba, Southern Sudan. At a time when few organisations were responding to AIDS, SSOPO was quick to recognise its impact on older people. Older peer educators and counsellors brought HIV prevention information to all members of the community and home-based care support to older women and men, while grandparents caring for children were supported in accessing school and health services.**

**SSOPO's origins lie in a programme implemented by 23 older people's committees in Juba in collaboration with HelpAge International. A needs assessment in 1999 revealed that older women and men lacked basics – shelter, food security, health, water and sanitation – and also wanted their rights better protected. The following year the rehabilitation programme began and the older people's committees supported the delivery of activities and continued to identify the needs of the community members. A coordinating body emerged from the committees which formally registered as an NGO in 2005 as SSOPO.**

**HelpAge  
International**

Leading global action on ageing

[www.helpage.org](http://www.helpage.org)



Kate Holt/HelpAge International

Caring for children orphaned by AIDS has physical, emotional and financial impacts on older people.

## Background

Scant information about HIV prevalence in Sudan exists and currently estimates are 2.3 per cent nationally, comparatively low for the region. But after years of civil war, followed by the peace agreement and the consequent demobilisation of soldiers and movement of people, the area has many factors that make it a favourable environment for the spread of HIV.<sup>1</sup>

SSOPO's own data revealed the impact on older women and men, who are caring for 60 per cent of orphans and vulnerable children (OVC) and 52 per cent of people living with HIV and AIDS (PLWHA) in two communities in Juba.

AIDS began to impact on community members as unexpected deaths occurred. Families directly affected tended to remain silent but neighbours and other community members sometimes talked about it and discussions about HIV began to surface at community meetings.

Although older people were being excluded from the limited HIV awareness work that was being implemented, an even bigger problem was that awareness within the community as a whole remained low. It was therefore evident that as well as meeting the specific needs of older women and men, it was necessary to contribute to a wider campaign to raise awareness of HIV within society as a whole.

## SSOPO's response to HIV and AIDS

In 2002, a programme was launched to raise awareness of HIV within the community; promote understanding of its impact on older people; and help older people, and those in their care, meet their basic needs. To date, work has been funded by CORDAID, UNICEF, St Christopher's Trust, Help the Aged and Comic Relief.

SSOPO launched an energetic awareness-raising programme in and around Juba. Community theatre events in public spaces, such as markets, have attracted audiences of around 200 people of all ages. Short dramas performed by community

youth workers or the Equatoria Youth Drama Society are followed by open discussions. These dramas have also been performed in prisons, shipyards and army barracks.

Discussions about HIV with audiences of up to 100 people have also been held at social gatherings at older people's centres, or social events such as funerals, weddings and community meetings. Video shows in collaboration with church leaders attract over 260 people of all ages from diverse backgrounds.

At a more intimate level, trained volunteer counsellors make pre-arranged home visits to talk to families and their neighbours in groups of up to 20 people.

Radio broadcasts in the form of panel discussions and dramas (based on the community theatre productions) are aired regularly on Radio Juba. In schools, the Anti-AIDS Student Association, supported by SSOPO, delivers HIV prevention and protection messages to audiences of 500 girls and boys aged 7-18. In two years SSOPO has reached 30,000 people (excluding data on radio audiences, which have yet to be discerned).

### **Evolution of care work**

The physical and emotional impact of caring for people living with HIV on older women and men has become evident. These stresses have been exacerbated by carers' own fears and anxieties, and the attitudes of other people towards those who are sick and their family members. Financial worries have also ensued as medical and children's needs arise.

To meet the needs of older carers, 15 volunteer counsellors were nominated by the communities. In the first year these volunteers were all older women and men, as it was believed they would have the respect of all age groups. This approach was mostly successful, although the workload was too much for some, who stood down. The following year, peer educators of all ages were trained.

The role of the counsellors evolved from information sharing with families in their homes, to counselling individuals, to providing hands-on care in homes. Initial anxieties about infection from contact with PLWHA were mostly eased through training sessions but for some counsellors, fears were only fully overcome through experience.

Older carers participated in three-day workshops to learn about caring for people with AIDS, including identifying and treating opportunistic infections, nutritional needs, and personal and environmental hygiene.

### **Impact**

The provision of information about HIV and training of carers relieved the older people and their families of many of their anxieties. After seeing their own children become ill and die prematurely, the older women and men were especially concerned about protecting their grandchildren from HIV infection. Once equipped with knowledge and understanding about HIV, older people found they could openly discuss issues with their grandchildren in a way that did not seem possible before.

**'I talk to my grandchildren about AIDS. I tell them not to misbehave and say they should be careful, especially the older girl now that she is reaching puberty. I talk to them about sexual intercourse and tell them not to pick up any sharp blades that they find.'**

*Older woman from Juba looking after three grandchildren.*

The wider community has also become more receptive to information about HIV, in part due to the radio broadcasts. Still, SSOPO had to adapt its messages when one particular community met a discussion about condoms with such hostility that it had to be abandoned. The group continued to work with the community and the next time a play was staged, attention was focused on sexually transmitted infections (STIs) and the audience was asked if the community had any such problems.

The ensuing discussion of STIs gave the community workers an opportunity to talk about HIV and the increased risk arising from untreated STIs. Discussions were then linked, without incident, to the use of condoms.

In addition to meeting the information needs of the wider population and older carers, direct support in the form of accessing food rations and paying school fees has contributed to easing the financial burden and meeting the nutritional needs of older people and the OVC and PLWHA in their care.

To achieve a longer-term impact the programme has engaged with key stakeholders involved in HIV prevention, care and treatment including the Country Coordinating Mechanism, Sudan AIDS Network, the Equatoria Task Force and the People Living With AIDS Association.

Participation in the local Equatoria Task Force has produced more immediate benefits than the national processes. The Task Force, of which HelpAge International is currently the Secretary, provides a mechanism for local co-ordination and collaboration. Efforts by this group together with UNAIDS have resulted in, for example, the opening of a voluntary counselling and testing centre where test results can be processed in situ rather than in Khartoum where they are subject to long delays.

Awareness raising and collaboration with other organisations working in Juba have created more understanding of the impact of HIV on older people and an appreciation of their role in prevention and care.

## Conclusion

HIV programming that is inclusive of the needs of older people has far-reaching benefits for members of the community of all ages. SSOPO meets the information needs of all sectors of the community as well as the specific needs of older people. The programme in Juba demonstrates the effectiveness of the active leadership and participation of older women and men in delivering HIV responses. As an entry point into the community, older people can facilitate outreach to adults and children of all ages.

1 WHO (2005)

**HelpAge International is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives.**

HelpAge International  
PO Box 32832  
London N1 9ZN, UK  
Tel: +44 (0)20 7278 7778  
Fax: +44 (0)20 7713 7993

Email: [hai@helpage.org](mailto:hai@helpage.org)  
Web: [www.helpage.org](http://www.helpage.org)

Registered charity number: 288180  
November 2007  
Front cover photo:  
Kate Holt/HelpAge International

**HelpAge**  
International

Leading global action on ageing

[www.helpage.org](http://www.helpage.org)