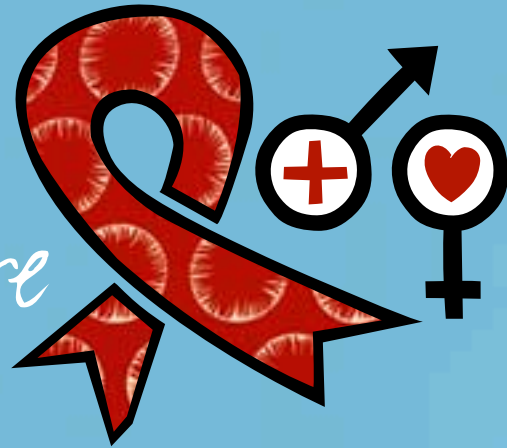


# Challenges of Care



## **VSO-RAISA Regional Conference 2007 Report Back**

Malawi : Mozambique : Namibia : South Africa : Zambia : Zimbabwe





Front cover: The Soweto Home-Based Care office, South Africa, where Frans de Jeu is a volunteer. (Photo: Frans de Jeu).  
 Above: Conference participants. Below: Eddington Mhonda, PADARE Mens Forum on Gender.



## Challenges of Care

VSO-RAISA Regional Conference Report Back  
 Pretoria, South Africa, 1 - 2 November 2007

### Conference organisers

✘ Bongai Mundeta, Naseem Noormahomed and Stephen Porter

### Report back

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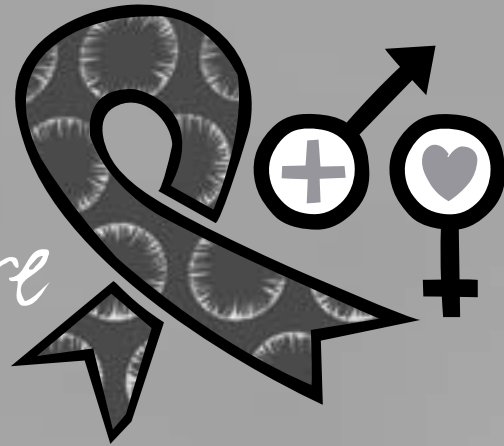
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# Challenges of Care

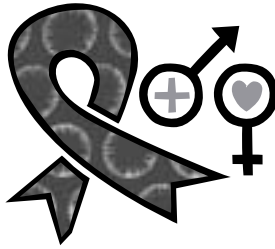


## VSO-RAISA Regional Conference 2007 Report Back

Malawi : Mozambique : Namibia : South Africa : Zambia : Zimbabwe



# Acknowledgements



VSO-RAISA would like to extend enormous thanks to all speakers, presenters and participants for their in-depth and extensive contributions at the conference on the challenges of care. People shared their personal experiences and expertise so openly and passionately that this was an incredibly moving and inspirational experience.

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Special thanks goes to His Excellency Paul Boateng, the British High Commissioner to South Africa. His passionate address helped to set the scene for the rich presentations throughout the conference.

The support of the regional team in the formation and execution of the conference also needs to be acknowledged. Thanks to Sonkho Phiri, Naseem Noormahomed, Stephen Porter and VSO Regional Director Liz Holmes.

A big thanks goes to Robin Hamilton who compiled this conference report and as ever to Ellen Papciak-Rose who continues to provide us with professional services in photography, design and illustration.

There are too many people and organisations to mention individually but without you, this conference and the solidarity and commitment expressed at the conference, to tackle issues around the challenges of care, would not have been possible.

Last, but not least, a thank you to our donors who funded the conference: Big Lottery Fund (UK), PSO and TMF (the Netherlands), Comic Relief (UK), and Irish Aid (Ireland).

Without all these people and organisations the conference could not go ahead and have been the success it was.

Thank You

Bongai Mundeta  
Regional Director  
VSO-RAISA



<b>Acronyms</b> .....	04
<b>About VSO-RAISA</b> .....	05
<b>Executive summary</b> .....	06
<b>Timetable</b> .....	08

## Day one

Thursday 1 November

<b>Opening remarks</b>	
Bongai Mundeta .....	11
<b>Plenary</b>	
VSO brief .....	11
<b>Plenary</b>	
Opening address: Challenges to women and girls in the provision of AIDS care .....	12
<b>Plenary</b>	
Women bailing out the state .....	14
<b>Plenary</b>	
Developing quality standards in volunteer management .....	16
<b>Plenary</b>	
Official opening .....	18
<b>Plenary</b>	
Voice of a care provider .....	19
<b>Plenary</b>	
The invisible: Children as caregivers.....	20
<b>Plenary</b>	
Briefing from the Southern African Development Community .....	21
<b>Parallel sessions</b>	
• Session 1 – Challenges of caregivers and community volunteers	
An integrated community HIV & AIDS programme .....	24
The experiences of a caregiver: A testimony .....	27
Challenges to caregivers.....	28
• Session 2 – Children as caregivers	
Areiketsetse le Bana Community Project.....	29
Child participation .....	31
Reencontro and home based care .....	32
• Session 3 – Good home based care practice	
The Moretele palliative care project .....	33
Assisting the poor and marginalised in Namibia .....	35
Community home based care in Zimbabwe.....	36
• Session 4 – Greater involvement of men in caregiving	
Volunteering in the Copperbelt of Zambia.....	38
Redefining masculinity in Zimbabwe.....	39
Thandizani: drawing men into home based care.....	40

# Contents

## Day two

Friday 2 November

<b>Recap</b>	
Bongai Mundeta .....	44
<b>Plenary</b>	
The elderly as caregivers.....	44
<b>Plenary</b>	
Greater involvement of men as caregivers.....	46
<b>Plenary</b>	
Home based care organisations' database software.....	47
<b>Plenary</b>	
Question and answer session.....	48
<b>Parallel sessions</b>	
• Session 1 – HBC policy and legislative frameworks	
MONASO's HBC experience .....	49
• Session 2 – HBC policy and legislative frameworks	
Challenges faced by community children caregivers in the face of HIV & AIDS.....	50
<b>Plenary</b>	
BONEPWA+ and living with HIV .....	51
<b>Plenary</b>	
Women's rights, HIV & AIDS and universal access.....	52
<b>Plenary</b>	
Supporting and managing voluntary care providers from the rights-based approach.....	53
<b>Plenary</b>	
Efficiency versus effectiveness: Country response information system (CRIS) .....	54
<b>Plenary</b>	
Development of action plans.....	54
<b>Closing remarks</b> .....	59
<b>Evaluation</b> .....	59
<b>Summary and conclusion</b> .....	59
<b>Delegates</b> .....	60
<b>VSO-RAISA contacts</b> .....	61

# Acronyms

**AIDS**

Acquired Immune Deficiency Syndrome

**ART**

antiretroviral treatment

**ARVs**

antiretrovirals

**ASO**

AIDS service organisation

**BONEPWA+**

Botswana Network of People Living with HIV and AIDS

**CBO**

community based organisation

**CEDC**

children in especially difficult circumstances

**CHBC**

community home based care

**CHEP**

Copperbelt Health Education Project

**DFID**

Department for International Development (UK)

**EU**

European Union

**FBO**

faith-based organisation

**GIPA**

greater involvement of people living with HIV & AIDS

**HBC**

home based care

**HIV**

Human Immunodeficiency Virus

**HIVSA**

HIV South Africa

**IGAs**

income-generating activities

**MACO**

Midlands AIDS Caring Organisation

**M&E**

monitoring and evaluation

**MONASO**

Mozambican Network of AIDS Services Organisations

**NAC**

National AIDS Council

**NGO**

non-governmental organisation

**OVC**

orphans and other children made vulnerable by AIDS

**Oxfam**

Oxford Committee for Famine Relief

**PLHIV**

people living with HIV

**RAISA**

Regional AIDS Initiative of Southern Africa

**REPSSI**

Regional Psychosocial Support Initiative

**SADC**

Southern African Development Community

**STI**

sexually transmitted infection

**TB**

tuberculosis

**UNAIDS**

Joint United Nations Programme on HIV/AIDS

**UNDP**

United Nations Development Programme

**UNICEF**

United Nations Children's Fund

**VCT**

voluntary counselling and testing

**VSO**

Voluntary Service Overseas

**WHO**

World Health Organization

# About VSO-RAISA

VSO is an independent development organisation that works primarily through volunteer development workers. VSO works in 34 countries towards a set of development goals identified in country strategic plans, linking the priorities of our partner organisations, international development targets and VSO's distinctive competencies. HIV & AIDS is one of the six corporate goals of VSO. VSO aims to combat stigma, support prevention, and increase the availability of treatment, care and support for those infected and affected by the HIV & AIDS pandemic.

In 2000, VSO started its four-year Regional AIDS Initiative of Southern Africa (RAISA) in six Southern African countries: Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe.

The purpose of the RAISA initiative is to support existing efforts in Southern Africa to respond to the HIV & AIDS pandemic, by strengthening the capacity of civil society and government to develop and work with partners in the implementation of a sustainable and effective multi-sectoral

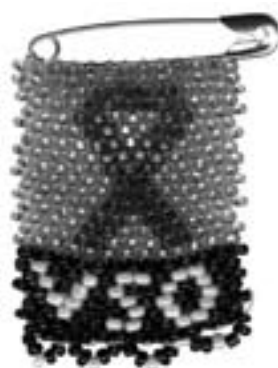
response to HIV & AIDS. The initiative works primarily (although not exclusively) on issues of prevention, treatment, care and support, and mitigating the socioeconomic impacts of HIV & AIDS. The initiative has a particular focus on people living with HIV, orphans and other children made vulnerable by AIDS, women and girls and youth.

This first phase of RAISA ended in 2004 and the second phase, 2005-2008, is now in implementation. RAISA II will continue to build the capacity of partners, by supporting mainstreaming, horizontal learning, networking and advocacy work. Capacity building in partner organisations is supported through: placements of volunteer development workers; small grants; and facilitating horizontal learning (including networking) between partner organisations in exchanges, workshops and conferences. The main sponsors of this project are the Department for International Development (UK) (DFID), Irish Aid, The Big Lottery Fund (BLF), Comic Relief, PSO and Thematic Co-Financing (through the Dutch Foreign ministry) (TMF).





# Executive summary



The 2007 VSO-RAISA Regional Conference was held at the Roodevallei Conference Centre near Pretoria, South Africa on 1 and 2 November 2007. It was attended by delegates from RAISA partner organisations in six Southern African countries and VSO representatives from different countries, as well as guest speakers and delegates from:

SADC, HelpAge International, ActionAid, Africare, Save the Children, Oxfam, Irish Aid, REPSSI, UNDP and UNAIDS.

The aim of the conference was to bring together stakeholders from different sectors, in order to create a forum for discussing innovative solutions to emerging issues affecting caregivers in community based organisations. Objectives included focusing on the challenges of care to women and children, identifying good HBC practices, discussing policy and legal frameworks for HBC, raising awareness of caregivers' needs, exploring how to engage men in HBC, and establishing networks for lobbying and advocacy.

In his opening address, Prof Michael Kelly outlined the 'feminisation' of the HIV & AIDS pandemic, as it increased the burden on women and girls. He saw women and girls as conscripted, forced labourers who were not often appreciated for their contribution to care.

As a result of HIV & AIDS, Prof Kelly asserted, women and girls had more to do, as household managers, as major producers of food, as those responsible for rearing children (including orphans), and as carers of the sick. Their increased household management burden meant that even if personally HIV infected, or ailing from some other illness, women had to continue to manage a household, provide care, produce food and generate income. Women experienced massive pressures to ensure the availability of food for the household, no matter what the cost. Furthermore, upon the death of a spouse due to AIDS, women were often stigmatised and driven from their communities, losing land and other assets in the process.

Prof Kelly urged addressing the poverty and food needs of households, empowering women, protecting girls' access to education, and providing a social protection framework, including cash transfers, food and paid employment.

Junaid Seedat described the findings of a study of female caregivers in six African countries. The study found that providing HIV & AIDS care drove many women deeper into poverty, and they received little support. Policy-makers failed to create enabling environments for caregivers. He said that a fundamental change in gender relations was required. Junaid urged comprehensive training for caregivers, care materials to be provided, financial compensation for the work that caregivers did, and care for the caregivers.

His Excellency the British High Commissioner to South Africa, Paul Boateng, opened the conference officially. He spoke of 'all the feathers of the eagle' as an appropriate metaphor for the talent he saw present at the conference. Governments needed to give a voice to volunteers, to allow them to speak up and express their needs. He urged recognition too, not just of caregivers' material needs, but also of their spirit.

Carol Dyantyi spoke eloquently about the experience of caregivers, drawing on her personal experiences. She noted the high emotional cost of looking after OVC, and described the stress factors that confront caregivers. Carol outlined a model of burnout, and provided a useful description of interventions for addressing burnout.

In addressing the issue of children as caregivers, Lynette Mudekanye mentioned the fact that all too often they were rendered invisible. Prime issues confronting child caregivers included balancing caregiving with school and play, the lack of protection, insufficient skills to provide care, insufficient materials or food, and a lack of role-models. She urged that children be involved and consulted, they be given both practical and emotional support, and they be assisted to manage the transition to adulthood. Vocational training was important to enable children to become independent adults.

Douglas Lackey outlined the challenges facing older people who were carers for OVC or PLHIV. Four advocacy messages underpinned his presentation: valuing the role of older caregivers, developing policies to support and assist





them, providing more resources for them, and providing better HIV prevention and caregiving information to older carers, especially women. He described a model for older carers which had been implemented in Tanzania. Douglas urged policymakers to remember older people in the HIV & AIDS pandemic.

The needs of caregivers (also described as care providers) received a great deal of attention at the conference. Caregivers often seemed to be left poorer and burned out if not properly cared for. There was extensive debate about incentives for caregivers. The consensus was that if caregivers received financial incentives, sustainability needed to be addressed. In the absence of financial incentives, it was important to assist caregivers in sustainable livelihoods – providing seed funding for a small business and giving skills training were mentioned as possibilities. Caregivers also needed the materials and knowledge to prevent self-infection with HIV or TB. Finally, relatives of those who were ill and receiving care needed to be educated about their own responsibilities, so that caregivers were not ‘dumped on’.

Organisations were encouraged to develop sound workplace policies for caregivers. A practical training toolkit for managing volunteers was presented at the conference. Another speaker urged organisations to empower caregivers, so that they could ensure that their human rights were met.

**A number of speakers addressed the issue of involving men in HBC. Key elements in successful campaigns to involve men included:**

- ⌘ Educating community and religious leaders, and traditional leaders about the importance of involving men;
- ⌘ Sensitising the community to the involvement of men, and obtaining their buy-in;
- ⌘ Providing both mixed-sex and single-sex discussion forums, to allow people to address concerns about involving men;
- ⌘ Considering both monetary and non-monetary incentives (such as training, food or food gardens) for men and women;
- ⌘ Challenging gender stereotypes;
- ⌘ Creating new role-models for men as caregivers.

*We were reminded not to forget our underlying humanity.*

The benefits of involving men included reducing the burden of care on female caregivers, encouraging men to be more involved in health care generally, improving community partnerships, and empowering women to take on leadership roles.

The issue of developing child participation was explored extensively. Children had different needs and concerns to adults. Child participation could ensure better decision making regarding children. The comment was made that ‘children are not the sources of the problem, but the resources needed to solve the problem’. Key steps in developing child participation were described. Delegates felt that at future conferences it might be useful to have children provide testimony in parallel sessions.

A number of speakers reflected moving personal experiences – of being caregivers, or of being HIV positive or of having TB – and brought the conference back to the essential human issues in the HIV & AIDS pandemic.

During the course of the proceedings we were reminded not to forget our underlying humanity.

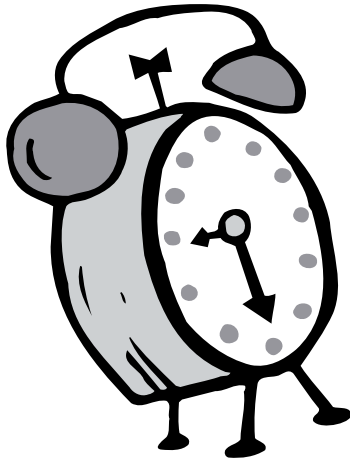
**Key recommendations**

- ⌘ Provide caregivers with ongoing training and support, both practical and emotional;
- ⌘ Ensure that caregivers can generate incomes, or have access to financial support;
- ⌘ Provide care for the carers, and address burnout issues;
- ⌘ Remember the special needs of older caregivers, including prevention messages;
- ⌘ Recognise that child caregivers need to be involved in finding solutions to their challenges;
- ⌘ Provide practical support to child caregivers;
- ⌘ Enable child caregivers to manage the transition to adulthood;
- ⌘ Develop workplace policies for caregivers and volunteers;
- ⌘ Translate official HIV & AIDS policies at regional and national level, into implantation and resource allocation at local level;
- ⌘ Develop child participation in programmes involving children;
- ⌘ Allow in future conferences for a parallel child participation programme;
- ⌘ Challenge gender stereotypes in HIV & AIDS care;
- ⌘ Involve more men in HBC activities.

# Timetable

## DAY ONE: Thursday, 1 November 2007

FACILITATOR	TIME	SESSION	ACTIVITY	KEY PERSON (DESIGNATION)	ORGANISATION
Sara Page	08h00	Plenary	Opening remarks Introductions and objectives	<b>Bongai Mundeta</b> (Regional Director)	- VSO-RAISA
	08h15	Plenary	VSO brief	<b>Liz Holmes</b> (Regional Programme Manager)	- VSO UK
	08h30	Plenary	Opening address: Challenges to women and girls in the provision of AIDS care	<b>Professor Michael Kelly</b> (VSO-RAISA Board Member)	- VSO-RAISA Board
	09h00	Plenary	Women bailing out the state	<b>Junaid Seedat</b> (Sponsorship Manager)	- ActionAid
	09h20	Plenary	Developing quality standards in volunteer management	<b>Michael Schoenke</b> (Programme Manager) <b>Ina Vermeulen</b>	- VSO-RAISA - Cape Town Child Welfare
	10h00	TEA			
Professor Kelly	10h30	Plenary	Official opening	His Excellency <b>Paul Boateng</b> , the British High Commissioner to South Africa	- British High Commission
	11h00	Plenary	Voice of a care provider	<b>Carol Dyantyi</b> (Director)	- Ikageng Itireleng
	11h30	Plenary	The invisible: Children as caregivers	<b>Lynette Mudekunye</b> (Senior Programmes Advisor)	- Save the Children
	12h00	Plenary	Briefing from the Southern African Development Community	<b>Dr Antonica Hembe</b> (HIV & AIDS Unit)	- Southern African Development Community (SADC)
	13h00	LUNCH			
Frida Bhebe	14h00	Parallel	Challenges of caregivers and community volunteers	<b>Elsie Choompa</b> (Executive Director) <b>Annah Wilima</b> (Caregiver) <b>Derrick Luwasha</b> (Programme Coordinator)	- VK Home Based Care Organisation - VK Home Based Care Organisation - Chitipa District AIDS Coordinating Committee
Liz Holmes	14h00	Parallel	Children as caregivers	<b>Thato Makhudu</b> (Community Outreach Officer)	- HIVSA
				<b>Thulani Makhoba</b> (Community Outreach Programme Manager) <b>Luisa Dgedge</b> (Nurse)	- HIVSA - REENCONTRO
	15h30	TEA			
Eric Mamboue	16h00	Parallel	Good home based care practice	<b>Mpho Sebabyoni-Mothasedi</b> (Chief Executive Officer) <b>Tauno Nakasole</b> (Project Officer M&E) <b>Erick Chikukwa</b> (Director)	- Moretele Sunrise Hospice - Yelula/U-khâi - New Dawn of Hope
Wedzerai Chiyoka	16h00	Parallel	Greater involvement of men in caregiving	<b>Pimmy Muzyamba</b> (Programmes Coordinator, Volunteer Management) <b>Eddington Mhonda</b> (Programmes Coordinator) <b>Maggie Mkandawire</b> (VCT Counsellor Coordinator)	- CHEP-National Volunteering Programme - Padare / Enkundleni Men's Forum on Gender - Thandizani Community-Based Prevention and Care
	17h30	Close			
	19h00	DINNER			
	20h00	Entertain- ment	Documentary	<b>Wedzerai Chiyoka</b> (Country Coordinator)	- VSO-RAISA



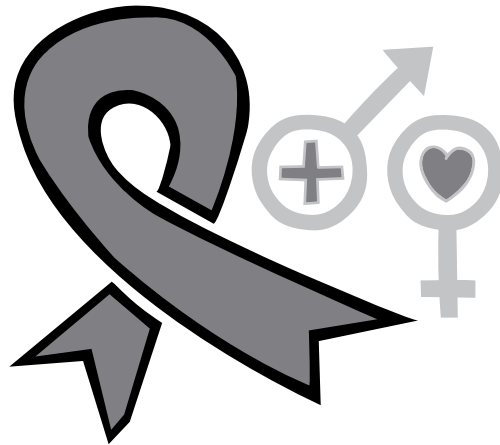
## DAY TWO: Friday, 2 November 2007

FACILITATOR	TIME	SESSION	ACTIVITY	KEY PERSON (DESIGNATION)	ORGANISATION
Professor Kelly	08h30	Plenary	Recap / Housekeeping	<b>Bongai Mundeta</b> (Regional Director)	- VSO-RAISA
	09h00	Plenary	The elderly as caregivers	<b>Dr Douglas Lackey</b> (Regional Advocacy Manager)	- HelpAge International
	09h30	Plenary	Greater involvement of men as caregivers	<b>Sekai Chikowero</b> (Representative)	- Africare Zimbabwe
	10h00	Plenary	Home based care organisations' database software	<b>Frans de Jeu</b> (Volunteer)	- Soweto Home-Based Care
	10h30	Plenary	Question and answer session		
	11h00	TEA			
Wedzerai Chiyoka	11h30	Parallel	MONASO's HBC experience	<b>Matilde Cunhaque</b> (Director) <b>Prince Mulondo Yosia</b> (Volunteer)	- MONASO Sofala - MONASO
Sara Page		Parallel	Challenges faced by community children caregivers in the face of HIV & AIDS	<b>Jennifer Kaberi</b> (OVC Technical Advisor)	- Chiradzulu District Social Welfare Office
Dr Tiwonge	12h00	Plenary	BONEPWA+ and living with HIV	<b>Onangoni Moalosi</b> (Vice-chairperson)	- BONEPWA+
	12h30	Plenary	Women's rights, HIV & AIDS and universal access	<b>Mike Podmore</b> (HIV & AIDS Advocacy and Policy Advisor)	- VSO UK
	13h00	Plenary	Supporting and managing voluntary care providers from the rights-based approach	<b>Hye-Young Lim</b> (Researcher)	- Centre for Human Rights, University of Pretoria
	13h30	LUNCH			
Professor Kelly	14h30	Plenary	Efficiency versus effectiveness: Country response information system	<b>Darlington Changara</b> <b>Zacharia Grand</b> (Representatives)	- Midlands AIDS Caring Organisation (MACO)
	15h00	Plenary	Development of action plans	<b>Stephen Porter</b> (M&E and Learning)	- VSO-RAISA
	15h30	Plenary	Feedback on action plans	Country Coordinators and Programme Managers	
	16h00	Plenary	Closing remarks and evaluation	<b>Liz Holmes</b> (Regional Programme Manager) <b>Bongai Mundeta</b> (Regional Director)	- VSO UK - VSO-RAISA
	16h30	TEA			



# Day One

## Thursday 1 November



*Roberto Pinauin (VSO South Africa), Liz Holmes (VSO UK) and His Excellency, the British Ambassador, Paul Boateng.*

# Plenary

## Opening remarks

Bongai Mundeta,  
VSO-RAISA Regional Director, South Africa

Bongai Mundeta enthusiastically welcomed all the delegates to the conference. She expressed her happiness that VSO-RAISA partners from Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe were present and able to participate in the two-day meeting. Bongai said that her wish was that the conference would be a fruitful exchange of views and experiences between all those who would attend the sessions.

### The **conference aim**, she said, was:

To bring together stakeholders from different sectors, ranging from community-based organisations, non-governmental organisations to policy planners, to create a forum for discussing innovative solutions to emerging issues that are affecting caregivers within community-based organisations.

### The **conference objectives** were:

- ✂ To raise awareness regarding the challenges for women and girls within HBC programmes of caring for people infected and affected by HIV & AIDS;
- ✂ To identify and disseminate good HBC practices that reduce the burden of HIV & AIDS care that falls on women and girls;
- ✂ To discuss the policy and legal frameworks that were required to address HBC and the continuum of care, including the role of the state;
- ✂ To raise awareness of, and discuss the economic, social, technical and personal needs of caregivers and community volunteers;
- ✂ To explore ways of engaging men in the provision of HBC;
- ✂ To discuss the possibilities of mobilising home based carers to establish networks for advocacy and lobbying.

### Bongai also identified a number of **sub-themes**:

- ✂ The challenges of caregivers (women and girls) and community volunteers in caring for people with HIV & AIDS;
- ✂ The elderly as caregivers;
- ✂ Children as caregivers;
- ✂ Greater involvement of men as caregivers;
- ✂ HBC good practice;
- ✂ HBC policy and legislative frameworks.

# Plenary

## VSO brief

Liz Holmes,  
Regional Programme Manager, VSO UK

Liz Holmes extended her own warm welcome to all the delegates. She saw all who were present as united in a common purpose: to learn from each other, and for each person to have the opportunity to give testimonials of their experiences. Liz highlighted the profound impact of sharing on the work that VSO undertook. In particular, she drew attention to the importance of RAISA to VSO at an international level. RAISA captured the very best of what we could do, but Liz believed that we could do it better, do more, and respond more effectively to the changing opportunities that presented themselves.

Liz said that VSO was seeking new partners, and also seeking to deepen its relationship with existing partners. She reminded delegates that in 2007 VSO celebrated 50 years of activity. In 1958, eight 18-year-old men went overseas with VSO. For VSO founders, Alec and Mora Dickson, this was the realisation of a vision. For the young men, it was the beginning of a journey of discovery. Fifty years and nearly 33 000 volunteers later, VSO are still at the forefront of innovative work in developing countries. Liz urged delegates to look forward to another 50 years of VSO innovation.

### She suggested that the priorities for the next three to four years might include:

- ✂ Increasing the work using national volunteers, who were able to support local organisations in unique ways;
- ✂ Increasing the work in health and strengthening health systems;
- ✂ Continue the focus on advocacy, particularly in relation to gender and power.

Liz wished all the delegates a successful conference. She invited all present to speak out honestly, and to share whatever was on their minds.

*Liz urged delegates to look forward to another 50 years of VSO innovation.*

# Plenary

## Opening address: Challenges to women and girls in the provision of AIDS care

Professor Michael Kelly,  
VSO-RAISA board member, Zambia



Prof Kelly delivered the opening address to the conference, on the challenges to women and girls in the provision of AIDS care. **His talk was followed by enthusiastic applause.**

He pointed first to the multiple responsibilities of women, from daily household management to preparing food, cleaning, laundry, generating an income, caring for children and nursing the sick. Even in the absence of HIV & AIDS all these tasks represented a heavy burden.

Prof Kelly went on to discuss the impact of HIV & AIDS on women and girls. HIV & AIDS increased their responsibilities and burdens: because of the feminisation of the epidemic, and because women and girls were at the forefront of the response to the epidemic.

*'... the feminisation of the epidemic means an increased burden and more responsibilities for women.'*

Globally, and in every region of the world, more adult women than ever before were living with HIV. In sub-Saharan Africa, 59% of infected adults were women: for every 10 infected adult men, there were 14 infected adult women. Women and girls were becoming HIV infected at younger ages than boys and men, and dying at younger ages. Prof Kelly mentioned a study in Zambia, which found that 61% of deaths were among women.

### Life Expectancy in RAISA Countries, 2006

	WOMEN	MEN
Malawi	42	41
Mozambique	46	44
Namibia	55	52
South Africa	49	47
Zambia	40	40
Zimbabwe	34	37

*Slides from Prof Kelly's presentation.*

### The Gender Reversal in Life Expectancy in Southern Africa

	Life Expectancy for WOMEN	Life Expectancy for MEN
1998	61	54
2004	48	46
2010	42	44

One result of the greater burden of HIV falling on women was that more children were being left without mothers. A second impact was an increasing burden of orphan care on elderly grandparents, often grandmothers.

As a result of HIV & AIDS, Prof Kelly asserted, women and girls had more to do, as household managers, as major producers of food, as those responsible for rearing children (including orphans), and as carers of the sick. Their increased household management burden meant that even if personally HIV infected, or ailing from another illness, women still had to manage a household, provide care, produce food and generate income. Women experienced pressures to ensure the availability of food for the household, even at the cost of sex and its consequent risks. Furthermore, upon the death of a spouse due to AIDS, women were often stigmatised and driven from their communities, losing land and other assets.



He described the compromised food-producing activities of women as a result of the HIV & AIDS pandemic. African women produced 60-80% of their countries' food; in sub-Saharan Africa they were overwhelmingly responsible for the production of vegetables and basic food grains. Yet, in AIDS-affected rural households women had less time and energy for food-producing or income-generating activities.

### Prof Kelly went on to discuss the demands of caring for children:

- ✂ Even with AIDS, women were expected to continue to care for children;
- ✂ Orphans increased the number of children women had to care for;
- ✂ AIDS care limited the time mothers had for the psychosocial interactions essential to the development of their children;
- ✂ Special time-consuming and emotionally exhausting care need to be provided for HIV-infected children;
- ✂ Girls were taken out of school to assist with child-minding and other tasks.

Caring for the sick represented a further burden for women and girls. When a male member of the household fell sick, women and girls provided care and took on additional duties to support the family. Urban family members who fell sick often returned to rural communities. Home care was the only option available to millions with AIDS, and was provided mostly by women. ARVs were not widely available in many Southern African countries – and so the care burden for women was not reduced.

Prof Kelly pointed out the misconception that women were 'volunteers' in the HIV & AIDS pandemic. On the contrary, he saw women and girls as being conscripted and forced labour, compelled to care for others whether or not they wished to do so. He said that women were not adequately appreciated for their contribution to care, because of patriarchal values.

It was important to remember the impact of HIV & AIDS on girls, Prof Kelly said. Girls were taken from school to assist in a range of household duties. This led to a double loss for girls: they had a poorer school education that could have reduced their vulnerability to HIV infection, and they lost the better economic prospects that an education could bring. Girls might have to contribute to household survival by being 'married off' at an early age, selling sex, working as house servants or performing other kinds of child labour.

### A long-term solution should include a broad social protection framework or strategy that would:

- ✂ Address poverty and the food needs of households, especially those with HIV or AIDS;
- ✂ Empower women;
- ✂ Ensure support for women and girls as caregivers;
- ✂ Protect girls' access to education.

A social protection framework should include cash transfers, food and nutrition transfers, participation in public works, etc. Social protection for the poorest, Prof Kelly argued, was affordable even in poor countries. He contended that ensuring universal access to HIV prevention, treatment, care and support would further help reduce the care burden on women and girls.

### He concluded with a quote from Jonathan Mann, speaking in 1995:

'The central issue in the AIDS pandemic is not technological or biological, but whether we are willing to address the inferior status of women.'

*Ensuring universal access to HIV prevention, treatment, care and support would further help reduce the care burden on women and girls.*



Junaid Seedat (ActionAid) and Prof Kelly.

# Plenary

## Women bailing out the state

Junaid Seedat, Sponsorship Manager,  
ActionAid, South Africa



Junaid started by describing the findings of a study of women in South Africa, Swaziland, Lesotho, Zimbabwe, Malawi and Mozambique who were involved in HBC. The study aimed to analyse the economic implications and provide a costing for HBC in different settings, including the loss of income by carers, and determine the most appropriate model for costing of HBC.

### The study found that:

- ✘ Nearly 70% of caregivers were women, rising to 78% where patients were bed-ridden. Where children provided care for parents, 64% were girls;
- ✘ Only 5% of the funds of HBC organisations were spent on 'education and training' for caregivers, compared to a high 44% on 'administrative costs', and 33% on 'provision of care';
- ✘ Materials and medicines, the cornerstone of health care, were often inadequate. For example, in Lesotho organisations reported sharing one HBC kit between two or three caregivers, which was only replaced annually. Caregivers, often poor, had to supply materials themselves or offer inadequate standards of care;
- ✘ All caregivers reported unacceptably high levels of stress, with 93% of CBO-supported caregivers suffering from emotional stress;
- ✘ Many caregivers became poorer because of their role. Nearly half reported that their incomes had changed as a direct result of being caregivers, and for 66% this meant a decline in incomes;
- ✘ For the 33% who experienced an increase in income it was primarily as a result of receiving stipends, social grants or being formally employed as caregivers. Two thirds of these increases were in South Africa, where strong HBC policies and organisations exist.

### Financial findings at a glance

- ✘ The total annual cost for HBC activities in the six countries studied was about R33 million (USD\$ 4 million) for 14 955 clients (or 12 044 households);
- ✘ There was a unit cost of R181 (USD\$ 22) per client per month;
- ✘ There was a unit cost of R6,04 (USD\$ 0.75) per client per day.

Junaid said that the reason why women had become burdened as caregivers was that public health systems could not provide adequate care. In Southern Africa health and welfare policies waned following the 1970s economic crisis and the structural adjustment policies of the 1980s and 1990s. Budgetary restrictions imposed by international financial institutions limited public health programmes. Africa also had a crippling shortage of health care workers.

The inability of health systems to care for all those living with HIV had led many governments to rely on HBC to fill the gap, Junaid argued. Most of those who provided this care were women, who were unpaid and already quite poor, and the additional financial and emotional burden of administering care frequently pushed them into destitution.

Women also 'lost opportunities' to claim their rights, as caregiving consumed a significant amount of women's and girls' time. Girls left school to care for sick parents and siblings, sacrificing their right to education, which echoed an earlier comment by Prof Kelly. For example, in Zimbabwe 76% of children who left school to provide care were girls.

Junaid reported that while women and girls provided care, they often did not receive adequate care when they themselves were ill with HIV or AIDS. For example, in Malawi caregivers had fewer female patients (29%), despite the higher HIV prevalence among women.

Furthermore, Junaid said, when women received care it tended to be provided by women. Indeed, chronically ill women, who received care, were often 'sent' back to their parents' homes, increasing the burden of care on mothers and grandmothers, whilst men remained in their immediate homes cared for by their wives or daughters.

The data of the study showed that in the HIV & AIDS pandemic female and child-headed households were the most vulnerable. High vulnerability resulted in higher dependency ratios, lower education levels and lower incomes.

*'It is only through a fundamental transformation in gender relations... that we will begin to see a change in the current picture (of the HIV & AIDS epidemic).'*

Junaid suggested that in Southern Africa many government declarations and policies recognised the weaknesses in public health systems, and the resultant necessity of shifting care for PLHIV to communities. Some countries acknowledged the need to provide care and training for caregivers. For example, Mozambique had legislated that caregivers receive 60% of the minimum wage, while South Africa had introduced stipends of R1 000 per month for caregivers, and offered a number of social grants to caregivers.

Indeed, Junaid conceded, national policies in Southern Africa were comprehensive. All six countries had strong national AIDS plans and HBC policies that recognised the additional vulnerabilities of women and girls. Many key international and regional policies and guidelines could provide leverage for influencing policy.

However, Junaid argued, most of these policies did not address how to ensure women were not further burdened by their role as caregivers.

Junaid said that despite numerous policies, women caregivers were not being protected. Policy-makers were failing to create enabling environments to address the burden of care. Policies would not change people's lives if they were not allocated sufficient funds, accompanied by meaningful implementation plans, an enabling environment and awareness campaigns.

For community-based care to be effective it needed to be supported and enabled by the public health system through:

- ⌘ comprehensive training and materials;
- ⌘ financial compensation for care work;
- ⌘ care for the caregivers;
- ⌘ increased, predictable, targeted long-term funds;
- ⌘ strengthened referral systems.

Junaid concluded by saying that international financial institutions needed to end anti-poor monetary policies. Women's rights needed to be addressed within broader poverty alleviation strategies.

*'Female caregivers who are carrying the burden of HIV & AIDS care are largely unrecognised, unsupported and not compensated. They are sacrificing their rights to equality, education and livelihoods, limiting their opportunities to secure their economic and social rights. This reality must not continue.'*

### Income expenditure of PLHIV households – women and girls battle under the care burden



Slide from Junaid's presentation.



# Plenary

## Developing quality standards in volunteer management

Michael Schoenke, Programme Manager, VSO-RAISA  
and Ina Vermeulen, Cape Town Child Welfare,  
South Africa



Michael presented briefly on the development of a quality standard toolkit for the management of volunteers in HIV & AIDS work. Ina then described how this particular toolkit had been implemented by her organisation, Cape Town Child Welfare.

By way of introduction Michael said that South Africa had a strong legacy of volunteerism. According to recent studies, over 1,5 million people actively contributed their time to non-profit organisations. Volunteer labour accounted for 49% of the non-profit workforce. Volunteering was also a mechanism for individuals to gain skills and experience. The size and scope of volunteering was expected to increase as more South Africans continued to take on work as caregivers and community volunteers, Michael added.

Mechanisms needed to be developed to ensure the proper support, development and protection of volunteers. VSO South Africa had been working with key civil society stakeholders to increase their capacity to more effectively manage local volunteers in their programmes. In 2007, a working committee was established to develop a Volunteer Management Systems (VMS) training toolkit. It aimed to establish quality standards for volunteering, particularly for those volunteers engaged in HIV & AIDS initiatives.

The VMS toolkit comprised 16 modules, which covered all elements of the volunteer management cycle. These included volunteer needs assessment and placement

development; recruitment, selection, orientation and training; risk exposure management and support facilities; record keeping; volunteer supervision and volunteer-staff relations; performance appraisal, recognition and retention; termination; budgeting and resource mobilisation; and volunteer programme assessment.

*The size and scope of volunteering was expected to increase as more South Africans continued to take on work as caregivers and community volunteers.*

According to Michael, the toolkit would ensure full integration of volunteering into the organisational processes of organisations (including programme planning, administration and reporting). It would also ensure increased application of organisational policies and procedures to allow for:

- ✘ effective management;
- ✘ rights and protection of volunteers;
- ✘ professional development of volunteers;
- ✘ recognition of the value that volunteers brought to an organisation;
- ✘ improved capacity of organisations to develop and sustain volunteer programmes.

### Benefits for volunteers working with HIV & AIDS included:

- ✘ Confidentiality of status for PLHIV working as volunteers;
- ✘ Enhanced information management and data protection for patients, families and community members;
- ✘ Support for volunteers through psychosocial support and debriefings;
- ✘ Risk exposure management: access to safety equipment, i.e. rubber gloves, to reduce exposure to blood and accidental needle exposure;
- ✘ Volunteer mentorship and development: opportunities for development through training and support, leading to access to new job opportunities.

Ina then went on to describe how Cape Town Child Welfare had implemented the VMS toolkit. Child Welfare's volunteer programme was called Isolobantwana (The eye of the child). It was started in 1997, following research showing that community members needed training to help protect children after hours. In 2001 the volunteer programme had

been extended to include training community members to trace extended families of children, and to support HIV-infected and HIV-affected children. In 2006 a Helpkids Hot-line offering a 24-hour telephone service had been added to the available services. About 200-250 local and international volunteers were involved at any one time.

Ina pointed out that her organisation needed volunteers in order to ensure that quality services were rendered to the organisation's clients. Volunteers were a benefit and a valued commodity for the organisation and should therefore be treated fairly and justly.

*Volunteers were a benefit and a valued commodity for the organisation and should therefore be treated fairly and justly.*

The **benefits** of implementing the VMS toolkit had included:

- ⌘ Strengthening of the volunteer programme and indirectly of the organisation at large;
- ⌘ Happier, better equipped and more sustainable volunteers;
- ⌘ Better services and protection of caregivers and children;
- ⌘ Continuous monitoring of the VMS;
- ⌘ Building of a pool of volunteers, and increased recruitment.

In conclusion, Ina said, the toolkit manifested new awareness and help in addressing the key personal needs of community volunteers and caregivers. The rights and livelihoods of volunteers were supported and protected in the long term. The toolkit would also generate a sustainable and increased human resource capacity to respond to the HIV & AIDS pandemic in the country.

## Questions & discussion

Questions and discussion followed the mornings' presentations.

The following points emerged:

- The controversial point as to whether or not volunteers should be supported with a stipend was discussed. The fear was expressed that if a stipend was paid, then the commitment of volunteers might be eroded.
- In response, one delegate said we needed to move away from the term 'volunteer' and speak rather about 'caregiver'.



# Plenary

## Official opening

His Excellency Paul Boateng,  
the British High Commissioner to South Africa



The British High Commissioner to South Africa, Paul Boateng, gave a stirring opening address to the conference about the importance of volunteerism in an African context.

Paul said that he was the product of missionary educators, as he had spent his youth in Ghana, West Africa, in the 1960s. Here volunteering had a special significance, insofar as individuals had a responsibility to care for others in the community. He referred to Kwame Nkurumah, who said that volunteering represented the African personality. He also alluded to Archbishop Desmond Tutu's words about *ubuntu*, 'we are what we are because of others'.

When he had moved to the UK, Paul said that he had encountered a different view of volunteering. The use of volunteers was rooted in the distant past, but they were seen as outmoded in post-World War II Britain. The state became the main provider of social services. Yet, Paul conceded, this pattern had changed in the previous ten years. Central or local provision of services, and the use of volunteers were no longer seen as in competition with each other. Instead, he said, 'we all need each other in order to deliver services', as nobody could deliver effective services on their own.

In the African context, community collective action was crucial and part of the normative response to the AIDS pandemic. He would like to give credit to the thousands of volunteers – frail and elderly, vulnerable and young – who were represented at the conference.

Governments should embrace volunteerism, and should ensure access to training, care and support for volunteers

that was flexible and responsive to their needs. Traditionally, governments tended to resent volunteers, who reflected passion and commitment, but were not subject to the instructions of government and might sometimes be in conflict with the government of the day. Nevertheless, volunteers bore part of the burden of social services and health care. Governments wanted volunteers to pick up the burden at no cost to government, and this was not fair. At their worst, Paul warned, governments could be destructive of volunteerism.

The challenge, Paul continued, was how to create an equitable partnership. Robust dialogue in the UK between volunteer organisations and the government had led to a compact between the two.

Government needed to give a voice to volunteers, to speak up and express their needs, to see that they were respected, and to ensure that their needs were taken seriously. Civil society, on the other hand, needed to speak up and articulate the needs of the poor. Volunteers and carers needed to be respected. Governments could do more to recognise their role and to acknowledge their need to make a living. Carers needed protection – for example, the needs of a teenage child caregiver to access education and to access an inheritance were crucial. Finally, Paul said, we should not ignore the spirit of people who were caring for others – they could not be compensated merely through material means.

*'You cannot take the spirit out of giving. Human beings are not just units of production, not just players in the market. We must recognise this.'*

In response to Paul's address, Prof Kelly commented that it had been worth coming to the conference just to hear what he had said. He had underlined the importance of effective partnerships, and the need to be open to the truth, honesty and integrity of partners. Prof Kelly highlighted the way in which Paul had put the spirit back into the work we were doing.

A delegate said in response to the opening address that bottlenecks were experienced in trying to reward volunteers. The policies for rewarding volunteers were in place but were not implemented – how do we ensure they are implemented? Paul replied that at the end of the day all action needed to be taken locally, and we needed to ensure that the political process reflected this. The British experience was that delivery at the local level worked best.



# Plenary

## Voice of a care provider

Carol Dyantyi, Programme Director,  
Ikageng Itireleng AIDS Ministry, South Africa



*'We are inspired by grandmothers and other ancestors who have gone before us – they are the foot soldiers.'*

Carol spoke eloquently about the experiences of care providers, drawing extensively on her own experiences of setting up an organisation to meet the needs of children in her community who had been made vulnerable by HIV & AIDS. She also gave a moving account of her own personal experiences of trauma.

**She related an anecdote of a 15-year-old girl talking to her on the previous day: 'Don't you remember? We buried my mother five years ago. I re-experienced it again today. At 9 am my mother could not breathe, at 11 am we called you, and at 12 she breathed her last, in your arms.'**

Carol said that stories such as these were typical of the experiences of care providers.

She continued by outlining the importance of caring for providers of care, given that a high emotional cost accompanies caring. Along with managing children's pain, there was frustration involved with working with children in especially difficult circumstances (CEDC). CEDC could be demanding, distrustful, difficult to communicate with, moody, fearful and helpless. They might also present a risk in terms of HIV infection to the caregiver or to other children in the environment. Finally, caring for care providers was often overlooked.

Carol said that the risk of high stress levels arose from a number of factors: hearing children's stories of trauma, and having to balance empathy and objectivity; experiencing the mistrust of CEDC towards their care provider; and the emotionally draining nature of the work.

Stress could result in a variety of psychological reactions (including secondary trauma stress and burnout). Secondary stress could flare up with little warning while burnout usually emerged gradually.

### Secondary stress factors which confronted care providers included:

- ✘ Confidentiality issues: care providers could be asked by children not to report incidents of abuse;
- ✘ Safety issues: care providers and children could be exposed to physically threatening situations;
- ✘ Justice issues: care providers could be frustrated by the lack of justice for children who faced abuse or ill treatment;
- ✘ Ethical issues: care providers might need to ensure the wellbeing of CEDC with little or no support from legal, justice or law enforcement agencies;
- ✘ Cultural issues: care providers might become stressed through working in an unfamiliar culture or subculture;
- ✘ Spiritual welfare: care providers needed an abundant measure of emotional and spiritual energy;
- ✘ Personal issues: through their work, care providers might find themselves re-living personal traumatic experiences and repressed memories.

According to Carol, burnout, unlike the stress of secondary trauma, emerged gradually. It occurred when stress had built up to an intolerable level. Stress was a part of burnout. She described a model for the stages of burnout stages, from the honeymoon stage, to disillusionment, frustration and despair.

*Know when to let go, and maintain a strong sense of identity and integrity.*

✘ Cont'd



## Techniques for preventing burnout:

### Sources

- ⌘ Symptoms manifested in physical, emotional and behavioural forms;
- ⌘ Acknowledge the demands of working with CEDC;
- ⌘ Personal history and issues impacted on the care provider.

### Transference

- ⌘ Transference meant that the care provider related and reacted to the CEDC as if they were a 'significant other' e.g. brother, sister, son or daughter.

### Limitations

- ⌘ Acknowledge limits – personal, emotional and professional.

### Beliefs

- ⌘ Know oneself, including one's limitations and boundaries;
- ⌘ Know when to let go, and maintain a strong sense of identity and integrity;
- ⌘ Be open to the children but maintain self-protection.

## In conclusion, Carol outlined some interventions to manage burnout better:

1. Acknowledge the situation;
2. Remember to take care of yourself – physically, emotionally and professionally;
3. Set boundaries and limits – evaluate goals, priorities and expectations, ensuring they are realistic and achievable;
4. The work environment should accommodate the needs of care providers;
5. Learn to let go of the children's pain: carrying this load did little to help you or the child!;
6. Adopt methods to relax the body at work. Deep breathing might help release tension. Stretching and reaching for the ceiling, rotating the head, rotating the arms and shoulders, touching one's toes and making deep knee bends all helped;
7. Progressive muscular relaxation, including tensing and relaxing body muscles, was very helpful;
8. Visualisation and auto-suggestion, including clearing the day's work from thought processes, were also useful to practise.

At the end of her presentation Carol quoted Judge Edwin Cameron. He suggested that we cannot escape grief and suffering but we can prevent further death. Our grief is present: we can allow it to give us a further experience of loss, or we can incorporate grief into our daily living. Africa needs healing AIDS beacons, and this is not a calling we can decline.

# Plenary

## The invisible: Children as caregivers

Lynette Mudekunye, Senior Programmes Advisor,  
Save the Children UK, South Africa



Lynette began her presentation by asking *why* children are involved in caregiving in the HIV & AIDS pandemic. She said the answer was that HIV & AIDS was a long, taxing illness, with an enormous toll. Friends and family members involved in care often had the need to withdraw as a coping mechanism. Eventually only children and the elderly remained to provide care.

Lynette said that children were often invisible in the pandemic. UNICEF, in a document entitled *A Call to Action*, described children as the 'missing face of AIDS', insofar as they watched their parents die and were seriously traumatised by the pandemic. Yet, Lynette pointed out, UNICEF made no mention of children being actively involved in providing on-going care for their parents and caregivers. We heard about orphans, and more and more about child-headed households. Yet how often did we hear about children who were living with and caring for an ill parent, or an aging grandparent?

*Children are the 'missing face of AIDS'.*

The primary responsibility in caring for an HIV-positive adult was often taken by older children, but many younger ones were also involved. More often girls were involved: 64% of child caregivers were female. Boy caregivers often went unreported, because it was socially unacceptable for boys to be caregivers.

Child caregivers were very common in Southern Africa, but also in other countries affected by the pandemic. Children might be involved in caring for ill parents, ill older siblings, and old and ailing grandparents. In her experience, the youngest primary child caregiver she had come across was 8 years old, and the youngest child caregiver involved in any capacity was only 4 years old.

Issues which children faced as caregivers:

- ✂ **Balancing caring with school and play** – looking after their own needs could lead children to experience feelings of guilt;
- ✂ **Lack of protection** – child caregivers were very vulnerable to exploitation and abuse;
- ✂ Children often had **insufficient knowledge and skills** to care properly;
- ✂ They might have **insufficient materials or food** to care properly for the PLHIV;
- ✂ They might lack anyone to talk to, help or guide them. The **lack of role-models** was especially acute for boys.

There was a range of ways in which we could help child caregivers. These included:

- ✂ Recognising the role they played, and how important they were to the person they were caring for;
- ✂ Recognising their ability to think and make their own choices, and understanding how resourceful they were;
- ✂ Consulting them and involving them. We needed to speak to them honestly;
- ✂ Helping them to find balance: to be able to go to school, have time to play, and encourage other children to spend time with them;
- ✂ Providing technical and material support in the form of training;
- ✂ Helping them to manage the transition to adulthood, including training and support for economic activities.

In answer to the question of who needed to be involved in helping child caregivers, Lynette mentioned schools, faith-based organisations, community groups (especially those involved in HBC), and other children.

A conference delegate commented after Lynette's presentation that we needed to remember the child's fundamental right to happiness, as reflected in various United Nations (UN) conventions, including the rights to play, to rest and to an education.

# Plenary

## Briefing from the Southern African Development Community

Dr Hembe, HIV & AIDS Unit,  
SADC, Botswana



In her introduction, Dr Hembe said that she appreciated meetings such as this, as they allowed her to listen more attentively to 'people on the ground'. She said that SADC remained the global epicentre of the HIV & AIDS epidemic. The epidemic appeared to be stabilising at a high prevalence. National prevalence rates in Southern Africa varied from 1% to over 35%.

Dr Hembe described SADC's mandate as being to promote sustainable growth, socio-economic development and poverty reduction. HIV & AIDS was the greatest obstacle to achieving this objective, as it undermined economic development and exacerbated poverty.

SADC's response to the epidemic had been to prioritise its response through the Regional Indicative Strategic Development Plan (RISDP), the Maseru Declaration and the Business Plan. Heads of state had endorsed all continental and global initiatives. The SADC Secretariat aimed to coordinate the regional response, and at country level support the three ones principles (one strategic framework, one M&E plan, and one coordinating body for HIV & AIDS in each country).

The five SADC priority areas for urgent action described by Dr Hembe were: prevention and social mobilisation; care, treatment and support; development and mitigation of the impact of the pandemic; resource mobilisation; and monitoring and evaluation.

✂ Cont'd

Dr Hembe went on to outline a five-year SADC business plan, with the following major priorities:

- ✂ Policy development and harmonisation;
- ✂ Capacity building for mainstreaming;
- ✂ Facilitating a technical response, resource networking, collaboration and coordination;
- ✂ Resource mobilisation;
- ✂ Monitoring and evaluation.

She highlighted the challenges faced by three categories of vulnerable caregivers: women, the elderly (especially grandmothers) and children (especially girls).

The progress and achievements of SADC in relation to HIV & AIDS included:

- ✂ All SADC member states now used the same frameworks and tools to monitor progress;
- ✂ The SADC HIV & AIDS Unit was now adequately staffed;
- ✂ Partnerships had been strengthened. Structures for decision making and information sharing had been created;
- ✂ A SADC Regional Fund for HIV had been established, to which member states had begun contributing;
- ✂ A framework to address psychosocial support for orphans and vulnerable children, and youth would be developed, under the auspices of UNICEF and REPSI;
- ✂ A SADC protocol on gender was being developed in consultation with member states, CBOs and the private sector;
- ✂ A proposal on cross-border ART was to be submitted in March 2008.

However, Dr Hembe admitted that a wide range of challenges remained. These included translating political commitment and resource allocation into action. Utilisation of available resources remained a difficulty, as did implementation of agreed frameworks. Another problem was coordination of HIV & AIDS actions in member states. Involvement of civil society organisations at member state and regional level was another issue. SADC lacked adequately skilled human resources and sufficient health facilities. A final challenge remained provision of services to vulnerable groups, such as OVCs, widows, refugees, mobile populations and migrant workers.

In conclusion, Dr Hembe said that SADC would intensify its response through the Business Plan with member states and key relevant stakeholders. Available expertise within and outside the region needed to be utilised. SADC would work with regional civil society organisations to benefit from their best practices and to share experiences. Finally, member states would be encouraged to engage in wide consultations to expedite the approval of the SADC Protocol on Gender.

## Questions & discussion

A discussion session followed, allowing delegates to pose questions to the speakers of the morning.

- One delegate said that he felt that in SADC, implementation lagged far behind policies. He asked why there was a separate protocol for women in SADC when the African Union already had such a protocol. Dr Hembe said in response that it was important to harmonise human rights, right down to local level and circumstances.
- A comment was made about the danger of SADC promoting male circumcision as an HIV prevention measure, as it could encourage men to engage in risky sexual behaviour without condom use. Dr Hembe said that there was a need to proceed with caution regarding circumcision: the scaling up of circumcision needed to be accompanied by better condom use. There was also the issue of traditional healers to consider: they were involved in providing circumcision too.
- One delegate expressed strong criticism of SADC, remarking that ten years on, the organisation was still 'putting on its running shoes' in relation to HIV & AIDS. The structures it created, he said, just mimicked global structures and served no useful purpose. Dr Hembe conceded in response that SADC could only move as fast as its member states.
- Another remark related to caregivers looking after OVC. A delegate commented that in Zimbabwe the experience had been that caregivers were overburdened and could not take care of children with HIV-ill parents.
- A delegate spoke about the need in relation to OVC to integrate the formal and informal schooling systems. In response, a speaker spoke about how in Gauteng, South Africa, schools had HIV & AIDS counsellors, who referred OVC to camps run by HIVSA (a RAISA partner in South Africa), where their needs could be addressed. Street committees (active in the anti-apartheid era) had been revived too, and could bring the needs of vulnerable children to the attention of schools and the welfare sector.



The translators: Dionisia Silva and Yolanda de Almeida.





Posters on display throughout the conference





# Parallel session

## Challenges of caregivers and community volunteers

⌘  
An integrated community HIV & AIDS programme

⌘  
The experiences of a caregiver: A testimony

⌘  
Challenges to caregivers

## An integrated community HIV & AIDS programme

Elsie Choomba, Executive Director,  
VK Home Based Care Organisation, Zambia



Elsie started by describing VK Home Based Care Organisation as a non-profit organisation implementing an integrated HIV / AIDS community programme in Zambia. VK stood for Victoria Kawanga, the woman who had initiated the HBC programme. The project was located in a peri-urban area close to Lusaka, Zambia. Its aim was to enable vulnerable groups of people to access basic HBC services within their communities.



*A picture from Elsie's presentation showing caregivers at a meeting in VK HBC.*



*Elsie brought cards, jewellery, bags and beautiful handmade clothes to the conference. The sale of these was part of VK HBC's income-generating activities.*

According to Elsie, the organisation faced a wide range of challenges, including an inadequate supply of food for patients, and a lack of transport to get very sick patients to their clinic reviews. They also had only a few male caregivers, which meant that providing care to males was difficult.

Patients faced challenges too, including loss of income when they had been the primary breadwinners. Patients tended to worry about family problems, which impacted negatively on their ability to recover. Some patients in denial of their status did not adhere to their medication. Lack of warm clothing and bedding exposed some patients to the cold.

Caregivers faced their own difficulties. Some caregivers confronted increasing poverty. Caregivers lacked the skills to deal with orphans and vulnerable children. Caregivers faced the risk of contracting HIV and TB whilst caring for and supporting community members without pay, especially since as many as three to four TB patients shared a single room. Inadequate supplies of basic care kits, the absence of emergency funds and increased burnout were other challenges for caregivers.

Lessons learned included that food supplements were key to patients' adhering to drugs. Another important lesson was that households where primary caregivers were children needed specialised help. Contributing to school bursaries for children of caregivers helped to sustain them in doing voluntary work in the care and support programmes. Furthermore, caregivers were motivated when they were given the privilege of taking local and international visitors to visit their clients. Setting targets for caregivers helped them to work hard and to be focused.

A crucial lesson, Elsie emphasised, was that training caregivers in sustainable livelihoods and microfinance contributed to reducing poverty levels in their households. Training of caregivers helped to enhance team spirit. Having

a medical clinic supporting the HBC programme gave caregivers the means to refer clients with complications. Integrated skills for caregivers enabled them to provide holistic support to households affected by HIV infection.

*'Coming together is just the beginning. Partnering together is progress and working together is success.'*

#### Key recommendations for the future included:

- ✘ Sustainable livelihood training and microfinance courses needed to be adopted and integrated in the training manual for caregivers;
- ✘ Organisations working with volunteers should network to promote sharing of information and best practices;
- ✘ The donor community should consider supporting a stipend for local and national volunteers;
- ✘ All programmes working with caregivers needed to develop and implement an HIV workplace policy.

In conclusion, Elsie said, in the response to poverty and HIV & AIDS, donors, governments and civil society needed to realise that: 'Running alone, you run fast BUT running in a group, you reach far.'

*'...training caregivers in sustainable livelihoods and microfinance contributed to reducing poverty levels in their households.'*

Annah began working as a volunteer caregiver. She told patients how to take TB treatment and ART at the right time. She also provided education about the importance of eating nutritious foods.





## The experiences of a caregiver: A testimony

Annah Wilima, Caregiver,  
VK Home Based Care Organisation, Zambia

Annah spoke movingly about her personal experiences of being a caregiver. She started out by saying that she believed her life was a miracle from God, and she was very grateful for the opportunity to be able to testify at the conference.

Annah told the delegates that she was a widow, whose husband had died in 1987. She took care of six children: three of my own and three children of late relatives. They lived in a rented house and she was not in formal employment. Annah said that she and her household survived by running a small shop from home, known as *kantemba*. When she had enough money, she bought goods in Zambia and took them to Botswana to resell. After selling these goods, she ordered blankets for sale back home in Zambia.

After the death of her husband, she had become very sick. She went to a government clinic, where she was diagnosed with TB. She started TB treatment in 1991 and completed it after eight months, feeling very healthy at the end of treatment. After seven years of being well, Annah said that she had a relapse. She started TB treatment again, this time being given 60 injections. Again, treatment was completed after eight months. Three years later, in 2001, she had a second relapse. This time treatment took the form of tablets and injections. She completed the treatment for a third time.

Against all odds, Annah related, in 2003 she became very ill and almost died. She was diagnosed with TB for the fourth time. This time round, her memory had been affected, and even now she still struggled to remember things.

She collected her TB drugs from VK Home Based Care Organisation. Here she was encouraged for the first time to go for VCT, and tested positive for HIV. When blood tests were done, her CD4 count was only 16. So ART was begun alongside TB treatment. 'My health has greatly improved, as you can see', Annah said. She reported that she had continued with ART to date. 'I went back to VK Home Based Care and told them that I am HIV positive and I want to become a caregiver so that I can help other people.'

Annah began working as a volunteer caregiver. She told patients how to take TB treatment and ART at the right time. She also provided education about the importance of eating nutritious foods.

'In my community where I live, I find some people bedridden due to TB or HIV. They don't want to take medicine, they just want to die. After telling them my status and seeing how I look, they feel better, because I tell them that, "Living with HIV infection is not the end of someone. You can live positively for so many years so long as you take good care of yourself." When I go back to visit them, I find them happy and taking medicine at the right time.'

*'I have seen that there is a lot of suffering for patients in our communities, especially women and orphans with little or no help at all. I want to use my remaining days before I die to help other people who are going through what I went through.'*

Annah said that she was now happy because she felt she could help other people to live positively. 'Right now I have 12 patients – four on TB medication and eight on ARVs. I am also looking after 15 orphans. Six are the children of my late relatives and nine are from the families of my patients.'

Delegates expressed their appreciation of Annah's telling her life-story, and many were deeply moved by her courage.

*'It's my lifestyle now to help someone each day of my life while I am still alive.'*



Left: Annah holds up her TB cards during her testimonial,  
Above: Annah and Charity Sisya (VSO-RAISA  
Zambia Programme Manager).



## Challenges to caregivers

Derrick Luwasha, Programme Coordinator,  
Chitipa District AIDS Coordinating  
Committee, Malawi



Derrick said by way of introduction that the district in which he worked was located in northern Malawi, about 720 km from Lilongwe. The focus of the Chitipa District AIDS Coordinating Committee was improved service delivery at community level, through implementation of a holistic integrated approach in the response to HIV & AIDS and associated effects, i.e. stigma and discrimination.

Derrick described the challenges to caregivers (women, girls and community volunteers caring for PLHIV) as including:

- ⌘ High drop-out rates for girls at school due to the burden of caring for the sick and affected;
- ⌘ Travelling long distances to provide services to clients;
- ⌘ An increased workload for both women and girls;
- ⌘ Burn-out of volunteers;
- ⌘ Caregivers not having a stable source of income;
- ⌘ Inadequate capacity building initiatives for caregivers;
- ⌘ Relatives of the chronically ill patient shifting responsibility to caregivers;
- ⌘ Increased numbers of the chronically ill demanding much from the caregivers, resulting in poorer quality of life for the volunteers;
- ⌘ Most programmes implemented not considering caregivers' needs;
- ⌘ Inadequate and erratic supplies of basic materials for service delivery.

The organisation had made a number of interventions to address these challenges. Technical support was provided in the form of training to volunteers, sourced funds for CBOs, and provided motivation to caregivers in the form of micro-credit (revolving funds). CBOs, in turn, now provided practical support and psychosocial support to volunteers, material and financial support, basic medicines, and facilitated referrals where needed.

As a result of these interventions, many caregivers were now engaged in small businesses. A number of developmental partners had responded to some suggested programmes. Finally, the community supported the initiatives that were addressing the problems of vulnerable groups.

Derrick outlined a number of lessons learnt. For example, the resources required by women and girls to improve their living standards were very small. Caregivers needed to be economically empowered to enable them to improve their standard of living. Many caregivers did not have the required skills to effectively manage the client and protect themselves from HIV infection, and this issue needed to be addressed. Caregivers' mobility needed to be improved through the provision of push bicycles and ambulance bicycles. Programmes needed to include incentives for volunteers and caregivers.

Relatives of sick people needed to understand the role they still had to play in caring for their relatives (the chronically ill). Finally, social and cultural factors that hindered male participation as caregivers need to be addressed, Derrick concluded.

*Programmes need to be made more flexible to deliberately include incentives for caregivers.*



*A picture from Derrick's presentation showing a child receiving support from community volunteers in Chipita.*

# Parallel Session 2

## Children as caregivers

⌘  
Areiketsetse le Bana  
Community Project

⌘  
Child participation

⌘  
Reencontro and  
home based care

## Areiketsetse le Bana Community Project

Thato Makhudu, Community Outreach Officer,  
HIVSA, South Africa



Thato Makhudu said that Areiketsetse le Bana Community Project had been set up in Soweto and parts of Mpumalanga in October 2005 following a needs assessment of OVC. The aim of the project was to reduce the impact of HIV & AIDS on OVC. Thato said that the project tried to reduce duplication of services in the community, and to increase effective use of services. A key principle of the project was to encourage child participation at all levels.

The project focused on one area at a time. A child protection committee would then be set up in the area, involving community members and local children. They would be trained on how to access social services, to set up child-led groups and to run information groups. When work in a particular area had finished, the project would be handed over to the child protection committee and the project would move on to another area.

A similar process would be carried out at schools in each area. A school would be identified, then a presentation would be made to the school, a baseline survey of needs carried out, and a workshop conducted with parents and learners about issues such as teenage pregnancy and substance abuse.

Finally, the project set up an NGO and CBO forum. Here training was provided for volunteers and staff. Between January and August 2007 the project assisted 2 097 children to access social grants.

⌘ *Cont'd*

Challenges of the project included volunteer fatigue, volunteers finding employment, other organisations which served the same area seeing the project as a competitor, and school principals sometimes not being interested in addressing the psychosocial needs of children. The recent teachers' strike had also disrupted the activities of the project, Thato admitted.

Solutions which had evolved include providing stipends for volunteers, forming a forum for organisations in Soweto involved in OVC work, getting the Department of Education to encourage the involvement of principals in OVC psychosocial programmes, and having an annual OVC conference.

A key element in the project's success was using networking to reach many people – this ensured that everyone who was interested was involved. The success of the project was reflected in the fact that more people now had access to available services, and they in turn could now teach others

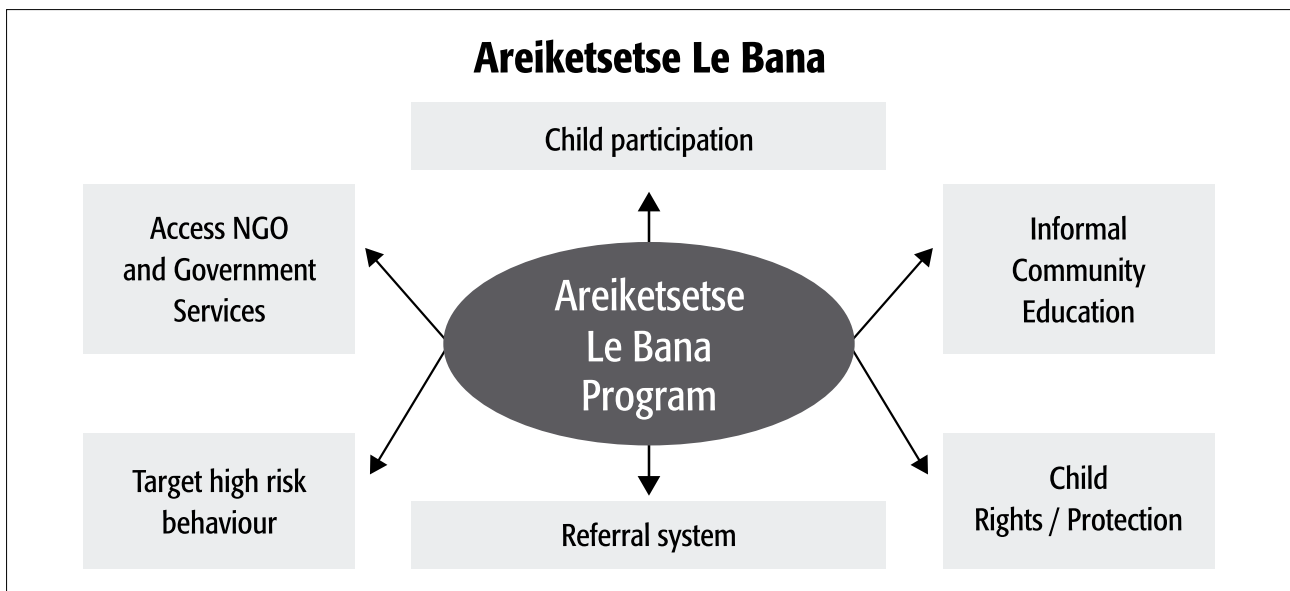
how to access services too. Thato felt that the project could be replicated in other parts of South Africa at minimal cost.

The organisation had also learned some valuable lessons in the first two years of its existence.

These included:

- ⌘ Not starting work without doing a needs assessment;
- ⌘ Sensitising the community to the project's work;
- ⌘ Maximising child participation;
- ⌘ Networking with other organisations.

Following his talk, Thato was asked what the project did when school principals were reluctant to participate. He replied that in such cases, the project took the matter to the provincial Department of Education, which then put pressure on the principal to address the needs of OVC.



Slides from Thato's presentation. Below: Youths at a peer education programme.

## Child participation

Thulani Makhoba, Community Outreach Programme Manager, HIVSA, South Africa



Thulani addressed the important issue of child participation in projects involving children. He started out by clarifying why child participation was essential, and provided three major reasons for it: children have different needs, concerns and aspirations to adults; child participation helps negotiate new kinds of relationships and partnerships with adults that avoid inequality; and child participation helps ensure better decision making on children's issues.

*'A big lesson learned from our project is that children are not the sources of the problem, but the resources needed to solve the problem.'*

The question then arose as to **when** children are mature enough for child participation. Thulani said that there was no one right age for all children. Even young children were capable of forming views on matters affecting them, and the views of the child needed to be given weight in accordance with age and maturity. A child was ready for child participation when he or she was able to formulate his or her own views.

### Barriers to child participation included:

- ⌘ Lack of funds and resources;
- ⌘ Adult decision-making structures excluded children – for example, meetings happened during school-time or in the evenings when children could not attend;
- ⌘ There was a lack of understanding of what participation meant;
- ⌘ Cultural norms such as African ideas of children not speaking out in the presence of adults might oppose child participation;
- ⌘ Fear of developing new ways of working;
- ⌘ Lack of knowledge of how to communicate with children;
- ⌘ Lack of opportunities to work directly with children.

Key steps in developing child participation were as follows:

1. Develop a structure for participation;
2. Decide who will be involved, how the children will be selected, and who the children will represent;
3. Decide how the children will be involved;
4. Allocate clear roles and responsibilities to both children and adults;
5. Strengthen the structures available to children: think of making use of child-led groups, kids clubs, soccer and netball clubs, drama clubs, children's camps.

Thulani suggested that community organisations, schools, youth clubs, conferences and community forums could all usefully try child participation.

The **benefits** accrued to both children and the organisation involved. It helped children to learn new skills, and gain experience. Children acquired self-confidence and enjoyed the process. Children were also given the opportunity to influence decisions affecting their lives, and to develop social networks. Hence they felt valued and empowered, Thulani said.

For organisations, the benefits of child participation included providing services which were much more responsive to their needs. Organisations became more accessible to children, and more efficient in providing needed services rather than just the services that organisations assumed children needed.

*'A programme designed for children without children is against children.'*

In response to questions after his presentation, Thulani said that there were as yet few resources to assist organisations develop child participation. However, he urged those interested to look at the REPSSI, Save the Children (Norway) and UNICEF websites for possible materials. Thulani was also asked how he coped with norms in other organisations which opposed child participation. He replied that his organisation tried as much as possible to educate parents and teachers. Delegates found Thulani's ideas very useful and felt they could greatly enhance work with children.

The comment was made that it would have been very useful to have children present at the conference to provide testimony, perhaps in parallel sessions. (A REPSSI delegate responded that it would not have been appropriate to have children in the sessions themselves – as some of the content might have been traumatising for them.)



## Reencontro and home based care

Luisa Dgedge, Nurse,  
Reencontro, Mozambique



Luisa spoke in Portuguese and her talk was immediately translated into English by a fellow delegate. She said that her organisation, based in Maputo (Mozambique), was called Reencontro (meaning re-gathering or meeting again). Reencontro was founded in 1998, and was active in seven districts in two provinces of Mozambique (Maputo and Gaza).

The main objectives of the organisation were to raise awareness of good HBC practices, to involve local structures in caring for children, and to support child-headed households.

Reencontro supported a total of 7 000 children using community volunteers. Most HBC clients were within the families of the 1 419 OVC which the organisation took care of in Maputo.

The volunteer programme worked as follows:

1. Community volunteers were trained by two accredited trainers in HBC;
2. Volunteers were then allocated work based in one of 11 areas;
3. Volunteers monitored each client's health and living conditions;
4. They were supported by community leaders and substitute mothers in each neighbourhood;
5. Vulnerable children are kept in their parents' homes wherever possible.

Luisa said further that nurses were responsible for HBC. The nurses were either retired or they worked part time for the organisation. The nurses assisted the community volunteers three times a week, and visited each neighbourhood twice a month.

Another component of Reencontro's work involved child carers. The majority of child carers looked after a surviving parent until the parent died. Some children stopped speaking or playing after their parent's death, and needed psychosocial support. Some now took care of younger siblings. Reencontro tried, wherever possible, to start supporting such children before the death of the second parent. Support to child carers took the form of monthly food parcels, stationery for school, school uniforms, school fees (where necessary), health care, psychosocial support, registration with government bodies, renovation of their homes and alternative shelter (where required).

Lessons learned include:

- ✘ Children were completely dependent on the organisation for food since they had no employment;
- ✘ There was more success with vocational training for children than with income generation activities;
- ✘ Community caregivers were able to teach the children about basic hygiene.

In conclusion, Luisa said that more funding was required for vocational training. There was also a need to involve community members in caring for child-headed households.

### Questions & discussion

- In response to questions after her talk, Luisa clarified that both men and women were involved in Reencontro's work. She also said that material support was provided to many of the 7 000 children whom Reencontro assisted, but psychosocial support was just as important. Such support included integrating children into social clubs and referrals to other organisations.
- Luisa was asked about how her organisation involved men in its HBC activities. She replied that the organisation engaged with communities, which always included men. It began at the top, involving male leadership. It also extended to training men and involving men in advocacy work.
- Another question related to children being given material support. Luisa replied that material support was provided until children reached 18 years of age – however, vocational training was also given, so that after that age, young people could support themselves.
- Another delegate spoke of the value of children's corners in Malawi, where vulnerable children were given food to take home, and provided with education about crucial issues and with play activities.

# Parallel session 3

## Good home based care practice

⌘  
The Moretele palliative  
care project

⌘  
Assisting the poor and  
marginalised in Namibia

⌘  
Community home based  
care in Zimbabwe

## The Moretele palliative care project

Mpho Sebanyoni-Mothasedi, Chief Executive  
Officer, Moretele Sunrise Hospice, South Africa



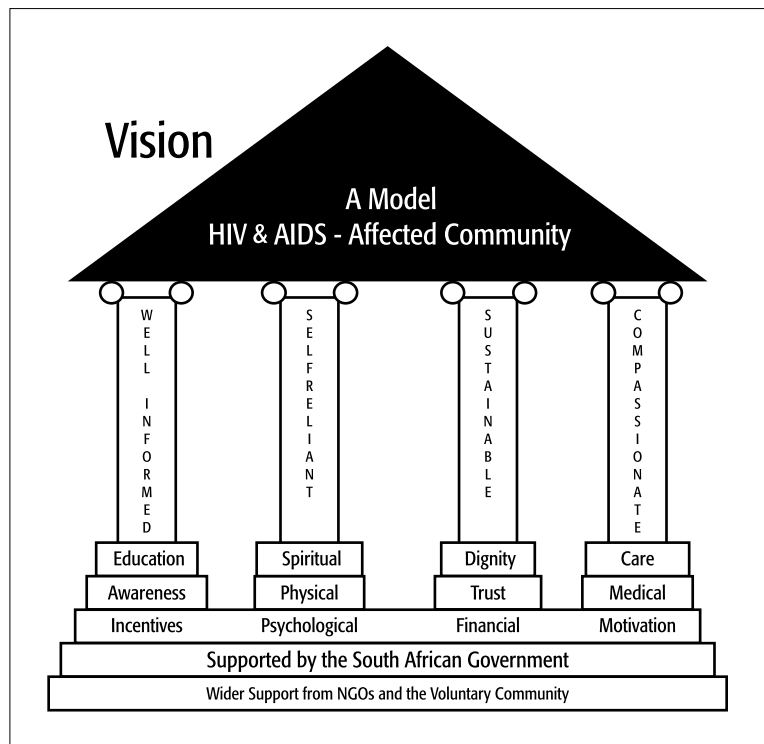
Mpho said that Moretele Sunrise Hospice was established in 1997 in response to the HIV & AIDS pandemic. Its mission was to provide comprehensive home based palliative care to people with life-limiting, advanced and progressive ailments, including HIV & AIDS. The organisation was an integrated home based and community based programme that applied a holistic approach to problems.

The Moretele Sunrise Hospice had arisen in response to escalating numbers of people infected and affected by HIV & AIDS and other conditions. Stigma and discrimination surrounding HIV & AIDS had led to the organisation forming support groups. Limited access to care and support for PLHIV had led to the planning of satellite stations for care. Poor referral systems had led Moretele Sunrise Hospice to form a partnership with health and social services and relevant stakeholders. In this way each burning issue which had arisen had been addressed in its own way.

*'A journey begins with a dream.'*

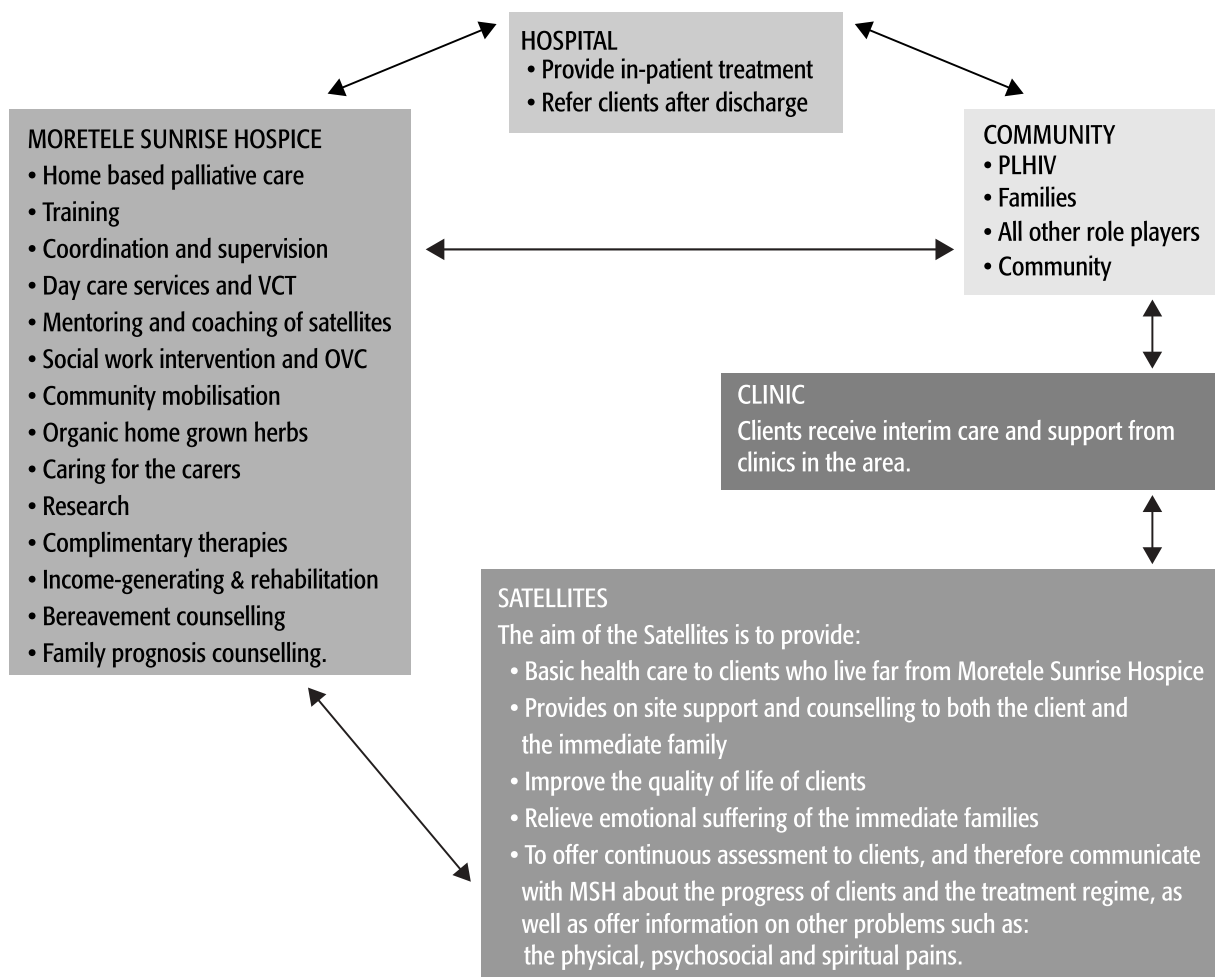
⌘ Cont'd

According to Mpho, an important lesson learnt was that collaboration was the key to success and sustainability. Caregivers formed the backbone of HBC and community care. Community support was essential in sustaining the project. She urged delegates to remember that HBC and community care were fundamental to holistic care. Neither of these were a second class form of care. Rather, HBC and community care had the capacity to keep people alive and living quality lives for longer.



Slides from Mpho's presentation.

## Sunrise Hospice: Integrated community and home based care model



## Assisting the poor and marginalised in Namibia

Tauno Nakasole, Project Officer M&E,  
Yelula/U-khâi, Namibia



Tauno Nakasole began by introducing his organisation, Yelula/U-khâi, which was based in Namibia. Tauno said that the overall objective of Yelula/U-khâi was to assist poor and marginalised people to mitigate the impact of HIV & AIDS on their livelihoods. Vulnerable individuals and communities

affected by HIV & AIDS in five regions of Namibia were mobilised to address the challenges of the HIV & AIDS pandemic, articulate and access their rights, and secure their own health and livelihood.

Beneficiaries of the organisation's services included OVC, PLHIV, CBOs, civil society networks, and other vulnerable groups affected by HIV & AIDS. Support was provided through networking, training, mentoring, the provision of grants and outreach activities.

In relation to OVC, the organisation aimed to enhance the capacity of CBOs and school boards to make provision for keeping OVC in schools, and to involve all stakeholders in building the circles of support for the wellbeing of children. Methods used to assist OVC included training school boards, developing community action plans, and sensitising and mobilising caregivers.

### The impact of Yelula/U-khâi included:

- ✘ Vulnerable children were identified by schools and communities, and referrals were made for support;
- ✘ Parents and caregivers began to take action to provide support to such children;
- ✘ Networking took place with community resources to support OVC.

Tauno said that his organisation now needed to train more resource people to scale up the programme. Members of child-headed households needed to be included in the trainings as positive speakers. He warned that the foster care process was a long and discouraging one, and it was important not to lose sight of the vision of making a difference to OVC.



Picture from Tauno's presentation showing the E.G. Oneshila soccer team that was established as part of an after school programme.



## Community home based care in Zimbabwe

Erick Chikukwa, Director,  
New Dawn of Hope, Zimbabwe



Erick began his presentation by saying that New Dawn of Hope operated from a resource-challenged suburb of Harare, Zimbabwe, called Mufakose, and ran a comprehensive community HBC programme. The programme had seven principles which underlay its success: provision of care; respite; integration of TB services; training of caregivers; provision of supplies and equipment; use of secondary caregivers; and sustainability.

**Provision of care** meant that New Dawn of Hope aimed to empower the primary caregiver to be able to competently care for a sick loved one at home. Because of the continued shortage of ARVs in the area of operation, there were a significant number of bed-ridden clients. Many needed intensive nursing, and the organisation had responded by establishing intensive care teams (ICT), with each ICT comprising four caregivers.

**Respite** referred to the fact that the primary caregiver (usually a family member) was seen as being the fifth member of the team. He or she was also seen as being at risk of burn-out. Where a client had been ill for a long time the organisation made arrangements for the PLHIV to be taken of by the local hospice, to give some respite to the primary caregiver.

Regarding **integration of TB**, Erick said that all new clients were actively encouraged to be screened for TB. Fortunately testing facilities for sputum were readily available. Family members exposed to a positive client were also screened. This had helped identify TB early, especially in infants, and had improved the chances of successful treatment. Support given to TB clients included food distribution, treatment buddies for adherence, and providing transport funds to attend clinics for check-ups.

**Secondary caregivers** were recruited from volunteers as far as possible. Erick described secondary caregivers as the 'engine' that drove the CHBC programme. A systematic approach to managing the most important human resources – the secondary caregivers – resulted in significant advantages to the organisation. Forty of the 90 secondary caregivers had bicycles, and 60 were on the food relief programme as a way of cushioning them against the harsh economic environment of Zimbabwe.



Picture from Erick's presentation showing New Dawn of Hope caregivers, staff and Erick.

It was important to maintain **adequate supplies and equipment**. He said that good planning of supplies ensured minimum disruption of work. One effective way of cutting costs was for the organisation to buy the items for caregiver kits and assemble the kits themselves.

*'secondary caregivers are the "engine" that drives the CHBC programme.'*

**Sustainability** was critical to any CHBC programme and had wider implications beyond the programme. At New Dawn of Hope, sustainability was ensured at the organisational, community and household levels. Providing training generated income, as did a poultry project – both enhanced organisational sustainability. At community and household level, secondary caregivers were taught how to improvise where equipment and supplies are lacking. The organisation also ran training courses for community members, to ensure sustainability of HBC beyond the life of the organisation. Clients, primary caregivers and other community members also received training in low input gardening. 'If our organisation were to cease operations this community will continue to care for its loved ones at home', Erick added.

In conclusion, Erick said: 'These best practices don't happen overnight and they don't come cheap either. The ability to stay the course is crucial; so is the need to be innovative and to think outside the box.'

### **Questions & discussion**

- In the time allowed for questions after the presentations, a comment was made that we needed to assist caregivers to generate an income for themselves. One idea was to provide small grants, which would enable caregivers to develop their own home businesses.
- Another delegate said that caregivers were at greater risk of contracting TB – particularly if they were themselves HIV positive. We needed to educate caregivers about the risks of TB and how to protect themselves. Workplace policies for caregivers should recognise the risks of both TB and HIV infection.
- A question arose as to how many clients each caregiver could care for. One delegate suggested five clients, but the number might differ from country to country, depending on local circumstances.
- Another comment made was that both the caregiver and the relatives of the client had responsibilities for the client. However, training was not provided to relatives, and so their responsibilities were often unclear.

# Parallel session 4

## Greater involvement of men in caregiving



Volunteering in the Copperbelt of Zambia



Redefining masculinity in Zimbabwe



Thandizani: drawing men into home based care

## Volunteering in the Copperbelt of Zambia

Pimmy Muzyamba, Programmes Coordinator,  
Volunteer Management, CHEP-National  
Volunteering Programme, Zambia



Pimmy started his presentation with a short history of the Copperbelt Health Education Project (CHEP)-National Volunteering Programme. The programme was established in 1988 in the Copper Belt, Zambia. It involved training, research, engaging volunteers in training, and providing mentorship to about 70 CBOs and NGOs.

Through consultation and capacity building training, CHEP had realised the need to integrate and formally recognise volunteering as a legitimate area for research. Therefore, as a way of integrating volunteer programmes, CHEP underwent a vigorous organisation capacity assessment (OCA) which was facilitated by VSO Zambia. The purpose of the assessment was to establish baseline measures of existing structures and the capabilities of the organisation as it implemented volunteering programmes, and helped design improved systems and procedures for CHEP.

The study revealed that in the Copperbelt region there were three main types of volunteering: self-help, participation, and advocacy and campaigning. Pimmy said that most of the partner organisations had in place ad hoc volunteer systems without proper management. Male involvement was still critical. Few executives were involved in volunteering.

*'For the spirit of voluntarism to be sustained, it is important that there is adequate dialogue with the community at the needs assessment, planning and implementation stages to determine incentives.'*

The study identified some key challenges for volunteers:

- ✘ Volunteers sometimes abandoned work at home to attend to patients;
- ✘ Volunteers walked long distances to follow-up patients;
- ✘ There was often inadequate equipment, such as bicycles, gloves, rain coats or umbrellas;
- ✘ Patients reported hunger due to inadequate nutrition;
- ✘ Sometimes volunteers themselves did not eat adequately;
- ✘ There was a shortage of laboratory staff for speedy diagnosis for TB;
- ✘ There had been more cases of TB among HIV-positive volunteers;
- ✘ All volunteers had an increased workload;
- ✘ It was difficult to keep volunteers motivated because of lack of funds in the context of high levels of poverty in Zambia;
- ✘ Some NGOs had let down volunteers repeatedly because of failure to secure funding.

Various lessons had been learned from the study, including the importance of capacity building. Support by local leadership and community leaders was essential to make programmes work. It was important to strengthen schools and community volunteer committees, e.g. for OVC. There was great benefit in bringing together various players with different HIV & AIDS/TB perspectives to synergise their competencies and expertise.

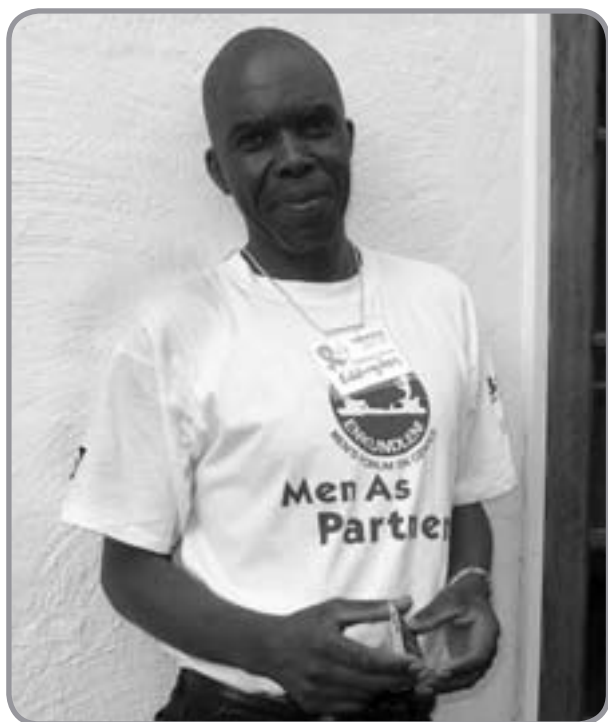
Pimmy made a number of recommendations regarding volunteers. Organisations should not just dump volunteers when they were no longer needed. Community volunteers needed to be given technical support in the form of capacity building and leadership training. They should be informed about the risks of TB infection and be given access to treatment and care. Finally, former TB treatment supporters could be utilised to a greater extent as volunteers.

The study had a number of important outcomes:

- ✘ Activities in CHEP's existing programmes had been formalised and integrated;
- ✘ A volunteer operational manual and guidelines had been developed. This fitted into the Zambian Strategic Plan on National Volunteering;
- ✘ Baseline measures of existing structures and capabilities had been determined;
- ✘ CHEP provided leadership through existing national and private bodies such as the National AIDS Council and the District AIDS Task Force;
- ✘ A CHEP National Volunteering Strategic Plan for 2007-2009 had been developed;
- ✘ CHEP had allocated a percentage of its budget to volunteering activities and had consulted with potential donors to continue supporting volunteering.

## Redefining masculinity in Zimbabwe

Eddington Mhonda, Programmes Coordinator,  
Padare / Enkundleni Men's Forum on Gender,  
Zimbabwe



Eddington began by describing the origins of the Padare / Enkundleni Men's Forum on Gender. Padare is a non-sexist men's CBO established in 1995 by five local Zimbabwean nationals for the sole purpose of mobilising men to work for a gender-just society. The forum was started to promote and facilitate ideas and actions to enable men's active participation in eliminating discrimination against women.

*'The main aim is to understand that masculinity arises from values handed down from generation to generation, and there are toxic aspects to this, which devalue women.'*

Eddington said that in 2004 a national HIV & AIDS conference was held in Zimbabwe which led to a challenge to Padare to get involved in care work. Two chapters of the forum responded. The expected outcome, he said, was that men would be able to complement the efforts of women in sharing the care work and burden of care in their communities. Men in Padare were motivated by a desire to be seen as men who care, not just in offering practical support, but also in offering emotional and spiritual support.

The work of Padare had taken a number of forms:

- ✘ **Redefining manhood** – Padare had embraced the challenge of getting men to question their own identities, including their behaviours, values and concepts;
- ✘ Men in the forum had **volunteered to do care work and support** through offering more emotional, practical and spiritual support to clients;
- ✘ One rural and four urban chapters of the forum had been established with **HBC programmes being run by men** in their communities on a voluntary basis;
- ✘ **Partnerships and strategies** had been established at community level through the involvement of influential individuals, agencies and ASOs to sensitise and mobilise for more male involvement in programming.

*'Men of quality are not afraid of equality!'*

A number of important lessons had been learned:

- ✘ Breaking down gender roles was possible;
- ✘ Men were keen to learn and to acquire better skills in relation to HBC;
- ✘ It was important to train people to develop gardens (and hence address food shortages);
- ✘ Will writing should be included in caregiving, so that women did not lose out on property rights when male partners died;
- ✘ Good male role-models could be created to encourage young men out of school to get involved in caregiving;
- ✘ The scale-up of toolkits on involving men in HBC for HIV & AIDS was important;
- ✘ Non-monetary incentives were very useful.

There had been some unique and interesting spin-offs from the forum's work. Visitors from Angola had been very impressed by the work and had requested documentation, so that they could replicate the programme in their own country. Men in the forum were increasingly willing to examine the impact of their own sexual behaviour on their partners. The forum had prompted more men to come forward for VCT, and to engage in dialogue about HIV & AIDS. Reports had been received of more men accompanying their female partners to clinics for prenatal and postnatal care.

*'Gender inequality is part and parcel of the process of causing and deepening HIV & AIDS in a society, and must therefore constitute part and parcel of measures to eradicate it.'*



## Thandizani: drawing men into home based care

Maggie Mkwandawire, Counselling Coordinator,  
Thandizani Community-Based Prevention  
and Care, Zambia



Maggie said that Thandizani Community-Based Prevention and Care was a lead NGO which had been formed in the Lundazi district (north-eastern Zambia) in 1999 in response to the HIV & AIDS epidemic. The word *thandizani* meant 'help one another' in the local language. Initially women had carried the major burden of HBC, but the burden became too much for women alone. A decision was taken to bring more men into HBC.

*As a result of the interventions, Maggie said, men involved in HBC had increased from 12 to 167, and women from 21 to 51. This represented a fourteen-fold increase in the number of men involved in HBC.*

The steps which had been taken to secure increased male involvement in HBC in Thandizani:

1. Community leaders, religious leaders and other influential people in district received information on the importance of involving men in HBC. Workshops looked at issues of culture and traditional practices, including practices that hindered men from being actively involved in care and support services;
2. Chiefs, headmen and some community members attending a two-day seminar on the importance of male involvement;
3. Once chiefs had been involved, community sensitisation meetings were held with men, women and youth. Meetings took the form of seminars and group discussions;
4. Traditional primary caregivers were also involved;
5. Since women sometimes declined to have men involved in HBC, it was crucial to talk to women in women-only forums about male involvement;
6. Mixed-sex forums were also held.

Male involvement in care and support services helped to reduce the burden of care on female caregivers at all levels and they felt better supported. There had also been other ancillary effects, such as more men escorting women to antenatal clinics and assisting sick family members in hospital wards and in homes. It was striking now, Maggie said, to see more men and more men assisting patients in hospitals. Men also became more involved in accompanying young children to clinics.

Another benefit of the interventions was that more women felt empowered to facilitate meetings. Women were also appointed to positions of responsibility in two chiefdoms. More girls (from affected families) were being given the chance to attend school, and boys had started to play an equal role in caring for the sick.

Some important lessons had been learned from the project. One crucial lesson was that involving community members and leaders, including traditional leaders, is a key to success. Another was that changing long-standing attitudes about gender roles is a slow process, and needs to be addressed on many levels.

In conclusion, Maggie said, the Thandizani method of male involvement in HBC had emerged as one of the best practices in Zambia. The concept had attracted both national and international interest regarding replication.

Delegates expressed warm appreciation for Maggie's presentation. The consensus was that the programme needed to be fully documented, so that other communities and other countries could learn from the programme and replicate its results.



Picture from Maggie's presentation showing a male volunteer involved in HBC.

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*Male involvement in care and support services helped to reduce the burden of care on female caregivers at all levels and they felt better supported.*

### **Questions & discussion**

- In the discussion session, the comment was made that women are just as constrained by cultural norms as men are. We need to challenge gender stereotypes for both sexes.
- Eddington was asked whether female clients felt uncomfortable about having male caregivers, especially regarding intimate activities such as being washed and personal hygiene. He said that it was usual for a female family member to help with more intimate tasks, to avoid embarrassment to patients. However, when women are seriously ill, it appeared that they were less likely to be embarrassed and self-conscious. In fact, some women had commented on how much they appreciated the quality of male caregiving.
- Eddington was also asked about sustainability of male involvement. He said that the limited use of incentives such as bicycles and T-shirts seemed to help. However, men who took part in the project were told that incentives were not guaranteed, and depended on availability of funding.
- Another question related to potential conflict between the role of being a caregiver and the role of breadwinner. Eddington clarified that the men involved were expected to strike a balance themselves.

# Evening entertainment



*Delegates were invited by Wedzerai Chiyoka to watch a documentary around VSO-RAISA's work in Zimbabwe*

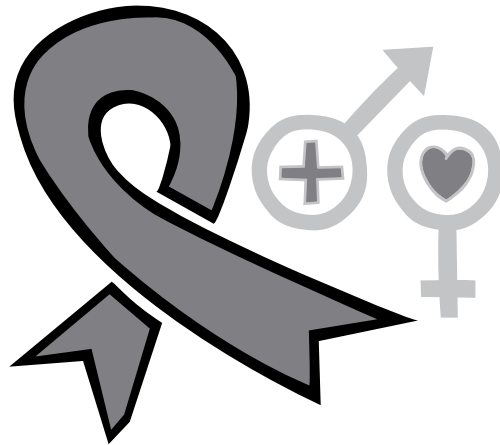


*Delegates participated in a drumming session with the Drum Cafe*



# Day Two

## Friday 2 November



*A few of the Zambian group preparing their country action plan: Frida Kabaso, Rebecca Lusumpha and Charity Sisya.*



# Plenary

## Recap

Bongai Mundeta, Regional Director, VSO-RAISA

Bongai Mundeta provided an overview of the first day of the conference. She highlighted a number of important issues:

- ⌘ Child caregivers were discussed, but were not present. This had been discussed, but it was decided that it was not appropriate for this conference. Child participation would be looked into in future;
- ⌘ The importance of workplace policies in preventing caregivers from being infected was highlighted;
- ⌘ The issue of the virtually unlimited demands on caregivers was striking: there was very little or no off-duty time due to the needs of the community;
- ⌘ Male involvement was possible and desirable;
- ⌘ Volunteer management had been highlighted on day one as a mechanism to retain volunteers, safeguard their rights and provide ongoing psychosocial support.



*The issue of the virtually unlimited demands on caregivers was striking: there was very little or no off-duty time due to the needs of the community.*

# Plenary

## The elderly as caregivers

Dr Douglas Lackey, Regional Advocacy Manager, HelpAge International, Kenya



In a plenary session Douglas outlined his work in Kenya with older people, and described eloquently the challenges of involving older people in programming.

He highlighted two ways in which HIV & AIDS devastates older people:

- ⌘ As the **infected**, through sexual activity (UNAIDS estimates that 7% of older people in sub-Saharan Africa have HIV & AIDS);
- ⌘ As the **affected**, carrying the burden of care for OVC and PLHIV (40 - 50% of OVC are cared for by older people).

Older people frequently suffer the loss of adult children, and then have to take responsibility for OVC when they are already frail and weak, and have limited incomes. Douglas said that 60% of caregiving in Namibia and Zimbabwe was provided by grandparents, and especially grandmothers. However, we should not see older caregivers as only women: 20% of people over 50 years of age who were looking after OVC were actually male.

*'All home based care must address the needs of older people too.'*

ANALYSIS OF CASH TRANSFER CAREGIVERS DATA: KENYA				
Caregivers in age cohorts of below 17 years to above 50 years				
Age Cohorts	Proportion of Caregivers	Disaggregation of Caregivers by Sex		Average OVC Per Caregiver
		% male	% female	
≤ 17 years	0.6% (119)	42.0% (50)	58.0% (69)	2.9
18 – 24	4.9% (1,028)	23.3% (240)	76.7 % (788)	3.1
25 – 49	55.2% (11,540)	15.5% (1,790)	84.5% (9,750)	3.2
50 + years	39.3% (8,220)	18.7% (1,539)	81.3% (6,681)	3.1
<b>Total</b>	<b>100% (20,907)</b>	<b>17.3% (3,619)</b>	<b>82.7% (17,288)</b>	<b>3.1</b>

Slide from Douglas's presentation.

Four key advocacy messages that Douglas wanted us to take home:

- 1. Value the role and work of older carers**  
Public recognition of older carers is crucial. It is vital to generate resources, ensure the rights of older carers, and provide support;
- 2. Develop policies that support and assist older carers**  
All HBC policies and programmes must address the specific needs of older carers, different from the needs of younger people;
- 3. Provide more resources for older carers**  
Older carers need economic support, e.g. social grants, to help with the costs of care, and compensation for time taken away from income-generating activities. Older women's legal rights to land, inheritance and protection by the law need to be realised. Older carers need legal advice and literacy programmes, to help them obtain entitlements for themselves and those in their care;
- 4. Provide more HIV prevention and caregiving knowledge to older carers (especially women)**  
Home based carers need more information on HIV prevention, transmission, care and treatment that is age-appropriate and accessible. They lacked training particularly on issues related to ART.

Douglas described in detail an HBC model for older carers of PLHIV in Tanzania developed in 2006/07 in 57 communities in four districts. Partners included four municipalities and five local NGOs, together with the Tanzania Ministry of Health. Older carers were selected from communities to receive training in HBC and counselling. Selection criteria included basic literacy, community acceptability, good interpersonal skills, discretion and physical strength. A target had been set of training two home based carers per village, aiming for gender balance. Training ran for 21 days, and took place in the communities. At the end of the training, HBC kits were provided to graduates.

The graduates of the training were encouraged to share their knowledge with other older carers. Support groups were set up for PLHIV and for home based carers. Mutual support was encouraged. It was important too for refresher training to be provided and support mechanisms to be ongoing.

In addition, Douglas said, self-advocacy groups were established for older carers, comprising on average five or six people. The self-advocacy groups aimed to advocate for more inclusive policies for older people and improved support. The project also sought to link older carers to support services, such as NGOs, FBOs, health centres and social service staff.

Another important link was with traditional healers, especially as older people were more likely to make use of them. Older carers were trained to establish good relationships with traditional healers, so as to allow exchange of information on care issues, and enhancing referrals.

Finally, Douglas drew attention to an advocacy initiative that he regarded as important: the final draft of the SADC Regional Strategy and Action Plan for Universal Access to Prevention (2008-2010). He said that pressure from various interest groups had led to the inclusion of older carers in the plan, so that they should also be given protective equipment when doing HBC, adequate training on prevention and access to information on care of PLHIV.

In contrast, he said, the UNAIDS Practical Guidelines for Intensifying HIV Prevention specified 13 most at-risk populations, but failed to include home based carers or older people. However, UNAIDS was to rectify the omission.

Concern was expressed that older people involved in HBC had been left out of the SADC policy documents. Other delegates agreed that this was a major problem, and decided to strategise as to how to rectify this oversight.

*We all need to support Africa's new mothers (i.e. older women)!*

# Plenary

## Greater involvement of men as caregivers

Sekai Chikowero, Africare Representative,  
Africare Zimbabwe



Sekai spoke to the conference about her organisation's experience of involving men in community HBC. In 2002, Africare launched a project called Male Empowerment (MEP) to involve men in the Mutasa district of Zimbabwe in HBC. The two objectives of the project were to increase male care and support to households affected by HIV & AIDS, and to reduce stigma and discrimination by increasing communication about HIV & AIDS.

By October 2007 the project covered three districts and had assisted 3 500 clients. She said that to date 400 voluntary counsellors and caregivers had been trained in HIV prevention, basic nursing, infection control and bereavement counselling. The volunteer numbers were equally split between men and women. Twenty supervisors were trained to take leadership of the volunteers. HBC kits were provided and replenished on a monthly basis.

Food security and food provision was another focus of the project, Sekai said. From March 2004 monthly food rations were provided to some 2 000 HBC clients. Training was also provided in developing household nutrition gardens using drip kit irrigation. More recently, an internal savings and lending scheme had been introduced, to enhance volunteer motivation.

The project had moved carefully to obtain the active support of the communities to involve men. Steps taken included:

- ✘ Holding consultative meetings with the relevant ministries and District AIDS Action Committees;
- ✘ Involving community leaders as carers;
- ✘ Involving traditional leaders – such as chiefs and ward councillors;
- ✘ Asking communities to select caregivers for training;
- ✘ Involving stakeholders in planning and monitoring.

According to Sekai, until 2004 a stipend was provided to all volunteers. HBC kits, irrigation drip kits and project T-shirts had been handed out. Food relief was also an important element of the project.

*One of the slogans of the project was:  
'Are you man enough to care?'*

Volunteers visited homes at least once every week and were able to carry out rapid syndrome-centred diagnoses. Each volunteer provided care for a maximum of five clients. Volunteers were also tasked with providing prevention messages, accompanied by youth.

Some major challenges for the project:

- ✘ Sustaining volunteer motivation;
- ✘ Having limited access to VCT, treatment for opportunistic infections, ART and prevention of mother-to-child transmission (PMTCT);
- ✘ The challenges of getting men to do the actual physical nursing care;
- ✘ The difficult socio-economic climate in Zimbabwe;
- ✘ Ever-rising costs of HBC kits;
- ✘ Reduced time for client visits as volunteers needed more time to look after their own households.

A number of valuable lessons had been learned. Motivation *and* incentives were equally important in building a spirit of volunteerism. The involvement of both men and women had improved the quality of HBC provided, Sekai believed. Complementary programmes such as nutrition support and assistance with nutrition gardens helped improve the economic status of affected households.

In reply to questions after her presentation, Sekai clarified that male and female caregivers were paired, so that they could share HBC tasks in a culturally appropriate way. Regarding the lendings scheme, she clarified that partly owing to Zimbabwe's hyper-inflation, micro-loans were extended and repaid within approximately a week. They were used for buying seed, paying school fees, and buying medicine.

# Plenary

## Home based care organisations' database software

Frans de Jeu, Volunteer,  
Soweto Home-Based Care, South Africa



Frans started his presentation by saying that an alternative title for it might have been 'How a project can get out of hand'! He said that he was a volunteer from the Netherlands who had no previous experience of developing databases – in fact, he worked in marketing. He had been in South Africa since May 2006, and was now a volunteer with Soweto Home-Based Care, an NGO based in central Jabavu, Soweto. This organisation was a cooperative of 25 volunteers, offering HBC to PLHIV. Previously all administration and record-keeping for the organisation had been in the form

of hard copy. This meant that it was easy for records to get damaged or lost, and reporting was very labour intensive.

*An alternative title for my presentation could be: 'How a project can get out of hand'!*

He had taken the NGO's need for a simple, user-friendly database to a Dutch company, VX, where he had previously been employed. The company had helped him to develop a database solution in the form of a stand-alone product that could be used on a simple computer system. The database system could capture data about employees, clients and home visits, and could generate reports for donors and management.

Once it had been developed, Frans provided simple training to the staff and volunteers at Soweto Home-Based Care. The organisation had been very happy with the product and found it answered their needs for more efficient and accessible records. He had also assisted another 14 NGOs throughout South Africa to implement the software for their own use.

Later VX had undertaken to upgrade the software, and to add further features, taking into account the increasing numbers of OVC which Soweto Home-Based Care was helping. The new features would enable the system to accommodate multiple users, and to merge information from different sites. The new system would be ready in December 2007.

Frans gave a simple demonstration at the conference of how the database worked. A number of delegates from different countries expressed interest in, and enthusiasm for learning more about the database, and implementing it in their organisations. He undertook to meet them during the remainder of the conference, and investigate the possibility of travelling to other African countries to assist in setting up the database.



Picture from Frans's presentation showing the Soweto Home-Based Care office where he is a volunteer.

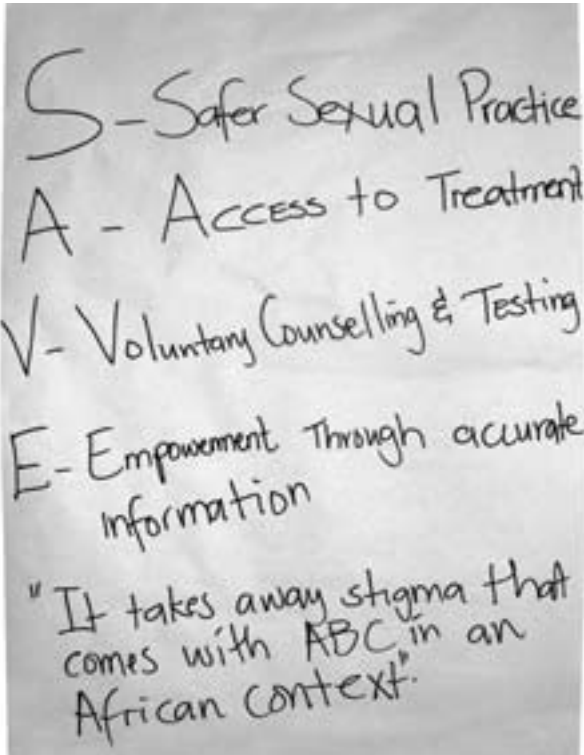


# Plenary

## Question and answer session

Professor Kelly chaired a half hour of questions and discussion

- The question was raised as to whether the same messages about prevention worked with older women, given that their circumstances differed. The comment was made that older women often responded that safer sex was not relevant to them, given that they claimed to have no sexual partners. In response, the 'SAVE' model was suggested as a useful option, where S = safer sex, A = accessibility to treatment, V = voluntary counselling and testing, E = Empowerment through accurate information.



- Another delegate said that for years, women had carried the burden of HBC without their contribution being recognised. Were incentives introduced only because of male involvement in HBC, and would it increase the disparities between men and women? In reply, a speaker from Zimbabwe clarified that her despite her HBC project stopping incentives in recent years, men still participated in the project. This suggested that incentives alone were not the primary motivator for involvement. In addition, incentives in her project were offered to both men and women.
- One comment made was that new prevention messages needed to be developed for older people, and new VCT services to meet the special needs of older people needed to be considered.
- A question asked was about the fact that NGOs excluded men with antisocial behaviour in terms of choosing home based carers – should not similar stringent criteria apply to the choice of women to become carers? The answer provided by a Zimbabwean delegate was that the criteria were applied equally to men and women, so no discrimination took place.
- Delegates asked a number of questions about micro-loans, including whether loans were given to groups, and whether a short repayment period was always appropriate. In reply, the comment was made that group loans were possible and viable – the group would come with a proposal as to how and when the loan would be repaid. Hyper-inflationary environments had specific needs in terms of short repayment periods, different to other countries.
- A further comment was that carers were right to expect incentives – it was not ethical to expect a breadwinner to work without an incentive. A delegate cautioned that incentives should only be provided if they could be sustained. Perhaps activities (such as skills building) could be a better form of incentive.
- The issue was raised as to whether the motivation to involve men in HBC was motivated by a desire for gender equality, or by the need to relieve the burden of HBC for women. Sekai Chikowero responded that her project had been motivated by the need to relieve the burden on women. However, male self-reflection was, she felt, essential to the project.



Parallel Session Sign Up  
 1. Policy & legislative framework (Mozambique)

## Parallel session 1 Policy and legislative frameworks

### MONASO's HBC experience

Matilde Cunhaque, Director, MONASO Sofala  
 and Prince Mulondo Yosia, Volunteer, MONASO,  
 Mozambique



Matilde and Prince presented in a parallel session of the conference on HBC policy and legislative frameworks. MONASO is an acronym for the Mozambican Network of AIDS Services Organisations, an umbrella body which coordinates NGOs involved in the prevention, community care and reduction of the impact of HIV & AIDS.

In November 2005 MONASO began a campaign for improvement in HBC by focusing on the protection of

human rights and reducing stigma and discrimination. It worked in collaboration with RENSIDA, the national network of PLHIV and other NGOs and CBOs. Another role that MONASO played was to be a go-between between ASOs, and the Mozambican Ministry of Health and the NAC.

#### Activities which MONASO had engaged in:

- ⌘ Raising awareness through debates at national level, particularly regarding access to care and treatment;
- ⌘ Advocating for government to pass a law concerning the rights of PLHIV – remembering that most caregivers were PLHIV;
- ⌘ Training female caregivers about gender and advocacy, to enable them to participate in public campaigns;
- ⌘ Improving the quality of care of caregivers by collaborating with the Ministry of Health in funding trainings, training caregivers and offering accreditation of caregivers.

The challenges which MONASO had faced included the fact that most caregivers did not understand existing HBC policies and legislative frameworks. Some of the policies were not well-defined or complete, e.g. policies for infected caregivers. In addition, caregivers sometimes felt too intimidated to take part in meetings with government and donors.

MONASO found that once NGOs, PLHIV and the private sector came together to express a common point of view, the government was willing to deal with the issue. It was important to take into consideration traditional norms in developing HBC policies. Through developing close links with the NAC, MONASO was able to ensure that caregivers were given stipends, regular training and HBC kits. Facilitating government and caregivers talking to each other brought about faster change.

They said that a number of key lessons had been learned. Civil society needed to develop more capacity to advocate and lobby the authorities regarding HBC issues, such as confidentiality and ethics. Working with the NAC could help improve working conditions for caregivers. Cross-cutting issues such as gender and human rights needed to be addressed at community level. Finally, greater involvement of PLHIV was crucial to the development of HBC policies.

# Parallel Session Sign Up

## Policy & Legislative Framework (Malawi)

### Parallel session 2

#### Policy and legislative frameworks

### Challenges faced by community children caregivers in the face of HIV & AIDS

Jennifer Kaberi, OVC Technical Advisor,  
Chiradzulu District Social Welfare Office, Malawi



Jennifer began her presentation by saying that in Malawi one in five households cared for OVC, of which half were headed by women. Some 83 000 children were living with HIV & AIDS, of whom 5% were on ART.

According to Jennifer, the main challenges in taking care of OVC were limited financial resources, a huge increase in the reported incidence of child abuse, problems with sustainability of community based organisations, and a heavy workload for community volunteers. Other challenges included limited capacity (few people had the requisite skills and knowledge), few children living with HIV & AIDS accessing treatment and increasing numbers of OVC.

She drew attention to the fact that organisations working with OVC sometimes duplicated services and failed to coordinate their efforts.

The main strategy that had been developed to address these issues was to use a community based approach, working from the bottom up. In this way 90% of the rural population in target areas had been reached. As far as possible, decision making involved people at grassroots level.

#### Action taken included:

- ✘ Designing a community-based and child-focused programme which included early childhood development and community-integrated management of childhood illnesses;
- ✘ Providing a programme for older OVC, which included skills training through village polytechnics, community youth centres and communal gardens;
- ✘ Registering older OVC nationally;
- ✘ Providing educational support for older OVC;
- ✘ Investing in training of child caregivers and communities;
- ✘ Ensuring community child protection strategies, including committees and workers specially designated to look after vulnerable children;
- ✘ Using the child parliament to give children a voice;
- ✘ Organising child corners, where children could enjoy safe play.

A major achievement of the programme for OVC was the use of cash transfers to provide a safety net for such children. Various policies on child development and survival had been developed. Support had been extended to communities at grassroots level to care for OVC. Finally, ART was now free and accessible through government hospitals.

The success of the programme owed a great deal to the mobilisation of resources at both local and international level. Sound community structures had been developed to care for and support children. Food security had been ensured in vulnerable households through a subsidised farm inputs programme. Finally, advocacy for children's rights had taken place through a range of forums and campaigns.

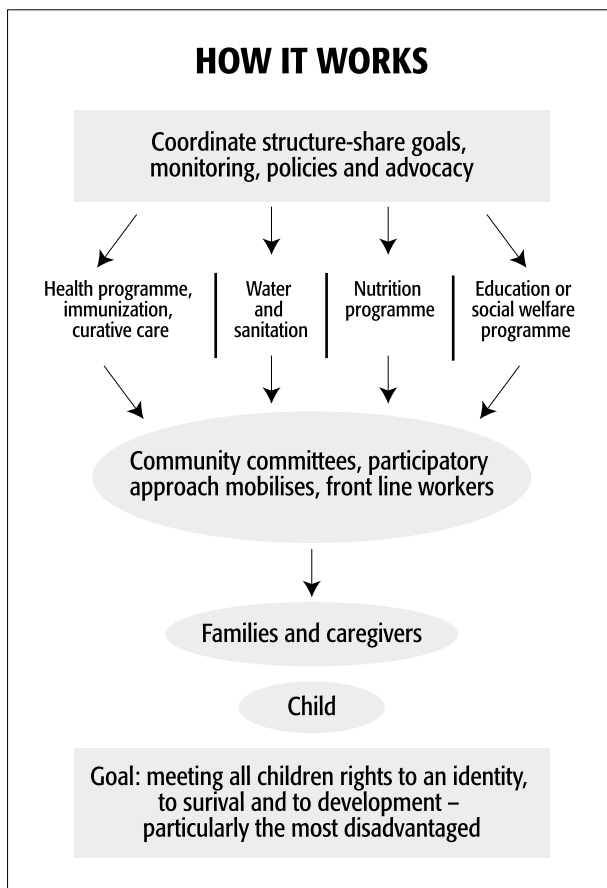


Her recommendations for programmes of a similar nature in other countries were:

1. Build the capacity of the community on actual needs;
2. Disseminate policies to grassroots level, and begin implementation there;
3. Provide incentives to community volunteers wherever possible;
4. Direct financial resources to communities. Try as much as possible to encourage communities to generate their own income;
5. Implement sustainable projects which have community backing;
6. Design advocacy campaigns for child protection;
7. Provide support to community caregivers;
8. Ensure continuous monitoring and evaluation of the programme.

Regarding volunteers in the Malawi programme, Jennifer suggested that they were not always given opportunities to develop and grow. She urged delegates to create more volunteer-friendly environments. A delegate from South Africa agreed enthusiastically with Jennifer's comment, saying that she herself had been a volunteer, but with the right encouragement, she had been able to develop her skills substantially, and take up full-time employment.

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Slide from Jennifer's presentation.

# Plenary

## BONEPWA+ and living with HIV

Onangoni Moalosi, Vice-chairperson,  
BONEPWA+, Botswana



Onangoni spoke about some of the challenges he had experienced in living with HIV. He said that although Botswana had a very high prevalence rate, and in spite of excellent HIV & AIDS programmes, stigma in the country continued to be high. This made the work of the Botswana Network of People Living with HIV and AIDS (BONEPWA+) in exposing ordinary people to the stories and experiences of PLHIV even more important.

BONEPWA+ had expanded rapidly in recent years, and now had 42 support groups throughout Botswana. Its main office was in Gaborone. One of its main projects was to teach schoolchildren about HIV & AIDS. BONEPWA+ believed that the testimonies of PLHIV were very powerful in making schoolchildren take the issue of HIV & AIDS seriously. The work in schools was being undertaken in collaboration between BONEPWA+, the Ministry of Education and the Ministry of Health.

A second project where BONEPWA+ had made considerable progress related to food security for PLHIV. Here PLHIV were each given five chickens to raise, as a means of augmenting diet and improving income levels.

Onangoni said that most of the members of BONEPWA+ who were prepared to speak out publicly about their status were women. He was one of only three men in the organisation who were willing to disclose their HIV status in public. Nevertheless, he said, BONEPWA+ provided a great opportunity to reach out to other people.



# Plenary

## Women's rights, HIV & AIDS and universal access

Mike Podmore, HIV & AIDS Advocacy and Policy Advisor, VSO UK



Mike presented the preliminary findings of a report by VSO and ActionAid on women's rights in terms of HIV & AIDS, including access to HIV services. He said that the research was a response to the lack of action by the international community regarding women's vulnerability to HIV & AIDS.

### The report aimed to:

- ⌘ Explore the drivers of the HIV & AIDS pandemic for women and girls;
- ⌘ Describe the impact on HIV & AIDS on women and girls;
- ⌘ Describe the barriers women faced in accessing HIV services;
- ⌘ Explore the challenges that care providers faced.

Gender inequalities and violations of women's rights drove the pandemic, and took many forms, from denial of sexual and reproductive rights, and violence against women, to the lack of female-friendly health services, poverty and minimal economic rights. A gender-sensitive human rights-based approach saw the state as a duty-bearer, i.e. as responsible for seeing that women enjoyed the rights which the law provided for. It ensured a framework for holding governments to account.

Proposed solutions included women's participation, investment in female-friendly health systems, legal protection and holding donors and multilateral companies accountable for the aid they provided.

In terms of access to care and support for PLHIV and

their families, Mike saw five major domains as needing attention. **Support programmes** needed to focus on the family, rather than just the individual, and needed to include primary care providers. **Medical care** needed to shift away from preferential treatment for males to funding initiatives that challenged gender norms. **Psychosocial services** could provide increased funding for support groups for women and girls, do capacity building for organisations that assisted female PLHIV, encourage groups to increase female membership and boost female leadership, and coordinate support groups within the formal health-care system.

**Socio-economic benefits** for women and girls needed to include social protection measures, financial support, micro-credit, income generation opportunities, training options and economic empowerment of women. **Legal measures** proposed included providing information materials on property and inheritance rights, making legal services accessible to women, providing information in accessible forms, and ensuring women and girls could access legal aid.

Mike said that the South African expression, 'You strike the woman, you strike the rock' came to mind when one considered how women care providers carried on providing care to PLHIV and OVC even in the most dire of circumstances. He said that he preferred the term 'care provider' to 'caregiver', as the term care provider emphasised the social value of the service provided.

Primary care providers needed targeted financial support such as care grants, as well as access to other support options such as cash transfers, loans and micro-credit schemes. Income generation projects, food schemes and not having to pay fees for health care were other important ways of supporting care providers. In addition, more vulnerable groups (such as girls and older women) needed specific support in the form of pensions or cash transfers.

Mike distinguished secondary care providers from primary care providers, insofar as they were commonly called 'volunteers'. Volunteers also needed to have their rights enshrined in employment law and in workplace policy. There was also a need, articulated several times at the conference, to involve more men as secondary care providers. Finally, secondary care providers needed to be included in funding proposals.

Lastly, Mike spoke about psychosocial impact issues. Firstly, there was a need to build community-based care and HBC alliances for support, sharing of learning and rights advocacy. Then care providers needed to be given counselling and psychosocial support. All staff should enjoy regular training by accredited trainers. It was also important to provide essential equipment such as gloves and home based kits.

The report was to be finalised and launched in London in late November 2007. He hoped that it would be the basis of advocacy on women's rights and HIV & AIDS.

# Plenary

## Supporting and managing voluntary care providers from the rights-based approach

Hye-Young Lim, Researcher, Centre for Human Rights, University of Pretoria, South Africa



Hye-Young said in her introduction that it was important to understand the rights-based approach as it could empower those working in HIV & AIDS to obtain rights for caregivers. She clarified the difference between a need and a right: a need is an aspiration, whereas a right is an entitlement. Non-satisfaction of a need could not be enforced, whereas non-fulfilment of a right was a violation of law, and so the courts could provide redress.

*A need is an aspiration, whereas a right is an entitlement.*

Six core principles of the rights-based approach:

- ✘ **Universality and inalienability** – every human being is entitled to their rights just because they are human. No one can lose their rights;
- ✘ **Indivisibility, inter-dependence and inter-relatedness** – all human rights are equally important as they are all connected. For example, political and socio-economic rights are equally important;

- ✘ **Equality and non-discrimination** – discrimination on a number of grounds is prohibited in many country's constitutions, usually including sex, race, colour, ethnicity, age, language, religion, politics, disability, birth or other status;
- ✘ **Participation and inclusion** – the right to take part in public affairs is enshrined in the Universal Declaration of Human Rights and also the International Covenant on Civil and Political Rights;
- ✘ **Accountability and rule of law** – states have an obligation to respect, promote, protect and fulfil the rights of citizens;
- ✘ **Empowerment and entitlement** – the capabilities of poor people to participate in and influence institutions that affect them need to be expanded.

Hye-Young said that the rights-based approach is the starting point for programmes. As far as possible, we should try to help rights-holders (such as PLHIV) to claim their rights, and put pressure on duty-bearers (such as government departments) to fulfil their obligations.

She went on to list the major international human rights treaties, and showed that most countries in Southern Africa had signed almost all of the agreements. This provides a good starting point as it enables civil society to apply pressure to governments to make the agreements in the international treaties real.

Voluntary home based carers are rights holders too. She said that they were entitled to non-discrimination, equitable and satisfactory working conditions, safe working conditions, rest and leisure, reasonable limitations of working hours, physical and mental health, participation in decision-making processes with their organisation, and participation in periodic evaluations of their organisation.

According to Hye-Young, VSO could assist by sensitising partner organisations to human rights issues, helping partners to develop policies for volunteer home based carers and enhancing coordination between organisations. VSO could also advocate with governments and donor agencies to sensitise them socio-economic realities in the countries where projects were running, and so ensure these realities were taken into account when planning.

Finally, Hye-Young urged us not to let governments off the hook. Governments needed to move beyond rhetoric and agreement with international treaties, to make practical and real international rights laws.

*Hye-Young urged us not to let governments off the hook.*

# Plenary

## Efficiency versus effectiveness: Country response information system (CRIS)

Darlington Changara and Zacharia Grand,  
Representatives of the Midlands AIDS Caring  
Organisation (MACO), Zimbabwe

Darlington said by way of introduction to his talk that the country response information system (CRIS) was a data management tool, developed for reporting on global indicators, which could be used at different levels in a country affected by HIV & AIDS. At country level it could be managed by the NAC. CRIS was in line with the three ones principle (one monitoring body, one coordination structure, one strategic framework).

In terms of CRIS, core indicators were standardised by UNAIDS and a country could then select its own indicators from the list. He illustrated the use of CRIS with the example of Zimbabwe. There the NAC had set up a structure whereby each organisation involved in AIDS work at district level fed information about its activities to provincial level, from where the information flowed to the M&E department of the NAC every month.

For HBC, the process was as follows:

- ✘ Data was collected from the community using national forms;
- ✘ For each intervention, a core output indicator was filled in using the forms;
- ✘ Organisational databases were used to collect the indicators monthly;
- ✘ The report forms were then used to feed into CRIS;
- ✘ The information was collated nationally by the NAC.

Problems that had been identified included that not all organisations in Zimbabwe had begun implementing CRIS, and so statistics were incomplete. In addition, staff members in the National AIDS Council were not fully conversant with the software used in CRIS, and so when problems occurred, they could not always assist. Finally, the reporting system did not allow for innovations at local level to be reported.

In the question time after the presentation, other Zimbabwean delegates commented that CRIS worked well in some rural settings. What sometimes created difficulty was that each donor had their own unique reporting format. Volunteers needed proper training to use the CRIS system.

# Plenary

## Development of action plans

Stephen Porter, M&E and Learning,  
VSO-RAISA Country Coordinators and  
Programme Managers, South Africa



*We need to slow down and enjoy life. It is not only the scenery you miss [when you travel too fast], but also a sense of where you are going and why.*

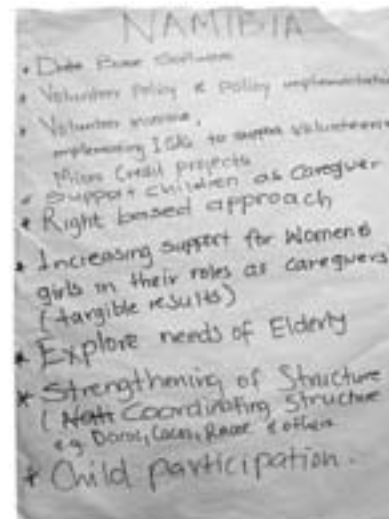
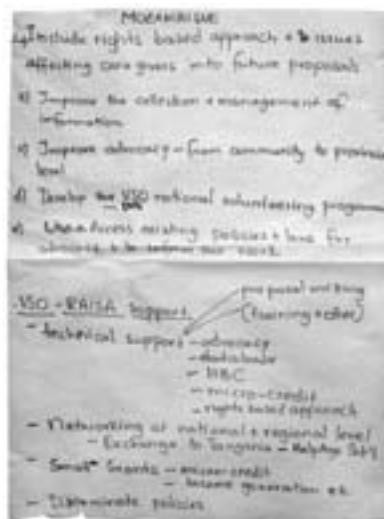
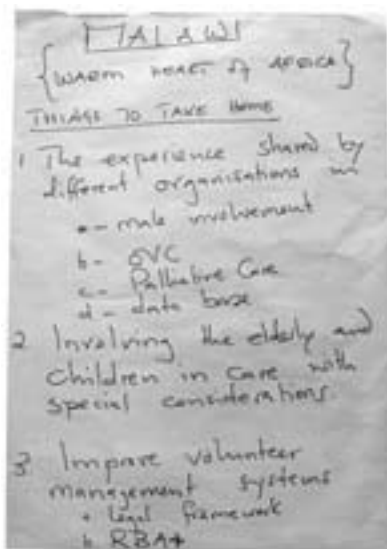
Stephen led the process of each country's delegates developing their own action plans. He invited participants to meet in small groups based on country membership, to discuss the way forward following the conference. Groups were constituted for Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe. In addition, one group comprised participants who did not fall into any VSO-RAISA country programmes, including delegates from funders, the UK and other African countries. This group designated itself 'Utopia'.

He asked three questions in the evaluation process:

1. What three main things will you take away from the conference, and which you are willing to commit to doing?
2. How can these aspects improve your work?
3. How can VSO-RAISA support this?

The groups met for 20 minutes to come up with answers to these questions and then reported back to the plenary session. **The reports are shown over the next few pages.**





## Country action plans

### **MALAWI** committed to:

- ⌘ Enhancing male involvement in HBC
- ⌘ Addressing the issues of OVC and palliative care
- ⌘ Helping set up a database for project work
- ⌘ Involving children and the elderly in care with special considerations
- ⌘ Improving volunteer management systems, including using a legal framework.

The Malawi delegates said that these aspects could improve the work by improving effectiveness and efficiency in:

1. Service provision
2. Organisational development
3. Motivation
4. Ensuring better sustainability
5. Motivating volunteers and staff better
6. Scaling up of operations.

They suggested that VSO-RAISA could help this process by facilitating:

- ⌘ Networking and horizontal learning
- ⌘ Advocacy on key issues
- ⌘ Improved training
- ⌘ Better resource mobilisation.

### **MOZAMBIQUE** committed to:

- ⌘ Including in future proposals a rights-based approach
- ⌘ Including in future proposals issues affecting caregivers
- ⌘ Improving the collection and management of information
- ⌘ Enhancing advocacy, at community and provincial levels
- ⌘ Develop the VSO national volunteering programme
- ⌘ Making use of existing laws and policies for advocacy.

The Mozambican delegates felt that VSO-RAISA could help this process in the following ways:

- ⌘ Providing technical support, in the form of proposal writing, training, help with databases, HBC and a rights-based approach
- ⌘ Assisting with advocacy
- ⌘ Networking at national and regional levels
- ⌘ Providing an exchange programme with Tanzania with regard to HelpAge International
- ⌘ Helping with small grants for micro-credit and income generation
- ⌘ Dissemination of policies.

### **NAMIBIA** committed to:

- ⌘ Improving the database software and implementing correction of data
- ⌘ Using a rights-based approach
- ⌘ Providing volunteer incentives
- ⌘ Implementing IGAs to support volunteers and micro-credit projects
- ⌘ Support children as caregivers
- ⌘ Enhancing child participation
- ⌘ Improving support for women and girls in their roles as caregivers
- ⌘ Exploring the needs of the elderly
- ⌘ Strengthening coordinating structures, such as partnering government bodies with NGOs in the coordination of HIV & AIDS activities.

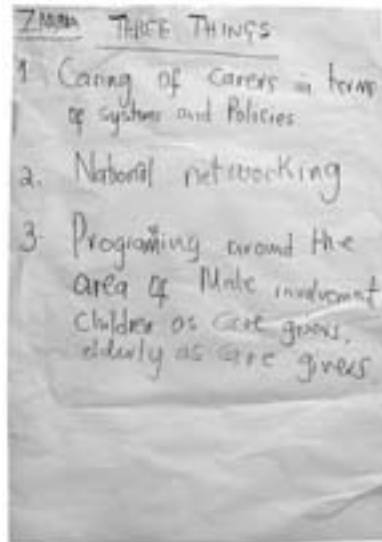
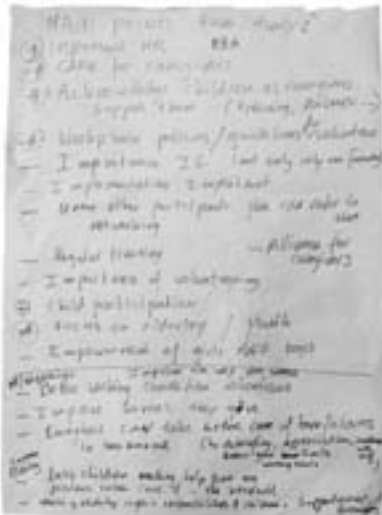
The group of delegates from Namibia felt that these aspects could improve the work in the following ways:

1. Helping in understanding policy and policy implementation
2. Helping in provision of micro-credit to help support caregivers
3. Support improvements in the database system
4. Strengthening HBC policy.

They suggested that VSO-RAISA could assist this process in the following ways:

- ⌘ Helping implement volunteer and HBC policy
- ⌘ Technical support to implement policies
- ⌘ Financial support to carry out activities.





**SOUTH AFRICA committed to:**

- ⌘ Better implementation of a human-rights approach, to ensure improved working conditions for volunteers
- ⌘ Caring for caregivers
- ⌘ Acknowledging and supporting children who were acting as caregivers – providing emotional as well as material support
- ⌘ Providing workplace policies and guidelines for volunteers
- ⌘ Enhanced child participation in the organisation
- ⌘ Empowering both girls and boys
- ⌘ Empowering the elderly – through strengthening families and support groups.

The South African delegates said that these aspects could improve the work in the following ways:

1. Improved delivery of services
2. Better working conditions for volunteers
3. Improving the services provided by volunteers
4. Reducing burn-out
5. Teaching the elderly about rights and responsibilities of children
6. Empowering children as caregivers
7. More use of support groups.

The South African delegates requested that VSO-RAISA assist this process in the following ways:

- ⌘ Helping with capacity building
- ⌘ Training in child participation and volunteer management

- ⌘ Recruiting and mentoring volunteers more effectively
- ⌘ Providing guidelines for children as caregivers
- ⌘ Advice on using a rights-based approach
- ⌘ Helping with advocacy for children’s rights, including foreign children in school
- ⌘ Enhancing exchange programmes involving volunteers and caregivers.

**ZAMBIA committed to:**

- ⌘ Caring for the carers
- ⌘ Sharing information
- ⌘ Programming for more male involvement
- ⌘ Greater involvement of the elderly and of children as carers.

The Zambian group thought that these aspects could improve the work in the following ways:

1. More networking
2. Uniting civil society in confronting respective governments
3. Sharing information on best practices.

The Zambian delegates asked VSO-RAISA to assist this process in the following ways:

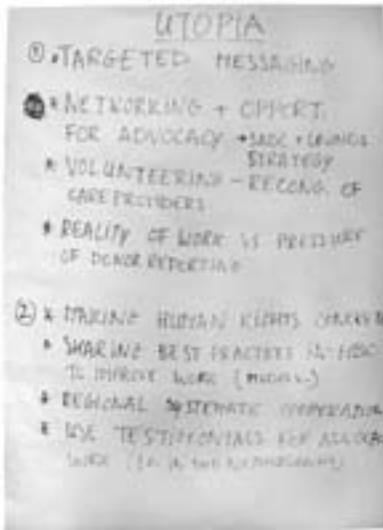
- ⌘ Technical support
- ⌘ Training
- ⌘ Exchange visits at a national level.

**ZIMBABWE committed to:**

- ⌘ Data collection and information management
- ⌘ Volunteer management using incentives, motivation and non-monetary rewards, coordination and more standardisation
- ⌘ Updating programmes to include the elderly and improve their care
- ⌘ Improve the quality of caring for the carers.

The Zimbabwean delegates said that VSO-RAISA could assist this process in the following ways:

- ⌘ Continuing to link up with HelpAge Zimbabwe, e.g. joint materials / programme development
- ⌘ Volunteer management system training
- ⌘ Exploring database development with Frans de Jeu.



## UTOPIA

The Utopia group could obviously not commit to formal plans, given that its members came from a range of settings in different countries.

However, the group's members highlighted the following as what they would take away from the conference:

- ⌘ The need for targeted messaging to include young and old people
- ⌘ The importance of collaboration, using all available opportunities
- ⌘ The need to utilise UNAIDS policies
- ⌘ The importance of recognising and using providers and caregivers
- ⌘ The need to acknowledge providers and caregivers in creative ways
- ⌘ Pressures of donor reporting, including easing the reporting process
- ⌘ Importance of making human rights concrete
- ⌘ Need to apply best practices more widely
- ⌘ Need to learn from RAISA in terms of systematic work.



## Country groups preparing their action plans

*Top and left: Zimbabwe, Right: South Africa, Bottom: Namibia.*





**Country representatives  
presenting their action plans**





## Closing remarks

Liz Holmes, Regional Programme Manager, VSO  
and Bongai Mundeta, Regional Director, VSO-RAISA



Liz congratulated the delegates on the plans they had made in the previous session. She felt it had been very useful at the conference to revisit what we were all doing, to talk to other community organisations, and to plan how to turn new and innovative ideas into practice.

Liz said that she felt challenged by the personal stories she had heard on many levels, especially at community level. She was struck by the debate around different terms, for example, caregiver versus care provider. Could we still speak of 'grassroots', and what did the term 'volunteer' now mean?

She said she recognised the absence of policy to protect caregivers. Another challenge that she observed reflected in the conference was the need to engage more effectively with regional organisations such as SADC.

Liz wished everyone a safe journey home, and encouraged them to keep up the high energy levels she had seen displayed at the conference.

Bongai handed over individual gifts to the Country Coordinators as a gesture of thanks for all their hard work. She said that the gifts were small, as a demonstration of her commitment to being fully budget-conscious!

After the closing remarks, Zambian delegates led the conference in **singing and dancing**, so ending the proceedings on a note of celebration and hope.



## Conference evaluation

Stephen Porter, M&E and Learning, VSO-RAISA

Stephen handed out evaluation forms to all the delegates, asking them to provide feedback, as it would assist in improving the quality of future VSO-RAISA conferences.

As for volunteer carers I hereby paraphrase Winston Churchill and say: "Never in the history of public health has so much been owed by so many to so few"

"Our leaders need to be with us at these kind of platforms, to be informed and observe"

"Excellent conference, very informative, relevant, productive, well organised and facilitated"

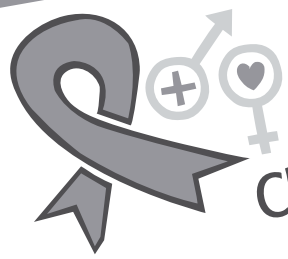
"This has been a really great conference. Thanx X X X"

## Summary & conclusion

The conference allowed a diverse range of delegates who were involved in the HIV & AIDS pandemic in different ways to share their experiences and different forms of knowledge. What emerged from the conference was a sense of determination that even with limited resources, it is possible to make a difference to improving home based care.

Caring in the context of HIV & AIDS takes a variety of forms, and includes home based care, using volunteers, involving both men and women, drawing in both the very young and the elderly, and the involvement of PLHIV themselves. We need to be vigilant in not only providing care for people who are infected and affected by HIV & AIDS, but also in caring for the carers, which includes ourselves.





# VSO-RAISA

Regional Conference  
South Africa | 1-2 Nov 07

## Challenges of Care

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**Onangoni Moalosi**  
BONEPWA+

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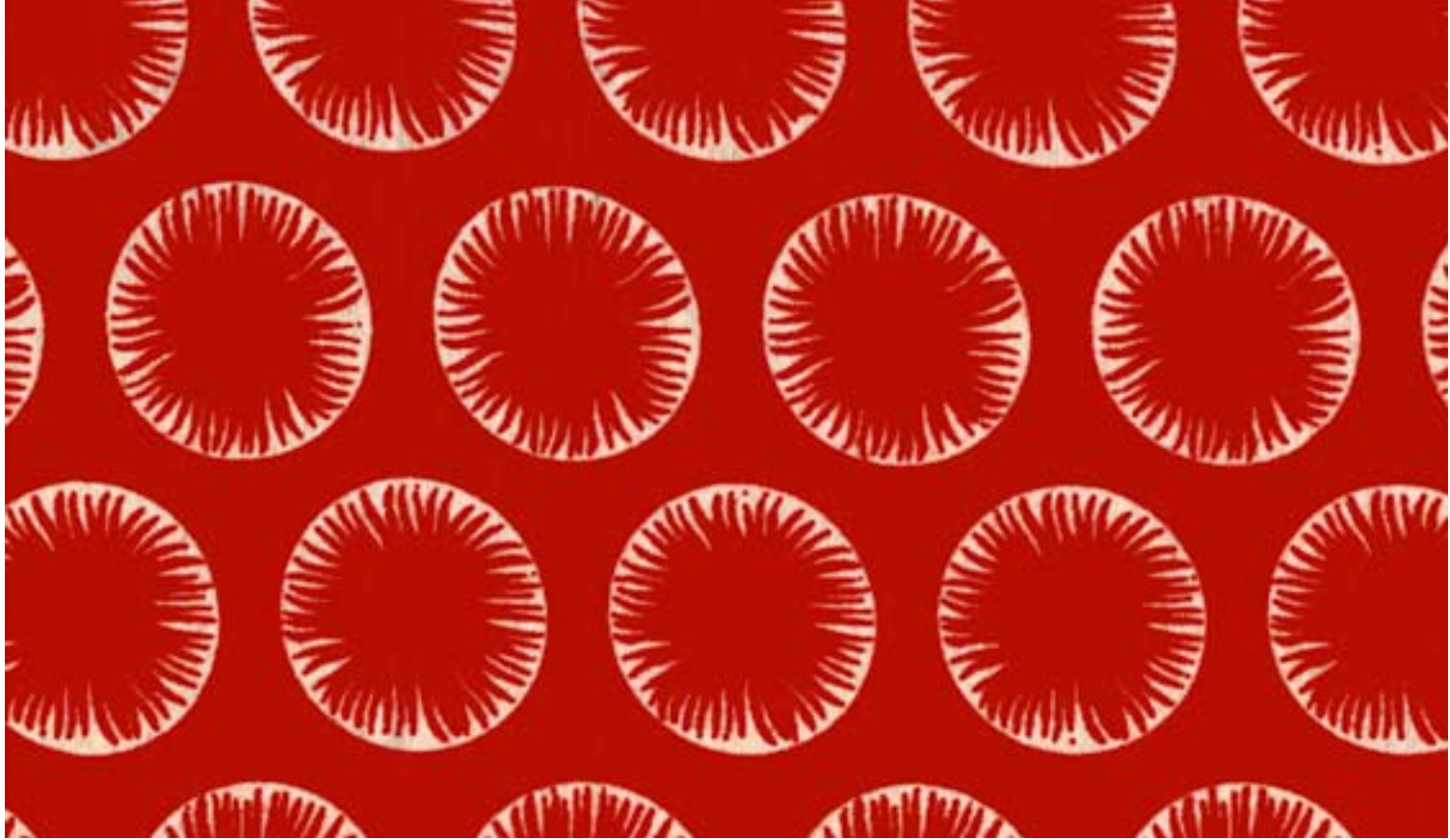
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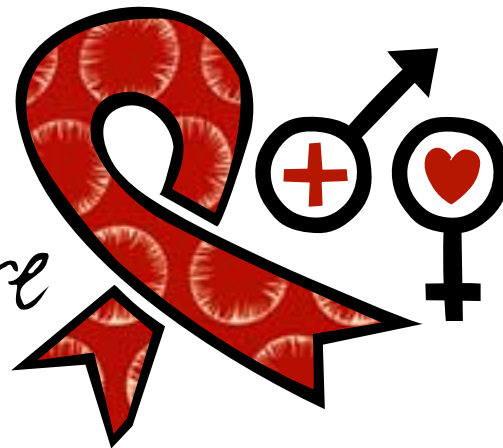
[www.vso.org.uk/raisa](http://www.vso.org.uk/raisa)



*'Female caregivers who are carrying the burden of HIV & AIDS care are largely unrecognised, unsupported and not compensated. They are sacrificing their rights to equality, education and livelihoods, limiting their opportunities to secure their economic and social rights. This reality must not continue.'*

Junaid Seedat, ActionAid, South Africa

## Challenges of Care



## VSO-RAISA Regional Conference 2007 Report Back