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tel: +27 (0)11 486 0245 fax: +27 (0)11 486 0275
23 Marico Road Emmarentia
P O Box 85535 Emmarentia 2029
email: conference@vosesa.org.za
website: http://www.vosesa.org.za/sadcconference

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Reducing the Burden of HIV and AIDS Care on Women and Girls in the SADC Region: Insights from the VSO-RAISA programme

Discussion paper prepared by
Volunteer Service Overseas (VSO)
Regional AIDS Initiative of Southern Africa (RAISA)
charity.nshimbi@vsoint.org
Volunteer and Service Enquiry Southern Africa (VOSESA)
research@vosesa.org.za

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Contents

Acronyms

C&HBC	community and home-based care
CSO	civil society organisation
GEMSA	Gender and Media Southern Africa
NGO	non-governmental organisation
PF	parliamentary forum
PHC	primary health care
PLWHA	people living with HIV and AIDS
RAISA	Regional AIDS Initiative of Southern Africa
TB	Tuberculosis
VSO	Volunteer Service Overseas
WHO	World Health Organization

Abstract

With 1.8 million out of 2.6 million HIV infections worldwide (UNAIDS 2010), sub-Saharan Africa remains the epicentre of the global AIDS epidemic. In many SADC countries, the high morbidity and mortality from HIV and AIDS place significant demands on already under-resourced health services. The effectiveness of formal health systems is compromised by resource constraints, the brain drain, and high absenteeism and death rates among health personnel due to HIV and AIDS.

Community and home-based care (C&HBC) programmes are popular in Southern Africa and renowned for their ability to provide a continuum of care for the chronically ill in their homes in a relatively cost effective, sustainable and comprehensive manner that complements institutional care. The C&HBC model enhances the capacity of families/communities to offer affordable quality care for the sick. It is driven by community volunteers, most of whom are women and girls, in dire need of help. Up to 80 per cent of volunteer care providers in C&HBC programmes are women (VSO-RAISA & WHO 2009). Their working conditions are unregulated, legal frameworks to protect their rights are non-existent/weak, and organisations that use volunteers neglect their responsibilities/obligations towards them. The volunteers are unrecognised, overwhelmed by work, psychologically burdened by others' problems and inadequately supported.

Drawing on the decade-long experience of the Voluntary Services Overseas Regional AIDS Initiative for Southern Africa (VSO-RAISA) and its partners in Southern Africa, this paper argues that scaling up HIV and AIDS services in C&HBC programmes requires fundamental changes on many levels. Recognising the rights of care providers, and providing a supportive environment for them to provide quality care, is a fundamental entry point to addressing this challenge. The responsibility for making these fundamental policy changes rests with those who hold power and bear the duty to respect, protect, promote and fulfil the rights of care providers – national governments, donors, civil society and other key players involved in the fight against HIV and AIDS. It is now time to recognise the contributions of community volunteers in the fight against HIV and AIDS, and to support and empower them to understand their rights and to demand them.

By 2012, VSO-RAISA and partners hope to successfully influence the adoption of national care work policies in three of the seven programme countries - Malawi, Zambia and Zimbabwe.

1 Introduction

The bulk of care in C&HBC programmes is provided by community volunteers. A 2009 study conducted by VSO-RAISA and the World Health Organization (WHO) shows that up to 80 per cent of volunteer care providers in C&HBC programmes are women and girls in need of dire help (VSO-RAISA and WHO, 2009). Their working conditions are unregulated, legal frameworks to protect their rights are non-existent/weak, and organisations that use volunteers neglect their responsibilities/obligations towards them. The volunteers are unrecognised, overwhelmed by work, psychologically burdened by others' problems and inadequately supported.

The paper draws on the decade-long experiences of VSO-RAISA[1] and its partners in Southern Africa to address the HIV and AIDS epidemic in the region. First the paper provides background on HIV and AIDS in the region and argues that greater emphasis should be placed on 'care' as a response to the epidemic. Subsequently, the role of community volunteers, and particularly women, in providing care to those affected is discussed. The paper then argues that there is an urgent need to recognise the rights of and provide greater protection for care providers, and to create a supportive policy environment so that they can provide the quality care that is so needed in communities in the region.

The efforts of the VSO-RAISA to promote greater recognition of community volunteers through research, advocacy, policy development and partnerships are also then discussed. In conclusion, the paper outlines lessons learnt through the work of the VSO-RAISA and its partners that can contribute towards supporting and empowering community volunteers in SADC.

2 Background on the care agenda and HIV and AIDS in the SADC region

The *UNAIDS 2010 Global Report* states that while global HIV and AIDS prevalence rates are falling, sub-Saharan Africa, with 1.8m of the 2.6m new global infections, still registered the majority of the new infections in 2009, although this rate is lower than that of 2001.[2] Furthermore, just over 50 per cent of people living with HIV and AIDS (PLWHA) are women and girls. Only 35 per cent of people who currently require HIV treatment are accessing such treatment. However, the knowledge of HIV prevention has increased among people aged between 15 and 24 years.[3]

The long term and progressive nature of HIV and AIDS means the health care needs of those infected change over time from basic clinical treatment of opportunistic infections to day-to-day palliative care and support. HIV-positive people may remain healthy for years before succumbing to illness and death. In many SADC countries, the high morbidity and mortality from HIV and AIDS have placed significant demands on already under-resourced health care services. Formal health care systems in these countries are still recovering from the health sector reforms and structural adjustment programmes of the mid-1990s. A significant proportion of hospital beds in most SADC countries are occupied by HIV-positive people. The effectiveness of formal health delivery systems has also been

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[1] The VSO-RAISA is a comprehensive programme that addresses the HIV and AIDS epidemic in Southern Africa. At its core, RAISA strengthens the capacity of organisations and communities to deal more effectively with the pandemic and to realise the rights of people living with and affected by HIV and AIDS. This is achieved primarily through the provision of highly skilled and experienced international volunteers who work with partner organisations on a daily basis over an extended period of time.

[2] UNAIDS (2010) Global Report: UNAIDS Report on the global AIDS epidemic, available [online] at URL: http://www.unaids.org/globalreport/Global_report.htm[accessed: 20 February 2011]

[3] Ibid.

compromised by the brain drain that has seen many trained health professionals leaving their countries of birth in search of greener pastures, and high absenteeism and increased death rates among hospital staff.[4]

Despite the heavy demands on these weak formal health care services, it is important to note that the majority of those affected remain in the community and are cared for by family members at home; these people do not have the benefits of formally organised health care provision. This is due to the fact that many people choose not to access formal health care services or are unable to, given the lack of services as well as the stigma attached to PLWHA. For example, most people living with HIV will seek symptomatic relief from pharmacies or treatment from out-patient clinics. However, as the chronic nature of the illness becomes apparent, many will seek treatment from traditional healers. Those who know or suspect that they have HIV might also be reluctant to obtain treatment in the public health sector for a variety of reasons including stigmatisation, fear of disrespectful treatment from health professionals, or merely from their awareness that there is no cure. In addition, many people living in poor countries have inadequate access to existing services in general.

Given the absence of a cure for HIV, HIV and AIDS policies that were prioritised during the first decade of the epidemic's history (1980s to 1990s)[5] emphasised prevention. However, the reality is that prevention alone is insufficient, as large numbers of people have already developed full-blown AIDS, and need to be supported with care and support programmes. Unfortunately, the care agenda took long to materialise; it only came into being in the middle of the 1990s. By the time the care agenda registered as a priority issue, the formal health care sectors of the most hard-hit countries were ravaged by structural adjustment and health sector reforms, and were therefore unable to cope with the increased demands for care of those affected.

In the current context, effective medical treatment for PLWHA is increasingly becoming available. Nevertheless, formal health care systems in SADC member states are still unable to meet the demands placed on them. The provision of care through community-based volunteers thus remains a critical feature of the response to the HIV and AIDS epidemic throughout the region and requires greater recognition and support.

There is some concern that efforts to make antiretroviral treatment available to the many millions who could benefit from its use will overshadow and diminish interest in the further development and expansion of the care agenda. This could have profound implications for many millions of people who are sick and dying of AIDS and their care providers, for whom such life-enhancing therapies remain out of reach. And even when people access this treatment, they need to have access to nutritious food for the medication to take proper effect. Sadly, food insecurity is a major issue among vulnerable groups in the SADC region.[6]

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[4] Adapted from Ogden J, Simel E, Careen G (2004) "Expanding the Care Continuum for HIV and AIDS: Bringing Carers into Focus."Horizons Report, Population Council and International Center for Research on Women.

[5] During this period, there was a lot of emphasis among programmers and implementers on raising awareness about HIV and AIDS, and fighting stigma and discrimination about the epidemic. However, despite the huge investments in awareness and the high awareness levels in Southern Africa, the number of new HIV infections is very still high (UNAIDS 2010). For this reason, current programmes are prioritising HIV prevention. This, however, does not mean treatment, care and support are less important.

[6] VSO-RAISA, WHO Africa (2009) ''Scaling up HIV Prevention, Treatment, Care and Support in Community and Home-based Care Programmes and Reducing the Burden of HIV and AIDS Care on Carers in SADC".

3 Volunteering and community and home-based care

C&HBC is an integral part of the formal health care system. This is not a new concept in the region as there are many organisations involved in such work. C&HBC has received wider attention in Southern Africa for its ability to provide a continuum of care for the chronically ill and PLWHA in their home environment. It provides services in a relatively cost effective, sustainable and comprehensive manner, and it complements institutional care. It has been hailed for reducing congestion in hospitals, thereby reducing health/hospital expenditures in the face of the rising number of chronically ill persons (PLWHA, and patients with cancer, TB and incurable illnesses). Apart from providing care and support to clients/patients, B&HBC also seeks to enhance or build the capacity of clients' families to offer affordable, quality care for their relatives.

VSO-RAISA's experience is that C&HBC programmes provide the bulk of care to people living with HIV in most parts of Africa. There are various C&HBC models, e.g. church-linked, hospital-linked, non-governmental organisation (NGO) linked and vertical community models[7]. However, the common thread that runs through all of these programmes is that care is given by voluntary care providers.

Because volunteering is culturally specific, a universal definition would be too generic to capture both its socio-economic and cultural dimensions. The practice of volunteering is not new in African societies. In Botswana, for example, *letsema* (work party), *letsholo* (donation of time and other resources for the benefit of other community members) and *mafias* (donation of livestock to underprivileged members) were commonly practised. The spirit of volunteering continues in the contemporary context and, given the tremendous need for C&HBC, community volunteering has proven to be invaluable in supporting PLWHA. In Zimbabwe, for instance, volunteering is deeply rooted in the culture, and traditional support systems are based on the principles of solidarity and reciprocity. Volunteering is a way of demonstrating solidarity.

Considering the current socio-economic situation in Southern Africa, it is not feasible to apply a conventional understanding of volunteering, which holds that a volunteer gives his/her labour freely, without any expectation of a financial reward or compensation. The beneficiaries of a volunteer's work are outside his/her family group. The labour is freely given, rather than compelled, or seen as an obligation or duty. The conventional definition of volunteering also excludes community service or welfare to work programmes. Furthermore 'voluntary work' performed during emergencies falls outside of this definition.

VSO-RAISA's experience from Southern Africa is that community volunteers mainly come from underprivileged backgrounds. The reality in Southern Africa is different than in other parts of the world. HIV and AIDS is an emergency, and care providers are providing a service in resource limited settings under extremely difficult conditions. Most of them are worse-off economically as a result of care giving (VSO-RAISA & WHO 2009). Care providers therefore expect some financial or material compensation for their services, as their clients/patients also expect a lot from them. However, volunteering is primarily undertaken to show solidarity, rather than for financial and personal gain.

Further to this, the feminisation of tuberculosis (TB), HIV and AIDS has resulted in women and girls bearing the burden of infection as well as care and support. Older persons providing this care and

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[7] The vertical community model primarily focuses on providing palliative care in the home. It is not integrated with services offered by other actors in the community (NGOs, faith based organisations and others). It is not linked to formal health centres, and referrals to and from the health centre and the community are weak. This model does not address the medical, psychosocial, spiritual and emotional needs of clients/patients.

support mostly lack the resources, energy, skills and knowledge to provide quality care at a time when they should be provided with care themselves. This renders 'Africa's future fathers and mothers' a vulnerable group of people who now have to face the reality of reversed roles of parenting and care provision. Up to 80 per cent of volunteer care providers in most C&HBC programmes are women (VSO-RAISA & WHO 2009).

This could be explained largely by the division of labour based on traditional gender roles and the perception of volunteering and non-economic activities. First, the conventional division of gender roles in societies assigns the role of care provider to women. Women and girls are seen as mothers, housewives and care providers. Secondly (and related to the first point), care provision is often seen as informal, voluntary work and not necessarily considered a formal economic activity. Again, informal non-profit voluntary work is often seen as women's work, which is another case of taking women's labour for granted and considering it less important than what is considered to be formal income generating activity. The fact that in South Africa, where care providers are given a small stipend, the level of male participation is much higher than in surrounding countries seems to support this view. Despite increasing interests in C&HBC work among men, it is often noted that men prefer paid work and get involved when there is a financial incentive.

This C&HBC approach gives back hope to individuals, families and communities. Key issues in C&HBC include:

- integrating C&HBC with formal health care services and other community outreach programmes,
- training care providers, and
- recruiting and retaining care providers.

Addressing burnout among care providers is an indispensable and integral part of volunteer management. Behaviour change and positive prevention are also vital in reducing the burden of HIV and AIDS care on care providers.

4 Protecting volunteers

As voluntary work is not perceived as remunerated, volunteering is often excluded from legal protection under the labour laws in the SADC region. In fact, policies or standardised rules regulating working conditions and the workload of care providers seem to be lacking in general. Yet community volunteers in many societies in Southern Africa are often in dire need of help. Apart from the heavy workload with patients, care providers are often required to walk long distances between patients. They cover a large area where public transportation is lacking or the cost of transportation is a prohibiting factor. Their working hours and conditions are unregulated and undocumented.

There is need to create a legal framework to protect volunteers as they are not recognised as rights-holders in labour law, and organisations that use volunteers neglect their responsibilities and obligations towards volunteers. C&HBC care providers are often overwhelmed by their workload, psychologically burdened by others' problems and suffering from poverty – all without adequate support. Indeed, it is time to recognise the contributions of voluntary care workers in their communities, to support them in their fight against HIV and AIDS, and to empower them to understand and demand their rights.

5 Recognising and supporting community-based volunteer care providers through policy

Scaling up HIV and AIDS prevention, treatment, care and support in C&HBC programmes is a fundamental step towards achieving universal access to HIV and AIDS services and addressing the Millennium Development Goals in sub-Saharan Africa. Such scaling up action would entail strengthening community responses to other primary health care (PHC) services, including the integration of TB management, among other chronic conditions. Recognising the rights of care providers, and providing a supportive environment for them to provide quality care, are fundamental entry points to addressing this challenge.

The 2008 Ouagadougou Declaration on Primary Health Care and Health Systems in Africa[8] acknowledges the importance of strengthening community based responses to health challenges in Africa, especially in view of formal health systems weakened by, among others, brain drain, poor health infrastructure and a high proportion of new HIV infections. The Ouagadougou Declaration tasked African member states to, among other things, promote inter-sectoral collaboration and public-private partnerships, including between civil society and communities, with a view to improving the use of health services and taking appropriate action on the economic, social, demographic, nutritional, cultural and environmental determinants of health. Member states also committed themselves to the implementation of strategies that address human resources for health needs – including management, retention and motivation – in order to enhance the coverage and quality of health care.

Despite commitments by SADC heads of state who are signatories to many international and regional declarations, such as the Maseru Declaration on HIV and AIDS and the Ouagadougou Declaration referred to above, there is still very limited support for care providers involved in HIV and AIDS programmes. Under Article 27 of the SADC Protocol on Gender and Development, SADC heads of state committed themselves to putting in place policies that protect the rights of women and girls involved in care work on HIV and AIDS by 2015.

Unfortunately, at present only Namibia has a national care work policy that recognises and provides for the needs and rights of women and girls involved in HIV and AIDS care work. The responsibility for making these fundamental policy changes lies with those who hold power and bear the duty to respect, protect, promote and fulfil the rights of care providers – national governments, donors, civil society and other key players involved in the fight against HIV and AIDS in the region. It is against this backdrop that the VSO-RAISA has been undertaking activities that will contribute to the attainment of the requirements of Article 27(c) of the SADC Protocol on Gender and Development and reduce the burden of care on women, girls and older persons.

6 VSO-RAISA’s approach and methodology of regional policy engagement

Together with other key regional actors, VSO-RAISA has been advocating for favourable conditions and for the implementation of C&HBC programmes that address the needs and rights of voluntary care providers involved in HIV and AIDS care work at community level. Among others, the VSO-RAISA, Gender Links, Gender Media Southern Africa, Save the Children UK, the Southern African Region of the Network of African People Living with HIV and AIDS and the Regional Psychosocial

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[8] http://ahm.afro.who.int/issue12/pdf/AHM12Pages10to21.pdf

Support Initiative raised the issues affecting care providers at the 2008 SADC heads of state summit. This resulted in the formulation and adoption of Article 27(c) of the SADC Protocol on Gender and Development. This Article stipulates that:

> "State parties shall by 2015: Develop and implement policies and programmes to ensure appropriate recognition of the work carried out by care-givers, the majority of whom are women, allocation of resources and psychological support for care-givers as well as promote the involvement of men in the care and support of People Living with HIV and AIDS."[9]

This paper provides some insights and experiences into VSO-RAISA's work in Southern Africa.

The VSO-RAISA programme was launched in 2000, and is now in its third phase (2009 to 2013). Initially, the programme focussed on all the HIV and AIDS components of prevention, treatment, care and support, and impact mitigation. Advocacy for favourable national policies was a key issue cutting across all components; this advocacy was carried out in partnership with other regional actors. Through international volunteer placements, training-of-trainer workshops, exchange visits, conferences and small grants provided to local partner organisations, the VSO-RAISA helped to build the capacity of communities across the region to respond to the challenges of HIV and AIDS. In its third phase, the VSO-RAISA has established a niche in the area of care and support, particularly around advocacy on national care work policies across the region. Prevention is still a priority, and is now being integrated into C&HBC programmes supported by the VSO-RAISA in Southern Africa.

Since the Ouagadougou Declaration, the VSO-RAISA, with a mandate from SADC, has taken the lead in strengthening community responses to TB, HIV and AIDS through collaboration with its partners, with technical assistance from the WHO's Africa Regional Office (AFRO). VSO-RAISA and the WHO's experience in Southern Africa is that strengthening TB, HIV and AIDS C&HBC programmes also entails reducing the burden of HIV and AIDS care on care providers, most of whom are women, girls and older persons who work voluntarily.

The VSO advocacy campaign on reducing the burden of HIV and AIDS care on women and girls started in 2004. Some of the initiatives that the VSO has participated in as part of this campaign include:

- developing the VSO policy brief "Reducing the burden of HIV & AIDS care on women and girls" (2006),
- researching women's rights with ActionAid ("Walking the Talk" 2007),
- chairing the Consortium on AIDS and International Development Care and Support Working Group entitled "What do we really mean by HIV care and Support?",
- co-founding a new global coalition called the Caregivers Action Network, and
- co-leading the UN Review of UN General Assembly Care and Support Indicators.

In the Southern Africa region, the VSO-RAISA has recognised the need to address challenges faced by care providers in C&HBC and focus on reducing the burden of care on women, girls and older persons in particular. Reducing the burden of care in this instance requires developing innovative ways of addressing challenges faced by care providers. These include actively involving care providers in the review formulation of C&HBC policies, standards and guidelines; allocating resources in the national budgets to pay trained, certified and registered secondary care providers monthly allowances/salaries; and targeting traditional leadership in mobilising men and boys to become more involved in the delivery of PHC services in C&HBC programmes.

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[9] SADC Protocol on Gender and Development, http://www.sadc.int/index/browse/page/465

Thus, working with partners and volunteers, the VSO-RAISA through its regional operations has been successful in getting C&HBC on the SADC agenda through several initiatives such as:

1. the VSO-RAISA Advocacy Strategy 2007-2010,
2. the Challenges of Care VSO Regional Conference 2007,
3. the Male Involvement in HBC Study by VSO-RAISA 2008,
4. the SADC Partnership Forum 2008,
5. the HIV and Gender VSO Regional Conference 2009; and
6. partnerships with the WHO's AFRO, and the Regional Alliance of AIDS NGOs, among others.

Some of these activities are briefly outlined in the following sections.

7 Research for a regional situation analysis of HCBC

In partnership with the WHO Africa, the VSO-RAISA embarked on a consultative process in six SADC member states to develop a regional framework to address C&HBC concerns and reduce the burden of care on women and girls. Key findings of the 2008/09 study conducted by the VSO-RAISA and the WHO show that an estimated 80 per cent of care providers in selected SADC countries are women and girls; these females play a key role to leverage public health systems in the region.[10]

The 2009 VSO-RAISA and WHO research reveals that many care providers are not adequately trained to caring for people living with HIV. In fact, regional consultations from Action AID[11] show that C&HBC organisations spend only 5 per cent of their annual budgets on training care providers. Despite this, several studies confirm that C&HBC programmes provide at least 90 per cent of care to people living with HIV in most parts of Africa. In addition, training of care providers is not standardised; for instance, South Africa and Mozambique provide 69 days and 15 days training respectively.[12]

Furthermore, in terms of remuneration of secondary care providers[13], the 2009 study by the VSO-RAISA and the WHO's AFRO shows that that there is a lack of standardisation at country level. A comparison between South Africa and Mozambique shows alarming discrepancy of stipends; whereas the South African average stipend lies between R500 and R1 000 (between US$63 and US$127), the average Mozambican stipend is 600MTn (US$22). To make matters worse, survey results in six SADC countries indicate that care providers are further burdened by clients who expect medical supplies, cleaning materials and food among other things.[14]

The study also identified the services offered by care providers:

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[10] VSO-RAISA, WHO Africa (2009) ''Scaling up HIV Prevention, Treatment, Care and Support in Community and Home-based Care Programmes and Reducing the Burden of HIV and AIDS Care on Carers in SADC''..

[11] Action AID (2006) "Women Bailing Out the State." Study on C&HBC in four Southern African countries.

[12] VSO-RAISA, WHO Africa (2009) ''Scaling up HIV Prevention, Treatment, Care and Support in Community and Home-based Care Programmes and Reducing the Burden of HIV and AIDS Care on Carers in SADC".

[13] A secondary care provider is trained and provides health care services at the community and home level. This person is usually linked to C&HBC programmes supported by NGOs, faith based and other organisations

[14] VSO-RAISA, WHO Africa (2009) ''Scaling up HIV Prevention, Treatment, Care and Support in Community and Home-based Care Programmes and Reducing the Burden of HIV and AIDS Care on Carers in SADC".

8 Services undertaken by care providers[15]

Table 1: Services undertaken by care providers

Prevention	Treatment	Care and support
• Condom distribution • Family planning education • Counselling for HIV testing • Infant feeding guidance • Education on infection prevention and control • Education on anti-retroviral treatment • Community education on sexually transmitted infections • Community education on HIV testing • Home testing • Palliative care	• Adherence support • Refilling prescriptions • Treatment follow-up • Treatment of minor ailments • Training household members in treatment literacy and adherence • Facilitating referrals of clients to health centres/professionals • Palliative care	• Providing psychosocial support to clients and their families • Provision of transport to clients • Physical care • Nursing care • Training household members in care and support • Assisting with household chores • Nutrition support • Referring clients and their families to social services and other agencies • Resource mobilisation

Finally, the findings from the 2009 VSO-RAISA and WHO suggest that the current state of care work in the region is not only unsustainable but also promotes the disempowerment and marginalisation of women and girls. Thus, the greater involvement of men in C&HBC could contribute to enhanced gender parity of those providing care to PLWHA as the burden on women and girls will be reduced, thereby leading to broader benefits for all in affected communities.

The VSO-RAISA's experience and findings from the 2009 VSO-RAISA and WHO study show that while males are less involved in C&HBC programmes because of the cultural perception that women are the care providers, they play a complementary role in care provision. Men and boys go out of their homes to look for jobs to provide income, food and other needed resources for the family as well as carry out other physical (manual) tasks in the home. Men often provide security, as well as psychological and emotional support to clients and families. Their main role is no longer limited to transporting the sick to health centres and providing resources to support C&HBC. As care providers, men can be as effective as women. Male and female care providers can also work together harmoniously, each contributing to quality of care in different ways. Men bring the added value of physical and counselling support to C&HBC. Involving men in HIV and AIDS care work therefore leads to improvement in care and support of PLWHA.

Some concerted efforts to scale up the active involvement and participation of males (men and boys) in C&HBC programmes have taken place within the region in recent years. Various NGOs – including the VSO-RAISA, Africare and the Southern African AIDS Trust – support the male involvement initiatives of local partner organisations involved in C&HBC programmes.

The previously held assumption that males cannot be involved in care work is gradually changing. Instead, men are seen to be playing a positive and complementary role in C&HBC programmes. This finding is also supported by a finding from an undated Africare study conducted in Zimbabwe:

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[15] Ibid.

> "Men are willing to play a practical role in promoting the health of their families and communities; men can be effective HBC Care Providers, capable of providing nursing care, psychosocial support, and assistance with household chores to affected individuals and households; and men accept that providing care to people living with AIDS and other chronic illnesses is an appropriate and acceptable behaviour."[16]

9 Engagement with SADC parliamentary forum members of parliament

The VSO-RAISA has been working with the SADC parliamentary forum (PF) on the issues of reducing the burden of care on women and girls and increasing the involvement of men in C&HBC. To this end, two workshops (2009 and 2010) have been held with SADC PF members of parliament.

Baroness Margaret Jay, a UK member of parliament and a VSO short term volunteer, facilitated the 2009 workshop, where she imparted her tactics in presenting HIV and AIDS issues and assisted attendants to better articulate similar issues in their respective parliaments. The workshop in 2010 brought together 20 SADC PF parliamentarians from Angola, Botswana, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Zambia and Zimbabwe. Ambassadors of Sweden and the Netherlands also attended the workshop, as did several civil society organisations (CSOs). The workshop aimed to raise awareness of the need to reduce the burden of care on women and girls of PLWHA as well as orphans and other vulnerable children.

From these workshops, a care work policy brief has been developed with the SADC PF, to inform members of parliament focusing on HIV and AIDS about reducing the burden of care. In response, some members of parliament have successfully mobilised men to provide care. Honourable Kayembe from Malawi has to date mobilised 200 men to provide C&HBC in Dowa District; previously there were only 30 men providing such service in the district.

10 Advocacy and capacity building

In 2010 VSO-RAISA and RAISA gender and media partner Gender and Media Southern Africa (GEMSA) developed the *Making Care Work Count Policy Handbook*. The publication has been designed to support regional care work policy development advocacy campaigns as required by Article 27(c) of the SADC Protocol on Gender and Development. The objectives of the handbook include to influence the development, adoption, implementation and enforcement of policy frameworks that promote the recognition and support of care providers in the context of HIV and AIDS, and to promote public engagement on care work related issues. An integration of the research conducted by the VSO-RAISA and the WHO and GEMSA suggests six principles that need to inform care work policies:

1. **Remuneration:** People doing the work of government have a right to be financially rewarded.
2. **Logistic and material Support:** It is imperative that care providers are provided with care kits as well as other support, such as uniforms for identification, bicycles, food packs, monthly monetary allowances, soap, free medical treatment, financial support for income generating projects, raincoats, umbrellas, agricultural inputs, stationery and transport

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[16] Africare Zimbabwe (undated publication) "Man Enough to Care: Involving Men in HBC Programmes in Zimbabwe".

allowances, among others, to provide quality care.

3. **Training and professional recognition**: Protocols of training and accreditation should be developed through a governing body within the country to regulate and standardise the training.
4. **Psychosocial support:** Care for care providers should be prioritised with psychosocial support programmes developed and provided to care providers.
5. **Gender equality**: The gender dimensions of HIV should be recognised and catered for.
6. **Public private partnerships:** There is a need to advocate for stronger public private partnerships in the delivery of PHC services through C&HBC programmes.

Capacity-building sessions have been held in Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe, with CSOs as well as with national AIDS councils and health ministries participating in some countries to outline advocacy processes to support their efforts. The main components of these processes include:

- country mapping and stakeholder analysis,
- building a coalition;
- influencing policy uptake and implementation,
- developing an advocacy and lobbying plan, and
- monitoring and evaluation.

To date, the handbook has been used to facilitate the drafting of two policies – one in Malawi and one in Zimbabwe. CSOs in Mozambique and Zambia have begun using *Making Care Work Count* to influence the development of a care policy.

In addition, several learning exchange visits have taken place to support the various countries formulating care work policies; heads of nursing services in Malawi and Zimbabwe have exchanged and so have members of parliament from Malawi and Mozambique.

11 Draft policies

With support from the VSO-RAISA and GEMSA, members of parliament and civil society as well as government officials developed draft national care work policies in Malawi and Zimbabwe. The Malawian government will be reviewing this policy in 2011 to ensure that it addresses the needs and rights of community volunteers involved in HIV and AIDS work, including the provision of resources, incentives and other support required in the delivery of HIV and AIDS services.

The VSO-RAISA would like to see the adoption of national care work policies in at least seven of the SADC countries in which it operates – i.e. in Lesotho, Mozambique, Malawi, Namibia, South Africa, Zambia and Zimbabwe – by 2012. This will be achieved by closely working with the ministries of health, national AIDS councils/commissions, and community based organisations working in C&HBC programmes and representatives of care providers in these countries. Where draft policies have been developed, the VSO-RAISA will support local partners and care providers to convene and provide feedback to these draft policies to ensure that the needs and rights of care providers are adequately reflected. The VSO-RAISA and its partners will also develop mechanisms for ensuring that these policies are effectively resourced, and that they are implemented and monitored.

12 First ladies in the SADC and advocacy

The VSO-RAISA has mobilised the first ladies of Malawi, South Africa, Namibia and Lesotho to raise awareness of the burden of care on women and girls.

The first ladies are already engaged in advocacy work for the plight of care providers. During a presentation at an annual HIV and AIDS conference in 2010, the South African first lady highlighted the common issues faced by women and girls. She also raised these issues at an African Union meeting in Addis Ababa in January 2011.

13 Future activities

The activities outlined above will continue, with additional activities undertaken to strengthen the advocacy campaign. These activities include hosting a first ladies' conference to mobilise support for the campaign. The VSO-RAISA has worked closely with East African countries including Kenya, Uganda and Tanzania in supporting the establishment of the Caregivers Action Network that provides a platform for care providers to be heard. To this end, the VSO-RAISA and the Regional Alliance of AIDS NGOs and various other networks for PLWHA work together to form regional caregiver action networks to support care providers for the Southern African region.

National care work policies will be formulated in Mozambique, Zambia and Lesotho. The process of developing these policies will be consultative and involving the ministries of health, national AIDS councils/commissions, and community based organisations working in C&HBC programmes and representatives of care providers. The VSO-RAISA and the GEMSA policy advocacy handbook will be a useful tool in this process. The policies to be developed will take into account the needs and rights of community volunteers involved in HIV and AIDS work. Learning from other countries will be supported through exchange visits.

The VSO-RAISA intends to strengthen strategies to mobilise more men to provide HIV and AIDS care and support to PLWHA in communities across Southern Africa. Best practice male involvement has been documented and will be shared among partners across the region. The continued engagement of role models and influential community leaders such as chiefs, headmen and members of parliament has proven to be an effective strategy in this regard, and will continue.

14 Summary

While a comprehensive evaluation of the impact of the processes and activities is yet to be undertaken, it is evident that some impact has been made. Men have been more involved in C&HBC as a result of, among other things, strategies provided at capacity building workshops; care policies, some of which are still in the draft stages and some of which are already being adhered to; and an increased awareness of the issues affecting care providers.

15 Sixteen lessons learnt[17]

Over the years, a number of challenges were encountered and lessons learnt in implementing the various advocacy initiatives. The key lessons are:

1. **Advocacy takes time:** Because of its very nature – which involves influencing perceptions, opinions, attitudes and policies – advocacy takes a very long time to produce the desired results. Organisations, including VSO-RAISA and partners, need to be reminded to be patient as they pursue various advocacy initiatives around the reduction of the burden of HIV and AIDS care on women, girls and older persons in Southern Africa. Accessing the right authorities and decision

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[17] Adapted from VSO-RAISA Advocacy Initiatives document 2006- 2011 (unpublished).

makers in institutions such as the ministries of health and national AIDS councils to get them to understand the VSO-RAISA's advocacy agenda, and to co-operate and support this work, will take much more time than initially envisioned.

2. **Traditional leaders can help promote change:** Addressing gender disparities in community care and support and challenging risky cultural and traditional practices and attitudes can be more effective when men and traditional leaders are involved. Traditional leaders play an important role in challenging and changing some of the traditional and cultural attitudes, beliefs and practices related to care.

3. **Carve out an advocacy niche:** It is advisable and more effective to pursue one specific advocacy issue at a time. The VSO-RAISA settled for the reduction of the burden of HIV and AIDS care on women and girls in Southern Africa, which was very specific and unique. No other organisation was pursuing such an issue at regional level.

4. **Cultivating 'champions' is an effective strategy:** It is important to identify regional 'champions' that VSO-RAISA and partners can rely on to effectively roll out advocacy initiatives. Engaging influential figures in society – including members of parliament, first ladies and retired presidents such as Dr Kenneth Kaunda and Festus Mogae – is critical in scaling up advocacy initiatives. Hon. Ephraim Kayembe, a member of parliament from Malawi, has been one such regional champion who has selflessly dedicated his efforts to fight for the needs and rights of care providers. Such champions can share their experiences and may provide a source of inspiration to others. They also help the VSO-RAISA access authorities and decision makers in their efforts to influence national and regional policies.

5. **Men have a role to play in reducing the burden of care on women and girls:** Involving men in C&HBC programmes has proven to be effective in reducing the burden of care on women and girls. Men are highly mobile and vocal, and their increased participation in C&HBC programmes can help improve the dissemination of HIV and AIDS information in communities. However, most initiatives have largely focussed on recruiting male adults. To ensure sustainability of such community based interventions, it is critical to also mobilise and actively engage male youths.

6. **Flexibility is important in advocacy:** Once the advocacy issue and message has been agreed upon, it is important to remain open and flexible, and to incorporate other priorities as they emerge. For example, the initial focus of the advocacy of the VSO-RAISA and partners was around the reduction of the burden of HIV and AIDS care on women and girls in Southern Africa. However, in rolling out this strategy, it emerged that older persons and children were equally burdened by HIV and AIDS care. These additional target groups were incorporated along the way, without losing focus of the initial advocacy objectives and thrust. New partners Help Age International and the Regional Psychosocial Support Initiative were taken on board to enable the VSO-RAISA and its partners to effectively respond to the needs and rights of older persons and children involved in community care and support.

7. **Investing in evidence-based research has been worthwhile**: Evidence-based advocacy has proven to be very effective. It is therefore important to invest in research and other studies that will collect evidence, facts and figures to back the advocacy campaign. The regional study on the reduction of the burden of HIV and AIDS care on women, girls and older persons in Southern Africa, and the study on the involvement of men in C&HBC programmes in Malawi, Zambia and Zimbabwe were useful pieces of work that provided the VSO-RAISA and partners with the required evidence.

8. **Quality research takes time and resources:** While research is good and adds credibility to the advocacy work, it takes time and is costly, especially if it is participatory and consultative. It is important for organisations to make adequate provision for such research studies in their budgets, and to get technical support from established credible agencies, e.g. the WHO and the Centre for the Study of HIV and AIDS at the University of Pretoria.

9. **There is value in qualitative research:** Including men, women, girls and older persons in the research process through focus groups and in-depth interviews helped unearth a wealth of information around the needs and rights of care providers in Southern Africa.

10. **Government and civil society engagement is critical for promoting change in the region**: The model of engagement between parliamentarians and civil society that the VSO-RAISA and SADC PF have engaged in could have a profound and lasting impact across the region. The few members of parliament who have been trained with support from the VSO-RAISA could help further sensitise and train others in their respective countries, thus creating a critical mass of advocates for care work in the region. Through its programme offices in the region, the VSO-RAISA supports these members of parliament with small grants to roll out these initiatives. Care must be exercised that these members do not use these opportunities for personal political gain. Exchange visits among members of parliament, in-country and regionally, should also be promoted as a way of promoting shared learning and stimulating replication of local initiatives that help reduce the burden of care.

11. **Policies are important but not the only avenue for change:** While having national care work policies that address the needs and rights of care providers is important, it has to be remembered that policies alone are not enough. As some parliamentarians working with the VSO-RAISA have demonstrated in their constituencies, a lot can still be done in the absence of national policies to support the work of care providers. Community mobilisation, private sector engagement and male involvement are examples of interventions that could help reduce the burden of HIV and AIDS care on care providers while national policies are being crafted and revised. In addition, policies need to be comprehensive, going beyond HIV and AIDS to the broader care needs of communities. This means organisations involved in issues other than HIV and AIDS should also be consulted in the policy formulation and review processes.

12. **Monitoring and evaluation systems should be improved**: There is need to define the mechanisms for monitoring and evaluating the implementation of the national care work policies once they have been finalised and approved by governments. Issues to consider include, among others, who will monitor, which tools will be applied, how monitoring will be undertaken, at what frequency, and what would be the role of care providers in the process. It may happen that a good policy is in place but implementation is slow, or that key stakeholders and target groups are not aware of the existence of such a policy.

13. **There is an urgent need to quantify the contribution of care work:** Advocacy around care work could further be strengthened if information on the costing of care work can be made readily available. Unfortunately, this appears to be a significant gap in all C&HBC programmes across the region. Evidence from this research will help strengthen regional advocacy on care work.

14. **There needs to be greater engagement of care providers in the development process:** The importance of active engagement of care providers in national processes to review and/or develop C&HBC policies has been highlighted in studies commissioned by the VSO-RAISA and GEMSA. An idea to facilitate the formation of a regional care providers' network has also been placed on the regional agenda. It is important that somebody, perhaps the VSO-RAISA and

GEMSA, should take the initiative to create this important forum, which will become the mouthpiece and voice of care providers in Southern Africa. In order to ensure that such an organisation is sustainable and that care providers are actively consulted in its formation caution should, however, be exercised to avoid imposing this idea on care providers. The regional network could also have national chapters, and will benefit from the experiences of establishing similar regional networks. While there could be donor interest to support a people's organisation of this nature, the future sources of funding for the network should also be considered from the onset.

15. **The media has an important role to play:** The use of the media, particularly community media, to give care providers a voice and to highlight the plight, needs, rights and contribution of care providers in the fight against HIV and AIDS has not been fully explored. Community media are closer to the ground, can challenge attitudes and mindsets on gender issues and can put care work on the media agenda. Community media are also driven by social objectives rather than profit. These media also have a rights agenda – this agenda allows for a focus on diversity and the right of all marginalised people – including women, PLWHA and other interest groups – to be heard. Parliamentarians could utilise community media to reach their constituencies and to brief the public about issues of care work. The VSO-RAISA and GEMSA are currently finalising discussions on how care work can be profiled more effectively through community media in Southern Africa.

16. **Regional alliances are important but difficult to sustain given competing priorities:** While regional alliances are important as they provide a strong and unified voice in advocacy campaigns, the competing priorities and commitments in organisations within the alliance at times make it difficult to engage effectively with targeted regional bodies and stakeholders.