Swaziland has been severely affected by HIV, with estimations indicating a prevalence rate of 25.9 per cent. The development challenges that accompany such an epidemic are substantial, requiring multifaceted and innovative responses from government and communities in order to prevent transmission, improve access to treatment and care, and mitigate social and economic impacts. One such response is the Swaziland Positive Living (SWAPOL) initiative, which was formed in 2001 as a coping strategy for five HIV positive women who were encountering stigma and discrimination from their families and community members. For the SWAPOL members, the common goal of living positively has served as a strong cohesive force for the survival of the initiative. The initiative’s developmental approach gives members the opportunity to access services and build their capacity within a supportive environment. This working paper provides an overview of the SWAPOL initiative and outlines the challenges and constraints with which it has had to come to grips.
CoopAFRICA contributes to improving the governance, efficiency and performance of primary cooperatives, other social economy organizations and their higher level structures in order to strengthen their capacity to access markets, create jobs, generate income, reduce poverty, provide social protection and give their members a voice and representation in society.

CoopAFRICA’s approach consists of assisting stakeholders to establish a legal and policy environment conducive to the development of cooperatives; providing support services through identified ‘Centres of competence’; promoting effective co-coordinating structures (e.g., unions and federations) and establishing and maintaining challenge fund mechanisms, for ‘services’, ‘innovation’, and ‘training’. These funds are accessible through a competitive demand-driven mechanism and a transparent selection of the best proposals.

CoopAFRICA and its network of ‘Centres of competence’ provide different types of services: policy and legal advice; studies and publications; training and education; support to field projects; development or adaptation of didactical and methodological material; networking; advocacy; and promotion of innovative cooperative ventures among others.

CoopAFRICA is located in the ILO Office for the United Republic of Tanzania, Kenya, Rwanda and Uganda, and is part of the Cooperative Programme (EMP and COOP) of the Job Creation and Enterprise Development Department of the ILO. The programme works in partnership with the International Cooperative Alliance (ICA), the UK Cooperative College, the Committee for the Promotion and Advancement of Cooperatives (COPAC), the International Trade Union Confederation (ITUC-Africa), the International Organisation of Employers (IOE) and the African Union Secretariat. CoopAFRICA is a multi-donors programme primarily supported by the UK Department for International Development (DfID). It also receives support from the Swedish International Development Cooperation Agency (Sida), the Government of Finland, the Arab Gulf Programme for United Nations Development Organizations (AGFUND) and the German Cooperative and Raiffeisen Confederation (DGRV).

The ILO Programme on HIV and AIDS in the World of Work (ILO and AIDS) was set up in 2000 to help strengthen the global HIV and AIDS response at and through the workplace. In 2001, the ILO developed the Code of Practice on HIV and AIDS and the world of work and became a cosponsor of UNAIDS. The key objectives of ILO and AIDS are to raise awareness of the social, economic and development impact of HIV and AIDS through its effects on labour and employment; to help governments, employers and workers contribute to universal access to HIV prevention, treatment, care and support; and to eliminate discrimination and stigma related to HIV and AIDS.

The ILO-Sida programme on HIV and AIDS prevention and impact mitigation in the world of work in Sub-Saharan Africa is an innovative programme addressing different dimensions of the HIV and AIDS response through a common strategy led by different ILO departments. The programme aims to reduce the impact of the pandemic in Sub-Saharan Africa by addressing the world of work vulnerabilities and strengthening the application of the policy and legal frameworks for the protection of infected and affected workers. The programme started in December 2005 and is funded by the Swedish Development Cooperation Agency (Sida) over the course of four years and comprises three components: 1) The transport sector through a corridor approach aiming to increase knowledge on HIV and AIDS and minimize risk behaviours; 2) The informal economy and cooperatives to mitigate impact of HIV and AIDS and improve working conditions in informal settings; 3) Enhanced legal and policy compliance.

The programme covers 14 countries in the sub-region (Lesotho, South Africa, Mozambique, Malawi, Zimbabwe, Botswana, Ethiopia, Nigeria, Burkina Faso, Mauritius, Togo, Benin, Cameroon, Democratic Republic of Congo) but the main programme countries are Benin, Cameroon, Ethiopia, Malawi, Mozambique, South Africa, and Zimbabwe.

A new phase of the Sida programme has been negotiated and will focus on economic empowerment to reduce the HIV vulnerabilities along transport corridors (Zambia, South Africa, Malawi, Mozambique, Zimbabwe and Tanzania) for a period March 2011-March 2013.
Positive living with HIV in the Swazi social economy

K. J. B. Keregero and Emma Allen

2011

Series on HIV/AIDS impact mitigation in the world of work – responses from the social economy
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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Treatment</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>AWDF</td>
<td>African Women’s Development Fund</td>
</tr>
<tr>
<td>CANGO</td>
<td>Coordinating Assembly of Non-Governmental Organizations</td>
</tr>
<tr>
<td>FAO</td>
<td>Food and Agriculture Organization</td>
</tr>
<tr>
<td>FLAS</td>
<td>Family Life Association of Swaziland</td>
</tr>
<tr>
<td>HBC</td>
<td>Home Based Care</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immuno-deficiency Virus</td>
</tr>
<tr>
<td>ICW</td>
<td>International Committee for Women Living with HIV and AIDS</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labour Organization</td>
</tr>
<tr>
<td>LDS</td>
<td>Lutheran Development Services</td>
</tr>
<tr>
<td>NERCHA</td>
<td>National Emergency Response Council on HIV and AIDS</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Government Organization</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People Living with HIV and AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother-To-Child Transmission</td>
</tr>
<tr>
<td>SAC</td>
<td>Southern Africa Campaign</td>
</tr>
<tr>
<td>SFTU</td>
<td>Swaziland Federation of Trade Unions</td>
</tr>
<tr>
<td>SIDA</td>
<td>Swidish International Development Cooperation Agency</td>
</tr>
<tr>
<td>SNAT</td>
<td>Swaziland National Association of Teachers</td>
</tr>
<tr>
<td>SWAGAA</td>
<td>Swaziland Action Group Against Abuse</td>
</tr>
<tr>
<td>SWANNEPHA</td>
<td>Swaziland National Network of People Living with HIV and AIDS</td>
</tr>
<tr>
<td>SWAPOL</td>
<td>Swaziland Positive Living</td>
</tr>
<tr>
<td>TASC</td>
<td>The Aids Support Council</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV and AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<tr>
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<td>United Nations Children’s Fund</td>
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<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>WILSA</td>
<td>Women and Law in Southern Africa</td>
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Acknowledgments

This study could not have been accomplished without the support of the ILO’s Cooperative Facility for Africa (CoopAfrica) and the ILO Programme on HIV and AIDS and the World of Work (ILO/AIDS). Contributions of various individuals and institutions have facilitated the production of this paper. In particular, comments, suggestions and other inputs provided by Emma Allen, Celeste Coetzee, Julia Faldt, Margherita Licata, Fatumah Mrisho, Elizabeth Mwakalinga, Carlien van Empel, Philippe Vanhuynegem and Philip Wambua are gratefully acknowledged.

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Executive summary

Swaziland has been severely affected by HIV, with estimations suggesting a prevalence rate of 25.9 per cent (UNAIDS, 2010). This context has seen the country’s life expectancy become one of the lowest in the world, with over 60 per cent of all deaths in Swaziland AIDS related (UNDP, 2009). The development challenges that accompany such an epidemic are substantial, requiring multifaceted and innovative responses from government and communities in order to prevent transmission, improve access to treatment and care, and mitigate social and economic impacts. One such response is the Swaziland Positive Living (SWAPOL) initiative, which was formed in 2001 as a coping strategy for five HIV positive women who were encountering stigma and discrimination from their families and community members.

SWAPOL has succeeded in building up a grassroots network of support groups whose members feel they own the initiative. Currently SWAPOL serves 5700 members in support groups across 54 rural communities. Its mission is to provide support and improve the quality of life for people living with HIV, orphans and vulnerable children (OVC) and affected families. It carries out its mission through a range of integrated advocacy, capacity building and service provision activities. For instance, SWAPOL provides home-based care services and mobile clinic services to enhance access to antiretroviral and care for people living with HIV (PLHIV). SWAPOL also provides support and legal assistance associated inheritance law to prevent unlawful property grabbing from women and OVC. Finally to support communities in coping with the economic implications of HIV and AIDS, SWAPOL provides training in various aspects associated with positive living and income generation. These activities are supported by donors and partners, and are an integral part of the national response to HIV and AIDS.

However, as a community based organization, SWAPOL faces challenges and constraints. The social context means that there is enormous demand for the services provided by SWAPOL, but it is constrained by the supply of funding. SWAPOL’s status as an NGO also limits its ability to litigate on behalf of its members, which is a major setback for its provision of legal assistance to widows and OVC whose property has been, and is being, unlawfully grabbed by family members. Both these issues require further strategizing from SWAPOL.

SWAPOL also has to operate with the local political economy, which means that at times it has been unable to reach out to people because of chieftaincy disputes. As SWAPOL advocates for the disadvantages and challenges local structures, it has had to trend carefully to ensure that its activities are primarily concerned with human rights activism rather than political activism. However, the common goal of living positively serves as a strong cohesive force for the survival of support groups and the organization itself.
1. **Introduction**

The International Labour Organization (ILO) is supporting implementation of the Swedish International Development Cooperation Agency (Sida) funded programme ‘HIV and AIDS Prevention and Impact Mitigation in the World of Work in Sub-Saharan Africa’. The programme seeks to increase knowledge about initiatives that respond to HIV and AIDS in the social economy.

To progress this objective, this working paper presents a case study of an organization called ‘Swaziland Positive Living’ (SWAPOL). It is intended that policymakers, civil society organizations and development partners, especially those associated with HIV and AIDS, would be able to draw upon lessons provided by this case study to enhance responses to HIV and AIDS in the social economy. This study is one of the three case studies that are reporting on responses to HIV and AIDS in the social economy within Sub-Saharan Africa. Each case study follows a structured methodology to enable comparison across the studies.

1.1 **Overview of Swaziland Positive Living**

The story of Swaziland Positive Living (SWAPOL) is closely linked with that of its founding director, who learned about her HIV status accidentally in 1999 after taking a medical examination as a pre-requisite for the award of a scholarship to study abroad. When she went for the medical examination, she did not know that she was also being subjected to an HIV test and that the scholarship could not be awarded to anyone with HIV. Subsequently, she was subjected to stigma and discrimination from family and community members and she experienced pressure that resulted in her leaving her in-laws’ home. As a coping strategy, she and four other women started an organization for women living with HIV.

Initially, the main purpose of the organization was to offer help and counseling to women with HIV and their families and friends. However, because of the magnitude of the epidemic in Swaziland, more women joined and the organization started to grow. Currently SWAPOL serves 5700 members in support groups in 54 rural communities and it has become an NGO. Services and support are provided to PLHIV, orphans and vulnerable children (OVC) and their families. The focus areas of SWAPOL include the establishment and strengthening of support groups, agriculture and income-generating activities, operation of a mobile health clinic, operation of a legal unit, and support for orphan and social welfare. It supports building the capacity of community groups of PLHIV and advocating for women’s rights, particularly property rights. It also seeks to promote food security and good nutrition, provide health and care services to rural communities and provide psychological support and counseling services to individuals and bereaved families.

Over the years, SWAPOL has made many achievements. The organization has
played an important role in helping PLHIV to live a positive life by encouraging good nutrition, exercise, adherence to ARVs and participation in community activities. In locations where health centres are distant from communities, the mobile clinic has enhanced people’s access to treatment and medication. SWAPOL’s agricultural projects have increased food security and also allowed income from the sale of produce. The activities offered by SWAPOL provide a positive support network for PLHIV and have given them hope. The strong network of support groups that directly enhance the day-to-day lives of communities has led to the emergence of community ownership of the programme, with support groups determining their own direction and community members becoming increasingly willing to help one another.

SWAPOL has demonstrated that it is proactive in its approach and willingness to adapt to circumstances. The organization has also established strong support groups in communities and built capacity of caregivers through training programmes. Its advocacy activities benefits from its economy of scale, which largely relies on committed and loyal volunteers at the community level.

1.2 Methodology

This case study uses qualitative techniques, including key informant interviews with members of SWAPOL, and analysis of secondary sources to inform the subject. Interviews were obtained from four purposively selected main actors of SWAPOL, three of whom are founder members of SWAPOL and one a programme coordinator. A further eight purposively selected beneficiaries were selected for interviews, all of whom were members of support groups. The beneficiaries included two widows, one OVC, one male member of support group, three female members of support groups and one female HBC recipient. All the main actors and beneficiaries were purposively selected on the basis of their knowledge of SWAPOL and its activities and their willingness to avail themselves for face-to-face interviews.

1.3 Guide to the document

This section has provided an introduction and an overview of the SWAPOL. Section two describes the socio-economic context in which SWAPOL operates. Section three considers the initiative in practice and outlines the activities of SWAPOL and how it has mainstreamed HIV across all of its activities. Section four focuses on the voice of beneficiaries section five provides conclusions and lessons learned. Where possible, maps, figures and pictures have been included.
2. Socio-economic context

2.1 Social and demographic factors

The Kingdom of Swaziland is a landlocked country surrounded by South Africa and Mozambique. The population of Swaziland was 1,018,449 in 2007, with approximately 79 per cent of the inhabitants residing in rural areas and approximately 70 per cent of the population aged below 30 (UNDP, 2009). According to the Household Income and Expenditure Survey in 2001, 69 per cent of the population lives below the poverty line, and approximately 21 per cent of the population is considered to be food insecure. In terms of international poverty lines, 62.8 per cent of the population fall below the USD $1.25 poverty line, while 81 per cent fall below the USD $2 per day line (World Bank, 2010). Despite this Swaziland continues to hold a lower-middle income status.

The indicators of human development have been falling over the last two decades in Swaziland. For example, life expectancy is currently estimated to be 47 years, which is a drop from 1990 when it was estimated to be 60.5 years (UNDP, 2010). The drop in human development indicators is linked to HIV and AIDS, with Swaziland being deeply affected the virus. Swaziland currently has highest prevalence rate in the world, at 25.9 per cent (UNAIDS, 2010). The epidemic has seen the traditional family structure change and now there are growing numbers of single parent families, grandparent families and child-headed families. Family support networks are shrinking, subsequently reducing the traditional safety nets that have previously existed in Swazi society.

Swazi society has strong patriarchal traditions. Gender determines the entitlements to resources, as well as access to production and income. Sexual violence is also common, with just under half of all Swazi women having experienced sexual violence in their lifetime (Government of Swaziland, 2009). Gender inequality is exacerbated by unsupportive legislation, especially inheritance law. It is also exacerbated by high levels of gender-based violence and increases in the unpaid care burden associated with HIV and AIDS, which primarily falls onto women. Moreover, often it is the head of the household who becomes infected with HIV, and this subsequently puts pressure on the household budget through loss of income and time poverty as care burdens increase.

The Swazi population is young when compared to other countries, with 39 per cent of people aged 0 to 14 years (See figure1). This implies a limited stock of human capital and associated challenges for provision of an effective public sector and a robust private sector. To illustrate, the health system faces several limitations, including a shortage of adequately skilled nurse-midwives and doctors for maternal care. Lower wages in the public sector has meant that skilled workers have often been incentivized by national and regional private sector options. There is a shortage of highly skilled people and this shortage has been probably exacerbated by the death of skilled people arising from HIV-related illnesses.
Health outcomes are worsened by the lack of safe drinking water and sanitation systems. Swaziland exhibits regional inequality in this regard, with access to safe drinking water at 87 per cent in urban areas and 51 per cent in rural areas (UNDP, 2009: 43). This increases vulnerability to malnutrition and illness, especially for people with weakened immune systems. Many of the public health problems in Swaziland could be addressed through preventative measures. However, public health expenditure is limited and tends to be skewed towards curative care, even though preventive care is most likely to benefit the poor more. The accessibility of the poor to social and health infrastructure is limited by lack of income and mobility constraints.

One third of Swazi children are considered to be orphaned and vulnerable, with 130,000 children being orphans (World Bank, 2010b). The Swazi Demographic Health Survey from 2006-07 found that despite efforts to provide social assistance to vulnerable groups, the majority of OVC still receive no external support. The survey found that only 34 per cent of OVC received school-related assistance, eight per cent received social or material support and five per cent received medical support (UNDP, 2009: 29). Even though Swaziland has adopted more progressive policies to support access to education for OVC, the grants have only been partially and effectiveness of outreach is poor. To overcome gaps in access to education the Government is now beginning to phase in universal free primary schooling.
2.2 Economic and labour market characteristics

In the period after independence in 1968, Swaziland was characterized by impressive economic growth, propelled by the negative political developments that prevailed in Mozambique and South Africa. At that time many firms located in Swaziland in order to gain access to the South African market. However, drastic changes in economic growth occurred in the 1990s following political changes in both Mozambique and South Africa, and many firms relocated. Swaziland lost much of its foreign investment and the GDP growth rate plummeted from 12.9 percentage points in 1989 to 3.5 percentage points in 1999 (See figure 2). In 2009 GDP amounted to USD $3 billion (current USD), with a growth rate of 1.2 percentage points.

Figure 2: Swaziland growth trends (1980-2009)

Source: World Bank (2010a)

The Swazi economy, particularly the agricultural sector, is dualistic with a small number of highly developed commercial operators and a large number of informal subsistence farmers. The major crops include maize, cotton and sugarcane. However, agriculture accounts for only a small percentage of GDP, namely 7.3 per cent in 2009. Industry accounted for 49.4 per cent of GDP, while services accounted for 43.3 per cent of GDP in the same period (World Bank, 2010a). The Swazi economy is also very closely linked to South Africa. It exchanges 90 per cent of its imports and 70 percent of its exports with South Africa (UNDP, 2009). Swaziland imports its staple food, maize, and imports have been increasing while domestic production
has been declining. These declines are largely attributed to environmental hardship (drought) and loss of productivity due to HIV related factors.

Swaziland is not considered to be a resource rich country, and recent policy advice for driving development and economic growth in the country has therefore tended to recommend knowledge and technology driven options, as well as skilled labour export to surrounding resource rich countries (World Bank, 2010b). However, Swaziland’s falling socio-economic indicators have seen the stock of human capital depleted and capacity to produce a skilled workforce is an ongoing challenge. Preventing the further spread of HIV and fostering inclusive growth in order to allow the majority of the labour force access to improved social and labour market opportunities is highly important to prevent further social stratification.

The unemployment rate has been increasing over the years, and was reported at 28.2 per cent in 2008 (World Bank, 2010a). The youth are the hardest hit, with an unemployment rate of 60 per cent. The labour force participation rate across the population is low, at 63.4 per cent, when compared to countries that have similar poverty statistics. This is most likely due to the high incidence of HIV. Many workers are engaged in the informal economy in low productivity agriculture and are vulnerable to environmental shocks, such as drought. Growth in formal sector employment has been static, which leaves new labour force with few options and many turn to the informal economy as unemployment is not a viable option. Employment elasticity estimates are comparatively low in Swaziland, meaning that for every 1 percentage point increase in economic growth, employment would increase by 0.6 percentage points (ILO, 2009).

The informal economy mainly consists of small and medium enterprises (SMEs). The SMEs in Swaziland are found in transport, farming, marketing, manufacturing and distribution of handicraft, microfinancing, training and food processing. Structures that typically support SMEs to increase their economies of scale, such as business associations and the cooperative movement, are weak (Hlatshwako, 2010). Over 40 per cent of firms in Swaziland expect to make informal payments to public officials for the processing of licenses and meeting regulations (World Bank, 2010a). Firms report that these practices, along with high tax and high crime rates, are the major challenges that they face in their business.

Gender-based constraints are a major concern in the economy. Swazi tradition tends to accord women a position of strength and power at domestic level, but there are structures that have perpetuated inequality and constrained their involvement in the economy. One of these factors is associated with the Swazi law and custom, which denies women direct access to property and loans. The second is the customary land tenure system that vests control of land in men, and the third is the general under-representation of women in the public sector (Keregero and Keregero, 2000).
2.3 HIV and AIDS

Swaziland is one of the countries that is most affected by HIV and AIDS. In 1993, the epidemic was declared to be a national disaster and as it worsened, it was declared to be a national crisis. Swaziland currently has the highest HIV prevalence rate in the world, at 25.9 per cent (UNAIDS, 2010). It also has a very high HIV incidence rate, meaning that for every 100 people without HIV, three will become infected every year (See table below). The HIV epidemic is having a devastating impact in both economic and social spheres.

Table 1: HIV in Swaziland

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Estimate</th>
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<tbody>
<tr>
<td>Adult HIV prevalence, 2010</td>
<td>25.9%</td>
</tr>
<tr>
<td>Estimated number living with HIV, 2007</td>
<td>Range between 171 000 to 187,937</td>
</tr>
<tr>
<td>Women as percent of adults living with HIV and AIDS</td>
<td>59%</td>
</tr>
<tr>
<td>Annual rate of new HIV infections in adults aged 15 to 49</td>
<td>3%</td>
</tr>
<tr>
<td>Projected number of new infections in adults in 2008</td>
<td>13,060</td>
</tr>
<tr>
<td>Projected number of new infections in children in 2008</td>
<td>3,147</td>
</tr>
<tr>
<td>Projected AIDS deaths amongst adults in 2008</td>
<td>9,247</td>
</tr>
<tr>
<td>Projected AIDS deaths amongst children in 2008</td>
<td>2,711</td>
</tr>
<tr>
<td>Estimated (total) number of orphans in 2008</td>
<td>Range between 110 460 to 117 373</td>
</tr>
</tbody>
</table>

Source: Government of Swaziland (2009)

HIV prevalence across regions has followed a trend similar to the national outlook, however HIV is more common in urban than in rural areas. Young adults are more vulnerable to becoming infected with HIV than other segments of the population. Overall, women are more likely to be HIV positive than men. According to the Swaziland Demographic and Health Survey (2006 – 2007), HIV prevalence was higher among those without formal education than those with education. The main method of transmission of HIV is through heterosexual intercourse.

The proportion of the population with HIV in need of antiretroviral treatment is much greater than that receiving it, with only 64 per cent of women and 36 per cent of men who are eligible receiving the treatment (Government of Swaziland, 2009). The National Multi-sectoral Strategic Framework for HIV and AIDS 2009 – 2014 notes that (2009, 54):

“Stigmas, fear of abuse and youth unfriendly services remain obstacles for people to access treatment. Some women are unable to disclose their status within their families and to their in-laws for fear of rejection and stigmatisation, and often drop out of treatment. Other women are said to hide their tablets from their husbands in fear of being ostracized, resulting in poor compliance with treatment schedules.”
There is a need for services that are accessible, discreet and supportive. Involvement of communities and members of the social economy are key in this regard. However, initiatives that have supported community based programmes have tended to be inadequately resourced and operated by volunteers. Moreover, support for decision-making and planning within communities has been limited, and the capacity of communities to implement community based responses needs to be strengthened.

OVC are greatly affected by HIV and AIDS through death or loss of productivity of family members, and their need for care and support is stretching the capacity of the Government to deliver. Two-thirds of orphans have been affected by parents dying of HIV-related illnesses (UNDP, 2007). Care of OVC has therefore become a critical issue and amadladleni (neighborhood care points) have been used to provide care and psychosocial support.

The national response to HIV and AIDS has evolved in six phases over 20 years. The current phase is the “National Multi-sectoral Strategic Framework for HIV and AIDS 2009 – 2014”. The initiative builds on the previous frameworks and the National Multi-sectoral HIV and AIDS Policy of 2006. It mainstreams gender and human rights issues. It adopts a results-based management approach, while creating opportunities for decentralization. The framework also gives consideration to building synergies between Swaziland’s overall development priorities and the HIV and AIDS response.

Over the years the national response to HIV and AIDS has been able to raise public awareness, introducing a national antiretroviral treatment programme. It has introduced mandatory screening of donated blood for HIV, syphilis and Hepatitis B, introduced a HIV national sentinel surveillance system, and provided a fund for supporting school fees for OVC. The response has been multi-sectoral, and included a combination of extension of health support services, as well as community based initiatives and education programmes. However, the persistent and high prevalence of HIV, and its impact on the economy and society, has behooved a new approach.

The National Multi-sectoral Strategic Framework for HIV and AIDS 2009 – 2014 has four thematic areas, including prevention, treatment and care, impact mitigation and response management. Prevention focuses on awareness raising, voluntary counseling and testing, prevention of mother to child transmission and male circumcision. Care, support and treatment interventions that are supported by government and donors are designed to prevent the onset of opportunistic infections and promote early detection and treatment of infections. Services provided have therefore supported the uptake of antiretroviral, treated opportunistic infections and provided home based care services. Impact mitigation seeks to support OVC and PLHIV, while response management focuses on coordination, monitoring and evaluation and sustainability. Human resource development, retention of skilled workers and local ownership are therefore priorities. The framework is guided by principles including:

- Prioritization of measurable impacts and outcomes;
- Evidence-based choices;
• Gender equality and equity;
• Mainstreaming;
• Meaningful involvement of PLHIV;
• The three ones principles;
• Knowledge management;

All government and non-governmental agencies have been called upon to mainstream HIV and AIDS in their operations. The framework sees representative bodies from the social economy playing a key role in coordination and implementation through their decentralized networks. However, it also recognizes that the potential of civil society organizations has not been realised due to lack of resources and inadequate capacity for resource mobilization.

3. The initiative in practice

The formation of SWAPOL in 2001 was a demonstration of courage and willpower by five HIV positive women who were encountering stigma and discrimination from their families and community members. It began in 1999 when its founding and current Director found out that she was HIV positive after taking a medical examination as a pre-requisite for a scholarship award. Her HIV positive status not only ruled her out of contest for a scholarship, but also subjected her to subsequent discrimination and stigmatization.

Initially established as a support group to empower families of PLHIV to cope, accept and deal with HIV, the group gradually evolved into a professional organization that was registered and incorporated in 2003 and transformed into an NGO in 2008. SWAPOL is now located in 54 rural communities scattered in Shiselweni (21), Manzini (17), Hhohho (13) and Lubombo (3). Selected communities where SWAPOL operates is shown figure 3.
The organization seeks to empower PLHIV so that they can have a better future and to provide access to treatment, care, support and healthcare to PLHIV. The mission of SWAPOL seeks:

To provide a holistic approach for improving the quality of life for the infected and affected people in rural communities, in an effective and efficient manner.

In many ways the SWAPOL initiative reflects the values and principles of organizations from the social economy. For instance, SWAPOL is an association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations. The ethical values of SWAPOL reflect those of a cooperative enterprise, in that they value honesty, transparency, accountability, gender sensitivity, confidentiality and being community driven.

Overall, SWAPOL has 19 members of staff and a Board of Directors (the organizational structure of SWAPOL is outlined in the figure below). The Director is the overall administrator of SWAPOL and is responsible for overall management of the organization, ensuring adherence to appropriate policies and procedures,

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1 The ethical values of cooperatives include honesty, openness, social responsibility and caring for others.
2 The Board of Directors composed of seven members drawn up as follows: Rev. B. Mkhumane (Chairperson), Dr. Khosi Dlamini (Medical Doctor), Dr. Thokozile Sibiya (Lecturer, University of Swaziland), Ms Ellinah Hlatshwako (Farmer and Founder Member), Mr. Simo Sihlongonyane (Government Accountant), Thulisile Dladla (Sewing Support Group Member) and Ms Siphiwe Hlophe (Founder Member and Director).
and supervising and appraising staff. She initiates and directs the development of proposals and plans for funding and resource mobilization. She also ensures that the implementation of activities is consistent with the action plan and monitors the implementation of projects as per targets. The Director serves as liaison and contact person between SWAPOL and the government, partners and collaborating NGOs, and reports to donors, the board, and the Annual General Meeting. She visits communities to get first-hand information on the situation and scrutinizes government policies for HIV and AIDS.

**Figure 4: Organizational structure of SWAPOL**

[Diagram of organizational structure]

**Source:** SWAPOL

The National Coordinator is responsible for organizing, monitoring and management of SWAPOL activities, management of organizational records and preparation of reports for submission to partners. Other members of staff include officers responsible for finance, monitoring and evaluation and human resource. The specialized operational areas have various dedicated project officers.

The partners of SWAPOL consist of donors, the Government and working collaborators. As an NGO, SWAPOL is recognized by the Government, which provides it with medicine, VCT equipment and accessories. Funding for SWAPOL is largely derived from grants, donations and contributions from local and external sources. This financing arrangement has implications for organizational

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3 Donors include: OSISA, the Stephen Lewis Foundation, AWDF, NERCHA, UNICEF, Children of Africa Fund and SAC. The key working collaborators include: ICW, LDS, AMICAALL, SWAN-NEPHA, Council of Swaziland Churches, TASC, FLAS, Imbita Women’s Finance Trust, SWAGAA, WILSA, Yonge Nawe, CANGO, Save the Children, Ministry of Health – TB Programme, SFTU, SNAT, Ministry of Agriculture, FAO, UNICEF, UNAIDS, UNFPA, Swaziland Hospice at Home and WHO.
sustainability in the long run. Even though SWAPOL has been enjoying the benefits of generous funding, the management is cognizant of the bleak future in foreign funding. The organization’s strategic plan has cautioned that excessive dependency on foreign donor support can reduce opportunities for local resource mobilization and may impede the generation of innovative ideas that can ensure sustainable growth. SWAPOL has been investigating alternative funding strategies and has also been reviewing its overheads to ensure the organization is fulfilling its mission in an efficient and effective manner.

All the beneficiaries of SWAPOL activities are based in rural areas across all the four regions of Swaziland. Women constitute the overwhelming majority (98 per cent) of the beneficiaries. The beneficiaries are highly vulnerable and generally fall below the poverty line (SZL 128.60 per month / USD $22.00 per month) (UNDP, 2007). As such, they lack sufficient income to meet with basic daily needs. Moreover, many of the beneficiaries are female heads of households, who have been made vulnerable by either losing their spouse or have been “abandoned” by their spouse and extended family.

The main activities of SWAPOL are currently focused on HBC, agriculture and nutrition, capacity building, OVC, sexual and reproductive rights, and property grabbing, inheritance and law (See table below).

### Table 2: Activities of SWAPOL

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home-based care</td>
<td>SWAPOL provides HBC in-home care through family members with the support of skilled caregivers who are able to meet spiritual, material, psychosocial needs. This activity has been enhanced through an outreach mobile clinic, which provides services to 35 communities. The key services that are provided include treatment of opportunistic infections, monitoring of ARV, referral services, VCT and supporting caregivers.</td>
</tr>
<tr>
<td>Agriculture and nutrition</td>
<td>SWAPOL promotes food security and nutrition for PLHIV and their households, while also contributing toward greater dietary diversity. It has played an important role in the emotional well-being of the beneficiaries by lowering stress caused by insufficient access to food. This activity includes training PLHIV in gardening and agricultural skills, initiating income-generating activities and educating communities on the importance of good nutrition.</td>
</tr>
<tr>
<td>Capacity building</td>
<td>SWAPOL builds the capacity of community based support groups to organize, plan and implement their own programmes to respond to HIV and AIDS. SWAPOL supports the establishment and strengthening of community support groups of PLHIV by providing training on HIV and AIDS and TB, positive living, nutrition for PLHIV, HBC, community counselling, treatment literacy (ARV and TB literacy), leadership for good governance and project management.</td>
</tr>
</tbody>
</table>
Orphans and vulnerable children

SWAPOL has registered a number of HIV positive OVC and provided food and transport for them to go for medical checkups. It has identified 425 OVC and paid school fees in full (including uniforms) for 350 of them. The programme targets child-headed households and other extreme cases. SWAPOL also works with NCPs to strengthen community coordination and the support/referral services that they provide to OVC.

Sexual and Reproductive Rights

SWAPOL advocates for women’s issues, particularly sexual rights for HIV positive women. This involves scrutinizing sexual and reproductive health policies with a view to finding gaps that ought to be addressed. The policies and guidelines being examined are: The Second National Multisectoral HIV and AIDS Policy, the PMTCT Guidelines, the national HIV and AIDS Clinical Care Guidelines, HIV Testing and Counseling Guidelines, and Antiretroviral and PEP.

Property Grabbing, Inheritance and Law

SWAPOL supports widows and children who are vulnerable to property grabbing by in-laws and by family members through provision of legal assistance. It has established a legal advice centre and prepares cases to be taken to court. It has also organized forums to discuss inheritance laws and the effect they have on women and widows, in order to support access to justice.

Source: SWAPOL

Through its interventions, SWAPOL has provided easy access to treatment and medication through its mobile clinic, enabled PLHIV to refill ARVs and access treatment, and enhanced the open distribution and collection of condoms. This is important, as awareness raising activities increase demand for services, support and products that facilitate safer sex – and it is crucial that this demand be met while also ensuring that people do not feel judged for accessing such facilities. The monitoring of ARVs by caregivers has helped most PLHIV to continue taking their medication.

There has been a perceived improvement in the sexual behaviour of people in communities where SWAPOL is working, which may have contributed to a reduction in the number of new HIV infections in these areas. Community members are also more knowledgeable about HIV and AIDS, which has helped to reduce stigma and discrimination and led to greater freedom and openness in talking about HIV and AIDS. As a result, people are increasingly visiting SWAPOL offices for voluntary testing and counseling (VCT).

At the local level, SWAPOL has built a strong network of support groups in communities that directly impact on the day-to-day lives of members and non-members in their collective response to HIV and AIDS. As a result, community ownership of the programme has grown, with local support groups dictating the direction of the programmes. In the communities where SWAPOL works, it plays
an important role in helping PLHIV to live a positive life by encouraging good nutrition, exercise, monitoring ARVs and participation in community activities. It has given support to OVC and widowed women who have often encountered property grabbing from family members. The introduction of agricultural and nutrition projects has enabled PLHIV to eat a more balanced diet, while also enabling them to generate income through sale of surplus produce.

As an NGO, SWAPOL faces challenges and constraints in implementing its mission and carrying out its activities. The social context means that there is enormous demand for the services provided by SWAPOL, but it is constrained by the resource limitations that have implications for both service quality and outreach. The funding that SWAPOL receives is also intended for selected activities, which at times limits its ability to respond to the needs of members. This has behooved SWAPOL to strategize on financial viability, in order to strike a balance between dependency, sustainability and innovation.

Implementation of SWAPOL programmes is limited by structural constraints, such as an inability to pursue strategic litigation matters, as NGOs are barred from litigating on behalf of other people. SWAPOL also has to operate with the local political economy, which means that at times it has been unable to reach out to people because of chieftaincy disputes. As SWAPOL advocates for the disadvantaged and challenges local structures, it has had to tread carefully to ensure that its activities are primarily concerned with human rights activism rather than political activism. However, the common goal of living positively serves as a strong cohesive force for the survival of support groups and the organization itself.

Monitoring and evaluation tools that track service provision and outreach have recently been developed in order to enhance the efficiency and effectiveness of SWAPOL’s operations and to ensure that the initiative is in line with the National Multi-sectoral Strategic Framework for HIV and AIDS 2009 – 2014.

4. Views from the field

SWAPOL provides services to women with HIV who have been abandoned by their family, to orphans and vulnerable children who have lost their parents to AIDS and to other members of communities who have been affected by HIV. The people to which SWAPOL provides services have tragic stories.
Box 1: Celani goes to school

Celani lives with his two younger siblings and became head of the household after his mother died and father remarried. Celani’s father built a new house with his wife, but later he also became sick and died. When Celani’s father died his new wife claimed all the belongings, including roof materials, which had been left in Celani’s mother’s home. This left Celani and his younger brothers in a desperate situation.

Celani and his siblings were introduced to SWAPOL at the *amadladleni*, where they used to get their meals. Since then SWAPOL has supported the family by providing day-to-day basic necessities and scholarships for their schooling. SWAPOL has also got Celani involved in its agriculture activities and provided maize so that the family can produce some of its own food.

The founding members of SWAPOL also have tragic stories. For instance, the story of the founder of SWAPOL resonates strongly – she was denied opportunities for studying abroad and this loss was compounded by rejection from her family and community members. However, seeking coping strategies and searching for new social networks allowed her to channel their personal tragedy into a positive way forward.

Box 2: Positive living for widows’ support networks

Ellen is one of many women in Swaziland who lost their husband after they had gone abroad for work in South Africa. At that time people did not know what was killing these men, and concerned widows formed a support group. Through this group they managed to help those who were sick and operated gardens as an income generating project.

With time Ellen learned that her husband had succumbed to AIDS and as a surviving spouse, she saw the need to educate others about HIV and AIDS. She met the founding members of SWAPOL through community programmes that were educating women about HIV and AIDS.

For many PLHIV life becomes characterized by stress, helplessness, deprivation and a feeling of being unwanted. SWAPOL offers a support network, care services and opportunities that help people to come to grips with their HIV status, while also enhancing their livelihood through income generating activities. Importantly, the activities of SWAPOL are driven by the members of each localized support group. For instance, one support group in Mgomfelweni that has 30 members manufactures peanut butter, which they then sell to community members. The money raised is used to assist OVC in meeting their school fees. This activity allows the members of SWAPOL to work together in a productive setting that is socially supportive.
Box 3: An opportunity to connect with like-minded people

Goodness was pregnant with her third child in 2002, when her husband who was a soldier got sick. She convinced him through the help of a nurse to get tested for HIV and they discovered that they were both HIV positive. He died two months after she gave birth to her third child and, as per Swazi tradition and custom, she was forced to stay indoors after the death of her husband while her mother-in-law went to claim for his benefits from his employer.

Left with little support from her family network, Goodness was referred to SWAPOL. SWAPOL has helped Goodness to cope with HIV by providing counselling services and by providing opportunities for income generating through community gardening. She is also currently working as a home-based care-giver and also works with her amadladleni to provide counselling and motivation services. Her life has changed tremendously since joining SWAPOL and she values being associated with a network of people with similar circumstances to hers.

SWAPOL’s organizational approach mobilizes communities and organizes them into support groups. This approach demands that SWAPOL be relevant and responsive to communities’ needs. It also relies on each group’s ability to foster values such as self-help, self-responsibility, democracy, equality, equity and solidarity, which are needed for cooperative ventures. The support groups are the pillars of the SWAPOL initiative, providing strong grassroots advocacy networks that allow SWAPOL to have a strong voice at community, regional and national levels.

Box 4: Starting over with positive living

Thembi had a recurring back problem and was trying to get medical attention when a relative encouraged her to get tested for HIV. When she was found to be HIV positive, her lover left her. In the midst of depression she was referred to SWAPOL, which offered her a pathway to rebuilding her life. She now participates in SWAPOL activities through her amadladleni, which engages in gardening, sewing, producing seedlings and savings and credit cooperative. SWAPOL provided training on gardening, savings and credit, and bookkeeping, which has built the confidence and commitment of Thembi and the amadladleni members for positive living.

The outcomes accruing from collaboration or association with SWAPOL vary for each person who is involved, and can include access to treatment, a wage-income, proceeds from income-generating projects, payment of children’s school fees and home-based care services.
Many of the people involved in SWAPOL have reported to have regained a sense of purpose and recognized the need to live a positive and independent life. SWAPOL has provided them with the space to talk freely about HIV and AIDS and the confidence and skills to provide care services through cooperating with each other. They consider SWAPOL as a “safe haven” where they can talk freely about their status, share experiences with others, and assist each other with respect to living a positive and independent life.

**Box 5: Sharing knowledge and benefits**

Phindile is 30 years old and started taking ARVs in 2006 after she learned she was HIV positive. At that time she had a CD4 count of below 100. She contacted SWAPOL and started ARVs, and her health slowly began to recover. Phindile’s CD4 count is now more than 1000. Through SWAPOL’s home-based care programme, she was able to receive treatment at home and also through their mobile clinic, which greatly enhanced her comfort.

Phindile’s involvement with SWAPOL has boosted her confidence and she is no longer afraid of becoming destitute. She is now open about her status and has been teaching other people in the community about HIV and AIDS. She considers the training they have received in nutrition, home-based care and management as valuable for supporting the sustainability of her *amadladleni*.

The knowledge that SWAPOL members have gained has also instilled a spirit of activism, which questions the *status quo* and challenges society to come to grips with social issues. The attitude towards PLHIV in the communities where SWAPOL works has improved and there is increasing realization that HIV infection is not a death sentence. This has led to an increase in the number of people taking ARVs and generated pressure on government and policy makers to provide these services for free.

The support groups catalyzed by SWAPOL are motivated by their common economic, social and cultural aspirations and needs. However, many initiatives are funded through seeding funding that comes from donors, which affects sustainability. The key informants interviewed viewed the continued availability of reliable donors as the only realistic way of keeping the organization operational in the long-run.

However, it was also realized that this view is limiting and given SWAPOL’s ability to mobilize community members’, further consideration could be given to local ownership. While some services, such as health care services will need continued support in the future, the economic production activities that SWAPOL fosters could potentially adopt more sustainable operational models that allow members more economic participation.
5. Conclusions and lessons learned

The SWAPOL initiative is in line with the Government’s strategies that are guiding the national response to the epidemic. In this context, SWAPOL is operating as an implementing partner in realizing this policy. The disproportionate effects of HIV infections on women, especially for widows and OVC are the focus of SWAPOL. SWAPOL provides these groups with support and assistance to help reduce their vulnerability. For instance, SWAPOL offers legal assistance to avert incidences of unlawful property grabbing by family members.

SWAPOL has succeeded in building up a grassroots network of support groups whose members work cooperatively to meet their economic, social, and cultural needs. SWAPOL offers a support network, care services and opportunities that help people to come to grips with their HIV status, while enhancing their livelihood through income generating activities. Importantly, the activities of SWAPOL are driven by the members of each localized support group. Within the support groups a self-help spirit can evolve and has been mobilized to improve members’ livelihoods. The relevance of the projects to the real-life situations of support groups and community members, as well as the close working relationship with traditional leaders, has contributed to increased community ownership of SWAPOL activities. The support groups could be described as the pillars of the SWAPOL initiative, providing strong grassroots advocacy networks that allow SWAPOL to have a strong voice at community, regional and national levels.

SWAPOL has provided a space to talk freely about HIV and AIDS in communities throughout Swaziland. It has given its members the confidence and skills to provide care services through cooperating with each other. Subsequently, there has been reduced stigma and discrimination, increased enrolment into antiretroviral treatment programmes, increased adherence to ARVs, increased empowerment through knowledge and ability to engage in income-generating activities, and improved confidence in the desire to live positively among members of support groups.

As an NGO, SWAPOL faces challenges and constraints in implementing its mission and carrying out its activities. The social context means that there is enormous demand for the services provided by SWAPOL, but it is constrained by the resource limitations that affect both service quality and outreach. Implementation of SWAPOL’s activities is limited by structural constraints, such as an inability to pursue strategic litigation matters, as NGOs are barred from litigating on behalf of other people. SWAPOL also has to operate with the local political economy, which means that at times it has been unable to reach out to people because of chieftaincy disputes. Furthermore, as SWAPOL advocates for the disadvantaged and challenges local structures, it has had to trend carefully to ensure that its activities are primarily concerned with human rights activism rather than political activism. It also has to maintain good communication with government structures at the national and local levels to ensure that its actions and messages are not misperceived.
However, the common goal of living positively serves as a strong cohesive force for the survival of support groups and the organization itself. One of SWAPOL’s strengths is its ability to mobilize and organize community members. To make the initiatives of more sustainable, further consideration could be given to the relation between the organization and its members, as well as how the organization promotes members economic, social and cultural needs and aspirations.

An important issue that SWAPOL is grappling with is economic viability. It is currently reliant to a large extent on donor funding. Further consideration could be given to local resource mobilization and revenue-raising activities in order to take advantage of innovations that can support sustainable growth of the organization. For instance, the economic production activities that SWAPOL fosters could potentially adopt more sustainable operational models that allow local members more economic participation. Importantly, this lesson is not unique to SWAPOL. It applies to many NGOs and community organizations in Swaziland and beyond. It points to the need for organizations to identify strategies and common bonds that can forge commitment to cooperation, while allowing for diversity and independence among those cooperating.

A second issue is that although the change from a mere support group superstructure to an NGO has provided greater latitude and scope for SWAPOL activities, the new status has imposed limitations on the organization. Importantly, its ability to litigate on behalf of its members has been limited. This is a major setback to SWAPOL in its effort to provide support and legal assistance to widows and OVC whose property has been, and is being unlawfully grabbed by family members. It may be useful for SWAPOL to evaluate the various alternative organizational structures available in Swaziland to see if another organizational structure is more suitable for providing such services. Supporting policy reform processes should also be considered, as should the forging of partnerships with like-minded agencies that are able to take legal action.

In summary, positive living is a strong cohesive force that has enhanced the spirit of cooperation, willingness to help one another, motivation to live, feeling of safety and belongingness among members of SWAPOL. This has given enormous strength and power to grassroot structures and enhanced the spirit of local ownership within the organization.
List of references


Positive living with HIV in the Swazi social economy
Swaziland has been severely affected by HIV, with estimations indicating a prevalence rate of 25.9 per cent. The development challenges that accompany such an epidemic are substantial, requiring multifaceted and innovative responses from government and communities in order to prevent transmission, improve access to treatment and care, and mitigate social and economic impacts. One such response is the Swaziland Positive Living (SWAPOL) initiative, which was formed in 2001 as a coping strategy for five HIV positive women who were encountering stigma and discrimination from their families and community members. For the SWAPOL members, the common goal of living positively has served as a strong cohesive force for the survival of the initiative. The initiative's developmental approach gives members the opportunity to access services and build their capacity within a supportive environment. This working paper provides an overview of the SWAPOL initiative and outlines the challenges and constraints with which it has had to come to grips.