Nurturing a community-based response:  
A special report on the impact of ActionAid’s  
HIV/AIDS work during 1998
Acknowledgements:

The Impact Assessment Unit would like to thank the many people who have contributed in various ways to this report. Madhulika Choudhary, Helen Elsey, Clare Ansell, Alice Walter and Linnea Renton were all involved in pulling together information on activities and impact. Advice, support and critical written input also came from Jackie Bataringaya in Harare, Janet Duffield in Mozambique, Elizabeth Ongom in Uganda, Nafeesur Rahman in Bangladesh, Dede Bruku in Ghana, Ebrima Sowe in The Gambia, and John Nugugi in Kenya. The Impact Assessment Unit hopes that this report accurately reflects the realities of change as identified by community groups, partner organisations and ActionAid country programme staff.

Impact Assessment Unit
ActionAid
August 1999
List of acronyms

AIDS  Acquired immune deficiency syndrome
CASM  Centre for Advocacy and Social Mobilisation (Bangladesh)
CBO  Community-based organisation
Cedar  Concern for Environmental and Development Research (Bangladesh)
DACU  Disability and AIDS Co-ordination Unit (Bangladesh)
DFID  Department for International Development (UK)
EUDO  Entebbe United Development Organisation (Uganda)
Gasco  Gomba AIDS Support and Counselling Organisation (Uganda)
HIV  Human immunodeficiency virus
Kango  Kenya AIDS NGO Consortium Organisation
Monaso  Mozambique Network of AIDS Service Organisations
Nacwola  National Community of Women Living with HIV/AIDS (Uganda)
NGO  Non-governmental organisation
SED  Social and Economic Development (Uganda)
SFA  Strategies for Action
SFH  Strategies for Hope
TASO  The AIDS Support Organisation (Uganda)
Theca  Traditional Healers Educators and Counsellors for AIDS Awareness (Uganda)
UNAIDS  Joint United Nations Programme on AIDS
Unaso  Uganda Network of AIDS Service Organisations
UTPS  Unity through Population Services (Bangladesh)
WHO  World Health Organisation
YAAC  Youth AIDS Association Chawente (Uganda)
ZNNP+  Zimbabwe National Network of People living with HIV/AIDS
ZAN  Zimbabwe AIDS Network
Summary

This report shows that ActionAid is now widely recognised as having particular expertise in the area of HIV/AIDS work, especially in sub-Saharan Africa. ActionAid’s work differs from that of other international NGOs because it concentrates on promoting a community response to HIV/AIDS. Seeing the real long-term success of ActionAid’s work therefore requires an ability to assess behaviour change. This is complex at the best of times, but when we are talking about sexual behaviour it is particularly difficult. Attributing such changes to the work of one local organisation or to a set of activities carried out by ActionAid is equally problematic.

Despite the difficulties (and often the absence of corroborative information from different stakeholder groups) it is clear from the evidence available that some degree of change is occurring. These changes can be identified at several levels – the individual, the community, the national and the international. This report analyses the outcome, impacts and influence of ActionAid’s work at these four levels. In conclusion, it shows that ActionAid’s HIV/AIDS work is innovative and is having some localised impact. ActionAid needs to capitalise on the strength of this work and continue to develop its HIV/AIDS programme by continuing to try to influence key Northern and Southern institutions to take effective action to the AIDS pandemic.
Introduction

ActionAid needs to know about the lasting change its work – and its partners’ work – has on the lives of the men, women and children that it is trying to help. This change might be intended or unintended. It might be positive as well as negative. Understanding change is important not just to donors, or supporters, it is also crucial for ensuring that interventions are constantly improving the lives of people that they are intended to benefit.

One way to look at ActionAid’s work is to assess expenditure. During 1998 ActionAid spent £43.4 million on programmes across the world. In Africa, ActionAid worked in 14 African countries, reaching nearly 300,000 families in 39 project areas. In Asia ActionAid worked in five countries spanning 105 project areas. 1998 saw the first full year of ActionAid’s work in Latin America. The programme covered seven project areas in four countries: Guatemala, Haiti, Dominican Republic and Brazil.

However an analysis of expenditure does not tell us about the effectiveness of the work. In order to do that we need to look in depth at what changes are occurring as a result of that expenditure – and at whether those changes are improving people’s lives. One important way to assess change, or impact, is to look across the regions on a thematic basis. As ActionAid increasingly develops a strategic approach, and its work becomes more international, it will become more important to look across the entire programme. This report does precisely that. It concentrates on one key aspect of ActionAid’s work – that of HIV/AIDS.

This report examines the outcomes, impact and influence of ActionAid and ActionAid’s partners’ work on HIV/AIDS during 1998. It is split into six sections:
1. Section one briefly examines the development of HIV/AIDS work within ActionAid’s programmes
2. Section two provides an overview of the spread of the epidemic world-wide
3. Section three summarises ActionAid’s and its partners’ work across the world during 1998
4. Section four looks in more detail at ActionAid’s work in three countries:
   - Uganda – where ActionAid supports local community-based organisations to carry out innovative support and counselling work in their communities
   - Mozambique – where, by contrast, ActionAid is supporting national movements and networks
   - Bangladesh – where ActionAid is supporting local community-based organisations and NGOs which focus on work with groups vulnerable to high-risk behaviour.
5. Section five attempts to draw together the evidence and assess the outcomes, impact and influence of ActionAid and ActionAid’s partners’ work on HIV/AIDS during 1998
6. Finally, in section six we analyse some of the challenges that face ActionAid’s HIV/AIDS work as we move into the next millennium.
1. The development of ActionAid’s HIV/AIDS work

How the work began

Since AIDS was first recognised in the early 1980s, ActionAid has built up a significant amount of experience in both HIV/AIDS prevention, support and care for individuals and families affected by the epidemic. ActionAid responded to people’s needs and as such the focus of the work was initially at grassroots level. However, as the work developed, these experiences have also fed into influencing work both through advocacy campaigns and through the spread of best practice.

Initial programmes

The starting point for HIV/AIDS work was in 1987 when ActionAid provided financial and technical support for the founding of The AIDS Support Organisation (TASO) in Uganda. TASO was set up at local level by a group of Ugandans determined to do something practical to help people with HIV/AIDS and their families. By late 1990 almost 5,500 clients were registered with TASO at centres throughout the country. These centres provided counselling, HIV/AIDS education, medical care and material assistance.

Unite against AIDS photo

In 1989 ActionAid initiated a series of publications under the title Strategies for Hope with the aim of promoting positive thinking and practical action in the field of HIV/AIDS care, support and prevention, particularly in sub-Saharan Africa. The series produces and distributes books and videos that document successful, innovative responses to HIV/AIDS work by NGOs and community groups.

As the impact of HIV/AIDS in sub-Saharan Africa became more and more apparent in the early 1990s, ActionAid decided to build on the experiences gained from its support to TASO and the Strategies for Hope series. To this effect, Strategies for Action was introduced as a pilot in Uganda and Malawi in 1992. The Strategies for Action programmes operate at national level and focus on supporting community-based responses to the effects of HIV/AIDS. The Strategies for Action programmes have flourished in Uganda and Malawi where they continue to provide support to over 100 local AIDS projects and networks.

2. Photo. “Care and counselling helps people with HIV/AIDS to live positively”

Through the Strategies for Hope series a training package named *Stepping Stones* was published in 1995. This consists of a manual and workshop video which set out a participatory approach to working with communities on issues of HIV, gender, communication and relationship skills. Unlike many training packages *Stepping Stones*
offers follow-up support to its users, through the Stepping Stones Training and Adaptation Project.

The development of HIV/AIDS work within ActionAid’s country programmes

Since the mid-1990s all ActionAid country programmes in Africa (with the exception of Somaliland) have developed an HIV/AIDS component to their work. Recent emphasis in the Africa region has been on how to integrate HIV/AIDS issues effectively into all aspects of its programme work and how to initiate work in countries worst hit by the epidemic (eg Zimbabwe).

ActionAid programme response in Asia has been slower, perhaps due to the slower onset and different characteristics of the epidemic in this region. However, ActionAid Bangladesh has been working with partner organisations to increase awareness of HIV/AIDS since 1995. As yet, the young ActionAid programmes in Latin America have not begun any systematic work in this area.
2. World-wide overview of the HIV/AIDS epidemic

The facts world-wide

- 47 million people have been infected with HIV since the beginning of the epidemic
- 5.8 million people were newly infected with HIV in 1998
- 13.9 million people have died from AIDS since the epidemic began
- 33.4 million people are living with HIV/AIDS, including 1.2 million children
- 43% of people living with HIV/AIDS are women

The Global Report, UNAIDS, December 1998

ActionAid’s work is severely affected by the AIDS epidemic. Not only has ActionAid lost a considerable number of staff to the disease, but the disease also undermines development work throughout the world. This is an appalling human tragedy in any terms. According to UNAIDS more than 95 per cent of all HIV-infected people now live in the developing world – which has also experienced 95 per cent of all deaths from AIDS. The repercussions of this pose a huge threat to development – declining child survival rates, falling life expectancy, overburdened healthcare systems, increasing numbers of orphans, labour shortages and falling business profits are some of the indicators. Between 25 and 50 per cent of Malawi’s education and healthcare staff are expected to have died of AIDS by the year 2005.

Africa is the epicentre of the epidemic. It is said that 70 per cent of the people who became infected with HIV in 1998 live in sub-Saharan Africa. Today there are an estimated 21.5 million adults and 1 million children living with HIV in sub-Saharan Africa.

No country in Africa has escaped the virus, however there are regional variations. The bulk of new infections are concentrated in southern Africa, which now demonstrates easily the highest prevalence rates of HIV infection. In Zimbabwe, Zambia, Namibia and Botswana between 19 and 26 per cent of the adult population are infected, while around 10 per cent are infected in the east African countries of Kenya, Uganda, Ethiopia, Rwanda and Tanzania.

10 million people living with HIV/AIDS in India

Prevalence rates in Asia are currently less immediately alarming with Cambodia the highest at 2.4 per cent. However in the larger countries, such as India, the numbers infected are extremely alarming. In Latin America and the Caribbean prevalence rates
HIV/AIDS presents special problems because it is a new disease, there is no cure, no vaccine and, to date, there is no cheap and effective treatment. (The combination therapies available to infected people in the North are neither affordable nor accessible to those in South.) Moreover infected people do not show symptoms for many years, and therefore each infected person may unknowingly infect many others. In addition the stigma that still surrounds HIV hinders people from protecting themselves and others from infection, or from seeking care and support.

- It is estimated that there will be 10 million AIDS orphans by the year 2000 – more than the combined populations of Scotland, Wales and Ireland
- There are more than eight million orphans in Africa alone.

In summary, the epidemic is far from being under control. HIV/AIDS hits people during their most productive years (between the ages of 15 and 49) and the numbers of people affected by the impacts of HIV/AIDS are much higher than those infected. This has huge implications for the capacity of countries to escape from pervasive poverty. The tragedy of the epidemic will increase as more people infected with HIV fall sick.
3. ActionAid’s response: An overview by country of ActionAid’s and ActionAid’s partners’ work during 1998

Given the extent of the problem, what is ActionAid’s response? This map juxtaposes the HIV/AIDS prevalence rates with a brief overview of ActionAid’s work in 16 African and Asian countries, including work undertaken during 1998.

Africa

Burundi
Work began in the autumn of 1998 with the appointment of an HIV/AIDS co-ordinator, and ActionAid Burundi is now working in partnership with the National AIDS Control Programme. In 1998 it:
- initiated a network of HIV/AIDS projects in Ruyigi region
- networked nationally and conducted sensitisation workshops at local level.
The Burundi programme had a small initial budget of £14,417, as work was just beginning¹.

Ethiopia
Ethiopia has a well-established HIV/AIDS programme and is supporting five local initiatives, mainly in prevention but increasingly in care and support. In 1998 it:
- carried out successful national level lobbying (with a range of national networks) for the ratification of the national HIV/AIDS policy
- carried out collaborative sensitisation work in two project areas with the Ministry of Health
- supported a national radio campaign. It also funded and influenced the script of a successful TV programme
- specifically targeted sex workers in two urban project areas.
Expenditure in 1998 was £28,000.

The Gambia
The Gambia’s programme in HIV/AIDS is fairly small and focuses on the Stepping Stones package which (in collaboration with four partner organisations) was piloted in three communities. ActionAid is also carrying out collaborative community sensitisation work with the Ministry of Health in four programme areas.

Ghana
In Ghana ActionAid:
- carried out Youth Peer Education and radio programmes for community sensitisation in two regions in conjunction with Unicef and the Ghanaian Red Cross Society
- carried out HIV/AIDS sensitisation work and staff training in three programme areas
- trained children in HIV/AIDS and sexually transmitted diseases awareness

¹ Information on expenditure in some countries is not available due to the HIV/AIDS work being fully integrated into other country programme work.
• gave financial support to a students group for HIV/AIDS training
• completed a collaborative study on *Migration and HIV/AIDS*, which culminated in an international seminar.
Expenditure in 1998 was £51,000.

**Kenya**
ActionAid Kenya plans to increase the HIV/AIDS component of its work throughout its programme areas. In 1998 it:
• collaborated with the Ministry of Health to carry out sensitisation in 15 programme/project areas
• provided managerial and technical support to 45 local AIDS organisations
• together with the HIV/AIDS national consortium, which it is actively involved in, successfully lobbied the government to pass a bill regarding protection of the rights of people affected by HIV/AIDS. This is the most influential Kenyan organisation working on networking and advocacy
• made a concerted effort to train staff at all levels in HIV/AIDS issues.
As HIV/AIDS work is integrated at the programme level, separate budget details are not available for 1998.

**Liberia**
Initial work in Liberia was carried out through cross-border initiatives from Ghana and Sierra Leone. In 1998 communities were sensitised through peer counsellors in one district.

**Malawi**
ActionAid Malawi has the largest national team working on HIV/AIDS. Its Strategies for Action programme was established in 1992 and:
• works in 20 out of the total 26 districts
• provides training and capacity-building to 47 local AIDS projects and 16 networking bodies
• at national level, lobbied for appropriate changes to the Ministry of Health’s National Aids Control Programme.
Expenditure in 1998 was £129,000.

**Mozambique**
ActionAid Mozambique has been formally working on HIV/AIDS since 1997. It works at three distinct levels:
• at the national level ActionAid focuses on strengthening Monaso (an umbrella organisation for NGOs, church groups and self-help groups) and collaborating with Kindlimuka (an association of people living with AIDS)
• at provincial level ActionAid promotes collaborative work through Monaso in the area of counselling, social mobilisation and support to people living with AIDS
• at local level, ActionAid works (both directly and through partners) in four project areas and surrounding regions, to stimulate community responses to HIV/AIDS. Target groups include vulnerable women, police and youth.
During 1998 the Mozambican programme cost £101,318.
Rwanda
ActionAid Rwanda has recently recognised HIV/AIDS as a key area in its country strategy paper. During 1998 initial work focused on identifying partners and submitting funding proposals to donors.

Sierra Leone
ActionAid’s work on HIV/AIDS is still in its early stages although during 1998:
- ActionAid Sierra Leone carried out community sensitisation projects in three project areas
- staff were trained in HIV/AIDS awareness.

Uganda
Uganda has a strong, national Strategies for Action programme, which was established in 1992. It works with 30 local NGOs, community-based organisations and networks in 13 districts and all seven ActionAid project areas. During 1998:
- at the national level it played a major role in facilitating the formation of the Ugandan Network of AIDS Support Organisations
- the Ugandan programme hosted a regional documentation workshop to increase capacity to document experiences and best practice
- the ActionAid team also built the capacity of ActionAid staff so that they felt confident to use the Stepping Stones methodology
- ActionAid Uganda made progress in integrating AIDS work into all aspects of their development programme.
Expenditure in 1998 was £166,000

Zimbabwe
Co-ordination of ActionAid’s networking and advocacy work is carried out from ActionAid’s Africa regional office in Zimbabwe. In 1998:
- a Strategies for Action programme was established which now has secured funding for three years
- ActionAid provided technical support for two Stepping Stones workshops which were held for the Zimbabwe AIDS Network
- a training programme on monitoring and evaluation of HIV/AIDS and sexual health was held
- the first Stepping Stones workshop was held exclusively for people with AIDS.
Zimbabwe has an annual budget of £60,000 for HIV/AIDS work.

Asia

Bangladesh
The Disability and AIDS Co-ordination Unit works through 13 partner organisations. It:
- focuses its work on street children, sex workers, truck drivers and garment factory workers
- carries out innovative work to raise awareness among religious leaders and members of parliament
- during 1998 sponsored a hot-line service on sexually transmitted diseases, HIV/AIDS and confidential testing.
The total budget for 1998 was £35,000.
India
During 1998 ActionAid India:
- established an HIV/AIDS unit and developed a start-up strategy
- forged strategic alliances with two networks and initiated six collaborative projects
- conducted HIV/AIDS sensitisation workshops for all programme staff
- collaborated with partners to produce a CD-ROM on HIV.

Nepal
ActionAid Nepal has recently begun work on HIV/AIDS, and in 1998 carried out a review into existing activities in the country with a view to elaborating a strategy for its own work. It is now working with two partner organisations in two project areas to carry out an HIV/AIDS integrated community development programme and is also working with communities to raise awareness of the sexual health consequences of girl trafficking.

Pakistan
ActionAid Pakistan’s HIV/AIDS work is in its early stages. It is now planning to integrate HIV awareness with existing health programmes, while during 1998:
- a network of government and NGOs was formed during a World AIDS Day seminar organised by ActionAid Pakistan
- a working group was set up to look at what response the ActionAid team could make to HIV/AIDS.
4. Looking in more depth

In this section, we look in more depth at ActionAid and ActionAid’s partners’ work during 1998 in three countries – Uganda, Mozambique and Bangladesh. The case studies were chosen to reflect three different ways of working. In Uganda ActionAid supports local level community-based organisations which are working to change behaviour and practice in their communities; in Mozambique ActionAid supports capacity-building of national networks; and in Bangladesh ActionAid is supporting a number of partners which are trying to change high-risk behaviour. In each case study we outline the national response to the epidemic, provide an overview of ActionAid and ActionAid’s partners’ work during 1998, and discuss what difference, or what impact, this work is having on people’s lives.

Case study 1: Nurturing local organisations: Strategies for Action in Uganda

Uganda has become synonymous with HIV/AIDS in sub-Saharan Africa. This is partly due to the high levels of recorded HIV/AIDS cases in the early years of the epidemic, but also due to the extent and visibility of the response. President Museveni was the first African leader to face up to the challenge of AIDS and provide the political will to encourage an effective response. Civil society also took a strong lead in providing prevention, care and support. Prominent people living with HIV/AIDS spoke publicly about their situation creating a more open and tolerant environment. These combined responses have ensured that Uganda is now one of the very few countries that can boast a decline in new HIV infections. ActionAid Uganda played an important role in this response through supporting local organisations (for example TASO).

It is this approach of nurturing small local organisations that underpins ActionAid Uganda’s Strategies for Action programme. During 1998 Strategies for Action supported 30 organisations working on HIV/AIDS in 13 districts of Uganda. The level and nature of support that each organisation receives from Strategies for Action is tailored to meet its needs and support them to move towards the ideal of sustainability. In reality many community-based organisations are not self-sustaining. However an extensive participatory review of the Uganda Strategies for Action programme in 1998 showed that many of the local organisations have been able to make some improvements in the situation of people living with AIDS and increase awareness and support for communities struggling with the impacts of AIDS. This case study highlights the difference that community-based organisations are making in five areas of their work: influencing behaviour change; working with traditional healers; support and counselling; supporting income generation; and caring for orphans.

1. Influencing behaviour change

The Strategies for Action supported groups are using a variety of strategies to promote behaviour change. One popular strategy is to train and support AIDS educators. The
educators are trained in communication skills so they can discuss HIV/AIDS issues effectively with all the members of their communities (for example the Bugarama Women’s club works with women and youth). The social map below was drawn during the Strategies for Action review to assess the extent of the outreach work of AIDS educators from the Youth AIDS Association in Chawnte.

**SOCIAL MAP.... YAAC**

Several of the groups use drama and song as a vehicle for communicating and discussing HIV/AIDS in communities. One such organisation is Muni community group in Arua, northern Uganda. Muni have a very active youth ‘rap’ group who regularly perform their songs with messages of HIV/AIDS awareness targeted at the young people in the area.

The difference this work has made

It is very difficult to assess behaviour change – and even more difficult to attribute that change to particular activities or interventions. Nevertheless, during the Strategies for Action review community members identified several important changes that had taken place which, they said, were a result of the Muni group’s activities. These are shown in the ‘Before and Now’ diagram below.

**MUNI BEFORE AND NOW DIAGRAM**

2. Working with traditional healers

Another group that has had an impact on changing people’s behaviour, and increasing awareness about HIV transmission, is a group of traditional healers known as Theca. Traditional healers play a very important role in Ugandan healthcare. In rural areas about 75 per cent of the population consult a traditional healer before going to a medical clinic. In light of this, several traditional healers in the Kampala and Luwero areas formed a group and requested support from Strategies for Action to be trained as HIV/AIDS counsellors and educators. The Theca members identified many areas of their work that had changed because of the training. Significant changes are: greater cleanliness of instruments; not sharing instruments between patients; and importantly, a greater number now refer patients on to hospitals rather than trying to treat them themselves. Traditional healers talk of these changes:

“I used to give out love potions to women so they could attract lots of men. Now I counsel them to only have one partner. If they still want the love potion I give them condoms to use.”

Woman traditional healer, Luwero

“Now I keep everything clean and don’t share instruments between patients. I throw away all the dressings and boil any metal things.”

Woman traditional healer and birth attendant, Luwero

---

2 Traditional Healers Educators and Counsellors in AIDS Awareness.
One negative repercussion of ActionAid’s work with traditional healers has been a significant drop in their income. Whereas Theca members used to earn an average of US $200 (£140) a day, they are now finding it difficult to earn US $20 (£14). Greater honesty about what they can achieve through traditional remedies and higher referral rates have altered their earning capacity.

3. Support and counselling

Strategies for Action also works with many groups of people living with HIV/AIDS. Kuluva Hospital in Arua District has a very active HIV/AIDS programme supported by Strategies for Action. They provide counselling and medical care for people with AIDS and preventative counselling and life-skills development for young people. Some people living with AIDS in Kuluva have set up their own group to offer mutual support in the face of the stigma and rejection that many people living with AIDS experience. The effects of this support are very personal, however many people who receive support find the strength to share their personal experiences with others in their community. Such personal testimonies bring home to people the reality of HIV/AIDS and can play a powerful role as a prevention strategy. The Strategies for Action review highlighted the difference that counselling can have on people living with the virus:

“When I first tested positive I stayed in hiding and used to cry and cry and feel as if I was breaking down. So I felt I had to come out. I’ve learnt through the group how to talk about it openly. Now people can’t gossip about me as I am open about my real situation.”

Woman member of Kuluva support group

4. Supporting income generation and raising self-esteem

In recent years Strategies for Action has begun supporting many community-based organisations to set up and run small businesses. This has not always been successful – particularly in areas where markets are insufficient. Only three out of the thirteen small

---

3 SED: The Catholic Church of Uganda’s Social Economic Development Department.
businesses covered in the Strategies for Action review in 1998 were running at a profit. When they are successful though, income-generation schemes can bring a great feeling of dignity and worth back to the lives of people living with HIV/AIDS. A member of Nacwola4 explains how her small business has improved her life:

“When my husband died, I felt I had nothing left to live for. I felt useless and a burden to my relatives. The tailoring has given me something to do every day and when I am making the clothes I don’t think about any of my troubles.”

Nacwola member

5. Orphan support

Finally, one of the very visible impacts of AIDS in Uganda is the increasing number of orphans whose parents have died of AIDS-related illnesses. The extent of the problem prompted Strategies for Action to support the Entebbe United Development Organisation (EUDO) to work with street children.

The difference this work has made

Until a few years ago it was common to see street kids trying to eke out a living and survive on the streets of Entebbe. Nowadays, the numbers of street children has slightly reduced. EUDO has given the street children the opportunity to become involved in making handicrafts, which the group then sells to provide for the children’s needs. EUDO also has a drama and dance group of which many of the children are keen members. Being involved in these activities not only helps the children to have a better start in life, but also reduces their vulnerability to HIV/AIDS.

In summary, the Strategies for Action programme in Uganda is contributing in small but significant ways to influence behaviour change in localised communities. The support to local organisations is helping them to make small improvements in the lives of people living with AIDS and increase awareness and support for communities struggling with the impacts of the virus.

4 NACWOLA: The National Community of Women Living with HIV/AIDS.
Case study 2: 
Capacity building at national level: ActionAid’s HIV/AIDS work in Mozambique

The second in-depth study looks at ActionAid’s HIV/AIDS work in Mozambique during 1998. Here ActionAid’s work during 1998 concentrated on developing strong partnerships with organisations working at national level (as well as working with communities in four project areas). A three-year grant was secured for HIV/AIDS capacity-building work in April 1998. This helped finance work with two nation-wide organisations – Monaso (an umbrella organisation for NGOs, church groups and self-help groups) and Kindlimuka (an association of people with HIV/AIDS). This case study examines the effects this support had.

The context: HIV/AIDS in Mozambique

The first case of AIDS in Mozambique was identified in 1986. Wartime isolation had kept the country relatively immune from the AIDS virus then sweeping its neighbours in sub-Saharan Africa. But with the return of refugees (and a return to normal cross-border trade and traffic) AIDS has found a fertile breeding ground in a population desperately poor, with high unemployment, little access to healthcare, and low levels of education.

Despite the efforts of the over-stretched Ministry of Health, in 1998 the estimates of HIV infection in Mozambique were frightening – 14 per cent of people between 15 and 49 years are now believed to be HIV positive. And the number of cases of AIDS is rising. In the first three months of 1998, the number of new AIDS cases was more than the total new cases reported for 1997.

Developing work at national level: Support to Monaso

Monaso’s aim is to provide local NGOs/CBOs with training, access to information and advice, and support in linking them to donors. During 1998, ActionAid provided significant technical and financial (£22,976) support to Monaso work, helping Monaso with its aim to become an effective national support organisation. This support has taken a variety of forms:

♦ Training. During 1998, ActionAid supported Monaso at national and provincial level (in Zambezia and Maputo) in training of counsellors and activists

---

5 Mozambique Network of Aids Service Organisations.
6 Meaning ‘Wake up!’ in Shanganna.
Networking. ActionAid supported Monaso to network and exchange experiences and ideas with similar organisations (both within Mozambique and elsewhere in southern Africa)

Strategic planning. ActionAid supported Monaso’s strategic planning process and specifically contributed to the development of Monaso’s strategy on advocacy

Involvement of people living with AIDS/HIV. In 1998 ActionAid funded two members of Kindlimuka to network with sister organisations in Zimbabwe. ActionAid also funded a person from Zambezia living with HIV/AIDS to participate in the Monaso strategic planning process and provided funds for people living with HIV/AIDS to be involved in all Monaso activities (from counselling to supervision and co-ordination) in Zambezia and Maputo

Funding costs. ActionAid covered the cost of two salaries for Monaso in Zambezia as well as funding training and counselling programmes

Supporting information distribution. ActionAid has translated two Strategies for Hope books (numbers 12 and 13) into Portuguese. These books have been distributed throughout the country by Monaso after training from ActionAid in setting up a database for disseminating information

Increasing Monaso’s voice. During 1998 ActionAid supported Monaso to become a voice for communities at national level. ActionAid’s work has helped facilitate good links between Monaso at national and provincial levels and link Monaso to local organisations and activists.

The difference this work has made

The effects of ActionAid’s capacity-building work are hard to measure but nevertheless real. Monaso is an embryonic organisation, but becoming progressively stronger with ActionAid’s (and other agencies’) support. The work during 1998 can be said to have had the following effects:

Strengthening Monaso as an umbrella organisation

Monaso now constitutes a recognised national resource, especially at provincial level, supporting local initiatives as trainers of activists and counsellors, and as a mobilising force for community activity. Through 1998 it has gain:

- **Greater clarity about its role.** Through its strategic planning process, Monaso has developed a clear vision and role for its organisation
- **Increased capacity for information distribution.** Monaso now has a database of contacts for national distribution of information on HIV/AIDS. Following on from this work, it looks likely that Unicef will support them to set up a database on research materials available on HIV/AIDS
- **Increased funding.** ActionAid initially funded Monaso (and is still supporting core staff costs). However, as Monaso has grown in reputation it now attracts the support of other organisations
Increased collaboration. Monaso has facilitated collaboration between organisations and government health services, particularly in the area of increased access to HIV/AIDS counselling.

Furthermore, ActionAid’s support has helped Monaso develop strong links with local organisations. In particular the organisation has developed links with Kindlimuka and will be promoting the involvement of people living with AIDS in influencing work during 1999.

Strengthening advocacy and influencing

Monaso’s national advocacy work is still in its early stages. However, as a result of support from ActionAid and other donors, Monaso is now well placed to begin advocacy work in the area of counselling and in promoting collaboration with people living with HIV/AIDS.

Photo: “Think of life! Avoid AIDS”. Mozambique

Secondly, the organisation has made some headway in its influencing at provincial level and, although progress is slow, key government representatives are now engaging in the debate. A Maganja businessman (and President of a local AIDS committee) describes initial steps in influencing district level authorities:

“…one impact which is clear and important to us is that the District Administrator is showing a huge interest in AIDS now, to the point that he called a public holiday in Maganja on the first of December this year [World AIDS Day] to allow all government workers to participate in the commemoration activities. He even organised decorations along the route of our AIDS march. It was a grand gesture from an Administrator”.

Sr Idelito Orlando from Maganja

Thirdly, as a result of Monaso’s visit to Zambezia, the Governor has undertaken to prepare a strategic plan for the province during 1999. This is a small, yet significant, breakthrough because it will mean mobilising the full force of all the national ministries.

Progress is slow, but it is being made. As this case study has shown, in Mozambique the team are helping build the foundations of a strong national response to the HIV/AIDS epidemic.

2 photos of sex workers in this section

Case study 3: Targeting high-risk behaviour: An overview of HIV/AIDS work in Bangladesh
The third case study of ActionAid’s work is taken from Asia. Due, in part, to the slow on-set and varying characteristics of the epidemic in this region, ActionAid’s work here is quite different to that in Africa. This in-depth study highlights work carried out by ActionAid Bangladesh during 1998, where work focused on targeting groups vulnerable to high-risk behaviour. Once again, this case study examines what difference ActionAid’s work has made.

**The context: HIV/AIDS in Bangladesh**

The exact situation of HIV/AIDS in Bangladesh is not clear due to lack of testing facilities, unwillingness of getting tested, lack of counselling and to a great extent the lack of awareness of the disease. In December 1998 government figures indicated 104 cases of HIV/AIDS. However, UNAIDS estimates that there are 21,000 HIV positive cases in Bangladesh.

Bangladesh is one of the poorest and most densely populated countries in the world. Unemployment and increased population pressure in rural areas has resulted in considerable domestic and international migration. Migration from rural to urban centres has resulted in overcrowding and unhygienic conditions. Poverty, low literacy rates, unequal gender relations, high rates of sexually transmitted disease, infections and unhygienic blood transfusion practices further exacerbate the potential spread of the epidemic. An additional factor driving the spread of the epidemic is thought to be the issue of men who have sex with men. Risk is heightened by widespread misconceptions about HIV/AIDS and the stigma attached to the discussion of sex and sexual practices.

ActionAid Bangladesh’s work on HIV/AIDS can broadly be divided into three areas:

- Work with national level organisations that are aiming to influence key decision makers in the country (eg MPs and Imams – religious leaders)
- Work in the Jagrata Juba Shangha project area, where ActionAid directly supports sex workers by providing treatment for sexually transmitted diseases, HIV/AIDS awareness-raising, condom distribution, alternative income generation activities and education/day care for sex workers’ children
- Provision of support to local community-based organisations to extend their work on HIV/AIDS. This programme is unique to ActionAid’s work because it focuses on those vulnerable to high-risk behaviour (migrant workers, sailors, truck drivers, sex workers etc).

Different statistics suggest that there are approximately 100,000 women who are engaged in sex work. Most of them cater to approximately five clients a day to earn their living.

**Influencing at national level**

ActionAid Bangladesh (through its Disability and AIDS Co-ordination Unit) supported four national level partners during 1998. It provided support to the:
• National Sexually Transmitted Diseases /HIV network (of which it was a founding member)
• Adolescent Family Life Education forum (which works with adolescents addressing issues related to health and social behaviour)
• National level telephone help line
• The Centre for Advocacy and Social Mobilisation (CASM), which aims to influence decision makers to make official commitments to work with NGOs on HIV/AIDS prevention.

Supporting community-based organisations

Work with community organisations takes a different approach. ActionAid Bangladesh’s interventions in this sector are primarily directed at improving the quality of lives of vulnerable and marginalised groups. To this end it supported four local NGOs:

- Mamata7. An organisation that works in Chittagong slum areas with poor women, youth and sex workers. It also works in the seamen’s hotels, the Bangladesh Marine Academy and with garment workers. During 1998, Mamata organised HIV/AIDS orientation workshops, discussion sessions and work in schools reaching a total of 4,991 people
- Unity Through Population Services (UTPS). An NGO that provides family planning and maternal/child health related services. ActionAid Bangladesh provided this organisation with funding and technical assistance for its programmes in 20 garment factories where it provided counselling on sexually transmitted diseases, AIDS, health support and condom promotion
- Concern for Environmental Development Research (Cedar). During 1998 ActionAid Bangladesh supported Cedar’s work with truck drivers and migrants coming through the newly revitalised land port of Hilli. This organisation opened a rest house in Hilli and provides health services, recreational facilities, medicines, treatment for sexually transmitted diseases and HIV/AIDS counselling. Over 10,000 people took advantage of services during 1998
- Padakhep8. ActionAid Bangladesh also supports work orientated at street children. During 1998, Padakhep started a small centre for street children to come to bath and sleep under fans during the hot and humid summer. As the centre has developed, the children now come for health education, sex education and recreation. Padakhep works with groups of children who carry out peer education in their own communities, attracting more children to come to the centre.

The difference this work has made

Bangladesh’s work on HIV/AIDS has developed slowly. A major barrier has been the cultural conservatism in matters related to sex and the accompanying inability to talk openly about sex-related topics. Other factors affecting the programme have been the impact of widespread flooding during 1998, which naturally disrupted service provision and influencing work (particularly of MPs who had more pressing issues).

---
7 Meaning ‘maternal affection’ in Bangla.
8 Meaning ‘Foot step’ in Bangla.
Despite the setbacks, small steps forward have been made. These are mainly in the area of slowly breaking down the cultural barriers surrounding the open discussion of sexual diseases and the embarrassment of using services.

**Changing discourse**

Advocacy work at national level has begun to slowly influence decision makers’ discourse. As a result of CASM’s work, the Bangladeshi government now has a national HIV/AIDS policy (albeit unimplemented). Individual MPs involved in the training workshops have also been more active. Two small examples illustrate that there is some change:

- Following a Padakhep training session, an Imam from a leading mosque covered the issue of HIV/AIDS in discussions with the congregation during weekly prayers
- Similarly, after a CASM workshop, Begum Rowshan Ershad (ex First Lady and MP) talked at three public meeting about HIV/AIDS prevention, openly visited brothels in her constituency and encouraged NGOs to work with sex workers. This is a significant change in a country where people (particularly women) do not openly talk about sex and where sex workers are generally ostracised.

**Greater acceptance of services**

Hotline services are also, very slowly, becoming more accepted and cultural taboos more frequently challenged. At first only a few people were calling and sending letters. However, by the end of 1998, the centre received an average of 20 calls and 15 letters a day. Callers have recently asked for face-to-face counselling and complained about the phones being engaged. Community-based work is also gradually becoming more accepted – and indeed demanded – by users:

- In Hilli (where over 10,000 people took advantage of services in 1998) truck drivers are now requesting testing facilities
- The number of street children making regular use of day centres has risen from 25 to 253. Furthermore, some child drug users are managing to give up their drug habits
- During 1998 demand for HIV/AIDS support rose dramatically. During the year, 5,300 women and 3,500 men received some kind of support. Factory owners (who were initially hostile to services being provided for their employees) are in some cases now helping to finance services and in other cases allowing space and time for employees to get advice and help.

Progress is slow and change inevitably takes a long time. ActionAid’s support to partners is helping localised, marginalised groups but the problem is huge and growing daily. Unfortunately, as yet, there is little evidence of changed behaviour.
5. Outcomes, impacts and influence of ActionAid and ActionAid’s partners’ work during 1998

In putting together this report it has been quite a challenge to find real evidence of impact. This indicates two areas that ActionAid needs to work on. Firstly, the development and sharing of participatory monitoring and evaluation techniques that can be used by ActionAid staff, community-based organisations and community members to assess change as a result of their work. Secondly, a change in the requirements and style of reports. Staff and communities are often aware of changes that have taken place, but frequently the emphasis in reports is on activities and sometimes on outputs, but rarely on the consequences of work and the longer-term impact.

Seeing the real long-term success of ActionAid’s work requires an ability to assess behaviour change. This is complex at the best of times, but when we are talking about sexual behaviour it is particularly difficult. Attributing such changes to the work of one local organisation or to a set of activities carried out by ActionAid is equally problematic. Despite the difficulties (and often the absence of corroborative information from different stakeholder groups) it is clear, from the anecdotal evidence available, some degree of change is occurring. These changes can be identified at several levels – the individual, the community, the national and the international. In this section of the report, we try to analyse the outcomes, impacts and influence of ActionAid’s work at these four levels.

a) Change at individual level

All of ActionAid’s country programmes working on HIV/AIDS have a component of prevention work. Much of this work focuses on raising awareness about HIV transmission and personal strategies for prevention. There is evidence that this kind of work can increase individual knowledge and understanding of these issues. For example in Ghana after a community adult peer education programme 85 per cent of community members knew that HIV was transmitted through unprotected sex and 72 per cent knew that sharing injection needles was also a route of transmission.

Assessing whether this understanding translates into behaviour change is more difficult. The recent review of Uganda’s Strategies for Action support to community-based organisations suggests that behaviour change is taking place (albeit very slowly). The kind of changes that localised community groups recognised were:

- Reduction in schoolgirl pregnancies
- Reduction in the practice of 'widow inheritance'
- Fewer discos and more used condoms outside bars
- Reduction in sexually transmitted diseases (although this was only recognised among the young people)

Diagram: Community identified indicators of behaviour change
Increased numbers of young people going to AIDS educators and clinics for condoms. Anecdotal evidence shows that the Stepping Stones training package can also have an important impact on individual behaviour change. One young man explains in a recent review in Tanzania:

“I loved too much – nowadays, I love with limitation. I was giving half my salary to girls but since I have put a limitation to girls, all my salary goes to my wife.”

Male member of Pasada SS Club

Similarly, a sex worker from Ethiopia explains how her training as a peer educator by the ActionAid-supported organisation, Propride, helped her to insist on condom use:

“I used to hear the word AIDS but didn’t know what it meant. After the training I insist on condom use by clients and I myself continue in good health. We speak with one voice now to refuse clients who won’t use condoms. If they resist, I tell them ‘Your money is not worth my life. If I get AIDS your money will not save me or pay for my treatment’. So we will not have bare sex. I strongly advocate condom utilisation with my peers.”

Beyenech, 20-year-old sex worker in Addis Ababa

These changes are clearly vital in the prevention of HIV/AIDS, however they also signify wider changes in society. Being able to facilitate communication between men and women marks an important shift in gender relations. It must be noted that achieving this quality of change requires well-trained facilitators and a long-term commitment from all the stakeholders: government, donors, ActionAid, local organisations and communities.

As is shown in the case studies in this report, the change in the lives of people living with AIDS is a very significant feature of the work of Strategies for Action and other ActionAid programmes concentrating on care and support. Experience from Uganda, and elsewhere, shows that an environment of openness is vital for people to be able to face up to the challenge of HIV/AIDS and protect themselves and others. Where ActionAid’s partners are working with people living with HIV/AIDS, the benefits are clear:

“After the counselling and support from Nacwola, I could see that HIV isn’t the end of everything and that you can live normally and even make some money.”

Nacwola member, Uganda

b) Change at community level

With continual quality work in these areas of prevention and care, the changes at individual level can develop into wider changes felt at community level. These changes are more difficult to attribute directly to ActionAid’s or its partners’ work. However, specific communities have noted some very important changes at
community level – more openness towards people living with the virus, the social acceptability of widows not remarrying or being inherited, less girls dropping out of school due to unwanted pregnancies, and more communication between men and women.

Supporting community organisations can, in itself, have a very positive effect. A community-based organisation that grows strong and whose work the community respects can help to give hope that it is possible to improve people’s lives. ActionAid’s work has helped community-based organisations to access funding and support. Strong and active organisations can bring hope and courage to communities who may believe that HIV/AIDS was just too difficult and challenging to deal with – this is a vital change of perception. It is often difficult for community organisations to reach this point. Most of their members work as volunteers, who often leave if they find remunerated employment. Further, the nature of the pandemic is such that any response, however well planned and carried out, may still seem like a drop in the ocean. There are some community-based organisations that have grown into fully-fledged NGOs (e.g. TASO\(^9\) in Uganda and MAICC\(^10\) in Malawi) and can sustain themselves independently of ActionAid.

\[\text{Diagram. ActionAid helps stoke the fire of change}\]

\(\text{c) Change at national level}\)

\(\text{Influencing policy}\)

National level changes are even more difficult to attribute to ActionAid and its partners alone. Throughout its programmes, ActionAid plays an important role in supporting the establishment of national networks and supporting local organisations to carry out their own advocacy work. Naturally, changes at national level are influenced by a myriad of reasons. Nevertheless, ActionAid can show that, in certain instances, influencing work is contributing to national level changes:

\(\text{♦ In Kenya, Kanco}\(^11\) (an active national network of which ActionAid is one of the founding members) plays a vital role in mobilising its member organisations to campaign for changes in policy and practice. One recent success has been to lobby the government to pass a bill protecting the rights of people living with HIV/AIDS}\)

\(\text{♦ In Malawi, lessons learnt through ActionAid’s Strategies for Action work have directly influenced the National Aids Control Programme}\)

\(\text{♦ In Bangladesh, CASM’s training workshop for MPs has been said to have influenced the development of a national policy on HIV/AIDS (see case study in this report).}\)

\(\text{Encouraging an appropriate national level response}\)

In some countries, ActionAid’s work is contributing to the early development of appropriate national level responses to the epidemic. In Sierra Leone and Burundi

\(\text{9 The AIDS Support Organisation (Uganda).}\)

\(\text{10 Mpomela AIDS Information and Counselling Centre.}\)

\(\text{11 Kenya AIDS NGO Consortium Organisation.}\)
(where national HIV/AIDS work is in its early stages) ActionAid and its partners are playing a key role in motivating organisations to see that something can be done to respond to HIV/AIDS. In Sierra Leone, workshops have been held with community leaders on sensitisation to the dangers of drug abuse. In the Gambia, ActionAid has been able to support the Department of State for Health to train peer educators in HIV/AIDS. In its more established programmes (Uganda, Ethiopia, Malawi) ActionAid’s work has influenced other development agencies by illustrating the importance of nurturing a community response.

**Building strong foundations**

The value of networking at national level is equally difficult to measure. It is part of a long-term strategy to influence change – a strategy that is hard to monitor, but nevertheless is known to reap long-term rewards. It is the foundation of a strong, rooted movement to affect change. The work carried out by Monaso and Kindlimuka in Mozambique (see case study) is an example of early work to support embryonic movements.

One step in this process is to encourage learning and sharing between organisations. Due to the varied nature and experiences of HIV/AIDS work in each country programme, ActionAid is in a unique position to facilitate learning across countries. For example, during 1998, ActionAid co-ordinated a ‘study tour’ for several members of the Zimbabwe National Network of People living with HIV and AIDS (ZNNP+) to visit local organisations in Uganda. The Zimbabwe network explained the impacts of the tour in their report:

> “The study tour was an eye opener to the delegates. While a lot of similarities existed between our programmes, in Uganda they have made headway. The tour also gave the delegates an opportunity to review strategies on a comparative basis while trying to adapt some of our strategies.”

ZNNP+ Study Tour Report 1998

**d) Change at international level**

Influencing the approach to HIV/AIDS on an international level is a real challenge. With its close links to communities living with the realities of HIV/AIDS, ActionAid is well placed to act as a vehicle for raising these issues with key institutions which have a global remit. Progress is naturally very slow.

**Raising profile**

One step on the long road is raising the profile of ActionAid’s and ActionAid’s partners’ work on HIV/AIDS. Due to ActionAid’s work with Strategies for Action, communities, local organisations, Strategies for Hope and Stepping Stones, ActionAid is increasingly becoming recognised as an important international player in the HIV/AIDS field. ActionAid, with other NGOs, has participated in a consultative process with UNAIDS to influence the future direction of their international HIV/AIDS response. In the North, ActionAid has been an active member of the UK
NGO AIDS Consortium, which has been able to raise HIV/AIDS issues with other international NGOs and with the Department for International Development.

The Strategies for Hope series and associated Stepping Stones training package have been very important vehicles for influence, sharing of information and spread of learning. This influence has been felt far beyond the countries in which ActionAid conducts programme work.

**Strategies for Hope**

The Strategies for Hope series has proved to be both inspirational and influential. The case studies, and the individual first hand testimonies of real people living and dealing with HIV/AIDS, seem to have been particularly valued features. Strategies for Hope has influenced organisations and people at so many levels – from individuals and community-based organisations to governments and UN organisations. The Strategies for Hope database now holds over 19,000 addresses world-wide of individuals and organisations involved in HIV prevention, care and support. In an independent review of the global impact of Strategies for Hope materials, over 75 per cent of respondents stated that the materials had helped them “a lot” or “very much” in making decisions about their HIV and AIDS work:

“The booklets have helped us to help people to unfold. Before, having AIDS was like a curse and a cause for shame, for the person and also for the family members.”

Stella Kabaganda, Kampala, Uganda

<table>
<thead>
<tr>
<th>Africa</th>
<th>Asia/Pacific</th>
<th>Europe</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>645,329</td>
<td>25,351</td>
<td>47,625</td>
<td>747,956</td>
</tr>
<tr>
<td>% of total</td>
<td>86.2</td>
<td>3.4</td>
<td>6.4</td>
<td>(100)</td>
</tr>
</tbody>
</table>

**Stepping Stones**

The Stepping Stones participatory training package has been received by over 1,500 organisations in 103 countries. It is seen as unique in the way it incorporates gender relations, communication and negotiation skills into HIV prevention.

---

12 A network of development NGOs working on HIV/AIDS with a base in the UK.
This manual has undoubtedly had a lot of influence. A key indicator of this is the number of times it has been adapted and translated into different languages. Indeed, a number of organisations (without any funding from ActionAid) have translated *Stepping Stones* into a local language including organisations in Cambodia, Sri Lanka and Mozambique. Most recently we have learned of Swahili, Russian and Latin American Spanish translations, as well as plans in Ethiopia for an Amharic version.

“This manual has been of tremendous benefit and help to stakeholders, middle level managers and entire health workers in the district. It has increased the knowledge and proficiency of those health workers who were solely for homebase care and counselling unit for HIV/AIDS patients. In line with communication and interpersonal relations to workers and clients, its benefit cannot be overemphasised.”
Frederick Ofosu, Ministry of Health, Odumase-Krobo, Ghana, 1997

“In my estimation one of the most valuable recent additions to the quite scanty written materials available in [this] area.... UNAIDS has included this resource package among the ‘key documents’ recommended for use in innovative community mobilization programmes.”
Noerine Kaleeba, UNAIDS, 1997

“It is clear that Stepping Stones materials have been enthusiastically received and put to good use... Feedback has been overwhelmingly positive. Real change has been reported, particularly in the kinds of areas in which conventional HIV/AIDS prevention strategies have been notoriously weak... The changes noted by respondents indicate that Stepping Stones serves a more profound function in promoting behaviour change: addressing the less tangible and deeper aspects of interpersonal communication.”
Dr Andrea Cornwall, evaluation of questionnaire survey of *Stepping Stones* recipients, 1997
5. Future developments of HIV/AIDS work within ActionAid

In summary it is fair to say that ActionAid is now widely recognised as having particular expertise in the area of HIV/AIDS work, especially in sub-Saharan Africa. ActionAid’s work differs from that of other international NGOs because it concentrates on promoting a community response to HIV/AIDS. The flexible nature of ActionAid’s support encourages small community-based organisations to take forward their own ideas and, in doing so, promotes innovation. An additional strength of ActionAid’s work is that HIV/AIDS is not viewed in isolation but in the broader context of gender and reproductive health.

A recent review of ActionAid’s work found that ‘in the areas of literacy and HIV/AIDS, ActionAid has built expertise [which] has paid off developmentally by being replicated and sought after’\(^{13}\). This review strongly recommended that the agency focus on developing its comparative advantage, and ActionAid staff working in HIV/AIDS reinforce these recommendations. They identify five key areas that require future development:

- **Promoting innovative tools**
  ActionAid can, and should, take a lead in promoting innovative tools, namely gender-sensitive, participatory, community-based approaches to HIV prevention and care. This should include capacity-building with partners at all levels.

- **Sharing between countries**
  There is still a great need for sharing experiences and promoting learning between countries and across regions. ActionAid should build on the success of previous exchange visits between community-based organisations in order to benefit other struggling local organisations.

- **Documentation**
  Documentation is a crucial component in sharing learning between organisations, countries and regions. ActionAid should continue to build on the experiences of Strategies for Hope in this area, and improve the documentation of its HIV/AIDS work. There is a huge need to support community-based organisations to record and document their own experiences and disseminate those experiences to other regions, countries and organisations.

- **Involving people living with HIV/AIDS**
  ActionAid needs to make a commitment to promote the explicit and open involvement of people living with HIV and AIDS in its work. HIV/AIDS is also an issue for ActionAid’s staff. This is increasingly being recognised in policies and all country programmes need to put these policies into practice to support and protect their staff. The Strategies for Action programme in Malawi and the Africa Regional office have actively promoted the recruitment of people with HIV/AIDS. This strategy could be very powerful in overcoming stigma in other high prevalence areas.

\(^{13}\) Tom Dichter, ActionAid review 1999 Taking stock summary report, pages 15-16.
Developing participatory monitoring and evaluation

As this report has emphasised, there is an urgent need to encourage the development of effective participatory monitoring and evaluation techniques so that community organisations themselves can monitor the impact of their HIV/AIDS work. The 1998 participatory review, in Uganda, illustrated the power of good participatory work to increase ownership and influence immediate corrective actions to improve ongoing interventions. There is also an urgent need for ActionAid to develop its monitoring of capacity-building work with community-based organisations.

Challenges for the future

Three key challenges face ActionAid’s HIV/AIDS work as we move towards the next millennium:

1. Scaling up

Firstly, ActionAid’s reputation in the HIV/AIDS field rests very largely on its experience in sub-Saharan Africa. This is true despite ActionAid spending less than £1 million on HIV/AIDS work during 1998 (less than 2.3 per cent of total expenditure). As the number of HIV infections continues to rise, and as the impacts of AIDS are felt in more and more communities, so ActionAid must be able to scale up its HIV/AIDS work. This does not necessarily mean more expenditure, but it does mean expanding ActionAid’s work into countries with exceptionally high prevalence rates and, crucially, influencing governments and civil society groups to respond appropriately to the epidemic. Indeed, Uganda’s success in reducing the number of new HIV/AIDS infections has come about through a combined response from strong civil society groups coupled with political will. It remains to be seen whether this response can be emulated by other countries.

2. Mainstreaming HIV/AIDS into all ActionAid work

Secondly, due to the sensitive nature of HIV/AIDS, ActionAid has found it difficult to truly integrate HIV/AIDS into its programme work. Due to staff training and continual advocacy work from the HIV/AIDS team, many country programmes are increasingly recognising the inter-related nature of HIV/AIDS work with general development issues such as education, water, agriculture, emergencies etc. However there is still more work to be done. Ongoing staff training is essential to ensure the full integration of HIV/AIDS work into all programmes and to ensure that HIV is not seen in isolation, but is part of a response to sexual health issues. The importance of integration should be reflected in ActionAid’s strategic documents at corporate, regional, country and local levels. After all, human health is a basic right.

3. Develop influencing/advocacy work

Finally, the 1999 ActionAid-wide review Taking stock suggested that ActionAid choose no more than four ‘key advocacy areas’ in which to ‘commit itself to becoming expert’\textsuperscript{14}. HIV/AIDS work is singled out as an area of expertise – it makes sense to

\textsuperscript{14} Ibid. page 55.
build on our experience and influence the policies and practices of key institutions in the South and the North. As this report has shown, ActionAid has worked successfully in several countries with national networks that have become strong advocates for change in HIV/AIDS policy and practice. This kind of support to national advocacy networks must be expanded to countries where HIV/AIDS issues are often treated superficially or simply ignored.

As this report has endeavoured to show, ActionAid’s HIV/AIDS work is innovative and is having localised impact. However, behaviour change is inevitably slow and problematic. ActionAid needs to continue to develop its HIV/AIDS work, building on the strength of its more established programmes and continuing to try to influence key Northern and Southern institutions to take effective action.