

WHY ADVOCATE ON HIV?



'The challenge now is to sustain this leadership, to keep AIDS at the top of the agenda, and to accelerate action at national and local level. Any slackening of leadership would be fatal. The epidemic reached global proportions precisely because it took so long for the world to act. And although we are beginning to make progress, there remains a long way to go.'

DR PETER PIOT, EXECUTIVE DIRECTOR OF UNAIDS,
WORLD AIDS DAY 2007

tearfund

Why advocate on HIV?

Writer: Emma Aston

Thanks to the following for their comments:

Rentia Agenbag, Tope Akinwande, Rachel Blackman,
Mike Buckley, Rachel Carnegie, Paul Cook, Alice Fay,
Degu Jerene, Philippa Newis, Veena O'Sullivan,
Patricia Sawo and Joanna Watson.

Cover photos: Marcus Perkins / Tearfund

Illustrations: Rod Mill, Bill Crooks, Steve Pickering

Design: Wingfinger

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Tearfund is a Christian relief and development agency building a global network of local churches to help eradicate poverty.

Tearfund, 100 Church Road, Teddington, TW11 8QE, UK

For further information contact
ppadministrator@tearfund.org

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Glossary

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral drugs
CBOs	Community-based organisations
G8	Group of Eight – the world's eight richest countries
HIV	Human Immunodeficiency Virus
IHP	International Health Partnership
MDGs	Millennium Development Goals
NGOs	Non-governmental organisations
PRSPs	Poverty Reduction Strategy Papers
UN	United Nations
WHO	World Health Organisation

Introduction

This booklet is for organisations that are engaged in work with people who are living with or affected by HIV but have not yet considered carrying out advocacy on HIV.

In this short guide, we look at what advocacy is, what global and local commitments have been made to address HIV, and why advocacy on HIV is necessary.

We look briefly at how to begin advocacy work on issues around HIV, and recommend further resources and contacts.

The aim of this booklet is to inspire organisations to integrate advocacy into their work in responding to HIV, in order to bring long-term positive change.



What is advocacy?

Advocacy is about influencing people, policies, structures and systems in order to bring about change. It is about influencing those in power to act more fairly.

Tearfund defines advocacy as...

'seeking with, and on behalf of, poor people to address the underlying causes of poverty, bring justice and support good development through influencing the policies and practices of the powerful.'

Advocacy is firmly rooted in the Bible, and is based on God's commitment to justice:

'Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy.'

PROVERBS 31:8-9

Advocacy complements other approaches to development because it:

- tackles root causes of poverty and injustice and brings long-term change
- sees people as agents of change in their own communities
- can change power structures, unjust practices, and systems of injustice that keep people in poverty
- can help to generate more resources for other development work.

Advocacy can involve a number of activities, including research, lobbying, campaigning, prayer, networking, awareness-raising and media work.

Advocacy is not necessarily confrontational. Decision makers, such as governments and local leaders, are often aware that there is a problem and will welcome suggestions about how it can be solved. Advocacy work can take place on many levels and varies according to the problem and the types of groups involved. The roles of an advocate include facilitating communication between people, negotiating, demonstrating good practice and building alliances.¹

¹ For more detail about carrying out effective advocacy work, see *ROOTS 1 and 2: Advocacy toolkit*, Tearfund UK, 2002

HIV is an important issue

In 2007 it was estimated that almost 33.2 million people globally were living with HIV and over 25 million had died since the first cases of AIDS were identified in 1981.² HIV is having a huge impact in some places. Education and health systems are weakened as teachers, nurses and other staff who are living with HIV are unable to work. HIV is increasing the demand for health services. Furthermore, there is declining food consumption among the children of families who take in orphans. It is crucial to work with people living with HIV, understanding their priorities and supporting them in their advocacy.

Key advocacy issues in relation to HIV include:

PREVENTION Prevention of HIV infection is seen as the most effective long-term way to reduce the number of people affected by HIV. We must encourage governments and national bodies to design and implement effective and comprehensive prevention strategies.

TREATMENT Anti-retroviral (ARV) drugs have the potential to dramatically improve the health and extend the lives of people with HIV. There are many challenges to providing ARV treatment and treatment for opportunistic infections, such as funding, sustained supply and distribution of drugs, the complexity of treatment regimens, availability of medical staff and monitoring for drug resistance. Despite the international commitment for universal access to comprehensive HIV services, access for the majority of poor and marginalised people is far from a reality. Governments should ensure universal access to all by 2010 as agreed at the UN General Assembly in 2005 following the G8 Summit.

CARE AND SUPPORT Many people are affected by HIV. The number of children orphaned and made more vulnerable due to HIV is rising, though this is often not considered a priority. Children's issues must be prioritised both at international and national levels. Adults must also receive assistance as they take on emotional and financial burdens whilst caring for people living with HIV.

RESOURCES There has been an increase in the global financial resources committed to the response to HIV, but this funding has not always been made available. Funding commitments must be upheld.

GENDER INEQUALITIES Gender inequalities as well as biological factors make women more vulnerable than men to being infected and affected by HIV.³ We need to make sure that government policies address the rights and needs of women in relation to HIV.

2 *AIDS epidemic update 2007*, UNAIDS, 2007

3 More information can be found on the WHO site on gender and HIV, www.who.int/gender/hiv_aids/en/

The global situation

In the year 2000, at the UN Millennium Summit in New York, all UN Member States signed up to the Millennium Development Goals (MDGs). The aim of goal 6 is to, 'Combat HIV/AIDS, malaria and other diseases', and a target within this goal aims to, 'Halt and begin to reverse the spread of HIV/AIDS'.⁴

In 2005, at the UN General Assembly, all UN Member States committed to providing universal access to comprehensive HIV prevention, treatment, care and support programmes by 2010. (This is generally known as the '2010 commitment').⁵

The International Health Partnership (IHP), launched in September 2007, aims to improve the way that international agencies, donors and countries work together to develop and implement health plans and create and improve health services for poor people. The IHP needs to create mechanisms to ensure that civil society can be fully engaged in this process.

Achieving the MDGs and HIV-specific commitments is the responsibility of all governments and international financial institutions such as the World Bank. However, governments are struggling to keep their promises. This could be due to lack of finances, lack of political will or weak infrastructure.

At Tearfund UK, we are advocating for UK and European governments to spend more money, more effectively, in countries of the South in order to increase access to HIV prevention, treatment, care and support services.

This donor-focused advocacy and action is not enough. Many of the changes needed to meet this target have to happen in the countries themselves. Tearfund partners are encouraged to advocate at a national level to their own governments.



4 More information about the MDG commitments can be found at www.un.org/millenniumgoals

5 More information about the commitments made at this meeting can be found at www.dfid.gov.uk/g8/hiv.asp

The situation at country level

Every member country of the UN has agreed to achieve the MDGs, to fulfil the universal access commitments, and to implement the 'three ones' principle:

- one national plan
- one country-level monitoring and evaluation system
- one coordinating body.

HIV affects countries differently so the national plan to address HIV varies from one country to another. In this context, country-level advocacy is very important as civil society groups responding to HIV are often best placed to understand the context of their own country, and correctly address the HIV-related issues that are specific to their own country.

It is important for development organisations to know about the HIV epidemic in their country so that they can advocate for the changes that are needed to improve responses to HIV.

If a national plan is not working well, the government will often be aware of this, and would benefit from input of people who are able to suggest alternatives or help develop a solution.

When planning advocacy work, consider who has the power to make decisions about the changes that are needed. Advocacy work can involve engagement at local or national levels – successful advocacy is not always about realising change at national level. Changes at a provincial or local level can be just as effective.

In addition to a national AIDS plan, there may be other government plans and strategies where HIV is addressed, such as Poverty Reduction Strategy Papers (PRSPs). It is important to understand how these plans and strategies affect development work.



Governments have a responsibility

- Governments have a responsibility to uphold their citizens' rights, including their right to medical care and security in the event of sickness.⁶
- Government policy can affect the programmes of NGOs, and the communities they work with, in positive and negative ways.
- Governments need to be held accountable for the promises they have made and their progress towards ensuring services are provided. Every government has made commitments to addressing HIV in its National Plan of Action.
- By advocating on issues such as HIV, we can help our governments to develop transparency, participation, openness and accountability.
- Without the involvement of government, most behaviour change programmes and health care systems will not be sustainable.
- Governments should act responsibly, not only in addressing the HIV epidemic in their own country, but also when acting as a donor to another country.

CASE STUDY

Stigmatisation, Thailand⁷

Almost 80% of the women living with HIV in a project run by Tearfund partner Siam-Care in Thailand tried to get rid of their children's vaccination records because 'HIV positive' was stamped in big letters on the front page. The mothers wanted their privacy respected and did not want health personnel to know about their HIV status through reading their children's vaccination books. Unfortunately, when the books were destroyed, important vaccination, child development, and health records were lost.

In August 2000 Siam-Care, together with CAR (Centre for Aids Rights), organised a meeting with other NGOs working with women living with HIV to find out whether the problem existed elsewhere. It did, and the information was documented. Together the NGOs came up with a new design for vaccination books, which did not state the mother's HIV status. Siam-Care and CAR then presented possible layouts for new vaccination books to the Ministry of Public Health, which appointed a committee (including NGOs) to look at a new vaccination book. In March 2001 a new vaccination book was produced, leaving out the mother's HIV status.

When NGOs work together with the relevant government department, changes can be made.

6 For a full outline of the UN Universal Declaration of Human Rights visit www.un.org/Overview/rights.html

7 Case study taken from *ROOTS 1 and 2: Advocacy toolkit*, Tearfund UK, 2002

Civil society organisations should be involved

- When a government fails to fulfil its duty to its citizens, the citizens have a legitimate right and responsibility to hold the government to account.
- Local civil society groups (including the local church), have the right to engage in political debate in order to influence policy with, and on behalf of, the poorest members of the community.
- Good government policies are based on experience and knowledge of the activities that are successful and those that are not. CBOs and NGOs have a wealth of experience of project implementation and working with communities, which should be shared.
- Achievement of the MDGs and 2010 commitments requires greater participation from civil society at all levels, including representatives of vulnerable and high-risk groups. All stakeholders, including government and civil society, need to work together if goals and targets are to be reached.
- Governments should consult their citizens on policy decisions. The experiences and opinions of civil society should inform their policy-making.
- Northern countries are placing increasing pressure on Southern country governments to consult their citizens on development issues.
- CBOs and NGOs can enable the voices of people who are poor to be heard by those in power. Grassroots leaders who have developed effective HIV services and programmes should participate in local and national dialogues about policy.



- CBOs and NGOs are also in a good position to raise awareness amongst communities of the importance of responding to HIV.
- All stakeholders, including government and civil society, need to work together if goals and targets are to be reached.

CASE STUDY

Orphans, Rwanda⁸

African Evangelistic Enterprise (AEE) works with orphans whose parents have died of AIDS and child-headed households in the Kibungo Region in the east of Rwanda. They have two associations that operate through a sewing workshop and a carpentry shop where children are trained and sell their goods. The Rwandan Revenue Authority is responsible for collecting taxes and they asked the associations to pay (which they could not afford) or close down. AEE, as a partner of these associations, used its size and contacts to arrange a meeting with the Ministry of Social Affairs. At the meeting they explained that those working in the associations are either orphans or members of child-headed households and should therefore be treated in a more charitable way and exempted from paying taxes. The ministry agreed and said that all partners of AEE should be exempt due to the development work they are doing.

CASE STUDY

Marginalised populations, India⁹

Since 1992, IMCARES (Inter-Mission Care And Rehabilitation Society) has been running the IMPACT (Inter-Mission Prevention of AIDS Through Care and Training) project, responding to HIV in the slums of Mumbai. IMCARES aims to raise awareness and transform community attitudes towards people living with HIV, from stigma to acceptance. It is working to advocate for access to treatment and to enable the local church to help provide care for people living with or affected by HIV. Through working with local churches, IMCARES is reaching hidden and marginalised populations such as slum communities, sex workers and eunuchs.

8 Case study taken from *ROOTS 1 and 2: Advocacy toolkit*, Tearfund UK, 2002

9 Case study taken from *Transforming lives: Church-based responses to HIV*, Tearfund UK, 2007

Churches have a role to play

As Christians we are called to model Christ. Christ loves all people and illustrated God's compassion whilst on earth by reaching out to those in need.

- Churches provide much of the care and support for communities affected by HIV through a combination of practical, emotional and spiritual support.
- At the same time, the church needs to hold governments accountable for their responsibility for the long-term care and support of citizens. The churches should seek to share their expertise with government bodies and work with them to develop solutions.

As Christians we condemn no one, but offer them the same grace that we as Christians have received.

- We therefore need to be committed to removing all forms of stigma and discrimination. The church is in a good position to educate people and mobilise them to take part in advocacy work.

Jesus spoke out against injustices and on issues which were taboo in the time that he lived on earth.

- We need to learn from his example and not be afraid to talk about issues which are not normally spoken about, such as sex or gender violence which make people more vulnerable to HIV infection.
- Local churches are an integral part of the community and therefore understand local needs. They can be a vehicle for bringing the voices of those affected by HIV to the attention of the authorities in order for them to make good decisions about how to lift people out of poverty.

CASE STUDY

Legal rights, Zimbabwe¹⁰

In Zimbabwe, Salvation Army's Masiye Camp project realised that orphans and vulnerable children often find it difficult to access legal services. They may not know where to find such services or how to use them, and they often lack resources to pay. The mobile law clinic seeks to bring legal services to children, rather than waiting for children to find them themselves. The clinic refers children to the relevant professionals. In this way, it complements existing structures rather than competing with them. The mobile unit visits all the clubs and schools linked to Salvation Army's HIV and AIDS programme on a regular basis. To make it attractive to children, the unit is housed on a trailer with a thatched roof and painted in bright colours. A popular puppetry team travels with the clinic to provide education and entertainment.

10 Case study taken from *ROOTS 8: HIV and AIDS: Taking action*, Tearfund UK, 2005

- Christian denominations have unique reach, linking thousands of local churches to national and international networks. The church has great potential to speak out about issues related to HIV and government commitments at national and international levels.



CASE STUDY

Funding for children orphaned due to AIDS, Burkina Faso¹¹

In Burkina Faso, more than 800,000 children are affected by HIV and AIDS. Many of these children are neglected. Christian Relief and Development Organisation (CREDO) organised an advocacy campaign to ensure that these children are cared for. The targets of the campaign were the political decision-makers. CREDO began by raising the awareness of the general public so that the advocacy work was well-supported. This included NGOs, the religious community, women's groups, children and people living with HIV.

Awareness-raising activities included a procession of 6,000 children, a musical concert, a day of prayer and sensitisation in churches, films about AIDS and a debate on television.

The result of the advocacy campaign was that the government allocated a larger budget to the care of orphaned children. In addition, the church was mobilised so that it supports children at the grassroots.

¹¹ Case study taken from *ROOTS 8: HIV and AIDS: Taking action*, Tearfund UK, 2005

Next steps

- Find out more about what advocacy involves by reading *ROOTS 1 and 2: Advocacy toolkit*.
- Consider whether you currently have the organisational capacity and support required for advocacy work. If not, consider the areas of development that are needed in order to do so.
- Make sure that HIV is integrated into your organisation's own development work. If you are telling others what you think they should be doing, you must be prepared for your own work to be held up as an example.
- Try to gain a better understanding of the national policy context, by researching the existing policy frameworks and structures. Useful questions to ask include:
 - What does the HIV epidemic look like in our country? UNAIDS provides recent statistics by country such as the number of adults and children living with HIV, adult prevalence, and adult and child deaths due to AIDS. (www.unaids.org/en/KnowledgeCentre/HIVData/default.asp)
 - What national laws exist in relation to HIV?
 - What is the government's policy, plan and strategy on HIV?
 - What are the strengths and weaknesses of the current policy, plan and strategy and their implementation?
 - Who holds responsibility for implementing the national AIDS plan?
 - What is happening in practice at national, regional and local levels?
 - Are the funds getting to where they are needed? Do rural areas get the same levels of services as urban areas?
 - What services is the government providing in areas such as prevention, testing and counselling, and treatment?
 - What services are other stakeholders providing?
 - Are these services targeted where they are most needed? If not, why not? How is civil society involved? Is its role recognised and valued?
 - Is there a national co-ordinating body that brings together all stakeholders? Is there a civil society network or coalition (secular or Christian) working on HIV?
 - What are the top three issues related to HIV in our country that might benefit from advocacy work?
- To avoid duplicating work and to strengthen your advocacy efforts, find out which other organisations in your country or region are carrying out advocacy work on HIV. Arrange a meeting with them to discuss how you could work together.
- Tearfund's Regional Teams and Advocacy Group will be happy to discuss ideas with you and offer advice.

Useful networks and organisations

Global

CARE USA

151 Ellis Street, NE
Atlanta, GA 30303, USA
www.care.org

Ecumenical Advocacy Alliance

150 route de Ferney
PO Box 2100
CH-1211 Geneva 2
Switzerland
www.e-alliance.ch

ICASO

based in Canada
www.icaso.org

International HIV/AIDS Alliance

Queensberry House,
104–106 Queens Road
Brighton, BN1 3XF, UK
Email: mail@aidsalliance.org
www.aidsalliance.org

The Micah Network

www.micahnetwork.org

Open Society SOROS

400 West 59th Street
New York, NY 10019, USA
www.soros.org

UNAIDS

www.unaids.org

National

EHAIA WCC

operate in Africa
PO Box 2100
CH-1211 Geneva 2
Switzerland
www.oikoumene.org/?id=3131

Health and Development Network

based in Thailand
www.hdnet.org/v2/home/
*Partnership platforms are operating in:
Ireland, Thailand, Uganda, Zambia, Zimbabwe,
Cambodia, Malaysia and Vietnam*

Micah Challenge

www.micahchallenge.org

Treatment Action Campaign

PO Box 2069
Cape Town, 8001
South Africa
www.tac.org.za/community

There are many other national networks carrying out advocacy work on HIV. Find out about these by asking other NGOs that are responding to HIV.

Further information

- *ROOTS 1 and 2: Advocacy toolkit*, Tearfund UK
- *ROOTS 8: HIV and AIDS: Taking action*, Tearfund UK
- *Working Together? Challenges and opportunities for international development agencies and the church in the response to AIDS in Africa*, Tearfund UK



tearfund

www.tearfund.org

100 Church Road, Teddington, TW11 8QE, United Kingdom

Tel: +44 (0)20 8977 9144

Registered Charity No. 265464

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