

# id21 insights

communicating international development research



## Dealing with HIV and AIDS

Solutions in ordinary people's actions

**T**wenty-five years of knowingly living with HIV, the global community is still falling behind the virus in its alarming, complex and often hidden progress. Despite many diverse and creative successes in committed peoples' responses and many lessons drawn along the way, few have been widely adopted. What can we learn from this diversity of response?

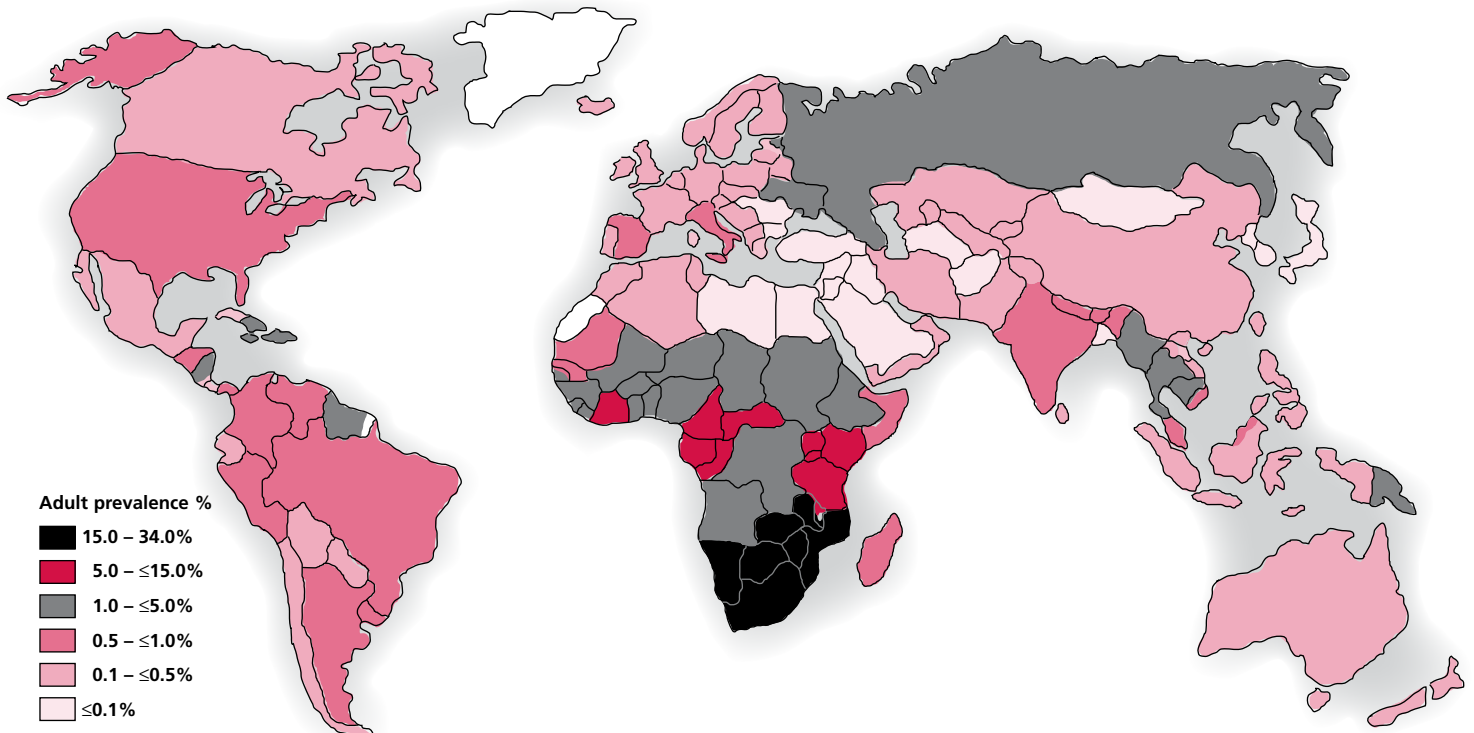
Capturing and scaling up the creativity and local relevance of diverse responses is a major challenge. Whilst it is true that 'community responses' are crucial to respond effectively, the focus on 'community' can also lead to over-simplified analyses of – and responses to – the epidemic. We need to be specific and question the simple notion of a geographically confined village community as a reference point. We also need to know

what works and find better ways of applying those lessons effectively in different contexts and at a greater scale.

Civil society groups have often led the way. A passionate – sometimes desperate – drive to respond to HIV and AIDS, and their own diversity unites them. This issue of *id21 insights* features examples of such real-life responses and asks: how can we move forward to catch up with the virus?

**About 39 million adults were thought to be living with HIV/AIDS in 2005. Close to 4 million became newly infected with HIV and 3 million died because of AIDS-related causes. African countries are the worst affected and there is no clear evidence of HIV prevalence declining in many of them.**

Source: Report on the Global AIDS Epidemic, Joint United Nations programme on HIV/AIDS, 2006  
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Tony Barnett from the London School of Economics and Political Science provided academic advice on this issue.

#### Facing up to stigma

Stigma and discrimination have compromised many responses and stifled others from the outset. Uncomfortable issues raising old taboos or ideas of 'social evils' around sex, sexuality, drugs and racism have triggered fear and denial of

▶ the epidemic. **Juan-Jacobo Hernandez** provides an example of how deep-rooted homophobia is in Mexico and a sense of the long road ahead. Experiences from training programmes in Africa, as **Sue Clay** and **Chipo Chiyya** report, show both hope and the challenges in dealing with stigma.

### Learning to talk about sex before having it

General HIV awareness messages can be inadequate for sustaining behavioural changes, while participatory methods which explore local vulnerabilities and priorities can involve people in empowering and lasting ways. **Gill Gordon's** article on the lessons from eastern Zambia shows how despite fears around discussing sexual issues in traditional communities or schools, local non-government organisations (NGOs) can work with educational authorities to make effective sexual health education a reality.

### Men as part of the solution

Although many participatory approaches have paid attention to gender issues, men's involvement has been partly affected by analysis that sees them as the problem rather than as a part of the solution. The Stepping Stones programme in Ghana and Men as Partners projects in southern Africa use more enabling approaches and offer useful lessons for mobilising and involving men. **Colette Harris** shares her experience of working with men in Ecuador an inspirational example from Latin America – a region rarely discussed in relation to the HIV/AIDS epidemic.

### Focusing on the most affected

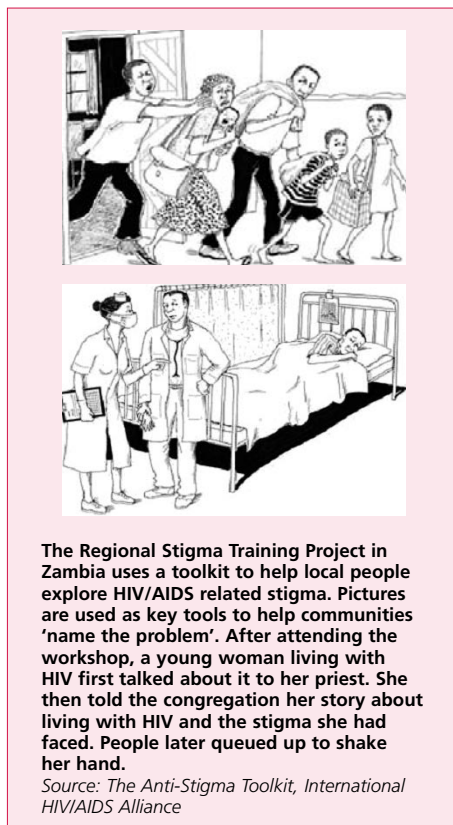
Some community-based general responses and campaigns have been problematic. Either they have been based on an idealised notion of 'local communities', have not involved those most affected by HIV and AIDS or they have further excluded certain groups. Rights-focused participation and empowerment for the most vulnerable groups is possible, as **Meena Seshu** and **Meena Shivdas'** article on sex workers in India illustrates. Transformative approaches are crucial to build community and social networks amongst groups, such as sex workers or men who have sex with men. Regrettably these groups are still often overlooked, particularly in much of Africa.

Although unified mainly by knowing their HIV positive status and dealing with stigma, HIV positive people's movements have made important advances in terms of developing new senses of community and citizenship around health issues. **Steven Robins** presents an interesting example of 'responsible citizens' and new forms of male involvement emerging out of AIDS activism in South Africa.

There is increasing focus on dealing with all aspects of HIV/AIDS in a sequence: prevention, care, treatment and impact mitigation. Formal programmes, however, tend to link and integrate only a small number of, often technical, aspects of this sequence. This sequence can best be tied

together at local levels combined with support from more global levels. **Vinh-Kim Nguyen** explains how HIV positive people from Burkina Faso and Côte d'Ivoire, with involvement and collaboration of partners in the West, became 'therapeutic citizens' – organising themselves and meeting different needs in a client-centred way. Local-global connections can be highly empowering for local leaders and organisers.

Along with various formal or informal community based organisations and NGOs, faith based organisations (FBOs) have an extensive presence. **Geoff Foster** argues that the work of FBOs with communities in most of sub-Saharan Africa, and such approaches, have been under-exploited in the past. Development instruments, such as microfinance schemes have also been used to reach out to HIV and AIDS affected or vulnerable people, as described by **Julia Kim** and **Paul Pronyk**. Strengthening and supporting these different safety nets for the HIV and AIDS affected and those in danger of becoming destitute, on a large enough scale to make a real difference is a priority and a challenge.



### Can these approaches be scaled up?

National programmes and policies need to allow these types of developments to emerge at district and local levels, whilst finding a balance in the trade-off between scale and standardisation versus diversity and local context-specificity. **Tony Barnett** describes personal encounters in Uganda pointing to the problem that local responses may not always correspond with 'politically correct' Western perspectives.

This issue of *id21 insights* highlights promising ways forward. It shows we have to:

- deal with the reality of stigma and discrimination as an underlying obstacle to all responses
- educate young people on sex early enough
- make sure boys and men are involved to take on responsibilities
- focus on more in-depth and empowering activities for those who are most affected
- recognise and build on (rather than 'add on') the fact that HIV positive people have a key role to play in leading responses in prevention, care, treatment and mitigation
- acknowledge that religion is a major factor in people's experiences of the epidemic and that FBOs have an under-tapped role in helping people and a responsibility to examine organised religion's potential in perpetuating or overcoming stigma and discrimination in communities.

The value of diverse responses demands that we find better ways to help scale up the coverage, quality and impact of civil society action. Priorities at national institutional and policy levels include:

- rethinking health systems to involve clients, communities and affected groups in planning and negotiating HIV testing, treatment, care and social protection arrangements
- access to medical information and regulatory frameworks which take account of the changing realities of peoples' health seeking behaviour and medical procurement patterns at local levels: this includes effectively linking prevention with HIV testing, counselling and care, and other social protection measures
- recognising that successful approaches developed by community groups, inspired leaders and alliances between activists and professionals can be scaled up through new ways of partnering between formal systems and civil society
- giving more thought and commitment into scaling up support for such processes through ways which move beyond funding and macro-level targets
- recognising that there may be tensions between local responses and some widely approved global approaches ■

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### See also

*AIDS: Questions for Development*, IDS Policy Briefing 32, by Jerker Edstrom, Laura Turquet and Ingrid Young, July 2006 (PDF)  
[www.ids.ac.uk/ids/bookshop/briefs/PB32.pdf](http://www.ids.ac.uk/ids/bookshop/briefs/PB32.pdf)  
*Renewing our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS*, The NGO HIV/AIDS Code of Practice Project, Oxfam Publishing, by Julia Cabassi, 2004 (PDF)  
[www.ifrc.org/cgi/pdf\\_pubs.pl?health/hivaids/NGOCode.pdf](http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/NGOCode.pdf)



# Talking freely about sexuality in Zambia

**V**arious factors make young people vulnerable to HIV/AIDS: earlier puberty and later marriage, sexual and gender norms, sexual abuse, poverty, mixed messages about sexual behaviour and lack of condoms. Schools and communities in Zambia work together to build knowledge, values and skills and create positive peer pressure to help young people.



The Zambian 'Young, Happy, Healthy and Safe' project uses participatory visual tools to help teenagers to be aware and take care of their sexual and reproductive health. Photo Credits: Gill Gordon/ International HIV/AIDS Alliance

The International HIV/AIDS Alliance supports 'Young, Happy, Healthy and Safe' (YHHS), a Zambian non-governmental organisation, to implement a pilot project for improving young people's sexual and reproductive health and preventing HIV/AIDS.

Leaders, traditional counsellors, young people, teachers, health workers and parents came together with YHHS in 13 schools and their communities to analyse causes of vulnerability to HIV/AIDS and suggest strategies for reducing them.

Traditional counsellors compared their own lives as young people with the current generation and recognised how changes required them to adapt their teachings. Boys are now taught to avoid sexually arousing herbs, having sex with each other and coercing girls into having sex. They learn about HIV/AIDS, condoms, gender equality and women's right to sexual choice.

In the Chewa culture, girls who attain puberty learn to perform sexually and show such skills through erotic dances at graduation ceremonies. Pressure to practice sex, and abuse from the watching men puts the girls at risk.

Girls on attaining puberty, now learn about delaying sex by refusing sex and managing sexual urges through masturbation, and about using condoms when they start having sex. Prior to marriage, they learn about sexual performance, reducing HIV transmission risks in partners and babies and other sexual health issues.

Teachers, pupils aged 10 to 15 years, the parent-teacher association and Ministry of Education staff work with community leaders to create a safer sexual environment for children in and out of school. This includes sex education, life-skills lessons for teachers, pupils and parents. It also focuses on education and advocacy for cultural change and stopping sexual abuse, and liaison with police and leaders in charge of customary legal systems.

## What has changed?

- Teachers, pupils and parents talk more openly about sexual life, to take better decisions and develop skills to resist rights violations.
- Pupils and parents report that there is less sexual harassment by school mates and teachers: pupils are able to assertively refuse sex and report abuse.
- Traditional leaders now advise teachers not to allow parents to marry off their girls early.

- Public dancing by girls has stopped in the communities where the project works.
- Teachers report a drop in the numbers of girls leaving school because of pregnancy.

## What are the lessons?

- When communities and schools work together sex education becomes more relevant, coherent and effective for young people in and out of school.
- Trusted adults with knowledge of sexual health; clear boundaries for behaviour; life-skills and a supportive school and home environment are important.

- Sex education can enable young people to talk about sexual issues and gender in safer and non-stigmatising ways if initial lessons build trust and co-operation.
- Carefully managed single and mixed gender group learning activities can build positive peer pressure for more caring and equal gender relations ■

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### See also

*Choices – a Guide for Young people*, Macmillan Education, London, by Gill Gordon, 1999

## Can a workshop change stigma?

**Irrational fears and judgements, misinformation and traditional beliefs fuel stigma against people living with HIV and AIDS. Although policy change and advocacy are important for creating an environment free of stigma, individual behaviour change is equally important.**

The Regional Stigma Training Project, based in Zambia has been training national teams of trainers in eight countries: Zambia, Tanzania, Ethiopia, Uganda, Mozambique, Kenya, Nigeria, Senegal, Burkina Faso and Cote d'Ivoire, since 2004. Using the Anti-Stigma Toolkit developed with the International Center for Research on Women these teams are trained on stigma issues. The trainers then carry out community workshops and train faith-based, community-based and non-governmental organisations to integrate stigma into their existing programmes.

### Anti-Stigma Toolkit

The kit started off as simple exercises to help research assistants find ways of talking to the local community about stigma. These exercises showed the need for better tools to help people explore stigma and its many facets. The toolkit now contains over 100 participatory exercises exploring the causes of stigma, such as fears about HIV transmission or moral judgements; looking at strategies for coping with stigma and ways of naming and changing stigma in different settings.

As attitudes to stigma change and evolve, the toolkit is also evolving. New modules are developed with community members, for example, on stigma surrounding men having sex with men. Trainers take the toolkit into the local communities and work to make anti-stigma efforts an everyday part of

people's lives. Stigma modules are integrated into training courses for counsellors, health workers and teachers.

The answer to behaviour change, however, lies in the stigma workshops:

- The safe atmosphere of the workshops leads people to explore and share experiences together and the sharing raises awareness.
- Simple reflection exercises, role-plays and discussions focusing on topics such as gender, language or rights make participants realise the harm stigma causes and the need to change their behaviour and attitudes.
- Although the workshops are intensive and immediate results are on an individual level, they also look at how the toolkit can be rolled out to make a wider difference.

Focus group discussions are regularly held with participants trained by trainers, who talk about changing stigma. Evaluations of these stigma workshops, nearly always include comments such as: 'it was different from other workshops' and 'I have changed since coming to this workshop'. Stigma is often quoted as being the biggest barrier to dealing with the epidemic.

The programme is half way through its planned time period and a formal evaluation is yet to be conducted but there is certainly evidence that the workshops are creating steps for a way forward.

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### See also

*Kanayaka – the light is on: Understanding HIV and AIDS related Stigma in Urban and Rural Zambia*, Report from ICRW, Washington and the ZAMBART project, Zambia, by Virginia Bond et al, 2003 (PDF)  
www.icrw.org/docs/kanayaka.pdf

## Managing masculinity in Ecuador

**A project in rural Ecuador worked with a youth group to reduce gender-based power imbalances. Drawings, role plays and focus group discussions helped group members cope with complex issues in innovative and transformative ways.**

At the participants' request, alcoholism was tackled first. The young men acted out a role play showing how they pressurise each other into drinking in order to maintain a show of appropriate masculinity. They then discussed the implications. The result was they agreed to stop pressurising each other to drink and made a pact that they would no longer consider alcohol consumption an essential attribute of local masculinity.

In a later session the men used a similar approach to explore the social environment that can lead to casual sex. This seemed to happen mostly after drinking and almost invariably as a result of peer pressure. One or two men would suggest having sex and the rest would feel obliged to go along, not only by having sex but also by pressurising others into it.



One group member said, 'If I refuse to accompany my mates to prostitutes I am jeered at. They used to say I was gay. Now I am engaged to be married they say I am under my old lady's thumb'. In this case too, the men agreed to reassess the links between masculinity and sexuality and subsequently to stop coercing each other into having sex with multiple partners.

Alcohol consumption reduced

significantly, starting shortly after the agreement and still perceptible a year later. It was harder, however, to substantiate whether

**Men's involvement has been partly affected by gender analysis that sees them as the problem rather than as a part of the solution. Men can play a key role in tackling HIV/AIDS. A non-governmental organisation worker in Kenya wears a shirt that says "Men make a difference."**

*Photo Credits: 2001 Edward Reilly/ Lutheran World Relief, Courtesy of Photoshare*

the men who claimed to have changed their sexual practices had actually done so.

Some learning points:

- Young people engaged with the project because of interesting activities that encouraged them to think about their lives from fresh viewpoints.
- Peer pressure around masculinity was the most significant issue for both men and women.
- The project helped its male participants realise the potentially negative consequences of the ways they would do almost anything to avoid mockery of not being 'real men'.
- Agreeing to stop peer pressure had a major impact on the behaviour of those who had felt coerced into conformity and even made some difference to that of the rest.

This approach can only work if there is a large group of men involved who support each other. It needs careful handling in urban settings where men interact with many other peer groups, most of which may not be included in the project.

It is especially important to convince large numbers to make changes in order to produce long-term impact, focusing particularly on strong leaders, who can have significant influence.

Women's participation is also vital, both to support their men-folk's decisions and to make corresponding changes in their own gender identities ■

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**See also**

*Transformative Education for Development: a Journey of Personal Exploration*, IDS Working Paper, IDS, Brighton, by Colette Harris, forthcoming 2006

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## Life and dignity: standing up against homophobia

**Octavio Acuña a soft-spoken gay man who worked for AQUESEX – a non-governmental organisation in Mexico, was murdered in 2005.**

He was a well-known and committed gay, HIV/AIDS and human rights activist in Querétaro, a beautiful but homophobic city in the heart of conservative Mexico. Many of his colleagues, friends and others fighting for similar issues believe that this commitment and activism led him to his death. The legal battle is still on to prove that Octavio was indeed murdered because he was gay and was involved in HIV issues. Popular belief is that his murder cannot be interpreted in any other way.

AQUESEX, its local partners and the state HIV/AIDS programme called for action which inspired a national wave of protests to denounce this hate crime and demand justice.

Several organisations joined hands: Letra S, the National Commission to Prevent Discrimination, Colectivo Sol, Amnesty International, the International HIV/AIDS Alliance, the National HIV/AIDS control programme and many other civil society organisations, intellectuals and gay and HIV leaders launched a campaign demanding justice and to stop homophobic crime and stigma. Gay HIV activists led this strong social response and brought into public focus the intolerable situation of homophobia, violence and repression.

### An ongoing battle

Where homophobia is deep-rooted, as it is in Querétaro, it is difficult to say concrete changes happened as a result of the protests. The inertia, silence and unwillingness to talk openly about homophobia and discrimination have changed to some extent. We hope for changes in the way homosexuality is addressed in the local media. AQUESEX monitors the print media for reports to respond to homophobic comments on homosexuality and gay men.

People involved in denouncing the murder and action for justice, however, continue to receive threats and have been shadowed by unidentified vehicles and people. Octavio's partner, was summoned to court under the pretext of recording his testimony for indicting a murder suspect, but it really was an attempt to harass and frighten him.

Local people have become indifferent to this issue as the case has no relevance for them anymore. After the initial action the national and international pressure died down and the local authorities withdrew.

Changing attitudes and fighting stigma continue to be a major challenge. However, by standing up to defend their rights, protect their lives, and fight and condemn homophobia and discrimination, gays have shown what vulnerable people can do to stand up for their dignity.

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## Sex workers have rights too

**Women sex workers have faced the worst of the HIV/AIDS epidemic in India. Although they suffer high levels of HIV infection, some programmes contribute to the stigma sex workers carry, by labelling them core transmitters of infection. Others programmes typically regard sex workers as victims with little ability to change anything.**

SANGRAM – a non-governmental organisation started working with sex workers in 1992 to create a sustainable response to the HIV/AIDS epidemic. SANGRAM views sex workers as individuals who can change their own circumstances and become agents of change. It started a peer based programme with sex workers in Sangli, Maharashtra, which includes:

- HIV/AIDS education, condom distribution, training and counselling those who are unable to persuade their clients to use condoms
- helping sex workers with sexually transmitted diseases and other health problems to access medical care and related services.

In 1996, the programme broadened into a collective of women sex workers against injustice – VAMP (Veshya Anyuk Mukti Parishad). VAMP tries to build a common identity among the women and empower them to find their own solutions. It now works with more than 5,000 women, through 60 peer educators.

### Why the VAMP approach works

VAMP gained recognition as a collective that has prevented HIV transmission while ensuring that women sex workers are treated as human beings, with the same rights and dignity as other people. The programme has been successful because it:

- is peer-focused, with the 'educators' and the 'educated' living in similar circumstances where they can understand each others' experiences
- is women-centred, based on their needs, perceptions and experiences rather than what the programme thinks the women need
- is process-oriented, emphasising how sex workers can effectively negotiate safer sex with clients
- empowers sex workers, which is a central goal rather than a by-product of peer education
- fosters a common identity among sex workers as an end in itself, rather than a means to prevent HIV/AIDS
- links HIV/AIDS to other vulnerabilities, such

as violence, discrimination, gender and human rights violations.

- frames HIV/AIDS within a context of sexuality, gender and rights: condoms are viewed as life-saving equipment that women sex workers must have access to, as a right.

It is important to train women in various rights issues, such as law, inheritance and property rights. HIV/AIDS interventions relating to sex work can work only through an approach that places human rights, dignity and the status of vulnerable groups as core values.

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## HIV positive men as responsible citizens and patients

**South Africa's national anti-retroviral therapy programme and the Treatment Action Campaign (TAC) have been at the forefront in fighting HIV/AIDS. Rolling out anti-retrovirals nationally and ensuring treatment adherence is far from easy, however. HIV positive people can help themselves and others by being responsible citizens.**

By 2005 in South Africa, 150,000 people were on anti-retroviral therapy (ART): of these 70,000 got it through the public sector. Although up to 700,000 people are estimated to need ART, only 18 percent of those who need it from the public sector are accessing it. Access to treatment is also uneven between rural and urban areas and across provinces.

Of equal, if not greater, concern is whether a patient follows the prescribed treatment routine closely (treatment adherence) which is vital. Expanding and accelerating ART at the expense of ensuring that patients know how to take the drug properly has compromised adherence and increased the likelihood of drug resistance. 'Second line' drugs needed to cope with ART resistance are very expensive.

### Creating empowered patients

South African public health professionals are calling for 'empowered patients' who understand HIV/AIDS issues well and who can help in dealing with the current situation. This demand for a 'new contract'

between health care providers and patients is similar to the *Medicins Sans Frontières* and TAC treatment literacy approaches that seek to produce knowledgeable and 'responsible citizen-patients'.

HIV positive people can fulfil their role as responsible patients as well as citizens by demonstrating treatment adherence, disclosing their HIV status, using condoms, abstaining from alcohol abuse and smoking and so on. The aim of this is to promote health rights and responsibilities and create non-hierarchical relations between providers and patients. Support from the community promoting the rights of people living with HIV and AIDS is essential to achieve this.

However, most public health settings are hierarchical and often authoritarian. Since support groups do not exist everywhere, how can we produce these empowered and knowledgeable citizen-patients? Several questions arise:

- Are health care workers willing and able to initiate processes of 'patient empowerment'?
- How can HIV/AIDS programmes reach out to men, given that clinics in South Africa, and elsewhere, are usually 'women's spaces' and men tend to attend clinics only when they are seriously ill?
- How can men be persuaded to be tested, and if HIV positive to commit themselves to treatment adherence, lead responsible and healthy lifestyles, and practice 'safe sex'?
- How to involve men more actively in HIV/AIDS community mobilisation?

The Khululeka Men's Support Group in Gugulethu, Cape Town is a good example of how men can to change their lifestyles and become involved with community-based HIV/AIDS work. Strong and charismatic

leadership from Phumzile Nywagi, a former TAC activist, inspired these men to get involved.

The group does AIDS awareness work in bars, railway stations and prisons. They also tackle problems relating to substance abuse amongst themselves and others.

This group of 20 men living with HIV and AIDS made innovative attempts to develop new ways of thinking about themselves and living out their roles as men. Combined with ART and community-based activism (such as participating in the TAC and men's support groups) they were able to mutually support themselves, promote long-term treatment adherence and adopt 'responsible' lifestyles.

Experience from the Khululeka Men's Support Group shows:

- Community-based support that promotes community health mobilisation, specifically targeting men living with HIV and AIDS, needs to be developed and supported.
- Programmes should stress health rights and responsibilities.
- Men's groups can help men and women, to recognise the significance of rights in relation to sex, gender and health, while also emphasising responsibility and vulnerability ■

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#### See also

'From Rights to "Ritual": AIDS activism and treatment testimonies in South Africa', *American Anthropologist* 108 (2): 312-323, by Steven Robins, June 2006  
*Sexual Rights and Sexual Cultures: Reflections on the 'Zuma Affair' and new masculinities in South Africa*, *Journal for Southern African Studies*, by Steven Robins, forthcoming 2006

## Rural Uganda making sense of HIV/AIDS

**1989: Rakai District, Uganda. Gwanda is a small isolated village, a beautiful place close to Tanzania near Lake Victoria but with a sad reputation. It is situated in the epicentre of the AIDS epidemic and of the war, when the Tanzanian troops came to overthrow Idi Amin.**

People created their own local responses to the AIDS epidemic – probably just as effective as the short-term programmes and medium-term programmes being implemented from Geneva, via Kampala.

Mr Julius, a local village leader asks: 'Why are you asking questions about agriculture? Don't you know about AIDS – it is killing many people.' He explains that the local community had decided to ban discos! By stopping teenagers from dancing together at weekends and confiscating sound equipment – through a very intrusive local bye-law – Julius and the other elders had made their own intervention. Since then, many other similar local interventions have contributed to reducing transmission rates and prevalence in Uganda.

**Local public health responses have been an effective part of Uganda's fight against HIV/AIDS.**

2005: Gwanda is now very different: four hours from Kampala, good road and mobile phones. The chairman of the Parish Council, Mr Samuel, aged 30, explains how he became an AIDS orphan when he was seven, in 1982. He and his older sibling raised themselves and the younger ones. He pointed to the school and said, 'Ninety percent of the children there are AIDS orphans'.

Mr Samuel, now, feels responsible for preventing the spread of HIV but how can he do this? Pointing to the lakeside settlement he says: 'I go down there regularly. When I see a girl from this village working as a 'barmaid' or a young boy working as a fisherman, I beat them back to school!' He cracked the knuckles of his right hand for emphasis, the sharp snap leaving no doubt that physical force would be used if he thought it appropriate.

Uganda's prevalence level fell to around 5 percent from 20 percent in the late 1980s. Local public health responses such as those described above have been an effective part of Uganda's achievement. We need to think about this in relation to both 'one-size-fits-all' such as 'Abstain, Be faithful, Condomise', and generalised human rights based approaches. Pragmatic heterogeneity, not ideology, is the key to good public health strategy!

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*This article is based on field-visit notes from Uganda over the past 20 years*

## Global communities respond to HIV/AIDS

**When international AIDS donors agreed in 1994 that 'greater involvement of people with HIV and AIDS' (GIPA) was a good policy, they did not expect its impact to be so far-reaching. Twelve years later, GIPA is much more than a policy. It has generated a transnational therapeutic movement and new forms of community.**

Several factors made GIPA a sensible approach:

- the success of the gay community in developed nations in controlling HIV/AIDS
- human rights-based approaches had gained popularity over established 'contain and control' public health strategies
- the 'access to treatment' movement helped to shift the response from a prevention dominated one to that which combines treatment with anti-retrovirals.

All this had a wide impact, for instance, it provided a powerful and effective voice for modifying the global intellectual property regime through amendments to TRIPS (trade related aspects of intellectual property rights) to make HIV/AIDS drugs accessible to patients. GIPA also gave rise to a global network of people.

The motivation for the transnational advocacy coalitions was the relationships formed between grassroots activists and people living with HIV and AIDS in developed and developing nations. How did these encourage new forms of community and citizenship?

In Burkina Faso and Côte-d'Ivoire, a group of people living with HIV and AIDS, and HIV/AIDS activists were already doing HIV prevention in 1994. As in many other countries, these prevention activists were quickly sensitised to the issues and challenges around treatment and care. This was possible partly because of their prevention programmes and, more directly,

**'AIDS isn't over until it is over for everyone' – A banner at the 16th International AIDS Conference in Canada, Aug 2006.**

*Photo credits: Lise Beaudry / IAS*



because some activists found out that they were HIV positive themselves. This strengthened personal ties between HIV positive activists across countries and led to a practical solidarity around the issue of treatment.

In the absence of donor support, developed country activists shared drugs and informal advice with other activists who set up temporary and informal treatment and support programmes. African activists were essentially experimenting and learning from experiences. In the process they built an impressive community experience-based knowledge and practice around treatment.

Lessons learnt include:

- Limited resources can put a strain on those delivering the services about who gets treatment and who does not.
- The long-term impact of treatment creates communities of people who share a powerful experience of regaining health: they are bound by a common experience, practical solidarity and sometimes even marriage.
- Due to their links these communities are uniquely placed to respond to the challenges that treatment poses.
- Restoring people ill with HIV to good health creates opportunities and challenges for prevention that need to be met at the community level and not just through programmes for individuals.
- Donor policies can help to create the forms of community they wish to strengthen: therapeutic communities of people with HIV could not have formed without a policy for empowering them.

With the global policy shift towards treatment in 2000, activists and community workers have become essential to scaling-up access to treatment and for new prevention technologies. It is important now to:

- Help people with HIV and AIDS to build their individual and community abilities to tackle the epidemic over the long term
- develop strategies to use therapeutic activism and access to treatment as forces to change health care delivery across countries
- find ways to learn from local experiences and challenges in delivering health care programmes ■

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### See also

*Antiretroviral Globalism, Bio-politics and Therapeutic Citizenship*, Background paper for the Governance, Equity and Health Conference 2005, by Vinh-Kim Nguyen, 2004

[www.idrc.ca/es/ev-82528-201-1-DO\\_TOPIC.html](http://www.idrc.ca/es/ev-82528-201-1-DO_TOPIC.html)



## Community and faith-based groups lend a hand

**Several households falling into poverty as a result of HIV/AIDS desperately need support systems. African communities have modified existing safety net mechanisms and pioneered new responses such as home-based care programmes, support groups and orphans and vulnerable children initiatives. But how long can self-resourced initiatives continue to function?**

Safety nets protect people from the worst effects of poverty. They prevent poor households from making hasty decisions to sell productive assets and increase their chances of escaping destitution. Without state-run programmes, the extended family and local community are the best source of help for people facing unexpected income loss. Community safety nets:

- help households in greatest need
- respond quickly to crises
- are cost efficient, based on local needs and available resources
- involve the specialised knowledge of community members.

Although community safety nets are crucial for tackling poverty they are poorly understood. Though often seen as straightforward mechanisms with a clear definition, in reality they are diverse - ranging from savings associations, burial societies, cooperatives, philanthropic groups or individuals. Safety nets are constantly changing, accommodating changes within society.

Faith-based groups are an important component of safety nets and are sometimes the only source of support for extremely poor people:

- A UNICEF survey of religious congregations in ten different areas of Africa found that 97 percent are working with orphans and vulnerable children.
- Most churches in Namibia have an HIV/AIDS programme, often involving economic support, though few receive external assistance.
- Many responses go undocumented - a believer sharing her food with a neighbour dying in a mud hut, for example - perhaps unsurprising as they involve poor people serving the more needy ones.
- Some programmes involve volunteers from faith based groups caring for several people in ways that are uniquely in tune with people's needs, often in situations of extreme poverty.

Community groups provide vital economic support and carry a huge burden of care yet remain largely invisible to governments, non-government organisations and international bodies. They receive a very small portion of the huge amounts of aid provided annually for HIV/AIDS initiatives.

**Faith based organisations provide a lot of the health care in many African countries. Members of the Zambia Council of Churches march as a part of a campaign which tries to involve religious and community groups in stopping further spread of HIV/AIDS.**

*Photo credits: 2005 CCP, Courtesy of Photoshare*



**Faith-based groups are an important component of safety nets and are sometimes the only source of support for extremely poor people.**

The economic burden of the HIV/AIDS epidemic is shifting with communities taking on increasing responsibilities. However, the much glorified 'resilience of the poor' has its limits. We cannot assume that poor people can continually adapt to changing conditions and still survive. Programmes based on the idea that poor people can support needier people are an unsustainable and unacceptable form of social welfare.

Strategic responses to strengthen community safety nets to prevent them from collapsing under the strain of people facing destitution are essential:

- Studies need to evaluate safety nets, understand the role of community groups and assess the value of transfers from community members to destitute households.
- Toolkits should be developed to assist agencies such as health sectors, for example, to map community safety nets.
- Model programmes that build skills and provide financial support to groups contributing to safety nets should be pioneered.
- Formal safety net programmes should build on existing community safety net mechanisms ■

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*Under the Radar – Community Safety Nets for Children Affected by HIV/AIDS in Poor Households in Sub-Saharan Africa, Report for UNRISD, by Geoff Foster, Jan 2005 (PDF)*  
[www.sarpn.org.za/documents/d0001830/Unrisd\\_children-HIV\\_Jan2005.pdf](http://www.sarpn.org.za/documents/d0001830/Unrisd_children-HIV_Jan2005.pdf)

### Useful web links

HIV and AIDS Resource Guide

[www.eldis.org/hiv aids](http://www.eldis.org/hiv aids)

International Community of Women Living with HIV/AIDS

[www.icw.org](http://www.icw.org)

Health and Development Networks eForums

[www.healthdev.org/eforums/cms](http://www.healthdev.org/eforums/cms)

United Nations Development Fund for Women Portal for Gender and HIV/AIDS

[www.genderandaids.org](http://www.genderandaids.org)

International HIV/AIDS Alliance Online toolkits

[www.aidsalliance.org/sw7390.asp](http://www.aidsalliance.org/sw7390.asp)

Treatment Action Campaign

[www.tac.org.za](http://www.tac.org.za)

Exchange on HIV/AIDS, Sexuality and Gender

[www.kit.nl/exchange](http://www.kit.nl/exchange)

International Harm Reduction Association

[www.ihra.net](http://www.ihra.net)

Naz Foundation International

[www.nfi.net](http://www.nfi.net)

Network of Sex Work Projects

[www.nswp.org](http://www.nswp.org)

Africa Regional Sexuality Resource Centre

[www.arsrc.org](http://www.arsrc.org)

South East and East Asian Sexuality Resource Centre

[www.asiasrc.org](http://www.asiasrc.org)

Latin American Centre on Human Rights and Sexuality

[www.clam.org.br](http://www.clam.org.br)

Instituto Promundo

[www.promundo.org.br](http://www.promundo.org.br)

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# Preventing intimate partner violence and HIV

**F**or women who face physical or sexual violence from a partner, refusing sex, insisting on fidelity or condom-use are not realistic options. Even if women change their own risk behaviour, they are at increased risk of HIV infection.

Intervention with microfinance for AIDS and gender equity (IMAGE) is a collaborative study between the University of the Witwatersrand, the Small Enterprise Foundation in South Africa and the London School of Hygiene and Tropical Medicine. It found that integrating an HIV/AIDS component into existing programmes, such as microfinance can help women facing violence from their partners.

An established microfinance programme combined with participatory education on gender and HIV/AIDS can socially and economically empower women and reduce intimate partner violence.

Through training sessions over six months, women who were microfinance clients explored issues such as gender roles, culture, sexuality, communication, relationships, violence and HIV/AIDS. Women leaders then encouraged their loan centres to mobilise communities and work with men and youth on these issues.

The project was evaluated as a cluster-randomised intervention trial involving over 850 women and 4,000 young people in rural South Africa. It found that:

- Two years after the programme started, participants' risk of physical or sexual intimate partner violence in the past year reduced by more than half.
- Household economic well-being and social networks of participants improved.
- Increased self-confidence, ability to communicate with partners about sex and solidarity with women helped women to reject and oppose violence, expect and receive better treatment from partners, leave abusive relationships and raise public awareness about intimate partner violence and HIV through public demonstrations.
- IMAGE households showed greater communication between generations about sex and HIV.

Lessons offered are:

- Violence within an intimate relationship can be reduced within the time period of a programme.
- Reducing violence should be funded as a central component within national HIV/AIDS programmes.
- Addressing basic needs, for example through income generation, can motivate vulnerable groups to sustain their contact with an HIV intervention over long periods: most independent health interventions find it difficult to do so.
- HIV/AIDS funding should be used to develop other inter-sectoral partnerships that integrate intimate partner violence and HIV interventions into existing programmes, for example through job skills retraining, literacy, and water and sanitation programmes.

- Broader macroeconomic policies and gender equity policies should also adopt these empowerment strategies ■



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<http://hermes.wits.ac.za/www/Health/PublicHealth/Radar/Home.htm>

**See also**

*Effects of a structural intervention for the prevention of intimate partner violence and HIV in South Africa: a cluster randomized trial*, Presented at the XVI International AIDS Conference, Canada, Abstract no. THPE0252, by Paul Pronyk et al, 2006

[www.iasociety.org/abstract/show.asp?abstract\\_id=2184944](http://www.iasociety.org/abstract/show.asp?abstract_id=2184944)

*Microfinance and HIV prevention – emerging lessons from rural South Africa*, Small Enterprise Development 16 (3), pages 26-38, by Paul Pronyk, Julia Kim, James Hargreaves, M Makhubele, L Morison, C Watts and J Porter, 2005



**Women protest against violence and HIV/AIDS in South Africa. Women who have a violent partner are at increased risk of HIV infection as they find it difficult to insist on fidelity or condom-use, or refuse sex. The IMAGE study found that microfinance programmes could empower women by including a strategy to prevent HIV and oppose violence.**

*Photo Credits: Rural AIDS and Development Action Research Programme, South Africa*



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