

id21 insights

communicating international development research



Dealing with HIV and AIDS

Solutions in ordinary people's actions

Twenty-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?

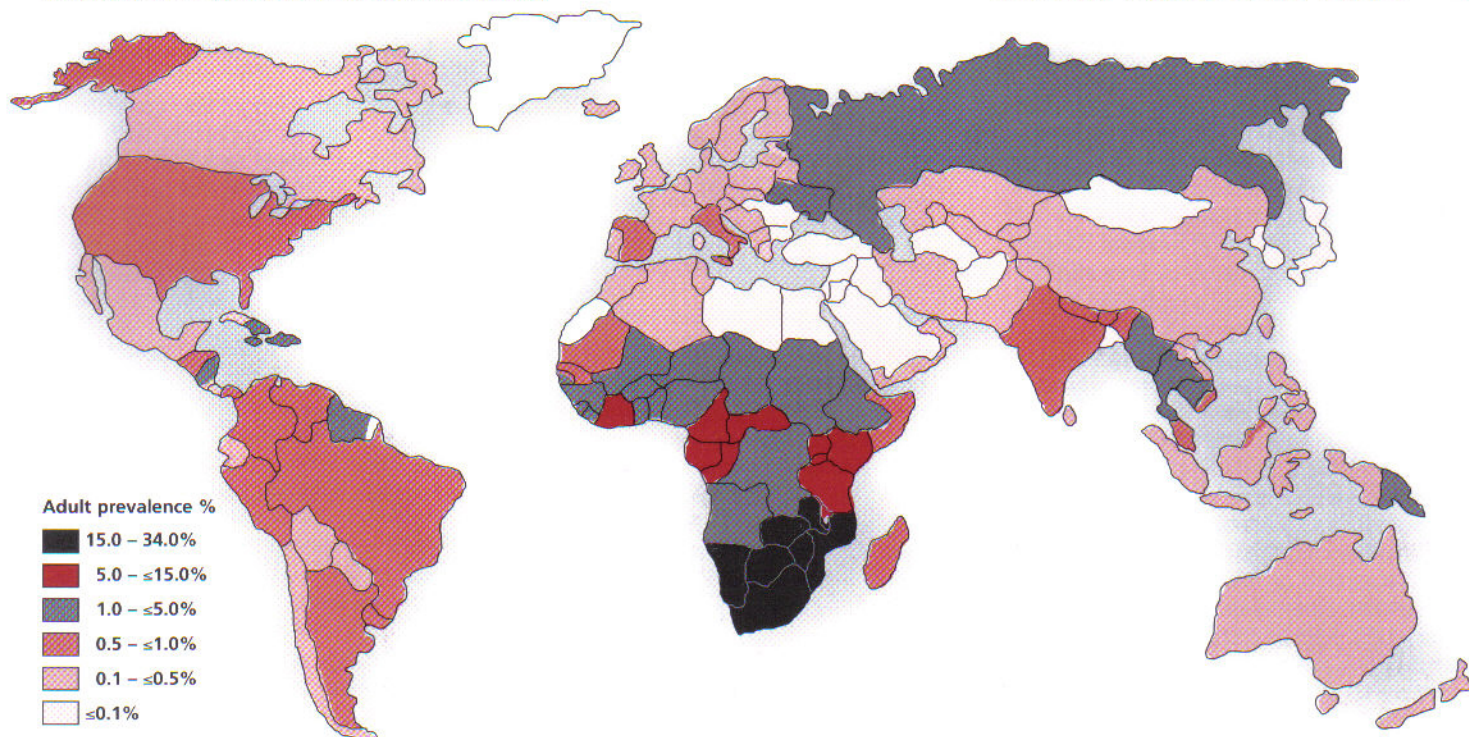
Capturing and scaling up the creativity and local relevance of diverse responses is a major challenge. Whilst it is true that 'community responses' are crucial to respond effectively, the focus on 'community' can also lead to over-simplified analyses of – and responses to – the epidemic. We need to be 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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In this issue

Editorial	1
Fighting stigma	3
Talking about sexuality	3
Masculinity in Ecuador	4
Homophobia in Mexico	4
Sex workers have rights	5
Involving HIV positive men	5
Linking local and global activists	6
Common sense in Uganda	6
Role of faith-based groups	7
Useful web links	7
Preventing violence and HIV	8

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.



The Regional Stigma Training Project in Zambia uses a toolkit to help local people explore HIV/AIDS related stigma. Pictures are used as key tools to help communities 'name the problem'. After attending the workshop, a young woman living with HIV first talked about it to her priest. She then told the congregation her story about living with HIV and the stigma she had faced. People later queued up to shake her hand.

Source: *The Anti-Stigma Toolkit*, International HIV/AIDS Alliance

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 ■

Jerker Edström

Institute of Development Studies, University of Sussex, Falmer, Brighton BN1 9RE, UK
T +44 (0)1273 678758 F +44 (0)1273 621202

J.Edstrom@ids.ac.uk
www.ids.ac.uk

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

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/hiv/AIDS/NGOCode.pdf