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HIV and AIDS REPORTER: focus on social mobilisation and HIV 20 September 2006

produced by the [IDS Health and Development Information](#) team in collaboration with [Eldis](#) and the [DFID Health Resource Centre](#)

This is our monthly email bulletin, bringing together research to inform policy debates on HIV and AIDS in developing countries.

The HIV and AIDS Reporter aims to provide readers with a more in-depth look at a particular area of HIV-related policy. This month's theme is on [social mobilisation and HIV](#). The bulletin also features summaries of new documents and other additions to the [HIV and AIDS Resource Guide](#).

Reporter Archive - A reporter archive is now available on the HIV and AIDS Resource Guide. See previous issues of the HIV and AIDS Reporter at <http://www.eldis.org/hiv aids/archive.htm>

All documents listed below are available free on the web. If you are unable to access any of these materials online and would like to receive a copy of a document as an email attachment, please contact i.young@ids.ac.uk.

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Feature: social mobilisation and HIV

One of the unexpected outcomes of the recent [International HIV/AIDS Conference](#) in Toronto was the emphasis and visibility of people living with HIV and AIDS (PLWHA). Several sessions looked at the history of GIPA (Greater Involvement of People living with AIDS), while others emphasised the need to move beyond GIPA to look at the meaningful involvement of PLWHAs (MIPA). This new emphasis on MIPA recognises that GIPA has not yet been achieved, and that often the involvement of PLWHA is tokenistic. This call for greater and more meaningful involvement recurred throughout the conference, in various sessions, poster presentations, demonstrations and in the global village.

'Our best resource is to listen to science and to technology and to people living with HIV and AIDS'
(Kevin De Kock, WHO)

Although the Toronto conference has been criticised for not sufficiently mainstreaming the voices and priorities of PLWHAs, the plenary discussion on Thursday 17th August hosted a lively debate around GIPA, MIPA and issues of social mobilisation in response to HIV and AIDS. The session was titled '[Time to Deliver: the price of inaction](#)'. An inspiring and inspired session with activists from South Africa, Russian Federation, Kenya and Jamaica, the participants emphasised the importance of leadership at every level, including in homes, hospitals, communities and governments.

'We will take hold of the future, or the future will take hold of us'
(Musimbi Kanyoro, World YWCA Kenya)

Often the most effective way that people most affected by HIV and AIDS have influenced social change in their favour is when they have banded together and spoken up about an issue that is important to them. [Treatment Action Campaign \(TAC\)](#) in South Africa is an example of how a process of social mobilisation raised the issue of access for all to treatment and care on the political agenda and contributed to a national policy change in 2003.

Social mobilisation – such as the formation and evolution of social movements - is a process that can enable people most affected by HIV and AIDS to drive responses to the epidemic at the local, national and international level. Recent research has focused on spaces of public engagement as a means of understanding how decisions are made, and the influence of individual citizens and civil society on these decisions. Researchers have distinguished between key elements in this process of engagement: types of spaces (closed, invited and claimed spaces); the types of power relationships that operate within each space (explicit, hidden and invisible); and the venues in which these debates occur (local, national and global). Others have further differentiated between claimed and autonomous spaces. Claimed spaces are those in which people claim entry to institutions where they should be included (but haven't been invited), while autonomous spaces are those outside the structures of the state where people mobilise for themselves and develop their confidence, skills, solidarity and strength towards achieving their objectives

'If maybe I could say it directly the way I want to say it, then I would be heard the way I want to be heard'

(Vuyisa Dumile, Khululeka Men's Support Group South Africa)

By focusing on space and dynamics of power, we can better understand social mobilisation and its role in facilitating inclusive social change. Social movements are present and active in each of these spaces. It is their participation in and creation of autonomous spaces that makes them unique and powerful compared with more institutionalised forms of social activism: by originating outside of existing structures or other regulated spaces, social movements are inherently flexible to be driven by the needs, objectives and priorities of their members. This is not to romanticise movements, which are often driven by the loudest voices and the agendas of the most powerful members; but to recognise that different processes create alternative spaces for debate. In many ways HIV social movements are MIPA in action, often originating from no 'external' involvement, and entirely designed and initiated entirely on the terms of people most affected.

Communication is central to processes of social mobilisation. It allows links to be made between

likeminded people, groups and organisations, as well as supporting advocacy with external audiences. At the local level, the Khululeka Mens' Support Group in Guguletu South Africa who rely on word of mouth, informal networks and regular Sunday meetings to attract new members. One way that Khululeka show their support to HIV positive men is to attend (and sometimes arrange) funerals for men who have been discriminated against or stigmatised because of their status. At the international level, the [International Community of Women living with HIV/AIDS \(ICW\)](#) is run by—and for—HIV positive women. They have strong networks at the local, regional and international level. Much of ICW's work is less visible but no less powerful behind-the-scenes activism through lobbying, so that change can happen without confrontation. Each of these examples highlights how communication supports each group work towards its objectives, and indeed how flexible and nuanced communication needs to be to respond to the needs and contexts of the members.

Key questions for consideration include:

- How does social mobilisation influence inclusive social change?
- How can communication most effect social and policy changes so that they are inclusive and driven by the needs and priorities of people most affected?
- What is the role of media (including mass media and new/alternative media) in supporting or challenging these groups or movements?
- Who speaks on behalf of whom? Whose voices are the loudest? Whose perspectives are the most influential in shaping the course of social mobilisation?

Panos will build on [their discussion paper](#), two pilot projects (in Cape Town, South Africa and in Recife, Brazil) and an open discussion on the AIDSPortal for a report to be released in 2007. This project will be developed over the next few months and Panos welcomes your thoughts and feedback on the ideas raised above.

For more on this, see the Panos project on [social movements](#) or contact [Lucy Stackpool-Moore](#), AIDS Programme Office with Panos London. You can also contribute to the AIDSPortal discussion on this topic. To register for the AIDSPortal and contribute to the discussion, visit <http://www.aidsportal.org/>

Many thanks to Lucy Stackpool-Moore for writing this feature.

Suggested resources:

- [Panos](#)
- [Participation.net](#)
- [Development Research Centre on Citizenship, Participation and Accountability](#)

Recommended readings

[We are one but we are many](#)

Author(s): Stackpool-Moore, L.

Produced by: Panos AIDS Programme, 2006

This paper, from Panos London, explores how social movements can be powerful forces for inclusive social change in local, national and international responses to HIV and AIDS. The paper, prepared as part of a larger project on social mobilisation, will be the starting point of an online discussion in June 2006. The paper aims to look beyond current debates and explores how the processes of communication motivate people to act. Specifically, it asks: how social movements influence social

change; how social movements ignite passion and commitment to action; how dialogue generates action that contributes to social change; and what is the role of communication and media in helping social movements achieve their objectives?

The paper argues that the lived experiences of people living with HIV and AIDS can best inform and steer the response to HIV and AIDS, but that this has not happened. It calls for creative and critical thinking about how communication can best support inclusive social change. More attention needs to be paid to the powerful role of social movements to stimulate social change, provide mutual support and capitalise on passions and motivations; and the critical role of communication in social movements needs to be recognised. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22098>

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Making space for citizens: broadening the 'new democratic spaces' for citizen participation

Author(s): Shankland, A.

Produced by: Institute of Development Studies (IDS), Sussex, UK ,2006

This IDS Policy Briefing explores the new democratic spaces that have opened up for citizen participation in a range of countries, including Angola, Brazil, Bangladesh, Bolivia, Uganda, Mexico, Canada and the United Kingdom. The briefing outlines how attempts at increasing democratic participation of citizens has led to an increase of councils, committees, panels, public hearings and other stakeholder fora. The authors argue that while some efforts have increased participation and others emphasise the responsiveness on the part of policymakers and service providers, the most successful often combine the two approaches.

The authors outline how more attention needs to be paid to key contextual factors (historical, legal and cultural) and institutional design. Key issues for policy makers include: importing a 'best practice' model will not guarantee success; a clear legal framework is necessary; institutional arrangements and processes will need to be flexible; participation takes time; and the additional costs of citizen participation need to be met. Key challenges for civil society include: a clearly established, small group of representatives should be chosen to negotiate on behalf of their constituents; representation and lessons learned needs to be shared with the wider body; links with other spaces are vital; and engagement should be a strategic choice.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22571>

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Revitalising the global movement of people living with HIV

Author(s): Kafle, R. et al

Produced by: Global Network of People Living with HIV/AIDS (GNP+), 2005

This report, from meeting of people living with HIV and AIDS (PLWHA) in Nairobi, Kenya in November 2005, calls for a widespread "conscientizacao" - a radical mobilisation of HIV positive communities worldwide. The document outlines how mobilisation should be centred on the lives of PLWHA, take GIPA (Greater involvement of people living with AIDS) to a higher level of meaningful active participation, and respect and promote human rights. Other principles of action include: empowering HIV positive individuals and groups; being accessible, transparent and accountable; investing in human resource needs and new leadership; and ensuring that global action is based on country realities.

The document highlights the critical need to make secure the active participation of PLWHA in organisations working at a global level. The meeting identified seven areas for urgent action to revitalise the global movement of PLWHA: making universal access to quality treatment a reality; on-going promotion and defence of human rights; increasing the radical mobilisation/conscientizacao of positive communities; reclaiming GIPA through guidelines, setting indicators and monitoring; organisational development for local organisations of PLWHA; urgent resource mobilisation for local

efforts of PLWHA; and improving the transparency, inclusiveness and coordination in the global movement.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22573>

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Enhancing the greater involvement of people living with HIV (GIPA) in NGOs/CBOs in India

Authors: Cornu, C.

Produced by: International HIV/AIDS Alliance, 2006

This handbook, from the International HIV/AIDS Alliance, explores the different dimensions of GIPA (greater involvement of people living with HIV/AIDS), and is based on experiences of NGOs (non-governmental organisations) in India. The handbook is a collection of information sheets and participatory activities for NGOs who want to work towards GIPA in their work. It aims at sensitising NGOs, building individual skills and organisational capacities so that NGO management, staff and volunteers can discuss and plan together how to meaningfully involve people living with HIV and AIDS (PLWHA) in their organisations.

This handbook is divided into four modules. Module one introduces a framework to help understand what involvement is, explores different levels of involvement and considers issues of disclosure of HIV status and the visible involvement of people living with HIV. Module two considers why PLWHA should be directly involved in HIV and AIDS work and provides management, staff and volunteers the opportunity to explore why the involvement of PLWHA is beneficial for their organisation. Module three provides a set of practical activities to plan greater involvement of PLWHA. Module four provides steps to make GIPA happen, including: ways to mobilise PLWHA, ways to build a supportive environment for them to be involved, particularly through the development and implementation of a workplace policy on HIV and AIDS. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22570>

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AIDS activism - new opportunities for citizenship in South Africa?

Produced by: id21 health, 2004

Post-apartheid South Africa has witnessed the growth of social movements using on-the-ground and network-based modes of organisation that operate at the same time in local, national and global political environments. Networks across countries and grassroots mobilisation have allowed HIV/AIDS activists to use tactics confronting the state while supporting it to be more inclusive. Research from the University of Stellenbosch in South Africa explores the organisational practices and strategies of the Treatment Action Campaign (TAC), a Cape Town-based social movement.

Founded in 1998, TAC campaigns for affordable treatment for those with HIV/AIDS, treatment for pregnant women with HIV, equality of treatment within South Africa's public health system and wider spread of knowledge about HIV/AIDS treatment. TAC has challenged the fatalistic perception that little can be done for South Africa's spiraling AIDS death toll. TAC's grassroots mobilisation is driven by volunteers drawn from unemployed working class black women and youth, middle class professionals, religious leaders and congregations, teachers, trade unionists and community-based organisations. The strength of its support has enabled TAC to reject government accusations that its activists are 'unpatriotic' and 'anti-African' for challenging President Mbeki's support for scientists who question the links between HIV and AIDS.

Available online at: <http://www.id21.org/health/s8bsr2q1.html>

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Missing the message?: 20 years of learning from HIV/AIDS

Author(s): Scalway, T.

Produced by: Panos AIDS Programme, 2003

This document critically re-examines the successes and failures of the last 20 years of the global response to AIDS. It argues that current international interest, funding and mobilisation for AIDS create a unique opportunity to build an effective response to the crisis, and that it is time for a fundamental reappraisal of HIV communication strategies.

The document argues that past successes have been characterised not only by strong national leadership but also by open public debate in which ownership and local participation are vital. It has been found that what works is when the energy, anger and mobilisation of civil society have been at the forefront of responses to HIV/AIDS. However, too little in today's response to AIDS fosters these dynamics. Therefore, communication approaches in the response to AIDS should move from putting out messages to fostering an environment where the voices of those most affected by the pandemic can be heard.

There are three areas which urgently require more emphasis, thought and attention. Challenges in each of these areas include:

- Local policy environment:
 - longer-term engagement
 - greater inclusiveness in consultation
 - more participatory decision-making
 - greater transparency
- Local media environments:
 - critical reappraisal of media training
 - work on media structure, legislation and regulation
- Local civil society:
 - emphasis on advocacy
 - emphasis on more sophisticated relations with the media

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC14250>

Summaries of other documents in the HIV and AIDS Resource Guide

Missing the target: off target for 2010: how to avoid breaking the promise of universal access

Produced by: International Treatment Preparedness Coalition (ITPC), 2006

This report, from the International Treatment Preparedness Coalition (ITPC), follows on from a 2005 study that explored specific barriers and potential solutions to AIDS treatment delivery in six countries. This report finds some progress but argues that a lack of national leadership and slow implementation of reforms continues to prevent treatment delivery. Key findings show: a lack of

collaborating government and donor agencies in the Dominican Republic; a need to reform national guidelines to reach children and ensure greater equity in India; AIDS treatment services are undercut by food shortages in Kenya; suspension of Global Fund grants in Nigeria; an urgent need for injecting drug user services in Russia; and improved treatment access for children and men in South Africa.

The authors argue that the Global Fund to fight AIDS, TB and Malaria needs to identify new strategies to address failing grants and weak country-coordinating mechanisms. The WHO (World Health Organization) needs to show tangible outcomes in terms of workable national plans and reduction in barriers. UNAIDS needs to show faster progress on UN collaboration and implement a true strategic plan for universal access. And PEPFAR (President's Emergency Plan for AIDS Research) needs to end policy prescriptions that undermine service delivery and build more human resources capacity.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22179>

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From access to adherence: the challenges of antiretroviral treatment

Author(s): Hardon, A.; Davey, S.; Gerrits, T.; Hodgkin, C.;

Produced by: World Health Organization (WHO), 2006

This report demonstrates that access to antiretrovirals (ARVs) is only one part of the treatment equation. The study presents studies from Botswana, Tanzania and Uganda. It argues that without targeted patient support, patients may not take their medicines regularly or frequently enough (adherence), and lose the therapeutic benefits of treatment. Reasons found for adherence failure include: lack of resources for food to accompany ARVs; alcohol or substance abuse; work-related problems such as not getting time off to go to the clinic or stigma in the workplace; long travel time to clinics and long waits at the end; and stigma and discrimination in the community and at home.

The report makes a number of key recommendations. Enforcement of legislation is needed to protect the rights of workers to access to treatment without fear of discrimination. Training and supporting community counsellors is needed for those who operate from home. The registration and consultation fees at health clinics for those on antiretroviral therapy (ART) should be waived. Providing food support to those on ART is needed, especially at the beginning of treatment when appetite increases. The possibility of a transport voucher scheme for people who cannot afford to go and pick up their medicines should also be explored.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22158>

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AIDS, poverty, and hunger: challenges and responses

Authors: Gillespie, S. (ed)

Produced by: International Food Policy Research Institute (IFPRI), 2006

This book is based on the International Conference on HIV/AIDS and Food and Nutrition Security: From Evidence to Action that took place in Durban, South Africa in April 2005. The book provides a forum to review emerging knowledge on the interactions between AIDS and hunger and to better understand what it implies for poverty, food and nutrition-relevant policy and programmes. The book is organised around three main themes. Theme one: interactions – considers those between agriculture and other rural livelihood systems, the spread of HIV and the impacts of AIDS at different levels. Theme two: local responses – details capacities and strategies of households and communities to reduce infection risk (resistance) and respond effectively to the impacts of HIV and AIDS (resilience). Theme three: policies, programmes and interventions – reviews processes and impacts of food- and nutrition-relevant policies that have sought to prevent the spread of HIV and/or mitigate the impacts of AIDS.

The editor argues that we should not be blind to AIDS, nor should we be blinded by AIDS. Rather, an

HIV lens, not a filter, needs to be employed in order to see the interactions and overlapping set of problems between HIV and AIDS, food insecurity and malnutrition. Moreover, greater emphasis needs to be placed on learning from, supporting and enabling community-driven responses and innovations.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC15299>

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Girl power: the impact of girls' education on HIV and sexual behaviour

Author(s): Hargreaves, J.; Boler, T.

Produced by: ActionAid International, 2006

This document addresses the feminisation of the HIV/AIDS epidemic in Africa. The report asserts that HIV prevention campaigns often do not address the increased vulnerability of young women because they fail to deal with limited power to determine who to have sex with, or when and how to have sex. Current research in this field has linked girls' education and decreased vulnerability to HIV infection. This document conducts a systematic review of the evidence on the impact of schooling on sexual behaviour, and on HIV rates. The report calls for the abolishment of school fees, and also calls for governments and donors to invest more in primary and secondary education.

Chapter one explores the issues that underlie the rapid spread of HIV infection among young women. This chapter also identifies some mechanisms through which girls' education might affect HIV risk. Chapter two details the methodology used in analysing the evidence and in reaching the conclusion. Chapter three outlines the results of the study, while the fourth chapter contains the conclusion and recommendations.

On reviewing the available research on girls' education and on HIV rates, this study finds that formal education influences vulnerability to HIV aids by:

- exposing girls to HIV and AIDS education, which helps prevent HIV
- providing psychosocial benefits for young women, helping them to build their self-esteem and capacity to act on HIV prevention messages
- leading to better economic prospects, which in turn lead to lifestyle changes that can influence HIV vulnerability
- influence the level of power within sexual relationships
- affect the social and sexual networks of girls

This report makes several recommendations, including the following:

- HIV prevention messages need to address gender and power dynamics within sexual relationships
- priority needs to be given to the education sector response to HIV and AIDS
- gender equality, must be fostered in schools, and schools need to promote positive role models and challenge negative gender stereotyping
- schools need to respond to the problem of teenage pregnancy by providing comprehensive sex education to reduce pregnancy and improve sexual health
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Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22629>

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