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HIV and AIDS REPORTER: focus on citizenship and AIDS 18 July 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 citizenship and AIDS](#). The bulletin also features summaries of new documents and other additions to the [HIV and AIDS Resource Guide](#).

New Reporter Archive - A new 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/hivaids/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: citizenship and AIDS

The term citizenship implies membership in a community, often governed by national or political states, with certain rights and privileges. However, in an increasingly globalised world, many are rethinking what citizenship means and how it is experienced. People living with HIV and AIDS, local communities and organisations are connecting through what some have called a shared AIDS citizenship – the result of local forms of citizenship engaging with national processes and global networks. Examples of this include: the requirement of CSO (civil society organisations) participation in national applications to the Global Fund; the involvement of community health workers in HIV education, treatment and care programmes; and increased advocacy in demanding treatment and support. But what does AIDS citizenship really mean and what effect is it having?

Researchers and activists have been exploring these issues. Steven Robins and others have suggested that, for anti-retroviral therapy (ART) to work, people will have to be active, empowered citizens rather than passive recipients of services. For instance, people will need to play an active role in encouraging high levels of compliance with treatments, in order to reduce the risk of drug resistance. Robins highlights how ART, along with the provision of support and social belonging for PLWHA, is capable of transforming the traumatic experiences of stigmatised illness into new forms of social commitment and active citizenship. Vinh-Kim Nguyen has argued that new forms of citizenship combining the biological (being HIV positive) with the social or political (claiming rights to treatment) have emerged as a result of the new global networks. This “therapeutic citizenship,” Nguyen argues, has become a rallying point for transnational activism.

Many agree that there has been a shift in terms of how rights and responsibilities are understood and experienced, and that new, non-hierarchical relationships between citizens, health systems and governments are developing in some places. However, questions remain as to how these relationships and experiences can be mainstreamed. Moreover, we need to ask how the long term effects of HIV and AIDS will continue to change how people experience citizenship and how these citizens will engage with the global issues.

For more information, see:

- HIV and AIDS Key Issues Guide on [Vulnerability, HIV and AIDS](#)
- [Development Research Centre \(DRC\) on Citizenship, Participation and Accountability](#)

Recommended readings

Science and citizens: global and local voices

Author(s): Scoones, I.; Leach, M.; Cockburn, K.

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

This IDS Policy Briefing argues that public engagement in scientific debates and policy processes is necessary to address how research agendas are framed and the social purposes they serve, and to ensure that poorer people and communities will benefit from them. The briefing contains three case studies, including: rice and biotechnology in India; anti-retroviral drugs in South Africa; and health problems in India's industrial zones.

Key questions include:

- what new perspectives on the links between science, technical expertise and citizen participation emerge from comparing cases across different issues and settings?
- what difference does globalisation make to the policy processes which govern science and

technology development?

- what does this tell us about approaches to risk, regulation and public participation?
- how might the notion of "cognitive justice", involving dialogue between the different knowledges and perspectives held by scientists and members of the public locally and globally – help to further debate and practice?

The bulletin concludes that by exploring how science and citizenship claims are emerging around different issues we can see how diverse knowledges evolve in different settings, according to particular histories and dynamics in relationships between science, states and international political economy and society.

Recommendations include:

- policymakers, civil society and activist groups (together with researchers) should carefully consider what conditions and what avenues of participation offer routes to more vital forms of dissent, to genuine negotiation, and to political and practical solutions based on mutual recognition and respect
- such approaches need to work in tandem with citizen mobilisation (through the media and internet, public protest and challenges through the courts).

It argues that there is a need to think about how a new politics of science and citizenship can open up debates through participation and deliberation, rather than closing them down.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22302>

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Rethinking rights and responsibilities in a time of AIDS

Author(s): Robins, S.

Produced by: HIV and AIDS Resource Guide, 2005

This article, written for a South African newspaper, explores the debates over rights and responsibilities for people living with HIV and AIDS (PLWHA). Many public health practitioners have called for compulsory AIDS testing, citing the rights and responsibilities of citizens when it comes to health matters. However, the author outlines how this view assumes that everyone is capable of acting from a position of rational choice and individual agency. Yet AIDS has shown that millions of people do not have bodily autonomy and free choice in health matters. Moreover, rights and responsibilities are complicated by negative social constructions of AIDS and by the fear, blame and shame that this can produce.

The author suggests that "responsibilised" citizens are needed. This is where citizens have a right to health care but they also have responsibilities: for ARV treatment to work, people will have to be active, empowered citizens rather than passive patients of the nanny state. The author argues that ARV treatment, along with the provision of support and social belonging for PLWHA, is capable of transforming the traumatic experiences of stigmatised illness into new forms of social commitment and active citizenship. Compulsory testing and HIV status would likely push the disease even deeper underground. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC20709>

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Rights passages from "near death" to "new life": AIDS activism and treatment testimonies in South Africa

Author(s): S. Robins

Produced by: Institute of Development Studies (IDS), Sussex, UK, 2005

This IDS working paper explores how the combination of illness experiences and involvement in treatment programmes has dramatically altered the lives, identities and futures of people living with HIV and AIDS (PLWHA) in South Africa. The author examines the treatment testimonies of PLWHA to explore how the moral politics of AIDS activism contribute to new forms of citizenship, that are concerned with rights-based struggles and creating collectively shared meanings of illness and stigmatisation experiences. The author considers how rights and responsibilities approaches can take hold in the context of extreme stigma, shame, denial and fear related to AIDS; and what role the state, service providers and civil society should play in these contexts.

The author finds that the extremity of near death experiences of full-blown AIDS, and the profound stigma attached to it, produce the conditions for AIDS survivors' commitment to new life and social activism. Participation in treatment programmes can produce a radical transformation of identity that goes beyond traditional concepts of rights and citizenship. The author also suggests that these changes in identity can result in citizens becoming more active and responsible, an outcome that public health professionals believe is required for safe and effective AIDS treatment to take place. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC20713>

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Antiretroviral globalism, biopolitics, and therapeutic citizenship

Authors: Nguyen, V-K.

Produced by: IDRC, 2004

This chapter from the book *Global Assemblages* explores how AIDS is producing new forms of actors and subjects, such as therapeutic citizens. The author outlines how HIV has been able to bring together a range of different phenomena, such as condom demonstrations, CD4 counts, sexual empowerment, and an ethic of sexual responsibility and compliance with drug regimes, into a stable, worldwide formation. These new global networks have helped to produce a form of therapeutic citizenship. This biopolitical citizenship is based on being HIV positive (biological) together with certain (political) claims to rights (i.e. access to treatment) and "ethical projects" – ways of integrating being HIV positive into a moral order.

The author explores this concept through experiences of a local Friendship Centre for people with HIV and AIDS in Burkina Faso, and finds that therapeutic citizenship is becoming a significant force in local African settings. Where widespread poverty means that neither kinship nor the state can protect individuals, therapeutic citizenship can offer an alternative. For instance, therapeutic activism has been spearheaded by those who have access to treatment on behalf of those who do not. The author also describes how therapeutic citizenship has become a rallying point for transnational activism, where claims based on illness carry more weight than those based on poverty or injustice. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC14315>

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Summaries of other documents in the HIV and AIDS Resource Guide

Women lead

Author(s): Omang, J.; Darvich-Kodjouri, K.

Produced by: Centre for Development and Population Activities (CEDPA), 2006

This publication, from the Centre for Development and Population Activities (CEDPA), provides powerful stories of a range of women who are actively engaged in the response to HIV and AIDS. Each woman's story describes her experiences and the AIDS situation in her respective country. Country experiences include Zimbabwe, Uganda, Ukraine, Kenya, Swaziland, Bangladesh, Nepal, USA and Pakistan. These stories emerge from a month long workshop run by CEDPA in October 2005, which aimed to build leadership abilities, technical expertise and programme management skills of women.

The experiences show that women and girls are the ones bearing the burden of the disease. Stigma prevents many women from finding out their status and HIV positive women who publicly acknowledge their status face discrimination and violence. But women are also leading the response to HIV and AIDS, and many are working to combat stigma and discrimination against those living with HIV and AIDS. They are also working to raise awareness about prevention methods, mobilising communities to support the care of patients, and demanding the availability of treatment and services. Finally, they are working in partnership with men and boys, who are central in the response

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22327>

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NGO support toolkit

Produced by: International HIV/AIDS Alliance, 2006

This toolkit, produced by the International HIV/AIDS Alliance, is designed to support non-governmental organisation (NGO) and community-based organisation (CBO) programmes in HIV and AIDS that deliver both funding and technical support. As the HIV epidemic evolves and civil society responds to new challenges, the range of organisations and institutions involved is expanding. NGOs and CBOs play a critical role in providing essential services, identifying needs and gaps, and working with marginalised and vulnerable communities. However, the organisational and technical skills and ability of these organisations, as well as the quality of programmes, vary. This toolkit aims to support these organisations in their increasingly important work.

The toolkit covers a series of themes about establishing and running an NGO/CBO support programme. The seven themes include: NGO support programmes, strategic planning; partner and project selection; technical support; institutional change, monitoring and evaluation; and NGO support programme management. Each themed section provides explanatory introductions and guidance based on the Alliance's experiences, and includes reports, tools, templates and links to further information. This toolkit is also available on CD-ROM.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22331>

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Supporting safe and effective ARV treatment in India: building treatment friendly communities

Authors: Panda, S; Kaul, S.; Dhaliwal, M.; Rohini, R.; Nembialkum, G.

Produced by: International HIV/AIDS Alliance, 2006

This rapid situation assessment, from the International HIV/AIDS Alliance, explores the psychological, social and material needs of those on ART (anti-retroviral therapy) in India (Manipur and Andhra Pradesh). It also explored the challenges faced by people on ART and quality of existing services. Findings revealed that perceived and actual stigma and discrimination at community level, including that from public sector health care providers, were key barriers to accessing care, treatment and support.

The report concludes that building HIV treatment friendly communities requires building on existing community strengths and structures, as well as working at multiple levels. At the household and individual level, the report recommends comprehensive "treatment literacy" programmes,

psychosocial support to people on ART, and strong outreach and skills building programmes for women and girls, as well as families and carers. At the community level, including health care centres and hospitals, increased sensitisation is needed to reduce stigma and discrimination. Strong partnerships between civil society, educational institutes and private companies are also needed in order to effectively engage with communities. The report calls for advocacy at national and state levels, as well as with donors, to provide support for community engagement, ART roll out and free universal access at the point of delivery.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22334>

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Promoting more gender-equitable norms and behaviors among young men as an HIV/AIDS prevention strategy

Author(s): Pulerwitz, J; Barker, G; Segundo, M; Nascimento, M
Produced by: Horizons, 2006

This report, produced by the Horizons Program and Instituto Promundo, examines the effectiveness of interventions designed to improve young men's attitudes toward gender norms and to reduce the risk of HIV and sexually transmitted infections (STIs). The study examined a range of interventions set in Rio de Janeiro, Brazil with groups of men aged 14 - 25 living in low-income communities. Key findings show that, before interventions, young men were at high risk of HIV/STI and that inequitable gender norms were associated with increased risk. However, it was also found that more equitable gender norms and related behaviours can be successfully promoted, and there were significant improvements in HIV/STI outcomes.

Study findings indicate that addressing inequitable gender norms, particularly those that define masculinity, can be an important element of HIV prevention strategies. These findings suggest that group education interventions can successfully influence young men's attitudes toward gender roles and lead to healthier relationships. The findings also provide empirical evidence that a behaviour change intervention focused on combating inequitable gender norms is associated with improvements in HIV/STI risk outcomes. The study and intervention reported in this document has inspired ongoing adaptations in other countries, including India and Mexico. [adapted from author]

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC22341>

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See the HIV and AIDS Resource Guide for a complete list of new additions at:
www.eldis.org/hiv aids/

See the complete list of new additions, announcements, job adverts at: www.eldis.org/hiv aids/

The HIV and AIDS Reporter is produced by the IDS Health and Development Information team in collaboration with the DFID Health Resource Centre (HRC) and Eldis.

The IDS Health and Development Information team promotes health and equity in developing countries through the provision of high quality, accessible information to policymakers and practitioners. IDS Health and Development Information currently has three flagship products:

- Health Resource Guide - www.eldis.org/health
- Health Systems Resource Guide - www.eldis.org/healthsystems
- HIV and AIDS Resource Guide - www.eldis.org/hiv aids/

The HRC provides access to technical assistance and information for the Department for International Development (DFID UK), and its partners, in support of pro-poor health policies as well as health systems, service delivery and public health topics and programmes.

Eldis currently includes descriptions and links to over 4,500 organisations and over 16,000 full-text online documents covering development and environmental issues. It can be searched or browsed free over the Internet.

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