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HIV, AIDS and Advocacy Speakers

Nonkosi Khumalo, Treatment Action Campaign (TAC), South Africa

Nonkosi Khumalo is a mother and an AIDS activist. She currently serves as the Chairperson of TAC. She began her tenure at TAC in 2001 as the organisation's National Executive Secretary. Shortly after, she served as the National Women's Health Programmes Coordinator where her focus was on evaluating Mother-to-Child Transmission Programmes, and the availability of Post-Exposure Prophylaxis for rape survivors in public health facilities. In 2004, Nonkosi was promoted to lead TAC's Treatment Project. She is currently working on the implementation and research of the National Strategic Plan (2007–2011) for the South African National AIDS Council, serving as an Executive Member of the University of Natal for the Movement Against Women Abuse and as a board member of the AIDS Rights Alliance of Southern Africa. Contact: khumalo@section27.org.za;

Founded on 10 December 1998 in Cape Town, South Africa, The Treatment Action Campaign (TAC) advocates for increased access to treatment, care and support services for people living with HIV and campaigns to reduce new HIV infections. With more than 16,000 members, 267 branches and 72 full time staff members, TAC has become the leading civil society force behind comprehensive health care services for people living with HIV&AIDS in South Africa. Since 1998, TAC has held government accountable for health care service delivery; campaigned against official AIDS denialism; challenged the world's leading pharmaceutical companies to make treatment more affordable and cultivated community leadership on HIV and AIDS. TAC's efforts have resulted in many life-saving interventions, including the implementation of country-wide mother-to-child transmission prevention and antiretroviral treatment programmes. TAC has received world-wide acclaim and numerous international accolades, including a nomination for a Nobel Peace Prize in 2004. On 30 August 2006 the New York Times named TAC, "the world's most effective AIDS group". <http://www.tac.org.za/community/about>

Nonkosi Khumalo will focus on the strategies that have worked with TAC in South Africa. She will also talk about the challenges ahead for the AIDS movement that might hinder the progress towards Zero Infections, Zero Deaths and Zero Stigma.

Some of these threats are:

- Diminishing political commitment to fighting HIV/AIDS - New global priorities and less focus on social investments,
- Diminishing finances and their direct impact on the response to HIV/AIDS - Global Fund, PEPFAR as examples...give real life examples of South Africa and Swaziland
- Diminishing voice of the AIDS movement globally
- Re-emergence of pharmaceutical profiteering over lives as experienced in South Africa in the late 90's and early 2000s

Eduard Grebe, AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town, South Africa

Eduard Grebe is a PhD candidate in the AIDS and Society Research Unit (ASRU), Centre for Social Science Research, University of Cape Town, South Africa. The study 'Civil society leadership in the struggle for AIDS treatment in South Africa and Uganda' investigates the role of civil society activism in the global HIV/AIDS response and national responses of South Africa and Uganda, with a particular focus on the movement for antiretroviral treatment access. He earlier worked as a Policy Officer in the Southern African Clothing and Textile Workers' Union, as a Researcher, and as the National Treatment Project Coordinator of the Treatment Action Campaign (TAC). Eduard Grebe's research interests include civil society leadership in the AIDS response, transnational social movements, complexity and networks in social reflection and complexity in ethics and political philosophy. He published a series of journal articles on these topics. (see: <http://www.cssr.uct.ac.za/asru/researchers/grebe>). Contact: eduardgrebe@gmail.com

The challenge of transnational prevention and treatment advocacy in an era of resource constraints and shifting global priorities: reflections from South Africa

The Treatment Action Campaign in South Africa is one of the most prominent HIV/AIDS activist movements to have emerged in the developing world. It contributed to the emergence of a global coalition in favour of access to antiretroviral treatment (and a consensus on the moral imperative of such access), in part through the active exploitation of transnational advocacy strategies and by participating in broad 'networks of influence'. It was also a major force helping to compel the abandonment of state-supported AIDS denialism and policy change in favour of ART in South Africa. Furthermore, evidence from survey research suggests it successfully promoted accurate beliefs about HIV/AIDS and safer sex among ordinary residents of Cape Town communities.

However, TAC and its civil society allies face a number of major challenges. Its transition from an adversarial relationship with the state to one of supporting the implementation of national HIV/AIDS policy (including the continued scale-up of treatment) is incomplete, complex and fraught with difficulty. Global resources for HIV/AIDS is under severe pressure: the financial crisis, a general 'backlash' against AIDS-specific funding and shifting priorities (for example climate change) has resulted in constrained Global Fund, PEPFAR, bilateral and private funding that has had an impact across the continent. Coupled with specific problems, including late disbursement of Global Fund grants, this has resulted in TAC and other advocacy movements operating in perpetual crisis mode. Finally, a loss of momentum in global treatment activism and a worsening intellectual property rights climate (especially in India) raises serious questions about the attainability of universal access to treatment and about improved access to second-line and salvage therapy in poorer countries.

This paper therefore reflects on the strategic situation facing global prevention and treatment advocacy, through the lens of the Treatment Action Campaign's experience in South Africa. It tentatively suggests potential courses of action for advocacy movements.

Joshua Mavundu, BHASO (Batanai HIV and AIDS Service Organisation, Zimbabwe)

Joshua Mavundu, the Advocacy officer of BHASO in Masvingo, Zimbabwe, has been the key driver of the Meaningful Involvement of People living with HIV and AIDS (MIPA) in Masvingo Province since 2007. He has been consulted with various companies and NGOs as a technical HIV expert. Being the first Masvingo advocacy chairman, he has successfully led to advocate for over 200 issues at local level in Masvingo Province and the initiative is a best practice in Africa. He facilitated the formation of the Advocacy And Treatment Literacy Trust and is the Co-writer of the Advocacy Training Manual (2010), the Treatment literacy manual for PLHIV (2011) and the study "Local level Advocacy in Health and Rights: A case of Masvingo Province in Zimbabwe" (2011). <http://www.bhaso.org/>, contact: jmavundu@gmail.com; scrutinize@bhaso.org)

Local Level Advocacy: Universal access to treatment and attainments of human rights

The Zimbabwe National HIV and AIDS Strategic Plan II (ZNASP) places rights as a guiding principle for the response to HIV. The reality however is that the rights of people living with HIV are severely compromised. Rights that are currently not enjoyed by PLHIV include the right to treatment, the right to quality health care, the right to non-discrimination and equality before the law, the right to participate in public life and the right to freedom of expression and information. The meaningful involvement of people living with HIV is unevenly implemented, and often, those living with and most affected by HIV remain absent.

The presentation focuses on the local advocacy efforts of PLHIV (45731) in Masvingo province in Zimbabwe, between 2009 and 2011. Broadly aimed at the greater realisation of the rights of PLHIV, by PLHIV, this study highlights the structures established to support local, district level advocacy and provincial levels, the support given to these structures and the results of the advocacy efforts undertaken.

Key results from local advocacy efforts on HIV and Human Rights in Masvingo include:

- The increase in ART sites from one site, charging user fees, in Gutu District in 2010 to one initiating site and 14 local clinics providing no-cost, comprehensive ART and opportunistic infection services in Gutu.
- 73 police and prison officers agreeing to undergo training on the rights of PLHIV and 2 support groups being established in established subsequently.
- User fees for ART services being done away with following a sit in, petitioning by 1,000 PLHIV and a series of meetings at district and provincial level.
- An apology being printed in the local press and a HIV column being following stigmatizing coverage of the advocacy team's user fee action

Conclusions: On a case by case basis incremental but real changes are being pushed for and secured by PLHIV in Masvingo. The strength of this approach lies in social investment in ordinary community members and creating the space for them to be the agents of their own development. The result of this work is often qualitative, with PLHIV taking actions that advance the realisation of their right to prevention, treatment, care and support. It also results in PLHIV feeling that they have the ability to influence the agenda, to seek greater accountability from decision makers and to bring about change. When given the right support, these teams are a strong model for providing the space and structure for people living with HIV to create a shared vision for a rights-based community health agenda; to advance the Meaningful Involvement of People Living with HIV (MIPA) principles; and to advocate for the realisation of Universal Access in Zimbabwe.

Aashish Masih, World Vision India, Faridkot, India

Aashish Masih works as Community Based Performance Monitoring Manager with World Vision India, based in Faridkot, Punjab. He facilitates the "Citizen Voice and Action" program, working closely with the community: He provides training to staff and community members on citizen voice and action. The focus is on community empowerment to access, demand rights and improve facilities at community level. He facilitates Community Based Organisations (CBOs) on tools of empowerment on rights i.e. health, education and child rights and creates a platform for local advocacy. Aashish Masih has a master in Public Administration from Annamalai University, India. <http://www.worldvision.in/1452>, contact: aashishmasih20011@gmail.com

The role and empowerment of local advocacy on HIV and health in India. The Citizen Voice and Action approach

Citizen Voice and Action (CVA) is a "social accountability" methodology that transforms the dialogue between communities and government in order to improve services (like health care and education) that impact the daily lives of children and their families. "Social accountability" refers to civic engagement by communities (other than voting) designed to improve the performance of government.

Citizen Voice and Action works by educating citizens about their rights and equipping them with a structured set of tools designed to empower them to protect and enforce those rights. First, communities learn about basic human rights, and how these rights are articulated under local law. For example, the right to health in a particular community might include the right under local law to have certain vaccines available at a local clinic. Next, communities work collaboratively with government and service providers to compare reality against government's own commitments. Communities also have the opportunity to rate government's performance against subjective criteria that they themselves generate. Finally, communities work with other stakeholders to influence decision-makers to improve services, using a simple set of advocacy tools.

Citizen Voice and Action is a rather complete social accountability approach in that it combines a citizen education phase with a well-structured service monitoring phase and a targeted advocacy phase. While other organizations undertake social accountability work as a "project" or short term initiative, Citizen Voice and Action benefits from World Vision's long-term presence in communities. Over time, communities undertake more challenging advocacy actions. As more and more communities begin to implement CVA, World Vision can broker partnerships and coalitions among them so that they can address common, systemic issues related to high levels of government policy.

Paulina Alex, Nelico, Tanzania

Paulina Alex is the Co-founder and Executive Director of the *New Light Children Centre Organization (NELICO)* and has a BA in Sociology. Before founding NELICO in 2005, she was working as the center manager and social worker at Kuleana Centre for Children's Rights Organization and as Senior Safety Officer at the Geita Gold Mine Tanzania. She has over 10 years of experience in development interventions, particularly in the areas of advocacy. She has been addressing the capacity gap of vulnerable groups in the society and their representative structures to take action against, HIV/AIDS, Child Rights violation, corruption, gender inequality, poverty and Governance issues, participatory community development, girls education, addressing the connection between child rights violence and HIV/AIDS in Tanzania. <http://nelicotz.org/home>. Contact: newlightforchildren@yahoo.com.

HIV, AIDS and Advocacy: Bringing about change in policies and practice

NELICO (*New Light Children Centre Organization*), an NGO based in the Geita District in Tanzania, focuses on advocacy, prevention and mitigation of the impact of HIV and AIDS. It got engaged in advocacy because of the increasing number of orphans and vulnerable children affected by HIV and the number of people living with HIV and AIDS (PLHA) among youth. NELICO sees its role in advocating with communities, private institutions, government/ politicians to change and amend the laws and policies. NELICO provides legal aid to PLHAs (Eg sexual abused), sensitizes and rises consciousness in PLHAs (especially youth) to speak out and advocate for their rights.

To reach its objectives, NELICO networks and builds alliances with the Gvt, NGO's, CBO's volunteers/Faith Based Organizations and communities and provides psychosocial support and solution focused approach to PLHAs, youth and the community as the main strategies.

- As a result of advocacy, an increased number of youth is attending VCT and more clinics are providing ARV's. There are now HIV/AIDS committees in each ward all over the country. The National HIV/AIDS policy of 2007 and the HIV and AIDS (prevention and control) Act of 2008 in place. Stigma and discrimination of PLHAs is decreasing what has led some PLHAs to speak openly about their status and to demand their rights.
- There still are many challenges ahead: Inadequate number of health attendants, lack of balanced diet for many PLHAs using ARVs, stigma and discrimination still exists especially in the rural areas due to lack of awareness, limited resources to deal with HIV/AIDS advocacy, unfriendly language used by health attendants and the desire to have children after using ARV's.
- The way forward: Continue to mobilize resources to enable the organization to reach rural communities, continue advocacy on implementation of the HIV/AIDS policy and Act, continue building alliances with national and International NGO's on HIV advocacy, and continue with psychosocial support and solution focused approach to youth.

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