

THE ROLE OF CITIZEN ACTION IN MITIGATING THE NEGATIVE IMPACTS OF HIV AND AIDS

Mwanja Ng'anjo

This discussion features accounts of individual and collective citizen action in combating the negative impacts of HIV and AIDS on their own lives and the lives of others in their communities. Some implications for the broader AIDS discourse from these examples of citizen action are also given. The fight against HIV and AIDS has been recognised as a global fight. No country can contain and fund the fight singlehandedly. Indeed most countries' AIDS budgets are made up largely of donor funding from global funding houses such as the Global Fund and various UN agencies (Kristof & WuDunn, 2009; Mukotsanjera, 2008). This, however, does not mean that citizens do not have a major and indispensable part to play in challenging the effects of HIV and AIDS in their lives and the lives of citizens in their communities.

The current HIV and AIDS debate has largely excluded ordinary citizens, who regard the conversation as one between experts in which their contribution either does not count or could not be useful. Citizens need spaces where they can define the problem as they experience it in their communities and where they can propose solutions as equal, resourceful and talented governance partners with government and civil society (Strom, 2005). The HIV and AIDS discussion needs to become inclusive of citizens so that their needs can be reflected in policy design at every level of government. When citizens become active in facing up to problems such as HIV with policy makers and planners, they develop capacity and confidence to take ownership and responsibility for common concerns in public life.

CONTENTS

CITIZEN ACTION.....	1
COLLECTIVE CITIZEN ACTION.....	3
IMPLICATIONS FOR THE BROADER AIDS DISCOURSE.....	4
CONCLUSION.....	5
REFERENCES.....	6

Citizen action

Citizen action is espoused in the notion of active citizenship, to which there is no universally accepted definition, and no standard model of what an active citizen really is (The FACE IT! Project, 2007). Jochum, Pratten and Wilding (2005) describe active citizenship as "re-engaging citizens with decision-making processes (especially at the local community level) and sharing risks and responsibilities between citizens and state". In writing about active citizenship, Kearns (1992) refers to the calls for "individual citizens to recognise their moral responsibilities to care and provide for their needy neighbours, and to meet their obligations to give of their talents and skills in the management of public and welfare services".

Citizen involvement happens at different levels, from community to national and international levels. Active citizenship therefore refers to action and empowerment, with these characteristics:

- “Participation in the community (involvement in a voluntary activity or engaging with local government agencies)
- People [that] are empowered to play a part in the decisions and processes that affect them, particularly public policy and services
- Knowledge and understanding of the political/social/economic context of their participation so that they can make informed decisions
- [People that are] able to challenge policies or actions and existing structures on the basis of principles such as equality, inclusiveness, diversity and social justice,” (The FACE IT! Project, 2007)

In the context of mitigating the negative impacts of AIDS, citizen action can therefore be defined as including the key characteristics of active citizenship described above, consisting of engagement or efforts by groups or individuals in the fight against AIDS and the numerous challenges it brings. The following are two illustrations of positive citizen action by individuals living with HIV.

In the first half of 2011, Gary Allpass made news headlines in South Africa when he challenged his former employers for unfair dismissal after they found out that he was HIV positive. Allpass took the matter to Labour Court where his former employer was found to be guilty of illegally terminating his employment. His former employers insisted that Allpass was not dismissed due to the mere fact that he disclosed his HIV positive status but claimed that the dismissal was as a result of a ‘breach of trust’ because Allpass had not disclosed his HIV status during the initial job interview. Nonetheless, judgement was passed in favour of Allpass and his former employers had to pay for legal costs incurred by Allpass as well as his remuneration totalling a year’s salary (Mkhwanazi, 2011).

The experience of Gary Allpass has several lessons on citizen action in the fight against HIV and AIDS. To begin with, his decision to take legal action against his employer shows that individuals can challenge those who discriminate against them on the basis of their living with HIV. Furthermore they can be compensated in certain instances where their human rights have been violated. The Allpass case confirms the fact that people living with HIV are protected by the law and can claim their constitutional rights.

Noé Sebisaba’s story also demonstrates action that can be taken on an individual level to counter negative impacts of AIDS. A citizen of Burundi, Sebisaba fled the country with his family in 1996 and settled in the Kanembwa refugee camp in neighbouring Tanzania. In 1998, while living in the refugee camp, he discovered that he was HIV positive after trying to donate blood to a patient that needed a transfusion. His wife, who was also HIV positive, died of an AIDS-related illness in 2001, and a few weeks later Sebisaba decided to openly declare his HIV status to some leaders in the refugee camp. The news was not well received. When word spread, Burundians in the refugee camps were confronted and accused of bringing AIDS to the camp (Nolen, 2007; UNAIDS, 2009).

Even though Sebisaba was initially ostracised by his family and community – being the first person in the refugee community to openly declare that he was living with HIV – he embarked on a personal journey of challenging stigma and discrimination. He founded a grassroots community organisation called STOP SIDA to involve more refugees and local communities in the AIDS response. He also started to disseminate HIV awareness messages at public events through individual contacts, visits and peer groups (Nolen, 2007; UNAIDS, 2009). To date, STOP SIDA has distributed educational materials and advocated support and care for those infected with and affected by the virus in a number of camps in western Tanzania.

While it is obvious that, on their own, individual efforts in fighting HIV and AIDS can be limited, individual action that receives support multiplies the impact, as was the case with Sebisaba. There are many challenges when individuals want to act in mitigating the impact of HIV and AIDS. Examples of obstacles include lack of resources, limited knowledge, inhibited access to social and economic justice, inhibited access to treatment, care and support, and violations of human rights. The important lesson is that individuals who want to actively engage in the fight against AIDS have to decide to take the first steps and then mobilise for support. “Using himself as an example, Mr Sebisaba found a unique way to help individuals and communities become agents of change in challenging HIV,” UNAIDS (2009).

Collective citizen action

The beginning of 2011 saw a shortage of anti-retrovirals (ARVs) in Zambia. This led to the rationing of ARVs from the usual dosages of three to six months to only two weeks. The stock-outs were largely attributed to a funding freeze by the Global Fund to Fight AIDS, Tuberculosis and Malaria in Zambia. The Global Fund suspended disbursement of money to Zambia’s Ministry of Health in August 2009, when it was discovered that expenditures could not be accounted for. In addition, Zambia’s authorities reported on fraud in the Ministry of Health, also upon which an examination by the Global Fund revealed that the Ministry of Health mismanaged grants. The Global Fund then demanded that the Ministry of Health reimburse \$8 million of unspent money. It also demanded that action be taken against the individuals involved in the expenditures that could not be properly accounted for (IRIN, 2011).

An important outcome of this account is that the citizens of Zambia who were concerned and affected by the drug shortages decided to rally and hold the government accountable for the stock-outs. To this end, activists from People Living with HIV on ARV treatment petitioned the health authorities to look into the stock-outs through the Treatment Advocacy and Literacy Campaign (TALC). The Ministry of Health responded to the petition (which was called ‘Life for two weeks not enough’) through the Ministry of Health’s permanent secretary who offered an apology (Chakwe, 2011). Although funding has now resumed in Zambia, civil society has been asked to closely monitor government spending in order to curb any more stock-outs of vital medicines in the country (IRIN, 2011). Other important outcomes of this example of collective citizen action point to the importance of transparency, effectiveness and efficiency. If the principles of accountability, transparency, effectiveness and efficiency were upheld there would be little need for citizen protests for communities to access their rights.

Swaziland Positive Living (SWAPOL) provides an example of the positive results of collective citizen action against HIV and AIDS. The organisation was founded by Siphwe Hlophe and four HIV-positive women in 2001. The women had experienced stigma and discrimination from their families, relatives and community members, so they came together to take action to improve the quality of life of people living with HIV and AIDS. SWAPOL has since grown and operates in rural communities with more than 1 000 members (Nolen, 2007; SWAPOL, 2011).

The antiretroviral therapy (ART) distribution and adherence monitoring by community groups model, launched by Médecins Sans Frontières and the provincial authorities in Tete Province, Mozambique, is another example of collective citizen action in mitigating the effects of HIV and AIDS (Decroo et al., 2011). Since its inception in 2008 the model is reportedly in the vanguard of redressing,

“one of the most worrisome trends in treating the disease: the growing number of patients across Africa who fail to collect their lifesaving antiretroviral medicines. The simple solution [...] was to organize patients into groups of six. They would then take turns making the monthly trip to pick up refills, cutting the number of times each had to go to town — to just two a year, from 12,” (Dugger, 2011).

The Community ART Group model in Mozambique was put in place by capitalising on the power of collective action by patients in order to improve access to treatment, patient retention as well as lessen congestion at health services. Decroo et. al. (2011) report that the results from this model are very satisfactory in terms of mortality and retention in care, which show how workable out-of-clinic approaches can be in mitigating the effects of HIV and AIDS.

In solving problems faced by communities, citizen-centred action calls for citizens to be proactive. The scenarios from Zambia, Swaziland and Mozambique above illustrate a significant lesson for citizen action in HIV and AIDS. The fact that people who were concerned about a problem in their community came together to seek a solution, highlights a key principle of collaborative problem-solving in communities that recognises that the problem of HIV and AIDS needs to be owned by whole communities so that the talents and resources of every citizen can tackle it (Strom, 2005).

The fact that people who were concerned about a problem in their community came together to seek a solution, highlights a key principle of collaborative problem-solving in communities

Implications for the broader AIDS discourse

When dealing with AIDS issues in their multifaceted dimensions, it is imperative that both government bodies and citizens are given a voice and space, so that the conversation and action can be centred on issues of common concern. Citizens need to become actively involved in HIV and AIDS policy formulation. The following are some of the policy implications that emanate from the cited examples of citizen action in this discussion:

- **Advocacy for more citizen action** – Programme and policymakers in the field of HIV and AIDS need to recognise the fact that in dealing with the pandemic, ordinary citizens' voices need to be brought to the fore and the discussion on AIDS should be less expert-driven (Idasa, 2010). Citizens need to make themselves part of the conversation and policy makers need to create spaces where citizens' voices can be heard and their views taken on board in planning and policy making. The example of Gary Allpass challenging his unfair dismissal from work shows that ordinary citizens can challenge discriminatory practices in the workplace and elsewhere. This is also demonstrated in the work of Noé Sebisaba and Siphiwe Hlophe. It would therefore be recommended that programme and policy makers engage citizens along with technical experts in the field.
- **Accountable governance** – An active citizenry would help usher in more transparency, accountability, as well as efficiency and effectiveness in the management of

AIDS resources. The Zambian example cited in this article is one example of how collective citizen action can hold governing authorities accountable and call for more transparency. This is especially true for Eastern and Southern Africa, the epicenter of the global HIV epidemic and where 16.1 million people are now living with HIV (UNAIDS, 2010). To hold governments accountable, citizens need to be informed about their rights. Citizens also need to see evidence in government planning and policy process that their views are taken into account; that they are regarded as equal partners by government in determining and prioritising issues that affect their lives. The fight against HIV and AIDS is a global fight. Global institutions, in their varying capacities, play different roles. It therefore remains up to all concerned stakeholders – ordinary citizens, government officials, policymakers, donors and their agencies and the private or independent sector – to engage with one another in finding and using channels that will allow citizens to be truly liberated and feel that they have the freedom to engage with all stakeholders as equal partners in identifying HIV and AIDS problems and proposing solutions that are relevant to their own communities. As argued by AIDS International Accountability (2011), “a key aspect of making accountability actionable and to promote country ownership is meaningful participation of civil society including people living with, affected by and vulnerable to HIV [...]”

- **Protection of rights** – While countries like South Africa have sound frameworks to protect human rights, people are unable to claim them. It could be that people are unaware of their rights. It is also possible that they are unable to access legal services due to inhibiting costs (Mkhwanazi, 2011). Legal services need to be more accessible to citizens in order to ensure that their rights can be upheld. It is one thing to have solid legislation on paper, and quite another to have legal services through which people’s rights can be protected, especially those living with HIV. A survey in Africa by the United Nations Office on Drugs and Crime (2011), reveals that,

“The laws governing legal aid recognize a lawyer-centred model. However, the numbers of practising lawyers in African countries are low in proportion to the overall population. Further, the large majority of these lawyers reside in urban areas, whereas the majority of the population live in rural or peri-urban areas. Thus, most people live outside of the reach of lawyers who can provide them with legal aid services. While the laws respect a right to legal aid, State budget allocations to legal aid are minimal in many countries.”

Conclusion

Governments and experts cannot tackle HIV and AIDS on their own. They need citizens to help frame the problem, propose solutions and be actively involved in addressing the effects of the epidemic in their communities. Citizens need to feel part of efforts to mitigate the impact of HIV on their lives and communities. The kinds of actions described earlier in this article are just some examples from different African countries where citizens have become active partners. From a policy perspective, more citizen-orientated action needs to be encouraged, and citizens themselves need to hold their governments accountable in protecting their rights and mobilising local resources in fighting AIDS in a transparent, effective and efficient environment.

References

- AIDS International Accountability. (2011). Stronger Language on Accountability in the Political Declaration on HIV and AIDS. Retrieved August 1, 2011, from <http://aidsaccountability.org/?tag=hlm-2011>
- Chakwe, M. (2011, January 29). PLWAs petition Simbao over HIV, TB drugs shortage. *The Post*. Retrieved from http://www.postzambia.com/post-read_article.php?articleId=17760
- Decroo, T, Telfer, B, Biot, M, Maïkéké, J, Dezembro, S, Cumba, L, das Dores, C, et al. (2011). Distribution of Antiretroviral Treatment Through Self-Forming Groups of Patients in Tete Province, Mozambique. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 56(2), e39-e44.
- Dugger, C. (2011, September 26). Sharing Burdens of Living With AIDS. The New York Times. Retrieved from <http://www.nytimes.com/2011/09/27/health/27mozambique.html?scp=1&sq=tete,%20mozambique&st=cse>
- Idasa. (2010). *Idasa's Governance and AIDS Programme – five year strategic plan*. Pretoria: Idasa.
- IRIN. (2011). Zambia: Third-line ARVs available soon. Retrieved August 3, 2011, from <http://www.irinnews.org/report.aspx?ReportID=92124>
- Jochum, V, Pratten, B, & Wilding, K. (2005). *Civil renewal and active citizenship: a guide to the debate*. London: National Council for Voluntary Organisations. Retrieved from http://www.ncvo-vol.org.uk/sites/default/files/UploadedFiles/NCVO/Publications/Publications_Catalogue/Sector_Research/civil_renewal_active_citizenship.pdf
- Kearns, AJ. (1992). *Active Citizenship and Urban Governance*. *Transactions of the Institute of British Geographers*, 17(1), 20-34.
- Kristof, D., & WuDunn, S. (2009). *Half the sky*. New York: Vintage Books.
- Mkhwanazi, A. (2011). Justice for HIV-positive man. Health-e. Retrieved from <http://www.health-e.org.za/news/article.php?uid=20033084>
- Mukotsanjera, V. (2008). *HIV/AIDS financing and spending in Eastern & Southern Africa*. Pretoria: Idasa.
- Nolen, S. (2007). *28 stories of AIDS in Africa*. London: Portobello.
- Strom, M. (2005). *Citizens at the centre – AIDS Councils as catalysts for unlocking citizen power*. Pretoria: Idasa.
- SWAPOL. (2011). *Swaziland for Positive Living*. Retrieved July 15, 2011, from <http://www.swapol.net>
- The FACE IT! Project. (2007). *Active citizenship*. Retrieved from http://www.faceitproject.org/active_citizenship.htm
- UNAIDS. (2009). *Addressing the HIV-related needs of 'people on the move'*. Retrieved August 4, 2011, from <http://www.unaids.org/en/Resources/PressCentre/Featurestories/2009/June/20090619STOPSIDA/>
- UNAIDS. (2010). *Latest epidemiological trends from the 2010 'Global Report on the AIDS epidemic'*. Retrieved from <http://www.unaidsrsta.org/regional-country-profiles-home/regional-profiles>
- UNODC. (2011). *Access to Legal Aid in Criminal Justice Systems in Africa: Survey Report*. New York: UNODC. Retrieved from http://www.unodc.org/documents/justice-and-prison-reform/surveylegal_aid_Africa_Ebook



© Idasa 2011
357 Visagie St, Pretoria 0002
Tel: 012-395 0500
Website: www.idasa.org

First published 2011

Production by Idasa Publishing

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, without prior permission from the publishers.