

Defeating AIDS: The role of human rights

The UNAIDS Reference Group on HIV and Human Rights

'Human rights defined the AIDS response. They should define the "end of AIDS" and the global health response beyond.'

– Statement by the UNAIDS Reference Group on HIV and Human Rights, provided in the context of the work of the UNAIDS/Lancet Commission, *Defeating AIDS – Advancing Global Health*, 20 December 2013

The elaboration of a post-2015 development agenda presents crucial opportunities, but also serious risks. The UNAIDS Reference Group on HIV and Human Rights has observed with deep concern that there are calls for the response to HIV to be subsumed under a broader health paradigm, without any attention to the human rights infringements – including discrimination, criminalisation, violence, marginalisation and stigma – that continue to drive HIV vulnerability and affect those living with and vulnerable to HIV. Furthermore, some of the hard-fought innovations in, and lessons from, the HIV response are at risk of being lost in the post-2015 development world. The international community cannot afford to ignore these lessons if we are to sustain the response to HIV, address the failures to date in that response and eventually overcome the epidemic. Indeed, these lessons should inform efforts to advance and transform global health more broadly.

The reference group wishes to highlight several key principles and lessons that should be reflected in the post-2015 development agenda:

1. The unprecedented shared responsibility and global solidarity demonstrated in the HIV response must be continued and expanded to global health.

The international community has recognised that enjoyment of the highest attainable standard of health is a human right for all and that, correspondingly, states must take steps towards realising this right commensurate with their available resources – not as a matter of charity or ethical obligation, but as a matter of legal obligation. These duties not only fall upon states vis-à-vis those within their borders, but also entail duties of international assistance and co-operation. The AIDS response has witnessed a commitment to realising the right to health that has never been seen before in global health – even as it remains a goal far from being fulfilled. Where there has been political commitment, the mobilisation of communities claiming their rights, and investments to develop life-saving prevention and treatment services and get them to those in need, the results have been impressive.

This is a key lesson that goes beyond AIDS. Such global solidarity must not be a one-off in the history of global health that disappears if and when we ever achieve an 'end to AIDS', which in any case is a far-off goal. Long-term 'sustainability' should not be narrowly defined as national financial self-reliance to fund health; it should also give sufficient attention to the permanent role of donor countries. A premature move toward the 'end of aid' that undoes this shared responsibility and global solidarity is as premature as any declaration of the 'end of AIDS'. Indeed, such a move will deal a fatal blow to our efforts to actually achieve an end to the epidemic and transform global health.

2. Non-discrimination must be at the centre of the global HIV and health response.

While increased domestic funding reflects the fact that many states are taking their human rights obligation to work towards realising the right to the highest attainable standard of health more seriously, they must at the same time meet their obligations with respect to non-discrimination and equality. The international community and civil society must continue in the role of watchdogs to ensure, in particular, that states provide services to the marginalised and criminalised among those affected by HIV and other health conditions. Necessarily, this requires states to ensure a social and legal environment that enables access to such services and provides redress for denial of access, including where motivated by discrimination.

The AIDS response has uniquely included a willingness, at least in some quarters, to address states' human rights failures in

Box 1 UNAIDS/Lancet Commission

The UNAIDS/Lancet Commission, *Defeating AIDS – Advancing Global Health*, was established in May 2013, bringing together Heads of State, policy-makers, people living with HIV, development experts, young people and private sector leaders. The commission aims to catalyse expertise and political momentum to shape the debate on the future of HIV and health in the post-2015 development agenda and accelerate progress towards the end of AIDS. The UNAIDS Reference Group on HIV and Human Rights sees the commission as an important platform for galvanising commitment to the HIV response in the post-2015 development agenda, and for reinforcing the central role of human rights in addressing HIV and advancing global health more broadly.

responding to a health challenge, including the exclusion and criminalisation of key populations particularly affected by HIV based on stigma and punitive laws (e.g. men who have sex with men, sex workers, people who use drugs, prisoners and detainees). Any efforts to advance global health in the post-2015 agenda must include, continue and expand this approach.

The seeming reluctance of international donors to continue to support HIV responses in middle-income countries, based on the assumption that these governments can and will deploy their own domestic resources, also raises concerns about discrimination. In a number of these countries, it is by no means clear that sufficient domestic resources will be deployed nor that the state will be willing to address the needs of marginalised key populations. They may instead continue punitive and discriminatory approaches to these populations, thereby undermining an effective response to HIV and health more broadly.

3. Populations most affected must be meaningfully involved in health-programme and policy planning, decision-making and implementation.

The people living with an illness or health condition have directly experienced the factors that contribute to vulnerability, the impacts of the illness and strategies to manage them, and the opportunities for and barriers to prevention, care, treatment and support. In the case of HIV and some other communicable illnesses, those affected are disproportionately poor, members of marginalised populations, and facing stigma and/or violence because of their serostatus, sexuality, drug use, involvement in sex work, race or ethnicity, or other forms of prejudice. Their involvement in designing and delivering the response improves its effectiveness and acceptability, while also contributing to the rights to self-determination and participation. The participation and contribution of people living with HIV in the HIV response, while as yet not complete or consistent, has been essential to effective responses. The international community must incorporate this important lesson into its post-2015 development practice in order to build upon and accelerate progress achieved thus far.

4. Health and well-being includes, but must extend beyond, the health sector.

The successes to date of the HIV response have been based on a focus on people and their full range of human rights, including health, non-discrimination, freedom from violence, access to justice, gender equality, and participation in decision-making on the programmes and policies affecting them. The health sector obviously has a crucial role to play, but it alone cannot deal with the human rights abuses and social determinants of vulnerability, discrimination, poverty, and morbidity and mortality. Furthermore, in some instances, and especially for some of the most marginalised populations, health services have themselves been the site of human rights abuses. This reality must be addressed if the health sector is to be the key constructive element that it must be in the response to HIV and in global health efforts more broadly.

While universal health coverage is heralded by some as the solution that will move the world towards global health equity, it is a goal that is too narrow to achieve health and well-being on its own. It is also too narrowly focused on strengthening the health sector versus other important sectors (e.g. education, social protection, civil society). Strengthening health systems and the coverage of

necessary biomedical interventions is an important and necessary goal, but it will not on its own bring about universal access to HIV prevention, care, treatment and support, or bring about health more generally. Such efforts must be accompanied by sustained and resourced action outside the health sector, including the removal of human rights-related barriers.

5. The appropriate balance among health, non-discrimination and intellectual property must be found.

Private intellectual property claims should not trump the human rights to health and non-discrimination. Yet, the current international intellectual property regime does not ensure the equitable development or distribution of medicines needed globally. The international community's post-2015 development agenda must include substantial revision to this regime, so that medicines and other public goods are available to all. In particular, achieving the goal of universal access to HIV treatment has relied, and continues to rely, on generic competition to lower the price of medicines – at times and in places requiring states to make use of flexibilities in intellectual property law, even as that law is shaped by international agreements.

The HIV epidemic and global mobilisation, in response to the urgent need for life-saving medicines to treat millions of people, have illustrated starkly the deficiencies of the current regime and the critical importance of ensuring countries have the ability to devise policies, including in the area of intellectual property, to address public health needs. Other essential aspects of the right to health, including treatment of other communicable and non-communicable diseases and health conditions, require this as well. Ongoing efforts, through various international processes, to restrict these policy options for countries are a matter of grave concern and must be featured centrally in discussions about the post-2015 development agenda and the place of global health in that agenda. This concern is heightened by recent developments such as the announcement of a Blue Ribbon Task Force – spearheaded by the Global Fund to Fight AIDS, Tuberculosis and Malaria together with the GAVI Alliance, UNDP, UNICEF, UNITAID and the World Bank – which seems to embrace the concept of 'tiered pricing' of pharmaceutical products before establishing the conditions under which this can support, rather than undermine, the rights to health and non-discrimination.

The international community ought to embrace the recommendations of the Global Commission on HIV and the Law that are aimed at ensuring that countries are able to address domestic and global health needs and, in particular, call for the current international intellectual property regime to be reviewed and revised in a manner consistent with international human rights law and public health requirements.

6. Criminalisation and other punitive approaches that undermine HIV, human rights and global health must be ended.

The post-2015 development agenda needs to take up the challenge of how the criminalisation of, and other punitive measures against, key populations has been and remains a central obstacle to overcoming AIDS and other conditions, such as tuberculosis and hepatitis C. It is critical that the international community speak not only of stigma and discrimination as barriers to addressing HIV, but explicitly name criminalisation – e.g. of men

who have sex with men; of sex workers, their clients and their workplaces; of people who use drugs; of people living with HIV – as human rights failures that states and others must address as a very necessary element of ending AIDS and of advancing global health more broadly. If the UNAIDS/*Lancet* Commission fails to issue clear, unequivocal statements on such fronts, then it will have failed to articulate some of the key lessons learned from the HIV pandemic.

The international community should incorporate into the post-2015 development agenda the recommendations of the Global Commission on HIV and the Law and the Global Commission on Drug Policy that are aimed at eliminating the ongoing stigmatisation, marginalisation and criminalisation of people living with HIV and key populations affected by HIV.

Conclusion

The HIV response has been exceptional compared to other health and development issues – in the degree to which communities have mobilised, resources have been invested and realisation of human rights has had a central role in achieving results for people, including those most marginalised. The lessons learned already from this exceptional response, and why and how that exceptionalism has been necessary, must be carried through right to the end of the epidemic and beyond. Otherwise, we risk falsely declaring ‘the end of AIDS’ with AIDS becoming another disease of those who are poor and marginalised.

We all want to achieve the end of AIDS, but in speaking of an end we must stress the very difficult, costly and transformative work yet to be done. We must clearly outline the difficult challenges that lie ahead. Among others, these include: ending stigma and discrimination; overcoming intellectual property barriers to equitable and sustainable access to treatment; maintaining political and funding commitments; removing punitive laws, including those that criminalise key populations; ensuring participation of affected populations in programme and policy decision-making; and, more generally, creating enabling legal and social environments that are necessary to deliver on the promises of universal access to HIV prevention, care, treatment and support.

We must call for a clear focus on those who risk being left behind and must point out that things must be done differently to protect their rights. We must all speak boldly and honestly not only of the successes of the HIV response, but also of the failures – including the ongoing human rights failures – because both offer key lessons to galvanise future commitment and action, not only to end AIDS eventually but also to transform and advance global health more broadly.

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The UNAIDS Reference Group on HIV and Human Rights was established in 2002 to advise the Joint United Nations Programme on HIV/AIDS on all matters relating to HIV and human rights. The reference group speaks with an independent voice; thus, its views do not necessarily reflect the views of the UNAIDS Secretariat or any of the UNAIDS co-sponsors.