

TEST AND TREAT FROM THE PERSPECTIVE OF HUMAN RIGHTS

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ABIA

BRAZILIAN INTERDISCIPLINARY
AIDS ASSOCIATION

Global AIDS
Policy Watch

Where are we going?

As we move deeper into the fourth decade of the global HIV epidemic, it is important to reflect in a meaningful way on where we have come from, and, equally important, on where we are going. Over the past 34 years, we have witnessed the terrible human tragedy of a global epidemic out of control, fueled by horrible social inequalities and unconscionable irresponsibility on the part of so many governments and officials. Yet we have also witnessed a most remarkable process of global mobilization, first on the part of affected communities and activists, and then gradually on the part of local and national governments and intergovernmental organizations. Especially during the past decade, we have passed through a time of unprecedented scale-up of the global response to AIDS. But we have also seen scale-up stall in many parts of the world, impeded by an extended global financial crisis as well as by a so-called “AIDS backlash” in some parts of the global public health and development fields, which have criticized the level of resources that have been committed to the fight against the HIV epidemic. For some, new advances in biomedical technologies both for prevention and treatment of HIV infection have offered hope of greater effectiveness in overcoming the social, political, and economic barriers that seem to be slowing progress and threatening to replace a still-incomplete process of scale-up with an impending “scale-down” of both the resources and the gains that we thought we had achieved in recent years. Against this backdrop, the leaders of the global response to the epidemic have tried to offer optimism and renewed hope. They have begun to talk realistically about “the cure for AIDS”. They have also confidently announced the imminent arrival of “an AIDS-free generation”. They have elaborated new targets such as “90-90-90” and have promised us that this will make possible “the end of AIDS in 2030”. But for anyone who remembers the long history of earlier targets, both in the fight against HIV

and in the field of global health more broadly (“Health for All by the Year 2000”, to cite just one poignant example), it is hard not to wonder where we are really going? Does all the sloganeering and seemingly exaggerated optimism really move us forward? Or is it a smokescreen that covers up the reality of reduced resources, a reliance on narrow technological and technocratic solutions, and a lack of sustainability that is transforming scale-up into scale-down in countries and communities around the world? Like all polarized debates, the truth probably lies somewhere between the extremes of unrealistic optimism and immobilizing pessimism. Yet precisely because of this, it is urgent that we engage in critical reflection and analysis about the current state of global AIDS policy, and about the trends and tendencies that are guiding the global response to the epidemic. We need realistic assessments and critical thinking even more than we need cheerleading and inspiration. This is the challenge that Global AIDS Policy Watch seeks to take up with this inaugural issue of the *GAPW Bulletin*. We hope to contribute to thoughtful analysis of the key challenges that confront us as we seek to confront the epidemic. We want to contribute to a growing global dialogue and a truly public debate about where we are headed as we seek to respond to the global HIV epidemic in the midst of its fourth decade. We want to prioritize the insights and perspectives of people and communities from the Global South, which are all too often ignored or taken for granted in designing supposedly global policies. Most of all, we invite you to join us, and to take part in this debate, as we seek collectively to find new ways forward of enabling us to take advantage of important technical and technological advances without sacrificing our undying commitment to human rights, social justice, and solidarity as the crucial ethical and political principles that must underlie all our actions to confront HIV and AIDS in the early 21st century.

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Layout:

A 4 Mãos Comunicação e Design

GAPW is an initiative of Brazilian Interdisciplinary AIDS Association (ABIA). Founded in 1987, ABIA is Brazil’s leading HIV and AIDS research and advocacy organization. ABIA has been mobilizing society to confront the HIV and AIDS epidemic in Brazil, as well as the struggle for access to treatment and care and protection of human rights of people living with HIV and AIDS.

GAPW is supported by Hivos.



**Global AIDS
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About Global AIDS Policy Watch

Global AIDS Policy Watch (GAPW) is an initiative that is being launched by the Brazilian Interdisciplinary AIDS Association (ABIA) to monitor and develop constructive critical analyses of AIDS-related policies globally. GAPW seeks to create a knowledge and action network that brings together key stakeholders from NGOs, intergovernmental organizations, academic institutions, and policy makers. It will disseminate the results of strategic research aimed at supporting AIDS-related civil society organizations in order to provide more effective advocacy for issues related to sustainability, capacity building, and fundraising. The Secretariat and Steering Committee are based at ABIA in Rio de Janeiro, but the composition of its Advisory Council and the plan for its activities are global in nature, with a base in the Global South and a strong emphasis on South-South collaboration. It will function by involving participants from other organizations and civil society networks in all of the major geographic regions of the world. Strategic research including comparative case studies and systematic monitoring of AIDS-related policies will provide the foundation for producing white paper reports, short videos, and advocacy and policy briefings to be widely disseminated through various media platforms, seeking to strengthen the capacity of civil society to monitor global policy debates and initiatives relevant to the HIV epidemic, with a special focus on the perspectives, needs and priorities of societies in the Global South.

As we move through the fourth decade of HIV and AIDS, immense social and economic inequities remain the primary challenge to curbing the epidemic. The permanence of inequities can be traced through the shifting historical dynamics of the epidemic and the global responses to it. The 1980s were characterized both by suffering and stigma, and the politically charged first steps that were taken to build pioneering programs and policies aimed at responding to HIV and AIDS locally, nationally and internationally. In the second decade of the epidemic, frequent contradictory trends associated with administering it at different levels emerged alongside ideological conflicts between perspectives emphasizing more technical concerns and those that emphasize ethical and political values such as human rights and social justice. In the third decade, important conceptual and political contradictions between different approaches to the “scale-up” of the global HIV/AIDS response emerged that are crucial to analyze if we are to understand why inequities remain as one of the primary challenges to curbing the epidemic today. In some cases, the scale-up process compromised advocacy efforts, diverting activist attention towards a more technical response to the resources invested, contributing to the relative fragmentation of the broad social



movement/political coalition that had taken shape over the course of the first three decades of the epidemic. At the same time, recent technical and technological advances and innovations (including biomedical approaches to HIV prevention) may have reinforced some of these trends, while at the same time potentially offering important opportunities for rethinking our approaches to responding to the epidemic.

In the years between 1998 and 2008, the financial investment in research and treatment in low and middle-income countries exploded, increasing more than 20 times. In this period, innumerable efforts sought to systematize the challenges and monitor investments. However, many of these initiatives came from the Global North, and their monitoring strategies, although they had affiliates in the South, were still centered in the North. Examples include UNGASS 2001, the 3 by 5 initiative, the creation of the US PEPFAR initiative, and the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria. All of them involved the investment of massive resources that had the potential to completely restructure the field, yet placed little emphasis on the important role of civil society organizations and AIDS activists as “policy watchdogs” with a key contributions to make in relation to the politics of the epidemic.

At the end of the 2000s, the beginning of what is increasingly recognized as the most profound and sustained global fiscal and economic crisis in the capitalist system reduced funding available for non-governmental organizations while also unmasking the ways in which investment in public health in the contemporary world is tied to neoliberal economic processes. The perceived preference and increased investment in AIDS as compared to other global health priorities at a time of limited funding simultaneously gave rise to what many have described as an “AIDS backlash”. The current crisis has strongly impacted key vulnerable populations, interrupting treatment for people living with HIV and further inhibiting access to integral health services for sex workers, men who have sex with men and drug users. Reductions and restrictions placed on funding for civil society organizations have also negatively affected the reach and quality of prevention actions as in many contexts, causing many NGOs and CBOs to either close their doors or greatly reduce prevention actions. Given these various trends,

we find ourselves at an especially crucial moment when action is urgently needed to seek to reverse many of these trends – especially the growth of an increasingly technocratic and depoliticized global response to the epidemic. We especially need to try to significantly increase support for independent civil society groups to monitor government policy, strengthen surveillance systems, and build critical capacity for policy advocacy. We also need to highlight continuing importance of social and political analysis in relation to the epidemic and the fundamental contributions that social and policy research can make in relation to our most pressing challenges as we confront the epidemic in the 21st century.

A key challenge of establishing civil society monitoring groups lies in nature of the AIDS field as an area that is constantly in movement and characterized by diverse and shifting constituencies from a broad range of regions, academic areas, advocacy goals, specific population groups, and distinct, and at times contradictory, approaches to confronting the epidemic (such as biomedical and cost effectiveness approaches as opposed to human rights based responses). In such a context, the promotion of civil society organizations in southern regions as “policy watchdogs” of these diverse, complex and interrelated processes will be crucially important in order to bring gender, race, ethnicity, and generational inequalities to light. In addition, the pathways that shape HIV and AIDS policies in complex political and economic negotiations are often not transparent, making the close accompaniment by civil society organizations absolutely critical to clarifying such processes to interested constituencies and mobilizing informed responses. GAPW will concentrate its efforts in the monitoring of global AIDS policies through South-South cooperation, but also with a range of key partners in the Global North. In this way, the initiative emphasizes the importance of the perspective from which policies are monitored, and inverts previous tendencies in which the North has primarily exported ideas to the South. Instead, monitoring bases in the South will be central, and will be connected to global interdisciplinary and intersectoral networks of activists, researchers, and policy makers who will translate and disseminate knowledge, ideas and actions as a way to promote political activism that addresses inequities through a critical perspective on local, regional, and global levels.

The overarching goal of Global AIDS Policy Watch project is to strengthen the capacity of civil society to monitor global policy debates and initiatives relevant to the HIV and AIDS epidemic, with a special focus on the perspectives, needs and priorities of societies in the Global South. To reach this goal, GAPW will seek to gather information, analyze data, and disseminate findings that will make a key contribution to advocacy for more informed and effective policy debates and translational outcomes. As part of GAPW’s plan of work, monitoring will be developed around three primary areas: global health



Photo by Wagner de Almeida

The first meeting of GAPW gathered participants from Africa, Asia, North and South America

diplomacy; political, programmatic, and ethical principles guiding contemporary AIDS policy; and programmatic and policy indicators of government and non-governmental actions. Monitoring of global health diplomacy will focus primarily on accompanying the on-the-ground impact of policies and initiatives involving key intergovernmental collaborations and institutions at the forefront of the scale-up of AIDS actions, including PEPFAR, the Global Fund, UNAIDS and related organizations and initiatives. The second area of focus will be on the political, programmatic and ethical principles underlying the global response to the epidemic, and will involve both identifying the guiding principles of global AIDS policies, and evaluating policies in terms of their advancement of equity, equality, and human rights. Finally, GAPW will also monitor government and non-governmental policies and actions at a regional and local level. In this area, the focus will be primarily on the types and breadth of AIDS policies and programs implemented and prevention and treatment supplies and services. Together, these key areas will provide the focus for more specific activities and analyses as our work progresses.

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HIV and AIDS in the mandate of the Special Rapporteur on the Right to Health: genealogies, lessons learned, challenges that remain

Sonia Corrêa¹

On October, 2014, a group of around 30 researchers, activists and human rights experts² met in Delhi at the invitation of Anand Grover, the outgoing Special Rapporteur on the right to the enjoyment of the highest attainable standard of physical and mental health. The meeting was convened as the handing over of the mandate to Dr. Dainius Puras, who was nominated for the post in June 2014, and as an opportunity for the new Special Rapporteur to establish contacts and dialogue with the various constituencies that have been closely engaged with the mandate, since its creation in 2002.³

The meeting in Delhi was also a privileged occasion allowing us to take stock of political and normative struggles aimed at the realization of the right to health, their gains and challenges in multiple domains: communicable and non-communicable diseases, drug policies, sex work, sexual and reproductive health and rights, access to medicines, natural disasters and conflict situations. This article provides a bird's eye view on how the struggles around HIV and AIDS and related policy responses were outlined in these rich and multilayered conversations.⁴

HIV and AIDS, human rights and public health: challenges remain that are not exactly new

To begin with, at the meeting in Delhi, the political and policy debates around HIV and AIDS were fully recognized as one

fundamental strand of thinking and action that contributed to pave the paths towards the legitimizing of the right to health in the early 2000s. It was once again pointed out that, since quite early in the epidemic, claims have been made for public health interventions regarding HIV to have a number of core principles: community participation, non-discrimination, availability and accountability. Though not highlighted in the discussion, one relevant aspect of this trajectory was that the creation of the UN Right to Health mandate was itself a tributary of the same stream. In 2000, Brazil could propose the creation of the mandate because the right to health is enshrined in its 1988 constitution, but it has taken that stance with much energy because, since the early 1990s, the state had been implementing an effective rights-based policy response, which included Brazil's groundbreaking 1996 legislation guaranteeing free and universal access to ARVs.⁵

Notwithstanding, on various occasions during the meeting, the question was often raised "if and how the lessons learned from the response to HIV and AIDS could guide analyses and actions to propel the realization of the right to health in other critical public health areas, such as non communicable diseases or natural disasters"? It was also noted that progress has been made in the realm of the right to health broadly speaking since 2002. Today a number of major policy institutions use the language of the right to health. The best

¹ Co-Chair, Sexuality Policy Watch (SPW), Brazilian Interdisciplinary AIDS Association (ABIA).

² The list of participants is as follows: The outgoing and the incoming Special Rapporteurs Anand Grover and Dainius Puras, Abou Mere (Indian Drug Users Forum), Anya Sarang (Andrey Rykov foundation for health and social justice, Russia) Bhavani Fonseka (Alternatives, Sri Lanka), Daniel Tarantola (Independent consultant) Dragana Korljan (OHCHR) Fiona Landers (Harvard School of Public Health), Giten Khwairakpam (TREAT Asia/amfAR, Thailand), Heba Wanis (EIPR, Egypt), Jamshid Gaziyeu (OHCHR), Jashodhara Dasgupta, (Sahyog and IIMMNR, India), Julie Hannah (Essex University), Kazuko Ito (Human Rights Now, Japan), Khartini Slamah (ISEAN, HIVOS Program), Meg Davis (Global Fund for HIV, Tuberculosis and Malaria); Maitreyi Misra (National Law University, India), Padma Desoltali Health and Allied Themes, India), Primah Kwagala (Center for Health, Human Rights & Development, Rajat Khosla) , Richard Elliot (Canadian HIV/AIDS Legal Network), Sarojini N. (SAMA, India), Sasha Stevenso (Section 27, South Africa), Sheng Tingting (Asia Catalyst), Shiba Phurailatpan (Asia Pacific Network of People Living with HIV), Sonia Corrêa (ABIA, Sexuality Policy Watch, Brazil), Tripti Tandon (Lawyers

Collective, India), Vikas Ahuja (Delhi Network of Positive People, India), Walter Flores (Center for the Study of Equity and Governance in Health Systems, Guatemala), Kate Barth (Lawyers Collective, India) Gabriel Armas-Cardona (Lawyers Collective, India), Amritananda Chakravorty (Lawyers Colective, India). Professor Paul Hunt, the first mandate holder, and Judith Mesquita (Essex University) participated remotely.

³ See <http://www.globalhealthrights.org/blog/handing-over-the-mandate-of-the-un-special-rapporteur-on-health/>

⁴ I thank Mr. Anand Grover for the invitation of the Delhi meeting as an opportunity to meet Dr. Dainius Puras, but also as a learning experience in relation to the right to health panorama beyond the boundaries in which most of my work is concentrated.

⁵ Having in mind the groundbreaking role played by Brazil in the establishment of the Right to Health mandate it is both puzzling and disappointing that no mention to HIV and AIDS is to be found in country report presented to the 2012 Human Rights Council Universal Periodical Review.

illustration is perhaps the Global Fund whose guidelines are grounded in human rights standards of non-discrimination, informed consent and accountability.⁶

On the other hand, many voices underlined that more than a few challenges remain in relation to the articulation between public health and human rights. For example, human rights premises are frequently not incorporated by major institutions comprehensively across different areas, as would ideally be expected. One illustration of this that was mentioned was the long and intensive WHO cycle of debates on the social determinants of health and the report resulting from this effort that, which to the surprising of many of those present, largely sidelined the right to health frame.⁷ Some participants, in fact, expressed the view that today – even more than ten years ago – public health practitioners and policy makers affirm, without much embarrassment, that saving lives does not require policy and programs to be also guided by human rights.

In the context of this article, it is particularly significant that this rift is once again pronounced in the realm of HIV and AIDS policy frames, where the primacy and logic of public health has long been questioned. This is visualized without great difficulty in the case of technological or evidence-based interventions

clustered under the “test and treat” umbrella. Commenting on the marked shift underway in relation to HIV policy responses, Shiba Phurailatpan – from the Asian Pacific Network of People Living with HIV/AIDS (ANP+) – asked the group a difficult question: “Is this a trap that we ourselves have created? We have strongly called for human rights frame in order to improve the public health response and now we get technological-based public health interventions that may gloss over rights.” In such a context, the summary presented at the end of meeting by Professor Daniel Tarantola was really inspiring in recapturing the diagram crafted in the early 1990s by Jonathan Mann to trace the necessary “optimum balance” between public health and human rights approaches to HIV and AIDS.

A related topic examined in the same round of discussion was the continuous “challenge to present evidence”. In Delhi, there was no disagreement that solid evidence is critical in all efforts aimed at the realization of the right to health. However, cautious and insightful observations were also made in respect to this critical area of current policy debates. It was pointed out, for example, that requests for solid quantitative empirical evidence are highly dependent on the audience. If these requirements can hardly be circumvented in the case of public

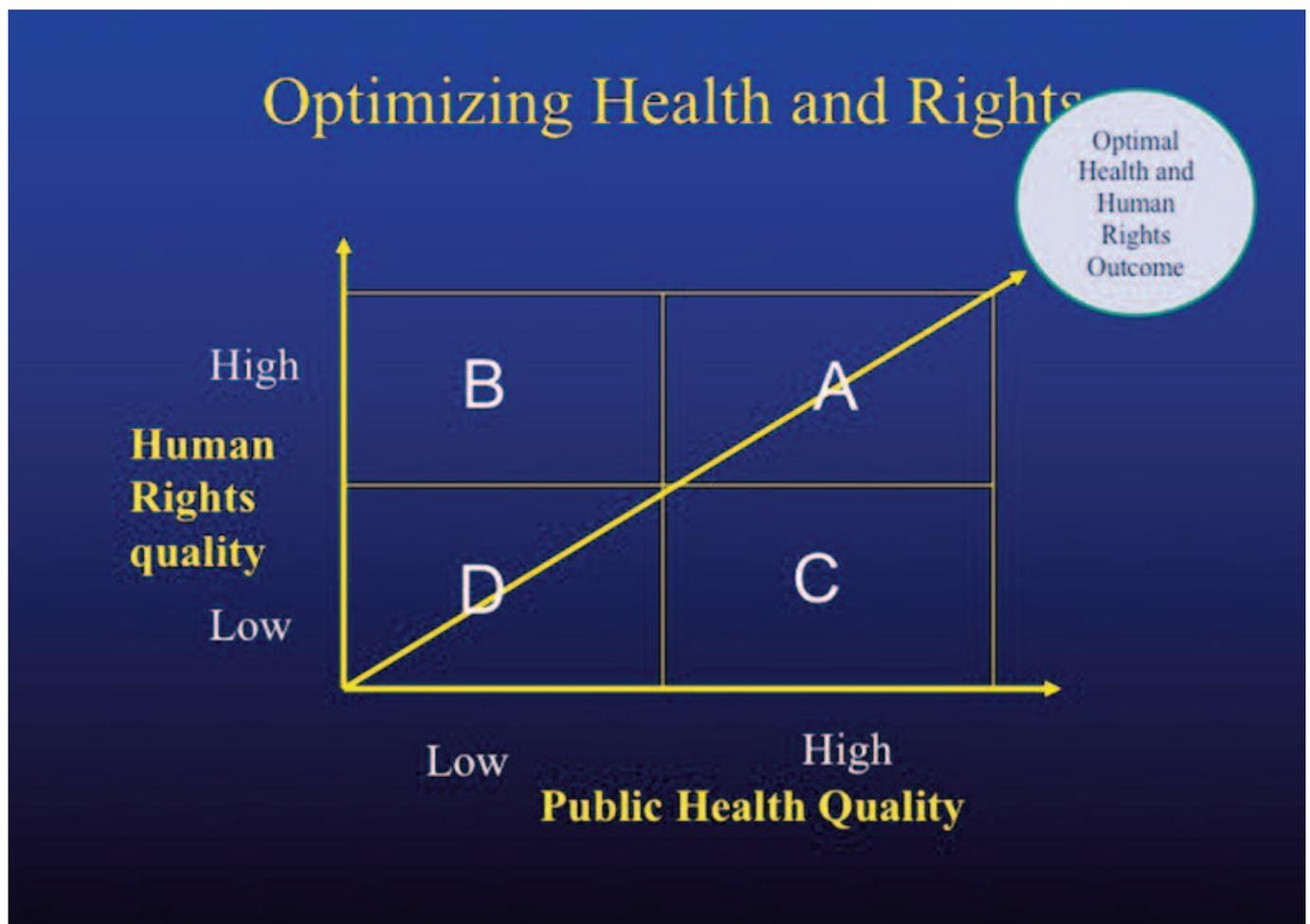


Image provided by Daniel Tarantola (based on a diagram originally developed by Jonathan Mann in the early 1990s)

⁶ See <http://www.theglobalfund.org/en/about/humanrights/>

⁷ See http://www.who.int/social_determinants/thecommission/finalreport/en/

health and biomedical communities, in other domains, which are also key for the implementation of the right to health, qualitative evidence is usually well received.

Another comment to be retained is that sound methodologies exist to prove glaring violations of the right to health, but it is much more difficult and complex to demonstrate the positive effects of human rights framed policies in terms of health outcomes. In relation, to this particular topic of discussion it is productive, perhaps, to recapture Richard Parker's critical comment that "epidemiological figures may help but they do not resolve everything."⁸

HIV and AIDS and the right to health at the frontlines

Past and present challenges in regard to the realization of the right to health in relation to HIV prevention, treatment and livelihoods were also looked at through the lenses of the affected communities – people living with HIV, LGBTI persons, migrants, sex workers and drug users – as well as in the round table on access to medicines.

HIV was central to the discussion on communicable diseases, in which three presenters addressed the topic from distinct but complementary angles.⁹ Richard Elliot (Canadian HIV/AIDS Legal Network) emphasized that fighting stigma and discrimination was and remains a non-negotiable principle of human rights-framed responses to the epidemic, a view that resonated with the discussions that took place in the panels on LGBTQI persons, drug policies and users, sex work and obstacles experienced by migrants in crossing boundaries but also accessing health care.

Elliot correctly reminded us that the women's health movement was the first to have articulated health and rights claims, even before the surge of the HIV epidemic, and Vikas called attention to the fact that reproductive health and rights have been, and still are, critical in the lives of women living



The meeting in Delhi recognized that political and policy dimensions of HIV and AIDS are central

Photo shared by the Lawyers Collective, New Delhi, India

with HIV. Both these interventions imply the need for the AIDS movement to cross boundaries and work closely in partnership with other constituencies engaged in right to health struggles, within a wider solidarity frame.

In exploring the persistent rift between public health and human rights, Elliot identified the critique of AIDS exceptionalism, that emerged especially in the last decade or so as another element to be taken into account.¹⁰ In his view, this strand propelled a schematic argument collapsing AIDS exceptionality and human rights and artificially opposes this pair to the dyad public health-social justice, viewed as more virtuous. He correctly observed that this binary framing is at odds with and voids the principle of indivisibility of rights legitimized at the Vienna International Conference on Human Rights (1993).

Tripty Tandon, from the Lawyers Collective, and Shiba Phurailatpan, from ANP+, entered the discussion through a different angle elaborating on the limitations of legalistic rights based perspectives to HIV and AIDS. Both strongly underscored that the HIV response was a community response before it was framed in legal human rights terms. In Shiba's words: "The indignant situation and tragedy of AIDS is what triggered the global activism on access to treatment." Tripty's intervention centered on her critique of the priority given to informed consent as a result from the adoption of a human rights frame. In her view, informed consent was put on

⁸ PARKER, Richard, O acesso à testagem e ao tratamento na perspectiva dos direitos humanos, *Boletim ABIA*, N.º. 59, pp. 8-11, 2014. See also PARKER, Richard; AGGLETON, Peter, Test and treat from a human rights perspective, *GAPW Bulletin*, this issue.

⁹ Although other health crises such as Ebola were to be included in the panel discussions, the speakers who had been invited to address these issues were not able to attend the meeting.

¹⁰ The idea of AIDS exceptionalism of course has a longer history (see, in particular, BAYER, Ronald, "Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?" *New England Journal of Medicine*, 324(21):1500-1504, 1991). On its history and recent use, see SMITH, Julia H.; WHITESIDE, Alan, The History of AIDS Exceptionalism, *Journal of the International AIDS Society*, 13:1-8, 2010.

a pedestal by activists, while for the affected communities themselves the priority was access to services and medicines. Shiba, in addition, briefly examined tensions within and across movements that arose in India as the prioritization of legal contestation of the criminalization of same-sex relations has been perceived by many as jeopardizing struggles around the rights to access services and medicines.

In commenting on the round table, Malu Marin (Seven Sisters in Bangkok) expanded further the analysis on the limits the human rights frame. She began by underlining that it can be very fragile in concrete policy terms. Revisiting the Filipino policy trajectory – which resonates with what is happening in many other contexts, including Brazil – she mentioned that if in 2000 a solid human rights frame was in place, in 2014 compulsory testing is underway and a provision to criminalize transmission is being debated. In her view, these regressions are occurring, among other reasons, because the sustainability of human rights policy frames requires strong investment in watchdogging. But today, as CSOs and communities become increasingly engaged in “project implementation,” critical monitoring and political activism is losing ground, when it is not jeopardized altogether.

In a subsequent panel the persistency or revival of mandatory testing for HIV was also identified as a major obstacle to the realization of the right to health of sex workers. Mandatory testing programs were cited by Khartini Slamah (ISEAN-Hivos PROGRAM) and Shen Tingting (Asia Catalyst), who also emphasized how in most of countries of the world criminalization of sex work, police raids and systematic abuse, incarceration, as well as religious, public (but also feminist) morality is negatively impacting on the ability of persons engaged in commercial sex to have access to services, information, STI prevention and adequate health care. Trypti Tandon (Lawyers Collective) complemented the analyses once again noting that one sharp limitation in the application of the right to health frame in the case of sex workers is that policy responses remain confined to the prevention and treatment of HIV, when these persons have many other health needs and aspirations. A way out of this persistent confinement, in Tandon’s view, would be to begin reframing these needs and aspirations through the lenses of labor rights and occupational health.

Access to medicines: old barriers, new trends

HIV and AIDS also figured prominently in the debate on access to medicines. The panel composed by Giten Khwairakpam (TREAT Asia/amfAR), Sasha Stevenson (Section 27, South Africa), Heba Wanis (Egyptian Initiative for Personal Rights) and Primah Kwagala (Center for Health, Human Rights & Development, Uganda) examined the policy conditions prevailing in relation to the access to drugs as one key component of the rights to health in highly heterogeneous contexts, in terms of Intellectual Property

Rights laws, funding patterns, structure and funding of the health system, but also the very prevalence of HIV.

In Asian countries, such as India and Thailand, as well as in South Africa, HIV prevalence is high and both patent laws and compliance with TRIPS rules constitute key barriers to access to treatment. In the case of Egypt, the most urgent problem concerns the price of old and new drugs for Hepatitis C because the incidence is very high and local industries face technical and strategic obstacles. In Uganda, HIV prevalence is high, but TRIPS compliance does not apply yet. However, other structural barriers can be identified, such as procurement, distribution, stocking, donor dependency and the restrictive effects of the Anti-Homosexuality Law.

These distinctions however are not so clear-cut. For example, Sasha Stevenson mentioned that South Africa is experiencing problems of stocking. The barriers of distribution and the bad functioning of public health care systems were also considered to be major problems in Asian countries. Furthermore, in these countries the policy debates around hepatitis C drugs have also gained relevance because of co-infection, but also under the effect of the pressures made and strategies adopted by pharmaceutical companies, in particular by Gilead.

In a nutshell, three key messages emerged from the panel discussion. The first is that debates and mobilizing around intellectual property rights issues can not be confined anymore to ARVs, but increasingly require the engagement with other communities negatively affected by the existing patenting system. Although not everywhere, patent law reform is a priority. Most importantly the divide between voluntary licensing and the use of TRIPS flexibility in both policy formulation and positions taken by the affected communities is increasingly pronounced and cannot be evaded politically. In his final comments on the subject Anand Grover remarked that movements organized around the right to the access to medicines are challenged to move beyond being reactive to the pharmaceutical companies’ strategies and, most principally, to revive transnational connectivity and solidarity.

To conclude

Although the Delhi meeting goal was broader than challenges regarding the HIV and AIDS human rights policies, the conversations it enhanced have illuminated the variety of ways in which HIV and AIDS have been, and continue to be, crucially important in shaping the conceptual and political landscape of health and human rights more broadly. GAPW has therefore a high expectation that the new Special Rapporteur will preserve the focus on HIV and AIDS, in its complexity, as one of the priorities of the mandate on the right to the enjoyment of the highest attainable standard of physical and mental health. ■

Financing and the Post-2015 Agenda: making the case for HIV

Malu Marin¹

In September 2015, the UN General Assembly will be adapting a new set of development goals, with 2030 as its end-goal timeline. The proposed goals, currently referred to as Sustainable Development Goals (SDGs), are envisaged to define the UN Member States' development priorities and financing in the next 15 years. Unlike the Millennium Development Goals (MDG) which included a specific goal for AIDS (Goal 6), the present articulation of the proposed SDGs, as agreed upon in the Open Working Group's (OWG) final Outcome Document,² include AIDS as one of the nine targets under the Health Goal. Overall, there are 17 proposed goals and 169 targets in the Outcome Document, which will be the main basis for the intergovernmental negotiation process at the 69th session of the UN General Assembly in September 2015.³ The AIDS target statement reads:

3.3 by 2030 end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases.

This iteration manifests a double-edged reality: progress has been achieved in many parts of the world in stemming the tide of new HIV infections and AIDS-related deaths; paradoxically, the global 'de-prioritization' of HIV in the development agenda could potentially undermine the future of the HIV response, threatening its sustainability and initial successes.

By the end of 2013, UNAIDS reported that 35 million people were living with HIV worldwide and new HIV infections were estimated at 2.1 million.⁴ These figures show a significant reduction in new infections, as well as AIDS-related deaths, primarily due to increased access to treatment by people living with HIV in the last decade. As of June 2014, around 13.6 million people were receiving anti-retroviral therapy, indicating



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Funding shortfalls threaten to undermine the global response to HIV

strongly that the 15-million-people-on-treatment-target will be met by 2015.

With the HIV situation improving or plateauing in many countries, it has become a concern that there is less compulsion for governments to make it a priority issue. This presents serious implications with regards to resource allocation and programming, especially for prevention programs for key populations and civil society organizations engaged in the HIV response.

HIV financing: is there money for HIV?

The prospect of sustained financing for HIV is dim. Resource tracking from UNAIDS notes that recipient governments of bilateral or multilateral HIV funding cannot expect donor governments, particularly from OECD countries, to continue or increase their contributions in the coming years. Funding commitments in 2013 fell to US\$8.07 billion, a 3% drop from 2012, which was largely due to the United States, the largest donor country in the world, decreasing its annual commitments.⁵ In addition, HIV assistance from the U.K., France, Germany, and the Netherlands in 2013, which are historically the four largest donors after the U.S., were all either at or below levels reached in previous years.⁶

Recent financing trends reveal that donor countries are shifting from bilateral to multilateral funding. An example of this is the increased contributions to the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). However, under the

¹ Malu Marin is with Seven Sisters in Bangkok, Thailand. She is a member of the Advisory Council for Global AIDS Policy Watch.

² http://www.un.org/ga/search/view_doc.asp?symbol=A/68/970&Lang=E

³ http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/68/309

⁴ UNAIDS, Fast-Track: Ending the AIDS epidemic by 2030, 2014.

⁵ UNAIDS and Henry J Kaiser Foundation, Financing the Response to HIV in Low and Middle-Income Countries: International assistance from Donor Governments In 2012, July 2014.

⁶ UNAIDS and Henry J Kaiser Foundation, Financing the Response to HIV in Low and Middle-Income Countries: International assistance from Donor Governments In 2012, July 2014 p 6.

New Funding Model (NFM) of the Global Fund, there are restrictions in terms of eligibility. Lower and upper middle-income countries will need to provide counterpart financing and ensure that the funding is targeted towards key populations, i.e., 50% for LMIC and 100% for UMIC. UMICs are ineligible if their disease burden is low or moderate. The situation is exacerbated by the fact that many countries are being reclassified into higher income levels, which impacts on the amount of support they will get from the Global Fund. This will have serious implications on countries. It also means that the money will be apportioned for the three diseases, which could result in less allocation for HIV.

In Asia and the Pacific region, only 24% of the total funding for HIV and AIDS from 2009-2012 was used for prevention, and of this, only 35% was spent on programs for key populations.⁷ The biggest share of the resources was spent on treatment and care (47%), with program management and administration coming in third with 18%. Spending on treatment is necessary to curb AIDS-related deaths, however, a disproportionate allocation that deprioritizes prevention, especially among key populations, may well lead to increases in new HIV infections, overturning the initial gains in the HIV response.

In many countries in the world, prevention is funded largely by external sources, while treatment and care is now increasingly being sourced from domestic resources. The emphasis on domestic financing is underscored by the inclusion of 'Closing the Resource Gap' as one of the ten targets emanating from the 2011 Political Declaration on HIV and AIDS. In the last five years, considerable efforts were undertaken by UNAIDS to track countries' HIV expenditures, investments and assistance, with the view that without increased investment, the HIV prevention and treatment targets will not be met.

The push for domestic spending sends a message to governments to not abdicate on their duty to fulfill the health needs of their citizens, particularly key populations who are often marginalized and unable to access health services and information. However, while evidence suggests that community-led HIV programs and services are most effective in ensuring that hard-to-reach populations are able to have access to these services, community-based networks and organizations running these services do not necessarily have access to government funding. In many instances, prevention programs are largely externally-resourced, with the Global Fund as one of the main donors. In Asia and the Pacific, 95% of funding for MSM and 94% of funding for sex workers are

externally sourced. Thus, the threat of reduced funding from international donors could have a chilling effect on the sustainability of community-led programs. There is also less optimism that governments will pick the tab for community-led programs, given the often testy relationship between government and civil society.

Currently, there are discussions around various schemes and approaches to sustain HIV financing, which are envisaged to respond to the funding threats. These include "transition funding", integration into national health financing systems, such as through social health insurance, or in sexual and reproductive health (SRH) programming, and inclusion in universal health coverage (UHC), among others. The concerns raised against HIV exceptionalism have also propelled the discussion towards integration, as having stand-alone, siloed HIV responses are deemed as unsustainable in the long term.

While the modalities of transition funding are still being discussed, there is considerable apprehension that civil society and community networks, especially among key populations, would bear the consequences of reduced resources the most. Apart from this, funding to address critical enablers such as reduction of stigma and discrimination, promotion of human rights, inclusion of gender and sexuality in the response and engagement of civil society and communities, would be the first to get cut off. UNAIDS notes that funding for human rights accounts for less than 1% of the US \$18.9 billion spent on the overall HIV response in 2012.⁸

The inclusion of HIV in UHC has been championed by the World Bank and the WHO, as a means to ensure that the HIV response is "mainstreamed" and integrated into national health systems. The WHO defines UHC as "ensuring that all people obtain the health services they need, of good quality, without suffering financial hardship when paying for them."⁹ Voices concerned and critical of UHC note that there is a risk that countries will seek to advance progress towards UHC by focusing on easier to reach populations, while excluding more marginalized populations including people living with and those most affected by HIV, such as men who have sex with men, sex workers, people who use drugs and transgender people.¹⁰ Thus, a parallel approach of addressing inequities and elimination of stigma and discrimination needs to be undertaken in order for UHC to work.

New targets for 2030

With the post-2015 process already rolling, UNAIDS has proactively gone ahead to develop its new round of treatment

⁷ UNAIDS Asia-Pacific Data Hub HIV Expenditure <http://www.slideboom.com/presentations/856026/HIV-expenditure>

⁸ UNAIDS, Halving HIV transmission among people who inject drugs: background note, UNAIDS/Programme Coordinating Board (35)/14.27, 25 November 2014, p. 12. Available on-line at: http://www.unaids.org/sites/default/files/media_asset/20141125_Background

[Note Thematic Segment_35PCB.pdf](#)

⁹ World Health Organization, What is Universal health Coverage?, October 2012. (http://www.who.int/features/qa/universal_health_coverage/en/index.html)

¹⁰ http://www.aidsalliance.org/assets/000/000/819/Health_in_the_post-2015_Development_Framework_original.pdf?1407230086

targets. Targets are essential in measuring achievements, as well as gaps and failures in the HIV response. In light of changing political and economic realities, scientific advancements in bio-medical research and heightened community engagement in the HIV response, governments need to ensure that they are able to take these contexts into account, as they move towards a future that requires considerable investment from their end. Ending AIDS in 2030 is now deemed as achievable, but the means of implementation have not yet been spelled out concretely in terms of global and national strategies and indicators.

The first group of targets to be developed for treatment, also known as 90-90-90, are as follows:¹¹

1. By 2020, 90% of all people living with HIV will know their HIV status.
2. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy.
3. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

These targets, along with WHO's recently launched treatment guidelines, i.e., initiation of treatment at 500 CD4 count or upon diagnosis if coming from a key population and practicing riskier behavior, are meant to scale up treatment and stem the tide of new infections. Discussions are ongoing on how these guidelines will be rolled out, with due consideration of current resource limitations and potential HIV funding glut. It also brings to light the challenges brought about by intellectual property barriers, which makes life-saving ARV drugs unaffordable in many countries. There are also persistent concerns about governments being able to ensure that they adhere to rights-based principles and approaches and that no violation of rights or coercion occurs throughout the entire cycle of HIV programming, in the desire to meet the targets.

Fast-tracking the end of AIDS by 2030

On occasion of the 2014 World AIDS Day, UNAIDS has launched a report on "fast-tracking the end of the AIDS". The report lays out resource requirements of countries to enable them to meet the goal of ending AIDS. Low-income countries will require US\$ 9.7 billion in HIV funding, lower-middle-



Community-led HIV programs may have reduced funding

Photo by Vagner de Almeida

income countries will need US\$ 8.7 billion, and upper-middle-income countries will require US\$ 17.2 billion in 2020.¹² The emphasis on investment for AIDS is underpinned on the premise that if the resources are reduced, there would be severe cost implications for HIV programming beyond 2020.

Despite the wealth of information on what is needed to overturn the HIV epidemic, global commitments and actions remain uneven. While civil society and communities strive to engage meaningfully in the response, without secure HIV financing from domestic and external sources, fast-tracking or ending the AIDS epidemic will be stalled. This entails that governments are able to mobilize resources through their budget allocations and have the fiscal space to do so. However, national budgeting is a highly political process that entails multiple levels of negotiations and trade-offs involving legislative and executive branches of government. This then requires vigilance on the part of civil society and communities to understand the budget process, in order to intervene effectively. It also entails monitoring government expenditures, in order to track whether the budget allocations are efficiently and properly spent.

The case for addressing HIV and AIDS has long been established. Not only will it lead to positive health outcomes, but will also contribute to fulfillment of human rights, achievement of gender equality and justice and tackling of social and economic barriers. Sustained investment in HIV programming, as a stand-alone response or integrated into existing health systems, from domestic or external sources, for treatment, prevention and enabling environment, will be requisite in enabling the end of AIDS. ■

¹¹ UNAIDS, 90-90-90 An Ambitious Treatment Target to Help End the AIDS Epidemic, 2014.

¹² UNAIDS, Fast-track: Ending the AIDS Epidemic by 2030, 2014.

Exploring trends and resistance to biomedical approaches to HIV prevention in contexts of female sex work

Laura Murray¹

What are the politics and history behind an HIV oral test on a brothel bed in Brazil? It is an image that marks a drastic shift away from previous rights-based campaigns in the country, and is a reflection of global trends towards biomedical responses to HIV in female sex work contexts. The Network of Sex Work Projects *Global Consultation on PrEP and Early Treatment as Prevention Strategies*² along with the Sex Worker Consensus Statement produced at AIDS2014,³ are indications both of these shifts, and of sex workers' trepidation with regard to the scale-up of biomedical strategies. At the meeting, *Right to the enjoyment of the highest attainable standard of physical and mental health*, held in October in Delhi and reported on by Sonia Correa in this issue, participants reported the lack of human rights-based HIV prevention programs and the dominance of biomedical approaches, mandatory testing and a denial of comprehensive treatment in sex work contexts. These are worrisome trends in HIV prevention intervention globally that deserve further attention.

Here, I seek to explore some areas where this shift is visible and point to others that will be further explored through the Global AIDS Policy Watch (GAPW) in a policy brief consisting of global case studies. The goal is not to question the effectiveness of biomedical strategies. It is to take a closer look at international guidelines on HIV and sex work and sex worker responses to examine when biomedical strategies appear to have taken center stage at the expense of human rights and community empowerment-based approaches that have proved to be effective in promoting sex worker health and rights in the field of HIV prevention.

Subtle, yet significant, shifts in international guidelines on HIV and sex work

The history of international efforts to address HIV and sex work



Photo by Laura Murray

The HIV oral test on a brothel bed in Belém do Pará, Brazil

dates back to 1989 when Jonathan Mann, in his role as the head of the World Health Organization's Global Program on Aids (GPA), invited sex worker leaders to a "Consultation on HIV epidemiology and prostitution".⁴ The statement from this first consultation highlighted the role of stigma and punitive laws in increasing sex worker vulnerability to HIV, while also noting the importance of meaningful sex worker involvement in program design and implementation. Yet as Joane Csete notes in her history of sex work and the global response to HIV, it took several decades of debate and political struggles both within and outside the UN system before UNAIDS developed official guidelines on HIV and sex work.⁵

In 2007, UNAIDS circulated their *Guidance Note on HIV and Sex Work*. Although the document was developed through global technical consultations with sex worker rights organizations, it "proved to be highly contentious"⁶ due to its lack of a human-rights approach, silence on the harms of criminalization, blurring of sex trafficking with sex work, and endorsement of "end demand" approaches and "alternative livelihood" programs for sex workers. Various organizations and groups mobilized critical responses to

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² Network of Sex Work Projects. *Global Consultation: PrEP and Early Treatment as HIV Prevention Strategies*. 2014. Accessed on October 22, 2014 from: <http://www.nswp.org/es/node/1948>.

³ Sex Worker Pre-Conference AIDS2014 Consensus Statement. Accessed on September 15, 2014 from: <http://www.scarletalliance.org.au/events/AIDS2014/consensus2014/>

⁴ CSETE, Joanne. *Victimhood and Vulnerability: Sex Work and the Rhetoric and Reality of the Global Response to HIV/AIDS*. In L.Murthy, ed. *The Business of Sex*, pp 45-80. New Delhi: Zubaan, 2013.

⁵ CSETE, Joanne. 2013. *Victimhood and Vulnerability: Sex Work and the Rhetoric and Reality of the Global Response to HIV/AIDS*, p. 50.

⁶ UNAIDS Reference Group on HIV and Human Rights. *Recommendations regarding the "UNAIDS Guidance note on HIV and Sex Work (April 2007)."*

the guidelines and the International Network of Sex Work Projects (NSWP) formed a Global Working Group on Sex Work and HIV Policy (GWG) to rework the guidance note.⁷ In 2007, the GWG publically presented a revised guidance note to UNAIDS, and in 2009, UNAIDS released its own revised version⁸ (without inviting comments from the GWG prior to publication).⁹

The 2009 *UNAIDS Guidelines on HIV and Sex Work* purport to take a “human-rights approach” and highlight the importance of addressing structural issues, violence, stigma and discrimination. However several key issues of concern to the GWG remained, such as the continued inclusion of references to reducing demand for sex work, the inclusion of “occupational alternatives to sex work for those who want to leave it” as one of the guideline’s pillars, and continued confusion between sex work and trafficking. UNAIDS refused the GWG’s request to revise the guidelines, yet agreed to fund an Advisory Group on HIV and Sex Work to develop annexes to complement it.¹⁰ The stated goal of the annexes was to “help shape programmes and policies on HIV and sex work that are *truly* human rights-based” [emphasis mine] and they centered on the following four topics: “Laws, enforcement and policies that impede effective HIV responses for sex workers; Shifting the strategic focus from the reduction of demand for sex work to reduction of demand for unprotected paid sex; Differentiating sex work and trafficking; and Economic empowerment of sex workers.”¹¹ Both the 2009 guidelines and annexes make explicit statements against mandatory and coercive HIV testing and prevention programs, yet there are no mentions of biomedical approaches to HIV prevention.

The WHO published the next set of guidelines explicitly focused on female sex work in 2012. Titled, *Prevention and Treatment of HIV and other Sexually Transmitted Infections for Sex Workers in Low-Middle Income Countries*, the document reinforces the importance of a human-rights, sex worker-led, community empowerment approach to HIV prevention, while also including

the results of an extensive literature review regarding various prevention technologies, including biomedical approaches such as periodic presumptive treatment (PPT) for STIs and early treatment.¹² Voluntary PPT as a short term, emergency measure and voluntary periodic screening for asymptomatic STIs are recommended, yet with very clear conditions about the possible negative effects of such interventions should they not be led by sex workers themselves – in particular, risks of being implemented as part of “coercive or mandatory public health regimes.”¹³ Voluntary Counseling and Testing (VCT) is recommended, and while “provider-initiated testing”¹⁴ is mentioned, there is no discussion of testing outside of health services. Treatment guidelines follow the WHO general recommendations (ARV use is for when the CD4 count is less than or equal to 350 cells.mm³) and there is no comment on PrEP (Pre-Exposure Prophylaxis).

To identify more recent shifts in testing and ARV guidelines, it is necessary to look beyond sex work-specific guidelines. For example, in the 2013 WHO *Guidelines for HIV Testing and Counseling, ART and HIV Service Delivery*, the terminology, “community-based HIV testing for key populations, with linkage to prevention, care and treatment services” is used.¹⁵ In 2014, the WHO published, *Consolidated Guidelines on HIV Diagnosis, Treatment, Prevention and Care for Key Populations*, and reinforced “community-based testing” as a, “strong recommendation with low-quality of evidence.”¹⁶ In these same guidelines, PrEP is only recommended for sex workers in a serodiscordant relationship, and early ARV initiation in all individuals in serodiscordant relationships.

A broader analysis of the WHO recommendations over the past five years signals a shift from a focus on rights-based strategies to rights being included as *enablers* for biomedically-focused interventions to be successfully implemented. For example, in the 2012 WHO recommendations for sex workers, the report starts with “Good Practice Recommendations” which focus on structural

⁷ SESHU, MEENA et al. UN Guidance Note on HIV and Sex Work “Reworked” by Activists. *HIV/AIDS Policy and Law Review*. 13(2/3): 95-97, 2008.

⁸ UNAIDS. *Guidance Note on HIV and Sex Work*. Geneva: UNAIDS, 2009. Available online: http://www.unaids.org/sites/default/files/sub_landing/files/JC2306_UNAIDS-guidance-note-HIV-sex-work_en.pdf

⁹ CSETE, Joanne. *Victimhood and Vulnerability: Sex Work and the Rhetoric and Reality of the Global Response to HIV/AIDS*.

¹⁰ UNAIDS Advisory Group on HIV and Sex Work. *The report of the UNAIDS Advisory Group on HIV and Sex Work*. Geneva: UNAIDS, 2011. Available online: http://www.hst.org.za/sites/default/files/20111215_Report-UNAIDS-Advisory-group-HIV-Sex-Work_en.pdf.

¹¹ Different from the 2009 guidelines, the 2011 guidelines come with a note stating that “The document does not necessarily represent the view of all members of the Advisory group on HIV and Sex Work, nor the stated positions, decisions or policies of the UNAIDS Secretariat or any of the UNAIDS Cosponsors.”

¹² World Health Organization. *HIV Prevention Programme. Prevention and Treatment of HIV and Other Sexually Transmitted Diseases for Sex Workers in Low and Middle Income Countries*. Geneva; World Health Organization. 2012.

Available online at:

http://apps.who.int/iris/bitstream/10665/77745/1/9789241504744_eng.pdf?ua=1

¹³ World Health Organization. *HIV Prevention Programme. Prevention and Treatment of HIV and Other Sexually Transmitted Diseases for Sex Workers in Low and Middle Income Countries*, Geneva; World Health Organization. 2012. p. 27.

¹⁴ Provider initiated testing is in health facilities. For more information, see the WHO guidelines: *Guidance on Provider-Initiated Testing and Counseling in Health Facilities*: http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf?ua=1

¹⁵ World Health Organization. *Summary of new recommendations of 2013 guidelines on HIV testing and counseling, ART and HIV service delivery*. 2013. Accessed on October 22, 2014. Available at: <http://www.who.int/hiv/pub/guidelines/arv2013/intro/rag/en/>

¹⁶ World Health Organization. *Consolidated Guidelines on HIV Diagnosis, Treatment, Prevention and Care for Key Populations*. Geneva: World Health Organization, p. 57, 2014. Available online at: http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431_eng.pdf?ua=1&ua=1

issues such as decriminalization and the need for anti-discrimination and violence protection policies.¹⁷ The first evidence-based recommendation is enhancing community empowerment among sex workers, followed by consistent condom use. In contrast, the 2014 WHO recommendations start with condom use, and are followed by PrEP for MSM and serodiscordant couples, and end with circumcision. Structural issues are addressed in the last table presented, as “Critical Enablers.” While there are no clear guidelines on how “community-based testing” should be implemented, it is a key component of the proposed strategies, as both PrEP and early treatment require people to know their HIV status to use these prevention technologies.

Sex worker-led responses

Sex worker groups internationally have called attention to these shifts in their own contexts, and responded with sex worker-led research¹⁸ and a Consensus Statement from the Sex Worker Pre-conference at AIDS 2014.¹⁹ The Consensus Statement is the result of a two-day meeting between sex workers from more than thirty countries before the International AIDS Conference (IAC) in Melbourne, Australia. Five topics are addressed in the consensus statement, including: 1) Biomedical developments; 2) Stigma and discrimination; 3) Human rights issues including the criminalization of HIV and sex work; 4) Migration and mobility, and 5) Funding. Biomedical developments are listed first, and concerns documented include being “forced to engage, without consultation, without adequate information” and “pressure from governments to be tested and pressure from clients who want workers to use PrEP in place of existing safe sex practices.”²⁰ Legal barriers, stigma and discrimination, lack of attention to workplace health and safety are among other concerns listed, along with shifts in funding away from human rights approaches towards biomedical ones. The Consensus Statement’s perspective on biomedical developments is well summarized in the following statement:

Legal Barriers for sex workers are still so significant that unless we resolve those issues first, through the full

“(.) testing is at the core of all of these strategies, and there is a notable lacuna in information, guidelines and best practices of what testing with sex workers might look like”

*decriminalization of sex work, test and treat or treatment as prevention are abstract concepts that have no meaning for sex workers but will divert resources away from approaches that we know work.*²¹

The cross-cutting themes throughout the rest of the 4 sections are well summarized in the following seven statements: 1) You can't stop HIV without sex workers; 2) The HIV sector must stop stigmatizing sex workers; 3) Sex workers are the experts in and for our community; 4) Nothing about us without us; 5) Decriminalization is required to end HIV; 6) Sex workers speak from lived experience; 7) Don't silence us, don't speak on our behalf. A meeting held in October of 2014 by the Latin American Platform of People in Sex Work (PLAPERTS) in Quito,

Ecuador, reinforced many of these statements, in particular, the role of sex workers as experts and protagonists in the HIV response and the urgent need for funding of community based responses.²²

In response to the increased focus on early treatment as prevention, NSWP conducted a *Global Consultation on PrEP and Early Treatment as Prevention Strategies*

that included 440 participants from 40 countries.²³ The results of the consultation found low levels of knowledge and trepidation with regards to PrEP and early treatment, principally in terms of the impacts of these strategies on health, the ethical issues of how they would be implemented, effects on condom use, and their potential for increasing stigma and further distancing attention and investment from structural interventions. The recommendations made based on the results of the consultation reinforce the importance of “access to accurate knowledge and information,” “adequate funding and support of sex worker-led organizations,” “full decriminalization of sex work,” and “research and data collection on the use of PrEP and early treatment amongst sex workers.”²⁴

In terms of testing, sex workers interviewed reported negative experiences of stigma and discrimination in public healthcare settings that contrasted with more positive experiences of sex worker-led and community-based testing. More specific details

¹⁷ World Health Organization. 2012. HIV Prevention Programme. Prevention and Treatment of HIV and Other Sexually Transmitted Diseases for Sex Workers in Low and Middle Income Countries. Geneva; World Health Organization. 2012.

¹⁸ Network of Sex Work Projects. Global Consultation: PrEP and Early Treatment as HIV Prevention Strategies. 2014. Accessed on October 22, 2014 from: <http://www.nswp.org/es/node/1948>.

¹⁹ Sex Worker Pre-Conference AIDS2014 Consensus Statement. Accessed on September 15, 2014 from: <http://www.scarletalliance.org.au/events/AIDS2014/consensus2014/>

²⁰ Sex Worker Pre-Conference AIDS2014 Consensus Statement, p. 1.

²¹ Sex Worker Pre-Conference AIDS2014 Consensus Statement, p. 1.

²² Plataforma Latinoamericana de Personas que Ejercen el Trabajo Sexual. Declaración de Quito, “Con los Sueños de Gabriela”. Posted on October 20, 2014: <https://www.facebook.com/1546032082274844/photos/a.1546036825607703.1073741828.1546032082274844/1561065204104865/?type=1>

²³ Network of Sex Work Projects. Global Consultation: PrEP and Early Treatment as HIV Prevention Strategies. 2014. Accessed on October 22, 2014 from: <http://www.nswp.org/es/node/1948>.

²⁴ PrEP has yet to be tested with female sex workers. A “demonstration project” of treatment as prevention and PrEP among female sex workers is currently in the recruitment phase in Benin. The study is sponsored by the Centre Hospitalier Universitaire de Québec, CHU, and includes Bill and Melinda Gates Foundation among its collaborators: <http://clinicaltrials.gov/show/NCT02237027>. This is the first study of its kind.

on what sex worker-led and community-based services might look like are not provided, and is something that is also missing in the literature. As previously mentioned, testing lies at the core of all of these strategies, and there is a notable lacuna in information, guidelines and best practices of what testing with sex workers might look like – especially considering the significant technological advances in the last few years that permit more mobility and require less technical training to use. How the human rights-based, non-stigmatizing approach advocated for so strongly in the 2011 UNAIDS Advisory Group report and 2012 WHO guidelines could be incorporated into such a program is something that needs to be further explored.

Who is being punished and who is being protected?

In the UNAIDS Press Release for *The GAP Report*, the executive director Michel Sidibé stated, “Whether you live or die should not depend on access to an HIV test. Smarter scale-up is needed to close the gap between people who know their HIV status and people who don’t, people who can get services and people who can’t and people who are protected and people who are punished.”²⁵

In the current context, it is worth reflecting on what protection and punishment might potentially look like. For years, the sex worker community has argued vehemently for a sex worker-led, community empowerment-based approach to HIV. Similar to the messages in the NSWP, the AIDS2014 Consensus Statement, and the PLAPERTS manifesto, they have urged governments to repeal laws that criminalize sex workers, and drawn attention to the devastating role that stigma and discrimination play in affecting sex workers’ access to health care. The international guidelines in 2012 marked a concrete international consensus of the effectiveness and importance of a human rights based approach. In 2012, two other important international reports were also published – *The Global HIV Epidemics Among Sex Workers*, published by the World Bank,²⁶ and the Global Commission on HIV & the Law’s report, *Risk, Rights and Health*²⁷ – both of which clearly position themselves on the need to actively address stigma, violence, criminalization

and marginalization – through policy changes and sex worker-led actions – if sex workers’ vulnerability is to be reduced and biomedical responses are to have any affect. Building on and citing the 2012 WHO and World Bank research, *The Gap Report* (to which Michel Sidibé refers), lists sex workers as one of the populations “left behind,” and lists four ways to “close the gap” that are all structural interventions: address violence, decriminalize sex work, empower sex work communities, and scale up and fund health and social services for sex workers.²⁸

The publication of *The Lancet* series on HIV and Sex Work in July 2014 provided additional strong evidence for the impact decriminalization could have on the HIV epidemic among sex workers,²⁹ the connections between human rights violations and HIV vulnerability,³⁰ significant associations between community empowerment based approaches and reductions in HIV³¹ and the importance of combining a biomedical approach with behavioral and structural components.³² The articles also point out that though proven effective, structural and community empowerment-based models of HIV prevention continue not to be adequately funded or scaled-up in many global regions, despite sex workers’ continued disproportionate risk to HIV and reduced access to health services.³³

All of this research supports what sex worker leaders have argued for decades. “Protection” for sex workers must go beyond access to condoms, an HIV test or ARV medications because until the “punishment” sex workers face just for being who they are in many parts of the world is adequately addressed, eliminating new HIV infections among the population will not be possible. Right now, many sex workers are being indirectly punished by the lack of international funding for these proven HIV prevention approaches that place equal importance on structural and biomedical approaches. There appears to be a gap between what the most recent research and even *The Gap Report* itself argues, and the increasingly biomedical focus of the WHO guidelines, and sex worker experiences. A question thus remains as to what extent the overwhelming evidence and voices of sex workers will be able to successfully balance structural approaches with biomedical ones.

²⁵ UNAIDS. Press Release: UNAIDS report shows that 19 million of the 25 million people living with HIV today do not know that they have the virus. Published July 16, 2014, online at: <http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2014/july/20140716prgapreport>

²⁶ KERRIGAN, Deanna, et al. *The Global Epidemics Among Sex Workers*. Washington DC: World Bank, 2012. Available online: <http://www.worldbank.org/content/dam/Worldbank/document/GlobalHIVEpidemicsAmongSexWorkers.pdf>

²⁷ Global Commission on HIV & the Law. *Risk, Rights and Health*. New York: UNDP, 2012. Available online: <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>

²⁸ UNAIDS. 2014. *The Gap Report*. Geneva: UNAIDS, p.197. Available online: <http://www.unaids.org/en/resources/campaigns/2014/2014gapreport/gapreport>

²⁹ SHANNON, Kate et al. Global Epidemiology of HIV among female sex workers: influence of structural determinants. *The Lancet*. 2014. Published

online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60931-4](http://dx.doi.org/10.1016/S0140-6736(14)60931-4).

³⁰ DECKER, Michele R et al. Human rights violations against sex workers: burden and effect on HIV. *The Lancet*. Published online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60800-X](http://dx.doi.org/10.1016/S0140-6736(14)60800-X)

³¹ KERRIGAN, Deanna et al. A community empowerment approach to the HIV response among sex workers: effectiveness, challenges, and considerations for implementation and scale-up. *The Lancet*. Published online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60973-9](http://dx.doi.org/10.1016/S0140-6736(14)60973-9).

³² BEKKER, Linda-Gail, et al. Combination HIV prevention for female sex workers: what is the evidence? *The Lancet*. Published online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60974-0](http://dx.doi.org/10.1016/S0140-6736(14)60974-0)

³³ BEYRER, Chris, et al. An action agenda for HIV and sex workers. *The Lancet*. Published online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60933-8](http://dx.doi.org/10.1016/S0140-6736(14)60933-8); BEKKER, Linda-Gail, et al. Combination HIV prevention for female sex workers: what is the evidence? *The Lancet*. Published online July 22, 2014: [http://dx.doi.org/10.1016/S0140-6736\(14\)60974-0](http://dx.doi.org/10.1016/S0140-6736(14)60974-0)

Test and treat from a human rights perspective¹

Richard Parker²

Peter Aggleton³



A tense relationship has always existed between community, science and public health

Since the late 2000s, biomedical approaches to HIV prevention and treatment have become increasingly central to global HIV and AIDS policy guidelines and initiatives. The reasons for this are complex. Among other things, the perceived lack of effectiveness of many behavioral interventions, together with the difficulty of influencing the most important structural factors shaping the epidemic are

especially important. But the controversy associated with many early efforts to scale-up of HIV treatment and prevention in the early 2000s also prepared the way for biomedical approaches, which for many seemed relatively straightforward in comparison to continued (and often heated) debates about the ABC (Abstinence, Be faithful, use a Condom) policies promoted by the PEPFAR Program of the US government, or

¹ A first draft of this article was presented at the 11o Seminário LGBT [11th LGBT] of the Brazilian National Congress held in 2014, whose theme was "AIDS: ways of knowing, ways of getting sick," organized by the Commission on Human Rights and Minorities, of the House of Representatives, together with the Commission of Participative Legislation and the Committee on Social Security and Family, both also of the House of Representatives; the Commission on Human Rights and Participative Legislation of the Senate; and in partnership with the Parliamentary Front in Defense of Human Rights, the Parliamentary Front for LGBT Citizenship and the Parliamentary Front for Confrontation to the STD/HIV/AIDS. Thanks to Congressman Jean Wyllys and the other organizers for the invitation and, in particular.

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some of the equally controversial (because of their much more explicit and positive exploration of sexuality) community-based prevention and education programs developed by affected populations at the frontlines of the fight against the epidemic. Within this context, biomedical approaches seemed to many to offer a relatively simple option, seemingly less fraught with moral controversy and condemnation.

It was, however, no accident that the ascendancy of biomedical approaches to the epidemic took place at roughly the same moment that HIV scale-up internationally appeared to be peaking, and what would prove to be a protracted global financial crisis was taking shape, placing serious limits on budgets for global health generally, and for HIV in particular. As international donors tightened their belts, the perceived simplicity of many biomedical approaches – and especially of programs focusing on treatment as prevention and “test and treat” held strong appeal.⁴

Yet as policies and programs such “test and treat”, increasingly take shape as the **new normal** in many middle- and even lower-income countries – promoted first and foremost by public health authorities,⁵ and especially in settings where rights-based policies in response to the epidemic have been tenuous at best, serious concerns have been raised about the ways in which the public health “targeting” of key populations may pressure members of marginalized and disempowered populations to agree to HIV testing, against their will or without the information and support needed for any form of informed consent. Concern has also been raised that such targeting may reproduce (intentionally or unintentionally) deeply problematic notions such as the idea of “risk groups”, and increasing stigma, prejudice, and discrimination towards these perceived groups. Even in countries that have demonstrated serious commitment to principles of human rights as part of the response to the epidemic, the risk that test and treat policies and programs may unintentionally undermine that historic commitment has been raised as a serious concern.⁶ How to guarantee that such approaches will be implemented in ways that will not subvert key aspects of human rights that we want to promote and preserve – in particular, dignity, inclusion, recognition and respect for diversity and difference – has emerged as one of the key challenges facing the response to HIV in the midst of the fourth decade of the epidemic.



Photo by Wagner de Almeida

Activism continues to make an essential contribution to resisting stigma and discrimination

The third epidemic: stigma, prejudice and discrimination

In order to better understand these human rights concerns as they relate to debates about “test and treat”, “treatment as prevention”, “treatment for prevention” and indeed “biomedical prevention” more generally, it is important to remember the past and some of the key conceptual shifts that have taken place over the years with respect to useful thinking about HIV and AIDS.

One of the earliest frameworks, developed in the late-1980s by Jonathan Mann and colleagues, especially through the work of the World Health Organization (WHO)’s former Global

⁴ GRANICH, Reuben M.; GILKS, Charles F.; DYE, Christopher; DE COCK, Kevin M.; WILLIAMS, Brian G. Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. *The Lancet* 373(9657):48-57, 2009; WAGNER, Bradley G.; KAHN, James S.; BLOWER, Sally. Should we try to eliminate HIV epidemics by using a “Test and Treat” strategy?. *AIDS* 24(5):775, 2010; CAMBIANO, Valentina; RODGER, Alison J.; PHILLIPS, Andrew N. ‘Test-and-treat’: the end of the HIV epidemic?. *Current Opinion in Infectious Diseases* 24(1):19-26, 2011

⁵ DABIS, François. Test and treat all as soon as possible. *The Lancet Global*

Health 2(1):e2-e3, 2014; EATON, Jeffrey W. et al. Health benefits, costs, and cost-effectiveness of earlier eligibility for adult antiretroviral therapy and expanded treatment coverage: a combined analysis of 12 mathematical models. *The Lancet Global Health* 2(1):e23-e34, 2014.

⁶ NGUYEN, Vinh-Kim; O’MALLEY, Jeffrey; PIRKLE, Catherine M. Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention. *AIDS* 25(11):291-293, 2011; PATTON, Cindy. Rights language and HIV Treatment: universal care or population control?. *Rhetoric Society Quarterly* 41(3):250-266, 2011.

Programme on AIDS, was the idea of the three epidemics: (1) the “first” epidemic of HIV infection; (2) the “second” epidemic of AIDS cases; and (3) what was described as the “third” epidemic, the epidemic of social responses to the first and second epidemics, characterized by social stigma and discrimination.⁷

Mann stressed that AIDS is not a simple fact, much less a simple or uniform biological entity. On the contrary, it is a complex **social phenomenon**, which develops historically in different stages, and through distinct and intertwined processes. The first epidemic, the epidemic of HIV infection, generally began silently and grew without being noticed, prior to the onset of opportunistic infections associated with AIDS. It was only with the onset of symptoms that the second epidemic became visible through clinical cases known as AIDS. This could happen seven, eight years or more, after infection with HIV. However, there was also a third epidemic, one that was just as dangerous as the first two. This third epidemic was the social response to HIV and AIDS – almost always based on panic, prejudice, stigma and discrimination.

Herbert Daniel, an early Brazilian AIDS activist, used to say that this third epidemic was more dangerous than the first two because of the **symbolic violence** that it involved. It was not a biological virus, but an “ideological virus” that installs itself on top of the biological realities of HIV, and which triggers negative social responses.⁸ It was this ideological virus that gave rise to what Paula Treichler described as “an epidemic of signification”⁹ – an epidemic in which stereotypes and stigmas abound, and in which the physical suffering that HIV and AIDS inflicted is paralleled by the emotional and psychological damage that human beings inflict on one another.

This is precisely the reason why some of the earliest, and most visionary, AIDS activists recognized the importance of locating the epidemic firmly within a human rights framework. Another Brazilian, Herbert de Souza (better known as Betinho), was among the first to make this connection. During a lecture given at the University of São Paulo’s Faculty of Law in 1987, he began to articulate a rights-based framework for thinking about the response to HIV as a way of combating the epidemic of stigma and discrimination. He began to develop perhaps the

earliest argument – or at least the earliest one that we are familiar with – for the cure of AIDS, affirming that even if AIDS presently had no cure, someday one would come, and that until then, **solidarity** must lie at the heart of the social and political response to HIV, precisely because it provides a vaccine against stigma and discrimination.¹⁰

It was roughly at the same time, or shortly thereafter, that Jonathan Mann began to stress the importance of human rights in the response to AIDS. In his informal briefing to the United Nations General Assembly on 20 October 1987 Jonathan Mann first articulated his idea of the third epidemic “that relentlessly follows the first two epidemics.”¹¹ And it was just after that, first in the 41st World Health Assembly in May of 1988, and then later in the address that he gave to the IV International Conference on AIDS in Stockholm, Sweden, in June of 1988, that Mann developed a compelling argument about why “stigmatization may itself represent a threat to public health.”¹² World Health Assembly resolution WHA 41.24, on the avoidance of discrimination in relation to HIV-infected people and people with AIDS, adopted on 13 May 1988, called on Member States “to protect the human rights and dignity of HIV infected people and people with AIDS”, and “to avoid discriminatory action” and “stigmatization” in the “provision of services, employment and travel” and “to ensure the confidentiality of HIV testing” and to promote the “availability of confidential counseling and other support services to HIV-infected people and people with AIDS.”¹³

Inequality, oppression and vulnerability

There is no aspect of the global HIV epidemic that has been as deeply rooted, as persistent, or as difficult to combat as the epidemic of stigma, and social ostracism that affects people living with HIV as well as those suspected to be at risk of infection. Today, as much as in the past, all three epidemics need to be confronted, and it is because of this that human rights are such an important weapon in the fight against AIDS. But in order to use a human rights framework successfully, we must face up to what might be described as a paradox between the universality of human rights, and the particular forms of “vulnerability” that many individuals, communities and populations face in relation to HIV.

⁷ DANIEL, Herbert; PARKER Richard. *AIDS, a terceira epidemia: ensaios e tentativas*. São Paulo: Editora Iglu, 1991; DANIEL, Herbert; PARKER Richard. *Sexuality, politics and AIDS in Brazil*. London: The Falmer Press, 1993.

⁸ DANIEL, Herbert. *A vida antes da morte/Life before death*, bilingual edition. Rio de Janeiro: Jaboti, 1989.

⁹ TREICHLER, Paula. AIDS, homophobia, and biomedical discourse: an epidemic of signification, in *How to have theory in an epidemic: cultural chronicles of AIDS*, Durham and London: Duke University Press, 1999, pp. 11-41.

¹⁰ SOUZA, Herbert de. *A cura da AIDS/The cure of AIDS*, bilingual edition. Rio de Janeiro: Editora Relume-Dumará, 1994.

¹¹ MANN, Jonathan. Statement at an Informal Briefing on AIDS to the 42nd

Session of the United Nations General Assembly, Tuesday, 20th October 1987, p. 3.

¹² MANN, Jonathan. AIDS: discrimination and public health. Address presented 13 June 1988 at the IV International Conference on AIDS, Stockholm, Sweden. Presented by Kathleen Kay. WHO/GPA/DIR/88.3. Available on-line at: http://whqlibdoc.who.int/hq/1988/WHO_GPA_DIR_88.3.pdf (accessed on 1 November 2014).

¹³ WORLD HEALTH ORGANIZATION. World Health Assembly resolution WHA 41.24. *Handbook of resolutions and decisions of the World Health Assembly and the Executive Board, Volume 3*. Geneva: World Health Organization, 1993, p. 122. Available on-line at: http://whqlibdoc.who.int/wha_eb_handbooks/9241652063_Vol1.pdf (accessed on 1 November 2014).



The epidemic is linked to poverty and economic exclusion

On the one hand, we have to recognize that in the abstract, AIDS has no gender, no race or ethnicity, no social class or sexual orientation. This fundamental principle of equality requires the defense of human rights for all people. It is only through the universality of this defense that we can possibly fight the third epidemic. At the same time, however, and perhaps this is one of the most difficult challenges, we must also recognize that the AIDS is not an “egalitarian” or “democratic” epidemic. People do not all face the same risks in relation to HIV. Vulnerability to HIV is patterned so as to render some groups more systematically vulnerable and at risk than others. It generally does this in such a way that most often those who are the weakest or the most structurally disadvantaged suffer most. Both the biological virus and the ideological virus move through – and exploit – the cracks, inequalities and fissures in society.¹⁴

This, in turn, leads to a second major issue that must be engaged with in understanding contemporary debates on policies related to testing and treatment, and why these must be interrogated from a human rights perspective: namely, the role of “structural violence” in affecting the vulnerability of certain groups and communities.¹⁵

The most basic thinking behind a test and treat approach, like most public health approaches, is based on mainstream epidemiological research – following the numbers in order to identify the populations at highest risk, and then “targeting” these populations with public health “interventions”. But a focus on structural violence, as on the social determinants of health more broadly, encourage us to remember that this kind of an approach will be seriously limited in its effects. We also need what Naomar de Almeida Filho has described, in a brilliant turn of phrase, as an “epidemiology without numbers,”¹⁶ in the form of a good theory of what it is that lies behind the patterns that epidemiological and prevention science reveal. In this respect, both theories of disease as well as theories or explanations of how a particular disease **moves socially**, are important. It is precisely this understanding that theoretical insight into the workings of structural violence can provide.

Through their linkage to structural violence HIV and AIDS move through society. The epidemic of HIV infection is fuelled by axes of social inequality. It is linked to poverty and economic exclusion, operates in tandem with racial and ethnic discrimination, and exploits inequalities of gender and sexuality. HIV feeds on sexual oppression, as well as profound

¹⁴ PARKER, Richard. *Na contramão da AIDS: sexualidade, intervenção política*. São Paulo: Editora 34, 2000.

¹⁵ GALTUNG, Johan; HÖVIK, Tord. Structural and direct violence: a note on operationalization. *Journal of Peace Research* 8(1): 73-76, 1971; FARMER, Paul, CONNORS, Margaret; SIMMONS, Janie. *Women, poverty, and AIDS: sex,*

drugs, and structural violence. Monroe, ME: Common Courage Press, 1996; FARMER, Paul. An anthropology of structural violence. *Current Anthropology* 45(3):305-325, 2004.

¹⁶ FILHO, Naomar Almeida. *Epidemiologia sem números: uma introdução crítica à ciência epidemiológica*. Rio de Janeiro: Campus, 1989.

inequalities between people of different ages. The epidemic is fuelled by population displacement, forced migration and homelessness. At times, there may be unexpected detours in the route followed, but almost everywhere social inequalities are fundamental determinants not only of vulnerability to HIV infection, but of who is most likely to become ill, or to have access to treatment afterwards. And it is precisely where inequalities are greatest, and where different kinds of inequality crosscut – that we see the greatest impact of the epidemic. Here, a synergy exists between multiple forms of structural violence, and because of this HIV is sometimes best thought of as a “syndemic” rather than just an epidemic.¹⁷

If we engage seriously with the notion of structural violence, we can begin to make a change in the paradigm through which we understand and respond to HIV.¹⁸ As a first step, it is essential to shift from thinking about individual risk and risk groups to thinking in terms of social vulnerability.¹⁹ This does not mean that there are no risk practices. Obviously, there are practices that are more or less risky, and practices that are more or less protective. However, when left without further qualification, the idea of risk assumes that an individual's behavior should be the central point of discussion. The idea of social vulnerability, in contrast, encourages us to focus also on the economic, social and cultural determinants of health in order to respond effectively to the epidemic.²⁰

Politics and confrontation

A third major issue that must be addressed in order to assess a policy such as test and treat from a human rights perspective is to understand **politics** as the essential field on which HIV prevention can be built. This does not mean that technologies have no importance. The techniques of safe sex, invented over the history of the epidemic above all by affected communities – utilizing technologies such as the male condom, later the female condom, and even more recently by biomedical technologies such as pre- or post-exposure prophylaxis (PrEP and PEP) are of the utmost importance. However, they add almost nothing if we fail to engage with the political issues that must be addressed in order to guarantee their availability and use as part of conscious and informed choices – choices made by persons cognizant of their own agency, and as persons who understand themselves as the subject of fundamental human rights. No matter how sophisticated technologies may be, if we fail to overcome the barriers produced by ongoing prejudice and discrimination, it will matter little what technical advances are on offer. In short, we

must create the conditions for diverse tools and technologies to be used by people who need and want them – and to create these conditions we must face up to politics as it impacts on the distribution of resources and power.

Politics here needs to be understood from at least two directions or perspectives. The first is in the more macro sense – in terms of partisan and even electoral politics, in those contexts where democratic political systems exist. The greatest impediment to confronting the epidemic for more than 30 years now has been the lack of political courage and political will on the part of leaders often at the very highest levels, and this is true almost everywhere. It happened during the Reagan administration in the USA in the 1980s, during the Mbeki government in South Africa government in the 1990s, and more recently, in Uganda and other countries where state-sponsored discrimination has contributed to a backlash against legitimate struggles for sexual rights. The worst impediments to the fight against HIV have always been political, hindering the possibility of meaningful actions in the face of the epidemic. If we do not engage with politics head-on, we will never make significant progress in tackling the epidemic in the more narrow spheres of public health, education or social welfare systems.

This is not to suggest that it is only in these large-scale political arenas, or on high-level political leaders, that we must focus our attention. We must also recognize there is another face to politics – as it reveals itself in the messages that underpin guidelines for programmatic action and policies for HIV prevention and care. It is therefore also necessary to analyze governmental practices, the practices of ministries, and the programmatic actions implemented and guided by these political views. In most discussions of HIV, there has been a remarkable lack of courage, even in the fourth decade of the epidemic, to place these topics on the table and discuss them openly and clearly as part of informed, public debate.

This lack of political courage is perhaps not surprising in the light of neoliberal tendencies in the international arena over roughly the same time as that when the HIV epidemic evolved. To the extent that a narrow economic rationality has so often been used as a guide for planning and programmatic action, suggesting that the money available must be rationed in specific ways, it is perhaps not surprising that even well-intentioned politicians and policymakers should have reached this conclusion. But this is precisely why a human rights approach remains so essential to moving actions forward.

¹⁷ SINGER, Merrill; CLAIR, Scott. Syndemics and public health: reconceptualizing disease in bio↯social context. *Medical Anthropology Quarterly*, 17(4):423-441, 2003.

¹⁸ KUHN, Thomas S. *The structure of scientific revolutions*. Chicago: University of Chicago Press, 2012. Kuhn defined “paradigm” as the accepted theories, values and scientific practices within which a particular field operates.

¹⁹ MANN, Jonathan; TARANTOLA, Daniel; NETTER, Thomas. *AIDS in the world*. Cambridge, Mass.: Harvard University Press, 1992; DELOR, François; HUBERT, Michel. Revisiting the concept of ‘vulnerability’. *Social Science & Medicine* 50(11):1557-1570, 2000.

²⁰ MANN, Jonathan, TARANTOLA, Daniel, and NETTER, Thomas, *AIDS in the world*. Cambridge, Mass.: Harvard University Press, 1992.

The conviction, articulated by AIDS treatment activists around the world, that **every life matters** – and that no one can be denied access to adequate treatment and care simply because of where they may have been born, or any other quality or characteristic that is somehow deemed unjustly to make their lives less worthy – offers an alternative perspective to the vision of scarcity and economic rationalization that was itself simply a façade for the continued promotion of underlying stigma and discrimination that has persisted on up to the present day.

The time is right to rediscover these basic human rights principles – principles that have too often been lost in the well-intended, but overly utilitarian logics of HIV scale-up. It is time also to extend them from questions of access to treatment and care, and to see that they have resonance too for access to prevention. This means re-politicizing the response to the epidemic in a positive way, and seeing clearly the ways in which the progressive biomedicalization of the HIV response in many parts of the world – cloaked in promises of “the end of AIDS” and imminent arrival of “an AIDS-free generation” – too often hides the reality of dramatic “scale-down” in the response to HIV as the world moves on to more pressing problems (climate change, the war on terror, Ebola, choose your favorite...).

Challenges for the future – and for the present

Today, countries in very different parts of the world are prioritizing and implementing HIV prevention policies such as test and treat – an approach that certainly has its importance, especially in settings where HIV has not yet generalized to the population as a whole. In such contexts, with expanded access to HIV testing and effective treatment for those who test positive, it is perhaps in theory possible to turn HIV into a chronic but manageable condition. Such an approach carries important benefits for primary prevention: when people who need treatment are actually being treated, it reduces their viral load, making HIV transmission to others less likely. With political will and an amount of money not that absurd, in principle it should then be possible to control a concentrated epidemic through the use of existing techniques and technologies.

However, it is important to understand that a number of different logics guide this type of strategy. If one of these logics

presents itself as technically reasonable, others may be less benign. Test and treat has also been adopted in a wide range of very different contexts as a cost-effective way to try to sustain HIV programs at a time when more than a decade of HIV scale-up has begun to give way to the contemporary reality of “scale-down.” In countries as different as Brazil and Vietnam, and as international agencies and donors vacate the field, often well-intentioned public health officials and practitioners in the front lines of the struggle for HIV prevention, treatment and care turn to this kind of strategy as a way of guaranteeing the sustainability of a minimal level of HIV service provision. In parallel, they may scale back other undertakings that in many places were largely dependent on external donors in any case: costly behavioral interventions, sometimes controversial community-based approaches, broad-based health education programs, and perhaps worst of all (at least from the perspective of the neoliberal logic that now dominates global AIDS policy almost everywhere), the kinds of structural changes that in the late-1990s and the early 2000s activists and researchers had so insistently called for – changes that could only be achieved with an even more massive influx of resources than was seen during the scale-up of HIV programs that took place in the 2000s.²¹

It should come as no surprise, therefore, that the so-called “AIDS backlash” (in which many from other sectors of the public health and global health fields have begun to question why so much money has been directed to fighting HIV), the new emphasis on



AIDS activists protest at AIDS2014 in Melbourne, Australia.

biomedical approaches to prevention, and the extended global financial crisis that began in 2007 and 2008 that has reduced spending on HIV and on global health more broadly, have coincided historically. Policies and approaches such as test and

²¹ KENWORTHY, Nora; PARKER, Richard, eds., Special issue: HIV scale-up and the politics of global health, *Global Public Health*, Vol. 9, Nos. 1–2, 2014.

<http://dx.doi.org/10.1080/17441692.2014.880727>



Photo by Wagner de Almeida

Social movements have been fighting for protection of their rights

treat “make sense” within this context. They seem reasonable. They appear cost effective. They offer shell-shocked public health officials and practitioners the hope of sustaining what may be most essential in their programs at a time when their budgets are otherwise being cut, and when the international donors who pumped millions into their coffers during the hey-day of HIV scale-up are on the run, seeking other urgent (and perhaps more scientifically “interesting”) problems to solve.

But no matter how technically reasonable such approaches may seem to be, they carry serious risks. On the one hand, these risks may be described as almost “programmatically”: the risk of transforming the response to HIV into a set of seemingly depoliticized biomedical practices and public health procedures – far easier and cheaper to sustain than earlier notions of political and social mobilization and community-led responses aimed at structural change. On the other hand, these risks are also conceptual, and, hence, strategic. To justify programmatic changes emphasizing biomedical approaches and mainstream public health programs, conceptual and analytic advances such as the analysis of vulnerability and the role of inequality as driving the epidemic, are increasingly abandoned.

What used to be described as “vulnerable populations” are nowadays characterized by official agencies as “key

populations” – those at risk of “being left behind.” Rather than encouraging their mobilization for community involvement and political change, key populations now need “targeted” or perhaps more benignly “brought along” through inclusion in well-intended programs that respect the limits of the health-care system and avoid calling for deeper structural change. But the risks here go well beyond those that are solely programmatic or simply conceptual. They travel to the heart of what long ago we came to understand as the third epidemic, reproducing many of its worst aspects. Key populations can too easily be reinterpreted as “risk groups,” and even well-intended efforts to test and treat can easily lead to the intensification of stigma and discrimination. As public health officials seek to identify the individuals and social groups most in “need” of intervention, they unwittingly and unintentionally deny the most basic principles of health and human rights we have fought so hard to articulate.

Obviously, there is no necessary reason why the various risks that identified here must necessarily be played out in this way, with tragic consequences. There is no doubt that to encourage people to be tested can stimulate conscious and informed choice. Where there is the necessary follow-up, adequate counseling, appropriate and accessible services available to people living with HIV, and true protection of their rights as citizens and their dignity as human beings, there is no question

that the risks pointed to can be overcome, with health promotion providing a source of empowerment rather than of stigma and discrimination. But here again, we face a political issue. In order to implement a policy of test and treat that is capable of respecting the most basic human rights, it is necessary first to establish the enabling conditions for the awareness that people must have in order to be able to make empowered and informed choices about their lives. This will only happen when they are able to make decisions not simply to follow a doctor's orders – to do what they are told to do at their local health post, or even by a community outreach worker, but to make conscious choices about testing (and treatment, if necessary) as an **active subject of rights**.

For biomedical prevention to become more than a technocratic directive depends upon the right to health being understood as fundamental to the rights of all citizens. It requires us to learn the lessons that more than 30 years of activist and community-based responses to HIV can teach us if we are interested enough to learn. Like the early treatment activists who organized community fora to discuss new options in the desperate search for effective therapies during the early years of the epidemic, for test and treat policies (and other biomedical responses to the epidemic that have become such a central priority in HIV programs today) to be more than an external imposition on

affected communities, they need to be adequately debated and discussed publicly. They need to be interrogated and endorsed by the populations that they are intended to serve. Only this way can they become part of what has been described as democratic science,²² and a democratic public health, rather than another exercise of compliant governmentality.

Building on the work of organizations such as the Treatment Action Campaign (TAC) or the International Treatment Preparedness Coalition (ITPC), we need to develop new forms of literacy with the communities that are the object of the current biomedical thrust – moving beyond treatment literacy itself in developing a kind of community-based prevention literacy that existed in earlier periods in the history of the epidemic, but which has become increasingly muted as HIV prevention became taken over by public health experts and international agencies.²³ Indeed, ultimately what we must construct is both treatment literacy and prevention literacy (or a **combination treatment/prevention literacy**, if you like) that will retain the best of the past while also embracing prevention more fully as part of the way forward. We also need to understand that implementing the kinds of new approaches and new technologies that are increasingly advocated as the road to success and the key to a world without AIDS will only be possible if we recover, or rediscover, the deep commitment to fundamental human rights rather than the empty sloganeering that seems to have taken over much of the global HIV response.²⁴

In short, for test and treat (or other approaches like it) to become the answer to HIV in the middle of this, the fourth decade of this epidemic, it is necessary for there to be a renewed focus on politics and the political. This will only happen with enhanced collective and community mobilization, itself the consequence of political will. It is necessary too to confront the return of stigma and discrimination and to strengthen the defense of human rights. It is in the political arena that these new battles must be fought, not in the technical field. Technical experts from international agencies and officials from ministries of health can be our allies – and sometimes they already are – but they are not (with rare exceptions) those best placed to do this kind of work. To confront the deepest challenges in this new phase of the epidemic, what is needed is the political effort of those most affected by HIV and, through their efforts, the mobilization of wider societies. In this respect, there remains much work to be done. Contrary to recent global rhetoric, AIDS is nowhere near finished, but the work that needs to be done is work that we know how to do.

Photo by Vagner de Almeida



It's necessary to confront the return of stigma and discrimination

²² EPSTEIN, Steven. Democratic Science: AIDS activism and the contested construction of knowledge. *Socialist Review* 21 (2):35-64, 1991.

²³ HEYWOOD, Mark. South Africa's treatment action campaign: combining law and social mobilization to realize the right to health. *Journal of Human Rights Practice* 1.1 (2009):14-36; MBALI, Mandisa. The Treatment Action Campaign and the history of rights-based, patient-driven HIV/AIDS activism in South Africa. In JONES, Peris; STOKKE, Kristian Stokke, eds., *Democratising development: the*

politics of socio-economic rights in South Africa, Leiden, The Netherlands: Martinus Nijhoff Publishers, pp. 213-44, 2005; CORNWALL, Andrea, and COELHO, Vera Schatten, eds. *Spaces for change?: the politics of citizen participation in new democratic arenas*. Vol. 4. London: Zed Books, 2007.

²⁴ AGGLETON, Peter, and PARKER, Richard. Moving beyond the biomedicalization of the HIV response: implications for community involvement and community leadership among MSM and transgender people. Forthcoming.

International Conference on AIDS reveals disconnect between global policy goals and local realities

Marcela Vieira¹



Photo by Wagner de Almeida

The 20th International Conference of AIDS held in Melbourne, Australia, provided a space for monitoring the advances and challenges of what has been happening in the world in response to the HIV epidemic. ABIA, in partnership with the *Fundación GEP-Group Efecto Positivo* (Argentina) and *ARASA - AIDS and Rights Alliance –for Southern Africa* (South Africa), organized an international dialogue to discuss new global trends of treatment and prevention from the perspective of civil society and communities and populations affected by the epidemic. This dialogue was also supported by ITPC - *International Treatment Preparedness Coalition* that organized the Treatment Access Networking Zone (NWZ), a parallel space in the Global Village used for community-based activities.

The dialogue was attended by Richard Parker, Director and President of ABIA, the Brazilian Interdisciplinary AIDS Association; Marcela Vieira, Coordinator of the Working Group on Intellectual Property from the Brazilian Network for the Integration of Peoples (GTPI/Rebrip) and whose secretariat

works at the headquarters of ABIA; Lorena Di Giano, of the *Fundación GEP* and Coordinator of RedLAM – the Latin American Network for Access to Medicines; Lynette Mabote, of ARASA, and Kajal Bhardwaj, a lawyer and activist from India, as well as militants and members of civil society organizations from different countries. It was developed as part of an agenda of activities developed by Global AIDS Policy Watch (GAPW), supported by HIVOS through a grant to ABIA.

Disconnection of policies and targets adopted by international organizations at the global level in relation to local realities was one of the major concerns identified by the participants. New goals – generally translated into slogans – are commonly advertised during the AIDS Conferences, and this one was no different. The slogan announced this time by UNAIDS was “90-90-90”, that is, 90% of people who have HIV must know their status, 90% of these must be undergoing treatment and, of the people on treatment, 90% should have undetectable viral load. According to UNAIDS, this would mean that 72.9%

¹ Marcela Vieira is Coordinator of the Working Group on Intellectual Property from the Brazilian Network for the Integration of Peoples (GTPI/Rebrip), a network of

organizations working on intellectual property issues, whose Secretariat is based at ABIA, the Brazilian Interdisciplinary AIDS Association, in Rio de Janeiro.

of the entire world population of people living with HIV should have an undetectable viral load in 2020. If these goals are achieved in the coming years, statistical models predict the end of HIV as an epidemic disease by 2030. This would be the long-awaited “end of AIDS.”

These are ambitious targets, reflecting what must be achieved around the world. They are often targets defined in the chill winds of Geneva, without much involvement of communities and people living with HIV/AIDS, or even of the governments of the countries hardest hit by the epidemic. They are, therefore, disconnected from local realities and problems.

In Brazil, for example, a recent report from the same UNAIDS that announced these new targets showed a growth of 11% of infections during the period from 2005 to 2013. One of the main causes was the growth of conservatism in the country. The exclusion of civil society organizations and of the affected communities in the construction of responses to the epidemic is also a contributing factor to the decline in prevention and the increase in the number of infections.

Currently, only 37% of people living with HIV receive antiretroviral treatment. In some regions of the world, such as Eastern Europe, this number is even less (21%). Even if the goal previously set by global agencies to treat 15 million people by 2015 (“15 up to 15”) is achieved, in itself, it is still very far from reflecting what actually needs to be done if the world wishes the end of AIDS.²

But, what does the end of AIDS really mean? The question was asked by the participants of the activity coordinated by

ABIA in the Global Village. It was concluded that the policies and goals defined “from the top down”, without the participation of affected communities and people living with HIV and AIDS, and even national governments, cannot succeed on their own. The new approach seems to be: “with HIV testing of a reasonable contingent of people, funding for treatment, and reaching the maximum number of people with treatment, then there will be, after that, the end of the epidemic.” However, much of the rhetoric on AIDS simply does not reflect the reality. Experience so far shows that without addressing political and social conditions, narrowly biomedical models will not get us anywhere. Moreover one must always respect the human rights of the people who currently live with HIV and AIDS.

Criticism of biomedical methods and legal-political changes

Stigma, discrimination and criminalization of perceived risk behaviors and groups most affected by the epidemic are widely recognized as among the different political and legal factors that act as an obstacle to the full treatment of people living with HIV and AIDS, making the global targets increasingly distant. However, unless these factors are debated with seriousness and eliminated, there will be no end to AIDS.

In spite of this, the 20th International Conference of AIDS revealed a global response to the epidemic in which there is more concern with implementing available biomedical advances for prevention and treatment than confronting the political and legal factors that impede the realization of real advances with respect to HIV and AIDS.

Laws that criminalize sexual behaviors between people of the same sex, sex workers, people who inject drugs, and people living with HIV increase structural violence and push them away from health services. They also prevent these groups from receiving information, guidance, and the full range of services that they need. Discrimination within health systems remains constant, and needs to be urgently addressed by public policies.

The global policies and goals announced in Melbourne will not be enough if the political, legal and social structures that oppress a large proportion of people affected by AIDS are not abolished. Science alone will not lead us to the “end of AIDS”.

New global trends in treatment and prevention

The participants in the conversation held by GAPW/ABIA in the Village about the new global trends in treatment and prevention were cautious with respect to many of the recommendations being made by international agencies.

Photo by Vagner de Almeida



The rhetoric on AIDS simply doesn't reflect reality

² WHO – World Health Organization. HIV/AIDS. Data and Statistics. People receiving antiretroviral therapy. December, 2013. Available at:

<http://www.who.int/hiv/data/en/>.



Photo by Wagner de Almeida

The meeting in the Global Village coordinated by ABIA and partners in Melbourne

In relation to the **pre-exposure prophylaxis (PrEP)** – the use of anti-retroviral drugs for HIV negative people to prevent the infection by HIV – as well as to **“test and treat”** and **treatment as prevention (TasP)** – the use of ARVs for HIV-positive people with normal immunity (CD4) in order to prevent the transmission of the virus – the evaluation of community-based participants on the new options for prevention was that they are welcome. The discussion highlighted, however, that more than 30% of the people who need treatment – not as prevention, but so that they can remain alive – do not have access to medicines. Global AIDS policies should therefore focus on how to make the medicines available to this group, and not only on expanding the treatment as a form of prevention, especially where treatment is already available.

Moreover, important concerns were pointed out with themes such as: (1) the restriction of the autonomy of the citizen in deciding when to initiate the treatment, (2) the mandatory and often non-confidential implementation of testing, and (3) the possible criminalization of the people living with HIV who decide not to initiate treatment as form of prevention of transmission, especially when they present a detectable viral load that is still low enough to not require initiating antiretroviral treatment. There is a great risk of that people living with HIV start to be seen as “threats,” transmitters of the virus and not as people who have rights that must be recognized, respected, assured and protected.

The meeting also emphasized that it is a mistake to bet only on technology as the primary form of prevention. New biomedical approaches to prevention are welcome, but they must consist of a variety of choices at the disposal of individuals, respecting existing diversity among people, whether or not they belong to the groups that are most vulnerable to the epidemic.

Participants highlighted the importance of more carefully analyzing the corporative interests that reinforce an almost exclusive emphasis on the biomedical model in addressing the epidemic. It is necessary to reflect critically about the power of the pharmaceutical industry and the expansion of medicalization. In addition to measures to reduce the price of anti-retroviral medicines, especially second and third line medications that are still inaccessible to the great majority of the people who need them, it is necessary to expand awareness of the measures that governments can adopt to minimize the negative effects of intellectual property protection on access to medicines.

The meeting reinforced the importance of constructing spaces for discussion and public debate among activists and between communities from different countries – one of the key goals that we have identified for Global AIDS Policy Watch as a new initiative that seeks to build transnational networks capable of promoting more effective policy responses to the HIV globally. ■



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