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HIV Testing, Human Rights, and Global AIDS Policy: Exceptionalism and Its Discontents

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Abstract

Two years ago, in May 2007, UNAIDS and WHO issued new guidelines on HIV testing. Prepared to meet the demands of the AIDS pandemic and the prospects of extending the benefits of antiretroviral therapy to regions where such treatment had been all but out of reach, the new guidance was the product of an extended period of sometimes acrimonious controversy both within the two UN agencies and globally. Those pressing for change had argued that a paradigm of testing that had emerged at a time when little could be done for those infected with HIV was inappropriate to the current moment. Those who viewed with skepticism, if not hostility, the claims that current practice and stringent ethical standards had become an impediment to effectively confronting the challenge of AIDS saw in the proposed changes a threat to the bedrock ethical principles of informed consent. In the end, of course, decisions about HIV testing will be taken by nation – states, with the recommendations of international organizations constituting but one element, however important, that will shape policy. Nevertheless, an examination of the history and the dynamics of the recent controversy and its outcome will provide a unique resource to those faced with policy choices; it will also provide a unique opportunity to lay bare the complex and politically charged relationships evolving between public health and human rights.

The Exceptionalist Paradigm Takes Hold

The HIV antibody test first became widely available in industrialized nations in 1985. It was a time of enormous anxiety about the emerging AIDS epidemic. Fear of discrimination, stigma, and social exclusion haunted the communities most at risk for infection. Such fear and the limits of clinical medicine provided the context within which the initial discussions of the ethics of HIV testing took place. While some public health officials urged wide-scale voluntary testing because it might serve as an important adjunct to counseling, as a prod to behavioral change, those who spoke on behalf of groups disproportionately burdened by HIV, especially gay men, saw the practice very differently. For them, it opened the prospect of identifying the already socially vulnerable to added harm (Franklin Judson, personal communication with the author, March 25, 1985; Bayer 1989).

Not only was the test dangerous but, opponents of its use argued, it was unnecessary to public health or clinical medicine. Those who were infected had to change their behavior to prevent transmission. Those who were negative had to change their behavior to protect themselves. Thus the HIV antibody test offered little. The critical thing was counseling. Furthermore, the discovery of a lethal infection, about which nothing could be done, presented the possibility of enormous psychological suffering. Out of the clash between the traditionalist perspective — one that favored routine testing conducted under conventional assumptions of presumed consent — and the viewpoints of those most at risk for the new disease would emerge a set of testing policies that stressed the importance of voluntarism, which underscored the centrality of counseling and embraced confidentiality as a prerequisite for effective programs (CDC 1986).

It was in this context that those who began to speak in the name of ethics and human rights sought to provide guidance, using language that would have a lasting impact on the international discourse on testing. The first major U.S. publication to discuss the ethics of HIV testing underscored the dangers of mandatory HIV testing or of testing that, while being formally voluntary, occurred under coercive contexts (Bayer, Levine, and Wolf 1986). Voluntary testing, in turn, required that individuals be notified that they would be tested, that they be provided with pre-testing counseling to ensure fully informed consent, and that they receive supportive posttest counseling to help interpret the significance of both negative and positive results. Finally, the results of testing, indeed the very fact that one had been tested, had to be kept confidential, not only because of the potential harm resulting from unapproved disclosure but also because the right to privacy had to be protected at all costs. Independently, in the United Kingdom, and reflecting the same impulse to protect the rights of the individual, David Miller and colleagues asserted, “The arguments for ‘routine’ screening are not as logical as they at first appear; at best they confer very limited benefits that can be as easily, if not better achieved, by other approaches. The risks to the individual patient of indiscriminate screening are considerable” (Miller et al. 1986: 943). Importantly, this analysis made clear that a radical change in therapeutic prospects would require a fundamental rethinking of testing: “If a potential vaccine or an effective anti-HTLV-III treatment were to become available the balance would abruptly change to the benefit of the individual” (ibid.).

Against this backdrop the World Health Organization (WHO) Special Programme on AIDS (the precursor to the Global Programme on AIDS) asserted in 1987 that the test for HIV antibodies could not be considered “just another test” (ibid.: 227). To extend the screening from blood donors to asymptomatic individuals and their at-risk partners required careful consideration of a wide host of “social and personal consequences” (ibid.: 226) associated with HIV testing, regardless of an individual’s actual serostatus. Citing the “privacy of the behavior” involved in the disease’s transmission, coupled with the lack of therapeutic options available at the time, the WHO advised that “screening programs must be approached with great caution” (ibid.: 221).

Five years later, the WHO warned about proposals for routine testing that failed to incorporate stringent protections of the principle of consent: “The term ‘routine testing’ is often used to refer to testing that is carried out unless the patient or client expressly refuses — or is conducted without the subject even knowing. When routine testing carries either of these meanings, it represents an approach to testing that does not require pretest counseling and explicit consent. As a form of testing without informed consent, it is ineffective and unethical” (WHO, Global Programme on AIDS 1992: 6).

Thus by 1992 there had emerged a broad international consensus about the ethical and human rights standards that had to govern HIV testing, whether provided in voluntary counseling and testing sites or in the context of clinical practice. This consensus would face increasing challenges from clinicians and public health officials who asserted that the “exceptional” treatment of the HIV test was neither warranted nor desirable (Bayer 1991).

Challenging the Paradigm

Just over a decade after the codification of the WHO’s normative regime for HIV testing the clinical and political context within which those standards had emerged had undergone a radical transformation. The pall of clinical impotence had been shattered. In 1994, the efficacy of AZT in radically reducing the rate of maternal fetal transmission of HIV was demonstrated (Connor et al. 1994). In the mid-1990s, the capacity of anti-retroviral therapy to alter the clinical course of AIDS had transformed the experience of HIV disease in developed nations (Pennisi and Cohen 1996). As important, an international movement had begun to challenge the pricing

structure for those therapeutic agents (Berkman 2001). In light of the prospect of preventing the birth of babies with HIV infection and of extending the lives of the already infected, a new discourse on HIV testing took hold.

At the end of 2001, the WHO convened a consultation to examine ways to rapidly increase access to HIV testing. While it acknowledged the contribution of the voluntary counseling and testing efforts, the consensus was that new approaches were necessary. While emphasizing the continued centrality of informed consent, the consultation concluded that the insistence on one-to-one individual pretest counseling was not an absolute pre-requisite of achieving such consent and that such counseling might in fact prove an impediment to testing. Most striking, the consultation suggested that the unusually elaborate protective regime that the WHO itself had helped shape might have become counterproductive: “It may be that the demanding procedures inherent in the VCT [Voluntary Counseling and Testing] approach may now inadvertently draw a high level of attention to HIV in a way that impedes the ‘normality’ of seeking and accepting HIV testing. Current approaches to voluntary testing may ironically perpetuate the stigma assumed with HIV and HIV testing” (WHO 2001: 4).

A year later, the WHO convened another consultation that issued a report far more insistent on the importance of moving beyond a model of testing that had been the hallmark of the organization’s early efforts: “Important developments in the political, social and care contexts of the epidemic compel the implementation of different, innovative, and expanded approaches to HIV testing” without abandoning the principles of voluntarism, informed consent, and confidentiality (ibid.: 10). Where treatment, but especially antiretroviral therapy, was available, testing had an obvious and essential role to play, but even where such intervention was not available, the knowledge of HIV status was acknowledged as critical in effecting behavioral changes to prevent HIV infection. As a consequence, the report called for the routine offer of HIV testing in clinical care contexts in which patients showed symptoms of AIDS, in antenatal clinics, and in places in which the test could benefit the patient in terms of “improving and managing health care” (ibid.: 17).

Most remarkable was the treatment of the issue of consent. Pretest counseling, so long considered essential to securing fully informed consent, was now replaced by pretest “information.” Further, the exceptionalism that formerly defined the WHO approach was explicitly rejected. In the context of clinical care, the HIV test was no different from any other “invasive test,” and the consent process should resemble that which obtained in the “normal process of consultation between a health care provider and a patient.” A recommendation from a clinician and an assessment of an individual’s readiness for the test would set the stage. If a patient declined to proceed with either the recommended course of action or the test, that preference would be respected (ibid.: 18).

Revealing a divide that would become crucial in years to come, the report noted that while some participants thought that offering patients HIV testing and counseling and providing the option of declining sufficed to meet the demands of informed consent, others believed that patients had to be explicitly asked if they wanted to refuse the test. Indicative of the shift that had occurred, the brief summary of the consultation issued some months later was titled “The Right to Know: New Approaches to HIV Testing and Counselling” (WHO 2003). It was against that right that putatively encumbering approaches to testing had to be judged.

When the WHO AIDS program under Dr. Jim Yong Kim adopted its “3 by 5 program” — with the goal of providing antiretroviral treatment to 3 million people by 2005 — the necessity of radically scaling up testing became an article of faith. In addressing the XV International AIDS Conference in Bangkok in July 2004, Kim declared, “[A] commitment to treatment scale up has allowed us to refine the joint WHO and UNAIDS policy on testing and counseling. With

the possibility of treatment, we feel it is critical to routinely offer testing and counseling in all health care settings” (Kim 2004). The changing perspective of the WHO both reflected and was amplified by increasingly insistent calls for change outside the agency. Because of the role they would ultimately assume in pressing the WHO to shift its position on testing, the views of Kevin De Cock took on special significance.

As early as 1996, De Cock, then a clinician in the United Kingdom, reported that he had been stunned by an encounter with a patient whose HIV-related medical condition had gone undiagnosed despite repeated clinical visits. As a consequence, he began to assert that medical advances in HIV treatment and care, and the failures of the VCT model, demanded a “reassessment of older norms concerning HIV testing. Without this, what was once protection of individual rights may now represent negligent practice and missed opportunities for prevention” (De Cock and Johnson 1998: 293). While underscoring his opposition to compulsory testing, De Cock emphasized the need for routinization. In breaking with the exceptionalist paradigm of HIV testing with its exacting requirements of consent, patients would be informed that they would be tested unless they specifically declined. The “informed right of refusal” was sufficient to meet the ethical demands of consent.

In 2002, De Cock, then working for the U.S. Centers for Disease Control (CDC) in Kenya, authored a frontal critique to those who had sought to frame HIV testing in terms of human rights. Titled “Shadow on the Continent,” it was a stark attempt to change the international terms of discourse for HIV testing. By focusing on potential risks to the individual, the human rights community had rejected testing strategies that might equal the scope of the burgeoning public health crisis posed by AIDS. His own understanding of the mission of public health and his vision of the material claims of social justice framed De Cock’s challenge. Normalizing HIV clinical practice and enhancing access to testing represented a crucial first step toward realizing the rights of “uninfected people to remain HIV negative, of infected individuals to benefit from treatment and prevention advice and of society to reduce the effects of HIV/AIDS” (De Cock, Mbori-Ngacha, and Marum 2002: 69).

De Cock was not alone. Botswana, a country with one of the world’s highest HIV/AIDS burdens, had also attempted to move beyond the exceptionalist stance. At a September 2003 conference in Gaborone that set the new direction, participants, troubled by the poor uptake of VCT in Botswana, discussed the relative advantages and disadvantages of routine testing, including the ability to extend treatment to people at an earlier stage of infection and concerns over the protection of patient autonomy. Given the state of public health emergency in Botswana, routine testing was found to be ethically defensible as long as individual rights were protected and HIV-positive individuals were provided with adequate social and institutional support (Rennie and Behets 2006).

Defending Human Rights

The increasing clamor for change by critics like De Cock — and the implementation of routine testing in Botswana in 2004, followed by that in Lesotho in 2005 — caused alarm among those committed to human rights principles. Cognizant of how far practice in fact diverged from the formal rules of consent, such advocates were especially troubled by the prospect that the universal recognition of the importance of scaling up HIV testing could erode the international regime on testing first established more than a decade earlier.

Striking in this regard were the deliberations and efforts of the UNAIDS Reference Group on HIV and Human Rights (hereafter, UNAIDS Reference Group) — an advisory body composed of experts on, and advocates for, human rights — created in 2002 in the newly established agency that sought to coordinate the efforts of United Nations (UN) groups in the struggle against AIDS. At the broadest level, members of the reference group were adamant in resisting

claims that the issue of HIV testing exposed the inevitable tensions between public health and human rights and that an unyielding commitment to the latter had upended efforts to advance the former. Such assertions cut to the core of the platform that had been painstakingly crafted since the mid-1980s under the aegis of Jonathan Mann and that others saw as his critically important legacy. It was imperative to reemphasize that “the evolving global response to HIV/AIDS continues to [build] on the powerful synergy between public health and human rights” (aUNAIDS Reference Group 2003a: 2). To that end it was essential to amass evidence “to dispel the notion that it is a failure of human rights that has impeded access to testing services while the main issues have been the failure of government to fully implement human rights” (bUNAIDS Reference Group 2004b).

The reference group was also concerned about perceptions that a human rights perspective had fostered the exceptionalist approach to HIV/AIDS, which in turn accounted for the dismal statistical picture on the extent to which people had been tested and made aware of their HIV status. Especially troubling was the notion that it was the insistence on creating a protective context for HIV, treating the HIV test differently from other diagnostic assays, that had contributed to the stigma universally recognized as a barrier to effective clinical and public health efforts. It was rather the persistence of stigma that necessitated such special protections (ibid.: 3).

When in the spring of 2004, after careful deliberations, the UNAIDS Reference Group issued its “Summary Guidance Note on Scaling Up HIV Testing,” its message to the leadership of UNAIDS was clear and simple. While scaling up HIV testing was crucial in light of changing therapeutic prospects, new opportunities could not occasion the undermining of the bedrock principle that testing in all settings required consent. Importantly, the guidance note did not foreclose modifications to what had long been held central: robust pretest counseling that underscored both the risks and benefits of testing and assured that the individual fully appreciated the significance of the test. The Reference Group understood that a vast scaling up of testing was incompatible with such an approach and therefore recognized “the need for innovative and less costly approaches to pretest counseling” (3). Yet the provision of “sufficient information” to ensure informed decision making could not be compromised.

At this juncture, the Reference Group remained formally agnostic on the benefits of approaches that stressed an opt-out approach to consent. This was possible because it had defined the latter so as to render it virtually indistinguishable from the opt-in it was designed to supplant: “A person must be able to opt-in or opt-out of an HIV test with knowledge of the possible consequences, alternate options for care and other services.” Furthermore, individuals must know that a refusal to be tested will have no impact on the quality of care they receive (ibid.). Thus the guidance explicitly rejected any systemic or routine practice of testing where the decision was not based on an explicitly solicited decision.

The Reference Group experienced a modicum of success as it sought, through internal communications over a two-year period, to influence policy at the WHO and UNAIDS. But its members, no strangers to activism, were well aware that they faced a broad challenge to their conception of HIV testing. To confront that challenge it would be necessary to address a much wider audience. Although the Reference Group had determined in 2003 not to respond formally to the publication in the *Lancet* of De Cock’s “Shadow on the Continent,” the substance of which it found profoundly disturbing, it took a collective decision to play a behind-the-scenes role in mobilizing international opinion against the erosion of a firm human rights foundation for HIV testing (bUNAIDS Reference Group 2003b).

What a response might be like was signaled by Sofia Gruskin, the reference group chair and the editor of *Health and Human Rights*, founded by Mann. At the Fifteenth International AIDS

Conference in Bangkok in mid-2004, she spoke out against the position so forcefully articulated by De Cock: “Recent and justifiable interest in scaling up HIV testing has resulted in a discourse that is highly politicized and that once again appears to be pitting public health goals against human rights norms. We must not allow public health and human rights to be framed as diverging concepts” (Gruskin 2004: 100). As the Reference Group had repeatedly asserted, the routine *offering* of HIV testing had to be radically distinguished from an opt-in or opt-out approach that entailed routine *imposition*. Nothing that subverted the voluntariness of testing would be acceptable from the perspective of human rights, nor would it prove effective public health practice. To those who had argued that changed clinical prospects and the history of voluntary counseling and testing dictated the need to move beyond the VCT model, Gruskin replied, “Public health workers have a legal obligation not to undercut human rights unless there is established evidence of significant public health gains: in relation to HIV testing no such evidence exists” (ibid.: 103). The focus on the evidentiary bases for asserting that rights-limiting approaches were imperative and the assertion that the burden of establishing that proof rested with those who would “restrict human rights in any way” would emerge as a constant refrain over the next two years (ibid.: 101).

To provide a public platform for Reference Group members, Gruskin opened the pages of her journal to a special symposium on HIV testing. Among the contributors were Daniel Tarantola, who was a close colleague of Mann’s at the WHO, Ruth Macklin, a prominent American bioethicist, and Mark Heywood, the head of the AIDS Law Project in South Africa and a leader of that nation’s Treatment Action Campaign. Turning arguments about HIV exceptionalism on their head, Heywood (2005:16) asserted, “I believe that, instead of arguing that the requirement of informed consent has been raised to an unjustifiably high level for HIV care (‘AIDS exceptionalism’), we should assert it has been tolerated at a low level for other communicable diseases, including tuberculosis.” The human rights paradigm that had taken hold in the context of AIDS should provide an exemplar for public health practice more generally. Finally, Heywood warned against the potential consequences for human rights if those armed with “beneficent” intent trifled with the rights of the less powerful: “From a human rights perspective, routine testing also carries the risks of becoming a war on ‘vulnerable groups’ — and later on, people with HIV — who must be identified so that the state ‘can help them’ (allegedly). This is paternalistic and coercive; and if the objective is improved HIV prevention and treatment, then routine testing will most certainly fail” (ibid.: 18).

To be sure, some in the human rights community had begun to see the issue differently. Most notable was Justice Edwin Cameron of South Africa’s Supreme Court of Appeal, who as an attorney, a gay man with HIV, and a judge had assumed a global role as an advocate of the rights of people with HIV. Faced with a catastrophic epidemic in a nation in which profound stigma and inexplicable political resistance to the provision of antiretroviral therapy had shaped the course of AIDS, Cameron (2006) chose to break with what he defined as the hobbling impact of exceptionalism. It was, he argued publicly, time to “normalize testing”: “The exceptionalism of AIDS, which was designed to protect those with HIV, now constitutes a source of risk and harm. The fuss and bother that surrounds HIV testing in healthcare settings where treatment is available constitutes an additional source of fear and inhibition for those with HIV and those who fear they have it, and reinforces their own conception of the exceptional, horrific and unacceptable nature of the infection.” If treatment was available, the consequence of diagnosis did not result in discrimination and ostracism, and confidentiality was assured, then HIV testing should be incorporated as a normal component of medical treatment.

The Birth Pangs of a New WHO Paradigm

Despite the appearance of dissenting views in the human rights community, it should come as little surprise that when De Cock assumed his role of the director of the HIV/AIDS Department of WHO in April 2006, he faced a wall of resistance as he tried to move swiftly to place his imprint on global HIV testing policy. This was all the more important since he believed that earlier pronouncements by the WHO on the need to forge a new approach to testing had been buried by time and lackluster performance and that the agency was in fact behind the curve given developments in Botswana and Lesotho (De Cock, interview with the author, Geneva, July 31, 2007). It would take more than a year to issue a new WHO guidance, and what emerged differed markedly from what might have been expected given the clarion call that first appeared in the *Lancet* in 2002.

By June, a draft document titled “Provider — Initiated HIV Testing and Counseling in Clinical Settings: Operational Recommendations” had been prepared by the WHO staff (WHO, UNAIDS 2006b). Crucial was the emphasis on clinicians’ obligation to initiate the testing process, which differed from the earlier focus on an approach that relied on individuals requesting an HIV test. From that point forward, the phrase “Provider-Initiated Testing and Counseling” (PITC) anchored discussions. Importantly but not surprisingly, given earlier discussion and the emerging consensus, the document spoke of pretest information rather than counseling.

But the draft also reflected De Cock’s perspective. Relatively little attention was paid to the human rights framework that had dominated earlier WHO and UNAIDS statements. On the all-important issue of consent, the draft returned to language of a “right to decline,” first used in 2002 by the WHO. Finally, in a significant departure from earlier statements issued by the WHO and UNAIDS, the new recommendations did not require that antiretroviral therapy be available before the initiation of routine testing.

This initial draft, which even De Cock later described as “not very good,” met with a hostile reception both within the WHO and UNAIDS and from the wider international community (De Cock, interview, July 31, 2007). At a closed consultation held in early July, those who came from Asia, where the language of routine testing was viewed as a cover for mandatory approaches, were clearly alarmed (WHO, UNAIDS 2006d). They and others charged that by shifting the burden to patients to decline testing, especially given the power imbalances that perforce define the clinical setting, the new guidelines would in effect deprive individuals of the right to choose.

Concerned by the limits of the initial draft and by the response it had provoked, De Cock called on a senior WHO colleague, Ian Grubb, a human rights advocate, to begin the process of redrafting the guidance. Grubb made clear to De Cock his discomfort with the failure to link testing to the availability of antiretrovirals. More stunning was his attitude toward the shift to an opt-out approach to consent. In a memorandum to De Cock on September 19, 2006, he wrote, “I confess I am still struggling with the notion [that the right to decline is the equivalent of informed consent]. ... This is not consistent with human rights norms as they have usually been understood. Indeed the assertions in the document that the guidelines for adults are consistent with a ‘human rights approach’ to me ring somewhat hollow and betray a lack of real understanding about what that really means.” Despite the gulf that initially separated them, Grubb and De Cock, each of whom recognized the importance of calling on the other’s expert knowledge and political skill, were able to forge an effective collaboration over the year-long drafting process.

The next iteration of the guidance, in October, sought to clarify matters that had seemed confusing or needlessly provocative in the earlier draft. More care was taken in defining the

epidemiological contexts within which the guidance was calling for a radically scaled-up approach to testing. In response to concerns that the term *routine testing* could imply testing without consent, the document now spoke of “routinely recommended testing.” In an obvious attempt to defuse the dispute unleashed by the June draft’s effort to define informed consent as the equivalent of the “right to decline,” the new version simply noted that health care professionals had an obligation to “obtain informed consent without coercion” and that patients had a right to decline an HIV test just as they could refuse any diagnostic intervention. Indeed, the issue of consent was almost buried in an extensive discussion of an “enabling environment” that addressed issues of stigma and discrimination. Nevertheless, in rejecting a proposal to employ the term *routine offer*, the document underscored its commitment to a fundamental shift: “Guidance from health care providers is not neutral but *recommends* HIV” testing (WHO, UNAIDS 2006a).

If the authors of the revised draft had hoped to begin building consensus they would soon discover the depths of opposition their initiative had sparked in human rights circles. Confidentially circulated in the Geneva offices of UNAIDS and the WHO, as well as in WHO regional offices, the draft met with hostility. A senior official in Geneva, especially concerned about the rights of women, challenged the assertion that the new recommendations represented no departure from an earlier testing policy statement issued by the WHO and UNAIDS. Challenging efforts to claim pedigree for the effort shepherded by De Cock, the critique asserted, “Certainly there is a perception out there that WHO has changed its policy. ... This is not something that can be fudged” (Isabelle DeZoysa to Donna Higgins, October 25, 2006, unpublished memorandum).

Far sharper words were to come from the WHO/EURO, which reflected concerns not only of the liberal democracies of Western Europe but also of the former communist states of Eastern Europe and the former Soviet Union. Warning that good public health intentions could lead to abuse and failure, the critique stated, “We therefore would like to caution about a hasty process that may lead to unprecedented, unintended negative consequences both technical and political.” Against a backdrop of inadequate treatment in Eastern Europe and a trend toward criminal persecutions for HIV transmission, the WHO/EURO saw in the new testing proposal a gateway to compulsion: “Routinely recommended HIV testing might become a mandatory one in [the] context of Eastern Europe, I am afraid” (WHO Euro Regional Office to WHO Geneva headquarters, comments on October 10, 2006, PITC draft; document in possession of author, October 27, 2006).

On November 27, 2006, nearly six months after the initial consultation, the WHO and UNAIDS released a draft of the guidelines for public comment for the first time. Citing the barriers to the increased uptake of VCT services and invoking the successful adoption of the opt-out model by Botswana, Kenya, and most recently the United States, the November draft embraced an opt-out approach to consent in that tests would be routinely performed on every patient unless the patient expressly declined. Notably, the guidance also recommended HIV screening “for all women of unknown HIV status in labor or, if this is not feasible, shortly after delivery” (WHO, UNAIDS 2006c: 23).

In response to the concerns raised by the WHO/EURO office and others who had warned that the language of routine testing would open the way to compulsion in practice, the November draft employed the terminology of “HIV screening.” To underscore the rights of the patient, the guidance carefully noted the importance of a “supportive policy and legal framework” that would “put in place protections against compulsory testing and unauthorized disclosure” and would “mitigate the potential negative outcomes of knowing one’s status” (ibid.: 29). Stressing the importance of a “minimum set” of HIV-related prevention, treatment, care, and support services, the November draft reiterated that “access to antiretroviral therapy should not be an

absolute prerequisite” for the expansion of testing. While the draft prescribed no definitive schedule for achieving universal access to treatment, it was important that there be a national “plan” for its eventual attainment (ibid.: 31).

The WHO and UNAIDS received 150 responses to the draft guidance from a broad range of international health and intergovernmental agencies, academic institutions, governmental and nongovernmental organizations, and unaffiliated respondents. While the number of responses was lower than may have been expected given the stakes involved, they further emphasized the gulf between the perspectives of those whose views were shaped by human rights and the leadership of the WHO/HIV AIDS Department.

The response of the UNAIDS Reference Group built on its earlier assertion that the distinction between opt-in and opt-out approaches was false and misleading: “Whether one characterizes the decision as ‘opting in’ or ‘opting out,’ the ultimate decider as to whether the HIV test will be performed or not in both client-initiated and provider-initiated testing is the individual” (aUNAIDS Reference Group 2007a: 2). In eviscerating the difference between opt-in and opt-out approaches, and thereby putting the issue of consent at the center of the conversation, the Reference Group attempted to weaken the WHO’s argument for a more fundamental shift in testing strategies toward a model perceived as profoundly threatening to human rights principles.

Reiterating its commitment to voluntary testing and counseling as the only approach to testing that truly preserved the principle of informed and voluntary consent, the Reference Group also objected to the implication that “VCT in itself is a limitation” and suggested that the “barriers to increase the uptake of testing should be more clearly identified, as well as the necessary actions to address them. ... These barriers are, however, not applicable to VCT only, but also to Provider Initiated Testing and Counseling and HIV testing in general” (ibid.: 2). Furthermore, the adoption of the term *HIV screening* in the document raised red flags for the Reference Group, which argued that it “does not make sense either from a public health or a human rights perspective in the way the guidelines use it and raises more problems than the ‘routinely offered’ terminology. ... It only states that people will be tested, but fails to mention the voluntariness of the test” (ibid.: 3). The concerns over the use of *screening* was not merely a terminological quibble, for it highlighted to the Reference Group and many others what they considered the more systemic failure of the new draft proposals to outline measures to ensure noncoercive consent and to maintain human rights standards.

The Open Society Institute (OSI) critique — authored by Ralf Jurgens, a longtime AIDS policy activist — was designed to and in fact did serve as a template for nongovernmental organizations (NGOs) around the world. Painstakingly detailed and embracing an array of issues that had come to define the human rights perspective on the new testing paradigm, the OSI statement especially emphasized the difficulty a patient would experience if he or she wanted to decline a doctor’s offer of an HIV test. In language not too dissimilar from that used earlier in the debates around testing, it stressed the possibility of a slide into coercive contexts of “choice” (Jurgens 2006).

An enduring concern about how stigma, discrimination, and violence defined the lives of people with HIV also informed the opposition to the effort to normalize HIV testing. And here the November draft was found especially wanting by its critics. Suggestions in the text that the empirical basis for such concerns was less than compelling provoked a sense of ire. The Global Network of People Living with HIV/AIDS (GNP+) thus asserted, “On the one hand, it is acknowledged as a serious issue that can affect people who receive a positive test; on the other hand it is dismissed because of lack of evidence” (qtd. in WHO 2007: 13). Especially provocative was what appeared to be the minimization of the pervasiveness of the threat of

violence, a matter of grave significance particularly for women. Any new guideline, said CARE International, “needs to consider the gender dimensions and women’s ability to protect themselves” (qtd. *ibid.*: 32).

Notably, on the charged question of whether ethical and human rights concerns dictated access to antiretroviral therapy as a necessary precondition for scaling up testing, there was no consensus among those otherwise united in opposition to what the WHO and UNAIDS had proposed. While some could accept the notion of a “progressive realization” of the right to care, others insisted that the logic of testing scale-up was predicated on the availability of such treatment (qtd. *ibid.*: 27, 50). In the absence of accessible antiretroviral therapy, there was no justification for pressing the case for increased testing.

In the end, what the public response to the November draft made clear was the extent to which the issue of testing had crystallized a fundamental disagreement over the extent to which the exceptionalism that had taken hold in the years of the AIDS epidemic should continue to inform responses of the global community. Furthermore, it underscored a deep fissure over the extent to which long-held beliefs about the manner in which human rights considerations should provide the foundations for thinking about public health policy. In the aftermath of the formal response period to the November draft, a question remained of whether the leadership of the WHO, and others who believed that the current stage of the AIDS epidemic demanded a new paradigm for HIV testing, would manage to craft a guidance that would foster such changes without precipitating a politically costly public rupture between those who spoke in the name of public health and those who viewed the global epidemic through the lens of human rights. What compromises would prove necessary to preserve the appearance of an unbroken bond? Would linguistic common ground merely paper over basic and irreconcilable differences?

As the WHO sought to move forward toward a final draft, the tensions that had played out over the previous six months reemerged. First was the question of what would count as consent to testing. De Cock knew that terms that had emerged as battle posts needed to be avoided. He recognized, for example, that the language of “opting out” and “opting in,” which he had hoped would capture the changes he sought, had become inflammatory. Confusion remained — or had been created — where he believed he had offered clarity. Nevertheless, he concluded that “we should avoid their use as far as possible. This will require careful language crafting.” Yet initially De Cock wanted to yield only on the matter of words; he was reluctant to give up on what had been his central position since his first calls for change a decade earlier. In rejecting proposals that he reconsider proposing that HIV tests be “routinely offered” — “It is too vague and not different from where we were before this process started” — he underscored what remained for him nonnegotiable: “Whatever the terminology, it needs to lead to testing being conducted unless the patient declines. ... This is probably the key issue in this whole discussion” (De Cock 2007).

The drafting period had also made clear to De Cock and his closest advisers that for strategic reasons he needed to distance himself from the U.S. CDC, for which he had worked, and from their own new recommendations on routine opt-out testing issued in September 2006. Their substance, with which De Cock largely agreed, and their provenance sounded alarms within the WHO. “Here,” said De Cock, “there is a lot of sensitivity about undue American influence” (interview, July 31, 2007).

An Enduring Conflict?

On May 30, 2007, the WHO and UNAIDS released their final version of the guidance to the global community (see WHO, UNAIDS 2007). Over the six months since the draft had first become available for public comment, the guidance had been altered to meet the concerns of its more vociferous critics both within the WHO and UNAIDS and internationally. While the

guidance still recommended — under appropriate epidemiological conditions — an opt-out model, it conceded the potential need for an opt-in approach for “ ‘highly vulnerable’ populations ... those most at risk for HIV transmission” (ibid.: 25). Such exceptions might constitute a significant proportion of those to whom the massive scale-up was directed. Furthermore, the final recommendations all but eroded the distinction between opting in and opting out that had been so central to De Cock’s effort to transform the context of choice regarding testing. Using an argument first put forward by the UNAIDS Reference Group in its critique on an earlier draft, the new document stated, “Whether patients ‘opt-in’ or ‘opt-out,’ the end results should be the same: an informed decision by the patient to accept or decline the health care provider’s recommendation of an HIV test” (ibid.: 20).

But in eviscerating the distinction between the two, the guidance was not merely engaging in an act of linguistic compromise. More had been yielded by De Cock and those who first championed the idea of the abandonment of the exceptionalist paradigm. The final recommendations gave far greater attention to delineating the minimum requirements for pretest information. Indeed, if the effort to eliminate the distinction between opting in and opting out appeared to signal a linguistic retreat for De Cock, the extensive pretest information proposed entailed a substantive one. In the discussion of what constituted an “enabling environment,” gender concerns were at the forefront. In considering the importance of a robust social, legal, and policy framework, the final document asserted that the “optimal delivery of Provider Initiated Testing and Counseling in the long term requires that laws and policies against discrimination on the basis of HIV status, risk behavior and gender are in place, monitored and enforced” (ibid.: 9).

And so in May 2007, De Cock had, after more than a year of debate, the new guidance he had sought since his arrival at the WHO in April 2006. De Cock was loath to acknowledge that the compromises he had been compelled to make represented a fundamental departure from the vision he had long advocated. Referring back to the London AIDS case that had so sparked his ire because of neglect, he stated, “I do not know if [that] patient would be less likely to slip through the net the way he did in 1996, but it would be far less likely in Africa than it used to be” (personal communication, January 30, 2009). A senior associate at the WHO had a less sanguine view: “He got the document but lost all the battles” (Ian Grubb, interview by the author, Geneva, May 2007).

The extent to which such compromises might have moved the global community beyond the divisive battles that had emerged years before the WHO had entered the fray was signaled in an editorial in the *Lancet*. Sofia Gruskin and Daniel Tarantola (2007), who as members of the UNAIDS Reference Group had been sharp critics of what they saw as a threat to the principle of consent, expressed cautious but general approval of the new guidance, which they saw as superior on ethical grounds to what the CDC had recommended.

But others were not so satisfied. Human Rights Watch (2007), which had persistently criticized De Cock and his efforts at the WHO, asserted in a press release on the day the new guidance was issued, “WHO and UNAIDS must do more than offer specific guidelines about testing and vague calls for better policy and legal frameworks. ... Expanding access to HIV testing is important. But it will only work alongside better prevention and treatment efforts, and an end to stigma against people living with HIV.”

The full fury of those who saw in the carefully crafted language of the new recommendations a subterfuge masking the erosion of rights was made clear at the International AIDS Society’s July 2007 meeting in Sydney, Australia. Michael Kirby, a justice of the High Court of Appeal in Australia, a longtime proponent of human rights, and a member of the UNAIDS Reference Group offered a searing denunciation: “The fundamental notion of health care ethics ...

demands affirmative patient consent to significant medical procedures. ... This is an individual right. It is not the privilege of health care workers to waive for the patient on the basis that ‘nanny knows best!’ ” The challenges of HIV testing will not be resolved, concluded Kirby “by embracing weasel words and ambiguous texts that pretend to endorse patient consent to HIV testing while in truth we impose mandatory testing on highly vulnerable people.” The International Community of Women Living with HIV and AIDS was equally scathing: “We behave like HIV testing evangelists. We want to push it ... even if we know that it can be harmful ... that it’s not going to work, that it’s not addressing the issues at hand” (Mthembu 2007).

If such denunciations might have been anticipated from those who had long made clear their opposition to tampering with the rights-based stance that had informed the exceptionalist perspective, a more stunning reversal came from an unexpected source. In September 2007, the UNAIDS Reference Group, which had in the past never publicly disagreed with a policy initiative of its parent organization, did so in its analysis of the HIV testing guidance issued four months earlier (UNAIDS Reference Group 2007b). Without the sharp language used by other human rights proponents, it made clear its fundamental disagreement with what had been released to the global community. In terms no different from those it had used in its intrainstitutional communications during the nearly year-long drafting process, the reference group declared that it “remained concerned that the adaptation of an ‘opt-out’ approach to testing ... may in practice result in a greater number of people being tested without their informed and voluntary consent” (ibid.: 3). Thus, as the first of its twelve recommendations, it urged nations as a first-line strategy to consider the adoption of an opt-in approach.

Conclusion

The encounter that preceded the issuance of the WHO and UNAIDS HIV testing guidance in May 2007 at times took on the quality of shadow boxing, and on other occasions it resembled hand-to-hand combat. Those locked in controversy struggled over who had claim to the terms that each sought to appropriate. *Testing*, *screening*, *routinization*, and *consent* became terms of fierce debate. While the arguments could assume technical or legalistic dimensions, they were almost always in fact about who would have the authority to employ them and to what ends. Even ambiguity, often the target of critique, could be strategically employed to redefine the terrain of controversy.

On the most fundamental level, however, the struggle that crystallized around HIV testing asked whether a human rights perspective informed by an exacting conception of individual rights should prevail over one in which the claims of public health could legitimately impose limits on consent. Too often the question was framed in terms of whether a particular approach to testing would prove more efficient and less labor intensive. And while such considerations were not unimportant, they were secondary. Of far greater significance was the question of whether prevailing consent requirements represented an impediment to the pursuit of the public health goal of arresting the HIV epidemic. Typically proponents of changing the human rights – informed regime on testing believed and asserted that an approach that assumed consent unless an individual declined would make it easier to say “yes”; that by making testing the default option individuals who might both for social reasons (fear of stigma and violence) and for psychological ones (fear of receiving a cruel diagnosis) fear opting in would be empowered to choose a course they indeed wanted to pursue. Less commonly articulated, but equally important, were assumptions about the extent to which the current context of the global HIV epidemic dictated the necessity of policies that would make it more difficult to say “no.” From that perspective it was in the interest of those with HIV infection to know their diagnosis because of the potential for their own clinical benefit. To such explicitly paternalistic reasons were added assumptions about how an increase in the number of people tested would increase

the proportion of those with HIV who knew their status. That would, in turn, enhance the prospect of a behavioral change so central to the public health duty to interrupt the transmission of HIV.

Very different was the outlook of those who came to the HIV testing controversy with human rights commitments. From that perspective only individuals had the moral authority to determine what was in their own best interest. Hence paternalistic justifications for making it more difficult to say “no” were, in principle, unacceptable, demeaning at best, and even oppressive. On the questions of whether a new approach to testing was necessary to empower those who might otherwise prove too fearful to consent to testing, or of whether making it more difficult to say “no” could be justified on standard public health grounds, human rights proponents typically demanded a level of proof that they believed simply did not exist.

When rights might be compromised, a heavy burden fell to those proposing new policies. And here to the deep substantive divide between the two camps was added a critical procedural disagreement about who bore the burden of proof, about what criteria should be used to measure the available evidence, and about what to do in the face of uncertainty. Those who believed that demanding requirements of informed consent represented a barrier to effective clinical and public health intervention had concluded the existence of a sufficient empirical basis for changing policy. The burden of proof fell to those who sought to preserve as preeminent an exacting conception of informed consent. Given the epidemic’s toll, whatever uncertainty there was had to be resolved in favor of an approach that might radically scale up HIV testing.

Underscored here was the fact that an enduring tension had emerged in the global response to HIV. If at the moment of its emergence the exceptionalist perspective had provided an almost universally accepted understanding of what the new global threat to health required, twenty years later, in the face of changing therapeutic prospects and of a vast pandemic burden, the earlier view no longer commanded such allegiance. Where there had been broad consensus, there was now disagreement, and no effort to resolve the challenge by repeated denials of tension between public health and human rights could turn back the clock. What this means for international policies on HIV and AIDS and for the broader questions posed by the health and human rights movement remains to be seen.

Envoi

In January 2009, Kevin De Cock joined colleagues in publishing a remarkable challenge to the global community. Based on mathematical modeling (Granich et al. 2009), the *Lancet* article proposed the possibility of eradicating HIV in nations heavily burdened by the disease. What would be required was repeated, universal testing and the provision of antiretroviral therapy to all infected persons. While framed in technical terms, the article underscored the kind of vast transformation that would be required in the HIV testing regime if such a dramatic global campaign were to be undertaken. These were transformations only intimated in the earlier debates that had surfaced at the WHO.

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