Treatment Refusal = Criminal?

June 12, 2011 By Sean Strub

I was pleased to have the chance to speak at the Global AIDS Treatment rally at Dag Hammarskjold Plaza, in front of the United Nations, last Wednesday, June 8, in New York City. The rally was organized by Health Gap, Housing Works and other organizations fighting for treatment choice and access for every person with HIV, an effort I fully support.

Here is an extended version of my comments (I only was able to deliver about half of this at the rally).

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A continuing disregard and trampling of the human rights of people with HIV drives this epidemic and until we recognize and address this fact, we will not defeat AIDS. This is no more clearly evident than in the fact that HIV-related stigma is today increasing, not decreasing.

In 1983, the revolutionary Denver Principles manifesto began with a defiant statement that reverberated powerfully throughout the intervening plague years: "*We condemn attempts to label us as 'victims,' a term that implies defeat, and we are only occasionally 'patients,' a term that implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'*

What those early activists did not articulate, and probably could not have imagined, was that the label we would need to fight against three decades later is that of *criminal*.

Sadly, the US is a global leader in HIV criminalization, exporting intolerance, ignorance and legal retribution around the world. Criminalization creates a viral underclass in the law, which treats people with HIV differently for behavior that, for those who do not have HIV, is unremarkable.

In Texas a man is serving 35 years for spitting at a cop; In Iowa a young man was sentenced to 25 years in prison for having sex *with* a condom, while his viral load was undetectable.

A woman in Georgia got 8 years for failing to disclose her status, despite the fact that it had been published on the front page of her local paper and two witnesses claimed she had disclosed.

There are hundreds of these cases and it continues to get worse. Just two weeks ago, the Nebraska legislature passed a bill that makes it a felony for people with HIV to sneeze or vomit in the vicinity of a public safety officer.

There is no more extreme manifestation of stigma than when government incorporates discrimination into the law, like with Jim Crow laws, or apartheid, or criminalizing people with HIV.

These laws are driven by a political and public policy leadership, abetted by the media,

that increasingly, insultingly and irrationally defines people with HIV principally as *viral vectors* or *potential infectors*, as a *dangerous population*, a *threat* to society that must be regulated and controlled.

This is not just in criminal prosecutions but it is also seen in HIV prevention and treatment policy-making that is veering towards the coercive, abandoning respect for individual autonomy and opening the door to tyranny, paternalistic or otherwise.

It is vital for all of us to understand how anti-retroviral treatment can reduce one's infectiousness, or provide some protection against infection for those who are negative.

That fact, for many is reason enough to start treatment, including some who do not medically need treatment for themselves, like those with high CD4 counts.

But it is wrong for anyone to assume *everyone* who has HIV "should" be on treatment in order to reduce infectiousness.

To encourage healthier HIV positive people--those with high CD4 counts for whom it has *not yet been proven will receive a net benefit* from anti-retroviral treatment--to commence treatment *while downplaying or disregarding the risks of serious long-term side effects* is unethical and dangerous.

So while we advocate for treatment to be made available to all who need it, including the millions who will die in the next few years if they do not get it, we must also make sure that ethical challenges inherent in so-called "test and treat"--promoting treatment for a public health objective, at the potential expense of the individual person with HIV--are addressed.

The Associate Director of the CDC, Harold Jaffe, says it is not clear that *"test and treat" "benefits the infected people themselves and indeed it may be harmful".* He notes that test and treat *"falls foul of the normal ethical standards of clinical medicine, which is to act in the best interests of patients."*

Writing about test and treat, the Economist noted *"people do not like taking medicine, particularly if they have no symptoms."*

For test and treat to achieve the desired societal benefit, they write, *"all those people, or, at least, the vast majority of them, would have to be persuaded to take (anti-retroviral drugs). That is difficult enough when someone is ill. The latest report from UNAIDS suggests that almost one in five of those put on the drugs stops taking them within a year. It will be even harder to persuade the asymptomatic to pop a daily pill or two for the public good."*

An avalanche of funding has provided an army of strategists and publicists to work with public health and community organizations to promote treatment to those for whom there is no scientific justification for such treatment. That is appalling, especially when only 1/3 of those in *immediate* medical need of treatment are able to get it.

We must never forget harms that have been perpetrated in the name of a supposed public good

and we must not, even inadvertently, contribute to those harms.

If we respect individual autonomy, we must provide objective information about both the potential rewards and risks of treatment without creating a false sense of urgency or need. To do otherwise is profoundly unethical.

Pioneering AIDS doctor Joseph Sonnabend, wrote last week that *"Respect for the autonomy of the individual may be the most important of the principles that form the foundation of medical ethics."*

John Christman described an attribute of personal autonomy as: *"the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces."*

The Economist noted test and treat will require a very high level of participation in order for it to work. What if too few agree to participate for it to be effective?

Do those of us with HIV present enough of a public health danger to trigger the use of legal mechanisms to intervene and force us to take treatment against our will?

There *are* times when we, as a society, impose medical treatment on some citizens, even against their will. We do that with criminals.

Might those who refuse treatment for the "common good" ultimately be considered criminals? Will they be seen as socially irresponsible, labeled enemies of society, selfish or unconcerned about spreading HIV? Have we begun to stigmatize those who, for whatever reason, have chosen not to take treatment?

NAM's newsletter asked the question bluntly: *"How long will it be before legislators--or judges--conclude that failing to take available treatment should be considered as contributory negligence in cases of HIV transmission or exposure?"*

Defining those of us with HIV as a threat to society and manipulating or coercing us into treatment, rather than empowering us to access healthcare and make well-informed treatment decisions for ourselves, is a dangerous threat to our rights.

Moreover, it will continue to fuel the epidemic, further disenfranchise the most at-risk populations and erode trust in the healthcare system, making people at risk *less likely* to get tested and, for those who need or want it, *less likely* to access treatment.

We are not criminals and we do not consent to coercion.

Another important section of the Denver Principles reads that people with HIV have the right *"To full explanation of all medical procedures and risks (and) to choose or refuse their treatment modalities."*

We must be vigilant against a creeping criminalization of our existence, be vigilant against those will sacrifice our human rights at the altar of a perceived public good, and to be vigilant against the "*arrogance of the well*“ that operates from an unstated but clear belief that we--those of us living with HIV--are ”*less than*"; are inferior beings with inferior rights to their arrogant supremacy.
