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Health Emergencies: Are Human Rights Funders Prepared?

Monday, July 21, 2008, 1:30 – 3:00pm

Facilitator:
Françoise Girard, Open Society Institute

Panelists:
Tawanda Mutasah, Executive Director, OSI Initiative for Southern Africa
Joe Amon, Director, HIV/AIDS & Human Rights Program, Human Rights Watch

Session Organizer:
Jonathan Cohen & Tamar Ezer, Open Society Institute

FG asked whether there are times in health emergencies (drug-resistant TB sweeping across Southern Africa, pandemic bird flu breaking out in China and starting to spread across Asia, HIV prevalence reaching 40% of the adult population in Swaziland) when it is permissible for governments to isolate individuals and restrict certain liberties?

JA first said that the criteria for an "emergency" must be examined: are these really crises or long-neglected endemic diseases? Disease threats are often defined as emergencies by politicians not public health experts, and the nature of what restrictions on liberties are permissible is often a function of this poorly defined (and with new emerging disease poorly understood), and insufficiently debated, question of whether or not a true emergency exists. He then highlighted the criteria set out in the Siracusa Principles, that must be met in considering restrictions on liberties: Is there a legal framework for identifying how restrictions on liberty will be put in place? Is there a process of oversight and due process? Is there a sense of proportionality of the risk vis a vis the severity of the measure taken to address it? Is this the least restrictive response? Have voluntary measures been considered? Moreover, it is critical to examine the nature of the particular disease: How dangerous is the disease? What are the dynamics of transmission? Are all groups equally at risk? What groups are affected, susceptible?

FG asked how such consideration would play out in the context of TB and HIV.

JA responded that unlike HIV, TB can be transmitted through casual contact. It is thus more legitimate to consider isolation of TB patients than HIV-positive individuals. However, for TB infection to occur, contact must be close and prolonged amidst poor ventilation. Additionally, as seen in Africa, a compromised immune system facilitates TB transmission. Moreover, 90% of those with TB have latent infections that do not affect their health and are not contagious.

FG asked about laws criminalizing HIV transmission in Africa and the applicability of human rights principles to assessing them.

TM responded that this is not just an African phenomenon; laws criminalizing HIV transmission are also on the books in Europe (Sweden, Netherlands, Finland, UK). The Siracusa Principles stress the importance of taking the least restrictive measure in response to disease. Moreover, measures must be based on scientific evidence regarding their efficacy. There is no evidence that criminalizing HIV transmission will reduce HIV transmission, and it may even worsen the problem by keeping people away from needed services. Restrictions in the name of public health must also meet the legality criteria: the law must be generally applicable, open to appeal, and judicially-administered. The criminalization laws already target a particular group, those who are HIV positive. It should not be all or nothing, but about proportionality and identifying the level of restriction really needed to achieve the public health objective in its particular context. Criminalization legislation ignores this proportionality and the need for nuanced responses.

JA pointed out that people are willing to engage in voluntary measures such as social distancing or home isolation during legitimate health crises. Rather than take the restrictive extremist approach, appealing for voluntary measures can lead to success from a public health perspective, whereas quarantine and more restrictive measures can be disastrous because people resist them. When SARS broke out in Beijing, there was a rumor that the entire city was going to be placed in quarantine. As a result, 245,000 migrant workers fled the city overnight.

TM added that implementing less restrictive measures does not mean that a problem is not taken seriously. He stressed the importance of an appropriate, ethical, rights-based response to the crisis and the need to train judges, lawyers, and medical authorities on the Siracusa Principles to assess the impact of policies and their fit with objectives.

JA cautioned against adopting knee-jerk responses just to appear to be doing something. These bear little relation to public health goals and tend to be the harshest and most restrictive.

FG referred to reports of TB confinement in South Africa leading to riots and people escaping hospitals due to intolerable conditions. She also raised the point that since infection control is not in place in a lot of hospitals, patients may actually contract XDR-TB while they are there receiving treatment for basic TB or other diseases. Health workers in these hospitals are also at risk.

JA explained that some of the South Africa discussions refer to the situation in New York in the 1990s as a model. However, New York provided outpatient treatment and used quarantine in a selected manner. The transfer of this model into South Africa without first putting into place the necessary infrastructure and without considering that in NY, people who were put in isolation were provided with good medical care, has been harmful. In South Africa, patients were not provided with the second and third line drugs that they needed and were put in quarantine where there was no opportunity for a cure and no opportunity to challenge their detention. It is thus not surprising that there were riots and break-outs. Also, XDR-TB in South Africa exists in the first place due to the lack of adequate care for HIV and TB. This structural problem still exists.

FG asked if it is possible to challenge radical measures initially taken by public health authorities to control a new, unknown disease once more information about the disease becomes available.

JA set out basic questions that need to be addressed at the outset of any outbreak: How quickly do you need to have judicial oversight? With mass quarantine, how can you guarantee judicial oversight? How infectious does a person have to be to be justifiably contained? What constitutes failure to follow medical guidance? Who gets the final word in determining medical guidance?

FG queried what human rights funders should do to prepare for these cases.

TM emphasized the importance for training for lawyers, judges, and medical professionals. We need lawyers and judges who understand public health issues and epidemiologists who understand human rights principles. If we are going to have judicial standards, we need judges who can apply them. It is further necessary to invest in health infrastructure supportive of rights (and to raise awareness of the need for this amongst the big bilaterals).

JA added that it is critical to provide information and training on both the health and legal sides. Government should communicate honestly about disease risk, uncertainty, and how they are working on an appropriate response. Partnerships between government and civil society are essential for effective information outreach to communities. A mechanism for civil society buy-in and engagement should be set up in advance. There also needs to be continued focus on human rights protections and the building of a culture of human rights within health authorities.

Main Points from Question and Answer Period

- Powerful donors are focusing more on clinical approaches and service delivery and moving away from rights-based approaches which challenge stigma, discrimination, and violence. There is thus a need to support the organization/empowerment of affected/infected groups so that they can have a stronger voice to assert their concerns. It is important to empower and build the capacity of affected, infected, and marginalized groups so that they can participate in public policy discussions.
- Human rights have gotten a lot of visibility in the public health arena but not a lot of understanding. Human rights advocates need to do a better job articulating the meaning and implications of rights. Discussions on human rights have become so abstract that public health people cannot engage. There is also an intentional taking over and perversion of human rights language in the public health arena (for instance, the use of the "right to know your status" which actually limits the right to health and ignores the relationship to other rights).
- Raising accountability for international human rights standards:
    - Donors should build capacity for and support litigation on public health matters using international and regional human rights instruments.
    - Universal Periodic Reviews with the new Human Rights Council are another mechanism to increase accountability for health and human rights.
    - Recent international health regulations dealing with global migration and transmission of diseases compelling governments reports to the WHO provide a step towards raising accountability at the international level.
    - The Global Convention on Tobacco Control compelled governments to report on steps they were taking against smoking, and there have been calls for a similar convention on public health more broadly. This indicates a trend towards thinking about diseases beyond borders and rights within a global context.
    - There has been a push for UNAIDS to incorporate a summary of civil society shadow reports into official UNGASS country reports, increasing their visibility and impact.

- It may be useful for a civil society working group to think about contingency plans to deal with health emergencies. Save the Children and CARE could provide useful facilitation. The best preparation for public health emergencies may be to strengthen public health infrastructure and respect for human rights generally.
- It's not just infectious diseases that have fallen under the category of "needing coercive emergency response." People found to be socially detrimental or infectious (drug users, sex workers) have also been placed under this category. They are regularly rounded up and put in "treatment" camps, where treatment does not really happen. Additionally, these round-ups are justified in terms of rights (e.g., the right to live in a drug free community).
- Quarantine and isolation is really a form of incarceration. In the US and globally, we see the criminalization of mental health, addiction, and poverty. Human rights funders have had a difficulty addressing poverty directly but it seems to be at the core of this trend.
- There needs to be more work with media to ensure scare tactics are not employed and that balanced, needed information reaches the public.
- Funders can fund civil society action and groups like Treatment Action Campaign, judicial support, the education of lawyers and judges, and dialogues between the public health and human rights communities.