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Item Type	Preprint
Authors	Parmet, Wendy E
Publisher	The International Council on Human Rights Policy
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Download date	2026-06-12 23:21:15
Link to Item	<a href="http://hdl.handle.net/20.500.12424/186065">http://hdl.handle.net/20.500.12424/186065</a>

# THE INTERNATIONAL COUNCIL ON HUMAN RIGHTS POLICY

## Project on Social Control and Human Rights

### Research Paper (Final Draft)

## PUBLIC HEALTH & SOCIAL CONTROL: IMPLICATIONS FOR HUMAN RIGHTS

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### PREFACE

1. On April 24, 2009 the World Health Organization (WHO) announced that it had received reports from the United States and Mexico about a new form of swine influenza, Type A (H1N1). Although the confirmed cases in the United States were relatively mild, the reports from Mexico were more alarming. Fifty-nine individuals, most of whom had been young and healthy, were dead in Mexico City alone.<sup>1</sup> Around the globe, health officials who had long been preparing for a fearsome influenza pandemic jumped into action. In Mexico City schools and public gatherings were cancelled.<sup>2</sup> In China, Mexican travelers were quarantined.<sup>3</sup> In Egypt, authorities slaughtered swine herds kept by Coptic Christians.<sup>4</sup>
2. By mid June 2009, cases were confirmed on six continents and the WHO declared that the world was experiencing an influenza pandemic.<sup>5</sup> Nevertheless, the panic that had gripped the globe in April began to subside. H1N1 appeared to be highly contagious, but in most cases, the illness was mild. Still, by November 2009, over 6000 people had died around the world and in contrast to the deaths generally caused by seasonal flu; many of those who died had been young and otherwise healthy.<sup>6</sup> But the apocalypse had been avoided, although officials cautioned that the virus could still become more deadly. If that happens, officials warned, more drastic social controls might be required.

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<sup>1</sup> World Health Organization [WHO], "Influenza-like Illness in the United States and Mexico," April 24, 2009, [www.who.int/csr/don/2009\\_04\\_24/en/index.html](http://www.who.int/csr/don/2009_04_24/en/index.html) (accessed on June 3, 2009).

<sup>2</sup> Tracy Wilkinson & Thomas M. Maugh II, "Mexico Scrambles to Contain Swine Flu Outbreak," *Los Angeles Times*, April 25, 2009, [www.latimes.com/features/health/la-sci-mexico-sivne-flu25-2009april25,0,3847221.story](http://www.latimes.com/features/health/la-sci-mexico-sivne-flu25-2009april25,0,3847221.story) (accessed on June 1, 2009).

<sup>3</sup> Andrew Browne, "China Forces Dozens of Mexican Travelers into Quarantine," *The Wall Street Journal*, May 4, 2009, <http://online.wsj.com/article/SB1214137876507580987.html> (accessed on June 1, 2009).

<sup>4</sup> Nadim Audi, "Culling Pigs in Flu Fight, Egypt Angers Herders and Dismays U.N.," *New York Times*, April 30, 2009, A-13.

<sup>5</sup> Dr. Margaret Chan, "World Now at the Start of 2009 Influenza Pandemic," WHO, June 11, 2009, [www.who.int/mediacentre/news/statements/2009/h1n1\\_pandemic\\_phase6\\_20090611/en/index.html](http://www.who.int/mediacentre/news/statements/2009/h1n1_pandemic_phase6_20090611/en/index.html).

<sup>6</sup> WHO, "Global Alert and Response—Pandemic (H1N1) 2009—Update 74," Nov. 13, 2009, [www.who.int/csr/don/2009\\_11\\_13/en/index.html](http://www.who.int/csr/don/2009_11_13/en/index.html) (accessed on November 13, 2009).

3. The still-unfolding history of H1N1 illustrates the challenges and paradoxes presented by social responses to public health threats, particularly infectious diseases. Without doubt, infectious diseases are a major source of premature morbidity and mortality, especially in low-income nations. Moreover, in an increasingly interdependent world, new diseases, such as H1N1, can and do spread around the globe with great speed. Sometimes they exact horrific tolls.
4. Citizens expect and international law requires that governments take steps to protect their populations from these dangers. Yet, many of the controls that governments use to identify, prevent, and respond to infectious diseases limit individuals' liberty of movement, privacy, freedom to travel and immigrate, and freedom to control their own body. The right to work and maintain a living can also be undermined. Frequently, these social controls are imposed disproportionately on vulnerable populations. Sometimes these controls provide little or no public health benefit.
5. This Report employs social control theory to explore the difficult and complex relationship between public health protection and human rights.<sup>7</sup> Although public health is a broad and contested concept that theoretically encompasses all of the factors that affect the health of populations,<sup>8</sup> this Report focuses on state responses to infectious diseases. Historically these diseases have been the prime target of state public health interventions; indeed, the modern bureaucratic state developed partially in response to infectious disease outbreaks.<sup>9</sup> Moreover, many of the controls and interventions that have been developed and used to protect populations from these diseases serve as models for interventions and policies that are aimed at other public health threats, such as obesity. Most importantly, infectious diseases, particularly those that are contagious and spread casually from one person to another, provoke deep and visceral fears in the human psyche. Because of both the risks they pose and the fears they engender, infectious diseases pose the greatest challenge for those seeking to secure both public health and human rights.
6. Social control theory can add to our understanding of that challenge by highlighting the role that the social discourse around risk plays in framing public health problems and the interventions used to meet those threats. By exploring public health interventions via the lens of social control theory, both human rights and public health advocates can garner a richer appreciation of the complex relationship between public health and human rights and new insights as to how both can be protected.
7. Social control theory explores the means by which society regulates the behavior of its members. Most relevant to this Report, the social control perspective can help examine "how social problems, crime and deviance are constructed and addressed and what all this means for human rights."<sup>10</sup> This perspective problematizes the exercise of public health interventions with human rights implications, forcing us to question the necessity of such measures and revisit widely-accepted assumptions about the inevitable trade-off between public health and human rights.

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<sup>7</sup> The research for this Report was limited to secondary sources appearing in English. In accordance with the Council's larger project, the primary focus is on the human rights implications of public health controls in high and middle income nations. In many low income nations, the most pressing human rights health problem is the absence of adequate public health interventions, rather than the human rights abuses created by specific interventions.

<sup>8</sup> For a fuller discussion see, Wendy E. Parmet, *Populations, Public Health, and the Law* (Washington, D.C.: Georgetown University Press, 2009), 5-10.

<sup>9</sup> George Rosen, *A History of Public Health* (New York: MD Publications, 1958), 7-13.

<sup>10</sup> International Council on Human Rights, Draft Synthesis Paper (October 21, 2009), 6.

8. Following the lead of the social control literature and the Council's project, this Report focuses primarily on public health interventions undertaken by high income countries in the global North. However, as the Report demonstrates, the threat that public health interventions pose for individual liberty and vulnerable populations is not limited to high income countries. Indeed, as the Report demonstrates, states around the world often rely on relatively similar interventions in response to infectious disease. These interventions often threaten, sometimes needlessly, the liberty and rights of individuals, particularly those who are most vulnerable in a particular state. In addition, many of the interventions that are undertaken are of limited utility in protecting populations from infectious disease. This is most problematic in those countries, particularly in the global South, where populations continue to face a high risk of death and disability due to infectious disease.
  
9. Section I begins by reviewing the right to public health protection under international law and discusses contemporary understandings of the relationship between that right and other human rights, especially in the face of serious epidemics. Section II uses social control theory to explore the role that social discourse and perceptions of risk play in constructing how societies view epidemics and respond to them. This Section demonstrates that the social controls that states use are determined not only by medical and epidemiological evidence, but also by the ways in which societies view and understand particular disease threats and populations. Section III examines several different infectious disease interventions from a social control perspective, exploring the threat that they pose to individual liberty and marginalized populations. Importantly, Section III provides neither a comprehensive catalog of all human rights abuses that have occurred in recent years in the name of public health nor a review of all of the public health interventions that affect human rights. Rather Section III uses examples of state responses to several relatively common infectious diseases, including HIV/AIDS, tuberculosis (TB), and influenza, to demonstrate how public health interventions can infringe upon human rights. Section IV explains why the existing international human rights framework is unable to ensure that public health protection does not result in the unnecessary infringement of human rights. The paper concludes by offering guidelines for human rights and public health advocates who seek to protect both public health and human rights.

## I. THE RELATIONSHIP BETWEEN PUBLIC HEALTH PROTECTION AND HUMAN RIGHTS

### A. Public Health as a Human Right

10. The term public health has many meanings and is used in many contexts. Most fundamentally it refers to the health of populations as well as the science that examines how disease can be prevented and health improved for populations through organized community efforts.<sup>11</sup> This focus on population health, as well as on collective efforts to secure it, distinguishes public health from both individual health and clinical medicine. Nevertheless, the three are closely interrelated. Public health efforts are critical to determining and ensuring the health of individuals within a population. Moreover, individual health services, such as immunization or the treatment of infectious diseases with antibiotics, can reduce the health risks faced by broader populations.
11. There is little doubt that the protection of public health, especially from infectious diseases, is an important state function. For millennia, horrific epidemics have undermined nations and altered the course of history.<sup>12</sup> In the fourteenth century, for example, the Black Death traveled from Eurasia to Europe, killing an estimated twenty to forty percent of those it encountered and significantly reshaping the political, economic, and cultural environment.<sup>13</sup> More recently, the 1918 influenza pandemic killed more people than World War I.<sup>14</sup> Even today, long after the development of vaccinations and antibiotics, infectious diseases continue to take a heavy toll. Each year, over six million people die from just three infectious diseases, HIV, tuberculosis, and malaria, and infectious diseases remain the leading cause of death for children and young adults in low income countries.<sup>15</sup> Infectious diseases also kill millions in high income nations. According to the WHO, respiratory infections remain the fourth leading cause of death in such states.<sup>16</sup> Even epidemics that kill relatively few people, such as the 2003 SARS outbreak, can wreak havoc on a region's economy.<sup>17</sup>
12. Infectious diseases are, by their very nature, social threats.<sup>18</sup> Although they are most directly caused by pathogens (bacteria, viruses, and prions), their ability to infect and harm humanity is determined largely by a variety of social factors, including sanitation, trade and travel, deforestation, urbanization, and behavioral patterns.<sup>19</sup> Moreover, even though individuals can often reduce their own risk of contracting an infectious disease (for example by practicing safer

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<sup>11</sup> Parmet, *Populations, Public Health and the Law*, 7-13.

<sup>12</sup> William McNeil, *Plagues and People* (Garden City, N.Y.: Anchor Press/Doubleday, 1976), 3.

<sup>13</sup> Philip Ziegler, *The Black Death* (New York: Harper & Row, 1971), 230-231, 251.

<sup>14</sup> Gina Kolata, *Flu: The Story of the Great Influenza Pandemic of 1918 and the Search for the Virus that Caused It* (New York: Farrar, Straus & Giroux, 1999), 7.

<sup>15</sup> WHO, *The Global Burden of Disease: 2004 Update*, 2008, 11-12, [www.who.int/healthinfo/global\\_burden\\_disease/GBD\\_report?2004update\\_full.pdf](http://www.who.int/healthinfo/global_burden_disease/GBD_report?2004update_full.pdf).

<sup>16</sup> WHO, "The 10 Leading Causes of Death By Broad Income Group (2004)," Fact Sheet No. 310, [www.who.int/mediacentre/factsheets/fs310/en/index.html](http://www.who.int/mediacentre/factsheets/fs310/en/index.html) (accessed on June 6, 2009).

<sup>17</sup> CBC News Online, "The Economic Impact of SARS," *Canadian Broadcasting Corporation*, July 8, 2003, [www.cbc.ca/news/background/sars/economicimpact.html](http://www.cbc.ca/news/background/sars/economicimpact.html).

<sup>18</sup> Many if not most chronic diseases are also partially socially determined, although the interdependence between the health of an individual and others is less obvious and direct than it is in the case of infectious diseases. Parmet, *Populations, Public Health and the Law*, 166-71. For a discussion of the role of socio-economic determinants of health, see Commission on Social Determinants of Health, WHO, *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health* (Geneva: WHO, 2009), [http://www.who.int/social\\_determinants/thecommission/finalreport/en/index.html](http://www.who.int/social_determinants/thecommission/finalreport/en/index.html).

<sup>19</sup> This point was made early on by René Dubois, *Man Adapting* (New Haven, Connecticut: Yale University Press, 1965), 169-78.

sex in the case of HIV, or avoiding uncooked food in the case of many food-borne infections), their fate is never wholly in their own hands. The risk they face depends largely on both the environment they inhabit and the disease's prevalence in the populations they encounter. With many communicable diseases, individuals benefit when others in their community are vaccinated or treated for an infectious disease.<sup>20</sup> On the other hand, an individual's own infection may increase the risk to others. As a result, infections are never purely private affairs; if their risk is to be reduced, collective action is essential. Most often the state is in the best position to provide, or at least create the conditions necessary for, such ameliorative actions.<sup>21</sup> For this reason, nations have a responsibility for protecting their populations' health, especially from infectious diseases.

13. International law supports the recognition of a human right to the opportunity to be healthy. For example, Article 25 of the Universal Declaration of Human Rights (UDHR) states:

Everyone has a right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.<sup>22</sup>

14. Although the UDHR is not binding on states, it serves as a "common standard" for evaluating human rights and is an important source of customary international law.<sup>23</sup>
15. The recognition of a right to health is even more firmly set forth in Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) which compels the approximately 150 signatory states (which does not include the US) to progressively realize, to the extent feasible given their available resources, "the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health" and undertake "the prevention, treatment and control of epidemic, endemic, occupational and other diseases."<sup>24</sup> In effect, Article 12 recognizes that the right to health obligates states to take actions to protect their populations from infectious diseases.
16. In 2000, the Committee on Economic, Social, and Cultural Rights (CESCR) released General Comment 14 which construed the right to health protected by Article 12 to compel even broader public health protections. General Comment 14 notes that the right to health is an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition, and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.<sup>25</sup>

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<sup>20</sup> As a result, infectious diseases are public harms and public health protection is a partial public good. David Woodward & Richard D. Smith, "Global Public Goods and Health: Concepts and Issues," in Richard Smith, et al., *Global Public Goods for Health: Health Economic and Public Health Perspectives*, 3-29 (New York: Oxford, 2003).

<sup>21</sup> In recent years, NGOs and other institutions of civic society have played an increasingly important role in public health protection. Civic Society Initiative, External Relations and Governing Bodies, World Health Organization, *Strategic Alliances: The Role of Civil Society in Health* (WHO, 2001), [www.who.int/civilsociety/documents/en/alliances\\_en.pdf](http://www.who.int/civilsociety/documents/en/alliances_en.pdf).

<sup>22</sup> Universal Declaration of Human Rights [UDHR], G.A. Res. 217A (III), art. III, 1, U.N. Doc. A/810 (Dec. 10, 1948).

<sup>23</sup> *Ibid.*, pmb.

<sup>24</sup> International Covenant on Economic, Social and Cultural Rights [ICESCR], art. 12, Dec. 16, 1966, 993 U.N.T.S. 3, S. Exec. Doc. D, 95-2 (1978); 6 I.L.M. 360 (1967).

<sup>25</sup> Comm. on Econ., Soc. & Cultural Rights [CESCR], General Comment 14, art. 12, *The Right to the Highest Attainable Standard of Health*, U.N. Doc. E/C. 12/2000/4 (2000).

17. According to the CESCR, the “right to health is closely related to and dependent upon the realization of other human rights” and encompasses both freedoms and entitlements.<sup>26</sup> It also obligates states to make available “functioning public health and health-care facilities,” the precise nature of which depend upon a variety of factors including a state’s level of development.<sup>27</sup>
18. With respect to infectious diseases, General Comment 14 explains that Article 12.2 of the ICESCR requires states to undertake individual and joint efforts “using and improving epidemiological surveillance and data collection on a disaggregated basis, the implementation or enhancement of immunization programmes and other strategies of infectious disease controls.”<sup>28</sup> Moreover, General Comment 14 clarifies that states can violate their obligations both through actions and inactions.<sup>29</sup> Hence, a state’s failure to take steps within its means to protect the health of its population may constitute a human rights violation.<sup>30</sup>
19. The obligation of states to protect the health of their populations can also be inferred from numerous other sources of soft law. For example, the Constitution of the World Health Organization (WHO) declares that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, or economic or social condition” and that “governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.”<sup>31</sup> In 1978 the so-called Declaration of Alma-Ata reaffirmed that health is a “fundamental human right” and that governments “have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures.”<sup>32</sup> Over twenty years later, the U.N. Commission on Human Rights established the position of Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health.<sup>33</sup> Since then the Special Rapporteur has issued numerous reports detailing the nature of the right to health, how it can be realized and enforced, and cases in which it has been violated.
20. The right to health is also recognized in many international and regional treaties, including the United Nations Conventions on the Rights of the Child, the Elimination of All Forms of Discrimination Against Women, the Rights of Persons with Disabilities,<sup>34</sup> as well as the treaties establishing the European and African Unions.<sup>35</sup> In addition, the constitutions of over 60 states

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<sup>26</sup> Ibid., 3.

<sup>27</sup> Ibid., 12(a).

<sup>28</sup> Ibid., 15.

<sup>29</sup> Ibid., 48-49.

<sup>30</sup> Whether or not a state’s inaction constitutes a human rights violation depends on numerous factors as set forth in General Comment 14 and Article 12, including the resources available to the state and the particular acts the state failed to undertake.

<sup>31</sup> Const. of the WHO., pmb., July 22, 1946, 62 Stat. 2679, 14 U.N.T.S. 185 (1948).

<sup>32</sup> WHO, Declaration of Alma-Ata, Arts. I & V, International Conference on Primary Health Care, USSR (Sept. 6-12, 1978), [http://www.who.int/hpr/NPH/docs/declaration\\_almaata.pdf](http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf).

<sup>33</sup> WHO & Office of the U.N. High Commission for Human Rights, “Fact Sheet 31 on the Right to Health,” 2008, <http://www2.ohchr.org/english/issues/health/right/>.

<sup>34</sup> U.N. Commission on Human Rights, *Economic, Social and Cultural Rights: The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health*, UN Doc. E/CN.4/2003/58 (Feb. 13, 2003) (prepared by Special Rapporteur, Paul Hunt submitted in accordance with Comm. Res. 2002/31), Annex I, <http://www.unhcr.ch/Huridocda/Huridoca.nsf/0/9843202995c286fc1256cecc005a18d>.

<sup>35</sup> William Onsiuu, “Globalization, Regionalism, or Both: Health Policy and Regional Economic Integration in Developing Countries, an Evolution of a Legal Regime,” *Minnesota Journal of International Law* 15(1)(2006): 111-188.

have some provision establishing either a right to health or health care.<sup>36</sup> Although courts have long been wary of enforcing these provisions, because of the inherent uncertainty of their specific mandates, in recent years the high courts of several countries have held that the right to health in their state is justiciable, at least to a limited degree.<sup>37</sup>

21. Despite the strong support for a right to public health protection, it is critical to recall that the right is not absolute. Rather, it is only one of progressive realization and is subject to resource availability. Or as the Special Rapporteur has stated: “States are expected to do better next year than they are doing today, while resource availability acknowledges that what is required of a rich country is of a higher standard than what is required of a low - or middle-income country.”<sup>38</sup> Moreover, the highest attainable standard of health necessarily depends upon biological, economic, and environmental conditions. Absolute health is never achievable, even in the richest nations. Hence, it is difficult to assert that the right to health demands that states engage in any particular public health intervention. Nevertheless, even if the content of the right to health is vague and often unenforceable, its recognition in relationship to public health can provide powerful normative and legal support for state intervention in public health.

## **B. Limiting Human Rights to Protect Public Health**

22. In order to protect the health of their populations, states institute many types of programs and policies. Some ameliorate the social and economic conditions that their populations face; for example, by supporting development.<sup>39</sup> In so doing, these programs seek to provide an environment conducive to health. Other interventions offer information, medicine, or health care. Such interventions actualize many of the core obligations set forth in General Comment 14, often without posing any significant threat to human rights or liberty.
23. Since the start of the HIV/AIDS epidemic in the 1980s, many public health workers and human rights activists have emphasized the complementary relationship between health and human rights, including socio-economic rights. Thus in groundbreaking work on HIV/AIDS, Jonathan Mann, the former head of WHO’s AIDS program, argued that human rights were supportive of population health. Mann added that because human rights “articulate the societal preconditions for human well-being” they offer a “form of guidance for public health efforts to analyze and respond directly to the societal determinants of health.”<sup>40</sup> This perspective is clearly reflected in General Comment 14 which specifies the positive obligations of states to address the environmental and social factors that affect health, as well as in many WHO and U.N. reports and recommendations on tuberculosis, HIV/AIDS, and the social determinants of health.<sup>41</sup>
24. For example, the *International Guidelines on HIV/AIDS and Human Rights*, published by UNAIDS, specifically state:

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<sup>36</sup> U.N. Commission on Human Rights, *Economic, Social and Cultural Rights*.

<sup>37</sup> Paul Hunt, U.N. Human Rights Council, *Implementation of General Assembly Resolution 60/251 of 15 March 2006, Entitled "Human Rights Council"*, U.N. Doc. A/HRC/4/28 (Jan. 17, 2007).

<sup>38</sup> *Ibid*, 15.

<sup>39</sup> Daniel Tarantola et al., *Human Rights, Health and Development, Technical Series Paper # 08.1* (UNSW Initiative for Health and Human Rights, Univ. of New South Wales, 2009), at <http://ssrn.com/abstract-1398608>.

<sup>40</sup> Jonathan Mann, “Medicine and Public Health,” *Hastings Center Report*, 27:3 (1997): 6-14.

<sup>41</sup> Committee on Economic, Social & Cultural Rights, "General Comment 14, The Right to the Highest Attainable Standard of Health", U.N. Doc. E/C. 12/2000/4 (2000); Commission on Social Determinants of Health, *Closing the Gap*.

Public health interests do not conflict with human rights. On the contrary, it has been recognized that when human rights are protected, fewer people become infected and those living with HIV and their families can better cope with HIV and AIDS.<sup>42</sup>

25. International development initiatives have likewise recognized the importance and interrelationship of health and human rights.<sup>43</sup>
26. Despite the widespread acceptance of the fact that human rights support and are often essential for the protection of public health, many public health experts and policymakers contend that the protection of public health, particularly from epidemics of infectious disease, requires interventions that may limit individuals' liberty of movement and privacy. Such interventions include surveillance, preventive detention via isolation or quarantine, travel bans, immigration bans, criminalization, and mandatory vaccination and treatment, as well as destruction of property. These interventions operate as, and have many features in common with, social controls that are utilized to address other types of perceived risk, such as the risk of terrorism or criminal activity.
27. International law largely permits states to limit individual liberties in response to the threat of infectious diseases. For example, Article 12 of the ICCPR lists public health as a justification for limiting most rights that are otherwise protected by the Covenant.<sup>44</sup> Likewise the recently revised International Health Regulations (IHR) compels states to undertake surveillance and report on "public health emergencies of international concern."<sup>45</sup> The IHR also authorizes states under certain circumstances to conduct medical examinations of travelers and bar their entry to prevent the spread of disease.<sup>46</sup> In addition, Article 5 of the European Convention on Human Rights limits that Articles' rights to liberty and security by explicitly permitting "the lawful detention of persons for the prevention of the spreading of infectious disease, of persons of unsound mind, alcoholics or drug addicts or vagrants."<sup>47</sup>
28. The view that liberties must be limited to protect the public from infectious diseases is pervasive in the reports and policies of public health bodies, particularly in response to so-called emerging diseases. For example, a 2008 report written for the WHO stressed that governments may need to quarantine individuals in the event of an influenza pandemic.<sup>48</sup> And in the wake of 2001 anthrax attacks on the United States mail, the United States Centers for Disease Control and Prevention (CDC) sponsored a "Model State Emergency Health Powers Act" (MSEHPA) that was designed to clarify and update a state's ability to conduct isolation, quarantine, and involuntary medical examinations on individuals during a "public health emergency."<sup>49</sup> According to one of the Act's authors, James Hodge, coercive infectious disease controls such as quarantine and forced vaccination have "traditionally been used by public health authorities

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<sup>42</sup> Joint United Nations Programme on HIV/AIDS [UNAIDS], *International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version* (Office of the United Nations High Commissioner for Human Rights and UNAIDS, 2006).

<sup>43</sup> Tarantola et al., *Human Rights, Health and Development*.

<sup>44</sup> International Covenant on Civil and Political Rights [ICCPR], G.A. Res. 2200A, UN. GAOR, Supp. No. 16, U.N. Doc. A/6316 (Dec. 16, 1966).

<sup>45</sup> WHO, World Health Assembly, Revision of the International Health Regulations [IHR], art. 5, Res. WHA58.3, 58<sup>th</sup> Sess. WHO Doc. WHA58/2005/REC/1 (May 23, 2005).

<sup>46</sup> IHR, arts. 23 & 31.

<sup>47</sup> European Convention on Human Rights [ECHR], art. 5, Nov. 4, 1950, Europ. T.S. No. 5; 213 U.N.T.S. 221.

<sup>48</sup> WHO, *Addressing Ethical Issues in Pandemic Influenza Planning* (WHO, 2008).

<sup>49</sup> Center for the Law and Public's Health, Georgetown and Johns Hopkins Universities, Model State Emergency Health Powers Act (2001) [MSEHPA], <http://www.publichealthlaw.net/MSEHPA/MSEHPA2.pdf>.

to control the spread of contagious disease. Few question their potential value in accomplishing the same, despite their potential to infringe on human rights.”<sup>50</sup>

29. Public health ethicists have articulated a variety of principles to mediate the tensions between coercive public health interventions and human rights. For example, writing in the 2008 WHO report, *Addressing Ethical Issues in Pandemic Influenza Planning*, Lawrence O. Gostin and Ben Berkman argue that compulsory measures are justified only when government has a “good faith belief, for which they can give supportable reasons, that a coercive approach is necessary.”<sup>51</sup> They also assert the importance of community participation, transparency, proportionality, and respect for distributive justice.<sup>52</sup> Similarly, a recent report by the Nuffield Council on Bioethics proposes that states rely upon an “intervention ladder” in which “higher the rung on the ladder at which the policy maker intervenes, the stronger the justification has to be. A more intrusive policy initiative is likely to be publicly acceptable only if there is a clear indication that it will produce the desired effect, and that this can be weighed favourably against any loss of liberty that may result.”<sup>53</sup> The Council added: “In general, public health policies should use the least intrusive means to achieve the required public health benefit.”<sup>54</sup>
30. As is discussed more thoroughly in Section IV, international and domestic law also attempt to balance the rights of individuals with the protection of public health. For example, Article 12 of the ICCRP permits the derogation of otherwise legally protected rights for public health purposes only when such derogation is “provided by law,” and is “necessary” and “consistent with other rights recognized” by the Covenant.<sup>55</sup> This provision and others authorizing the limitation of rights was interpreted in 1984 by the so-called *Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights*.<sup>56</sup> Briefly these principles permit states to abridge human rights only when such limitations are 1) in accordance with law, 2) based on a legitimate objective, 3) strictly necessary in a democratic society, 4) the least restrictive and intrusive means available, and 5) not arbitrary, unreasonable, or discriminatory. <sup>57</sup> Similar principles appear in Article 4 of the ICESCR which permits states to limit the rights recognized by the Covenant as long as the limitations are “determined by law” and are “compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.”<sup>58</sup>
31. These international human rights principles attempt to enable states to protect public health while still respecting human rights. Unfortunately, as this Report documents, these standards have sometimes proven inadequate. States around the world frequently respond to public health problems by employing highly coercive and often discriminatory social controls, especially on vulnerable populations. In many cases, these controls are neither necessary nor the least restrictive intervention possible. Frequently they are not well designed to address the health problem they ostensibly target. Often they are instituted despite the state’s neglect of less coercive measures that are likely to have far greater public health benefits.

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<sup>50</sup> James G. Hodge Jr., “Salient Issues in Public Health Law: Bioterrorism Law and Policy, Critical Choices in Public Health,” *Journal of Law, Medicine and Ethics* 30(2) (2002): 254-261.

<sup>51</sup> Lawrence O. Gostin & Ben Berkman, “Isolation, Quarantine, Border Control & Social Distancing Measures,” in WHO, *Addressing Ethical Issues in Pandemic Influenza Planning*, 30, 36 (quoting James F. Childress et al., “Public Health Ethics: Mapping the Terrain,” *Journal of Law, Medicine & Ethics* 20(2) (2002): 173).

<sup>52</sup> *Ibid.*, 37-39.

<sup>53</sup> Nuffield Council on Bioethics, *Public Health: Ethical Issues* (Nuffield Council on Bioethics, 2007), xviii.

<sup>54</sup> *Ibid.*, xx.

<sup>55</sup> ICESCR, art. 4.

<sup>56</sup> U.N. Economic and Social Council, Commission on Human Rights, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, U.N. Doc. E/CN.4/1985/4 (1984).

<sup>57</sup> Gostin & Berkman, “Isolation, Quarantine, Border Control & Social Distancing Measures,” 36.

<sup>58</sup> ICESCR, art. 4.

32. Social control theory helps to shed light on why states utilize such controls as well as why the existing international human rights framework may fail to provide an adequate check on controls that unnecessarily limit the rights and liberties of vulnerable populations. More specifically, social control theory exposes the critical role that the social construction of risk and discourse around risk have played in prompting states to take unnecessary and often ineffective liberty-limiting measures in the name of public health protection. By engaging with social control theory and using its insights to explore the relationship between public health and human rights, human rights activists and public health advocates can gain new insight into the limitations of the existing international law framework for the protection of both rights and public health.
33. Most importantly, social control theory suggests that in the current era, societies are becoming increasingly intolerant of risk.<sup>59</sup> At the same time, as the functions and activities of the state have devolved (or have been eroded), the protection of the public from risks has become one of the key, if not the, chief goal of the state.<sup>60</sup> In this climate, fear of a disease may be disproportionate to its actual risk. Moreover, people who have been or are infected with disease are easily characterized by the media and viewed by the public as dangerous deviants who threaten the well-being of others. In response, states limit the liberty (and degrade the dignity) of those who are either ill or are thought to threaten the health of others. But by authorizing states to impose these controls, public health practice and international law overlook the role that social factors play in determining the nature and extent of health risks, as well as how risks are perceived and what interventions are chosen. In fact, as Section II demonstrates, social factors, including media discourse and anxieties exacerbated by globalization, play an enormous role in shaping what public health threats are viewed as requiring state interventions and what controls are adopted. By failing to appreciate the impact of the social construction of public health threats, the global community has been too quick to accept the inevitability of limiting the liberty of individuals in the name of public health and too ready to devalue the positive role that human rights can play in promoting public health.

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<sup>59</sup> International Council on Human Rights, 40.

<sup>60</sup> *Ibid*, 13.

## II. THE SOCIAL CONSTRUCTION OF PUBLIC HEALTH RISKS

### A. Public Health Panics

34. In an ideal world, public health interventions would be based on the best available epidemiological and medical information about the severity and nature of the risk at hand and the efficacy of various interventions, as well as widely-accepted legal and ethical principles. In the real world, the science is often incomplete and the application of legal and ethical principles to particular cases is frequently unclear. Less obvious, social perceptions frame and often distort how societies perceive risks as well as the choices societies make in response to the risks they fear the most. This distortion can influence how a state views the relationship between public health and human rights, prompting it to believe all-too-readily and frequently needlessly that the protection of the former requires the narrowing of the latter. As a result, both the rights that are limited in the name of public health and the right to public health may be unnecessarily imperiled.
35. Throughout history, different diseases have become imbued with different social meanings. As Susan D. Moeller explains, “Disease, especially epidemic disease, is not only a biological phenomenon but a social, cultural and political one.”<sup>61</sup> Thus in medieval Europe, leprosy (Hansen’s disease) was regarded as a divine punishment. Those who were ill were seen as impure and sinful, deserving of their ostracism.<sup>62</sup> Although plague killed far more people, it elicited a less moralistic and more bureaucratic response.<sup>63</sup> Later people who had contracted syphilis were seen as wicked and loathsome, while tuberculosis became viewed as a disease of passion.<sup>64</sup>
36. Critically, the extent to which a disease is feared, and hence is met with strong social controls, often has little to do with either its lethality or its incidence. As medical historian Margaret Humphreys has noted, “[t]he diseases that cause panic are not usually the diseases that kill the most people on a daily basis.”<sup>65</sup> Rather a variety of factors, including the putrid nature of a disease’s symptoms, the speed with which it kills, and its capacity to travel and invade new spaces, seems to affect the level of fear. The way that officials and the media discuss and react to a disease also helps to establish how it is perceived.<sup>66</sup> Especially critical, however, is a disease’s novelty. New diseases are usually experienced as far more frightening, even if they are less lethal or less probable, than established, endemic threats.<sup>67</sup> Hence relatively rare diseases such as Ebola or SARS provoke deep terror and calls for decisive government action, while common and deadly diseases, such as childhood diarrhea or cardiovascular disease, elicit little concern and frequently are met with neglect by state officials.<sup>68</sup> Perhaps for this reason, as deadly infectious diseases have become less common in high-income countries, fear of them has increased.<sup>69</sup> And

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<sup>61</sup> Susan D. Moeller, *Compassion Fatigue: How the Media Sell Disease, Famine, War and Death* (New York: Routledge, 1999), 57.

<sup>62</sup> Johan Goudsblom, “Public Health and the Civilizing Process,” *The Milbank Quarterly* 64 (1986): 166.

<sup>63</sup> *Ibid.*, 168-169.

<sup>64</sup> *Ibid.*, 170-171; Susan Sontag, *AIDS and Its Metaphors* (New York: Farrar, Straus and Giroux, 1989), 24-28.

<sup>65</sup> Margaret Humphreys, “No Safe Place: Disease and Panic in American History,” *American Literary History* (2002): 845-55.

<sup>66</sup> Wendy E. Parmet, “Dangerous Perspectives: The Perils of Individualizing Public Health Problems,” *Journal of Legal Medicine*, 30 (2009): 83-108.

<sup>67</sup> Moeller, *Compassion Fatigue*, 61-62.

<sup>68</sup> *Ibid.*, 55-56; Cass R. Sunstein & Richard Zeckhauser, “Overreaction to Fearsome Risks,” *John F. Kennedy School of Government Faculty Research Working Paper Series, No. RWP08-079* (Dec. 18, 2008), <http://web.hks.harvard.edu/publications/workingpapers/citation.aspx?PubId=6152>.

<sup>69</sup> Moeller, *Compassion Fatigue*, 57-60.

with the increase in fear has come the demand that states take enhanced steps to gather information about (conduct surveillance) and control so-called emerging epidemics.<sup>70</sup>

37. The fear and reaction to infectious diseases, particularly new or emerging infectious diseases, often bear many of the hallmarks of a moral panic.<sup>71</sup> As in moral panics, officials and the media invoke stereotypical presentations as they promote the sense of danger, sometimes for their own institutional reasons. Thus public health officials, who have frequently faced tight budget constraints as state support for traditional public health activities has diminished, may amplify or take advantage of public health panics hoping that they will lead to increased funding, prestige, and even legal authority. Sometimes officials may simply fear that they will be blamed if they fail to act with alacrity.
38. The stereotypical presentations that officials and the media portray often reflect and reinforce pre-existing social tensions and concerns. The result is a public health panic that may be out-of-proportion to the actual danger posed by an emerging infection and which may divert attention (and resources) from critical, chronic, and endemic health threats. But, in contrast to some moral panics, the object of fear in a public health panic is not fanciful.<sup>72</sup> Public health panics ignite around actual infections that often have the potential to take many lives. Indeed, some public health panics have focused on diseases that have killed millions (e.g. HIV/AIDs) and in such cases, public health officials may be condemned simultaneously both for overstating and understating the problem. Thus the balance between neglect and over-amplification is a difficult one to maintain.
39. Disease panics are not new. For example, the U.S. experienced a “germ panic” centered on tuberculosis during the early twentieth century.<sup>73</sup> As Nancy Tomes explains, that panic began not because the incidence of tuberculosis increased, but rather because the fear of TB “served other compelling agendas” including popularizing the new germ theory of disease, responding to tensions created by the presence of new immigrant groups, and providing a focal point for advocating for “a broad range of social welfare measures.”<sup>74</sup> Likewise, Michael Sturma describes Australia’s campaign against sexually transmitted infections (STIs) during World War II as a full moral panic, stemming not from any increased threat of STIs, but rather from unease over the changing roles of women.<sup>75</sup> A similar panic about STIs occurred in the United States during World War I.<sup>76</sup> In all of these cases, fear of disease became intertwined with and served to substitute for deep-seated anxieties that were enhanced during times of war.
40. As with moral panics, public health panics often have their folk devils, those who are blamed for the problem that is feared. As Susan Sontag has noted, individuals with infectious diseases are frequently stigmatized; viewed as “the other,” they are seen as both biologically and morally hazardous to society.<sup>77</sup> As a result, those who are infected, or who are thought to be

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<sup>70</sup> See Section IIIA. For a fuller discussion of the point that anxiety about disease increases as the risk declines, see Deborah Lupton, *The Imperative of Health: Public Health and The Regulated Body* (London: Sage Publication, 1995).

<sup>71</sup> Nancy Tomes, “The Making of a Germ Panic, Then and Now,” *American Journal of Public Health* 90(2) (2000): 191-198. The classic exposition on moral panics is Stanley Cohen, *Folk Devils and Moral Panics* (London: Routledge, 1972).

<sup>72</sup> Humphreys, “No Safe Place.”

<sup>73</sup> Tomes, “The Making of a Germ Panic.”

<sup>74</sup> *Ibid.*, 193.

<sup>75</sup> Michael Sturma, “Public Health and Sexual Morality: Venereal Disease in World War II Australia,” *Signs* 13 (1988): 725-740.

<sup>76</sup> Alan Brandt, *No Magic Bullet: A Social History of Venereal Disease In the United States Since 1880* (New York: Oxford University Press, 1987), 57-121.

<sup>77</sup> Sontag, *AIDS and Its Metaphors*, 24-28.

infectious, are reviled and treated with “unrestrained callousness and hostility.”<sup>78</sup> Thus a disease’s victim becomes viewed as its vector. Not surprisingly, this transformation of the population at risk to the population that presents risk is especially apt to occur when a disease, as is so often the case, disproportionately affects poor or other already-vulnerable communities.<sup>79</sup> As David Musto has noted, “When an epidemic hits the lower classes hardest ... it provides that grain of sand on which the pearl of moralism can form.”<sup>80</sup> Often that pearl is then used, in conjunction with the fear of an epidemic, to justify the imposition of social controls on those who are blamed for the threat. In effect, as those who become ill are dehumanized and perceived of as dangerous to the broader community, their interests and even rights are easily overridden in the name of protecting the public health rights of others.

41. History provides ample examples of the process. For example, during the panics about STIs in both the U.S. and Australia, female sex workers and other women who were thought to be “unchaste” were widely vilified and blamed for endangering the public’s health.<sup>81</sup> Not surprisingly, these women bore the brunt of the social controls that were employed to protect the public from STIs. In the U.S. thousands of women were interned.<sup>82</sup> Likewise many women in Australia during World War II were subject to highly intrusive forced medical examinations.<sup>83</sup> In both cases, the role that men played in transmitting STIs was overlooked.
42. Throughout history, travelers and immigrants have borne a disproportionate share of the social controls imposed in response to public health panics. According to Eichelberger, “[t]he identification of a ‘risk group’ is part of ... boundary maintenance that creates and legitimizes the stigmatization of already marginalized populations, resulting in their identification with a disease.”<sup>84</sup> Looking at U.S. history, Howard Markel and Alexandra Minn Stern note that anti-immigrant rhetoric frequently utilized an “explicitly medical language” in which “the line between perceived and actual threat is slippery and prone to hysteria and hyperbole.”<sup>85</sup> Thus when bubonic plague appeared in San Francisco in 1900, Chinese immigrants were blamed for the outbreak. In response, health authorities imposed a series of harsh controls, including quarantines that targeted only the residences of Chinese-Americans and a law requiring all ethnic Chinese residents to be inoculated with an experimental vaccine before leaving the city. These measures were struck down by the federal courts which recognized both the discriminatory and irrational nature of the measures.<sup>86</sup> A short-time later, an Irish immigrant in New York, Mary Mallon, became vilified as “Typhoid Mary” for continuing to work as a cook while being a typhoid carrier.<sup>87</sup> Mallon was detained on an island in the Hudson River for the rest of her life, despite the fact that typhoid was a relatively common disease and many other carriers were detained only for a short time or not at all.<sup>88</sup>
43. The U.S. has not been alone in identifying immigrants with public health problems. To the contrary, the association of public health threats with “foreigners” seems to be common. For example, when smallpox arrived in Sydney in 1881, the population blamed Chinese immigrants,

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<sup>78</sup> Goudsblom, “Public Health and the Civilizing Process,” 183.

<sup>79</sup> Peter Washer, “Representations of Mad Cow Disease,” *Social Science and Medicine* 62 (2006): 457-466.

<sup>80</sup> David F. Musto, “Quarantine and the Problem of AIDS,” *Milbank Quarterly* 64(Supp. 1) (1986): 97-117, 98.

<sup>81</sup> Sturma, “Public Health and Sexual Morality,” 730-33.

<sup>82</sup> Brandt, *No Magic Bullet*, 87-90.

<sup>83</sup> Sturma, “Public Health and Sexual Morality,” 730-33.

<sup>84</sup> Laura Eichelberger, “SARS and New York’s Chinatown: The Politics of Risk and Blame During an Epidemic of Fear,” *Social Science & Medicine* 65 (2007): 1284-1295, 1285.

<sup>85</sup> Howard Markel & Alexandra Minn Stern, “The Foreignness of Germs: The Persistent Association of Immigrants and Disease in American Society,” *Milbank Quarterly* 80(4) (2002): 757-788.

<sup>86</sup> *Jew Ho v. Williamson*, 103 F. 10 (N.D. Cal. 1900); *Wong Wai v. Williamson*, 103 F.1 (N.D. Cal. 1900).

<sup>87</sup> Judith W. Leavitt, *Typhoid Mary: Captive to the Public’s Health* (Boston: Beacon Press, 1996).

<sup>88</sup> *Ibid.*, 162-201.

who were subjected to forcible vaccination and quarantine.<sup>89</sup> Roberta Bivens reports that in the United Kingdom rickets (which is not an infectious disease but is due a vitamin deficiency) became associated with the Asian community and Asian culture was critiqued as pathogenic.<sup>90</sup> More recently, people with Mexican passports were quarantined in China due to fears of H1N1.<sup>91</sup> In each of these cases, the identification of the feared disease with foreigners led officials to assume that public health protection demanded the derogation of that groups' rights rather than measures that were supportive of everyone at risk.

## B. Emerging Infections and Public Health Preparedness

44. In the last two decades, as globalization has intensified, fears about infectious disease have coalesced around the danger of so-called emerging diseases. These are newly discovered or newly drug-resistant pathogens, such as HIV, bovine spongiform encephalopathy (BSE), severe acute respiratory syndrome (SARS), Ebola, extensively drug-resistant tuberculosis (XDR-TB), and pandemic influenza, which are thought to pose a rapid threat to global health and for which public health officials are urged to prepare.
45. As many scholars have noted, the fear and drama of emergence, at least in the West, has come to take a stock form, utilizing formulaic plots and stereotypical characterizations. This form is what Priscilla Wald calls the "outbreak narrative."<sup>92</sup> As Wald explains, the outbreak narrative frequently relies first on the identification of an emerging infection; second on a discussion of the dangers posed by global trade and travel, which are said to facilitate the infection's rapid spread around the world; third on warnings about the perils of global interdependence, often personified in the form of so-called super-spreaders, people (typically foreigners) who rapidly communicate the emerging infection around the world; and finally, on the triumph of scientific authority, which presumably saves the world by acting with speed and rationality. According to Nicholas B. King, this "emerging disease world view," offers a "consistent, self-contained ontology of epidemic disease.... It comes equipped with a moral economy and historical narrative, explaining how and why we find ourselves in the situation that we do now, identifying villains and heroes, ascribing blame for failures and credit for triumphs."<sup>93</sup>
46. Although the emerging disease narrative often ends on a note of reassurance about the powers of science, thereby reinforcing the prestige and sometimes the authority granted to scientists and health officials, it reflects and heightens widely-held anxieties about globalization, ecological degradation, and lack of individual control, or as Laurie Garrett warned, a "world out of balance."<sup>94</sup> According to King, the perspective also recreates colonialism's obsession with boundaries and the dangers that can emanate from the developing world.<sup>95</sup> Hence, the story of someone getting on a plane in Africa and spreading a mysterious disease to a high income country is a common trope of the emerging epidemic literature.<sup>96</sup>

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<sup>89</sup> Lupton, *The Imperative of Health*.

<sup>90</sup> Roberta Bivens, "'The English Disease' or 'Asian Rickets'? Medical Responses to Postcolonial Immigration," *Bulletin of the History of Medicine*, 81(3) (2007): 533-568.

<sup>91</sup> Ibid.

<sup>92</sup> Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative*, (Durham, North Carolina: Duke University Press, 2007), 2-3.

<sup>93</sup> Nicholas B. King, "Security, Disease, Commerce: Ideologues of Postcolonial Global Health," *Social Studies of Science* 32 (2002): 763-89.

<sup>94</sup> Laurie Garrett, *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* (New York: Farrar, Straus & Giroux, 1994); Tomes, "The Making of a Germ Panic"; Moeller, *Compassion Fatigue*, 59.

<sup>95</sup> King, "Security, Diseases, Commerce," 772.

<sup>96</sup> The prime example is Richard Preston, *The Hot Zone: A Terrifying True Story* (New York: Random House, 1994).

47. Despite its reliance on widely-diffused (at least in the North) fears of globalization and interdependency, the emerging disease narrative did not arise *sua sponte*.<sup>97</sup> Rather it has been nurtured by science reporters, scientists, public health experts, government officials, and even health and human rights activists. For example, Randy Shilts' classic history of the early years of the HIV/AIDS epidemic, *And the Band Played On*, featured the story of Gaetan Dugas, the peripatetic, super-spreader who was implausibly credited with spreading HIV around the world, reinforcing both the idea that global travel enhances risk and the assumption that particular individuals must be to blame for epidemics.<sup>98</sup> Shortly after Shilts' published his masterpiece, infectious disease researchers began warning about the problem of "emergence." King dates the birth of these alarms to a 1989 conference sponsored by the National Institutes of Health and Rockefeller University.<sup>99</sup> Following that conference, the Institute of Medicine in the U.S. issued several different reports on the dangers of emerging infections.<sup>100</sup> These reports, as well as Laurie Garrett's influential paper, *The Return of Infectious Disease*, explicitly linked the threat of emerging infections to economic and security interests,<sup>101</sup> a tactic that helped researchers attract both funding and the avid attention of policymakers. At the same time, HIV activists and other advocates for the health care needs of people in Africa were quick to concur about the risk, perhaps in the belief that the West would turn its attention to the health care problems of low-income nations only if it thought its own health and security was at stake.<sup>102</sup>
48. By the mid-1990s, popular books such as Laurie Garrett's, *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* and Richard Preston's *The Hot Zone: A Terrifying True Story* brought the narrative to popular consciousness at least in the English-speaking world. Hollywood movies such as *Outbreak* further reinforced the perspective's essential elements, exporting its themes around the world. Both the public and policymakers took notice. For example, in 1996, public health officials from the U.S. and Europe agreed to establish a global early warning network to track and alert officials about emerging infections.<sup>103</sup> Since then the need for international cooperation and coordination against the global threat of infectious disease has been a standard feature of the emerging disease narrative. Yet to a large degree, the diseases provoking these calls for international cooperation have been ones that threaten populations in high income countries. With the significant exception of HIV/AIDS and to a lesser degree tuberculosis (TB), malaria and polio, the great infectious killers of low income nations have been failed to attract international attention and cooperation.
49. Since the 1990s, a variety of factors, including the discovery during the first Gulf War of Iraq's bioweapons program, increased knowledge about the biological weapons programs of the former Soviet Union, and experiments by the Japanese cult Aum Shinrikyo, provoked new worries about biological weapons.<sup>104</sup> In the mid-1990s U.S. President Clinton allocated \$158 million for research in bioterrorism defense and what was becoming known as

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<sup>97</sup> For a discussion of the development of the perspective, see Randall M. Parkard et al., eds, *Emerging Illness and Society: Negotiating the Public Health Agenda* (Baltimore: Johns Hopkins Univ. Press, 2004).

<sup>98</sup> Randy Shilts, *And the Band Played On: Politics, People and the AIDS Epidemic* (New York, Penguin Books, 1988).

<sup>99</sup> King, "Security, Diseases, Commerce," 767.

<sup>100</sup> Joshua Lederberg, Robert E. Shope, & Stanley C. Oaks, Jr., eds. *Emerging Infections: Microbial Threats to Health in the United States* (Washington, D.C.: National Academies Press, 1992).

<sup>101</sup> Laurie Garrett, "The Return of Infectious Disease," *Foreign Affairs* 75 (2006): 66-79.

<sup>102</sup> This point is made repeatedly in the literature of the era. Laurie Garrett, *Betrayal of Trust: The Collapse of Global Public Health* (New York: Hyperion, 2000).

<sup>103</sup> Norman Kempster, "Global Alert on Budding Epidemics Urged: Health Officials in U.S., Europe Agree on Warning Network to Deal with "Food-Borne" Illnesses, Plan Could Expand to Cover All Communicable Diseases," *Los Angeles Times*, Nov. 28, 1996, A44.

<sup>104</sup> Lawrence O. Gostin, "When Terrorism Threatens Health: How Far Are Limitations on Personal and Economic Liberties Justified?," *Florida Law Review* 55:5 (2003): 1110-1169.

“preparedness.”<sup>105</sup> By early 2001, key government officials in the U.S. were participating in “table top” exercises that simulated bioterrorist attacks on the United States.<sup>106</sup>

50. The fears about biological weapons appeared justified in the fall of 2001, when weaponized anthrax was sent in the U.S. mail, killing 5 people and sickening many more.<sup>107</sup> According to Jane Mayer, the anthrax attacks were particularly terrorizing to U.S. policymakers and helped to provoke the Bush Administration’s approach to terrorism.<sup>108</sup> They also helped to transform the emerging epidemic perspective into one which emphasized the similarities between naturally occurring infections and bioterrorism. As Nicholas King notes, like Typhoid Mary and Gaetan Dugas, the bioterrorist “personifies difference, transgression, and contamination...[t]his culpable foreigner exposes the increasing permeability of national borders and the vulnerability of American citizens in an increasingly interconnected world.”<sup>109</sup>
51. The incorporation of fears of bioterrorism with the emerging epidemic perspective helped to solidify the convergence between public health protection and national security,<sup>110</sup> or what David P. Fidler and Lawrence O. Gostin term “biosecurity.”<sup>111</sup> Biosecurity emphasizes the dangers of all outbreaks, whether natural or manmade, and counsels on the need for preparedness.<sup>112</sup> Essential to the latter, biosecurity proponents contend, is the development, clarification, and coordination of robust public health emergency powers, such as those suggested by the MSEHPA, sponsored by the U.S. Centers for Disease Control and Prevention and drafted by Georgetown and Johns Hopkins Universities in the fall of 2001. Premised on the assumption that government officials would need to invoke strong social controls if there was either a bioterrorist event or an emerging epidemic, the MSEHPA offered a model law that would allow officials to restrict civil liberties in the event of a “public health emergency.”<sup>113</sup> Although it was widely criticized by civil libertarians, the MSEHPA was adopted in whole or in part by many U.S. states. Perhaps more important than the MSEHPA’s actual content was the rhetoric used to justify it, which emphasized that officials would need to restrict individual rights in the event of a public health emergency.

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<sup>105</sup> Laurie Garrett, “U.S. Flunks Germ War Exercise,” *New Orleans Time-Picayune*, Feb. 22, 1999, 14E.

<sup>106</sup> Gostin, “When Terrorism Threatens Health,” 1113.

<sup>107</sup> Lawrence O. Gostin, *Public Health Law: Power, Duty, Restraint* (Berkeley: Univ. of California Press, 2d ed. 2008), 438.

<sup>108</sup> Jane Mayer, *The Dark Side: The Inside Story of How the War on Terror Turned into a War on American Ideals* (New York: Doubleday, 2008).

<sup>109</sup> Nicholas King, “The Influence of Anxiety: September 11, Bioterrorism and American Public Health,” *Journal of the History of Medicine* 58 (2003): 433-441.

<sup>110</sup> *Ibid.*

<sup>111</sup> David P. Fidler & Lawrence O. Gostin, *Biosecurity in the Global Age: Biological Weapons, Public Health and the Rule of Law* (Stanford, California: Stanford University Press, 2008).

<sup>112</sup> Georges C. Benjamin & Anthony D. Moulton, “Public Health Legal Preparedness: A Framework for Action,” *Journal of Law, Medicine & Ethics* 36 (Special Supp., 2008): 13-14.

<sup>113</sup> MSEHPA.

### **The Model State Emergency Health Powers Act**

In the fall of 2001, the United States Centers for Disease Control and Prevention asked the Center for Law and the Public's Health at Georgetown and Johns Hopkins Universities to draft a model law granting state governors and health officials emergency powers to use in response to a public health emergency. The Model State Emergency Health Powers Act (MSEHPA) was designed to serve as a template for discussion and consideration by state legislatures. Since 2001 many states have adopted some or all of its provisions.

The MSEHPA requires states to develop a public health emergency plan. It also mandates that health care workers report "all cases of persons who harbor any illness or health condition that may be potential causes of a public health emergency." In addition, the act empowers the governor to declare a "public health emergency" upon the "occurrence or imminent threat of an illness or health condition" that is caused by bioterrorism or a novel or previously eradicated infection which "poses a high probability" of a large number of deaths, long term disabilities, or substantial future harm to a large number of people. A governor's declaration of a public health emergency is unreviewable, although it can be overridden by a vote of both houses of the state legislature.

Upon the declaration of a public health emergency, the MSEHPA gives health officials a broad range of powers, including the power to control health care facilities, limit access to or from a stricken region, ration health care products, impose isolation and/or quarantine, and require individuals to submit to medical examinations, vaccination, or treatment (or be placed in isolation or quarantine if they refused to submit).

The Act requires that isolation and quarantine must be "by the least restrictive means necessary" to prevent the spread of contagion and that people detained be given "adequate food, clothing, shelter, means of communication... medication, and competent medical care." Individuals subjected to isolation and quarantine are given the right to petition for judicial review of their confinement as well as the right to be represented by counsel, at the state's expense. Both the state and its officials, however, are granted broad immunities for any deaths injuries that occurred as a result of their exercise of any authority granted under the Act.

Center for the Law and Public's Health, Georgetown and Johns Hopkins Universities, Model State Emergency Health Powers Act (2001) [MSEHPA], [www.publichealthlaw.net/MSEHPA/MSEHPA2.pdf](http://www.publichealthlaw.net/MSEHPA/MSEHPA2.pdf).

52. As David P. Fidler and Lawrence O. Gostin make clear, the biosecurity perspective was not unique to the United States.<sup>114</sup> For example, in 2000 the United Nations Security Council discussed HIV/AIDS as a security threat.<sup>115</sup> That same year, WHO initiated the Global Outbreak and Response Network, an international collaboration of technical organizations and surveillance networks designed to pool resources to promote the rapid identification and response to new disease threats.<sup>116</sup> And in 2004 the UN Secretary General's High-Level Panel on Threats, Challenges and Change emphasized the relationship between public health and international security.<sup>117</sup> A year later, Secretary General Kofi Annan called for an expanded role for the Security Council in the event of "an overwhelming outbreak of infectious disease that threatens international security."<sup>118</sup> That same year, the World Health Assembly ratified the IHR in response to the fears that diseases could be spread quickly by travelers.

<sup>114</sup> Fidler & Gostin, *Biosecurity in the Global Age*.

<sup>115</sup> Therese Murphy & Noel Whitty, "Is Human Rights Prepared? Risk, Rights and Public Health Emergencies," *Medical Law Review* (2009): 4.

<sup>116</sup> WHO, "Global Outbreak and Response Network," <http://www.who.int/csr/outbreaknetwork/en/> (accessed on July 17, 2009).

<sup>117</sup> Fidler & Gostin, *Biosecurity in the Global Age*.

<sup>118</sup> Murphy & Whitty, "Is Human Rights Prepared?," 7.

53. In the past decade, a cascade of incidents and outbreaks has been viewed through and reinforced the emerging disease perspective, effectively priming the world for future public health panics. Most importantly, although very few people died worldwide, the 2003 SARS epidemic highlighted the ease with which a new disease could rapidly spread around the globe. To many observers, SARS also demonstrated the need for enhanced surveillance, compulsory quarantine, and stronger controls on travel. Not surprisingly, the fear of SARS dramatically overshadowed the actual risk of the disease. A short time later, attention turned to the spread of H1N5 avian influenza, which was rapidly spreading among birds and appeared to be highly lethal (though not very infectious) in human beings. Spurred by the leadership of WHO, which warned that influenza pandemics could kill millions of people, cause “social disruption, and profound economic losses around the world,” nations began “preparedness planning” for a possible pandemic.<sup>119</sup> According to WHO, steps to be taken included enhancing surveillance capacity, improving coordination between health officials domestically and internationally, and reviewing a wide range of legal and ethical issues. Tellingly, WHO stated:

During a pandemic, it may be necessary to overrule existing legislation or (individual) human rights. Examples are the enforcement of quarantine (overruling individual freedom of movement), use of privately owned buildings for hospitals, off-license use of drugs, compulsory vaccination or implementation of emergency shifts in essential services. These decisions need a legal framework to ensure transparent assessment and justification of the measures that are being considered, and to ensure coherence with international legislation (International Health Regulations).<sup>120</sup>

54. In the spring of 2009 a new strain of influenza, Type A, H1N1 emerged in North America. Within days, the disease had spread around the world and dominated media coverage. For a short time, a full scale public health panic erupted. Fortunately, within a few weeks, it became evident that the virus was not as lethal as first feared. Most cases are mild. However, the disease can be fatal, and in contrast to seasonal flu, H1N1 is inflicting a disproportionate toll on the young. Most likely, the emergence of H1N1 and its rapid diffusion around the globe will reinforce the emerging disease perspective.
55. Critically, the emergence of diseases such as H1N1 or SARs affirms the paradoxical nature of the emerging disease perspective and public health panics. Without doubt, these diseases were and are real; they spread rapidly across the globe and have killed many people and have disrupted many more lives. Thus the lessons they teach about the risks of the spread of infection in the era of globalization are not false: diseases can spread and kill rapidly. Environmental disruption, trade, and travel can and do increase the risk of epidemics. To this extent, the emerging infection perspective tells a true tale that governments must not ignore if they are to fulfill their obligation to protect the health of their populations.
56. Nevertheless, the emerging disease perspective is problematic for several inter-related reasons. First, it threatens to detract attention and resources away from the many endemic and chronic conditions that pose far greater risks to most of the world’s population, especially in low income countries, but also in high income nations. Thus states devote limited public health resources to preparedness planning in lieu of interventions that target more frequent killers. Second, the perspective reinforces xenophobia and stereotypes, providing a framework by which new disease threats are blamed on the “other.” Third, it perpetuates the securitization of public health. As a result, states are more apt to rely on highly coercive social controls, rather than the affirmation of human rights, in the face of public health threats. In effect, by supporting public

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<sup>119</sup> WHO, “WHO Checklist for Influenza Pandemic Preparedness Planning,” 2005, [http://www.who.int/csr/resources/publications/influenza/WHO\\_CDS\\_CSR\\_GIP\\_2005\\_4/en/](http://www.who.int/csr/resources/publications/influenza/WHO_CDS_CSR_GIP_2005_4/en/).

<sup>120</sup> Ibid., 5.

health panics, the emerging disease perspective emphasizes the conflict between, rather than the compatibility of health and human rights, giving rise to policies that may do little to protect either.

### III. PUBLIC HEALTH SOCIAL CONTROLS AND HUMAN RIGHTS: CASE STUDIES

57. To some degree, all public health interventions are methods of social control. They all seek to influence or alter the social environment to promote public health. However, as discussed above, most public health interventions do not threaten human rights. Indeed, many public health interventions aim to improve public health by simultaneously supporting or fulfilling other human rights and needs, for example, by providing education or protecting individuals from torture or violence. In these situations, health and human rights are complementary.<sup>121</sup>
58. Conflicts between health and human rights arise, however, when states rely upon coercive interventions that limit the liberty or rights of individuals or populations. Many of these interventions are applied in response to infectious diseases, particularly contagious diseases, such as emerging epidemics, that engender tremendous fear. This Section reviews several coercive social controls that are commonly used in the face of infectious diseases and examines how they have limited liberty, privacy and equality.<sup>122</sup> These measures, which include surveillance, exclusion, preventive detention, and criminalization bear striking resemblances to social controls that states employ in response to other perceived social threats, such as terrorism or criminality.

#### A. Surveillance

59. The social control literature notes the widespread increase in recent decades of state, or state-sponsored, surveillance. This increase in surveillance, and the concomitant decrease in privacy, is firmly established in infectious disease control. Indeed, surveillance provides the foundation for all other public health interventions. It enables public health officials to attain the information they need to identify, analyze, and develop responses to health care threats, including infectious diseases. Perhaps for this reason, General Comment 14 specifically requires states to use and improve epidemiological surveillance.<sup>123</sup>
60. The IHR also compels states to enhance their surveillance capacities. The IHR defines surveillance as “the systematic ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary.”<sup>124</sup> Public health information can be obtained by health officials and others through a number of methods, many of which are involuntary. Not surprisingly, involuntary means of surveillance raise the greatest human rights concerns. These include:
- Case reporting - requires health care providers (or others) to report to officials about particular cases of a disease. Case reporting can be either anonymous (for example, using unique identifiers) or by name. It can also be used to identify, warn, or examine contacts of infected individuals (contact tracing);
  - Mandatory testing -requires the testing of particular individuals for a given disease. Mandatory testing is almost always accompanied by case reporting;
  - Screening - tests broad populations for a particular health condition; and

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<sup>121</sup> Even in these situations, human rights violations can occur if the interventions are applied in a discriminatory manner.

<sup>122</sup> This Report does not review the human rights impact of all of the many interventions that states use in response to infectious disease. Instead, it considers some of the most common and commonly-discussed infectious disease controls. Others that warrant further review include the control and dissemination of information, contact tracing, the regulation of the food supply, and the regulation of the health care system.

<sup>123</sup> CESCR, General Comment No. 14, art. 12, 16.

<sup>124</sup> IHR, art. 1.

- Syndromic surveillance - relies on mining vast amounts of data, including individually-identifiable data, such as purchases of medications, or internet searches, to gather public health information.
61. Information obtained from these methods can be critical to recognizing, understanding, and organizing a response to disease. Indeed, without information gleaned from such interventions, public health officials would not have been able to identify and protect the public from emerging epidemics such as HIV and SARS. It is for this reason, that WHO and public health experts around the world view surveillance as central to global efforts against infectious diseases. Moreover, global campaigns against pandemic influenza, XDR-TB, and other emerging infections have all stressed the need for enhanced surveillance, especially in developing countries. Indeed, some commentators have noted that emerging disease perspective and the convergence of public health with international security results in an almost insatiable demand for surveillance.<sup>125</sup> This demand raises critical questions about resource allocation and distributive justice; in particular, whether developing nations that face a wide-range of preventable endemic diseases should invest limited public health resources to augment their capacity to conduct surveillance about relatively rare diseases that have the potential to travel to other regions of the world.
  62. Despite its importance, surveillance operates as a social control that can have profound implications for liberty, privacy, and equality. Indeed, even the most benign forms of surveillance (from a human rights perspective), such as syndromic surveillance, which looks at individual medical information but does not compile individual names, can help construct notions of normality and expectations as to how people should live their lives.<sup>126</sup> From a human rights perspective, however, the most problematic forms of surveillance are mandatory testing and screening, especially when they entail the involuntary invasion of an individual's body. Mandatory reporting, in which personal medical information is reported to government officials without an individual's consent also threatens an individual's privacy, an interest explicitly protected by Article 17 of the ICCPR as well as Article 8 of the Charter of Fundamental Rights of the European Union.<sup>127</sup> This loss of privacy can result in a numerous negative social consequences, including ostracism, stigma, discrimination, and loss of livelihood. For this reason, the IHR requires public health officials to respect the confidentiality of identifiable health information.<sup>128</sup> Nevertheless, even the reporting and compilation of unidentified data, while critical to developing effective responses to health risks, and to spotting and addressing health disparities, can reinforce stigma and discrimination against vulnerable groups.<sup>129</sup> For example, information on the incidence of STIs among sex workers can help health officials protect the health of that vulnerable group, but it can also reinforce negative images and policies towards these workers.
  63. Despite the human rights risks they present, mandatory reporting requirements are relatively common. For example, New Zealand subjects approximately 50 diseases to mandatory reporting; in the U.S. CDC requires states to notify it about approximately 60 infectious diseases, although states' laws vary widely as to how many of these diseases are subject to

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<sup>125</sup> Martin A. French, "Woven of War-Time Fabrics: The Globalization of Public Health Surveillance," *Surveillance and Society*, 6(2) (2009): 101-115.

<sup>126</sup> Lupton, *The Imperative of Health*, 25.

<sup>127</sup> Charter of Fundamental Rights of the European Union, art. 8, Dec. 18, 2000 O.J. (C 364) 1.

<sup>128</sup> IHR, art. 45.

<sup>129</sup> Scott Burris, "Surveillance, Social Risk, and Symbolism: Framing the Analysis for Research and Policy," *Journal of Acquired Immunodeficiency Syndromes* 25 (2000): S120-S127.

mandatory reporting.<sup>130</sup> Many jurisdictions also require reporting about non-infectious diseases and health risks, including injuries, acts of violence, and even cases of cancer.

64. The use of mandatory reporting and other forms of surveillance in the HIV epidemic demonstrates the contentious relationship between surveillance, public health, and human rights. At the start of the epidemic, HIV was an emerging infection that triggered great fear and hence heightened demands for surveillance. Health officials and scientists had a pressing need to obtain data, both to learn about the disease's epidemiology and to develop prevention policies. Nevertheless, early surveillance data demonstrating the disproportionate incidence of HIV among gay men led initially to false assumptions that it was a gay disease, known for a time as gay-related immunodeficiency syndrome, or GRID. This association helped to reinforce stigma and discrimination and may have deterred people from seeking care or working with health officials. As a result, many health officials came to believe that both privacy and non-discrimination were crucial to preventing the spread of HIV. Not all states, or public health officials, however, accept these premises. Indeed, many assert that human rights protections have hindered prevention efforts, thereby undermining the "rights" of the uninfected to remain uninfected.
65. At the start of the HIV epidemic, many nations, including the U.S., Soviet Union, Italy, and Denmark, mandated name-based reporting of persons diagnosed with AIDS.<sup>131</sup> This mandate was relatively uncontroversial because people with AIDS were extremely ill and in need of medical care. In effect, absolute anonymity was not a viable option. However, once scientists developed a test to determine whether individuals who did not have AIDS were infected with the human immunodeficiency virus, a controversy erupted. Many health officials wanted named-based reporting because they felt that it would enhance the reliability of their data. Some health officials also wanted to be able to contact the sexual partners of those who tested positive. In contrast, HIV advocacy organizations and other public health experts rejected named-based reporting. First, they argued that given the epidemiology of the HIV infection, particularly the fact that people could have been infected years before they were tested, contact tracing was impractical, especially in high prevalence areas (contact tracing, however, has been used for HIV in some jurisdictions, such as Sweden).<sup>132</sup> Second, they argued that the use of unique identifiers, rather than names, would yield reliable data. Finally, they believed that assurances of confidentiality (which for all practical purposes could not be maintained if contact tracing was conducted) would not persuade those who feared discrimination to consent to be tested.<sup>133</sup> For this reason, many jurisdictions established anonymous testing sites. Advocates of named-reporting lambasted these moves as "AIDS exceptionalism" and argued that the names of individuals who were infected with HIV should be reported to public health authorities, just as the names of individuals with many other diseases are reported.<sup>134</sup> To many critics, the lack of named reporting denied officials with the information they needed to best address the epidemic.

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<sup>130</sup> Nuffield Council on Bioethics, Public Health Ethical Issues; Centers for Disease Control and Prevention [CDC], "Nationally Notifiable Infectious Diseases," CDC, <http://www.cdc.gov/ncphi/diss/nndss/phs/infdis.htm> (accessed on July 17, 2009).

<sup>131</sup> UNAIDS, *The Role of Name-Based Notification in Public Health and HIV Surveillance*, UNAIDS/00.28E (2000), [http://www.who.int/hiv/strategic/surveillance/en/unaids\\_00\\_28e.pdf](http://www.who.int/hiv/strategic/surveillance/en/unaids_00_28e.pdf).

<sup>132</sup> John A. Harrington, "The Instrumental Uses of Autonomy: A Review of AIDS Law and Policy in Europe," *Social Science & Medicine* 55 (2002): 1425-1434.

<sup>133</sup> For a discussion of the debate see Michael A. Stoto, "Public Health Surveillance in the Twenty-First Century: Achieving Population Health Goals While Protecting Individuals' Privacy and Confidentiality," *Georgetown Law Journal* 96 (January 2008): 703-709; Peter Baldwin, *Disease and Democracy, The Industrialized World Faces AIDS* (Berkeley: University of California Press, 2005).

<sup>134</sup> Named reporting can still be confidential, in the sense that the information is withheld from everyone other than health officials. WHO and UNAIDS recommend that all reporting be confidential, accompanied by counseling, and conducted only with informed consent. WHO & UNAIDS, "UNAIDS/WHO Policy

66. In recent years, the debate about named reporting has partially subsided. The development and scale up of highly active antiretroviral therapy (HAART) has undermined the argument that people will avoid testing if their names are reported. For this reason, in the U.S. CDC now requires named reporting.<sup>135</sup> On the other hand, the United Kingdom continues to reject mandatory reporting.<sup>136</sup> And after having initially required named reporting, Thailand abandoned it in favor of more anonymous approaches to surveillance in order to improve prevention efforts among high risk groups.<sup>137</sup>
67. From a human rights perspective, mandatory screening and testing raise far more complex issues than named reporting. In the HIV context, mandatory screening can be done by anonymously testing blood that has been drawn for other reasons, in which case it is known as unlinked anonymous testing (UAT). UAT has routinely been conducted at many antenatal clinics around the world. Although it does not violate a woman's right to confidentiality, it may violate her right to informed consent, a right that WHO and UNAIDS have identified as central to a "rights based approach" to HIV/AIDS.<sup>138</sup> In addition, in some cases, clinics have misled women as to the reason for the blood-drawing. For example, in Ethiopia, some clinics offered syphilis testing in order to conduct UAT for HIV.<sup>139</sup> By effectively deceiving patients, this practice jeopardizes their right to informed consent and threatens to undermine trust between patients and health care providers.
68. UAT may also be applied in a discriminatory manner. Thus as was noted above, UAT has often been employed only on pregnant women, an already vulnerable group. In addition, public clinics in some nations have provided care for patients essentially as an inducement to obtain testing. In other countries, such as Bangladesh, sex workers have been particular targets of UAT.<sup>140</sup> This use of UAT has the potential to reinforce stigma and discrimination against vulnerable populations.
69. Critics have also pointed to a very different type of human rights threat associated with UAT. Because UAT is anonymous, individuals who test positive for HIV are not identified and are not offered treatment. In effect, officials obtain the surveillance data they want without supporting the health needs of those from whom they obtain the information. As a result, UAT may help sustain a state's failure to support the health care needs and rights of its population.<sup>141</sup>
70. Even more problematic, from a human rights perspective, is the practice of forced, identified testing. Perhaps the most glaring example of the human rights abuses that may follow from involuntary testing comes from Cuba. In the 1986 Cuba began testing all blood donors and people who had spent time in Africa. By 1987 all pregnant women, all hospital patients, all inmates, and all patients with STIs were tested.<sup>142</sup> In 1989 Cuba opened its first HIV sanatorium and subjected those who tested positive to long-term confinement. That policy ended in 1994,

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Statement on HIV "Testing," WHO (June 2004), [http://www.who.int/ethics/topics/en/hivtestingpolicy\\_who\\_unaids\\_en\\_2004.pdf](http://www.who.int/ethics/topics/en/hivtestingpolicy_who_unaids_en_2004.pdf).

<sup>135</sup> Douglas Frye et al., "Concerns About Article on Code-Versus-Name Reporting of HIV," *Journal of Acquired Immune Deficiency Syndromes* 43 (2006): 249-250. A related issue, not discussed in this paper is whether health care providers have a legal and/or ethical duty to warn the sexual partners of HIV patients.

<sup>136</sup> Nuffield Council on Bioethics, *Public Health: Ethical Issues*, 66.

<sup>137</sup> UNAIDS, *The Role of Name-Based Notification in Public Health*, 15.

<sup>138</sup> WHO & UNAIDS, "UNAIDS/WHO Policy Statement on HIV Testing."

<sup>139</sup> Stuart Rennie et al., "Conducting Unlinked Anonymous HIV Surveillance in Developing Countries: Ethical, Epidemiological, and Public Health Concerns," *PLoS Medicine* 6(1) (2009): 0031, <http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1000004>.

<sup>140</sup> Ibid.

<sup>141</sup> Ibid.

<sup>142</sup> Sheri Fink, "Cuba's Energetic AIDS Doctor," *American Journal of Public Health* 93(5) (2003): 712-716.

although as late as 2004 individuals who tested positive were still spending up to three months in the sanatorium learning how to live with their disease.<sup>143</sup> Moreover, pregnant women are still subject to mandatory testing.<sup>144</sup> Although some advocates of coercive public health interventions have credited Cuba's policy with its relatively low incidence of HIV, and hence contend that the violation of informed consent and liberty of movement were outweighed by the public health protection achieved, others note that a variety of other factors, including the island's relative isolation and its strong health care system, are probably equally if not more responsible for its low HIV rates.

71. Cuba, however, is not the only nation that has imposed involuntary testing. Elizabeth Kantor reports that as of 2003, 19 U.S. states and the U.S. federal government required inmates to be tested for HIV.<sup>145</sup> In many cases, positive tests result in segregation from the general prison population. Similar practices occur in other nations.<sup>146</sup> In Europe, most jurisdictions have resisted mandatory testing, but early in the epidemic Bavaria instituted compulsory testing for sex workers, non-European immigrants, and new civil servants.<sup>147</sup> Other jurisdictions, including parts of China, Mexico, and Malaysia, have required testing in order to marry, thereby implicating not only rights to privacy and informed consent, but also rights to marry and form families.<sup>148</sup> Armenian law appears to permit mandatory testing without offering any assurances of confidentiality.<sup>149</sup> And as will be discussed further in Section B, many other nations continue to impose HIV testing on travelers and immigrants, in effect undermining their rights to informed consent, as well as to travel and immigrate.
72. Critically, these mandatory tests cannot be justified on public health grounds. To the contrary, while public health officials have a pressing need to obtain up-to-date surveillance data on HIV so that they can track the epidemic and allocate prevention and treatment programs where they are needed, this information can be usually be obtained via voluntary, confidential testing, especially when it is well-integrated into a nation's health care delivery system. Indeed, states are far more likely to obtain robust data if they support human rights by providing accessible health services and guarding against discrimination, than they are from involuntarily testing particular, vulnerable groups, such as prisoners, travelers, and sex workers.
73. Although most states accept that at least in the general population testing should only be done with informed consent, significant debates continue as to what that actually means and requires. For example, many public health practitioners and officials believe that laws requiring patients to explicitly consent to HIV testing impede wide-scale testing and thereby undermine prevention. Reflecting this perspective, in 2007 WHO and UNAIDS issued a new guidance for providers that recommended, except for highly vulnerable populations, an "opt-out" model of HIV testing in which all patients are advised to be tested, provided with relatively simple, basic

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<sup>143</sup> Shawn C. Smallman, *The AIDS Pandemic in Latin America* (Chapel Hill: North Carolina Press, 2007), 61.

<sup>144</sup> Hector de Arazoza et al., "The HIV/AIDS Epidemic in Cuba: Description and Tentative Explanation of its Low HIV Prevalence," *BMC Infectious Diseases* 7 (2007): 130, <http://www.biomedcentral.com/1471-2334/7/130>.

<sup>145</sup> Elizabeth Kantor, "HIV Transmission and Prevention in Prisons," *HIV InSight* (April 2006), <http://hivinsite.ucsf.edu/InSite?page=kb-07-04-13>.

<sup>146</sup> Cory Weinstein & Judy Greenspan, "Mandatory HIV Testing In Prisons," *American Journal of Public Health* 93(10) (Oct. 2003): 1617; Rick Lines, "HIV/AIDS and Prisoners: The Case Against Segregation," Prisoner's HIV/AIDS Support Action Network, <http://www.pasan.org/Publications/Anti-Seg.pdf>.

<sup>147</sup> John Harrington, "The Instrumental Uses of Autonomy: A Review of AIDS Law and Policy in Europe," *Social Science and Medicine* 55(8) (2002): 1425-34.

<sup>148</sup> Stuart Rennie & Bavon Mupenda, "Ethics of Mandatory Premarital HIV Testing in Africa: The Case of Goma, Democratic Republic of Congo," *Developing World Bioethics* 8(2) (2008): 125-137.

<sup>149</sup> Karine M. Markosyan, Aramays Kocharyan & Artur Potosyan, "Meeting the Challenge of Injection Drug Use and HIV in Armenia," *Health and Human Rights* 9(1) (2006): 128-151.

information about the test, and are assumed to have consented to testing unless they specifically ask not to be tested.<sup>150</sup> The UNAIDS Reference Group on HIV and Human Rights, an independent advisory board to UNAIDS, responded to this new guidance by noting that opt-out testing might in practice result in individuals being tested without informed and voluntary consent. The Reference Group further worried that an increase in provider-initiated testing might cause certain populations to forego needed medical care.<sup>151</sup> This debate continues.

74. The story of HIV testing is sometimes read as demonstrating the misguided triumph of HIV exceptionalism. In fact, the lessons are more complex. The debates that were waged and the battles that were fought during the early years of the HIV epidemic helped to demonstrate the need and value of surveillance, the risk to human rights that arise when fear and animosity to particular groups drives policy, and the ways in which respect for a wide range of human rights, including non-discrimination, privacy, and autonomy, can help safeguard the human right to public health protection.

## **B. Exclusion: Immigration and Travel Restrictions**

### *i. SARS and The IHR*

75. Public health interventions have long sought to exclude travelers and immigrants in an attempt to keep a disease out of a nation or region. In the middle ages, Venice sought to keep out plague by requiring ships and merchants to wait forty days before entering the city, a practice which gave rise to the English term “quarantine.” In the nineteenth century, nations responded to outbreaks of cholera by quarantining vessels and limiting trade. Perhaps not surprisingly, these interventions were criticized by advocates of free trade. In response to the controversy, France hosted the first international sanitary convention, which sought to produce a treaty clarifying states’ ability to limit travel and trade in order to prevent the spread of disease.<sup>152</sup>
76. Today nations utilize a variety of interventions to keep diseases out of their borders. Many of these interventions, including inspection of goods and bans on the importation of products that are suspected of causing disease, implicate the complex and difficult relationship between international trade, development, and public health.<sup>153</sup> Although the relationship between trade and public health protection is especially salient in the current era of globalization, this Report focuses on restrictions on travelers and immigrants. These restrictions can take several forms, including:
- Area- based travel restrictions – in which states either ban travel to or from particular regions;
  - Medical examinations and testing - states may require everyone or only non-nationals entering their country to undergo medical examinations and tests. States may also require travelers or immigrants to show proof of immunization;

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<sup>150</sup> WHO & UNAIDS, “Guidance on Provider Initiated HIV Testing and Counseling in Health Facilities,” (May, 2007), 5, [http://whqlibdoc.who.int/publications/2007/9789241595568\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf).

<sup>151</sup> UNAIDS Reference Group on HIV and Human Rights, “Statement and Recommendations on Scaling Up HIV Testing and Counseling,” (2007), [http://data.unaids.org/pub/BaseDocument/2007/070216\\_HHR\\_1\\_PITC.pdf](http://data.unaids.org/pub/BaseDocument/2007/070216_HHR_1_PITC.pdf) (accessed October 23, 2009).

<sup>152</sup> David P. Fidler, “The Future of the World Health Organization: What Role for International Law,” *Vanderbilt Journal of Transnational Law* 31 (1998): 1079- 1126.

<sup>153</sup> These issues are governed by the World Trade Organization and multi-lateral trade agreements.

- Disease-specific bans - states may ban individuals with particular diseases from either entering their country, immigrating, receiving asylum or working in their country; and
  - Isolation and quarantine - states may quarantine travelers, immigrants, or would-be asylum seekers for a period of time if they are suspected of having been exposed to an infectious disease. States may also isolate people with an infectious disease until they are no longer infectious.<sup>154</sup>
77. Contemporary international law grants states wide authority to impose a variety of controls on travelers and immigrants in the name of public health. In particular, the 2005 revisions of the IHR aims “to prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks, and which avoid unnecessary interference with international traffic and trade.”<sup>155</sup> To that end, the IHR authorizes WHO to issue advisories against travel to or from specific regions and recognize the power of states to impose a wide range of restrictions on both travelers and trade.<sup>156</sup> In addition, the IHR allows states to require travelers to present health information, including proof of vaccination, and to submit to a non-invasive medical examination “which is the least intrusive” necessary to achieve the intended public health goal.<sup>157</sup> In the event of an “imminent public health risk” states may, to the “extent necessary,” demand invasive medical examinations, vaccination or other prophylaxis, and impose “additional established health measures that prevent or control the spread of disease, including isolation, quarantine or placing the traveler under public health observation.”<sup>158</sup>
78. While permitting states to impose significant restrictions on travelers, the IHR also tries to protect human rights. In particular, the regulations specify that travelers who are subjected to quarantine or isolation, or are detained for medical examinations or other health purposes, must be provided with “adequate food and water, appropriate accommodation and clothing, protection for baggage and other possessions, appropriate medical treatment, necessary communication if possible in a language that they can understand and other appropriate assistance.”<sup>159</sup> Moreover, the IHR demands that in all cases travelers must be treated with “respect for their dignity, human rights, and fundamental freedoms.”<sup>160</sup>
79. The imminent risk to public health to which the IHR responds is both real and exaggerated. Most proximately, the IHR were drafted in response to the 2003 SARS outbreak, which spread in 2002 and 2003 from Guandong, China to many parts of the world in a matter of weeks. At the start of the outbreak, little was known about SARS other than that it was a contagious and often lethal respiratory disease that appeared to follow travelers. In response WHO advised that people postpone travel to several different parts of Asia as well as Toronto, Canada.<sup>161</sup> Many nations issued similar warnings. Taiwan went further and banned travelers from several affected

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<sup>154</sup> For a longer discussion of isolation and quarantine, see Section III C.

<sup>155</sup> IHR, Art. 2.

<sup>156</sup> The present discussion focuses on restrictions on human travelers, rather than the complex relationship between public health protection and trade, a relationship that is governed not only by the IHR, but also the WTO and a wide range of multi and bi-lateral trade agreements. It should be noted, however, that restrictions on trade in the name of public health can result in dire economic consequences, which can impact the socio-economic rights of affected populations. On the other hand, critics have often contended that states and the world community have favored free trade over public health.

<sup>157</sup> IHR, art. 23, 31.

<sup>158</sup> IHR, art. 31.

<sup>159</sup> IHR art. 32.

<sup>160</sup> IHR art. 32.

<sup>161</sup> WHO, "Update 42 - Travel Advice for Toronto, Situation in China," April 23, 2003, [http://www.who.int/csr/sars/archive/2003\\_04\\_29/en/](http://www.who.int/csr/sars/archive/2003_04_29/en/).

regions.<sup>162</sup> In other countries, passengers had their temperatures taken or were otherwise screened for symptoms.<sup>163</sup> Some health experts credit the use of travel controls with helping to contain the disease. However, there is very little evidence to support the conclusion that travel restrictions, as opposed to the isolation of sick patients and the careful use of infection control measures within hospitals, were effective.<sup>164</sup> Moreover, these measures not only interfered with travelers' liberty of movement, they imposed enormous costs on the travel industry, especially in Asia and Canada.<sup>165</sup> They may have also reinforced the association of SARS with people from Asia, helping to fuel discrimination against people of Asian ancestry in many parts of the world.<sup>166</sup>

ii. *HIV-Based Travel Restrictions*

80. Although the public health efficacy of SARS-based travel restrictions may be disputed, many other travel restrictions are far harder to justify from a public health perspective. Nevertheless, as Margaret Humphreys has noted: "Trying to erect a barrier to keep the home place safe while keeping disease out is an inevitable response to a traveling, panic disease."<sup>167</sup> Fear of traveling diseases also often provides a rationale or pretext for instituting xenophobic or racist policies.<sup>168</sup>

81. Once again HIV provides a prime example. Because HIV is not casually transmitted and is already prevalent throughout most

**Restrictions on Travel to Canada:  
A Case Study**

Many countries have imposed travel restrictions on people who are HIV positive. Canada is no exception.

Prior to 1991, Canada generally barred entry by people who were HIV positive, except for those traveling to the International AIDS conference in Montreal in 1989. In 1991, the policy was changed to permit short-term visits by people who were HIV positive. However, this policy was applied inconsistently at the border. In 1994, the Canadian clarified its position by stating that the proper inquiry was whether the HIV-positive individual's admission to the country would create an "excessive demand" on the Canadian health care system. In practice, this standard permitted most short-term visits.

While the "excessive demand" standard is friendly to short-term travelers, it creates barriers for immigrants. HIV-positive individuals are generally denied permanent residency to Canada based on the theory that their medical care would impose an "excessive demand" on the public fisc.

"Excessive demand" is not easily defined. As it stands, the determination is placed first in the hands of medical officers and ultimately the courts. On appeal, courts consider whether "humanitarian and compassionate" reasons exist for the granting of special relief; however, humanitarian and compassion claims may only be brought if there was a mistake of law or fact. The outcome of an appeal based on humanitarian grounds is unpredictable.

Alana Klein, *HIV/AIDS and Immigration: Final Report*, Canadian HIV/AIDS Legal Network 2001, <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=853>

<sup>162</sup> Sun Wire Services, "Outrage at Ban, Taiwan will Quarantine Canuck Visitors," *Toronto Sun*, April 28, 2003, 28.

<sup>163</sup> CDC, "Population Mobility and Public Health, The Case of SARS: Lessons Learnt," Seminar on Health and Migration, 9-11 June 2004 Session 11A, [http://www.iom.ch/jahia/webdav/site/myjahiasite/shared/shared/mainsite/microsites/1DM/workshops/Health\\_and\\_Migration\\_09110604/se2\\_conf\\_sars.pdf](http://www.iom.ch/jahia/webdav/site/myjahiasite/shared/shared/mainsite/microsites/1DM/workshops/Health_and_Migration_09110604/se2_conf_sars.pdf) (accessed on July 13, 2009).

<sup>164</sup> Kathryn Glass & Niels G. Becker, "Evaluation of Measures to Reduce International Spread of SARS," *Epidemiology & Infection* 134 (2006): 1092-1101; Andreas Schloenhardt, "From Black Death to Bird Flu: Infectious Diseases and Immigration Restrictions in Asia," *New England Journal of International and Comparative Law* (Spring 2006): 280-294.

<sup>165</sup> Jamieson Collins, "Severe Acute Respiratory Syndrome (SARS) and International Air Travel: A Survey of the Economic Impact and International Regulatory Changes," *Asper Review of International Business and Trade Law* 5 (2005): 43.

<sup>166</sup> Eichelberger, "SARS and New York's Chinatown."

<sup>167</sup> Humphreys, "No Safe Place."

<sup>168</sup> Markel & Stern, "The Foreignness of Germs."

of the world, policies that screen and bar HIV positive immigrants and travelers have little public health benefit. Moreover in 2001 nations agreed to eliminate all forms of discrimination against persons who are living with HIV/AIDS.<sup>169</sup> Nevertheless, a 2008 study by Joseph J. Amon and Katherine Wiltenburg Todrys found that 66 out of 186 nations for which they could find data imposed special entry, stay, or residence restrictions on individuals who were HIV positive.<sup>170</sup> Countries with restrictions include China, Vietnam, Sri Lanka, Saudi Arabia and Singapore.<sup>171</sup>

82. Perhaps not surprisingly, vulnerable populations are particularly affected by HIV-based travel restrictions. For example, a recent report by the United Nations Development Program (UNDP) documents the impact of HIV-based travel policies on women migrant workers to the Arab states from the Philippines, Sri Lanka, Bangladesh and Pakistan. These women are often subject to involuntary HIV testing, without informed consent or counseling, both prior to leaving their home country and when they are in the host country. If they are found to be HIV positive once they are working in an Arab state, they are often deported, usually with little or no assistance or support. They lose their livelihood and frequently face stigmatization and discrimination when they return home.<sup>172</sup>

83. U.S. policy towards immigrants and travelers who are HIV positive has also been troubling. By the time that a blood test was developed for HIV, the disease was already highly prevalent within many populations within the U.S.<sup>173</sup> Thus

### **Human Rights & HIV: A Look Back at Guantanamo Bay**

June 2009 marked the 16<sup>th</sup> anniversary of the closing of a detention camp at the United States military base at Guantanamo Bay, Cuba for HIV positive Haitian refugees and asylum seekers. For 18 months, approximately 200 people were confined as prisoners, living in a camp surrounded by razor barbed wire.

The large exodus of Haitians followed the military overthrow of President Jean-Bertrand Aristide in September 1991. Following the coup d'état, 40,000 Haitians fled by boat. The US interdicted many of the Haitians at sea and sent them to its military base at Guantanamo Bay.

Once they were at Guantanamo Bay, the U.S. Immigration & Naturalization Service interviewed the refugees to determine if they had a "credible fear" of prosecution. Those who did were considered "screened in" and became eligible for transfer to the US to pursue their asylum claim. In the fall of 1991, however, the INS began testing "screened in" individuals for HIV. Those who tested positive were interviewed again and required to demonstrate a new, higher standard, establishing that they had a "well-founded fear" of persecution." The INS denied requests by the refugees' attorneys to be present in these interviews. Service organizations challenged the constitutionality of the camps on behalf of the Haitian refugees.

Conditions at the camp were harsh. Detainees were kept behind razor-barbed wire and were forced to use garbage bags to keep out the rain. Medical care was inadequate. The INS refused requests by the military to fly some refugees to the mainland for medical care.

After legal battles and increasing political pressure, the camp was closed and the Haitians were allowed to enter the U.S. The U.S. government, however, successfully sought to have the court decision ordering the camp's closing to be vacated, thus preventing the landmark case from serving as precedent.

George Annas, "Detention of a HIV-Positive Haitians at Guantanamo- Human Rights and Medical Care," *New England Journal of Medicine* 329(8)(1993): 589-92. Nicola White, "The Tragic Plight of HIV-Infected Haitian Refugees at Guantanamo Bay," *Liverpool Law Review* 28(2)(2007): 249-69.

<sup>169</sup> Declaration of Commitment on HIV/AIDS, G.A. Res. S-26/2, 59, U.N. GAOR, 26th Special Sess., 8th plen. mtg., U.N. Doc. A/RES/S-26/2 (Aug. 2, 2001).

<sup>170</sup> Joseph J. Amon & Katherine Wiltenburg Todrys, "Fear of Foreigners: HIV-related Restrictions on Entry, Stay, and Residence," *Journal of the International AIDS Society* 11(1) (2008).

<sup>171</sup> Ibid.; Schloenhardt, "From Black Death to Bird Flu."

<sup>172</sup> United Nations Development Program et al., *HIV Vulnerabilities of Migrant Women: From Asia to the Arab States* (2008), [http://www2.undprcc.lk/resource\\_centre/pub\\_pdfs/P1105.pdf](http://www2.undprcc.lk/resource_centre/pub_pdfs/P1105.pdf).

<sup>173</sup> The U.S. Centers for Disease Control and Prevention estimates that there were approximately 130,000 new HIV infections in the U.S. during the mid-1980s. CDC, "CDC Fact Sheet, Estimates of New HIV Infections

HIV could not be kept out the U.S. by barring entry of individuals who tested positive. Nevertheless, in the late 1980s, the U.S. government prohibited people who were HIV positive from traveling into the United States. This policy drew widespread notice and condemnation in 1990 when many would-be participants to the Sixth International AIDS Conference in San Francisco were barred from entering the U.S. Still the ban was codified in 1993 and remained in effect until it was lifted in 2009.<sup>174</sup>

84. Far more troubling from a human rights perspective was the U.S. government's treatment of HIV positive Haitian refugees in the early 1990s. In 1991 after the overthrow of President Jean Bertrand Aristide, a large number of Haitians left by boat for the United States. Many were interdicted at sea and sent to Guantanamo Bay, where they were screened for their eligibility for asylum and tested for HIV. Those who were not HIV positive were processed and moved on, those who were HIV positive, including many who were otherwise found to be eligible for asylum, were kept at Guantanamo Bay, in some cases with their families, for well over a year until a federal court found the detention to be unconstitutional.<sup>175</sup>

iii. *TB-Based Travel Restrictions*

85. HIV and SARS are not the only diseases for which nations impose travel bans. Many nations bar either travelers, or more often, would-be immigrants, with a wide-range of infectious and sometimes non-infectious diseases, especially mental illness, a category that is extremely broad and often provides immigration officials with enormous discretion. In many cases, these bans cannot be justified as necessary for protecting public health. For example, China, the Philippines, and the U.S. exclude admission by people with Hansen's disease (leprosy), even though the disease is not highly contagious and is easily treated.<sup>176</sup> In addition, some countries bar people who have epilepsy, even though it is not infectious.<sup>177</sup>
86. The treatment of travelers and immigrants with different forms of TB is also illuminating. When an individual has an active, untreated case of TB, the disease can be spread via respiratory particles. Hence, travelers with active, untreated cases of TB, unlike those with HIV, can infect others with whom they come into casual contact. Nevertheless, the justifications for the wide range of restrictions that many governments place on travelers, and especially immigrants and asylum seekers, with TB are problematic. First, TB is treatable. Moreover, it is pervasive around the globe. According to WHO, over one third of the world's population has been exposed to TB and thus has either a latent or inactive case of the disease.<sup>178</sup> These people may develop an active and infectious case at some point in their life. Hence, a policy of barring people with active TB from entering a country is not apt to do much to prevent the spread of TB within the

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in the United States" (2008), <http://www.cdc.gov/nchhstp/newsroom/docs/Fact-Sheet-on-HIV-Estimates.pdf>.

<sup>174</sup> Department of Health and Human Services, Centers for Disease Control and Prevent, Proposed Rules, *Medical Examination of Aliens—Removal of Human Immunodeficiency Virus (HIV) Infection from Definition of Communicable Disease of Public Health Significance*, 74 Fed. Reg. 31798 (July 2, 2009).

<sup>175</sup> *Haitian Centers Council v. Sale*, 823 F. Supp. 1028 (E.D.N.Y. 1993), *vacated by* Stipulated Order Approving Class Action Settlement Agreement (Feb. 22, 1994)., *abrogation recognized by Cuban American Bar Assoc., Inc. v. Christopher*, 43 F.3d 1412, 1424 n.8 (11th Cir. 1995).

<sup>176</sup> Schloenhardt; "From Black Death to Bird Flu"; U.S. Department of Health and Human Services, 42 CFR 34.2(b)(3)(ii)(7).

<sup>177</sup> Schloenhardt; "From Black Death to Bird Flu."

<sup>178</sup> WHO, "Tuberculosis," Fact Sheet No. 104, Revised March 2007, <http://www.who.int/mediacentre/factsheets/fs104/en/>.

excluding nation.<sup>179</sup> Nevertheless, many nations screen and/or bar the immigration of people with TB. For example, Canada bars immigrants with active TB and requires individuals with inactive TB to submit to surveillance as a condition for their admission.<sup>180</sup> And although Australia screens asylum seekers for several diseases, including HIV/AIDS and sometimes Hepatitis B, active or untreated cases of TB are the only conditions that formally preclude the grant of a visa.<sup>181</sup> Individuals who have previously had TB are required to take a “health undertaking” which requires them to report to health authorities upon their arrival in Australia. Moreover, while Australia has recently reversed its policy of keeping on-shore asylum seekers in detention camps, those who seek asylum upon arrival remain behind razor wire while they undergo health checks.<sup>182</sup>

87. There are undoubtedly sound public health reasons to discourage or bar people who have diseases that can be spread via the air, such as untreated, active TB or influenza from flying, especially on long flights.<sup>183</sup> Nevertheless, the harsh treatment that some individuals receive may be problematic. For example, in 2007, Andrew Speaker, a U.S. national, was in Italy when U.S. health officials told him he had been diagnosed (incorrectly) with XDR-TB. CDC officials asked him to remain in Italy while they decided what to do next. Instead of complying, he flew from Prague to Montreal, and then drove to the U.S.<sup>184</sup> Although Speaker’s decision to fly across the Atlantic while potentially infectious cannot be defended; the treatment he received from public officials remains troubling from a human rights perspective. For example, Speaker’s personal medical information was made public, he became the subject of a world-wide manhunt, he was placed on the U.S.’s no-fly list, which had previously been reserved for suspected terrorists, was placed under a quarantine order when he returned to the U.S., and was widely vilified by officials who compared him to a terrorist.<sup>185</sup> Yet, given that XDR-TB was already present in the U.S., and that Speaker was not highly contagious, the public health risk he posed was relatively small, at least in relation to the treatment he received.<sup>186</sup>

*iv. Travelers and H1N1*

88. Similar signs of overreaction against travelers were also apparent in the early days of the H1N1 outbreak. As noted earlier, during the last several years, health officials around the world, with the encouragement of WHO, have prepared and planned for the possibility of an influenza pandemic. Many of these plans have relied on studies suggesting that travel restrictions could slow the spread of influenza and enhance a nation’s capacity to withstand a pandemic’s impact.<sup>187</sup> With H1N1 it quickly became apparent that such strategies were unlikely to be very

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<sup>179</sup> Richard J. Coker, “Compulsory Screening of Immigrants for Tuberculosis and HIV,” *British Medical Journal* 328 (2004): 298-300.

<sup>180</sup> Sarah Weibe, “Producing Bodies and Borders: A Review of Immigrant Medical Examinations in Canada,” *Surveillance and Society* 6(2) (2009): 128-141.

<sup>181</sup> Ignacio Correa-Velez, Sandra M. Gifford, & Sara J. Bice, “Australian Health Policy on Access to Medical Care for Refugees and Asylum Seekers,” *Australian and New Zealand Health Policy* 2 (2005): 23.

<sup>182</sup> Greg Ansley, “Razor Wire Cut for Australia’s Asylum Seekers,” *New Zealand Herald*, July 30, 2008, [http://www.nzherald.co.nz/human-rights/news/article.cfm?c\\_id=500838&objectid=10524256](http://www.nzherald.co.nz/human-rights/news/article.cfm?c_id=500838&objectid=10524256) (accessed on July 17, 2009).

<sup>183</sup> Thomas A. Kenyon et al., “Transmission of Multi-Drug Resistant Mycobacterium Tuberculosis During a Long Plane Flight,” *New England Journal of Medicine* 334(15) (1996): 933-938.

<sup>184</sup> For a fuller discussion, see Wendy E. Parmet, “Legal Powers and Legal Rights: Isolation and Quarantine in the Case of Drug-Resistant Tuberculosis,” *New England Journal of Medicine* 357(5) (2007): 433-435.

<sup>185</sup> *Ibid.*

<sup>186</sup> Wendy E. Parmet, “Dangerous Perspectives: The Perils of Individualizing Public Health Problems,” *Journal of Legal Medicine*, 30 (2009): 83-108.

<sup>187</sup> Joshua M. Epstein et al., “Controlling Pandemic Flu: The Value of International Air Travel Restrictions,” *PloS One*, 5(2007): e401.

effective. By the time the disease was identified, it was already widely disbursed. Containment was therefore difficult if not impossible to achieve. As a result, throughout the pandemic, WHO has maintained that travel restrictions are unnecessary.<sup>188</sup> Nevertheless, anti-immigrant advocates in the U.S. pointed to the epidemic to argue for cracking down on immigration from Mexico. In addition, several jurisdictions quarantined travelers. For example, early in the epidemic Australia quarantined passengers on a cruise ship<sup>189</sup> and China quarantined Mexican nationals, even if they had not been in Mexico during the outbreak.<sup>190</sup> Later, China continued to screen travelers at the border and place into quarantine those who showed flulike symptoms, as well as individuals who sat on a plane within three rows of anyone who had displayed symptoms of the flu. By the end of October, China had subjected over 2000 U.S. citizens alone to quarantine.<sup>191</sup> One man subject to such a quarantine described being ordered into the quarantine by health officials, having his passport confiscated, and being kept in an isolated hotel with a locked door for days, without clear information as to when he might be released. He wrote:

Those who know me know that I rarely lose my temper, but I lost it yesterday and many times since. I am angry because I see all of this as unfair. This hotel room feels like a prison and I'm being incarcerated for a "crime" that I did not commit with no way to prove my "innocence".<sup>192</sup>

89. Without doubt, the H1N1 pandemic is serious. States have a legitimate need to protect their populations from the disease. Most health officials believe, however, that quarantines are unlikely to do much good, given that flu travels quickly, people may be contagious before they show symptoms, and many people harboring the virus are likely to go undetected. China, however, reports that its aggressive approaches helped to slow the spread of the disease and reduce deaths. Whether they did so remains uncertain.<sup>193</sup> Moreover, significant restrictions on nationals from particular countries (such as those placed early in the epidemic on people from Mexico) may backfire if they deter states from following Mexico's lead in reporting new health threats to the international community.<sup>194</sup> Perhaps more importantly, border restrictions and other restraints on travelers may "create a false sense of security and a mistaken belief that people are safe simply because diseases are kept out."<sup>195</sup>

### C. Internal Preventive Detention: Isolation and Quarantine

90. Different forms of preventive detention within a nation have long been employed by states to stop the spread of infectious disease. The term "quarantine" is frequently used to refer to all such detentions. Public health practitioners, however, often distinguish between several different, but related, practices:

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<sup>188</sup> WHO, "Global Alert and Response, Travel," May 7, 2009, [http://www.who.int/csr/disease/swineflu/frequently\\_asked\\_questions/travel/en/index.html](http://www.who.int/csr/disease/swineflu/frequently_asked_questions/travel/en/index.html) (accessed on July 17, 2009).

<sup>189</sup> "Australia Prepared to Quarantine Swine Flu Ship," *The News International*, May 28, 2009, <http://thenews.jang.com.pk/updates.asp?id=78845>.

<sup>190</sup> Browne, "China Forces Dozens of Mexican Travelers into Quarantine."

<sup>191</sup> Edward Wong, "China's Tough Measures on Flu Appear to be Effective," *The New York Times*, Nov. 11, 2009, [http://www.nytimes.com/2009/11/12/world/asia/12chinaflu.html?\\_r=1&hp](http://www.nytimes.com/2009/11/12/world/asia/12chinaflu.html?_r=1&hp).

<sup>192</sup> James Fallows, "Journal of the Plague Year (Shanghai Edition)," *The Atlantic*, June 11, 2009, [http://jamesfallows.theatlantic.com/archives/2009/06/journal\\_of\\_the\\_plague\\_years\\_sh.php](http://jamesfallows.theatlantic.com/archives/2009/06/journal_of_the_plague_years_sh.php).

<sup>193</sup> Wong, "China's Tough Measures on Flu Appear to be Effective."

<sup>194</sup> Bradley J. Condon & Tapen Sinha, "Chronicle of a Pandemic Foretold: Lessons from the 2009 Influenza Pandemic," *Social Sciences Research Network*, May 3, 2009, [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1398445](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1398445).

<sup>195</sup> Schloenhardt, "From Black Death to Bird Flu," 286.

- Isolation - segregates one or more individuals who have or is thought to have a contagious illness. In many cases, the individual isolated is symptomatic and in need of medical care. Isolation can be short in duration, or it can last for decades, as occurred when people with leprosy were placed in isolation colonies for the duration of their lives. Isolation can be at home, in a hospital, or in a state institution;
  - Quarantine - restricts the movement of one or more individuals who are thought to have been exposed to a contagious disease, but are not yet ill. Individuals may be quarantined at home, at work, in a hospital, or in an institution. In contrast to isolation, quarantines are generally of short duration (limited by the incubation period of the disease at issue);
  - Sanitary cordon - is a form of quarantine that applies to a community or region. In effect, a boundary is drawn around an area in which a disease is or is believed to be present. Movement of individuals (and goods) into and out of the area is restricted; and
  - Social distancing measures - are less restrictive measures that attempt to reduce the interaction between people, and hence the spread of disease, by canceling public gatherings, closing schools, or applying curfews. These measures apply to both those who are ill and those who are not ill.
91. Most of these measures may be applied either voluntarily or involuntarily. Thus public health officials or health care providers may recommend that individuals stay home or refrain from going to work or school. Obviously when interventions are truly voluntary, the human rights implications are reduced, though not entirely negated. For example, strong social pressures may lead individuals to “voluntarily” stay home from work for a period of time, compromising their ability to support themselves or their family and jeopardizing their socio-economic rights. Of course, when voluntary quarantines are backed up by the threat of legal enforcement, they are no longer actually voluntary.
92. Coercive restrictions on movement, especially involuntary isolation and quarantine, create significant burdens. When these measures are applied involuntarily to particular individuals (as opposed to communities or regions), they constitute a form of preventive detention and raise many of the same human rights issues that are raised by other forms of preventive detention, including civil commitment due to mental illness. For that reason, the discussion that follows, while focusing on isolation and quarantine for infectious disease, will also refer at times to civil commitments for mental illness. As in the case of civil commitment for mental illness, involuntary isolation and quarantine implicates numerous civil, political, socio-economic, and social and cultural rights, including freedom of movement, the ability to maintain a livelihood, worship, and associate with others. Rights of privacy and the right to health may also be jeopardized. Stigmatization and discrimination may also follow. As was noted earlier, international and domestic law may authorize such infringements, but only when they are necessary for public health.<sup>196</sup> Under no circumstances does international law condone the discriminatory application of isolation, quarantine, or other restrictions of movement.<sup>197</sup> Nevertheless, isolation and quarantine have frequently been applied in a discriminatory manner, often for little or no public health benefit.
93. In many cases, isolation and quarantine are applied as an alternative to, or in conjunction with, other coercive public health interventions. For example, individuals may be isolated because of their unwillingness or inability to comply with recommended medical treatments. In such cases, isolation and quarantine become the alternative to coerced medical treatment. Similarly, public

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<sup>196</sup> The Siracusa Principles, 25-26.

<sup>197</sup> *Ibid.*, 54, 59 & 62.

health laws may authorize health officials to quarantine people who have refused to be vaccinated or undergo a medical exam.<sup>198</sup>

94. Historically, isolation and quarantine, as well as other restrictions of movement, have been imposed in response to numerous diseases, including Hansen's disease, smallpox, bubonic plague, typhoid, syphilis, and tuberculosis. Perhaps not surprisingly, these measures are often applied disproportionately on vulnerable populations. In many cases, detention has been used even when individuals have diseases, such as Hansen's disease, that are not easily transmissible between individuals.
95. With the advent of antibiotics, quarantine fell into disfavor and was used rarely. In recent years, however, quarantine has once again become "respectable."<sup>199</sup> In part this is due to its wide use during the SARS outbreak. Isolation has also seen a resurgence, especially in regard to TB. During the H1N1 outbreak, social distancing measures have also been used. Generally such measures, especially if imposed broadly and for a short period of time, infringe less dramatically on individual liberty than do isolation and quarantine, hence this section will focus on the latter two measures. It should be noted, however, that social distancing measures, particularly if they are kept in place for a lengthy period of time, may create significant economic hardships, especially for low income people. In addition, if supplies are disrupted, stores shut and public transportation shuttered, people may face difficulties obtaining necessary supplies, including food and medicine. Low income individuals, people with disabilities and chronic health problems, and the elderly are particularly vulnerable to such problems.<sup>200</sup>

*i. Quarantine – The Case of SARS*

96. In the late twentieth century, domestic quarantines, applied to nationals (as opposed to travelers and immigrants) who are not sick but may have been exposed to a disease were relatively rare.<sup>201</sup> However, in recent years, sanitary cordons have been placed around cities in Africa during outbreaks of Ebola or Marburg.<sup>202</sup> Health experts have questioned the effectiveness of these quarantines which left many stranded behind roadblocks with little food, water, or shelter, increasing the risk of outbreaks of other diseases.<sup>203</sup>
97. Quarantine was applied even more broadly during the 2003 SARS epidemic. During a few short weeks in the spring of 2003, thousands of people were quarantined in Toronto, Singapore, Hong Kong, and many parts of China.<sup>204</sup> Many of these quarantines were termed "voluntary" because officials did not obtain court orders, but relied on individuals complying with demands that were conveyed orally.<sup>205</sup> To call such quarantines voluntary, however, is highly misleading since those who failed to comply were often subject to legal orders and/or criminal sanctions.

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<sup>198</sup> MSEHPA, Sec. 604(a).

<sup>199</sup> Richard Schabas, "Public Health: Is the Quarantine Act Relevant," *Canadian Medical Association Journal* 176(13) (2007): 1840-1842.

<sup>200</sup> WHO, *Ethical Considerations in Developing a Public Health Response to Pandemic Influenza*, WHO/CDS/EPR/GIP/2007.2 (2007).

<sup>201</sup> The application of quarantines to travelers and non-nationals will be discussed in Sec. III C.

<sup>202</sup> Lubunga Bya'Ombe, "Congo Slaps Quarantine on Ebola Outbreak Area," *Reuters*, Sept. 11, 2007, <http://www.alertnet.org/thenews/newsdesk/L11853713.htm>; BBC News, "Angola Quarantine 'to Halt Virus,'" March 3, 2005, <http://news.bbc.co.uk/2/hi/africa/4386805.stm>.

<sup>203</sup> "Quarantine Eased by Government in Zaire," *New York Times*, May 20, 1995, I-9.

<sup>204</sup> Lesley A. Jacobs, "Rights and Quarantine During the SARS Global Health Crisis: Differentiated Legal Consciousness in Hong Kong, Shanghai, and Toronto," *Law and Society Review* 41 (2007): 511-551.

<sup>205</sup> *Ibid.*

98. Not surprisingly, the specific use and conditions of quarantine differed between jurisdictions. Given its population and caseload, Canada was fairly aggressive in its use of quarantine, detaining approximately 30,000 individuals, about the same number who were quarantined in Beijing, which had a far larger caseload.<sup>206</sup> However, in some ways, the quarantines imposed in Canada were relatively mild. Most individuals were quarantined in their home, although some health workers were subject to so-called work quarantines, in which they were able to leave home to work in hospitals that treated SARS patients.<sup>207</sup> In addition, in order to help provide financial support for people subjected to quarantine, the government eventually enacted legislation providing unemployment compensation and sick leave for those subject to quarantines.<sup>208</sup>
99. In China, the government initially failed to report or react to SARS, a complacency that provoked great criticism and helped lead to the 2005 IHR which compels states to report “public health threats of international concern” to the WHO, while also allowing WHO to rely on reports received from non-state actors.<sup>209</sup> In April 2003, however, China’s Ministry of Health listed SARS as an infectious disease and instituted a series of aggressive social controls, including prohibiting migrant workers from returning home and suspending Internet service to bars in Beijing.<sup>210</sup> Thereafter quarantines were imposed in hospitals and construction sites in Beijing, Shanghai, and other cities.<sup>211</sup>
100. As in Canada, the Chinese government provided compensation for at least some of the people subjected to quarantines.<sup>212</sup> Nevertheless, the quarantines aroused fear and anxiety and may have contributed to an exodus from Beijing. Moreover thousands rioted in the town of Chagugang when they thought that a school would be converted into a quarantine hospital.<sup>213</sup> Riots also occurred in Zhejiang Province where people felt that the quarantine station would not be able to meet their health care needs.<sup>214</sup>
101. Singapore also utilized quarantines during the SARS outbreak. Contacts of suspected cases of SARS were subjected to ten day home quarantines; those who were recovering from the disease or had been treated for it were placed under fourteen day home quarantines. Surveillance cameras were placed in the homes of people who were quarantined and they had to be available

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<sup>206</sup> National Advisory Committee on SARS and Public Health, *Learning from SARS-Renewal of Public Health in Canada*, (Public Health Agency of Canada: 2003), 35, <http://www.phac-aspc.gc.ca/publicat/sars-sras/pdf/sars-e.pdf>.

<sup>207</sup> Mark Rothstein et al., *Quarantine and Isolation: Lessons Learned from SARS: A Report to the Centers for Disease Control and Prevention*, Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine, Nov. 2003, 24.

<sup>208</sup> *Ibid.*, 58.

<sup>209</sup> IHR, art. 6.

<sup>210</sup> Ronald Keith & Zhiqiu Lin, “SARS and Chinese Politics and Law,” *China Information* 21 (2007): 403-424; Vincent R. Johnson & Brain T. Bagley, “Book Review - Fighting Epidemics with Information and Laws: The Case of SARS in China,” *Pennsylvania State International Law Review* 24 (2005): 157-176. Governments frequently try to control information during epidemics, sometimes by limiting the free flow of information, more frequently by trying to get their message across to the public. The many issues raised by the role of information control in public health are not explored in this paper.

<sup>211</sup> Rothstein, *Quarantine and Isolation: Lessons Learned from SARS*, 72.

<sup>212</sup> Joan Kaufman, “SARS and China’s Health-Care Response,” in Arthur Kleinman & James L. Watson, eds., *SARS in China: Prelude to Pandemic* (Stanford, California: Stanford Univ. Press, 2006), 53-68.

<sup>213</sup> Erik Eckholm, “The SARS Epidemic: Fear; SARS is the Spark for a Riot in China,” *The New York Times*, April 29, 2009, A1.

<sup>214</sup> Jonathan Watts, “SARS Sparks Chinese Riots,” *The Guardian*, May 6, 2003, <http://www.guardian.co.uk/world/2003/may/06/sars.china>.

to contact authorities at all times.<sup>215</sup> Individuals were also required to take their temperature twice a day. In lieu of staying at home, individuals had the option of serving their quarantine in a government facility, for which they had to pay SGD \$25.<sup>216</sup> Individuals who violated a quarantine order were required to wear an electronic monitoring tag during the remainder of their quarantine, were denied the financial allowance otherwise given to those who were quarantined, and were subject to fines and possible arrest.<sup>217</sup>

102. Although the SARS quarantines were relatively short, generally lasting less than two weeks, they still imposed significant burdens on those affected. Most obviously, the quarantines limited individuals' liberty of movement. They also interfered with the ability of those quarantined to earn their livelihood and support their family. According to the Naylor Report for the Public Health Agency of Canada, "Quarantined individuals lost income, suffered from boredom and loneliness, and most importantly, were fearful that might develop SARS or that they might spread SARS to family and friends."<sup>218</sup>
103. Other human rights burdened by the quarantines included the right to privacy (especially in Singapore where people were subject to constant surveillance) and, ironically, the right to health. The latter was particularly at risk in jurisdictions, such as China, in which individuals were quarantined en masse. By forcing uninfected people into an institutional setting with others who were infected, institutional quarantines increase the risk faced by those who are detained.<sup>219</sup> And even people who are quarantined at home can suffer health effects unless sufficient supports are put in place to ensure ample supplies of food and essential medical supplies. In addition, because quarantine is "inherently stigmatizing," it can provoke discrimination and augment panic and civil disobedience.<sup>220</sup> It can also undermine a community's trust of health officials, as the riots in China attest.
104. Despite the significant burdens imposed by the SARS quarantines, some health experts have used the SARS example as proof of the need for states to prepare to utilize quarantines during public health emergencies.<sup>221</sup> Others disagree, noting that mass quarantines probably played little or no role in slowing the epidemic.<sup>222</sup> SARS, it turns out, is not usually very infectious during its incubation period. The isolation of patients and strict infection control procedures in hospitals probably had more to do with stanching the epidemic than did the mass quarantines.

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<sup>215</sup> Rothstein, *Quarantine and Isolation: Lessons Learned from SARS*, 89.

<sup>216</sup> *Ibid.*

<sup>217</sup> *Ibid.*

<sup>218</sup> National Advisory Committee on SARS and Public Health, *Learning from SARS-Renewal of Public health in Canada*, 35.

<sup>219</sup> Therese Murphy & Noel Whitty, "Is Human Rights Prepared? Risk, Rights and Public Health Emergencies," *Medical Law Review* 17 (Summer 2009): 219-244.

<sup>220</sup> Arthur Kleinman & Sing Lee, "SARS and the Problem of Social Stigma," in Arthur Kleinman & James L. Watson eds, *SARS in China: Prelude to a Pandemic* (Stanford, California: Stanford Univ. Press, 2006), 173-195; Schabas, "Public Health: Is the Quarantine Act Relevant."

<sup>221</sup> Jason W. Sapsin et al., "SARS and International Legal Preparedness," *Temple Law Review* 77 (2004): 155-169.

<sup>222</sup> Schabas, "Public Health: Is the Quarantine Act Relevant."

ii. *Isolation*

105. In some situations isolation is far less problematic from a human rights perspective than is quarantine. When patients, such as those with SARS, are severely ill with an infectious disease, isolation within a hospital, especially one properly equipped to treat them, serves both their own interests and those of the broader community. The same situation applies when an individual with tuberculosis or pandemic influenza is isolated and treated for a brief time for treatment.
106. In some situations, however, isolation can be far more burdensome on human rights than is quarantine. That is because quarantines are generally of limited duration. In contrast, with diseases such as Hansen's disease, mental illness, and HIV, isolation can last for many years, if not a life time.
107. The use of isolation for mental illness, usually referred to as civil commitment, has been well studied and is for the most part beyond the scope of this Report. However, given the many similarities between isolation and civil commitment, a few points about the latter are worth noting. Like isolation and quarantine, the practice of separating people who are mentally ill has a long and problematic history. As many have noted, civil commitment has served as a powerful tool for social control and has frequently been applied to people who fail to conform to social expectations, as well as to highly vulnerable populations. For example, during the Soviet period, dissidents were routinely committed to mental institutions.<sup>223</sup>

**Detention for Being HIV Positive  
The Case of Eie Enhorn**

In 1994, Eie Enhorn, a 47 year old gay man living in Sweden, was diagnosed as being HIV positive. Prior to his diagnosis, Enhorn had transmitted the HIV virus to his much younger sexual partner.

In September 1994 the country medical officer, acting pursuant to the 1988 Infectious Diseases Act, issued an order that:

[prohibited Enhorn from having] sexual intercourse without first informing his partner about his HIV infection. He was required to use a condom. He was to abstain from consuming such an amount of alcohol that his judgment would thereby be impaired and others put at risk of being infected with HIV. If [he] was to have a physical examination, an operation, a vaccination or a blood test or was bleeding for any reason, he was obliged to tell the relevant medical staff about his infection. Also he was to inform his dentist [about it]. Moreover, [he] was to visit his consulting physician again and to keep appointments set up by the county medical officer.

After Enhorn failed to keep several medical appointments with the county medical officer, the officer petitioned the Country Administrative Court for an order that Enhorn be kept in compulsory isolation in a hospital for up to three months. In seeking the order, the officer stated that although Enhorn was not presently sexually active, he had a history of sexual relationships with younger men, did not think about the consequences of his actions, and did not want to change his behavior. A psychiatrist testified that he had met Enhorn twice and found that he misused alcohol and was at risk for destructive sexual relations. Later, psychiatrists opined that Enhorn had a paranoid personality disorder.

The court granted the order, but Enhorn failed to report to the hospital. The police then took him into custody. Over the next several years, the detention order was continuously extended. However, at several points, Enhorn absconded from the hospital. Evidence suggested that Enhorn was not sexually active during those periods. In total he spent over a year and a half in isolation.

In 2001 the court turned down another request to extend the detention order. In 2005 the European Court of Human Rights found that Enhorn's detention had violated Article 5 of the European Convention on Human Rights.

Enhorn v. Sweden, App. No. 56529/00 Eur. Ct. H.R. (2005).

<sup>223</sup> Sidney Bloch & Peter Reddaway, *Soviet Psychiatric Abuse: The Shadow Over World Psychiatry* (Boulder, CO: Westview Press, 1984), 16-21.

108. During the middle decades of the twentieth century, the practice of civil commitment, at least in high income nations in the West, came under harsh criticism from social theorists and human rights advocates.<sup>224</sup> In response, many nations enhanced the legal rights given to individuals who are civilly committed.<sup>225</sup> Most important for present purposes was the recognition by domestic and international law that commitment is justified only when it is necessary to protect either the individual or others.<sup>226</sup>
109. When commitment is imposed in order to protect the public, rather than the individual who is confined, it closely resembles isolation for an infectious disease. For this reason, the legal and ethical principles that have been developed in the context of civil commitment are frequently applied to isolation for infectious diseases.<sup>227</sup> These principles include the requirement that the state demonstrate that the individual actually poses a danger to others, that isolation is the least restrictive means of reducing the risk to society, and that judicial review be available in a timely manner.<sup>228</sup> As a result, a critical question in both commitment and isolation cases is the difficult and inevitably socially-biased determination of whether an individual presents a future risk to others in the absence of detention.<sup>229</sup> Seldom, however, is the question of dangerousness put in a broader context. Thus courts and policymakers rarely compare the risk posed by the individual to other risks faced by society. Nor do they usually consider the factors, outside of the individual's own control, that might mitigate or alter the equation.<sup>230</sup>
110. The use of isolation in the case of HIV exemplifies the problem. Because HIV is not transmitted through the air, individuals who are HIV positive cannot infect others through casual contact. Instead, they need to engage in particular behaviors to pose a risk to others. For these reasons, UNAIDS states firmly that "public health legislation should ensure that people not be subjected to coercive measures such as isolation, detention or quarantine on the basis of their HIV status."<sup>231</sup>
111. No state, with the exception of Cuba in the late 1980s and early 1990s, attempted to isolate everyone who was HIV positive. That approach, as was discussed in Section III A., led to a wide-spread deprivation of liberty. But paradoxically, from a human rights perspective, Cuba's mass isolation had one virtue: it avoided the discriminatory and arbitrary use of isolation that occurs when officials isolate a few unique individuals on the belief that they alone, because of their behavior, pose a unique risk to others.
112. While most countries have eschewed the wide-spread use of isolation in the case of HIV, in many states particular individuals have been subjected to preventive detention on the theory that

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<sup>224</sup> See, for example, Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (New York: Random House, 1965); Thomas S. Szasz, *The Age of Madness: The History of Involuntary Mental Hospitalization Presented in Selected Texts* (Garden City, NY: The Anchor Press, 1973), 1-4.

<sup>225</sup> Donald H.J. Hermann, "Barriers to Providing Effective Treatment: A Critique of Revisions in Procedural, Substantive, and Dispositional Criteria in Involuntary Civil Commitment," *Vanderbilt Law Review* 39 (1986): 83-106; John Legemaate, "The Rights of Involuntary Admitted Psychiatric Patients: European Developments, 75-91 in Kate Diesfeld & Ian Freckleton eds., *Involuntary Detention and Therapeutic Jurisprudence: International Perspectives on Civil Commitment* (Burlington, Vt: Ashgate Publishing Ltd., 2003).

<sup>226</sup> See, for example, *David v. Moldova*, 2007 App. No. 41578/05, Eur. Ct. H.R. (2007) (discussing the application of art. 5 of the European Convention on Human Rights to civil commitment).

<sup>227</sup> *Enhorn v. Sweden*, App. No. 56529/00, Eur. Ct. H.R. (2005); *Green v. Edwards*, 263 S.,E.,2d 661,663 (W. Va. 1980).

<sup>228</sup> *Reid v. U.K.*, App. No. 50272/99, 2003-III Eur. Ct. H.R. 94.

<sup>229</sup> Richard J. Coker, *From Chaos to Coercion: Detention and the Control of Tuberculosis* (New York: St. Martin's Press 2000), 152.

<sup>230</sup> *Ibid*, 47-81.

<sup>231</sup> UNAIDS, *International Guidelines on HIV/AIDS and Human Rights*, Guideline 3, 20(b).

their behavior creates an unacceptable risk of their transmitting the disease. The seminal case of *Enborn v. Sweden*, decided by the European Court of Human Rights, provides an illuminating example of the human rights problems that arise when particular individuals are singled out and isolated because of HIV.<sup>232</sup>

113. According to the Court, Eie Enhorn was a gay man in his forties who was diagnosed with HIV in 1994. Prior to being diagnosed with HIV, Enhorn had infected a 19 year old man with whom he had been intimate. After Enhorn failed to comply with orders issued by a county health official, a court ordered him confined to a hospital for up to three months. Over the course of the next several years, the order was repeatedly extended. Critically, there was no evidence that Enhorn had infected anyone with HIV after he learned of his diagnosis in 1994, even during the long periods in which he had absconded from the hospital.
114. The European Court of Human Rights concluded that Enhorn's confinement violated Article 5 of the European Convention on Human Rights, which permits the "lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants."<sup>233</sup> According to the Court, the deprivation of Enhorn's liberty was unjustified because "an essential element of the 'lawfulness' of a detention within the meaning of art. 5(1)(e) is the absence of arbitrariness."<sup>234</sup> Moreover, detention is only justified when it is necessary in the circumstances and is in accordance with the principle of proportionality.<sup>235</sup> Given that there was no evidence that Enhorn had exposed anyone to HIV since 1994, even during the long periods of time when he was outside of the hospital, the Court found that his isolation was not necessary to protect the public's health.
115. Although the Court based its holding on the fact that Enhorn's isolation was not necessary to protect the public's health, several additional features of the case deserve note. First, as Judge Costa highlighted in his concurring opinion, the Convention prohibits arbitrary detention. Yet, in many ways, Enhorn's isolation, like many other cases in which individuals with HIV have been isolated around the world, smacked of arbitrariness. By 1994, HIV was well established in Sweden. Moreover, the wide-spread isolation of HIV positive individuals was rejected by almost all nations, including Sweden. Many other policies, including education, syringe-exchange programs, and accessible testing and counseling were far more likely to protect the public's health than the isolation of one man. Yet officials never asked how Enhorn's detention fit alongside those other, less coercive policies. Nor did they ask whether the resources allocated to detaining Enhorn could be better spent in other ways, for example, by enhancing educational programs.
116. Most critical, officials did not consider why Enhorn, who had never been found to have infected anyone after learning about his illness, was singled out and isolated. Given the facts of the case, there is reason to suspect that Enhorn was detained because he was perceived of as a non-compliant deviant. The court noted that Enhorn was "odd," and that he was sexually attracted to younger men (but not minors). He also misused alcohol. In addition, he failed to accede to authority of the county health officer and his physician. Thus he was a difficult patient and a member of several stigmatized and vulnerable groups. All of these facts hint that Enhorn's isolation was not simply arbitrary and unnecessary, but also discriminatory and capricious. In other words, the assessment of whether Enhorn presented a risk to others was influenced by a variety of social perceptions about Enhorn, rather than the risk he actually posed.

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<sup>232</sup> *Enborn v. Sweden*, App. No. 56529/00, ECHR 2005/7.

<sup>233</sup> ECHR, art. 5(1)(e).

<sup>234</sup> *Enborn v. Sweden*, App. No. 56529/00, ECHR 2005/7.

<sup>235</sup> *Ibid.*

iii. *Isolation, Forced Medication and Tuberculosis*

117. In contrast to HIV, tuberculosis can be transmitted through respiratory particles. As a result, people with active and untreated cases of TB can infect others with whom they have casual contact.<sup>236</sup> TB experts recommend that patients be initially treated in isolation rooms, preferably with negative pressure (so that air flows into rather than out of the room).<sup>237</sup> When patients submit to treatment and respond rapidly there is little controversy.
118. From both a human rights and a public health perspective, problems arise in two related situations. The first concerns so-called non-compliant or recalcitrant patients. The second concerns patients with multi-drug resistant (MDR-TB) or XDR-TB who are not easily treated. In both cases, patients may be kept in isolation for long periods of time. To understand what is at stake in such situations, it is critical to note that treatment for TB is notoriously lengthy. Individuals need to take medication for many months, long after their symptoms have subsided. If they fail to complete a course of treatment, they are at risk of not only becoming infectious again (reactivating), but also of developing a drug-resistant form of the disease. These resistant strains may spread to others. Resistant strains are harder and more costly to treat.<sup>238</sup>
119. In the late 1980s and early 1990s, New York City faced an epidemic of MDR-TB. As Richard J. Coker explains, the epidemic was due many factors, including the HIV epidemic, cuts in the public health system, lack of universal health care, and increases in homelessness and incarceration.<sup>239</sup> This epidemic received a great deal of coverage in the media, spreading widespread fear of “innocent” or “deserving” individuals being put at risk by “undeserving” individuals who failed to take their medication. Perhaps not surprisingly, public health officials were happy to take advantage of this coverage, as it promised to bring not only attention to the TB problem but also new resources.<sup>240</sup>
120. In response to the epidemic, and the widespread anxiety about it, the city amended its public health regulations to facilitate the mandatory isolation of non-compliant patients, in other words, those who were cast as the

**Detention of a Tuberculosis Patient:  
A Case Study**

In July 2006, Robert Daniels, who held dual U.S./Russian citizenship, was living in Phoenix, Arizona. He was diagnosed with extensively drug-resistant TB and ordered to wear a mask. Despite the order, Daniels went out in public without a mask. Thereafter, county officials obtained a court order for his detention.

For almost a year, Daniels was held in jail ward of a country hospital. He was denied access to showers, hot water, or even a view of the outdoors. His mail was censored and he was monitored 24 hours a day by a video camera. During this time he was not given appropriate medical care.

After a lawsuit was filed challenging not the fact of his detention but the conditions in which he was held, Daniels was released and sent to a hospital in Denver for treatment. While he was there, doctors discovered that he did not in fact have an extensively drug-resistant form of the disease.

After Daniels had been treated and was no longer contagious, he returned to Phoenix. The Sheriff then threatened Daniels with prosecution for unlawfully exposing others to a disease. Fearing prosecution, Daniels fled to Russia. Nevertheless, he was indicted on two counts of introducing a disease.

George J. Annas, Wendy K. Mariner & Wendy E. Parmet, *Pandemic Preparedness: The Need for a Public Health – Not a Law Enforcement/National Security Approach*, ACLU, 2007. CBSNews.com, “Arizona TB Patient Faces Felony Charges,” March 25, 2008, <http://www.cbsnews.com/stories/2008/03/25/health/main3965233.shtml>

<sup>236</sup> Michael D. Iseman, *A Clinicians Guide to Tuberculosis* (New York: Lippincott Williams & Wilkins, 2000), 431.

<sup>237</sup> *Ibid.*, 436.

<sup>238</sup> WHO, “Drug-and Multi-Drug Resistant Tuberculosis (MDR-TB) - Frequently Asked Questions,” <http://www.who.int/tb/challenges/mdr/faqs/en/index.html> (accessed on June 25, 2009).

<sup>239</sup> Richard J. Coker, *From Chaos to Coercion: Detention and the Control of Tuberculosis*, 47-81.

<sup>240</sup> *Ibid.*, 85-91.

undeserving vectors of the epidemic. In addition, the new regulations permitted the health commissioner to order a patient to submit to directly-observed therapy (DOT), whereby healthcare workers observed individuals taking their medication.<sup>241</sup> As a result, although the city did not forcibly medicate individuals, it used the threat of detention to obtain acquiescence to treatment. Hence the policy implicated not only an individual's liberty of movement, but also the right to make decisions about one's own health care. To protect their rights, the city provided detained patients with lawyers and hearings. However, courts almost always upheld the detention. Moreover, Coker reports that "some patients' legal representatives viewed their role as supplementary to that of the Department of Health in encouraging patients to see their predicament and enabling them to accept detention."<sup>242</sup>

121. As a result of the change in policy, both DOT and the detention of non-compliant patients became fairly wide-spread. Coker reports that during the first two years of the policy, approximately 2 % of New York's TB cases were subject to regulatory intervention and about 1 % were detained.<sup>243</sup> Between 1993 and 1995, 116 patients in New York were detained. The median detention was for 23 weeks, but the longest was for 138 weeks. Several patients died while in detention, mostly from AIDS-related complications.<sup>244</sup>
122. Perhaps not surprisingly, given the demographics of TB in New York, most of the patients who were detained (over 90%) were from minority populations. Over 60% were homeless. Many had substance abuse problems and/or had spent time in prison.<sup>245</sup> Almost all of the patients in detention faced a multitude of problems that made compliance with a complex treatment difficult.
123. The assessment of New York's mandatory DOT/detention policy is controversial. Officials credited it with effectively reversing the city's epidemic.<sup>246</sup> Moreover some patients expressed gratitude to the city for helping them.<sup>247</sup> Critics, however, argued that the impact of DOT and detention on the epidemic is uncertain, as the policy was put in place in conjunction with a renewed emphasis on TB detection and treatment.<sup>248</sup> Moreover, jurisdictions such as France that lack laws authorizing detention for TB have comparable rates of TB as relatively similar jurisdictions, such as the UK, that utilize detention.<sup>249</sup>
124. Without a doubt, the human rights burdens imposed by compulsory DOT and detention were significant. As noted above, many detentions lasted for a long period of time. In New York, people were detained in hospitals, but in other U.S. jurisdictions that has not always been the case. For example, in 2007 a Wisconsin court upheld the confinement of a noncompliant TB patient in a prison after allowing the state to factor in the costs of detaining the patient in a hospital.<sup>250</sup>

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<sup>241</sup> Ibid., 101-112.

<sup>242</sup> Ibid., 129.

<sup>243</sup> Ibid., 122-129.

<sup>244</sup> Ibid.

<sup>245</sup> Ibid.

<sup>246</sup> T.R. Frieden et al., "Tuberculosis in New York City—Turning the Tide," *New England Journal of Medicine* 333(4) (1995): 229-333.

<sup>247</sup> Coker, *From Chaos to Coercion*, 17.

<sup>248</sup> Ibid.

<sup>249</sup> Robyn Martin, "The Exercise of Public Health Powers in Cases of Infectious Disease: Human Rights Implications," *Medical Law Review* 14 (2006): 132-143.

<sup>250</sup> *In re Washington*, 735 N.W.2d 111, 129 (2007).

125. Internationally DOT is now the “gold standard” in TB prevention.<sup>251</sup> However, in contrast to New York, many international TB control programs place less emphasis on coercion and detention and more on community support. For example, although WHO’s Stop TB Partnership calls for enhancing DOT, it emphasizes utilizing community health workers to observe and support patients rather than invoking legal authority to compel individuals to take their medications in front of public officials.<sup>252</sup> Moreover, WHO has endorsed the so-called *Patients’ Charter for TB Care* which affirms that patients have rights to second opinions, privacy, and “the right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination.”<sup>253</sup> In addition, the WHO’s Task Force on Extensively Drug-Resistant Tuberculosis recommends that, to prevent the spread of XDR-TB, the world should strengthen HIV and TB control programs, scale up services, strengthen laboratory services, expand surveillance, develop and implement infection control, strengthen advocacy, communication, social mobilization, and research. According to WHO, involuntary measures should only be used as a “last resort.”<sup>254</sup>
126. Despite this guidance, TB patients are still detained in many jurisdictions, including in many parts of Western Europe and Australia.<sup>255</sup> For example, the Public Health Act in England and Wales permits a justice of the peace to order the detention of TB and HIV patients who lack “lodging or accommodation in which proper precautions could be taken to prevent the spread of the disease.”<sup>256</sup> This Act has been used to detain TB patients and as Robyn Martin notes, appears to place homeless individuals, who lack appropriate lodging, at heightened risk for detention.<sup>257</sup>
127. Reports from South Africa are especially alarming. In recent years, South Africa has experienced a serious epidemic of XDR-TB. In response, large numbers of patients have been detained in poorly equipped and over-crowded TB hospitals, some of which have been described by the international press as “prison-like.”<sup>258</sup> Not surprisingly, outcomes in such facilities are often quite poor. Making matters worse, South Africa denies individuals who are hospitalized at state expense social welfare benefits, thereby further eroding the economic security of those who are detained.<sup>259</sup> Indeed, even experts that support the use of detention have cautioned against South Africa’s “victim blaming” approach and have asserted the importance of enhancing public information, counseling, infection controls in hospitals, and better support for patients.<sup>260</sup>

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<sup>251</sup> Stop TB Partnership, *Progress Report on the Global Plan to Stop Tuberculosis*, WHO 2004, 12, [http://www.stoptb.org/globalplan/assets/documents/WHO\\_HTM\\_STB\\_2004.29.pdf](http://www.stoptb.org/globalplan/assets/documents/WHO_HTM_STB_2004.29.pdf).

<sup>252</sup> Ibid.

<sup>253</sup> World Care Council, "Patients' Charter for Tuberculosis Care (2006 Edition)," [http://www.stoptb.org/globalplan/assets/documents/IP\\_OMS\\_Charte\\_GB\\_Epreuve.pdf](http://www.stoptb.org/globalplan/assets/documents/IP_OMS_Charte_GB_Epreuve.pdf).

<sup>254</sup> WHO, “WHO Guidance on Human Rights and Involuntary Detention for XDR-TB Control,” [http://www.who.int/tb/features\\_archive/involuntary\\_treatment/en/index.html](http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html).

<sup>255</sup> A.C. Hayward et al., “Epidemiology and Control of Tuberculosis in Western European Cities,” *International Journal of Tuberculosis and Lung and Disease* 7(8) (2003):751-757; Sanjaya N. Senanayake & Mark J. Ferson, “Detention for Tuberculosis: Public Health and the Law,” *Medical Journal of Australia* 180(11) (2004): 573-576.

<sup>256</sup> Public Health Act of 1984 (c.22)(revised), Sec. 38 (Eng.).

<sup>257</sup> Martin, “The Exercise of Public Health Powers in Cases of Infectious Disease.”

<sup>258</sup> IRIN, “South Africa: Prison-Like Hospitals for Drug-Resistant TB Patients,” *Reuters and AlertNet*, March 25, 2008, <http://www.alertnet.org/thenews/newsdesk/IRINf797562bdbd7d8bf693fb4f68621f.htm>.

<sup>259</sup> Carmel Rickard, *Balancing Acts: AIDS Review 2008* (Open Society Foundation for South Africa: 2008), 125-34.

<sup>260</sup> Jerome Amir Singh, Ross Upshur & Nesri Padayatchi, “XDR-TB in South Africa: No Time for Denial or Complacency,” *PLoS Medicine* 4(1)(e50) (2007): 19-25.

### **XDR-TB in South Africa: Forced Isolation in Prison Hospitals**

In Port Elizabeth, South Africa, the Jose Pearson TB Hospital detains its patients like prisoners, although they have committed no crime. Monitored by guards, the facility is surrounded by three fences topped with coils of razor wire to prevent patients infected with drug-resistant strains of tuberculosis from escaping. Yet, around the holidays, dozens of the patients have done just this: they cut holes in the fences, slip through electrified wires, or push through gates and past the guards in a desperate attempt to be with their loved ones. During one outbreak, 33 patients escaped, 21 returned voluntarily days later, but 4 only returned as a result of court order.

South Africa suffers the highest rate of TB infection in the world. Although non-drug resistant TB is treated on an outpatient basis with six months of drugs, patients with drug-resistant TB are required to stay in hospitals until they are no longer infectious. Patients with extensively drug resistant TB (XDR-TB) must spend up to two years in a hospital and away from their loved ones, facing the possibility of dying in isolation. Children are among those who are isolated.

Patients are detained, supposedly to ensure that they complete their complex and toxic drug regimes. Some experts argue, however, that the key to retarding the epidemic of drug-resistant TB is to ensure that patients with treatable forms of TB complete their own six-month therapy. South Africa has a cure rate of non-drug resistant TB under 60 percent, the third worst in the world. Many experts believe that greater compliance rates could be achieved if better care was provided in the communities.

South Africa's TB hospitals are proven breeding grounds for increased infections. In Jose Pearson, patients with multi-drug resistant (MDR-TB) TB and XDR-TB are housed separately, but they still interact. As a result, MDR-TB patients have been reported as contracting XDR-TB at an alarming rate. The hospitals are particularly dangerous for patients who are also HIV positive.

Authorities at Jose Pearson have tried to make the facilities more bearable. They have introduced soccer balls and sewing machines, a pool table, and flat-panel televisions. Still, the hospital remains prison-like. And authorities have enhanced security. One patient, who had previously escaped, reportedly appreciated the steps that the authorities had taken. Nevertheless, she told reporters that there is no replacement for her freedom.

Alertnet.org, "South Africa – Prison-Like hospitals for Drug Resistant TB Patients," March 25, 2008, [www.alertnet.org/thenews/newsdesk/IRIN/f7975b2b8bdb7d8bf69b3fb4f68621f.htm](http://www.alertnet.org/thenews/newsdesk/IRIN/f7975b2b8bdb7d8bf69b3fb4f68621f.htm) (assessed July 16, 2009).

Fiona Lloyd-Davies, "Life in the Shadow of Deadly New TB," *BBC News.com*, November 14, 2008, <http://news.bbc.co.uk/2/hi/africa/7729184.stm> (assessed July 16, 2009).

Celia W. Dugger, "TB Patients Chafe Under Lockdown in South Africa," March 25, 2008, [www.nytimes.com/2008/03/25/world/africa/25safrica.html?pagewanted=1](http://www.nytimes.com/2008/03/25/world/africa/25safrica.html?pagewanted=1) (assessed July 16, 2009).

#### **D. Mandatory Treatment and Vaccination**

128. International law and ethics recognize that individuals have a right of privacy that generally encompasses the right to control one's own medical care and treatment.<sup>261</sup> Nevertheless, in the case of an infectious disease an individual's failure to be vaccinated or to comply with treatment may increase the risk to others. Likewise, people with some mental illnesses may become more dangerous to others if they fail to take their medications. For this reason, states sometimes compel either vaccination or treatment. To do so, they may use a variety of different controls, including:

- Directly Observed Therapy (DOT) – in which individuals are required to take their medication while being observed by health workers;
- Isolation and Quarantine - individuals may be detained if they fail to take their medication (or be vaccinated);

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<sup>261</sup> ICCPR, art. 17.

- Loss of Benefits—individuals may lose access to valuable state benefits or opportunities if they fail to be vaccinated or take prescribed medication; and
- Forced Administration—the state may forcibly vaccinate or treat someone.

129. All of these methods raise both human rights and public health issues. From both perspectives, a key overarching issue is whether coercive treatment or vaccination can ever be justified given that many millions of people lack access to both treatment and vaccination. In effect, laws that force treatment on the few who resist it while ignoring the many more that lack access to it are inherently problematic. Not only do they undermine the autonomy of those who are coerced, they implicate serious questions of equity and justice. In addition, forced medical treatment and vaccination, like isolation and quarantine, may heighten stigma and erode a community's trust in public health officials. As a result these interventions may be less effective in protecting public health than officials would hope.

*i. Compulsory Medication*

130. As was discussed in Section III C, many jurisdictions employ DOT combined with the threat of detention to compel TB patients to adhere to their therapy. Highly active anti-retroviral therapy (HAART) for HIV raises many of the same challenges as TB therapy: patients must continue to take their medications for a very long time, (indeed, in contrast to TB therapy, HAART continues indefinitely); and the failure to comply with a prescribed course of treatment can increase the risk of drug-resistance. Moreover, as in the case of TB, many of the populations at highest risk for HIV are highly vulnerable and face many barriers that may make it difficult to comply with treatment. For this reason, scientists and public health officials have considered using directly administered anti-retroviral therapy (DAART) for HIV.<sup>262</sup> For now, these programs are mostly voluntary and thus do not raise the same degree of human rights concerns that were discussed in the context of TB.

131. In some jurisdictions, however, intravenous drug users (IDUs) have been subjected to compulsory treatment. For example, a WHO report notes that IDUs in Thailand have been sought out by police and local community authorities and forced into drug treatment.<sup>263</sup> In addition, Human Rights Watch notes that drug users in the Guangxi Province of China have been subjected to mandatory detoxification.<sup>264</sup> These efforts appear to complicate, rather than enhance, each nation's efforts to improve HIV prevention and treatment among their IDU populations.

132. Compulsory treatment has also been discussed widely in conjunction with public health emergency planning. For example, the Public Health Law Program of the Centers for Disease Control and Prevention in the U.S. has posted on its "Emergency Legal Preparedness" website "Materials Related to Compulsory Treatment."<sup>265</sup> Among those materials is a model petition

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<sup>262</sup> Timothy P. Flanigan, Lynn E. Taylor & Jennifer A. Mitty, "Use of Community-Based Directly Observed Therapy for HIV Infection: Lessons Learned for Treatment of Hepatitis C Virus," *Clinical Infectious Diseases* 40 (2005): S346-S348.

<sup>263</sup> WHO, Regional Office For Southeast Asia, *Scaling Up Antiviral Treatment: Lessons Learnt from Thailand*, (WHO 2007), [http://www.searo.who.int/LinkFiles/Publications\\_Scaling-up.pdf](http://www.searo.who.int/LinkFiles/Publications_Scaling-up.pdf).

<sup>264</sup> Joseph Amon, "An Unbreakable Cycle: Drug Dependency Treatment, Mandatory Confinement, and HIV/AIDS in China's Guangxi Province," *Human Rights Watch* (2008), [www.hrw.org/en/reports/2008/12/09/unbreakable-cycle](http://www.hrw.org/en/reports/2008/12/09/unbreakable-cycle).

<sup>265</sup> Public Health Law Program, "Emergency Legal Preparedness: Materials Related to Compulsory Treatment Authority," CDC, <http://www2a.cdc.gov/phlp/compulsoryTreatment.asp> (accessed on July 17, 2009).

from the Attorney General of New Hampshire for a court order requiring an individual to submit for medical treatment to be rendered “non-contagious.”<sup>266</sup> In addition, the MSEHPA, discussed earlier, would permit health authorities to treat individuals against their will, although individuals who are “unable or unwilling” to be treated for “reasons of health, religion, or conscience” would instead be subjected to isolation or quarantine.<sup>267</sup>

133. Despite these planning efforts, compulsory treatment today is most commonly used in the case of TB and mental illness. A full discussion of the compelled treatment for mental illness is beyond the purview of this Report,<sup>268</sup> but a few points are worth noting. First, as in the case of infectious diseases, compulsory treatment of people with mental illness is explained as being necessary both for the good of the individual and for the health of others. Second, like infectious diseases, mental illness is highly stigmatized. Third, as in the case of TB and HIV, treatment for mental illness is complex and long-lasting. Indeed, people may need to stay on medication for years, even in the face of severe side effects. Hence, as in the case of HIV and TB, compliance is problematic.
134. In recent years, several jurisdictions have implemented a variety of approaches to compel individuals to take antipsychotic medications. Particularly notable, but not the first, was New York’s outpatient commitment law, known as Kendra’s Law.<sup>269</sup> Enacted in 1999 and named after Kendra Webdale, a woman who was pushed in front of a subway train by a man with schizophrenia who was not taking his medication, Kendra’s Law allows mental health professionals to obtain court orders requiring individuals to take prescribed medications. As in the case of New York City’s DOT regulations, an individual who fails to comply with a court order issued under Kendra’s Law can be taken into custody for up to 72 hours.<sup>270</sup>
135. Supporters of Kendra’s Law and similar laws in other jurisdictions view them as less restrictive alternatives to institutionalization. Critics argue that such laws facilitate preventive detention and effectively override an individual’s right to decide his or her own treatment.<sup>271</sup> Moreover, critics note that such laws fail to respond to the inadequacy of services and facilities available in the community. In effect, treatment is mandated while the state fails to provide adequate community supports. In addition, like compulsory DOT, outpatient commitment laws rely on problematic assessments of future risk to override an individual’s right to make his or her own medical decisions. However, in contrast to mandatory DOT, laws requiring people to take psychiatric medications often operate in conjunction with laws that permit the state to forcibly medicate hospitalized patients, at least under certain circumstances.<sup>272</sup> Thus far, in the case of infectious diseases, states seem content to detain individuals who reject treatment. The forced administration of either antibiotic or antiviral medication has not been widely reported in the modern era.

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<sup>266</sup> Ibid.

<sup>267</sup> MSEHPA, Sec. 603.

<sup>268</sup> There is a vast literature on this subject. See, for example, Stanley S. Herr, Lawrence O. Gostin, and Harold Hongjueh eds., *The Human Rights of Persons With Intellectual Disabilities: Different But Equal* (New York: Oxford University Press, 2003); John Q. LaFond & Mary L. Durham, *Back to the Asylum: The Future of Mental Health Law and Policy in the United States* (New York: Oxford University Press, 1992); Sana Love, “The Involuntary Civil Commitment of Mentally Ill Persons in the United States and Romania: A Comparative Analysis,” *Journal of Legal Medicine* 23 (2000): 211-250.

<sup>269</sup> 1999 N.Y.S.B. 5762 §15(s).

<sup>270</sup> Ibid.

<sup>271</sup> Michael Perlin, “Therapeutic Jurisprudence and Outpatient Commitment Law: Kendra’s Law as Case Study,” *New York Law School Public Law and Legal Theory Working Paper Series*, No. 02-04 (March 2002), [http://papers.ssrn.com/Sol3/papers.cfm?abstract\\_id=301545](http://papers.ssrn.com/Sol3/papers.cfm?abstract_id=301545).

<sup>272</sup> *Riggins v. Nevada*, 504 U.S. 127 (1992); *Washington v. Harper*, 494 U.S. 210 (1990); *Varbanov v. Bulgaria*, No. 31365/96 Eur. Ct. H.R. 2000-V.

ii. *Compulsory Vaccination*

136. Vaccinations are among the most potent public health tools. As a result of wide-spread vaccination, smallpox has been eradicated as a naturally-occurring disease and other once-common scourges, such as polio and tetanus, have been virtually eliminated in much of the world. Today the rapid development and distribution of a vaccine remains a priority in response to the H1N1 pandemic.
137. For public health authorities, vaccination poses a particularly difficult ethical and policy dilemma. Although vaccines generally provide protection to individuals who are vaccinated, not everyone is fully protected. Moreover, not everyone is able to be vaccinated. However, when vaccination rates are high within a population, the population develops what is known as “herd immunity.” In effect, there are no longer enough people within the population for an epidemic to be sustained. Under those circumstances, even those who are not vaccinated can benefit from vaccination.
138. Unfortunately the effectiveness of vaccines makes them less desirable to many. As diseases become rarer within a community, individuals may come to fear the small risks of vaccines more than the risks of the diseases they prevent. As a result, individuals may opt to forgo vaccination and be a free-rider.<sup>273</sup> However, if many people make this decision, vaccination rates will plummet and herd immunity will diminish. For this reason, states have long employed a variety of measures to increase immunization rates.<sup>274</sup>
139. On occasion health officials have employed highly coercive tactics, including forcibly vaccinating individuals against their will. For example, Paul Greenough reports that WHO teams forcibly vaccinated people in rural villages in South Asia during the final stages of the smallpox eradication campaign.<sup>275</sup> More often, states compel vaccination by imposing sanctions or denying critical benefits (such as schooling) if an individual refuses to be vaccinated or to have his or her child vaccinated. For example, in Belgium, Italy, and Poland, parents can be fined or sent to prison for not vaccinating their children, although exemptions can be obtained.<sup>276</sup> In the U.S. almost all states require proof of vaccination before children can be enrolled in schools. However, all U.S. states permit medical exemptions and 48 allow for some form of religious or philosophical exemption.<sup>277</sup> In Canada, some provinces require either proof of vaccination or documentation of parental refusal of vaccination in order to enroll children in school. Unvaccinated children can be kept out of school if there is an outbreak of a vaccine-preventable illness.<sup>278</sup>
140. The widespread existence of various exemptions mitigates the coercive nature of most compulsory vaccination policies. In those jurisdictions where exemptions are relatively easy to obtain, compulsory measures work largely as default rules, requiring parents to have their children vaccinated unless they go through the trouble of obtaining an exemption. Whether these default rules are warranted is debatable. Evidence shows that many nations that rely only on voluntary vaccinations, including the United Kingdom and Sweden, manage to attain immunization rates that are comparable or better than those in countries that set default rules

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<sup>273</sup> Nuffield Council on Bioethics, *Public Health: Ethical Issues*.

<sup>274</sup> For an overview, see Daniel A. Salmon et al., “Compulsory Vaccination and Conscientious or Philosophical Exemptions: Past, Present and Future,” *The Lancet* 367 (2006): 436-42.

<sup>275</sup> Paul Greenough, “Intimidation, Coercion and Resistance in the Final Stages of the South Asian Smallpox Eradication Campaign, 1973-1975,” *Social Sciences & Medicine* 41(5) (1995): 633-45.

<sup>276</sup> Nuffield Council on Bioethics, *Public Health Ethical Issues*, 58.

<sup>277</sup> Salmon, “Compulsory Vaccination and Conscientious or Philosophical Exemption”.

<sup>278</sup> Nuffield Council on Bioethics, *Public Health: Ethical Issues*.

requiring vaccination.<sup>279</sup> On the other hand, Daniel A. Salmon et al report that vaccination rates are more prone to drop when there are media reports questioning the safety of vaccines in countries that rely purely on voluntary vaccination than in countries which have some sort of default rule.<sup>280</sup>

141. Although most jurisdictions reject highly coercive vaccination policies for their general population, the IHR permits states to show proof of vaccination in order to enter a jurisdiction.<sup>281</sup> In most instances, these requirements are not very burdensome and have not proven controversial. A recent U.S. requirement that female immigrants be vaccinated against the human papillomavirus has, however, provoked debate. The vaccination (marketed as Gardasil), is relatively new; hence long-term safety data is not yet available. Moreover, the vaccine is not required for school attendance. It is also far more expensive than most other vaccinations.<sup>282</sup> Although waivers are theoretically possible, they are quite costly. Without any reason to believe that immigrants pose a greater risk of spreading human papillomavirus than U.S. nationals, there is little reason to justify this disparate burden on immigrants.
142. As is true with mandatory treatment, mandatory vaccination also figures largely in public health emergency plans. For example, the WHO “Checklist” for pandemic preparedness advises jurisdictions to prepare for a pandemic by reviewing their powers to compel vaccination.<sup>283</sup> Likewise, in the U.S., the MSEHPA seeks to provide governors with the power to either compel a person to be vaccinated or put that person in isolation or quarantine if he or she is unable or unwilling to be vaccinated due to medical, religious or philosophical reasons.<sup>284</sup> During the current H1N1 outbreak, New York sought to compel health care workers to be vaccinated against the disease. A court, however, upheld a challenge brought by unions against the regulation.<sup>285</sup>
143. The plans that have been laid for compelling vaccination during a public health emergency are problematic for several reasons. First, the mandatory administration of any new vaccine, for which safety data may be incomplete (or non-existent) threatens not only individual autonomy but also, potentially, the public’s trust in health officials. Moreover, during an influenza pandemic, or almost any public health emergency, the most pressing problem will not be the failure of a few individuals to accept vaccination but an inadequate supply of vaccine. As the current H1N1 outbreak demonstrates, even high income countries are apt to face a vaccine shortage in the early stages of a pandemic. Low income countries will face even greater problems, as they will have difficulty obtaining, paying for, and distributing critical vaccines.<sup>286</sup> Given these shortages, the focus in preparedness plans on compelling vaccination and limiting the rights of the few who would reject it seems both ill-directed and unnecessary.

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<sup>279</sup> Salmon, “Compulsory Vaccination and Conscientious or Philosophical Exemptions.”

<sup>280</sup> Ibid.

<sup>281</sup> IHR, art. 31.

<sup>282</sup> Elizabeth R. Sheyn, “Putting an End to an Unintentional Result: Why The Requirement that Female Immigrants Receive the Gardasil Vaccine Prior to Becoming Permanent Residents Should be Suspended,” *Valpariso University Law Review* 44 (2009), [http://papers.ssm.com/sol3/papers.cfm?abstract\\_id=1397706](http://papers.ssm.com/sol3/papers.cfm?abstract_id=1397706).

<sup>283</sup> WHO, “WHO Checklist for Influenza Pandemic Preparedness Planning,” WHO/CDS/CSR/GIP/2005.4 (2005), <http://www.who.int/csr/resources/publications/influenza/FluCheck6web.pdf>.

<sup>284</sup> MSEHPA, Sec.603.

<sup>285</sup> Anemona Hartocollis and Swell Chan, “Albany Judge Blocks Vaccination Rule,” *New York Times*, Oct. 16, 2009, <http://www.nytimes.com/2009/10/17/nyregion/17vaccine.html> (accessed Nov. 19, 2009).

<sup>286</sup> WHO, “Transcript of Statement by Dr. Margaret Chan, Director-General of the World Health Organization, June 11, 2009,” WHO, [http://www.who.int/mediacentre/influenzaAH1N1\\_presstranscript\\_20090611.pdf](http://www.who.int/mediacentre/influenzaAH1N1_presstranscript_20090611.pdf).

## E. Criminalization

144. Social control theorists have noted an expansive use of criminal law in recent years. The criminal law, however, has long been used by states to protect public health, for example, by sanctioning violence or very dangerous behaviors. A full discussion of states' use of criminal law to protect health is well beyond the scope of this Report. Instead this Section focuses solely on the use of criminal law in relationship to infectious disease.
145. From a social control perspective, a state's attempt to criminalize the transmission of a disease, in effect to turn contagion into a crime, is highly noteworthy. Of course, a state has no less of an interest in sanctioning deliberate murder simply because the means used involved a pathogen. Thus laws outlawing the intentional spread of biological weapons, or the purposeful infection of another with contaminated blood, fit squarely within well-established international norms for criminal law and raise few human rights or public health objections, assuming that the criminal justice system meets human rights standards. The same can be said about laws that criminalize the attempt to infect other individuals, for example, by attempting to expose people to anthrax. Clearly neither public health nor human rights requires a state to wait until someone dies before it sanctions a person who is about to release weaponized anthrax.
146. In contrast, the use of criminal sanctions against individuals who unintentionally infect others should raise some alarms. Once again, HIV offers a striking example. In 2006, Johnson Aziga became the first man in Canada convicted of murder on the basis of infecting his sexual partner with HIV.<sup>287</sup> Although the evidence presented suggested that Aziga had lied to his partners and had acted with great disregard for their well-being, the fact that the first person convicted of such an offense was a Ugandan immigrant who was charged with infecting a white woman is noteworthy.<sup>288</sup> In effect, the first and only murder conviction in Canada related to a twenty-five year old epidemic comports with well-worn stereotypes about foreigners and racial minorities.
147. While murder convictions for the transmission of HIV are rare, scholars are reporting an increasing number of HIV-related criminal convictions around the world. In many cases, these convictions are based on the negligent or reckless (as opposed to intentional) transmission of

### **Criminalization of HIV Transmission in the United Kingdom: A Case Study**

Many countries have prosecuted people for the unintentional transmission of HIV. One notable example was the British case of *R. v Dica (Mohammed)*, [2004] Q.B. 1257 (C.A. (Crim Div)).

In July 2002, Mohammed Dica, an African immigrant to the United Kingdom, was arrested for recklessly transmitting HIV to two female sexual partners. According to the court, Dica knew that he was HIV positive, but did not inform two women with whom he had unprotected sexual relations. Both women became infected with HIV. Dica was prosecuted under a statute which states that "whosoever shall unlawfully and maliciously wound or inflict any grievous bodily harm upon any person, either with or without any weapon or instrument shall be guilty [of an offense]." In 2003, he was found guilty at trial and was sentenced to 8 years imprisonment.

In a 2004 the Court of Appeal held that Dica could be prosecuted under the statute as long as he did not inform the women of the fact that he was HIV positive. In effect, the fact that they had consented to unprotected sex did not mean that they had consented to the risk of contracting HIV. Dica was then retried and convicted.

The case has become a point of contention among public health experts and AIDS activists who have questioned the application of applying general criminal law statutes to the spread of infectious disease.

<sup>287</sup> Jordana Huber & Tiffany Crawford, "HIV Murder Verdict Sets Off Alarm," *National Post*, April 6, 2009, <http://www.nationalpost.com/scripts/story.html?id=1467690>.

<sup>288</sup> Rachel De Lazzer, "Drop Charges: Defense Claims HIV-Murder Suspect's Rights Violated in Jail," *The Hamilton Spectator*, June 11, 2008, <http://www.thespec.com/News/Local/article/384250>.

HIV. According to one study, there were more than 130 convictions in at least 36 EU member states for HIV transmission between 1988 and 2007.<sup>289</sup> As in Canada, there is reason to suspect that discrimination and stereotypical attitudes towards foreigners have influenced prosecutions. For example, 3 of the first prosecutions in the United Kingdom were against African immigrants. As Alison Mears notes, even if discrimination did not motivate these prosecutions, the attention they garnered may have reinforced discriminatory associations and stigma.<sup>290</sup> In addition, prosecutions based on the theory that an individual is reckless or negligent in engaging in unprotected sexual activity after knowing his or her HIV status may have the unintended consequence of deterring people from being tested and learning about their HIV status.

148. Public health experts and HIV activists have been particularly critical of HIV-specific laws. The *International Guidelines on HIV/AIDS and Human Rights* states that “Criminal and/or public health legislation should not include specific offenses against the deliberate and intentional transmission of HIV but rather should apply general criminal offences to these exceptional cases.”<sup>291</sup> Despite this guidance, Scott Burris and Edwin Cameron report that the criminalization of HIV infection has reached a “new pitch” with the drafting of a model law by West African parliamentarians that would criminalize the transmission of HIV through “any means by a person with full knowledge of his/her HIV/AIDS status.”<sup>292</sup> This model law has been enacted by at least nine countries in Africa.<sup>293</sup>
149. Many jurisdictions in the U.S. also have HIV-specific laws. For example, 23 states within the U.S. have laws prohibiting HIV positive individuals from having sexual relations without disclosing their status to their partner.<sup>294</sup> Some of these laws allow for extremely long sentences; for example, conviction under the Arkansas HIV disclosure law can result in thirty years in prison.<sup>295</sup> None of these laws require that HIV actually be transmitted. Moreover, in many states, individuals may be prosecuted even if they use a condom. Hence, these criminal statutes contradict public health messages that encourage people to use condoms and engage in safe sexual practices. Other statutes may confuse public health efforts by criminalizing the transfer of urine or saliva, even though these fluids do not transmit HIV.<sup>296</sup>
150. Despite the profusion of HIV-specific laws around the globe, prosecutions remain rare. Thus as with prosecutions under general criminal statutes, there is a significant risk that discrimination may influence individual prosecutions. According to Scott Burris and Edwin Cameron, a close scrutiny of the trial transcripts confirms this suspicion.<sup>297</sup> Critically there is no evidence demonstrating that laws specifically criminalizing the transmission of HIV have any positive public health impact.<sup>298</sup> To the contrary, criminalization of HIV transmission has been shown to increase stigma, reduce the quality of life of people living with HIV/AIDS, and detract from HIV prevention efforts.<sup>299</sup>

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<sup>289</sup> Alison Mears, “The Criminalization of HIV Transmission in England and Wales: A Brief Review of the Issues Arising,” *Current Opinions in Infectious Disease* 20 (2007): 47-53.

<sup>290</sup> Ibid.

<sup>291</sup> UNAIDS, *International Guidelines on HIV/AIDS and Human Rights*, Guideline 4(a).

<sup>292</sup> Scott Burris & Edwin Cameron, “The Case Against Criminalization of HIV Transmission,” *Journal of the American Medical Association* 300(5) (2008): 578-580, 578.

<sup>293</sup> Ibid.

<sup>294</sup> Carol L. Galletly & Stephen D. Pinkerton, “Conflicting Messages: How Criminal HIV Disclosure Laws Undermine Public Health Efforts to Control the Spread of HIV,” *AIDS and Behavior* 10(5)(2006): 451-61.

<sup>295</sup> Ibid.

<sup>296</sup> Ibid.

<sup>297</sup> Burris & Cameron, “The Case Against Criminalization of HIV Transmission.”

<sup>298</sup> Ibid.

<sup>299</sup> C. Dodds and P. Keogh, “Criminal Prosecutions for HIV Transmission: People Living with HIV Respond,” *International Journal of STD & AIDS* 17 (2006): 315-318.

151. Criminal laws that are not specific to HIV may also undermine prevention efforts. Many jurisdictions criminalize some of the behaviors and actions that are associated with an increased risk of HIV, including certain forms of consensual sex and use of intravenous narcotics.<sup>300</sup> In addition, in many parts of the world, possession of needles and syringes are illegal. Although these laws are occasionally justified on the theory that they deter behaviors associated with the transmission of HIV, they actually appear to undermine prevention efforts and increase risky behaviors.<sup>301</sup> For example, Human Rights Watch reports on how the harsh treatment of drug users in China's Guangxi Province has impeded the efforts of people who are HIV positive to access HIV treatment.<sup>302</sup> In Burma, HIV prevention efforts have been stymied by laws banning the possession of needles and syringes and the arrests of women carrying condoms.<sup>303</sup> In Mexico, arrests for syringe possession, which have occurred despite the fact that possession is ostensibly legal, have increased needle-sharing.<sup>304</sup> Laws against the possession of syringes and needles have also proven detrimental to HIV prevention in many parts of the U.S.<sup>305</sup> For these reasons the *International Guidelines on HIV/AIDS and Human Rights* counsels states to review and repeal laws regulating consensual sexual conduct by adults as well as laws criminalizing the possession, distribution and dispensing of needles and syringes. The *Guidelines* further state that the "criminal law should not be an impediment to measures taken by States to reduce the risk of HIV transmission among injecting drug users and to provide HIV-related care and treatment for injecting drug users."<sup>306</sup> Despite these guidelines, in much of the world the criminal law continues to impede rather than promote public health protection.

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<sup>300</sup> A full discussion of the impact of drug and prostitution laws on HIV is well beyond the scope of this study. For a general discussion of the impact of the criminalization of drug use and HIV, see Am Johal, "Health: Drug War Clashes with Fight Against HIV/AIDS," Oct. 3, 2007, *Interpress Service*, <http://www.aegis.com/news/ips/2007/IP071002.html> (accessed on June 28, 2009); Ricky N. Bluthenthal et al., "Collateral Damage in the War on Drugs: HIV Risk Behaviors Among Injection Drug Users," *International Journal of Drug Policy* 10 (1999): 25-38.

<sup>301</sup> The literature on this subject is vast. The discussion below simply provides a few examples from around the globe of criminal laws that have undermined HIV-prevention efforts.

<sup>302</sup> Amon, "An Unbreakable Cycle."

<sup>303</sup> Rhianna M. Fronapfel, "AIDS Prevention and the Right to Health Under International Law: Burma as the Hard Case," *Pacific Rim Law & Policy* 15 (2006): 169-198.

<sup>304</sup> For example, see, Robin A. Pollini et al., "Syringe Possession Arrests are Associated with Receptive Syringe Sharing in Two U.S.-Mexico Border Cities," *Addiction* 103(1) (2008): 101-108.

<sup>305</sup> Jennifer Taussig et al., "Syringe Laws and Pharmacy Regulations are Structural Constraints on HIV Prevention in the U.S.," *AIDS* 14 (2000): S47-S51.

<sup>306</sup> UNAIDS, *International Guidelines on HIV/AIDS and Human Rights*, Guidelines 4(b) and 4(d).

## IV. RECONCILING HUMAN RIGHTS, SOCIAL CONTROL AND PUBLIC HEALTH

### A. The Existing Legal and Ethical Framework

152. Both international and domestic laws offer a framework for reconciling the conflict between public health social controls and human rights. This framework provides a useful and necessary safeguard; but as this Report suggests, in practice it may fail to prevent and may even condone as lawful highly problematic and unnecessary (from a public health perspective) infringements on the liberties and dignity of individuals and vulnerable populations. This Section revisits the framework, explains why it is insufficient, and offers suggestions for more fully protecting both the right to public health and other human rights.

153. The limits that international and domestic law place on public health social controls vary greatly depending upon the jurisdiction, the social control, and the nature of the health threat. Nevertheless, several overarching principles appear widely in both domestic and international law. These principles include the previously-discussed *Siracusa Principles* which assert that social controls undertaken in the name of public health which abridge otherwise recognized human rights must be in accordance with law, non-discriminatory, and no more intrusive or restrictive of human rights than is necessary to protect public health. In addition, as cases under both the European Charter on Human Rights and the domestic law of many jurisdictions make clear, public health protections that infringe upon human rights must be proportional to the risk.<sup>307</sup> Thus the most intrusive public health measures, such as isolation and quarantine or mandatory treatment, may at times be justified for highly communicable, lethal diseases such as XDR-TB, but they cannot be justified for far less lethal diseases, such as the common cold.

#### **The Siracusa Principles on the Limitations and Derogation Provisions in the International Covenant on Civil and Political Rights**

The Siracusa Principles set forth criteria that justify the derogation of rights under the ICCPR in order to protect public health. Under the Siracusa Principles states may only derogate rights otherwise protected by the ICCPR if the derogation is:

- Instituted in accordance with law
- The least restrictive alternative
- Based on a legitimate objective
- Necessary in a democratic society
- Not arbitrary, unreasonable or discriminatory

The United Nations Human Rights Commission examines compliance with these principles in accordance with its powers to study, report, and make comments.

154. The international human rights framework also places a high premium on procedural justice. For example, individuals who are detained in the name of public health, such as occurs regularly with prolonged isolation for TB, are entitled to have their detention reviewed by an independent authority, most ideally a court. Article 9 of the ICCPR states that “Anyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings before a court, in order that that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful.”<sup>308</sup> Likewise, Article 5, Section 4 of the European Convention on Human Rights requires that anyone who is detained “shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.”<sup>309</sup> In the U.S., both the constitutional right to a writ of habeas

<sup>307</sup> *Enborn v. Sweden*, App. No. 56529/00, ECHR 2005/7.

<sup>308</sup> ICCPR, art. 9.

<sup>309</sup> ECHR art. 5.

corpus and the Due Process clauses of the Fifth and Fourteenth Amendments guarantee a right of judicial review, plus the protection of counsel, to individuals who are civilly committed.<sup>310</sup>

155. International law also clarifies that some rights are non-derogable; they cannot be abridged even to protect public health. Most relevant is Article 4 of ICCPR which asserts that rights against discrimination on the basis of race, color, sex, language, religion, or social origin cannot be denied even in the event of a public emergency.<sup>311</sup> Rights against torture, slavery, and genocide are also absolute and cannot be limited in the name of health.<sup>312</sup> Moreover, freedoms of thought, conscience, and religion are non-derogable, although manifestations of religion can be limited “as are prescribed by law and are necessary to protect public safety, order, health, or morals or the fundamental rights and freedoms of others.”<sup>313</sup>
156. In addition to these broadly applicable procedural and substantive limits on public health interventions, public health ethicists have articulated numerous ethical principles to guide public health policy, many of which are reflected in both domestic law and relevant international guidelines. Among the most important of these principles are transparency, community consultation, and equity.<sup>314</sup> In different ways, these principles all seek to ensure that the people who public health purports to protect are respected, included in the process of determining the policies that affect them, and have access to the benefits, not only the burdens, of public health interventions. Without doubt, these widely accepted legal and ethical principles, if followed, would help limit the abuse of human rights in the name of public health.
157. Equally important to the preservation of human rights in the face of public health threats has been the development of a robust global health and human rights movement that stresses the complementary relationship between health and other human rights and has advocated for global health equity. The impact of this movement has been most evident in the case of HIV, in which both local and global activists have moved the international community to confront the pandemic by increasing access to treatment and prevention, rather than by encouraging coercive, rights-limiting measures.<sup>315</sup> As a result, UN/AIDS guidelines and other international protocols respecting HIV are relatively protective of human rights and recognize that they support, rather than impede, public health protection. Nevertheless, as the discussion in Section III attests, human rights abuses continue in response to the HIV pandemic, as well as in response to other infectious diseases around which activists have played a less prominent role. The discussion below examines why the existing framework has proven to be inadequate to prevent such abuse.

## **B. Public Health Necessity and Public Health Panics**

158. The concept of public health risk is central to all existing legal and ethical principles relating to public health and human rights. As discussed above, the current framework posits that highly coercive social controls that infringe upon recognized human rights are only justified when they are *necessary* to protect public health. But what does that mean? How does a public health official or a society determine which threats merit coercive action?

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<sup>310</sup> U.S. Const. art. I, § 9, U.S. Const. amend. V, U.S. Const. amend. XIV.

<sup>311</sup> ICCPR, art. 4.

<sup>312</sup> ICCPR, art. 4.

<sup>313</sup> ICCPR, art. 4, 18.

<sup>314</sup> UNAIDS, *International Guidelines on HIV/AIDS and Human Rights*; Gostin & Berkman, “Isolation, Quarantine, Border Control & Social-Distancing Measures”; Marcel Verweij, “Equitable Access to Therapeutic and Prophylactic Measures,” in WHO, *Addressing Ethical Issues in Pandemic Influenza Planning*, WHO/IER/ETH/2008.1, 1-28.

<sup>315</sup> Raymond A. Smith & Patricia D. Siplon, *Drugs into Bodies: Global AIDS Treatment Activism* (Westport, CT: Prager Publishers, 2006).

159. Without doubt, the determination of whether the particular abridgement of a human right in the name of public health can be justified under the *Siracusa Principles* or international or domestic law must first be informed by medicine and epidemiology. In some cases, the science can demonstrate that an abridgement of rights cannot be justified because there is simply no causal relationship between the restraint of the individual's rights and the health risk at issue. Thus science makes clear that the isolation of an individual with a mosquito borne disease can never be justified since the isolation cannot stop the spread of the disease.
160. In most cases, however, science alone cannot offer a definitive determination as to the necessity or appropriateness of a particular social control. That is because while science can clarify the way that diseases are transmitted and shed light on the probabilities of risk that arise from particular types of human behaviors, it can never provide certainty as to the risks that particular individuals or groups will pose in the future. For example, the assessment of whether an identified non-compliant TB patient will remain non-compliant in the future is always based on conjecture. Likewise, science cannot tell us whether a particular individual with HIV will or will not continue to engage in high risk behaviors if provided with counseling. Science cannot also tell us with any certainty the social impact of any particular control. For example, a quarantine may be an effective intervention against SARS, but not if it causes people to flee a region in its anticipation. Likewise, criminalization of unprotected sex by people who know they are HIV positive will not reduce the risk of transmission if individuals avoid being tested in order to evade being prosecuted. Unfortunately, while empirical research can and should shed light on the efficacy of these interventions, the socially-contextual variables are so numerous and so dynamic that it is unlikely that epidemiology and social science research can ever provide clear and uncontestable answers as to the necessity, appropriateness, and efficacy of many rights-infringing social controls.
161. Moreover, science cannot decide the value that should be placed on either any particular risk or any human right. Thus science cannot decide whether any particular reduction in the risk of transmission warrants a ban on immigration, the denial of asylum, the abandonment of privacy, or preventive detention. The answer to those questions inevitably depends upon the value a society and the international community places on both health and human rights. Thus the fundamental question whether a particular risk, whose magnitude is invariably uncertain, justifies the deprivation of any individual liberty, is ultimately a social judgment to which there is no neutral scientific answer.
162. Given that the determination of whether particular uncertain risks merit the deprivation of individual rights cannot be answered by science, the existing legal and ethical framework is inevitably subject to social influences. In effect, the conclusions that the existing framework provides as to when and whether social controls are justified in response to a disease threat are determined in part by social understandings of disease, perceptions of the risk or riskiness of particular individuals and populations, and the values that a society places on various rights and liberties.
163. In addition, the existing framework is silent as to the timeframe or perspective that must be applied in analyzing whether a particular intervention is either necessary or the least restrictive means possible. In fact, interventions that may seem justified (or inappropriate) if one looks only at the short term may seem more problematic (or more appropriate) if the analysis includes a longer time horizon that takes into account the long term effects of the intervention under consideration as well as a wider range of alternative measures. As a result, although the existing framework provides a helpful guide for analyzing the appropriateness of public health social controls, it is inherently indeterminate in any particular case.

164. To see the impact of the indeterminacy of the existing framework, consider the case of a previously non-compliant TB patient. Under current international law, a health official can justify isolating that individual by demonstrating that he or she has been non-compliant with DOT and is likely (though how likely will inevitably be uncertain) to be non-compliant again. In that sense, the patient is dangerous to others and isolation can be viewed, at least in the short term, as the least restrictive means of protecting public health and hence legitimate under the *Siracusa Principles*.
165. Nevertheless, numerous uncertainties enter into the analysis. Most obviously, the assessment of any individual's future behavior, or dangerousness, is fraught with doubt. In addition, even if the individual remains non-compliant, the assumption that that would create a public health risk warranting the restriction of liberty is inherently subjective and value-laden. Without doubt, MDR-TB is a very serious disease that can be transmitted via respiratory particles. Isolating a non-compliant patient may prevent the transmission of his or her infection to one or more other people. On the other hand, TB is neither rare nor extremely infectious.<sup>316</sup> It is also treatable. Moreover, equal or more cases might be prevented in the long run by allocating the resources spent on detention to other interventions, such as expanding community-based care or providing better support for substance abusers. Hence the conclusion that the risk of future non-compliance by one patient justifies his or her indefinite detention depends to a great degree on how a society perceives the risk of that individual's transmission of MRD-TB in comparison to the broader risk posed by the epidemic or other health threats, as well as the society's valuation of the individual's liberty. Existing legal and principles offer little or no guidance as to where the focus should be.
166. The existing framework also fails to clarify how broadly the least restrictive alternative analysis should be applied. Should public health experts simply ask whether detention is the least restrictive means of reducing the risk posed by a particular non-compliant individual? Should public health experts ask instead whether a policy of detaining non-compliant patients is the least restrictive means of reducing the overall risk of TB in a community? Or, should public health experts ask whether the policy of detention is the least restrictive means of improving overall health in the community? The answers to these different questions are apt to be different. If the focus is on the risk posed by an identified individual with respect to a particular disease, the abridgement of his or her rights is far more likely to be viewed as the least restrictive means of protecting public health than if the focus is broadened to consider the most effective means of promoting the overall health of a community or population. Existing legal and ethical principles, however, offer little guidance as which vantage point is the appropriate one.
167. In the absence of any clear guidance or objective criteria for assessing which risks warrant strong social controls as well as the vantage point for determining the least restrictive alternative, social perceptions, including public health panics and discrimination, come into play. As this Report has documented, states frequently impose highly coercive interventions that initially appear to be justified to prevent a public threat. In hindsight, however, it often becomes evident that the perception of the threat, and the identification of the threat with particular individuals or groups, was fueled by a public health panic, antipathy to marginalized populations, and the deep desire to contain and control the risk.
168. In the midst of a full-blown public health panic, neither the *Siracusa Principles* nor any of the other widely-accepted but indeterminate international legal or ethical principles provide a firm foundation for either liberty or equality. During a public health panic, when societies perceive catastrophe as imminent, and view particular individuals or populations as deviant and

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<sup>316</sup> Coker, *From Chaos to Coercion*, 141-160.

responsible for increasing social risk, strong social controls will almost always appear to be absolutely necessary and the least restrictive alternative. Indeed, when a public health panic is in full bloom, almost all interventions taken against groups who are perceived as being associated with a disease, or having a higher risk of the disease, such as travelers, immigrants, and sex workers, will appear to be necessary and justifiable, and hence non-discriminatory and the least restrictive. Thus even if independent review demanded by procedural justice is available, and it seldom is during the midst of an outbreak, the abridgment of liberty is apt to be sustained.<sup>317</sup> As a result, the legal and ethical principles which seek to secure the protection of human rights in the face of public health interventions effectively legitimate the abridgment of human rights during a public health panic.

169. Even in the absence of a full public health panic, social constructions of risk influence perceptions of public health necessity and erode the ability of the existing legal and ethical principles to secure human rights. For example, many of the travel restrictions placed upon immigrants that were discussed in Section III are no longer sustained by contemporary public health panics. Nevertheless, the wide-spread association of diseases with foreigners and the broadly felt need to contain a disease outside of a state's boundaries help justify controls that actually make little public health sense. By granting states broad power to impose travel restrictions in order to protect public health, the IHR effectively sanctions these unnecessary infringements of liberty and unnecessarily restrict the breadth of the legal recognition of human rights.
170. Perhaps most importantly, the existing legal and ethical framework fails to prevent the distortion of public health resources and priorities created by social constructions of risk and public health panics. States frequently impose highly coercive controls in response to some public health risks, while paying relatively little attention, or devoting few resources, to other risks. In part, this is because the human right to health remains vaguely defined, is largely unenforceable, and is subject to progressive realization. Hence, existing international human rights law places few specific obligations on states to undertake the measures that are necessary to address the social, economic and environmental factors that play a far greater role in determining human health than do the specific pathogens or infected individuals that form the target of public health panics. In effect extant law permits states to respond to epidemics by imposing social controls and abridging human rights but it does not compel states to undertake meaningful measures before an epidemic strikes that might alter their population's vulnerability to potential epidemics.
171. The current H1N1 outbreak illustrates the problem. As Section II discussed, in the name of preparedness and biosecurity, states had developed elaborate plans in preparation for a potential influenza pandemic. Many of their plans included liberty-limiting social controls, including travel bans and quarantines, which were widely assumed to be necessary to contain a pandemic. There is little doubt that the use of such bans during the H1N1 epidemic would have been found to have been legal by international legal authorities. Moreover, had the epidemic been more lethal than it has been, the broad such of such measures would almost certainly have been advocated by public health officials and upheld by most courts around the globe.

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<sup>317</sup> There are relatively few examples of courts striking down public health interventions during a public health panic. One such example comes from San Francisco. In 1900 a court struck down a series of highly discriminatory measures imposed against Chinese-Americans in the face of a bubonic plague outbreak. *Jew Ho v. Williamson*, 103 F. 10, 26 (N.D. Cal. 1900). Far more typical, though still relatively rare, are cases such as *Enborn v. Sweden*, App. No. 56529/00, ECHR 2005/7, in which courts strike down public health interventions long after a disease has been introduced into an area and the panic has died down.

172. Yet, now that an outbreak has arisen, the limited efficacy of many of the containment preparations that were so central to preparedness planning is apparent. Even more striking, however, is the failure of the international community to institute many other interventions that might have mitigated the global impact of a pandemic. As the Director-General of the WHO has acknowledged, the H1N1 pandemic is almost assuredly going to prove more deadly to people in low income countries than to populations in high income countries. And even in high income countries, it is proving most lethal to individuals with chronic health problems. Yet, the social and economic rights that would compel states to address these pre-existing disparities remain significantly under-realized.<sup>318</sup> In effect, states have been busy preparing to impose social controls to contain an epidemic while neglecting the underlying social determinants and health system deficits that can make an outbreak especially lethal. As a result, both the right to health and many other human rights that are abridged in the name of health suffer.

### C. Recommendations

173. There is no simple way to assure that states will effectively and robustly protect the human right to health without impinging upon other human rights. No simple formulation of legal or ethical principles can suffice for all circumstances, nor can any simple statement of principles provide assurances in the face of the fear wrought by dangerous epidemics. Nevertheless this Report suggests several directions that both public health advocates and human rights activists should consider as they attempt to safeguard both public health and human rights.

#### 1) *Recognizing the dangers of public health panics:*

174. As this report has demonstrated, public health panics lay behind many of the human rights abuses that have been undertaken in the name of public health. In the midst of a public health panic, necessity appears to justify (both legally and ethically) broad limitations on human rights. More often than not, these limitations disparately impact marginalized and vulnerable populations. Frequently, hindsight shows that these limitations offered little or no public health benefits. Sometimes they were clearly counter-productive. This suggests that if both public health and human rights are to be protected, human rights activists should be vigilant in guarding against and discrediting public health panics. In particular, they should call into question the emerging infectious disease and biosecurity perspectives which are priming the world for public health panics and laying the foundations for the unnecessary restriction of human rights. In addition, human rights activists should recognize the high cost in both public health and human rights terms of their own campaigns that emphasize the dangers of interdependence and the risks of diseases emerging from low income countries. Arguments for supporting health and development programs in sub-Saharan Africa, for example, should be based on claims of justice and the interests of the people of that region, not on the dangers supposedly posed to the people of the North.

#### 2) *Emphasizing social determinants and endemic conditions:*

175. Public health panics focus on discrete dangers, diverting our gaze from more enduring, widespread, and often greater risks. In order to diffuse the power of public health panics, and the abuse of human rights that follow in their wake, it is critical for both public health and human rights activists to resist the temptation of focusing on discrete and fearful events, and work to garner support for addressing the myriad ongoing health problems that pose the greatest threat to human health and life in both high and low income countries. This requires shining the spotlight on chronic and endemic conditions and the many social determinants that undermine

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<sup>318</sup> Many of these rights are spelled out in the ECHR and General Comment 14.

health throughout the globe. Most importantly, support for public health agencies should not be based on the possibility that a plague will strike; instead, it should be based on valuing the work they do addressing common conditions day in and day out.

3) *Emphasizing the complementary relationship between health and human rights:*

176. Human rights activists and public health officials have widely accepted that health and human rights are generally complementary. However, there is still a commonly held assumption that their compatibility evaporates in the face of a public health emergency. That is not true. Human rights activists need to emphasize that the robust realization of human rights, particularly social and economic rights, enhances a state's ability to respond to and overcome a new epidemic. By protecting human rights, especially social and economic rights, a state is able to ensure that its population has the health and access to health care that becomes vital to withstanding any public health emergency. Moreover, by respecting the rights of all people, including the most vulnerable, health officials can earn the trust of the populations they will need to work with during an emergency. In contrast, if health officials abridge human rights and turn against marginalized populations, they risk losing the trust and support of that population during an emergency.

4) *Tying limits on human rights to the realization of human rights*

177. International law and widely-accepted ethical principles accept that states may abrogate some human rights when that is necessary for public health protection. However, the question of whether an abrogation is indeed necessary for public health protection is generally undertaken without regard to the state's fulfillment of its broader obligation under international law to provide the conditions necessary for health. Hence states are permitted to detain individuals to contain an epidemic even as they continue to deny their populations the clean water or rudimentary health services that would halt the epidemic. Human rights activists must work to ensure that the abrogation of human rights in the name of public health can never be accepted as "necessary" or "justified" as long as a state has failed to fulfill its limited obligations under the ICESCR to create the conditions necessary for health. In particular, highly coercive social controls cannot and should not be viewed as legitimate unless and until a state has done all that it is feasible for it to do to ensure the day in and day out health of its populations.

5) *Obtaining community participation and demanding accountable systems*

178. International law requires that independent review be made available when individuals are detained for public health purposes. This review is important, but it is insufficient for preventing or redressing unnecessary deprivations of human rights, particularly in the midst of public health panics. In order to deter abuses, and ensure that public health policies meet the needs of the people they claim to protect, public health systems must be developed with meaningful, not token, participation from affected communities.<sup>319</sup> In addition, public health officials must be held accountable for the human rights abuses they institute. At the present time, public health officials rightly feel that they will be taken to task if they fail to act with sufficient vigor in the midst of a public health panic. They are also apt to receive more authority, prestige, and potentially resources, if they emphasize the severity of a threat and the need for emergency actions. Hence every incentive points towards propagating public health panics and responding to outbreaks with liberty-limiting controls. To ensure that this is not the case, and that human rights are not unnecessarily abridged, systems need to be put into place within public health agencies, before the outset of a public health panic, to provide accountability and oversight and

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<sup>319</sup> Gostin & Berkman, "Isolation, Quarantine, Border Control and Social Distancing Measures."

to ensure that public health officials respect human rights while aiming to protect public health. Human rights groups can work now, before the next public health panic, to integrate community participation and accountability systems into local, national, and regional public health agencies.

#### **D. Conclusion**

179. The relationship between public health, social control, and human rights is complex and ever-changing. Public health is a human right. Yet, throughout history and still today, human rights are frequently limited in the name of public health. At times, no doubt, this is both necessary and justifiable. But far too often, social controls that are imposed to protect public health are neither necessary nor even beneficial to public health. Sparked by public health panics and the illusion that public health threats can be controlled by controlling people, states have too often abridged the rights of the vulnerable, while neglecting the social and economic conditions that foster epidemics and weaken the health of their populations. There may be no magic bullet to quash the epidemic of human rights abuses that occur in the name of public health, but by engaging with social control theory, and developing a greater sensitivity towards the social construction of public health risks as well as the importance of human rights to the protection of public health, human rights activists and public health advocates can reduce the risks that arise when panics drive public health policy.