

# THE GENESIS OF PUBLIC HEALTH ETHICS

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## ABSTRACT

*As bioethics emerged in the 1960s and 1970s and began to have enormous impacts on the practice of medicine and research – fuelled, by broad socio-political changes that gave rise to the struggle of women, African Americans, gay men and lesbians, and the antiauthoritarian impulse that characterised the New Left in democratic capitalist societies – little attention was given to the question of the ethics of public health. This was all the more striking since the core values and practices of public health, often entailing the subordination of the individual for the common good, seemed opposed to the ideological impulses of bioethics.*

*Of what relevance is autonomy-focused bioethics for public health, with its mix of justifications including those that are either implicitly or explicitly paternalistic or that seek to impose strictures on individuals and communities in the name of collective welfare? To examine the deep divide between the central commitments of bioethics and the values that animate the practice of public health, we focus on a series of controversies implicating the concepts of privacy, liberty, and paternalism.*

*Recognising the role of moral values in decision-making was a signal contribution of bioethics in its formative period. Over the past three decades a broad array of perspectives emerged under the rubric of bioethics but individualism remains central. As we commence the process of shaping an ethics of public health, it is clear that bioethics is the wrong place to start when thinking about the balances required in defence of the public's health.*

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In the beginning there was bioethics. The 1960s and 1970s witnessed extraordinary challenges to the broadly understood authority of medicine. Perhaps most strikingly, the paternalistic authority of physicians was brought into question by a new medical ethics that gave pride of place to the concept of

autonomy.<sup>1</sup> Paralleling the challenges to medical practice were those that involved the research enterprise. Against a backdrop of scandal and abuse, and haunted by the experience of the violations of human dignity that had occurred under the aegis of medical research in Nazi Germany, a new ethics of research took hold.<sup>2</sup> Informing that Nazi moral world-view was the basic belief that no individual should be required to participate in research endeavours – no matter how important for the public good – without his or her informed consent.<sup>3</sup> Thus, the ethics of clinical research and the ethics of medical practice were conjoined by a commitment to autonomy and individual rights.

Remarkably, as bioethics emerged and began to have enormous impacts on the practice of medicine and research – fuelled, to be sure, by broad socio-political changes that gave rise to the struggle of women, African Americans, gay men and lesbians, and the antiauthoritarian impulse that characterised the New Left in democratic capitalist societies – little attention was given to the question of the ethics of public health. This was all the more striking since the core values and practices of public health, often entailing the subordination of the individual for the common good, seemed to stand as a rebuke to the ideological impulses of bioethics.

Just how vast a gulf existed between the ethos of public health and the individualistic and antipaternalistic values of bioethics is given historical referent in the person of Herman Biggs. Biggs – a highly influential New York City health official who implemented a new set of public health interventions targeting the individual in the late nineteenth and early twentieth centuries – gave full expression to the moral foundations of public health: ‘The government of the United States is democratic, but the sanitary measures adopted are sometimes autocratic, and the functions performed by sanitary authorities paternal in character. We are prepared, when necessary, to introduce and enforce, and the people are ready to accept, measures which might seem radical and arbitrary, if they were not plainly designed for the public good, and evidently beneficent in their effects.’<sup>4</sup> It was the spirit

<sup>1</sup> David J. Rothman. 1991. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. New York, NY: Basic Books.

<sup>2</sup> *Ibid.* pp. 96, 99, 185–197.

<sup>3</sup> Terrence H. Ackerman. 1996. Choosing Between Nuremberg and the National Commission: Balancing of Moral Principles in Clinical Research. In *The Ethics of Research Involving Human Subjects: Facing the 21<sup>st</sup> Century*. Harold Y. Vanderpool, ed. Baltimore, MD: Frederick Press: 83.

<sup>4</sup> Hermann M. Biggs. 1897. *Preventive Medicine in the City of New York*. New York, NY: Health Department: 28, note 2.

of Biggs that informed thinking during the Progressive Era – the formative period of American public health.

When, at the beginning of the twenty-first century, a systematic effort to articulate an ethics of public health began, the deep differences between bioethics and public health would draw immediate attention.<sup>5</sup> In ‘An Ethics Framework for Public Health’, Nancy Kass thus writes, ‘codes of medical and research ethics generally give high priority to individual autonomy, a priority that cannot be assumed to be appropriate for public health practice.’<sup>6</sup> Similarly, Daniel Callahan and Bruce Jennings, in their effort to begin a broad engagement on the ethics of public health, argued, ‘In early bioethics, the good of the individual, and particularly his or her autonomy, was the dominant theme, not population health.’<sup>7</sup> That formative perspective, which retained its grip, compelled Callahan and Jennings to acknowledge that their own effort had to confront an epistemological ‘obstacle’: ‘the difference between the individualistic orientation of bioethics and the population and societal focus of public health.’<sup>8</sup> These challenges echoed the trenchant arguments made by Renee Fox decades earlier.<sup>9</sup>

Of what relevance is autonomy-focused bioethics for public health, with its mix of justifications including those that are either implicitly or explicitly paternalistic or that seek to impose strictures on individuals and communities in the name of collective welfare? To examine the deep divide between the central commitments of bioethics and the values that animate the practice of public health, we focus on a series of controversies implicating the concepts of privacy, liberty, and paternalism.

<sup>5</sup> James F. Childress, Ruth R. Faden, Ruth D. Gaare, Lawrence O. Gostin, Jeffrey Kahn, Nancy E. Kass, Anna C. Mastroianni, Jonathan D. Moreno & Phillip Nieburg. Public Health Ethics: Mapping the Terrain. *Journal of Law, Medicine, and Ethics* 2002; 30: 170–178. Public Health Leadership Society. 2002. *Principles of the Ethical Practice of Public Health*. Version 2.2. Public Health Leadership Society.

<sup>6</sup> Nancy E. Kass. An Ethics Framework for Public Health. *American Journal of Public Health* 2001; 91: 11.

<sup>7</sup> Daniel Callahan & Bruce Jennings. Ethics and Public Health: Forging a Strong Relationship. *American Journal of Public Health* 2002; 92: 169.

<sup>8</sup> *Ibid.* p. 170.

<sup>9</sup> Renee C. Fox. Advanced Medical Technology – Social and Ethical Implications. *Annual Review of Sociology* 1976; 2: 231–268. Renee C. Fox & Judith P. Swazey. 1988. Medical Morality is Not Bioethics: Medical Ethics in China and the United States. In *Essays in Medical Sociology*. Renee C. Fox, ed. New Brunswick, NJ. Transaction Books: 645–70. Rothman, *op. cit.* note 1, pp. 242–243.

## FIRST ENCOUNTERS: EPIDEMIOLOGICAL RESEARCH AND THE LIMITS OF CONSENT

Epidemiology is the foundational science of public health. Regulations designed to protect the autonomy and privacy of research subjects would require modification in the face of public health-focused research, regardless of whether it was conducted by government agencies or academic entities. Beginning in the 1970s, a discussion began about whether the emerging rules and regulations for human subjects' research would apply to epidemiological studies. Was informed consent necessary when research involved the use of extant records? Would imposing consent requirements for the examination of data sets involving large numbers of people – many of whom would be difficult or impossible to locate – render epidemiological research virtually impossible?<sup>10</sup> 'The clash between the privacy rights of persons and the need for access to and disclosure of personal health-related information', noted one observer, 'is the most frequent ethical dilemma to confront epidemiologists.'<sup>11</sup> In 1981, the United States Department of Health and Human Services (DHHS) issued regulations for the protection of human subjects explicitly exempting epidemiological research involving already existing data from informed consent requirements provided the risk to subjects was minimal, the research did not record data in a way that was individually identifiable, and the research could not otherwise be conducted.<sup>12</sup> The concession represented a relaxation of the fundamental principle that individuals could not be conscripted into research without their consent, for it was clear

<sup>10</sup> L. Gordis, E. Gold & R. Seltzer. Privacy Protection in Epidemiologic and Medical Research: A Challenge and a Responsibility. *American Journal of Epidemiology* 1977; 105: 163–168. L. Gordis & E. Gold. Privacy, Confidentiality and the Use of Medical Records in Research. *Science* 1980; 207: 153–156. L. Gostin. Ethical Principles for the Conduct of Human Subject Research: Population-Based Research and Ethics. *Law, Medicine, and Health Care* 1991; 19: 191–201. A.M. Capron. Protection of Research Subjects: Do Special Rules Apply in Epidemiology. *Law, Medicine, and Health Care* 1991; 19: 184–190. C.I. Cann & K.J. Rothman. IRBs and Epidemiologic Research: How Inappropriate Restrictions Hamper Studies. *IRB: A Review of Human Subjects Research* 1984; July/August: 5–7. N. Hershey. IRB Jurisdiction and Limits on IRB Actions. *IRB: A Review of Human Subjects Research* 1985; March/April: 7–9. K.J. Rothman. The Rise and Fall of Epidemiology, 1950–2000 A.D. *NEJM* 1981; 304: 600–602.

<sup>11</sup> John Last. 1996. Professional Standards of Conduct for Epidemiologists. In *Ethics and Epidemiology*. Steven S. Coughlin & Tom L. Beauchamp, eds. New York, NY. Oxford University Press: 57.

<sup>12</sup> Code of Federal Regulations, Title 45, Public Welfare, Department of Health and Human Services, National Institutes of Health, Office for Protection from Research Risks, Part 46, Protection of Human Subjects (45 CFR 46).

that the benefits of records-based research were significant enough to trump the claims of the individual.

The tension between the claims of individual informed consent and the demands imposed by record-based epidemiological research was also confronted in other economically advanced democratic nations. How these tensions were resolved reflected the extent to which the rights of the individual were given priority, judgements about how significant a burden would be entailed by insisting upon consent, and the social value accorded to such retrospective record-based studies. The Australian National Health and Medical Research Council, for example, required ethical review of all epidemiological studies and the consent of subjects unless such a requirement would render it impossible to conduct the study. In 1991, the European Union likewise proposed that that all studies undergo ethical review.<sup>13</sup> However, the proposed directive gave such priority to privacy and consent that epidemiologists expressed alarm over the future of their efforts. In response to arguments that the directive would make epidemiological research unfeasible, a 1995 directive made provisions for research without consent in instances where confidentiality was adequately protected, obtaining consent was impracticable, and the research was of sufficient importance. France and Germany passed similar provisions a year before the European Union approved its final directive, though at the end of the 1990s, concerns remained, especially in Great Britain.<sup>14</sup>

The Council of International Organizations of Medical Sciences (CIOMS) also addressed the issues imposed by the use of existing clinical records as part of its broader analysis of the ethical issues posed by epidemiological studies. In its 1991 report, it acknowledged that prior efforts to provide ethical guidance for biomedical research focused on 'patients and individual subjects' were not sufficient for studies involving 'groups' of people. Thus, while emphasising the importance of the principles of research ethics first propounded in the Belmont Report, it recognised that their application in the epidemiological context would require flexibility. Most important, the CIOMS epidemiological guidelines, like those from nations that had addressed these issues before, noted that individual informed consent was not always practical in epidemiological studies, while asserting that individuals and their representatives should 'normally' be told that their

<sup>13</sup> Baruch A. Brody. 1998. *The Ethics of Biomedical Research: An International Perspective*. New York, NY. Oxford University Press: 57.

<sup>14</sup> *Ibid.* pp. 62–63.

medical records or stored tissue samples might be used for future epidemiological studies.<sup>15</sup> In the end it was the duty of researchers who sought to undertake such record-based studies 'to explain to an ethical review committee how the study would be ethical in [the absence of consent].'<sup>16</sup>

## AIDS, PUBLIC HEALTH, AND ETHICS

The encounter over epidemiological research foreshadowed a more sustained and critical effort to enunciate an ethics of public health in the context of the AIDS epidemic, which began in the early 1980s. It is not surprising that when those schooled in bioethics first sought to address the ethical challenges posed by AIDS, they did so guided by the principles and values that had shaped the confrontation with medicine and the research enterprise.<sup>17</sup> Their efforts were informed by the intense concern of gay men about threats to privacy and civil liberties advocates fearful that AIDS would provide the occasion for the erosion of a set of substantive and procedural constitutional rights forged by the US Supreme Court. These concerns, in turn, were reflected in the posture adopted by public health officials in many cosmopolitan centres.<sup>18</sup>

Emerging from the complex mix of ideological, moral, and political forces was a commitment to treating AIDS differently from what the history of epidemic control might have suggested. In lieu of the compulsory tradition, that often involved mandatory case reporting by name, contact investigation, and where necessary the use of isolation, an 'exceptionalist' perspective took hold.<sup>19</sup> Focused on the centrality of education for mass behavioural change, the protection of the rights and privacy of people infected with HIV, and a rejection of coercive measures, the approach to AIDS was voluntarist at its core. A simple dictum emerged: no public health policy that violated the rights of individuals could be effective in controlling the spread of HIV. There was, therefore, no tension between public health and civil

<sup>15</sup> CIOMS. 1991. *International Guidelines for Ethical Review of Epidemiological Studies*. Guideline 3.

<sup>16</sup> *Ibid.* Guideline 2.

<sup>17</sup> R. Bayer, C. Levine & S. Wolf. HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs. *Journal of the American Medical Association* 1986; 256: 1768–1774.

<sup>18</sup> R. Bayer. 1989. *Private Acts, Social Consequences: Aids and the Politics of Public Health*. New Brunswick, NJ. Rutgers University Press.

<sup>19</sup> R. Bayer. Public Health Policy and the AIDS Epidemic: an End to HIV Exceptionalism? *NEJM* 1991; 324: 1500–1504.

liberties. Indeed, the protection of civil liberties was critical to the public health.

This view informed decisions in virtually all advanced democratic nations and was reflected on an international level in the effort to forge a relationship between public health and human rights.<sup>20</sup> While recognising that, in principle, limits on rights could be justified by the claims of public health, the United Nations Office of the High Commissioner for Human Rights and the Joint United Nations Programme on AIDS concluded that coercive public health measures were counterproductive since they tended to 'drive away people most in need of services and failed to achieve their public health goal of prevention through behavioral change, care, and health support.'<sup>21</sup> It was thus possible to declare that '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.'<sup>22</sup> Perhaps the most extreme formulation of this commitment to the protection of the rights of individuals was given voice by Jonathan Mann, who more than any other individual was responsible for seeking to embed public health in a human rights framework. He recognised the tension between public health and human rights, but in so doing, restated the conflict in a new way: 'For the present, it may be useful to adopt the maxim that health policies and programs should be considered discriminatory and burdensome on human rights until proven otherwise.'<sup>23</sup>

While AIDS provided the starting point, those committed to a health and human rights perspective saw the new articulation as having broad implications for public health more generally. If there were to be an ethics of public health, it would have to reflect in fundamental ways the values that gave birth to bioethics. Writing about the jurisprudential foundations of public health, George Annas challenged the relevance of *Jacobson v Massachusetts*, a 1905 case in which the US Supreme Court upheld mandatory smallpox vaccination, employing language that would serve

<sup>20</sup> David Kirp & Ronald Bayer, eds. 1991. *AIDS in the Industrialized Democracies*. New Brunswick, NJ. Rutgers University Press. Lawrence O. Gostin & Zita Lazzarini. 1997. *Human Rights and Public Health in the AIDS Pandemic*. New York, NY. Oxford University Press: xiv.

<sup>21</sup> Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. 1998. *HIV/AIDS and Human Rights: International Guidelines*. New York & Geneva. United Nations: 37.

<sup>22</sup> *Ibid.* p. 10.

<sup>23</sup> Jonathan M. Mann, Lawrence Gostin, Sofia Gruskin, Troyen Brennan, Zita Lazzarini & Harvey V. Fineberg. Health and Human Rights. *Health and Human Rights* 1994; 1: 16.

as the basis for the broad exercise of public health powers in the twentieth century: 'Today, almost one hundred years after *Jacobson*, both medicine and constitutional law are radically different. We now take constitutional rights much more seriously, including the right of a competent adult to refuse any medical treatment, even if life-saving treatment.'<sup>24</sup>

## SURVEILLANCE AND THE LIMITS OF PRIVACY

Since the end of the nineteenth century, surveillance has served as a critical element in the practice of public health. Central to the effort to monitor and intervene in the face of threats to the public health, surveillance has imposed on healthcare institutions and especially physicians the duty to report cases to confidential registries. Almost always such reports have included the names of the afflicted. Hence surveillance has represented a striking example of the ways in which the claims of public health could intrude upon the privacy of the clinical relationship. For most of the twentieth century such practices, *once established*, went unchallenged. AIDS provided the context for an assault on the privacy-limiting features of surveillance activities.

Soon after the first cases of AIDS were reported by the Centers for Disease Control in June 1981, state health departments in the US began to require that physicians and hospitals report by name each newly diagnosed case.<sup>25</sup> Once the capacity to test for the presence of the antibody to HIV became possible in 1985, it was only a matter of time before some public health official would seek to extend to HIV infection the reporting requirements that were in place for AIDS. The rationale for such reporting drew upon the history of public health: reporting would alert public health officials to the presence of individuals infected with a lethal infection; would allow them to counsel infected individuals about what they needed to do to prevent further transmission; would permit the authorities to monitor the incidence and prevalence of infection. Alert to concerns about privacy and confidentiality, health officials underscored the existence of administrative, regulatory, and statutory protections for reported names. There was no reason to believe that state health departments would fail to protect the identities of those with HIV when they

<sup>24</sup> George Annas. Blinded by Bioterrorism: Public Health and Liberty in the 21<sup>st</sup> Century. *Health Matrix* 2003; 13: 47.

<sup>25</sup> Bayer, *op. cit.* note 18, pp. 101–136.



had protected those with AIDS, tuberculosis, and other reportable infections.<sup>26</sup>

To these propositions, gay community-based antagonists to name-based reporting and civil liberties advocates retorted that AIDS was different: social hostility and AIDS-related hysteria could lead to changes in policy, legislatively imposed, that would permit for breaches that would never occur with other conditions.<sup>27</sup> And then those in registries would lose their jobs, their housing, and perhaps their liberty. These were arguments that impressed many health officials in states with relatively large AIDS caseloads. Reporting, they came to believe, would be counterproductive; it would drive people away from testing and counselling – essential control measures in the public health campaign against AIDS in the United States and elsewhere. It did not matter that public health departments had an exemplary record in protecting name-based reports.<sup>28</sup> If those most at risk for HIV had fears about what would happen to them, then that was all that mattered.

As therapeutic advances began to emerge in the late 1980s, fissures began to appear in the relatively broad and solid alliance against name-based reporting. The traditional values of public health began to reassert themselves against the privacy-based concerns that had prevailed during the epidemic's first decade. At the end of November 1990, the CDC declared its support for HIV reporting, which it asserted could 'enhance the ability of local, state and national agencies to project the level of required resources' for care and prevention services.<sup>29</sup> The House of Delegates of the American Medical Association endorsed the reporting of names as well, thus breaking with the traditional resistance of medical practitioners to such intrusions on the physician-patient relationship.<sup>30</sup> In 1991, New Jersey became the first high-prevalence state to require HIV-case reporting by name.<sup>31</sup> In the

<sup>26</sup> Ronald Bayer & Amy L. Fairchild. The Limits of Privacy: Surveillance and the Control of Disease. *Health Care Analysis* 2002; 10: 19–35.

<sup>27</sup> Bayer, *op. cit.* note 18.

<sup>28</sup> L.O. Gostin, J. Ward & C. Baker. National HIV Case Reporting for the United States: A Defining Moment in the History of the Epidemic. *NEJM* 1997; 337: 1166.

<sup>29</sup> Centers for Disease Control and Prevention. Update: Public Health Surveillance for HIV Infection – United States, 1989 and 1990. *MMWR* 1990; 39: 861.

<sup>30</sup> R. Bayer, *op. cit.* note 19: 1501.

<sup>31</sup> Intergovernmental Health Policy Project. Reporting in the States. *Intergovernmental AIDS Reports* 1989; November/December.

following years, the CDC continued to press for named reporting of HIV cases, an effort that assumed the dimensions of a campaign.

Although most, if not all, AIDS-service organisations as well as civil liberties advocates remained adamantly opposed to name reporting, arguing instead for the use of unique identifiers that could protect the privacy of people with HIV infection, the public health community, with the CDC in the lead, concluded that such an approach would simply impede the adoption of an effective system of surveillance. Nevertheless, marking the extent to which concerns for privacy continued to shape decision-making in public health, the CDC, in its 1999 recommendation for nationwide HIV case reporting, reluctantly opened the way to the use of unique identifiers in those states that preferred a reporting course that did not entail the use of names.

The debates that occurred over name-based reporting in the context of the AIDS epidemic would inevitably raise questions about the practice of surveillance itself as advocates of privacy, to the astonishment of public health practitioners, suggested that the warrant for the violation of privacy in the early twentieth century no longer deserved unquestioned obeisance.

## CONFINEMENT AND THE LIMITS OF LIBERTY

Isolation and quarantine represent the most plenary exercise of the state's authority in the name of public health.<sup>32</sup> Historically, the imposition of isolation and quarantines to control infectious threats was bounded by few procedural protections. The rights of the individual were viewed as subservient to the judgements of those with public health authority. As the pattern of morbidity and mortality underwent an epidemiological transformation in the twentieth century, as chronic conditions replaced infectious diseases as the pre-eminent threat, the role of quarantine and isolation became marginal to the practice of public health in the United States. There were lingering threats that called forth the

<sup>32</sup> Although the terms are often used interchangeably, isolation is the separation of individuals known to be infectious. In contrast, quarantine is the restriction of the activities of healthy individuals or populations exposed to a communicable disease. A.S. Benenson, ed. 1995. *Control of Communicable Diseases Manual*. Washington, DC. American Public Health Association. J. Barbera, A. Macintyre, L. Gostin, T. Inglesbury, T. O'Toole, C. DeAtley, K. Tonat & M. Layton. Large-Scale Quarantine following Biological Terrorism in the United States: Scientific Examination, Logistic and Legal Limits, and Possible Consequences. *JAMA* 2001; 286: 2711–2717.

exercise of the power to confine – tuberculosis, for example – but they were relatively uncommon.

The worldwide threat of Severe Acute Respiratory Syndrome (SARS) in 2002 posed starkly the question of when, in the name of public health, individuals and communities could be deprived of their liberty. In several respects, SARS took society back to a pre-therapeutic era: no definitive diagnostic test, a non-specific case definition, and no effective vaccine or treatment.<sup>33</sup>

Countries used one of the oldest public health tools in response to the first outbreak of SARS: isolation and quarantine, underscoring the tension between liberty and the imperative to protect the public's health. During the first SARS outbreak, public health authorities implemented isolation and quarantine in countries with diverse socio-political and constitutional traditions, ranging from China, Hong Kong, Vietnam and Singapore, to Canada and the United States.<sup>34</sup>

Confinement of individuals with disease and those exposed raised questions about the level of risk that justified loss of liberty. Frank cases needed to be isolated, but when a case was unconfirmed or when the individual had simply been exposed or was suspected of being exposed the justification for restricting liberty was problematical. Uncertainty about how wide to cast the net of quarantine for exposed, asymptomatic individuals was framed by the absence of a diagnostic assay that could rapidly distinguish between the infected and merely exposed with high specificity. But very broad quarantines were viewed as justifiable because of the uncertainties of risk.

Most jurisdictions confined patients in their homes or general hospitals, but others considered the construction of special infectious disease hospitals.<sup>35</sup> In Asia and Canada, authorities ordered mass quarantines or closures for schools, hospitals, factories, hotels, restaurants, places of entertainment, and residential buildings.<sup>36</sup> Some countries, particularly the United States, sought

<sup>33</sup> J.L. Gerberding. Faster . . . but Fast Enough? Responding to the Epidemic of Severe Acute Respiratory Syndrome. *NEJM* 2003; 348: 2030.

<sup>34</sup> B.R. Bloom. Lessons from SARS. *Science* 2003; 300: 701.

<sup>35</sup> Hong Kong Economic and Trade Office Tokyo. Press release. Available at: [http://www.hketotyo.or.jp/english/news\\_sars030605\\_e.html](http://www.hketotyo.or.jp/english/news_sars030605_e.html) (accessed 14 July, 2003).

<sup>36</sup> J.B. Kahn. Quarantine Set in Beijing Areas to Fight SARS. *New York Times* 25 April, 2003: A1. Centers for Disease Control and Prevention. Severe Acute Respiratory Syndrome – Singapore 2003. *MMWR* 2003; 52: 40–41. K. Bradsher. The SARS Epidemic: Economy; Outbreak of Disease brings Big Drop-off in China's Economy. *New York Times* 28 April, 2003: A1. A. Wayne. In Singapore, 1970s Law becomes Weapon Against SARS. *New York Times* 10 June, 2003: F4.

voluntary separation of exposed patients,<sup>37</sup> but others used more intrusive forms of enforcement. In Singapore, where thousands were subjected to quarantine, authorities used thermal scanners, web cameras, and electronic bracelets to enforce quarantine, supervised by a security agency.<sup>38</sup> In Hong Kong, the police department's electronic tracking system was used to enforce quarantine.<sup>39</sup> While recourse to compulsory measures posed few challenges to the underlying values of authoritarian regimes, officials underscored the extent to which the threat of SARS justified resort to coercive measures even in liberal democratic societies. In Canada, a high school was closed and 1500 students ordered to home quarantine because of a single case involving a student with symptoms of SARS; Ontario's commissioner of public health warned those who violated the home quarantine that he had the authority to hospitalise those who failed to adhere to the order.<sup>40</sup>

In the fall of 2003, as the international community braced for the possibility of a resurgence of SARS, it became clear that the isolation procedures used during the initial outbreak had been far too stringent. The CDC reported that individuals quarantined after contact with an asymptomatic SARS patient 'had no detectable risk' of infection. Moreover, there were no cases in which an individual transmitted the disease to his or her contacts while under quarantine. Thus, the CDC concluded that 'Focusing only on persons who had contact with an actively ill SARS patient would have reduced the number of persons quarantined by approximately 66 percent, without compromising its effectiveness.'<sup>41</sup> The CDC then elaborated a finer range of surveillance and quarantine recommendations, these included: passive monitoring on the part of the individual with no activity restrictions; active monitoring by healthcare workers either by phone or in person (which might or might not include explicit quarantine restrictions); working quarantine (for people, such as healthcare

<sup>37</sup> M.H. Cooper. Fighting SARS. *CQ Researcher* 20 June, 2003.

<sup>38</sup> World Health Organization. Severe Acute Respiratory Syndrome – Singapore, 2003. *Weekly Epidemiologic Record* 2003; 78: 161.

<sup>39</sup> World Health Organization. 2003. *Severe Acute Respiratory Syndrome (SARS): Status of the Outbreak and Lessons for the Immediate Future*. Geneva. World Health Organization.

<sup>40</sup> D.L. Brown. Sick of Quarantine in Toronto; After School's SARS Scare, Teens Bored by Week in Isolation. *Washington Post* 3 June, 2003: A20.

<sup>41</sup> Centers for Disease Control and Prevention. Efficiency of Quarantine during an Epidemic of Severe Acute Respiratory Syndrome – Beijing, China, 2003. *MMWR* 2003; 52: 1039. See also: WHO. SARS – Epidemiological Findings, Clinical Picture, and Case Management. Available at: <http://www.wpro.who.int/sars/docs/interimguidelines/part2.asp> (accessed 9 February, 2004).

workers, who provide essential services); focused measures (such as building closings or event cancellations) to increase the social distance among members of a group where transmission was believed to have occurred; and community-wide or regional measures (such as school closings and transportation system shut downs) to increase social distance in areas where extensive SARS transmission occurred, where there was a lack of clearly identifiable epidemiological links between cases, and where restrictions on known contacts was deemed insufficient.<sup>42</sup>

### PATERNALISM AND THE LIMITS OF AUTONOMY

For government to impose restrictions on those who represent a risk to others falls clearly within the broadly accepted exercise of state power in liberal societies and in principle entails no fundamental problem for the autonomy-focused perspective of bioethics. Problems emerge where the risk to others is uncertain. It is here that an important divide emerges between the judgements of those committed to autonomy and those whose first priority is the public health. It is a divide characterised by complex questions of what moral weight to give to the *likelihood* and *severity* of harm. However these matters are resolved, they raise issues that are fundamentally different from those posed by behaviours that represent primarily a threat to individuals themselves. It is here that the spectre of paternalism emerges, and that the tension between public health perspectives and autonomy-focused bioethics is positioned in its boldest relief.

Tobacco consumption represents the single most important cause of morbidity and mortality in advanced industrialised societies. It thus serves as an object lesson in the ways in which the antagonism towards paternalism has both shaped and limited public health policy.

In 1964, when the Office of the US Surgeon General issued the first report on the hazards of tobacco use, 50% of men and 35% of women smoked cigarettes.<sup>43</sup> This meant there were millions of smoking adults whose health and lives were imperilled. But as the American campaign against tobacco took its first halting steps in

<sup>42</sup> Centers for Disease Control and Prevention. Public Health Guidance for Community-Level Preparedness and Response to Severe Acute Respiratory Syndrome (SARS). Version 2; Appendix D1: Interventions for Community Containment. 8 January, 2004. Available at: <http://www.cdc.gov/ncidod/sars/guidance/D/index.htm> (accessed 9 February, 2004).

<sup>43</sup> US Department of Health and Human Services. 2000. *Reducing Tobacco Use: A Report of the Surgeon General*. Washington, DC. Government Printing Office.

the context of fierce resistance from the tobacco industry and its political allies, it avoided the taint of paternalism, the suggestion that the state was seeking to impose its preferences on those who smoked cigarettes.

Three broad sets of policies were adopted to confront the challenge posed by tobacco over the next four decades: restrictions on advertising; the imposition of taxes; and limits on public smoking. In each case, a public warrant for the measures adopted sought to demonstrate that it was third parties, innocent victims, or children that were the object of protective measures. Only insofar as warnings about tobacco, weak as they were, were posted on cigarette packages, did public health efforts direct themselves to those who bore the full burden of cigarette-related suffering, disease, and death.

Efforts to limit tobacco advertising, a complex matter in polities that accord protection to commercial speech, almost always focused on the claims of children. It was they who were vulnerable to the manipulations and seductions of advertising. If in order to protect them, it was necessary to limit advertising that could be viewed by adults – proposals in the US to ban outdoor advertising within 1000 feet of any school effectively meant a ban on all outdoor advertising in many communities – that was a price that had to be paid.

As public health officials came to recognise that cigarette consumption was price-responsive despite the addictive nature of nicotine, the possibility of facing the threat of tobacco-related disease by raising taxes became increasingly appealing. But the public justification of such taxes was almost always that either increasing the price of cigarettes would render them too costly for adolescents or that those who smoked cigarettes imposed healthcare costs on the non-smoking population.<sup>44</sup> Such externalities could be internalised by raising taxes on cigarettes. Indeed, fairness dictated the imposition of such burdens on smokers.<sup>45</sup> If such taxes also discouraged those who smoked from continuing their habit, that was simply an added advantage to a policy directed at the protection of non-smokers and those, who because of age, were an appropriate target of paternalistic interventions.

Finally, virtually from the dawn of the public health campaign against cigarette-related morbidity and mortality, the effort to

<sup>44</sup> Thomas A. Hodgson. Cigarette Smoking and Lifetime Medical Expenditure. *Milbank Quarterly* 1992; 70: 81–125.

<sup>45</sup> Kenneth E. Warner. Cigarette Taxation: Doing Good by Doing Well. *Journal of Public Health Policy* 1984; 5: 312–319.

restrict smoking in public settings has played a central role.<sup>46</sup> Such efforts *preceded* the first evidence that side-stream smoke posed a hazard – at least in enclosed environments – by more than a decade. By the end of the twentieth century, a radical transformation had occurred. Smoking, which was an integral dimension of the social world, was increasingly relegated to the private domain.<sup>47</sup> Debate over how far to press such restrictions ultimately had to confront the question of whether bans on outdoor smoking could be justified in terms of annoyance abatement rather than disease prevention. An antismoking activist declared, ‘Even if outdoor environmental tobacco smoke were no more hazardous than dog excrement stuck to the bottom of a shoe, in many places laws require dog owners to avoid fouling public areas. Is this too much to ask of smokers?’<sup>48</sup> Not all antismoking activists shared this view. Said the editor of *Tobacco Control*, ‘We need to ask whether efforts to prevent people from smoking outdoors risks besmirching tobacco control advocates as the embodiment of intolerant, paternalistic busy-bodies, who, not content at protecting their own health, want to force smokers not to smoke.’<sup>49</sup>

Despite such concerns, by the end of the twentieth century, the willingness to embrace explicitly paternalistic justifications for antismoking policy was becoming more evident, no doubt facilitated by the emergence of a sharp social gradient in cigarette consumption – those who are educated smoke less and less, those at the bottom of the social ladder continue to smoke.

The most dramatic reflection of the willingness to embrace paternalism was to be found in measures seeking to ‘denormalise’ smoking. We typically do not think of health promotion campaigns as paternalistic. But when they go beyond the provision of information and systematically seek to transform the very desires and preferences of those to whom they are directed, they assume a fundamentally different character. Indeed, the use of social marketing techniques to undercut smoking behaviour must be

<sup>46</sup> Ronald Bayer & James Colgrove. 2004. Children and Bystanders First: The Ethics and Politics of Tobacco Control in the United States. In *Unfiltered: Conflicts over Tobacco Policy and Public Health*. Eric Feldman & Ronald Bayer, eds. Cambridge, MA. Harvard University Press.

<sup>47</sup> Allan Brandt. 1998. Blow Some Smoke My Way: Passive Smoking, Risk, and American Culture. In *Ashes to Ashes: The History of Smoking and Health*. Stephen Lock, Lois Reynolds & E.M. Tansey, eds. Amsterdam. Rodopi Press.

<sup>48</sup> J. Repace. Banning Outdoor Smoking Is Scientifically Justifiable. *Tobacco Control* 2000; 9: 98.

<sup>49</sup> S. Chapman. Banning Smoking Outdoors Is Seldom Ethically Justifiable. *Tobacco Control* 2000; 9: 95–97.

viewed as paternalistic in impulse as well as practice. In a 1998 report, California's tobacco control programme openly advocated a social norm change designed to protect 'generations who have already reached adulthood.'<sup>50</sup> When New York City sharply increased tobacco taxes in 2002, the justification was not that smokers imposed costs on others, but rather that hefty prices might help force smokers to quit. The mayor of New York City saw this as an effort to save the lives of smokers themselves.<sup>51</sup>

## TOWARD AN ETHICS OF PUBLIC HEALTH

What the foregoing discussion has demonstrated is that those involved in the practice of public health embrace a set of values that are often, if not always, in conflict with the autonomy-centred values of those who take an individualistic and anti-paternalistic stance. But ethos is not ethics. When bioethics first emerged it confronted a tradition of medical practice and research within which paternalism still commanded both loyalty and impassioned defence. It was that dominant world-view that bioethics sought to overturn. In the context of public health, the question that needs to be addressed is whether paternalism and subordination of the individual for the good of the commonwealth should serve as the foundation for an ethics of public health or whether the perspective derived from the dominant autonomy-focused and anti-paternalistic currents in bioethics should serve as a point of departure for a thoroughgoing challenge to the fundamental values and practices of public health.

We begin with the conviction that at the core of public health practice is the charge to protect the common good, to intervene for such ends even in the face of uncertainty. This stance may, we believe, necessitate limits on the choices of individuals on grounds of communal protection against both hazard and paternalism. It is in this regard that this article may be distinguished from other recent efforts to articulate a set of moral considerations for public health, which have commonly focused on the centrality of social justice for public health.

During the twentieth century, public health interventions were often justified by an explicit or implicit invocation of the harm

<sup>50</sup> California Department of Health Services. 1998. *A Model for Change: The California Experience in Tobacco Control*. Sacramento, CA. California Department of Health Services: 4.

<sup>51</sup> Michael Cooper. Cigarettes Up to \$7 a Pack with New Tax. *New York Times* 1 July, 2002: B1.



principle. First enunciated by John Stuart Mill, that principle provides the standard for judging liberty-limiting acts of government.<sup>52</sup> It would be hard to imagine a set of ethical arguments that could challenge this posture. Indeed, limitations on the rights of individuals in the face of public health threats are firmly supported by legal tradition and ethics.<sup>53</sup> All legal systems, as well as international human rights, permit governments to infringe on personal liberty to prevent a significant risk to the public.<sup>54</sup>

Nevertheless, there are limits to the application of even the most central of precepts. In recent decades, efforts to bind the harm principle have focused on employing the least restrictive or intrusive alternative that could protect the public health against significant risk. But what constitutes a least restrictive/intrusive alternative and how the significance of risk is to be judged are only in part empirical matters. More important, moral judgements are involved. In fact, the tension between autonomy and public health perspectives is reflected in all such judgements. We believe that the standard appropriate to public health cannot be derived from the basic assumptions of a bioethics dominated by individualism.

The case of tuberculosis makes this clear. When individuals fail to complete the course of treatment they run the *risk* of reactivation and of developing multi-drug resistant strains of mycobacterium tuberculosis, which can be difficult and costly to treat, even deadly. The risk posed by any individual for such developments may not be judged 'significant.' But more important, when non-compliance characterises large numbers of individuals – as was the case in the US in the early 1990s – there is no question but that the threat to public health attains significance. It is therefore the *collective* hazard that provides the warrant for intervention even when the threat posed by any individual may not attain the standard of significance.<sup>55</sup> This is, of course, a point suggested by Geoffrey Rose in his now famous formulation of the ways in which

<sup>52</sup> John Stuart Mill. *On Liberty* quoted in: *The Philosophy of John Stuart Mills*. 1961. M. Cohen, ed. New York, NY. Modern Library: 185–319.

<sup>53</sup> Lawrence O. Gostin. Public Health Law in an Age of Terrorism: Rethinking Individual Rights and Common Goods. *Health Affairs* 2002; 21: 79–93.

<sup>54</sup> United Nations Economic and Social Council (ECOSOC). The Siracusa Principles on the Limitations and Derogation Provisions in the International Covenant on Civil and Political Rights. UN Doc. E/CN.4/1985/4, Annex. Available at: <http://www1.umn.edu/humanrts/instreet/siracusaprinciples.html> (accessed 7 July, 2003).

<sup>55</sup> Ronald Bayer & Laurence Dupuis. Tuberculosis, Public Health, and Civil Liberties. *Annual Review of Public Health* 1995; 16: 320–322.

small benefits to individuals from public health interventions may produce quite significant collective goods.<sup>56</sup>

The global outbreak of SARS discussed above provides an example of how in the face of grave threats a public health perspective may mandate interventions even when it is unclear whether such threats may become significant. The precautionary principle provides a starting point for the ethics of risk management. The principle stipulates an obligation to protect populations against reasonably foreseeable threats, even under conditions of uncertainty.<sup>57</sup> First articulated in the context of environmental hazards, the precautionary principle seeks to forestall disasters and guide decision-making in the context of incomplete knowledge. Given the potential costs of inaction, it is the failure to implement preventive measures that requires justification. Proponents of the precautionary principle explicitly defend their position by noting that entities that threaten the environment are best able to bear the burdens of regulation. Opponents warn that the imposition of such burdens may stifle economic progress and scientific innovation.<sup>58</sup> In general, the principle has only recently been explicitly invoked in the context of epidemic threats where pre-emptive actions may burden individuals and impose limits on their freedoms. Nevertheless, the precautionary principle has implicitly guided public health interventions designed to limit or forestall epidemic outbreaks.

The challenge to the precautionary principle is illustrated by quarantine in the case of SARS. Health officials had to act without full scientific knowledge about the nature of disease transmission. To avoid catastrophe, they took action that proved unnecessarily extensive. The only safeguard against the misuse of authority is transparency and an open acknowledgement that new evidence may necessitate a reconsideration of policies.

In the end, a focus on population-based health requires a population-based analysis and a willingness to recognise that the ethics of collective health may require far more extensive limitations on privacy, as in the case of public health surveillance, and on liberty, as in the case of isolation and quarantine, than would be justified from the perspective of the autonomy-focused

<sup>56</sup> Geoffrey Rose. Sick Individuals and Sick Populations. *International Journal of Epidemiology* 2001; 30: 427–432.

<sup>57</sup> J. Applegate. The Precautionary Preference: An American Perspective on the Precautionary Principle. *Human and Ecological Risk Assessment* 2000; 6: 413–443.

<sup>58</sup> J. Morris. 2000. *Defining the Precautionary Principle. Rethinking Risk and the Precautionary Principle*. New York, NY. Butterworth-Heinemann: 1–21.

orientation of the dominant current in bioethics. Compulsion and, indeed, coercion – so anathema to this tradition of bioethics – are central to public health. Nevertheless, it is important to recognise that while mandatory measures and recourse to coercion may be necessary, efforts designed to elicit the voluntary co-operation of those at risk for acquiring or transmitting infectious diseases are preferable and, indeed, may be more effective. From an ethical perspective, such efforts are desirable because they enhance the public's health without gratuitously burdening privacy and liberty. From a pragmatic perspective, such efforts reduce the necessity of invoking the coercive power of the state that may provoke resistance at a juncture when co-operation is essential. Thus, while a public health perspective will not privilege liberty and privacy, it does not follow that it should be insensitive to the importance of protecting individual rights.

More challenging is the question of the role of paternalism in public health. Mill's anti-paternalism has struck a powerful cord in American political culture, as we noted in our discussion of tobacco policy. Animated by a broad utilitarianism that seeks to maximise communal well-being, public health has embraced measures that go far beyond the very limited recognition of justifiable paternalism in conventional bioethical accounts.

In a striking example of the effort to justify paternalism in the context of occupational health regulations, Norman Daniels argued that the protection of workers against hazardous workplace exposures *that they themselves* might choose to risk could be justified because of the 'quasi-coercive' economic context within which workers were forced to choose.<sup>59</sup> But such a defence of paternalism is too limited. The central commitment to collective well-being requires a much more robust embrace of paternalism – one that goes beyond interventions designed to protect those whose choices are limited by lack of knowledge or understanding. We ought, for example, to protect motorcyclists from the hazards of unhelmeted riding not because they may impose costs on the community in the event of accidents or because they are too young to appreciate the hazards entailed, but because we are morally bound to prevent avoidable suffering and death.

It is not surprising that among the most forthright defences of public health paternalism has come from Robert Goodin, a utilitarian: 'We do not leave it to the discretion of consumers, however well informed, whether or not to drink grossly polluted water,

<sup>59</sup> Norman Daniels. 1985. *Just Health Care*. New York, NY. Oxford University Press: Chapter 7.

ingest grossly contaminated foods, or inject grossly dangerous drugs. We simply prohibit such things on grounds of public health. That appeal is justified, in turn, most standardly by recourse to utilitarian calculations . . . To a very large extent . . . the justification of public health measures, in general, must be baldly paternalistic. Their fundamental point is to promote the wellbeing of people who might otherwise be inclined cavalierly to court certain sorts of diseases.<sup>60</sup> The challenge, we believe, for public health ethics is to define those moments when public health paternalism is justified and to articulate a set of principles that would preserve a commitment to the realm of free choice.

The effort to shape public health policy in liberal societies will require a forthright acknowledgement of the tensions and trade-offs that will inevitably arise when the claims of public welfare and well-being intrude on privacy, individual choice, and liberty. Recognising the role of moral values in decision-making was one of the signal contributions of bioethics in its formative period. To be sure, over the past three decades a broad array of perspectives has emerged under the rubric of bioethics. Dissatisfaction with the historically dominant commitments to individualism has been reflected in communitarian claims, feminist perspectives, and now even in explicitly politically conservative formulations. Nevertheless, individualism retains its hegemonic status. It is thus that bioethics cannot serve as a basis for thinking about the balances required in the defence of the public's health. As we commence the process of shaping an ethics of public health, it is clear that bioethics is the wrong place to start.

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<sup>60</sup> Robert E. Goodin. 1989. *No Smoking: The Ethical Issues*. Chicago & London. The University of Chicago Press: 30–31.