PH856 Law and Ethics in Public Health Policy Development

Boston University School of Public Health

Spring 2018 April 6 – May 4

Instructor: Lora Sabin, MA, PhD

Associate Professor

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Office Hours: Available by appointment

Course Meeting Times: Fridays, 9 – 2:30 pm*

Course Location: Crosstown, 4th Floor, Room #446 (CHS conference room)

*With changes to be made depending on needs/availability of students and instructor.

Course Rationale and Description. Successful program and policy development often involve complicated ethical, legal, and policy-related issues. Students intending to be engaged in public health decision-making should be aware of these issues and comfortable considing and discussing them. The purpose of this course is to help students learn to examine and analyze the ethical and legal principles that should underpin public health decision-making and leadership, both in the U.S. and in global contexts. We will consider a range of different issues in the course, including: a) police power vs. individual freedom; b) the ethical issues related to compelling health-promoting behavior change; and c) fairness and equity related to climate change and other environmental crises. In order to strengthen skills related to discussin these issues, each student will be asked to lead class discussions in two short sessions. The course will mainly use group discussions, with occasional use of PPT slides. We will also have guest lecturers who are experts in their fields.

Course Goals

Students will acquire the knowledge and skills needed to critically analyze the ethical and legal arguments that should be considered before making decisions on programs and policies. They will also gain skills in leading discussions around these issues.

Learning Objectives

Students completing the course will be able to:

- 1. Discuss the major ethical, legal, and human rights principles relevant to public health policy-making, both in the U.S. and in other settings.
- 2. Apply relevant ethical, legal, and human rights principles to difficult and controversial public health decision-making.

- 3. Articulate clearly ethical and legal principles in the course of discussions or debates about public health policy.
- 4. Lead discussions that highlight and analyze the ethical, legal, and human rights ethics that bear on public health decision-making.

Communication

Feel free to email Lora anytime with questions or issues relating to the course or attendance: lsabin@bu.edu.

Use of cell phones and laptops in class

Open laptops during class can be very distracting—for both students and myself. Therefore, I ask that you refrain from using a laptop during our discussions, unless you are referring to course documents on your laptop. Thank you in advance for adhering to this rule. Also, please be sure to set aside or turn off your cell phones during class.

Readings

All readings will be publicly available. Most links are in the syllabus. Other notes and readings will be posted on Blackboard at least one week ahead of the session for which the readings are assigned. During the course, we may also decide as a group to add readings. If students have any problem accessing an assigned reading, please be in touch with Lora.

Student Evaluation

Student grades will be based on the following items (see below for more details on each assignment):

Leadership of case discussion	30%
Final paper, due by Monday, May 7, 5 pm.	50%
Class participation	20%
TOTAL	100%

Leadership of case discussion

Each student will be expected to lead one discussion during the course. These will be discussions during Sessions 3-7 of the course. Most sessions will be comprised of a major topic, with two sub-topics containing cases or problems for discussion. For each of these sub-topics, one student will lead a roughly one-hour (or perhaps a little longer) discussion. Discussion questions will be sent to the entire class and instructor at least 24 hours in advance of the course meeting. At our first class, we will allocate the sessions to students, with students expressing a preference for the session they would like to lead.

Final paper

Each student will write a final paper, <u>due on or before Monday, May 7th, at 5 pm.</u> Students may choose the topic for which they led a discussion, and may use and build on the opinions, arguments, and debates that were expressed during the class session, or may choose another topic. The paper should be 10-12 pages, double spaced (5-6 pages, single spaced). Students will use the ethics framework presented in Kass, "An Ethics Framework for Public Health" assigned for Week 1, or another framework, as they discuss the relevant ethical issues of their chosen topic. This should include addressing the following questions/issues: what are the public health goals of the program in question (or legislation/policy)? How effective is the program in achieving its stated goals? What are the known or potential burdens of the program? Can burdens

be minimized? Are alternatives available? Is the program implemented fairly? How can benefits and burdens of the program be fairly balanced (or more fairly balanced)?

Class participation

This is a small doctoral level seminar course, and the content and quality of our discussions will depend critically on students' level of preparedness and ability to contribute to the discussions in meaningful ways. With such a diverse and ambitious set of readings and assignments, and the focus of the course on class discussion informed by the readings, it is vital that students do all the readings in advance of class. Students are expected to contribute to class discussions in a thoughtful and respectful fashion, keeping in mind the goal of letting everyone have a voice and express their views and opinions. Such class participation should help prepare you for similar discussions you will have with professional colleagues in the future.

Academic and Professional Conduct

Academic misconduct is any intentional act or omission by a student that misrepresents his or her academic achievements, or any attempt to misrepresent his or her academic achievements. The following acts constitute academic misconduct:

- Cheating on examinations
- Plagiarism
- Misrepresentation or falsification of data
- Submitting the same work in more than one course
- Allowing another student to represent your work as his or her own

We are required to bring charges of academic misconduct to the attention of the Associate Dean for Academic Affairs who will review all such cases and decide upon an appropriate action. A student who is found guilty of academic misconduct may be subject to disciplinary action, up to and including dismissal from the School. We hope that this information will be completely irrelevant to this class!

We also believe in personal honesty and expect that if a student must be late to class, miss class, or cannot fulfill the assignments of this course in a timely manner, the student will be forthright about the reasons for these issues to the instructor and fellow students.

Course topics

Session	Date*	Topic	Facilitator	
1	April 6	Introduction to ethics and law in public health	Lora	
2	April 6	Human rights and health	Michael Grodin, Dept of Health Law, Policy & Management	
3	April 20	State power and freedom of the individual	tbd	
Thanksgiving break				
4	April 20	Public health screening and testing	tbd	
5	tbd	Changing behavior: ethical and legal issues	tbd	
6	May 4	Public health and use of scarce resources	tbd	
7	May 4	Environmental justice	tbd	

^{*}Changes to be made by mutual agreement of students and instructor. Tentatively: Session 1/2: April 6.
Session 3/4: April 20.

Session 5: tbd.

Session 6/7: May 4.

Session 1. Introduction to Ethics and Law in Public Health Friday, March 16th

In this first class session we will discuss the development of public health ethics as a field and review the basic structure and function of the American legal system. We will also discuss ethical issues in conducting human subjects research.

Objectives

After this session, students will be able to:

- Describe ethical principles relevant to public health policy;
- Create arguments to apply the various ethical principles in trying to resolve a public health issue;
- Describe and analyze ethical issues in conducting human subjects research, including issues that arise in global public health research.

Required readings (before class)

- Nancy E. Kass. An Ethics Framework for Public Health. *AJPH*. Nov 2001. Vol 91, No. 11. Available at:
 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446875/pdf/0911776.pdf
- James C. Thomas et al. A code of ethics for public health. Editoral. *AJPH*. July 2002. Vol 92, No. 7. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447186/pdf/0921057.pdf
- Leonard H. Glantz. Introduction to the Structure and Function of American Law. (You can skim this, but please make sure you are clear on the basic points in the paper.)

 Available on Blackboard.
- A. Walsh et al. "The way the country has been carved up by researchers": ethics and power in north-south public health research. *Int J Equity Health*. Dec 12, 2016. Vol 12, No. 1. Available at: https://www-ncbi-nlm-nih-gov.ezproxy.bu.edu/pubmed/27955670

Recommended readings

Sandro Galea. On Knowledge and Values. Dean's note. Posted on October 16, 2016.
 Available at: https://www.bu.edu/sph/2016/10/16/on-knowledge-and-values/

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Session 2 Human Rights and Health Friday, March 23rd

Profession Michael Grodin from the Department of Law, Policy, and Management will lead the class discussion. This session will focus on the development of modern human rights, the formal declarations that articulate these rights, the connection between health and human rights, and the meaning and limits of the "right to health."

Objectives

After this session, students will be able to:

- Describe the history, sources, documents, and enforceability of modern human rights;
- Articulate the differences between the UDHR, ICCPR, ICESCR, CEDAW, CRC, CERD, and CAT;

- Discuss the inextricable link between health and human rights;
- Discuss the source, nature, scope, and limits of the "Right to Health."

Required readings (before class)

- Sofia Gruskin and Daniel Tarantola. Health and Human Rights. In Gruskin et al (eds), Perspectives on health and human rights. Routledge Taylor & Francis Group, LLC: New York: 2005. Available on Blackboard.
- International Bill of Human Rights Fact Sheet. Available on Blackboard.

Recommended Readings

- Sofia Gruskin and Bernard Dickens. Human Rights and Ethics in Public Health. AJPH. Nov 2006. Vol 96, No. 11. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1751819/pdf/0961903.pdf
- Sofia Gruskin et al. History, principles, and practice of health and human rights. *The Lancet*. Aug 4, 2007. Vol 370. Available at:
 https://qmplus.qmul.ac.uk/pluginfile.php/243068/mod_book/chapter/5466/Gruskin%2020
 07.pdf

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Session 3. State Power and Freedom of the Individual Friday, March 30th

In this session, we explore issues in balancing the power of the state ("police power") and the freedom of the invidual. We will focus on issues around two topics: a) vaccinations and b) quarantine (isolation).

Objectives

After this session, students will be able to:

- Describe the origin and limits of "police power;"
- Discuss the ethical tensions that exist between community needs and individual freedom;
- Describe the constitutional issues that arise with mandatory vaccination and isolation;
- Apply the standards of "procedural due process" to the situation of infectious diseases.

Required readings (before class)

- Wendy E. Parmet et al. "Individual Rights versus the Public's Health 100 Years after *Jacobson v. Massachusetts. NEJM.* Jan 17, 2005. Vol 352, No. 7. Available on Blackboard.
- Wendy K Mariner et al. Jacobson v Massachusetts: It's Not Your Great-Great-Grandfather's Public Health Law. *AJPH*. Vol 95, No. 4. Available on Blackboard.

- a) Vaccinations:
 - John D. Treanor. "Influenza The Goal of Control. NEJM. Oct 4, 2007. Vol 357, No. 14. Available on Blackboard.
 - Amanda Marcotte. Why do rich people refuse to vaccinate their kids? Slate.
 August 14, 2013. Available at:
 http://www.slate.com/blogs/xx_factor/2013/08/14/rich_kids_and_vaccination_is_not_vaccinating_your_child_a new status_symbol.html

b) Quarantine (isolation)

- Norimitsu Onishi. As Ebola Grips Liberia's Capital, a Quarantine Sows Social Chaos. *The New York Times*. Aug 28, 2014. Available at:
 https://www.nytimes.com/2014/08/29/world/africa/in-liberias-capital-an-ebola-outbreak-like-no-other.html? r=0
- Massachusetts General Laws. Mass Gen Laws ch. 111, § 94A (2008).
 Hospitalization of Certain Persons with Active Tuberculosis; Certification, Transportation. Available on Blackboard.

Recommended readings

- Bayer R. 2007. Talking Point: The continuing tensions between individual rights and public health. *EMBO Reports*. Vol 8, No. 12. Available on Blackboard.
- Annas G. 2007. Talking Point: Your liberty or your life. *EMBO Reports*. Vol 8, No. 12. Available on Blackboard.

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Session 4. Public Health Screening and Testing Friday, April 6th

In this session, we focus on the human rights and ethical issues related to surveillance, screening, and testing. Our two main topics are: a) mammogram screening and b) HIV prevention.

Objectives

After this session, students will be able to:

- Articulate the conflicts between privacy and surveillance;
- Argue for and against the use of surveillance systems depending on the particular public health matter in question;
- Apply legal and ethical rules to the creation and regulation of surveillance and screening programs.

Required readings (before class)

- Wendy K. Mariner. Mission Creep: Public Health Surveillance and Medical Privacy.
 Boston Univ Law Rev. April 2007. Vol 87, No. 2. Available at:
 http://www.bu.edu/law/journals-archive/bulr/volume87n2/documents/marinerv.2.pdf
 And:
 - a) Mammogram screening:
 - o Judith Graham and Thomas H Maugh, II. Mammogram guidelines spark heated debate. *LA Times*. Nov17, 2009. Available on Blackboard.
 - Harald Schmidt. The Ethics of Incentivizing Mammography Screening. *JAMA*.
 Sept 8, 2015. Vol 314, No. 10. Available at: https://jamanetwork-com.ezproxy.bu.edu/journals/jama/fullarticle/2434692

b) HIV prevention

o Carla M. Obermeyer et al. HIV testing and care in Burkina Faso, Kenya, Malawi and Uganda: ethics on the ground. *BMC International Health & Human Rights*.

- 2013. Vol 13, No. 6. Available at: https://bmcinthealthhumrights-biomedcentral-com.ezproxy.bu.edu/articles/10.1186/1472-698X-13-6
- Dermot Maher. The ethics of feedback of HIV test results in population-based surveys of HIV infection. Bull World Health Organ. 2013. Vol 91. Available at: https://www-ncbi-nlm-nih-gov.ezproxy.bu.edu/pmc/articles/PMC3845269/pdf/BLT.13.117309.pdf

Recommended readings

- G. Moutel et al. Women's participation in breast cancer screening in France—an ethical approach. *BMC Med Ethics*. Aug 2014. Vol 15, No. 64. Available at: https://www-ncbi-nlm-nih-gov.ezproxy.bu.edu/pubmed/25127662
- A. de Jong, G.M. de Wert. Prenatal screening: an ethical agenda for the near future. *Bioethics*. Jan 2015. Vol 29, No. 1. Available at: https://www-ncbi-nlm-nih-gov.ezproxy.bu.edu/pubmed/25521973

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Session 5. Changing Behavior: Ethical and Legal Issues Friday, April 13th

This session will focus on policy efforts to change behavior. We consider both a) non-smoking hiring policies and b) workplace programs designed to improve health among employees.

Objectives

After this session, students will be able to:

- Analyze the appropriateness of using coercive or paternalistic measures to change behaviors;
- Analyze the role of "truth-telling" in public health campaigns to change behavior;
- Argue whether the goal of public health is a compliant or informed population.

Required readings (before class)

• Gary Taubes. Do We Really Know What Makes Us Healthy? The New York Times Magazine. Sept 16, 2007. Available on Blackboard. (This is somewhat dense, but has good information on scientific advancements and public health policy. Think of it as having good background info on this topic.)

- a) Non-smoking hiring policies
 - A.G. Sulzberger. Hospitals Shift Smoking Bans to Smoker Ban. *The New York Times*. Feb. 10, 2011. Available at: http://www.nytimes.com/2011/02/11/us/11smoking.html
 - Cleveland Clinic: New hires must be nonsmokers. AHC Media. August 1, 2008. Available at: https://www.ahcmedia.com/articles/13807-cleveland-clinic-new-hires-must-be-nonsmokers
- b) Health-promoting workplace programs
 - o Natasha Singer. Health Plan Penalty Ends at Penn State. *The New York Times*. Sept. 18, 2013. Available at: http://www.nytimes.com/2013/09/19/business/after-

uproar-penn-state-suspends-penalty-fee-in-wellness-plan.html

o Jena McGregor. Being Unhealthy Could Cost You – Money. *Business Week*. Aug 5, 2007. Available on Blackboard.

Recommended readings

 Harald Schmidt, et al. The Ethics of Not Hiring Smokers. Perspective. NEJM. April 11, 2013. Vol 368, No. 15. Available at: http://www.nejm.org/doi/pdf/10.1056/NEJMp1301951

Session 6. Public Health and Use of Scarce Resources Friday, April 20th

This session will focus on how policy decisions are made to recommend, encourage, or provide certain services or procedures, including vaccinations and treatment for diseases and conditions.

Objectives

After this session, students will be able to:

- Describe the tensions between access to health resources and the use of scarce resources;
- Articulate argments for scaling up provision of treatment and for various allocation approaches;
- Analyze issues related to recommendations for a specific vaccination.

Required readings (before class)

• Krutli P et al. How to Fairly Allocate Scare Medical Resources: Ethical Argumentation under Scrutiny by Health Professionals and Lay People. PLoS ONE. 11(7): e0159086. doi:10.1371/journal. pone.0159086. Available at: http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0159086&type=print able

- a. Provision of treatment
 - Russell Armstrong. Fairness and equity in the provision of anti-retroviral therapy: Some reflections from Lesotho. *Developing World Bioethics*. Dec 2010. Vol 10, No. 3. Available at: https://www.ncbi.nlm.nih.gov/pubmed/19912280
 - George J. Annas. The Right to Health and the Nevirapine Case in South Africa. NEJM. Feb 20, 2003. Vol 348, No. 8. Available at: http://www.nejm.org.ezproxy.bu.edu/doi/full/10.1056/NEJMlim022737
- b. Vaccination and the value of a life
 - Christopher J. Gill et al. The unattainable criteria for new infant vaccines. *Human vaccines & Immunotherapeutics*. May 2017. Available at: http://www-tandfonline-com.ezproxy.bu.edu/doi/full/10.1080/21645515.2017.1328334
 - Christopher J. Gill. Vaccines, Public Policy, and the Monetary Value of a Human Life. BUSPH This Week: October 22, 2017. Posted on Oct 18, 2017. Available at: http://www.bu.edu/sph/2017/10/18/vaccines-public-policy-and-the-monetary-value-of-a-human-life/

Recommended readings

• David Chinitz. Governing the allocation of scarce resources: is health care no longer a special case? *Isr J Health Policy Res.* June 2014. Vol 3, No. 23. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4077141/

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Session 7. Environmental justice Friday, May 4th

In this last session, we concentrate on questions of environmental justice and equity. We will discuss issues related to a) climate change and b) access to clean water.

Objectives

After this session, students will be able to:

- Analyze environmental justice as related to climate change;
- Describe an instance of an environmental crisis in the US, and the pros and cons of attempts to address it;
- Articulate the arguments for and against clean water as a human right.

Required readings (before class)

 Chakraborty J, et al. Environmental Justice Research: Contemporary Issues and Emerging Topics. *Int. J. Environ. Res. Pub Health.* Nov 2016. Vol, 13, 1072; doi:10.3390/ijerph13111072. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5129282/pdf/ijerph-13-01072.pdf

- a. Climate change
 - Jason A. Smith et al. Climate Change and Public Health Policy. *Jr of Law, Med & Ethics*. 2017. Vol 45, S1. Available at: http://journals.sagepub.com.ezproxy.bu.edu/doi/full/10.1177/1073110517703332
 - Sarah C. Walpole et al. Natural and unnatural synergies: climate change policy and health equity. *Bull World Health Organ*. 2009. Vol 87. Available at: https://www-ncbi-nlm-nih-gov.ezproxy.bu.edu/pmc/articles/PMC2755320/pdf/09-067116.pdf
- b. Access to clean water
 - The PLoS Medicine Editors. Clean Water should be Recognized as a Human Right. PLoS Med. June 2009. Vol 6, Issue 6. Available at: http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000102
 - David Rosner. A Lead Poisoning Crisis Enters its Second Century. Health Affairs. May 2016. Vol 35, No. 5. Available at: http://content.healthaffairs.org.ezproxy.bu.edu/content/35/5/756.full.pdf