Public Health Law 101

A CDC Foundational Course for Public Health Practitioners

Public Health Law Program
http://www.cdc.gov/phlp

PUBLIC HEALTH LAW 101:
A CDC Foundational Course for
Public Health Practitioners

Unit 2
Ethics and the Law in Public Health

Disclaimer

The contents of this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy. These course materials are for instructional use only and are not intended as a substitute for professional legal or other advice. While every effort has been made to verify the accuracy of these materials, legal authorities and requirements may vary from jurisdiction to jurisdiction. Always seek the advice of an attorney or other qualified professional with any questions you may have regarding a legal matter.

*Source: Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005).

Why Consider Ethics in A Public Health Law Course?

Including the topic of ethics in a course on public health law allows for:

- Exploration of ethical questions that arise in public health practice (e.g., influenza vaccine allocation)
- Development of participants' capacities to participate in deliberation and public exchanges about ethical issues in order to strengthen community trust and cooperation
- Enrichment of understanding of the public health profession's roles and professional values

Instructor notes

•Emphasize that public health officials increasingly must address ethical conflicts in day-to-day practice in order to be effective decision makers and leaders in the community.

Unit 2 Objectives

By the end of this unit, you should be able to:

- Identify different ethical and legal issues embedded in public health practice and policy

- Use ethics guides to facilitate analysis and deliberation about the needs, perspectives, and interests of stakeholders in cases and policies

- Foster the development of ethical justifications for public health actions and decisions — <u>when law is indeterminate or is unsettled</u>

Instructor notes

•This is an essential slide, as the objectives frame the content included in this unit. The objectives emphasize the importance of distinguishing legal and ethical issues in public health and of providing a language and framework to facilitate deliberation about and decision making on ethical issues.

**To Address Unit 2 Objectives,
This Unit Covers Topics:**

1. Definitions and Concepts
   - Complementary roles of law and ethics in public health
   - Ethics, morality, moral norms
   - Public health ethics

2. Ethical Decision Making: Ethics Guides and Case Examples
   - Professional ethics cases
   - Public health policy and practice case

3. Ethics in Practice: Incorporating A Code of Ethics in Day-to-Day Activities
   - Public Health Code of Ethics: *Principles of the Ethical Practice of Public Health*

Instructor notes

•This is an essential slide to show the order of the content included in this unit.

Topic 2.1
Definitions and Concepts

Definitions and Concepts

- <u>Law in Public Health</u>: Provides authority, limitations on state power, incentives and disincentives for behavior; often allows for much professional discretion

- <u>Ethics in Public Health</u>: Provides ongoing analysis, deliberation about, and justification for public health action and policy, often when law is indeterminate

<u>Law</u>
- Formal institution
  - Statutes
  - Regulations
  - Court decisions

- Public proceedings with a "reasonable person" standard

<u>Ethics</u>
- Less formal
  - Moral norms, values
  - Professional codes
  - Previous cases

- Publicly justifiable positions, based on ethical reasoning

Instructor notes

•Law and ethics are complementary social institutions in society to help public health officials mediate conflicts and questions about the relationship between the individual's and the community's interests in health and about the appropriate scope and means of public health.

•Ethical questions are embedded in almost every thing public health officials do from 1) deciding what constitutes a "public health problem" to 2) deciding what kind of intervention to use, e.g., whether to collect additional information about a problem, how to present and analyze data, and other public health actions that may be undertaken under the public health's broad legal authority to protect and promote the public's health.

•Questions may be posed: Can you think of an ethical issue in your every day work? Can you think of a situation where the law provides authority to act but it is not clear whether ethically you should intervene? (For example, targeting a public health intervention to a particular group which might suffer social stigma as a result.)

Definitions and Concepts:
Example of a Tuberculosis Outbreak in a Community and
Administrative Discretion under the Law

- Law in Public Health
  - Jurisdiction's laws provide authority to detain individuals who are non-compliant with the TB treatment regimen

- Ethics in Public Health
  - Public health officials must decide in a particular case whether and how to use that legal authority
  - Public health officials must demonstrate when imposing detention that protecting the public's health (a utilitarian value) carries more weight and should override an individual's moral claim (liberty interest to reject treatment and remain in the community)
  - Public health officials must act with both transparency and accountability to maintain public support and trust by explaining, "We are imposing detention because…."

Instructor notes

•This slide provides an example to illustrate that, while the law provides authority to intervene, the law also allows for professional discretion and judgment as to when and how to use that authority appropriately.

•The field of public health ethics emphasizes that the decision should take into account ethical considerations, as well as epidemiological, medical, political, and economic factors, and additionally should involve public transparency and accountability for the decision.

•The resolution of the conflict between individual interests and the utilitarian-public health claims requires an assessment of the empirical facts about the nature and incidence of the disease (e.g., the risk and gravity of the harm), as well as of the context (e.g., previous experience and relationship with those infected) where the outbreak occurs.

•Note the last point on this slide: The key word is "because." Even if reasons are not given at the moment, it is important that reasons for actions were thought through and that they be publicly justifiable.

**Definitions and Concepts:
Ethics and Morality**

- <u>Ethics</u> – The study of or deliberation about:
  - What choices should we make and why?
  - What <u>moral norms</u> should guide our actions?

- <u>Morality</u> – Refers to <u>moral norms</u> about right and wrong that are stable and widely shared in society
  - Provides norms that are a basis for ethical reflection, deliberation, and analyses

Instructor notes

•It is helpful to begin the discussion of ethics and morality by clarifying those terms, which are often used interchangeably. In fact, the terms are closely related but have different meanings.

•The key difference is that "ethics" refers to our <u>inquiry or examination</u> about what is good conduct and about our decision-making process when confronted with dilemmas about what is the right course of action.

•Morality, on the other hand, refers to our <u>beliefs</u> about what is good and bad, right or wrong. Morality is a social institution. It predates each of us; it is passed along through generations. People grow up with a basic understanding of moral norms, such as truth-telling, keeping promises, not killing or harming innocent persons.

• Morality encompasses moral principles, rules, standards of conduct, and values. As such, it provides reference points for our ethical decision-making process. What is the source of morality? Throughout history, many religious traditions and philosophical theories have offered perspectives on morality and have contributed to an understanding about what constitutes right and wrong human conduct and about what moral norms should guide human decision making.

Definitions and Concepts: Moral Norms

- Universal norms: Some moral norms are universal (e.g. we must not lie or kill the innocent)

- Particular norms: Some moral norms apply only to certain communities (e.g., professional norms, religious norms)
    - Professions accept particular moral norms as necessary for carrying out their roles (e.g., medical norms for informed consent)

- Norms are not absolute: When norms conflict, one norm can be overridden when justified (e.g., lying to save someone from being killed)

- Norms require interpretation and balancing when they appear to conflict

CDC

Instructor notes

•Moral norms often require interpretation in circumstances when we grapple with moral dilemmas. For example, in public health practice an official must sometimes decide between two competing obligations, such as respecting the rights of an individual and protecting the community's health. In the end, the official must decide which moral obligation outweighs the other and in acting must compromise an obligation that would stand if there were not a conflict.

•Particular norms, e.g., those found in codes of ethics for particular professions, provide guidance for practitioners about the ethics of conduct and actions in their practice. The general principles underlying such codes and particular norms are similar to those from every day life. However they are interpreted within the context of professional practice.

•Eliot Freidson explains: "To take a comparatively simple issue, while one might believe that lying is wrong, is it wrong for a physician to honor the request of a patient with a fatal but not immediately disabling condition that her family be lied to about her condition until final arrangements must be made?...Sensitive answers to those questions cannot be given by lay people unfamiliar with the variety of circumstances and issues involved in the practice of a discipline. Only when that concrete, specialized context is taken into account can the ordinary moral norms of daily life be translated into the ethics of practice." (Friedson, Eliot, "Professionalism The Third Logic," Chicago: Chicago University Press, 2001, pg. 215)

•Question for discussion: Are there any circumstances in which a public health official could offer ethical justifications for concealing information or misrepresenting the facts of a situation, for example, to prevent public panic or terror? Are there public health norms or an ethical consensus on truth-telling in public health?

Instructor notes

•This slide is provided to invite participants to think about the moral norms that operate, sometimes implicitly, in public health practice. Invite participants to answer the first bulleted question before providing the following ideas.

• A number of professional groups have offered perspectives on the moral norms that animate the practice of public health. Norms include: producing benefits; avoiding, preventing, and removing harms; producing the maximal balance of benefits over harms; respecting autonomous choices, protecting privacy and confidentiality; keeping promises and commitments; disclosing information as well as speaking honestly and truthfully; and building and maintaining trust. (See Childress J, Faden R, Gaare R, et al, "Public Health Ethics: Mapping the Terrain." Journal of Law, Medicine & Ethics, 30 (2002):170-178.

•The third bulleted question is posed to invite participants' reflection on real-world practice.

•Ask participants to think of cases in their practice where there may have been ethical conflict and to think about how the conflict was resolved.   For instance, in a study of public health ethics in practice, practitioners said ethical issues arose frequently and the major ethical issues they confronted fell into four categories: 1) public-private partnerships and collaboration in general; 2) the allocation of scarce resources and priority setting; 3) the collection and use of data and information; 4) politics and relationships with government officials. (GaareBernheim, R, "Public Health Ethics: The Voices of Practitioners." Journal of Law, Medicine & Ethics, 31 (2002): Special Supplement 104-109)

•At the end of discussion, the instructor may provide the following ideas:

•When we do real-world problem solving, we often implicitly draw on the moral norms in the profession. Interpreting and balancing moral norms that are in conflict in a case entails a rigorous analytic and deliberative process – that takes practice.

•The process can begin with an explicit exploration of the moral norms that seem involved in a dilemma, e.g., in the case of a potential serious infectious disease outbreak that is still being investigated, truth telling versus utility (if there is concern about community panic). Moral convictions often are gleaned from other related cases about which there does seem to be a moral consensus.   Before balancing competing moral norms, it is often helpful to specify how the norms were implemented in other previous cases – i.e., provide details and establish the circumstances in which a norm applies – and then assess how the norms are best implemented in the current case, given the particulars of that case.

•Take, for example, the public health value, respecting confidentiality in an outbreak. Exploring how that norm has been specified and interpreted in previous cases, such as for HIV named reporting or cancer registries, may provide guidance about the weight or strength of that norm in public health and whether it will override other conflicting norms in future ethical dilemmas, e.g. when deciding how to protect confidentiality in a pandemic flu.

•For discussion of the third question, one might introduce the following ideas: Public health involves collective action. Given the religious and moral pluralism in our society, it is inevitable that some conflicts about moral norms and decisions in public health cannot be resolved without controversy. Reaching publicly acceptable decisions may require imagination, compromise, arbitration, negotiation, syntheses, and reconciliation. Most importantly, it requires a time and place for deliberation in which people can disagree and deliberate about what is ethically required. Deliberation and fair process are the way communities air and resolve moral disagreements or find a way to cooperate despite residual disagreement. (See generally Daniels N and Sabin JE. "Setting Limits Fairly: Can

We Learn to Share Medical Resources?" New York: Oxford University Press, 2002)
•Invite participants to think of examples of issues which have been resolved through community deliberation on values, e.g., sex education in high schools.

Definitions and Concepts:
What does Public Health Ethics offer?

- **Vocabulary** and **frameworks**: to illuminate the ethical dimensions of cases and policies
- **General ethical principles:** which are "starting points" to guide ethical reflection about balancing the competing moral claims
  - Balancing moral claims is similar to the process officials use in understanding and making public health cost-benefit tradeoffs
  - Difference: Instead of focusing on "quantifiable" health gains or losses, public health ethics focuses on identifying, weighing, and balancing moral interests at stake in a particular situation

CDC

Instructor notes

•Based on the class discussion of the questions in the previous slides, the instructor might note that many professionals in public health practice recognize that there are ethical issues in pubic health practice, as just discussed, AND many believe that additional training in ethics – training based on cases – would be of great benefit. (GaareBernheim, R, "Public Health Ethics: The Voices of Practitioners." Journal of Law, Medicine & Ethics, 31 (2002): Special Supplement 104-109)

•The question then raised by this slide is, what might the field of public health ethics provide for practitioners in day-to-day practice? An example of providing a vocabulary and conceptual clarity: explicating the principle of utility, i.e., understood most simply to mean the greatest good for the greatest number of people. For deliberation about particular cases, e.g., addressing questions of how and to whom to allocate scarce resources for a pandemic flu, it may be useful to further clarify the principle of utility and distinguish between social utility and medical utility. That distinction may clarify whether the goal is to provide scarce resources to maximize medical treatment for a few who are sick or most at risk (medical utility) or to maximize social welfare. Social utility, which focuses on maximizing social welfare, can be framed either as broad social utility, which means maximizing overall social welfare, or narrow social utility, which might focus on providing the benefits to those who have specific essential roles in society. An example of narrow social utility might be vaccination for medical personnel in hospitals. Medical utility, on the other hand, focuses on maximizing the welfare of persons suffering from or at risk for disease. There are two aspects of medical utility one might consider, medical need versus the probability of a successful outcome. (Bernheim R, "Public Health Ethics in Action: Flu Vaccine and Drug Allocation Strategies," Journal of Law, Medicine & Ethics, Special Supplement (2005):102

Definitions and Concepts: What does Public Health Ethics offer?

- An approach to decision-making: to clarify reasons or justifications for particular decisions

- Categories of reasons and major themes*
  - Utilitarianism: Decisions should be judged by their consequences (i.e., maximize net utility for all parties affected by the decision)
  - Liberalism: Focuses on individual interests and human rights
  - Communitarianism: Emphasizes communal values, visions of common good, traditional practices

*See Roberts MJ, Reich MR. Ethical analysis in public health. *The Lancet* 2002; 359: 1055-1059

*See Roberts MJ, Reich MR. Ethical analysis in public health. *The Lancet* 2002; 359: 1055-1059

Instructor notes

•It is helpful to point out the distinctions between the three broad approaches or themes in public health ethics, i.e., utilitarianism, liberalism, and communitarianism, and also to emphasize that most individuals draw on all three types of arguments at different times and for different cases.
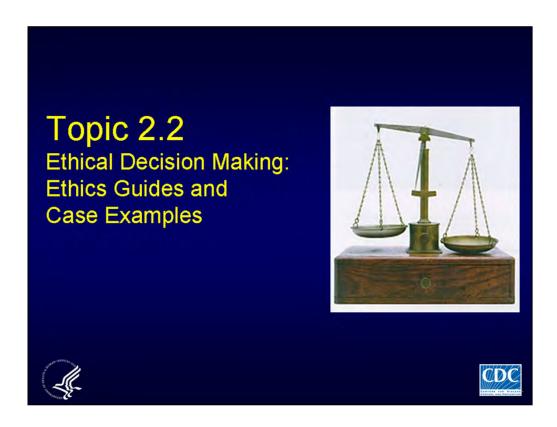
Instructor notes

•It is important to emphasize that for many issues and cases, there often is not one "right" answer, and the goal of ethical deliberation is to arrive at what seems to be the most "ethically" justifiable decision, all things considered, at that time and in a particular context.

•ANOTHER KEY POINT: Ethical decision making in public health is a process that involves not only reflection and analysis, but also social learning and relationship-building, grounded in trust developed over time (some might believe this is an important part of what is meant by public health leadership).

•An example: "In discussing public health responses to bioterrorism, for instance, commentators highlight the role of civic imagination in public health ethics, which in contrast to detached moral principles, can build community relationships and provide motivation and emotional energy for good citizenship." Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005), pg ??.

•The 2003 Institute of Medicine (IOM) report, "The Future of the Public's Health in the 21st Century," states suggests that building a community of stakeholders is central to the mission and role of public health officials: "All partners who can contribute to action as a public health system should be encouraged to assess their roles and responsibilities, consider changes, and devise ways to better collaborate with other partners. They can transform the way they 'do business' to better act to achieve a healthy population on their own and position themselves to be part of an effective partnership in assuring the health of the population. Health policy should create incentives to make these partnerships easier."

•Childress and Bernheim state that a strong community of stakeholders that "deliberates, collaborates, partners, and most importantly expects government officials to provide explicit public justification for their actions (including legislation, implementation of laws, and actions that fall within their legal discretion) will be more likely to foster its members' voluntary participation and trust." (Childress J and Bernheim, RG, "Beyond the Liberal and Communitarian Impasse: A Framework and Vision for Public Health." Florida Law Review 55 (2003): 1191-1219)

Topic 2.2
Ethical Decision Making:
Ethics Guides and
Case Examples

Instructor notes

•This section of the module uses the case method of discussion to introduce participants to the ethical analysis of public health issues. The module provides cases and an ethics framework to guide the discussion.

•IMPORTANT Note on the case discussion: The cases that follow are complex and ambiguous, as cases are in practice. Ambiguity sometimes frustrates participants searching for decision rules. Prepare students for this section by explaining that the case method, sometimes called the Socratic method, usually has a few characteristics: it is based on group discussion; the discussion takes place primarily among the participants, who are guided by open-ended questions from the instructor; and discussions involve an in-depth exploration of the context and situation. The focus of this section of the module is to model case discussions that can be incorporated into public health management and practice.

•IMPORTANT Note on the ethics framework: The framework in this module provides questions to guide case discussion and draws on numerous approaches or analytic camps in contemporary ethics: 1) One approach, often called "principlism," orders discussion of cases around ethical principles, such as autonomy and beneficence. This approach is often identified with the foundational work of Tom Beauchamp and James Childress in medical ethics, called Principles of Biomedical Ethic. 2) Another approach is "casuistry," which is a case-based method that emphasizes a pragmatic analysis of the particular details and context of each case. 3) Yet another approach is virtue ethics, which calls attention to the character and moral traits of the actor, such as honesty and transparency. The questions in this framework invite reflection about public health cases and decisions from all of these perspectives. The goal is to facilitate ethical reflection and deliberation in order to reach the best possible resolution "all things considered."

Public Health Case Analysis:
Types of Ethical Issues in Public Health*

- **Professional Ethics Cases**
  - Focus: ethical dimensions about being a public health professional and about professionalism
  - Include: conflicts of interest and conflicts of obligation
- **Policy and Practice Ethics Cases**
  - Focus: ethical dimensions of public health policy and practice
  - Include: allocating resources among competing needs; making trade-offs between collective goods and individual interests

*Source: adapted from Hastings Center Project on Ethics and Public Health -- as presented in Gostin LO. *Public Health Law and Ethics: A Reader.* Los Angeles, CA: University of California Press**;** 2002, pp 10-15.

Instructor notes

•Two "types" of cases are presented in the following slides. There are a total of 3 cases to discuss: one case that raises professional ethics issues (slide 20) and two policy/practice cases (slides 25, 26, 27) .

•Case 1 is presented on the next slide (slide 20); a framework to guide a discussion of the case follows on slides 21, 22, 23, 24.

•The same framework should also be used to guide discussions of the two policy/practice cases that follow on slides 25, 26, 27.

Public Health Case Example:
Professional Ethics (Case 1)

Case 1: With Whom to Partner?

The health department in a poor community with major dental health care needs is invited by a local fast food restaurant to be a partner on a dental health project. The restaurant, with support from its soda vendor, proposes to donate $100,000 a year to a health department dental free clinic. In exchange, the restaurant wants only to have its name and the name of the soda listed in very small print on health department educational material on dental health distributed to the community. Two health department officials, including the nutritionist directing the obesity program, believe such a partnership is unethical. What would you advise the health commissioner?

Instructor notes: Read the case and then immediately proceed to the following 4 slides, using the framework outlined on slide 21 and enriched with questions on slides 22, 23, 24 to elicit some of the following ideas from participants about this case.

- First, engage participants in a brief discussion of the issues in this case. From the perspective of the health department officials, what are the key issues in this situation? (To provide care for vulnerable populations; to maintain community relationships, trust, etc. Potential professional conflict: health department regulates and inspects restaurants.)

- A focus for this discussion is the range of stakeholders. The instructor can define "stakeholders" as those in the community who are in any way affected by the decisions. Who else has a stake in the decision? For each stakeholder, participants should identify the stakeholder's interests, goals, concerns; power and reputation in the community; and likely preferred outcome.

- The instructor might ask participants what the likely outcome of this situation would be in their agencies, and why? What are the values embedded in that decision?

- Ask participants what they would propose, and in particular, the reasons or justification for their proposal. Point out when participants are drawing on utilitarian, liberal, or communitarian perspectives. For example: If a participant suggests that it would be best for all stakeholders if the health department accepted the restaurant offer because a vulnerable group would be helped and the restaurant would have the opportunity to demonstrate its commitment to community health and to being a good citizen, that would be a utilitarian argument.

- After some discussion with different viewpoints offered, suggest that the group role play as an "ethics advisory committee" for the health commissioner, and that they must come up with a recommendation for the health commissioner. What would the decision be? What are the reasons for their decisions that they would provide the public?

Public Health Case Analysis: 3-Step Guide

1) <u>Analyze the ethical issues</u>: Assess identities of stakeholders, what they have at stake in the case, and in the alternate courses of action

2) <u>Evaluate the ethical dimensions</u>: Identify moral norms, general moral considerations, and/or ethical principles that may provide guidance about what to do

3) <u>Justify a decision</u>: Present sufficient grounds or reasons for a course of action based on moral norms, ethical principles, professional codes, and/or previous cases

Instructor notes

•This slide shows the three broad steps of case analysis and the ethics process that will be used to discuss the case on the preceeding slide.

•Frameworks can be useful to guide ethical analysis. This public health ethics framework draws on the major ethical considerations in public health discourse and is designed to provoke rigorous deliberation about decisions in public health agencies or ethics advisory groups. The framework contains the same 3 main prongs: 1) Analysis of the ethical issues; 2) Evaluation of the ethical dimensions of the public health options; 3) Justification for a particular action.

21

Ethics Guide for Public Health Decision Making:*
1. Analyze the Ethical Issues in the Situation

– What are the public health risks and harms of concern in this particular context?

– What are the public health goals?

– Who are the stakeholders and what are their moral claims?

– Is the source or scope of legal authority in question?

– Are precedent cases or the historical context relevant?

– Do professional codes of ethics provide guidance?

*Source: Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005), pg ??.

Instructor notes.

•Using Case 1 in slide 20, engage participants in an ethics deliberation as a group that must come up with a decision and justify it with reasons. Explore the case with the questions on this slide.

•For general preparation for this discussion, the instructor can review the following excerpt from Bernheim RG, Nieburg P, and Bonnie RJ. (citation above)

Analyze the Ethical Issues in the Situation

As a first step, public health officials will need to clarify the risks or harms of concern in the situation, as well as the goal of public health action. While answers to these questions often seem obvious, careful analyses may reveal separable concerns or unclear goals that limit good decision making and cloud justification. For example, for public health programs promoting sexual abstinence in youth, are the public health goals primarily STD prevention, healthy adolescent development, prevention of teenage pregnancy, or prevention of pregnancies outside of marriage? This question is not posed to challenge any one of these potential goals, but rather to clarify the goals in order to more clearly reason about and provide justification for the program.

The framework also poses questions to elucidate the moral claims of the various stakeholders in a particular policy or case, drawing on another approach to ethical analysis called "stakeholder theory." This approach is thought to have particular relevance for public health ethics since it implicitly focuses attention on the fundamental partnership of public health professionals with individuals and groups in the community in together assessing the value-laden benefits and harms of particular public health actions. Although essentially utilitarian, it makes explicit the costs and benefits to different groups and recognizes the complex ongoing nature of the human relationships involved.

In addition, the framework invites consideration of previous cases. An analysis of a new situation's relevant similarities to and differences from paradigm or precedent cases – cases that have gained a relatively settled moral consensus – often provides an important starting point or presumption in deliberation. Because ethical reflection on any public policy issue takes place within a particular community with a unique history and culture, the framework specifically asks that the conflicting ethical tensions be clarified in the political-social context, since ethical norms and tensions can vary from community to community. What may be morally acceptable in some communities, e.g., needle-exchange programs to prevent HIV transmission, may not be in others."

*Source: Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005), pg ??.

Instructor notes

•This slide poses questions that help participants assess the ethical aspects of the different options they can choose in the case.

•Example: For Case 1, if the participants believe that the health department should not accept the restaurant's offer, one would then ask: Does this decision produce a balance of benefits over harms? (This will lead to a series of questions, e.g., What are the opportunity costs in not accepting the restaurant's support? What are the harms of accepting support?) What about the rights of the restaurant owners to support the community and respond to community need? Case 1 is likely to involve a consideration of the final question on this slide, that focuses on the importance of professional and civic roles, particularly the role of the public health official.

Ethics Guide for Public Health Decision Making:*
3. Provide Justification for A Particular Public Health Action

- Effectiveness: Is the public health goal likely to be accomplished?

- Proportionality: Will the probable benefits of the action outweigh the infringed moral considerations?

- Necessity: Is it necessary to override the conflicting ethical claims in order to achieve the public health goal?

- Least infringement: Is the action the least restrictive and least intrusive?

- Public justification: Can public health agents offer public justification for the action or policy that citizens and in particular those most affected could find acceptable?

*Source: Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005), pg ??.

Instructor notes

•These questions are designed to address whether the option one chooses can be justified, because choosing one option usually means that one value, such as public health benefit, overrides another value, such as individual liberty. When overriding an important value, it is important that an action meet the conditions outlined in this slide. (Lawyers will recognize that these conditions are analogous to those that must be met to justify restrictions on constitutionally protected liberties.)

•Explicitly addressing these conditions also is useful in formulating explanations about the decision to the public. Public health officials should justify actions and policies with rhetorical strategies that build community support and trust. Appeals can be made to principles, rights, and duties, and also by acknowledging that, while a particular action does override important values, the action is likely to be "effective" and "the least restrictive infringement," given the situation.

Public Health Case Example:
Public Health Policy and Practice (Ethics Case 2)

- Case 2: Newborn Screening and Parental Consent
  The state legislature is considering a law that would require parental consent for newborn screening. Parental consent currently is not required, although newborn testing is not conducted over parental objection. Currently only a few states require consent. The health department has been asked to take a position on the pending legislation. What position should the health department take?

Instructor notes: Use the framework on the preceeding 3 slides (slides 22, 23, 24) to guide discussion about this case.

- This case illustrates the appropriateness of ethical analysis when the questions are, should there be a law, and, if so, what should the law be? Invite participants to provide reasons for their positions that are grounded in moral norms and attention to the ethical dimensions of the issues at stake for various stakeholders.

- Key questions: Who are the stakeholders and what are their positions? Are precedent cases and the historical context relevant?

- In addition to the questions in the ethics guide, the instructor might also ask: What are available options? Options include: mandatory screening without consent; Routine Screening with Advance Notification (Opt-In); Routine Screening without Advance Notification (Opt-Out), which includes screening and testing unless objection is raised; Voluntary Screening, which requires full consent and might also include a pre- and post-counseling session with each new mother.

- Some arguments offered against requiring consent from parents focus on the fact that the benefits of screening are obvious and substantial, relative to potential harms; that no "reasonable" parent would refuse screening; that obtaining consent from each parent is difficult, costly, and an unwarranted expenditure of time and money; and that the history of newborn screening has led to the current social acceptance of newborn screening as routine.

- Some arguments raised for requiring parental consent include: parental consent is necessary because refusal of newborn screening is not unreasonable, given the increasing list of diseases included in the battery of newborn tests and the low probability of many of them; newborn screening can have adverse consequences, such as psychological harms associated with false positive tests; long-term parental care taking is enhanced when parents are included in all clinical decisions about their children; and the process of obtaining consent does not have to be time-consuming or burdensome but rather can be part of an educational process that enhances the health professional-patient relationship.

25

Public Health Case Example:
Public Health Policy and Practice (Ethics Case 3)

Case 3: Using Public Health Funding

The state health department has just received funding to pilot innovative HIV outreach and education for high-risk groups. The department is considering an education project that includes distributing clean syringes and needles to drug users in order to provide sustained education outreach to this high-risk group.

Another potential use of the funds is educational outreach to low-income women by employing parish nurses to visit women in their homes.

Instructor notes

•This is a complex case. Again return to the framework on slides 22, 23, 24 to guide the discussion.

Public Health Case Example:
Public Health Policy and Practice (Ethics Case 3 cont'd)

Case 3: Using Public Health Funding (cont'd)

Some community members claim that providing clean syringes is unethical and others claim that the funds should be used for low-income women instead.

The health department's director for the state HIV/AIDS program strongly argues for using the new funds for a needle exchange program, based on studies that suggest it is the most effective outreach to the drug-using community and her assessment of current HIV incidence in the state.

There are no explicit legal restrictions in your jurisdiction regarding the provision of clean syringes and needles. However, such restrictions to attach to the use of federal funds for such purposes. Therefore, as health commissioner, what should you decide?

Public Health Case Analysis
Summary

- Case deliberation
  - Requires fair process and the involvement of appropriate stakeholders
  - Is best practiced in group discussions that involve listening; understanding others' perspectives; expressing and challenging each other's reasons, based on ethical values at stake in the case; and focusing on facts and details in the particular context
  - Should "…justify decisions in a way the public will find persuasive by pointing out that moral judgments, unlike scientific judgments, are 'everybody's job."*
  - Frameworks can be helpful to guide the moral conversation

*Nagel T. Moral epistemology. In: Institute of Medicine. Bulger RE, Fineberg HV, eds. *Society's Choices: Social and Ethical Decision Making in Biomedicine*. Washington, DC: National Academy Press, 1995:201–14.

Instructor notes

> •After the ethics discussions of the previous cases, this slide provides some insight about the process of case deliberation.

> •Invite participants to reflect on their case discussions in class: Did the process provide a useful platform for elucidating and discussing the ethical issues? How might the process be used in public health practice?

> •Usually participants describe the process favorably but express concern over the lack of concrete answers. A response: Ethical debate is a process that develops over time, and there are often no clear answers, although we wish there were. But there are often some ethically inappropriate answers and approaches and sometimes some creative solutions, and a process that involves listening to the concerns of peers and deliberating in a group is often helpful.

Topic 2.3
Ethics in Practice: Incorporating A Code of Ethics in Day-to-day Activities

Ethics in Practice:
Characteristics of A Code of Ethics

- A Code provides statement of moral norms to guide professionals in their practice and professional lives
  - Example: The Public Health Code of Ethics (see following slides)
- While professional norms often are stated in codes of ethics, professional duties and standards of conduct are sometimes also codified in law
  - Federal example: Standards of Ethical Conduct for Employees of the Executive Branch (at 5 CFR 2635) applies to all federal executive branch employees
  - State example: statute covering state employees is the "West Virginia Governmental Ethics Act" (at WVa Code Sec 6B-1-1)
- Codes of ethics lay foundations both for trust between professionals and those that they serve, and for profession's particular identity

Instructor notes

•Fostering professionalism is the focus of much attention in professional education and practice, and codes of ethics are thought to play an important role in establishing a profession's identity. Eliot Friedson, in his comprehensive study of professionalism, states that the ideology of professionalism "asserts above all else devotion to the use of disciplined knowledge and skill for the public good. Individual disciplines are concerned with different aspects of that good, in some cases the immediate good of individual patients, students or clients, in others, of firms and groups, and in others, the general good." (Friedson, Eliot, "Professionalism The Third Logic," Chicago: Chicago University Press, 2001, pg. 217)

•Questions for class discussion: What are the characteristics of a profession? (Professions are often characterized by a social commitment to service, self-regulation, specialized education, etc.) Have society's perceptions of the professions changed in recent years?

•An exploration of medical professionalism appeared in the Annals of Internal Medicine in 2002 and contained the following Preamble to a Charter on Medical Professionalism: "*Professionalism is the basis of medicine's contract with society*. It demands placing the interests of patients above those of the physician, setting and maintaining standards of competence and integrity, and providing expert advice to society on matters of health. The principles and responsibilities of medical professionalism must be clearly understood by both the profession and society. Essential to this contract is public trust in physicians, which depends on the integrity of both individual physicians and the whole profession." (Project of the ABIM Foundation, "Medical Professionalism in the New Millennium: A Physician Charter," Annals of Internal Medicine 136 (2002): 243-246)

•Class exercise or assignment: Participants could be asked to write a similar contract or Preamble for a Public Health Professionalism Charter.

The Public Health Code of Ethics:
Principles of the Ethical Practice of Public Health*

- History of the Code
  - Developed and promulgated by Public Health Leadership Society, beginning in 2000
  - Developed in consultation with public health professionals at all levels of practice
  - Adopted or endorsed by several national organizations, and numerous state agencies / associations
- A "living" document that may be revised, enriched, and interpreted over time by public health professionals

*Source: *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002)*, http://www.phls.org/. This is sometimes referred to as the "Public Health Ethics Code." *Principles of the Ethical Practice of Public Health* ("Public Health Code of Ethics ")

Instructor notes

•Codes of ethics generally describe the moral ideals and values of a profession, in part to lay the foundations for trust with those that they serve, and establish the profession's particular identity.

•In developing the Public Health Code of Ethics, public health professionals acknowledged that codes are often so general, particularly when first articulated by a professional group, that they provide limited guidance on specific cases.

•The final bullet emphasizes that the Code can be enriched over time, and that it can serve now as a guidepost for deliberation about the role and values of the profession.

The Public Health Code of Ethics
*Principles of the Ethical Practice of Public Health**

1. Public health (PH) should address fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes
2. PH should achieve community health in a way respecting individuals' rights
3. PH policies, programs, and priorities should be developed / evaluated with community members' input
4. PH should work to empower disenfranchised community members, aiming to ensure access to basic resources necessary for health

* *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002), http://www.phls.org/.

•*Adapted from: *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002)*,* http://www.phls.org/. This sometimes is referred to as the "Public Health Ethics Code."   See also Appendix A for fuller detail on each principle.

Instructor notes

•Emphasize the connections between Human Rights and the Public Health Code of Ethics

•The development of the Code of Ethics also included the creation of a document describing the values underlying the principles of ethics. SEE ALSO, the underlying values of the Code, which are available on the Public Health Leadership Society website at http://www.phls.org

•The first underlying value of the Code is "Humans have a right to the resources necessary for health. The Public Health Code of Ethics affirms Article 25 of the Universal Declaration of Human Rights, which states in part, 'Everyone has the right to a standard of living adequate for the health and well-being of himself and his family…." The idea of "human rights as a public health value" has been advocated as a way to focus attention on fundamental social and economic inequalities and expand the scope of public health.

The Public Health Code of Ethics
Principles of the Ethical Practice of Public Health[*]

5. PH should seek information needed to implement effective policies / programs that protect and promote health

6. PH institutions should provide communities with information needed for policy / program decisions and should obtain community's consent for implementation

7. PH institutions should act in timely manner within resources and mandate given by public

8. PH programs / policies should incorporate approaches that respect diverse values, beliefs, and cultures in community

[*] *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002), http://www.phls.org/.

•*Adapted from: *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002), http://www.phls.org/. This sometimes is referred to as the "Public Health Ethics Code."   See also Appendix A for fuller detail on each principle.

•*Adapted from: *Principles of the Ethical Practice of Public Health*, The Public Health Leadership Society (2002), http://www.phls.org/. This sometimes is referred to as the "Public Health Ethics Code."   See also Appendix A for fuller detail on each principle.

Instructor notes

•To address the question posed in the second bullet, an example might be Disease Surveillance and Outbreak Investigations

•Principles 5, 6 and 10 provide guidance about the need to provide information to the public that must be balanced against the need to protect confidentiality. Note that Principle 10 protects information that can bring harm to the individual *or community*

•Principle 5. PH should seek information needed to implement effective policies / programs that protect and promote health

•Principle 6. PH institutions should provide communities with information needed for policy / program decisions and should obtain community's consent for implementation

•Principle 10. PH institutions should protect confidentiality of information that can bring harm to individual or community if made public

A discussion of the issues: "The ethical dimensions of surveillance and outbreak investigations require a balancing of individual interests in privacy and confidentiality and the public's need for information. Surveillance for diseases for which reporting is mandated by law and investigation by competent government authorities of outbreaks of diseases of public health importance are activities for which individual consent is not explicitly required. However, the non-consensual nature of these data-collection processes means that attention to privacy and confidentiality concerns should be paramount in the process of collecting and storing the data and specimens. In addition, any invasion of privacy can be minimized—and more easily justified—by collecting only the identifying information clearly needed for subsequent disease-control efforts and by removing identifying information from data and specimens once maintaining that information is no longer useful.

Privacy and confidentiality, although partially overlapping concepts, are not identical. (27)   *Privacy* refers to the individual's interest in limiting access to his or her body (or to specimens) or to personal information. *Confidentiality*, which sometimes is considered a subset of privacy, refers to the legal and ethical obligations to restrict *redisclosure* of private information originally disclosed to others in a confidential (e.g., patient-doctor) relationship.

Outbreak investigations also may be ethically more complicated for other reasons. For example, some public health practitioners consider epidemic illness of uncertain origin in members of the public as sufficient justification for expecting the cooperation of ill people (or the cooperation of family members) in outbreak investigations without having to conduct formal and explicit informed-consent procedures. However, that rationale becomes less helpful when persons not directly affected by disease are involved in outbreak investigations. For example, the justification for not routinely obtaining standard explicit informed consent from persons serving as uninfected controls (e.g., randomly selected, unaffected neighbors or coworkers) in outbreak-related case-control studies is a more complex informed-consent issue." (Bernheim RG, Nieburg P, and Bonnie RJ. "Ethics and the Practice of Public Health," in Goodman RA (ed.), LAW IN PUBLIC HEALTH PRACTICE, 2nd ed., Oxford, New York, Oxford University Press (2005), pg ??.)