GOOD DECISION MAKING IN REAL TIME:

PUBLIC HEALTH ETHICS TRAINING FOR LOCAL HEALTH DEPARTMENTS

Student's Manual

Developed by the
Public Health Ethics Unit
Office of Scientific Integrity
Office of the Associate Director for Science
Office of the Director
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services

June 6, 2017

Department of Health and Human Services
Centers for Disease Control and Prevention

Student's Manual Table of Contents

Disclaimer

The findings and conclusions in this manual are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Acknowledgements

This training was originally developed through a collaborative effort between the Office of the Associate Director for Science, Centers for Disease Control and Prevention (CDC) and the National Association of County and City Health Officials (NACCHO) with support from Booz Allen Hamilton. The following individuals contributed to the original 2012 effort (the listing represents the individual's affiliation in 2012):

Office of the Associate Director for Science, CDC Project Members:

Drue Barrett

Gail Horlick

Michelle Houston

Lindsay Kramer

Kim Lane

Julie Orta

Leonard Ortmann

Ronald Otten

Booz Allen Hamilton Project Members:

Mark Ciampa

Erica Jeffreys

Carianne Muse

Project Advisory Committee Members:

Ruth Gaare Bernheim, University of Virginia

Alan Melnick, Clark, Cowlitz, Skamania, and Wahkiakum Counties, Clark County Public Health

Matthew Stefanak, Northeast Ohio Medical University and General Health District, Mahoning County, Ohio

Subha Chandar, National Association of County and City Health Officials

Case Developers:

Stephanie Morain, graduate student, Harvard School of Public Health (mandatory flu vaccine, smoke free policies, and obesity cases)

J.P. Leider, graduate student, Johns Hopkins University (lead abatement case)

Elizabeth Fenton, graduate student, University of Virginia (partnership case)

Gail Horlick and Patricia Sweeney, CDC (HIV surveillance case)

Public Health Law Consultants:

Leslie Wolf, Georgia State University

Matthew Penn, CDC Public Health Law Program

Preface

This training manual was developed to support state, tribal, local, and territorial health departments in their efforts to address ethical issues that arise in the practice of public health. It provides tools to enable participants to become conversant in ethics and confidently engage in discussion of realistic case studies that foster practical decision making. The training does not offer a formula for decision making, but an approach that recognizes that the process of ethical reflection is an ongoing challenge that deepens by incorporating it into one's daily routine.

To ensure its relevance and practicality, public health practitioners reviewed the training materials through the course of its development. In addition, ethicists and subject matter experts within and outside the Centers for Disease Control and Prevention (CDC) wrote or reviewed the materials to ensure its scientific accuracy and fidelity to established principles in the field of public health ethics.

The teaching combines an overview of public health ethics with case studies in public health on current topics. The overview introduces public health ethics and distinguishes it from clinical and research ethics. It offers a guide for analyzing ethical challenges in public health and discusses the use of tools for addressing these challenges, such as the case-based approach and stakeholder analysis. It also explores the overlap between law and ethics. Each case contains relevant scientific and regulatory background information and questions for discussion. The facilitator's manual contains additional questions, ethical points to consider, and a sample ethical analysis of the case.

We envision this as a living document. The original version of this manual was released in August 2012. In this version, we have updated the slides to better reflect our current training approach. We have also created a case repository on our CDC Public Health Ethics website which can serve as an additional resource for cases. This case repository can be found at https://www.cdc.gov/od/science/integrity/phethics/trainingmaterials.htm.

Public Health Ethics Unit
Office of Scientific Integrity
Office of the Associate Director for Science
Office of the Director
Centers for Disease Control and Prevention
June 6, 2017

Learning Objectives

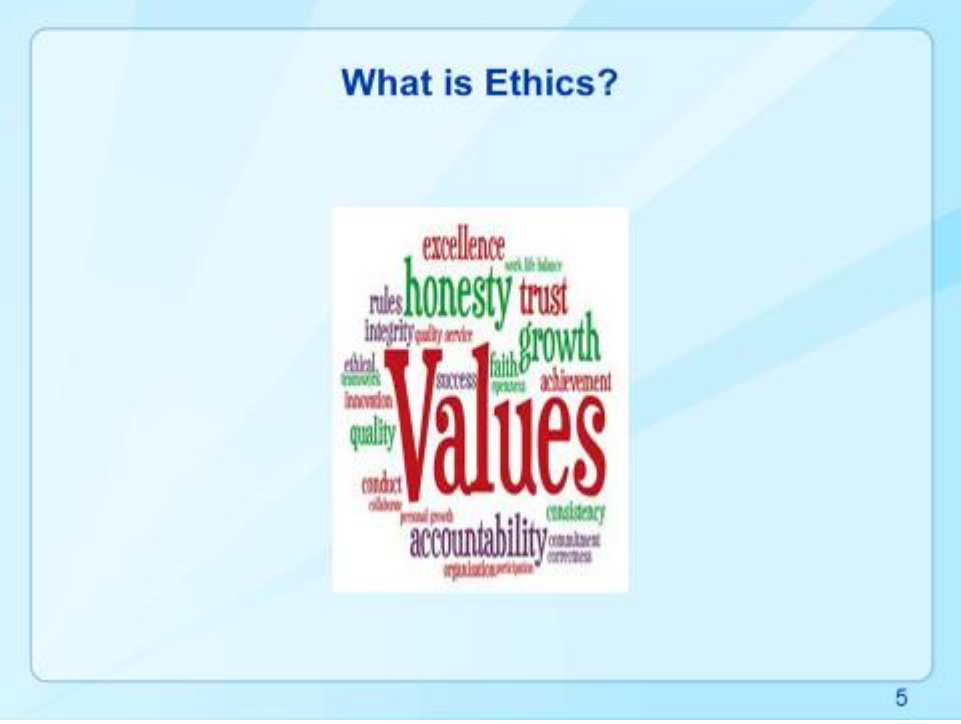
Through this training, participants will:

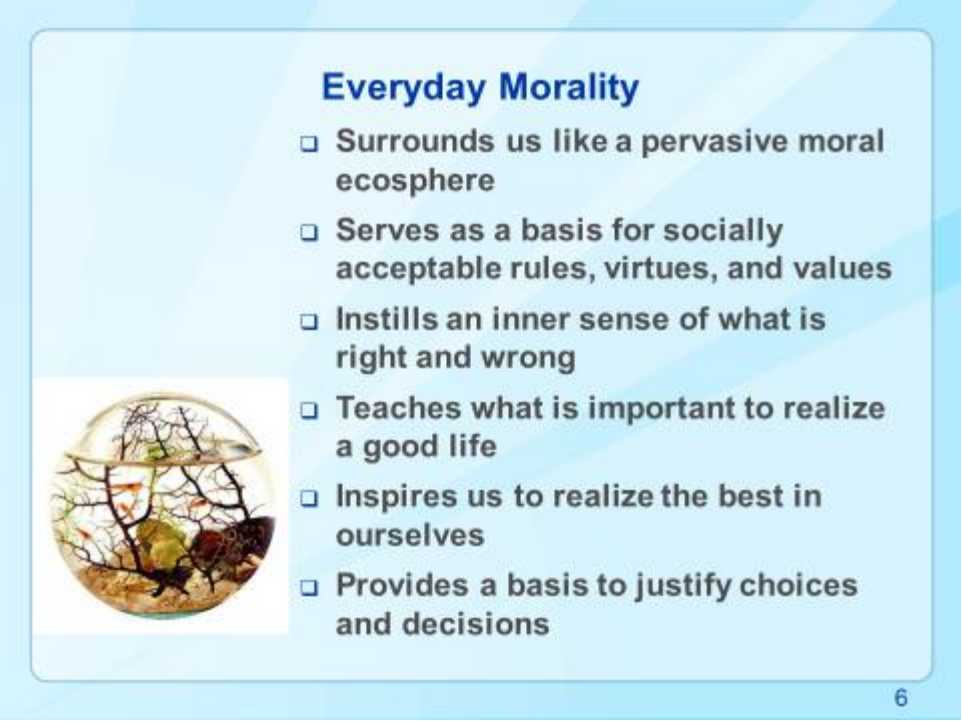
1. Gain an overview of public health ethics as a distinct field within health ethics
2. Learn how to apply a simple 3-step ethics framework in public health decision making
3. Learn about complementary public health ethics tools that can be used to explore or address ethical challenges that commonly arise in the practice of public health
4. Explore the overlap between ethics and law
5. Examine how the use of case studies can assist with exploring ethical issues in public health practice
6. Examine specific ways to integrate ethical considerations into the day-to-day decision making in local public health departments


Good Decision Making in Real Time:
Practical Public Health Ethics
for Local Health Officials
Developed by the
Office of Scientific Integrity
Office of the Associate Director for Science
Office of the Director
Centers for Disease Control and Prevention
Department of Health and Human Services
Originally Released August 2012
Revised June 2017
CDC
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
1

Section A: Introduction to Public Health Ethics

What is Ethics and Public Health Ethics?




Everyday Morality
Surrounds us like a pervasive moral ecosphere
Serves as a basis for socially acceptable rules, virtues, and values
Instills an inner sense of what is right and wrong
Teaches what is important to realize a good life
Inspires us to realize the best in ourselves
Provides a basis to justify choices and decisions
6

Why Do We Need the Formal Study of Ethics?

- **Lack of guidance**
  - Everyday morality sheds no light on a novel situation or technical issue
  - No regulations or statutes apply to the novel situation or technical issue
- **Lack of consensus**
  - Intense moral disagreement prevails among rival stakeholders
  - Existing laws, moral rules, or values conflict with each other
- **Need to weigh and prioritize values**
  - To allocate a scarce resource
  - To determine the optimal alternative in a given stakeholder context

7

Benefits of a Formal Approach to Ethics

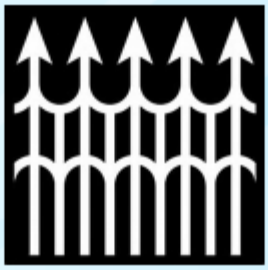
- Increased capacity to recognize ethical issues
- Vocabulary to address ethical challenges
- Ability to respectfully discuss ethical tensions
- Confidence in justifying decisions
- Greater transparency in decision making

- Enhanced public trust and relationship building
- Strengthened professional integrity and excellence

8

Basic Ethical Modes

Compass	Fence	Scale
Orientation	Limit or scope	Weighing
Agent	Action	Action's Impact



Adapted from: Hansson, S. Ethics and radiation protection. J. Radiol. Prot. 27 (2007) 147-156.

9

Ethical Theories

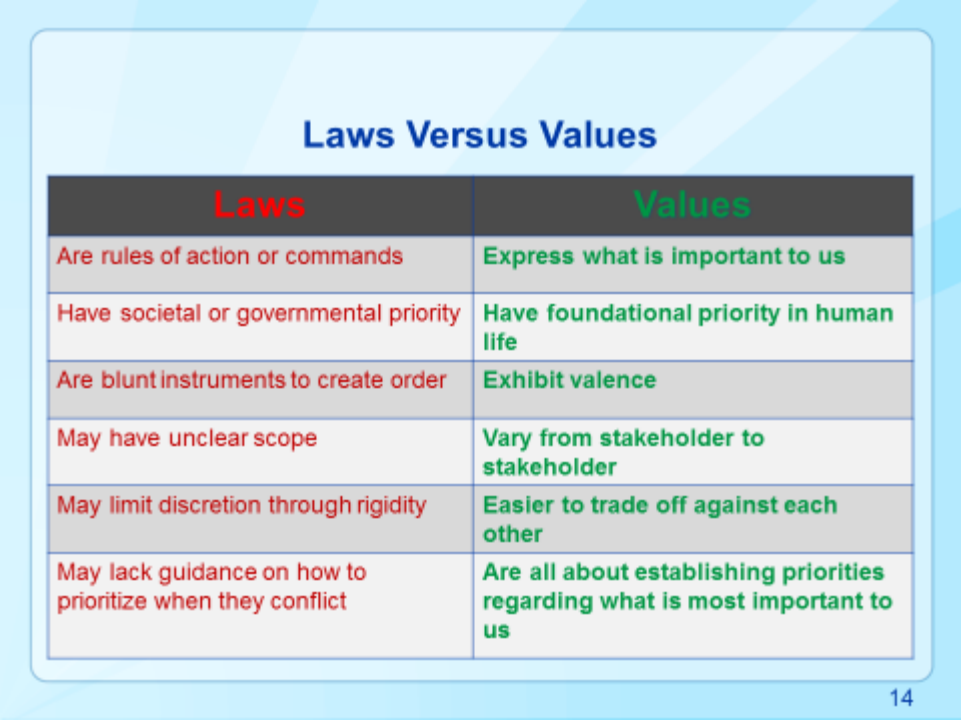
Theory →	Virtue Ethics	Deontology	Utilitarianism
Focus	Agent	Action	Result of Action
Key figure	Aristotle	Immanuel Kant	John Stuart Mill
Main concept	*Virtues*: acquired habits or skills that make persons effective in social or professional settings	*Duties*: ethical rules that bind or constrain action and prescribe obligations owed to one another	*Consequences*: good or bad results of actions, such as their beneficial or harmful effects on persons and society
Examples	Honesty, courage, modesty, trustworthiness, reliability, adaptability, transparency, scientific integrity	Ethical and religious commandments, human rights, respect for justice, autonomy, beneficence	Burdens, risks, harms, or costs versus the advantages, utility, benefits or savings resulting from interventions or policies
Ethical Action	Doing what a role model or person of good character would do in the given situation	Fulfilling an obligation or duty owed to oneself or society	Maximizing the net balance of benefits over harms, greatest good for the greatest number
Uses	Assessing the skills and capacities needed for success in a community, organization, or profession	Establishing compliance regulations, providing standards for evaluating actions and behavior	Conducting population-level utilitarian cost-benefit, risk-benefit, or cost-effectiveness analyses

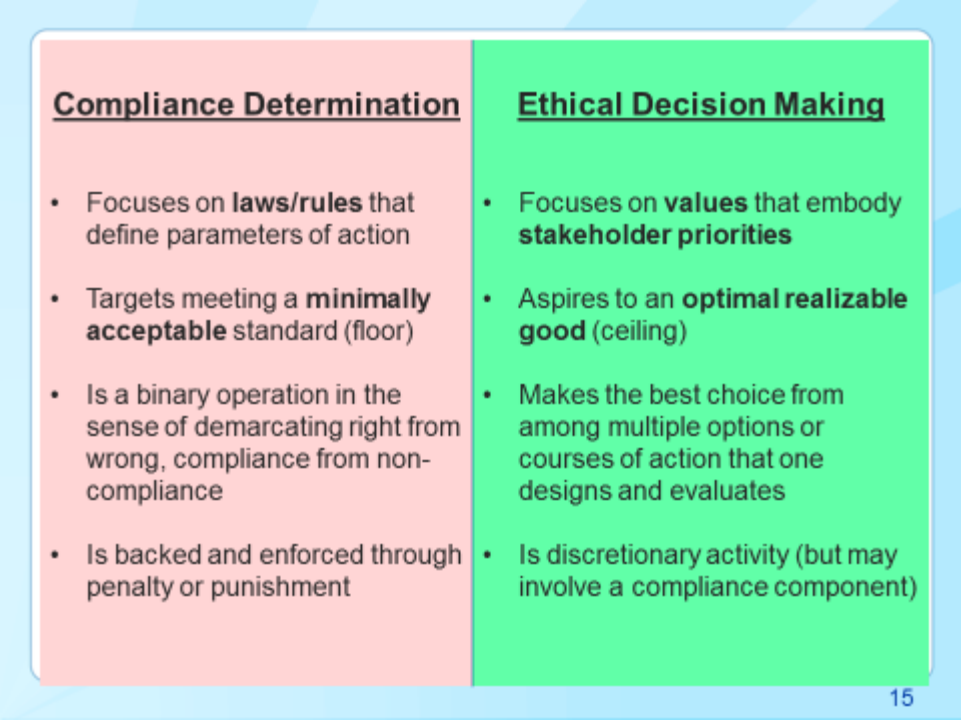
10


What is Public Health Ethics?
ME!
WE?
11


Four Ways of Describing Public Health Ethics
I. Challenges: The range and kind of ethical issues, problems and conflicts public health officials regularly face
II. Content: Ethical principles (rules, norms and values) relevant to the practice of public health
III. Stepwise procedure: Orderly approach to identifying and addressing ethical challenges in public health practice
IV. Standard practice: Upstreaming ethical decision making in order to splice an ethics-in-all-policies gene into the DNA of public health practice
12


I. Range of Ethical Challenges
Rules
Values
Employee/professional responsibility
Need to know rules or acquire relevant training
Compliance issue
Meet legal requirements and restrictions
So-called ethical compliance is really legal compliance closely based on ethical principles
Unanticipated ethical challenge/dilemma
If not a compliance issue, best addressed by a methodical approach
Ethical decision making in daily practice
Ethically-informed practice uses a methodical approach to design evidence-based interventions and policies that align with community and stakeholder values
13


Laws Versus Values
Laws
Values
Are rules of action or commands
Express what is important to us
Have societal or governmental priority
Have foundational priority in human life
Are blunt instruments to create order
Exhibit valence
May have unclear scope
Vary from stakeholder to stakeholder
May limit discretion through rigidity
Easier to trade off against each other
May lack guidance on how to prioritize when they conflict
Are all about establishing priorities regarding what is most important to us
14


Compliance Determination
Focuses on laws/rules that define parameters of action
Targets meeting a minimally acceptable standard (floor)
Is a binary operation in the sense of demarcating right from wrong, compliance from non-compliance
Is backed and enforced through penalty or punishment
Ethical Decision Making
Focuses on values that embody stakeholder priorities
Aspires to an optimal realizable good (ceiling)
Makes the best choice from among multiple options or courses of action that one designs and evaluates
Is discretionary activity (but may involve a compliance component)
15

Examples of Ethical Challenges Public Health Officials Regularly Face

- Complying with ethical and legal regulations
- Balancing individual liberty with protecting the public
- Managing potential conflicts of interest with donors
- Engaging communities in ways that foster trust
- Using and managing surveillance data in ways that protects privacy and confidentiality
- Allocating scarce resources
- Controlling infectious diseases
- Serving immigrants and refugees
- Negotiating political contexts and constraints

16

Example 1 of an Ethical Challenge from Public Health Practice

Environmental health

- Enforcing child lead poisoning prevention laws when families with lead poisoned children lack the resources to remediate lead hazards in their homes

17

II. Content
Core Values and Commitments*

- **Health** –protect and promote health, prevent disease, affirm human right to resources necessary for health
- **Community** – interdependence, solidarity, collaboration, trust building, health equity
- **Evidence-informed action** – translate best available scientific knowledge into public health interventions

*Adopted from the Public Health Leadership Society. 2002. Principles of the Ethical Practice of Public Health. https://www.apha.org/~/media/files/pdf/membergroups/ethics_brochure.ashx

18

12 Ethical Principles of Public Health Practice*

- Target prevention strategies that address root causes
- Respect rights of community members
- Give community stakeholders a fair hearing
- Achieve health equity
- Base programs on the right information
- Obtain community consent
- Respond to health problems in a timely manner
- Display cultural competence in implementing interventions
- Intervene to enhance the physical and social environment
- Maintain data confidentiality
- Ensure professional competence of public health practitioners
- Establish collaborations to build trust

*Adopted from the Public Health Leadership Society. 2002. Principles of the Ethical Practice of Public Health. https://www.apha.org/~/media/files/pdf/membergroups/ethics_brochure.ashx

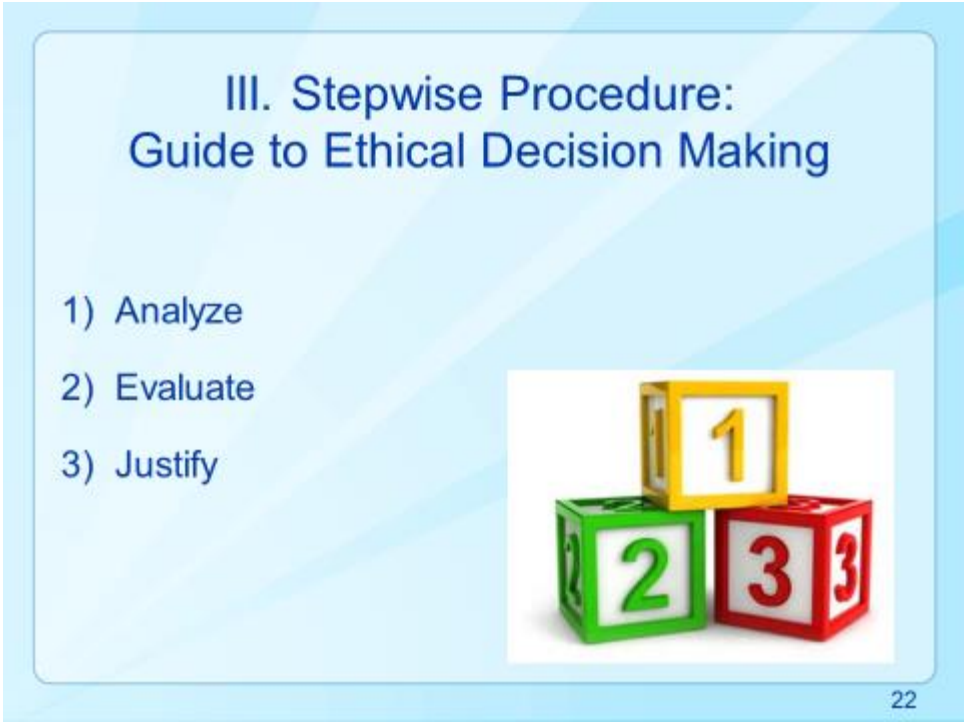
19


Belmont Principles:
Common to many health-related field of ethics, such as clinical ethics, research ethics, bioethics, and public health ethics
Respect for persons
Autonomy [informed consent, privacy protection]
Protection of those with diminished autonomy
Beneficence [and non-maleficence]
Promoting health and treating disease
Doing no harm
Maximizing benefits, minimizing harms
Justice
Giving persons what they deserve, equal access
Fair distribution of burdens and benefits
Procedural justice or due process
20

Clinical Ethics vs. Public Health Ethics

Clinical Ethics Focus	Public Health Ethics Focus
Individual autonomy central: focus on consent and privacy	Interdependence central: autonomy can be restricted to protect the public
Treatment of individual disease	Prevention of disease in population
Fiduciary relation to patient	Public stewardship
Individual informed consent	Community engagement
Individual patient benefit and harm	Populations and communities
Individual benefit and harm	Greatest net social good
Clinicians making medical interventions	Array of interventions and professionals
Authority based on doctor or profession	Authority based on police powers
Law, more of an adversary than an ally	Law/policy, a key tool of the profession
Justice focus limited to access to care	Social justice and health equity central

21

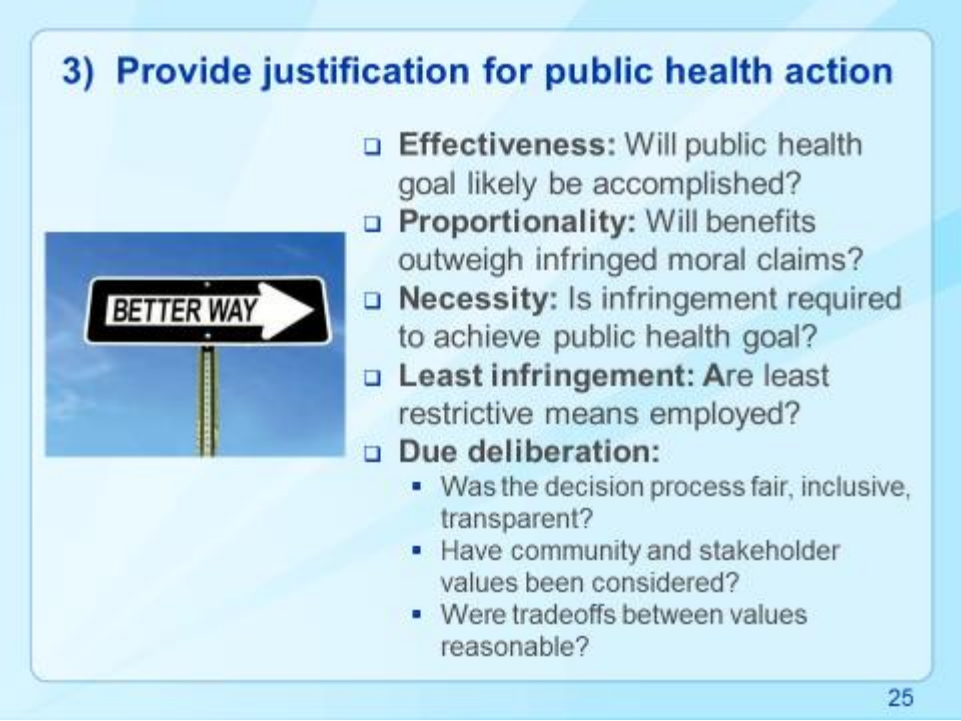

III. Stepwise Procedure:
Guide to Ethical Decision Making
1) Analyze
2) Evaluate
3) Justify
1
2
3
22


1) Analyze ethical issues
Public health goals – directly reflect core values and benefits to be achieved
Stakeholder moral values/claims
Risks and harms of concern
Source/scope of legal authority
Other constraints on action – ethical, scientific, financial, political
Ethically relevant precedents
Ethics tools and codes that provide guidance
23

2) Ethically evaluate public health options

- **Utility:** Does the public health action produce a net balance of benefits over harms?
- **Respect for individual and community:** Does the action respect existing individual and civic roles and take into account the impact on the community as a whole?
- **Justice:** Are benefits and burdens fairly distributed and is health equity promoted?
- **Contextual appropriateness**: has the action been adapted to local circumstances and does it incorporate community and stakeholder values?

24

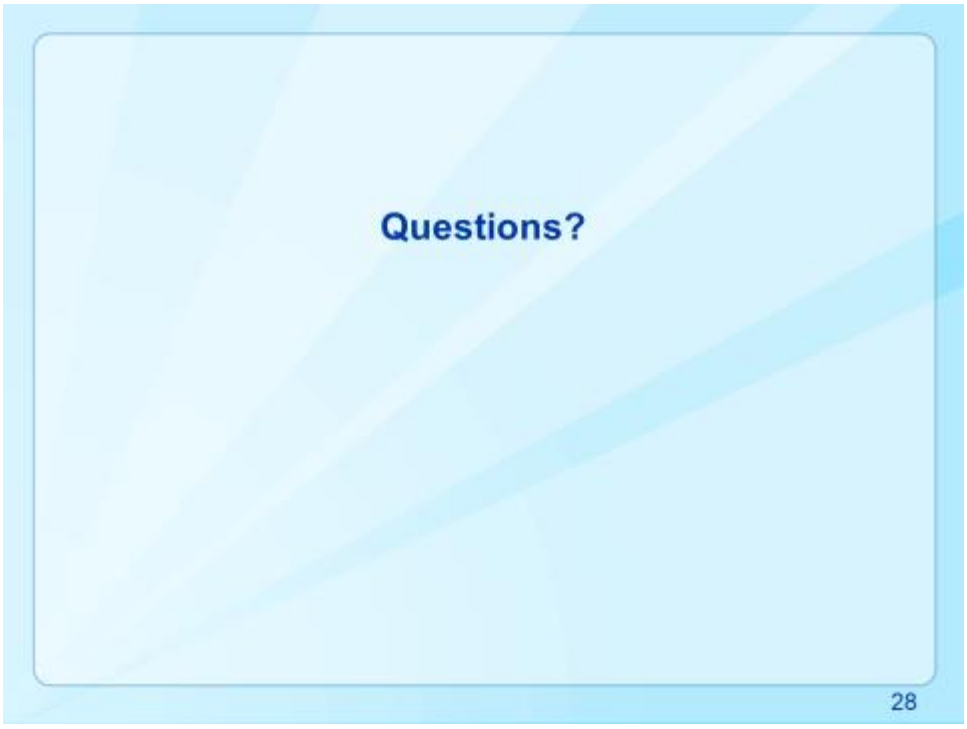

3) Provide justification for public health action
BETTER WAY
Effectiveness: Will public health goal likely be accomplished?
Proportionality: Will benefits outweigh infringed moral claims?
Necessity: Is infringement required to achieve public health goal?
Least infringement: Are least restrictive means employed?
Due deliberation:
Was the decision process fair, inclusive, transparent?
Have community and stakeholder values been considered?
Were tradeoffs between values reasonable?
25

IV. Standard Practice: Public Health Ethics-in-all-Policies Approach

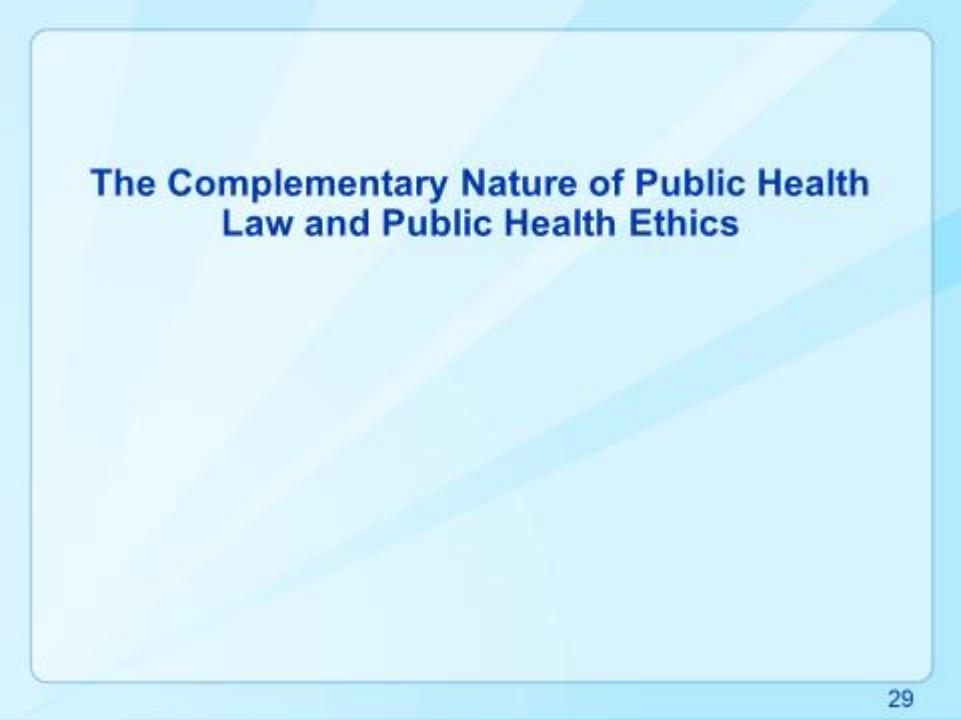
- **Precedents**
  - Writing across the curriculum; health in all policies
- **Key idea 1: intersectoral impact**
  - Though discipline specific, impact felt across disciplines
- **Key idea 2: upstream design**
  - Incorporates public health ethics into everyday practice
  - Brings public health ethics into the planning and design phase
  - Can be cost and time effective
  - Can prepare one for unexpected ethical challenges

26


Advantages of an
Ethics in All Policies Approach
Preparedness training for ethical challenges
Follows an appropriate, orderly, deliberate procedure
Informed by scientific and circumstantial evidence
Lays out various constraints on action
Makes relevant value assumptions explicit
Facilitates trade-offs between stakeholders
Provides stronger public justification for action
Can design more efficient, cost effective policies and interventions that are ethically sound and resonate with community values
27


Questions?
28

The Complementary Roles of Public Health Law and Public Health Ethics

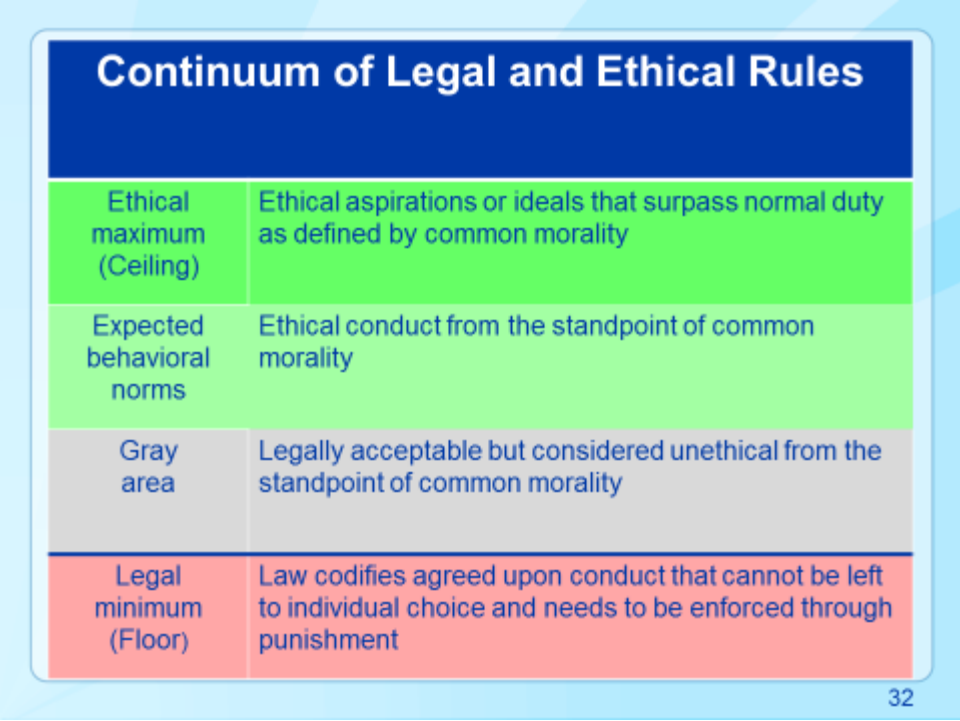


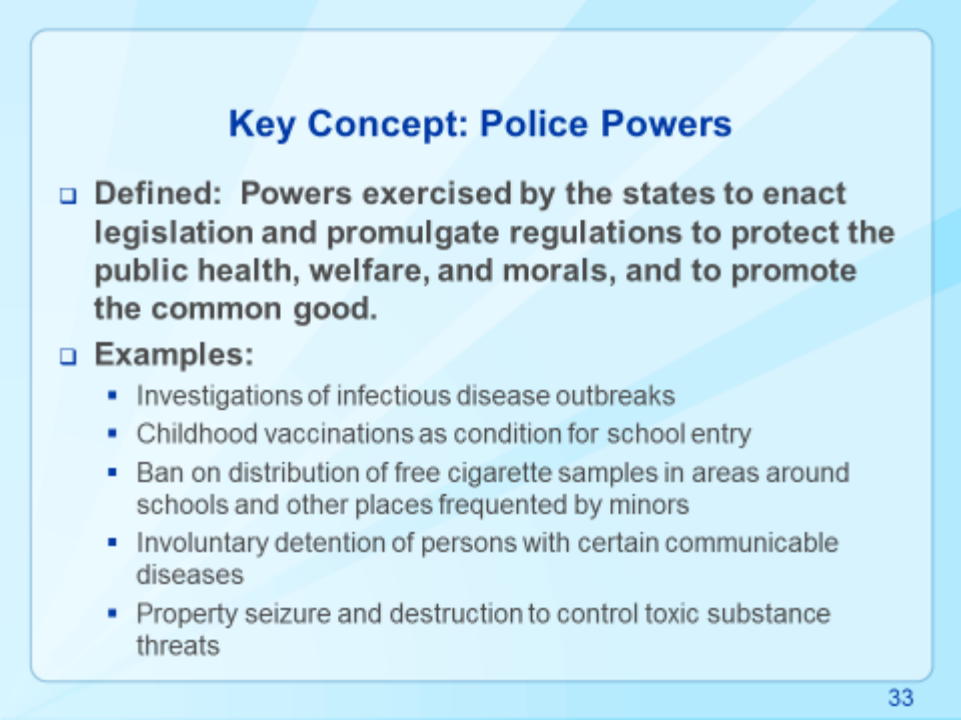

The Complementary Roles of
Public Health Ethics and Public Health Law
Why consider law in an ethics training?
Laws define the boundaries for lawful action
Laws may be a useful starting point for consideration of public health action
Laws may rely on common ethical principles
Laws may reveal social moral consensus
Laws and legal advice may provide the framework for decision making
30

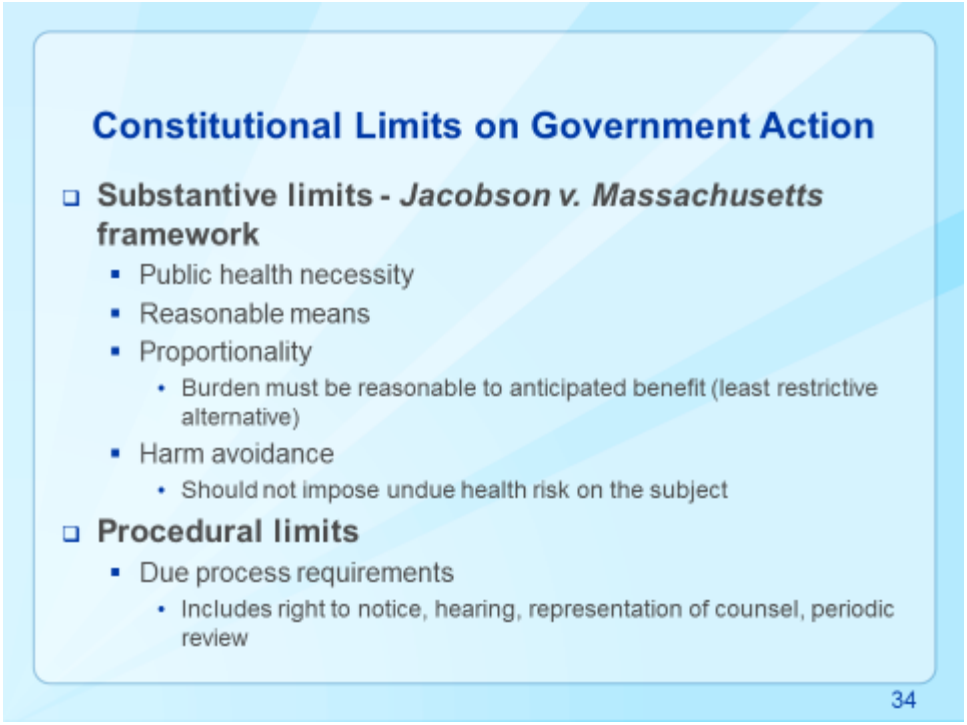
Ethics and Law Share Similar Decision Making Processes

- **Deliberate consideration and articulation of:**
  - Facts, questions, conflict
  - Options
  - Decision
  - Reasons for the decision
- **And, in the end, reasonable minds may still disagree**

31


Continuum of Legal and Ethical Rules
Ethical maximum (Ceiling)
Ethical aspirations or ideals that surpass normal duty as defined by common morality
Expected behavioral norms
Ethical conduct from the standpoint of common morality
Gray area
Legally acceptable but considered unethical from the standpoint of common morality
Legal minimum (Floor)
Law codifies agreed upon conduct that cannot be left to individual choice and needs to be enforced through punishment
32

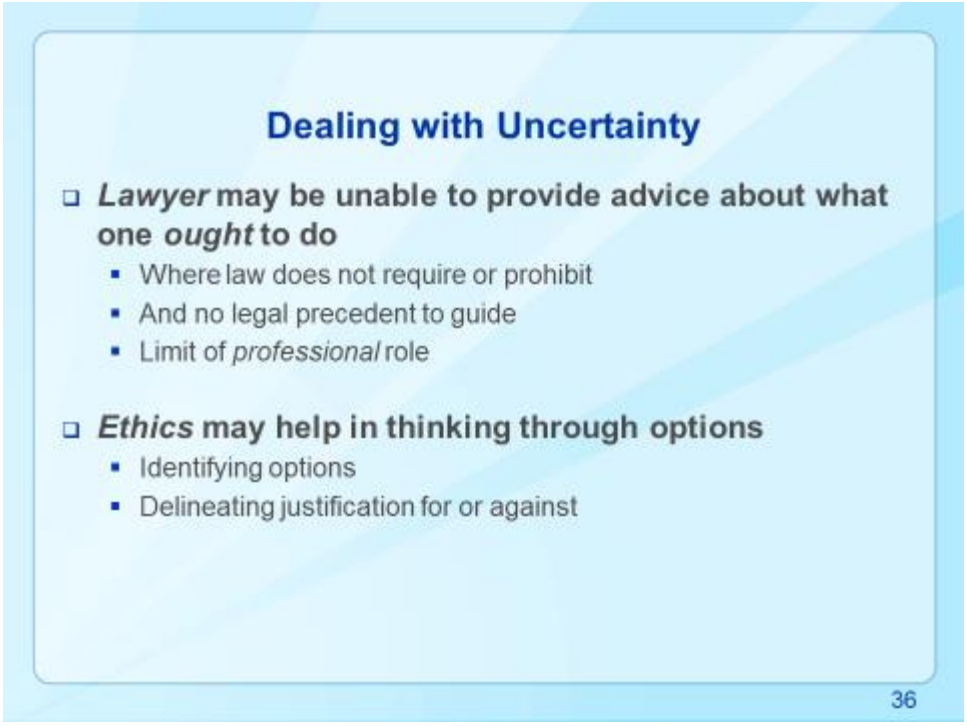

Key Concept: Police Powers
Defined: Powers exercised by the states to enact legislation and promulgate regulations to protect the public health, welfare, and morals, and to promote the common good.
Examples:
Investigations of infectious disease outbreaks
Childhood vaccinations as condition for school entry
Ban on distribution of free cigarette samples in areas around schools and other places frequented by minors
Involuntary detention of persons with certain communicable diseases
Property seizure and destruction to control toxic substance threats
33


Constitutional Limits on Government Action
Substantive limits - Jacobson v. Massachusetts framework
Public health necessity
Reasonable means
Proportionality
Burden must be reasonable to anticipated benefit (least restrictive alternative)
Harm avoidance
Should not impose undue health risk on the subject
Procedural limits
Due process requirements
Includes right to notice, hearing, representation of counsel, periodic review
34

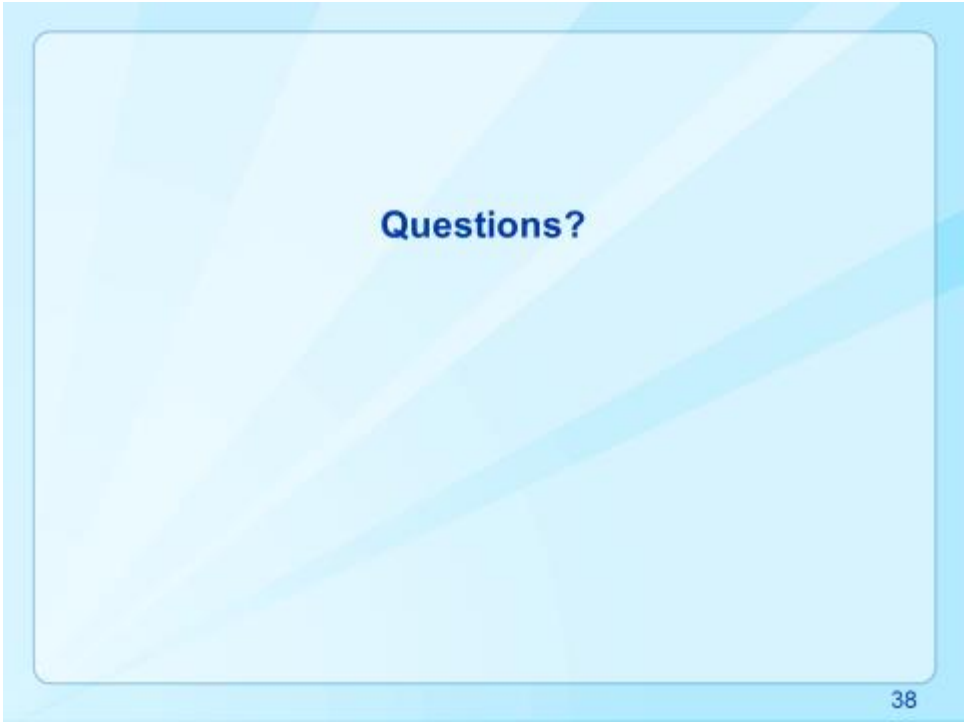
Parameter Setting Role of Law

- **Laws provide the boundaries**
  - Tell you what you *cannot* do
  - Tell you what you *must* do
  - Tell you what you *can* do
    - May be explicitly authorized in statute OR
    - May be inferred from statutes, case law
- **But may not tell you what you *should* do (among options)**
- **In some cases, law may conflict with what *ought* to be done**

35

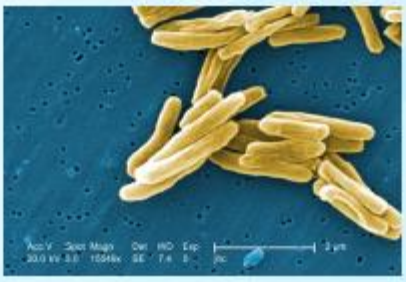

Dealing with Uncertainty
Lawyer may be unable to provide advice about what one ought to do
Where law does not require or prohibit
And no legal precedent to guide
Limit of professional role
Ethics may help in thinking through options
Identifying options
Delineating justification for or against
36


Summary
Law in Public Health: Provides authority, limitations on state power, incentives and disincentives for behavior; often allows for much professional discretion
Ethics in Public Health: Provides ongoing analysis, deliberation about, and justification for public health action and policy, often when law is indeterminate.
Law
Formal institution
Statutes
Regulations
Court decision
Public proceedings with a "reasonable person" standard
Ethics
Less formal
Moral norms, values
Professional codes
Previous cases
Publicly justifiable positions based on ethical reasoning
37

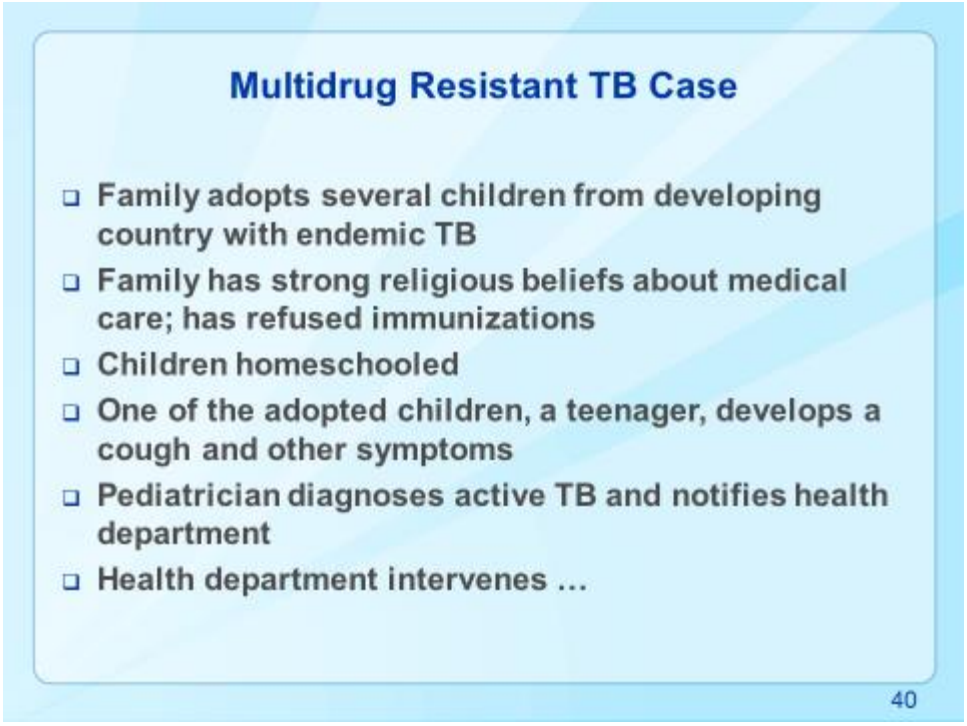

Questions?
38

Example 2 of an Ethical Challenge in Public Health Practice

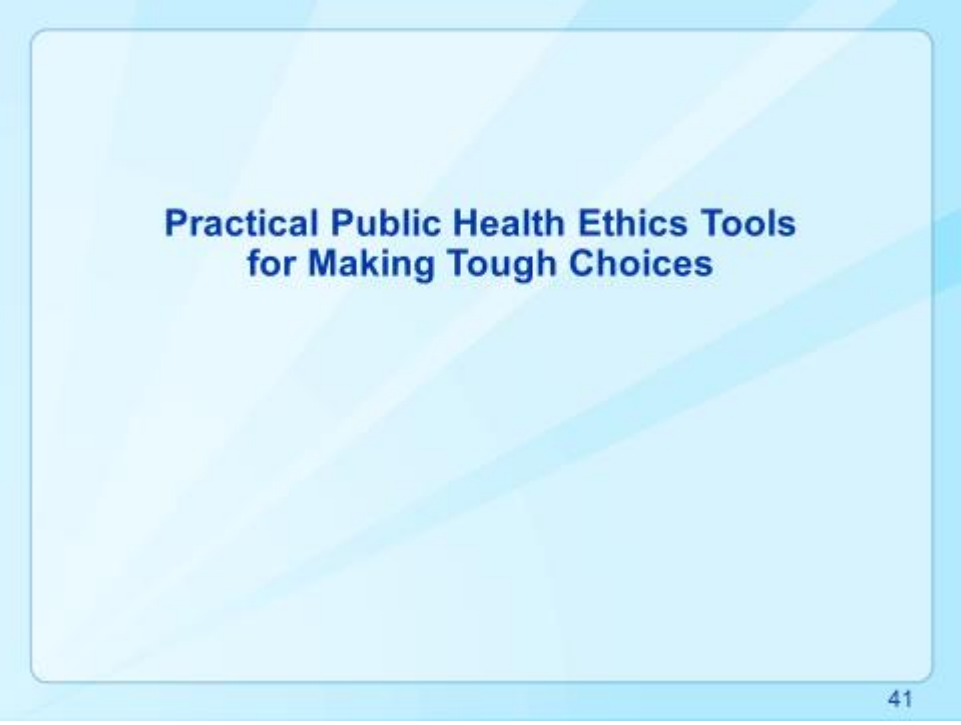
- **Multidrug resistant TB**
  - Integrating ethics and legal powers to address the health needs of the community while respecting rights of individuals and families



39


Multidrug Resistant TB Case
Family adopts several children from developing country with endemic TB
Family has strong religious beliefs about medical care; has refused immunizations
Children homeschooled
One of the adopted children, a teenager, develops a cough and other symptoms
Pediatrician diagnoses active TB and notifies health department
Health department intervenes …
40

Practical Public Health Ethics Tools for Making Tough Choices



Public Health Ethics Tools

- Case–based approach
- Stakeholder analysis
- Deliberative process
- Prioritizing values
- Professional values: *Principles of the Ethical Practice of Public Health*

42


Case-Based Approach
Traditional method of using cases to develop practical moral judgment and resolve ethical issues
The case approach reasons "up" inductively from particular instances to more generally applicable moral conclusions
Similar to the development of common law which uses legal precedents
43

Advantages of Case-Based Approach

- Encourages ethical reflection and discussion
- Reinforces ethical concepts in relation to concrete cases
- Elicits a variety of reactions
- Opens learners up to multiple perspectives on an issue
- Simulates the kind of practical situations practitioners face
- Prepares one for making tough practical decisions

44

Spotlight on Stakeholder Analysis

- Can make one aware of one's own unspoken assumptions
- Identifies potential partners and areas of tension
- Effort can be modulated to time and financial constraints
  - Fact finding
  - Stakeholder representatives
  - Focus groups
  - Community engagement
- User friendly result that resonates with the interests, values, and claims of all stakeholders

45

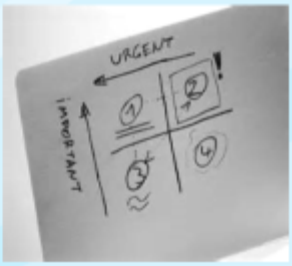
Spotlight on Deliberative Procedure

- Is consistent, inclusive, and transparent
- Gives stakeholders and their moral claims a fair hearing
- Ensures procedural justice
- Weighs stakeholder values in relation to core public health values
- Designs alternatives that resonate with stakeholders and are consistent with public health values
- Strives to achieve what is optimal for the given context

46

Spotlight on Weighing and Prioritizing Values

- Every choice implies prioritization
- Ethical conflicts frequently reflect prioritization disagreements
- Prioritization determinations are context specific
- Facts, constraints, and values of stakeholders co-determine the context
- Appeals to values or context can often resolve conflicts over rules, which stipulate obligations
- It is easier to negotiate or make trade-offs involving values, which are more flexible



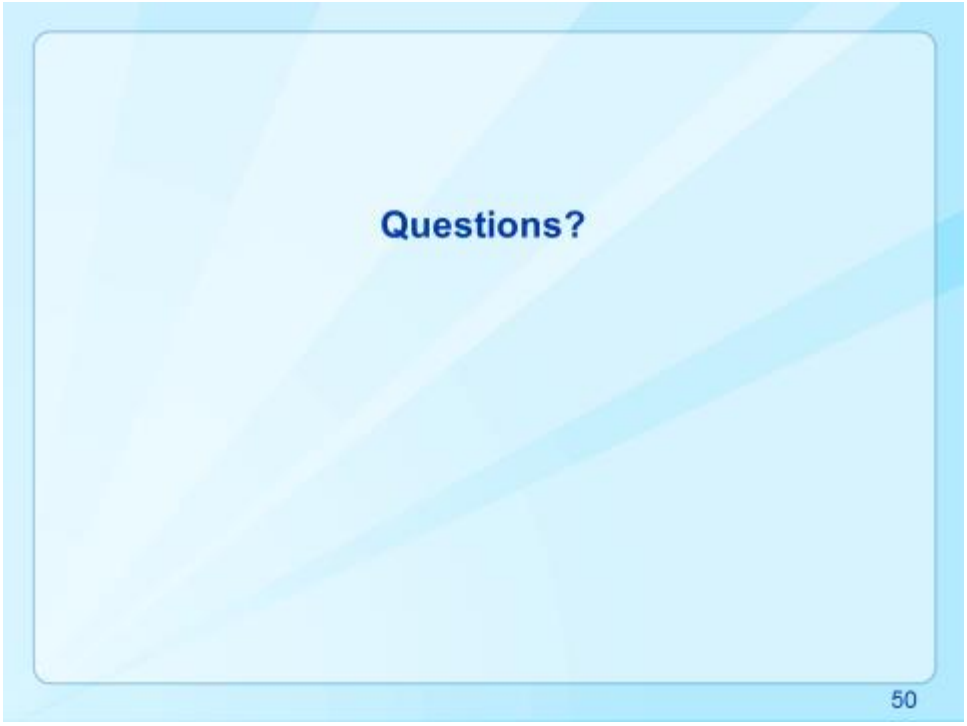
47


Prioritization Example:
Which Child Safety Seat is Best?
(All meet minimum safety and product standards)
Most economical
$40
OK ease of use
Acceptable safety
Most user-friendly
$231
A snap to use
Good safety
Most reliable
$494
A pain to use
Excellent safety
48

Appreciating the Result

- No single best answer
- Facts matter, but so do values
  - Bias in acquiring evidence versus meaning-conferring role of values in decision making
- Choice implies prioritization
- Best depends on context:
  - Goals of the program
  - Available evidence
  - Circumstances
  - Constraints on action
  - Relevant values

49


Questions?
50

Section B: Topics in Public Health Ethics: Case Studies

General Instructions for Use of Case Studies

The following modules address ethical concerns that are commonly encountered in the practice of public health, including:

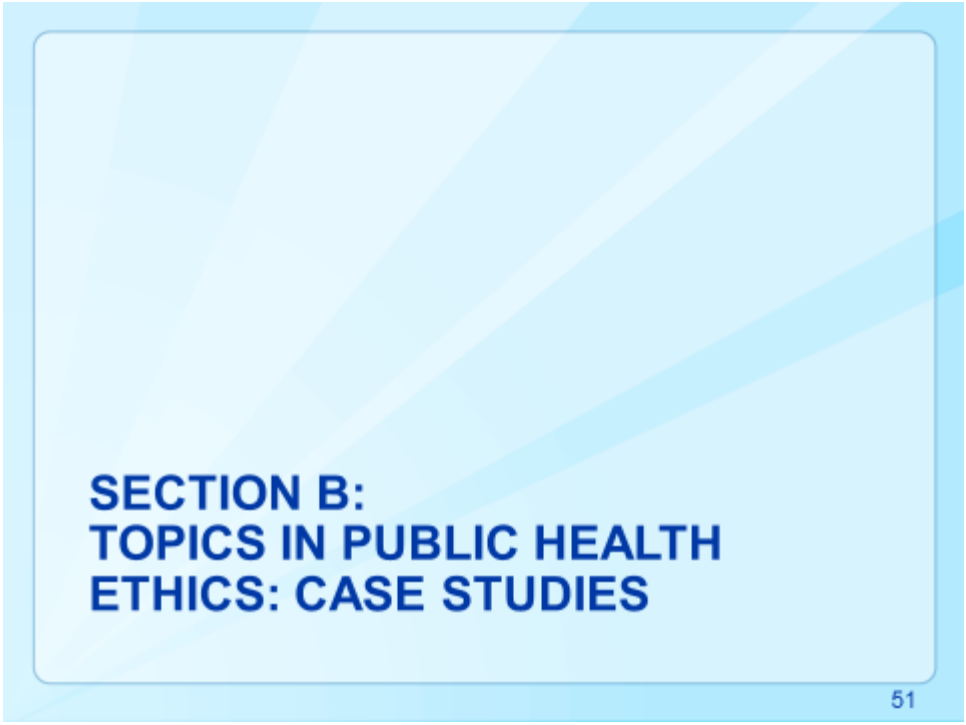
- Balancing the rights of individuals versus protecting the public good (Module 1)
- Allocation of limited public health resources (Module 2)
- Protection of underserved or marginalized populations (Module 3)
- Protection of individual privacy and data confidentiality (Module 4)
- Community engagement and information sharing (Module 5)

Each of these topics will be addressed through the exploration of case studies that illustrate some of the ethical aspects of the topic. The cases are structured to provide *background* information, a *case description*, and initial *discussion questions*. Your facilitator will raise some additional questions to assist with initiating or prompting discussion of the case and for exploring the ethical issues relevant to the case in greater detail. These additional facilitator questions include one or more *scenario shifts* which will enable you to explore how the ethical considerations of the case change if the context of the case changes. In addition, the facilitator may raise various other *points to consider* regarding the pros and cons of decision making regarding the case and may suggest some ways to analyze the ethical dimensions of the case.

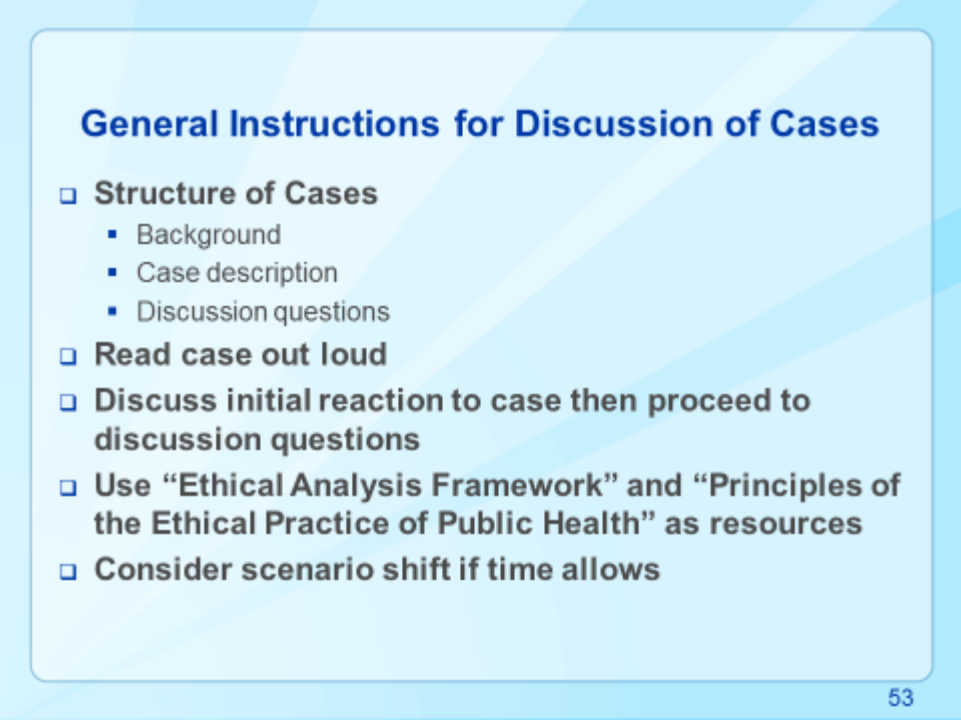
We recommend allowing 60 minutes for each case discussion; however this time can be modified to suit the available time. We recommend the following approach for case discussion:

- These cases are best discussed in small groups in order to ensure that all participants have an opportunity to provide input. We recommend groups of 8-10 people.
- Each participant will have an opportunity to provide input on the case. It is important that all group members participate. You may be called upon to provide your input if you are not speaking out.

- The opinions of all group members are important and all opinions should be respected. You should feel free to respond to others' comments or to share responses based on personal feelings. Personal information shared in the discussion should be treated as confidential and not discussed outside of the training.
- One or more group members will be asked to read the case out loud.
- The group should select a recorder to note the main discussion points and a reporter to summarize the group's reaction to the case when the entire class reconvenes.
- After hearing the case, each group member will be asked to briefly provide their initial reaction to the case using a "round robin" format. This initial discussion should be kept brief to ensure that all group members have an opportunity to respond. We recommend spending no more than 10 minutes for this part of the discussion. The purpose is to ensure that all group members begin to formulate their thoughts about the case and have an opportunity to contribute to the discussion.
- The group will then consider the *discussion questions*. You are encouraged to use the "Ethical Analysis Framework" and the "Principles of the Ethical Practice of Public Health" (found in Section IV of the manual) as resources for thinking through the ethical issues in the case.
- If time allows, the group will consider the *scenario shift(s)* to explore how context may impact the ethical considerations.


SECTION B:
TOPICS IN PUBLIC HEALTH
ETHICS: CASE STUDIES
51


Case Topics
Balancing the rights of individuals versus protecting the public good (Module 1)
Allocation of limited public health resources (Module 2)
Protection of underserved/marginalized populations (Module 3)
Protection of individual privacy and data confidentiality (Module 4)
Community engagement (Module 5)
52


General Instructions for Discussion of Cases
Structure of Cases
Background
Case description
Discussion questions
Read case out loud
Discuss initial reaction to case then proceed to discussion questions
Use "Ethical Analysis Framework" and "Principles of the Ethical Practice of Public Health" as resources
Consider scenario shift if time allows
53

Group Discussion of Case

Childhood Obesity Educational Campaign

54


Small Group Discussion of Cases
Break into small groups
Identify a recorder and one member who will report to the larger group
Take 30 minutes to discuss the case
55


Report from the Small Group Discussions
56

Case Studies

Module 1: Balancing the Rights of Individuals with the Protection of the Public Good

Introduction to the Topic

The 1905 Supreme Court case of Jacobson v. Massachusetts over compulsory vaccination law upheld the view that individual freedom is subject to the police power of the state and can be subordinated to the public welfare in situations where public safety demands it. This ruling provides a general mandate for public health to restrict individual liberty, but also establishes a condition for it, namely, protecting the public good. Many ethical issues arise in public health around the tension between individual and community interests. Resolving them often involves weighing liberty restrictions against potential harms or threats to public health and safety.

Case: Smoke-Free Policies in Outdoor Public Spaces

Disclaimer: This case study is solely an educational exercise and does not necessarily reflect the position of Centers for Disease Control and Prevention on this issue.

Background

Tobacco use is the leading preventable cause of death in the United States. The harms of tobacco use take a tremendous toll on health and financial resources, leading to one in five deaths (443,000 deaths each year) with total annual costs from associated health care expenditures and lost productivity exceeding $193 billion.[1] Smoking causes numerous health conditions, including cardiovascular disease, lung cancer and other lung diseases, infertility in women and other reproductive disorders, and multiple cancers across the body, ranging from the mouth down to the bladder.[2]

Smoking is especially concerning for public health, as the harms of tobacco use affect not only smokers, but also those around them who do not smoke. Secondhand smoke (SHS) causes an estimated 46,000 premature deaths from heart disease and 3,400 deaths from lung disease each year in the United States among nonsmoking adults.[1]

Increasing research and awareness of the harms of SHS have led to the passage of numerous comprehensive smoke-free policies, which prohibit smoking in all indoor areas of private and government workplaces, restaurants, and bars.

Comprehensive smoke-free policies have become commonplace in the United States. Recently, some jurisdictions have taken action to extend these policies prohibiting smoking to include some outdoor spaces, such as parks and beaches. Several health justifications have been offered in support of these policies. First, as described in a 2006 report by the U.S. Surgeon General, there is no risk-free level of SHS exposure.[3] Even brief exposures to SHS can cause adverse health effects, particularly among vulnerable populations, triggering asthma attacks in children and adverse events for individuals with heart disease.[4] Some evidence suggests SHS levels in outdoor spaces can be substantial under certain conditions, in which factors such as wind direction and close proximity can yield concentrations that rival those of indoor areas.[5] In addition to reducing the health impact of SHS, prohibiting smoking in outdoor spaces such as parks might have other benefits. Some studies have shown that children are influenced by adult smoking behaviors, suggesting that if children do not view smoking in public places such as parks, they may be less likely to grow up to become smokers themselves. Finally, the smoke-free policy may have a positive environmental impact, reducing the litter produced by discarded cigarette butts and the risk of cigarette-related fires—as well as the associated labor and other costs incurred by municipalities in litter removal and other maintenance.

In addition, these smoking bans also serve to promote health by increasing restrictions on the practice of smoking itself. By further restricting the permissibility of smoking, these smoke-free policies can be viewed as part of a broader anti-tobacco strategy aimed at changing social norms associated with smoking and tobacco use.[6,7] Such policies are consistent with a decades-long anti-tobacco strategy that has sought to "de-normalize" smoking from being an everyday, accepted—even glamorous—practice to one that is increasingly viewed as an undesirable behavior.[8,9] Finally, smoke-free policies may also provide motivation for tobacco users to quit smoking.[10] By reducing opportunities to smoke, these policies may support more individuals to begin cessation—and more to be successful at doing so. As nearly 70% of current U.S. adult smokers report that they want to quit completely, policies to support successful cessation have considerable potential to reduce smoking-related morbidity and mortality.[11]

Some objections to smoke-free policies have been made. First, opponents assert that the evidence base for the harm caused by SHS in outdoor spaces is not sufficiently strong to prohibit smoking in these areas. Studies which have measured the effects of SHS may not be comparable to the typical exposure in a park or other outdoor space.[12] If the health impacts of SHS to bystanders in these

outdoor settings are low, the primary force of extending smoke-free policies to outdoor spaces may be in reducing the harms to smokers themselves, which invokes consideration of the appropriate extent of paternalism to promote public health.[13,14] Further, opponents question whether indirect or behavioral harms, such as the risk to children for modeling smoking behavior, are sufficient justifications for restricting smoking.[15]

Case Description

An outdoor smoke-free policy has recently been proposed by your community's Board of Health. The policy would apply to all public parks and beaches. The Board has called you, the local health department director, to testify at the upcoming hearing on the potential policy. How would you, as the local health department director, evaluate whether and how the policy should be enacted?

Discussion Questions

Are there any legal considerations (e.g., laws or regulations mandating or prohibiting the activity) that must be taken into account?

1. Who are the stakeholders that should be considered in deciding if this policy should be enacted? What are the values and perspectives that these stakeholders bring to this issue?
2. What are the types of harms that this policy aims to address? What is the appropriate role for the health department in addressing these harms?
3. How does your understanding of the scientific evidence on the risk of SHS in outdoor spaces factor into the advice you will give the Board?
4. What long term effects could the policy have on maintaining the public's trust and support?

Scenario Shift

Would your recommendation change if the policy were to extend to all forms of tobacco, including chewing tobacco or snuff?

Case References

1. Centers for Disease Control and Prevention. Smoking-attributable mortality, years of potential life lost, and productivity losses—United States, 2000–2004. Morbidity and Mortality Weekly Report 2008;57(45):1226–8.

2. The health consequences of smoking: a report of the Surgeon General. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2004.

3. The health consequences of involuntary exposure to tobacco smoke: A report of the Surgeon General. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Coordinating Center for Health Promotion, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2006

4. Bloch M, Shopland, DR. Outdoor smoking bans: More than meets the eye. Tobacco Control, 2000;9:99.

5. Kleipeis NE, Ott, WR, Switzer P. Real-time measurement of outdoor tobacco smoke particles. Journal of Air and Waste Management Association 2007;57:522-34.

6. Bayer R, Stuber J. Tobacco control, stigma, and public health: Rethinking the relations. American Journal of Public Health 2006;96(1):47-50.

7. Bayer R, Colgrove J. Science, politics, and ideology in the campaign against environmental tobacco smoke. American Journal of Public Health 2002;92(6):949-54.

8. Brandt A. Blow some my way: Passive smoking, risk, and American culture. In: Lock S, Reynolds L, Tansey, E, eds. Ashes to Ashes: The History of Smoking and Health. Amsterdam. The Netherlands: Rodolpi BV, 1998:164-91.

9. Francis JA, Abramsohn EM, Park HY. Policy-driven tobacco control. Tobacco Control 2010;19 Suppl 1:16-20.

10. Hopkins DP, Razi S, Leeks, KD, et al. Smokefree Policies to Reduce Tobacco Use: A Systematic Review. American Journal of Preventive Medicine 2010;38(2S):S275-89.

11. Centers for Disease Control and Prevention. Quitting smoking among adults—United States, 2001–2010. Morbidity and Mortality Weekly Report 2011;60(44):1513-19.

12. Chapman S. Should smoking in outdoor spaces be banned? BMJ 2008;337:a2804.

13. Rabin R. Tobacco control strategies: Past efficacy and future promise. Loyola Los Angeles Law Review; 2008;41:1721-68.

14. Colgrove J, Bayer R, Bachynnski KE. Nowhere left to hide? The banishment of smoking from public spaces. New England Journal of Medicine 2011;364:2375-77.

15. Blanke DD, Cork K. Exploring the Limits of Smoking Regulation. William Mitchell Law Review 2007;34(4):1587-93.

Additional Resources for Module 1:

- Annas GJ. Bioterrorism, public health, and civil liberties. New England Journal of Medicine 2002;346:1337–42.
- Bayer R. Private acts, social consequences: Aids and the politics of public health. New Brunswick, NJ: Rutgers University Press, 1989.
- George A. Blinded by bioterrorism: Public health and liberty in the 21st century. Health Matrix *2*003**;**13:47.
- Gostin L. Public health law in an age of terrorism: Rethinking individual rights and common goods. Health Affairs 2002*;*21:79–93.
- Phillips MM, Ryan K, Raczynski JM. Public policy versus individual rights in childhood obesity interventions: Perspectives from the Arkansas experience with Act 1220 of 2003. Preventing Chronic Disease 2011;8(5):A96.
- Pope, T M. Balancing public health against individual liberty: The ethics of smoking regulations. University of Pittsburgh Law Review 2000;61(2):419-98.
- Resnik D. Trans fat bans and human freedom. American Journal of Bioethics 2010;10(3):27-32.
- Upshur RE. Principles for the justification of public health intervention. Canadian Journal of Public Health 2002;93:101–3.
- van Delden JJ, Ashcroft R, Dawson A, Marckmann G, Upshur R, Verweij MF. The ethics of mandatory vaccination against influenza for health care workers. Vaccine 2008;26(44):5562-66.

Module 2: Allocation of Limited Public Health Resources

Introduction to the Topic

Allocating resources is essentially an issue of fair distribution, which becomes more challenging the more limited the resources available for distribution. Scarcity forces one to prioritize values as a way to determine what programs will be curtailed or eliminated. Various allocation schemes represent different ways of prioritizing values. Facing program cuts, public health departments may be tempted to enter into partnerships that create conflicts of interest that could compromise their core values.

Case: Limited Resources and Public-Private Partnerships

Disclaimer: This case study is solely an educational exercise and does not necessarily reflect the position of Centers for Disease Control and Prevention on this issue.

Background

The public health system in the United States has long been underfunded. Analyses by the Institute of Medicine (IOM), the New York Academy of Medicine (NYAM), and the Centers for Disease Control and Prevention (CDC) have found that federal, state, and local health departments often are hampered by limited funds and consequently unable to carry out core functions.[1]

These already limited budgets continue to be cut. In January 2010, 53 percent of local health departments reported that their core funding had been cut from the previous year. Approximately 23,000 jobs - 15 percent of the local public health workforce - have been lost since January 2008.[1]

Budget shortfalls pose difficult decisions for local health departments about which programs will be discontinued. These decisions are often "tragic choices" in which programs that are valuable for the community's health must be sacrificed in order for other programs and services to survive.

In response to chronic underfunding and pressing health needs, public health agencies increasingly are looking to the private sector as a funding source, and in some instances public health organizations have developed partnerships with the private sector as a way to achieve important health goals. These public-private partnerships (PPP) have been promoted by the World Health Organization (WHO) and have played an instrumental role in addressing global health issues, such as access to drugs and vaccines in poor countries.[2,3] At the domestic level public-private partnerships

are increasingly used as an alternative way for local health departments to secure funds for valued programs and services that may otherwise be cut.

Case Description

You are the director of a local public health department facing a significant decrease in state funds for the coming financial year. The budget cuts threaten a major health promotion initiative developed in response to a recent study showing that rates of obesity are particularly high in your area. The planned initiative targets childhood obesity, and has received significant input and support from the local community. After budget cuts are implemented the cost of the initiative will exceed the department's available funds for health promotion activities.

A national company that makes products for the diet industry, including diet shakes and other meal supplements, has offered money to your department for health promotion activities in your community. Many of this company's products promote extreme diets and dieting techniques. The funds offered will enable the department to implement its planned initiative targeting childhood obesity.

In exchange for the funds the company wants their logo to be used on all educational materials distributed to the community.

Discussion Questions

1. Are there any legal considerations (e.g., laws or regulations mandating or prohibiting the activity) that must be taken into account?
2. Who are the major stakeholders in this case and what values or perspectives do they bring to the question about forming a partnership? What are the goals of the various stakeholders for forming this partnership and how might they come into conflict?
3. How do the impending budget cuts influence your reaction to the proposal made by the diet products company?
4. What are the potential risks and benefits for the health department of partnering with the diet products company?

5. Does the type of product the company produces make any difference to the decision to partner with the company?
6. What are the potential risks and benefits for the local community of a partnership between the diet products company and the health department?
7. What steps might you take to ameliorate public concerns about this partnership?
8. Would you recommend taking the money from this company?

Scenario Shift

Suppose the health department is considering a partnership with an organization or agency that receives sponsorship from the diet products company. In what ways would you consider this situation ethically similar or different from the case study?

Case References

1. Robert Wood Johnson Foundation. Investing in America's health: A state-by-state look at public health funding and key health facts, 2011. Available at: http://healthyamericans.org/report/83/
2. World Health Organization. Public-private partnerships for health. Available at: http://www.who.int/trade/glossary/story077/en/
3. Reich MR. Public-private partnerships for public health. Nature Medicine 2000;6(6):617-20.

Additional Resources for Module 2:

- Barnett DJ, Taylor HA, Hodge JG and Links JM. Resource allocation on the frontlines of public health preparedness and response: Report of a summit on legal and ethical Issues. Public Health Reports 2009;124:295-303.
- Bernheim R. Public health ethics in action: Flu vaccine and drug allocation strategies. Journal of Law, Medicine and Ethics 2005;33(4 Suppl):102-5.
- Buse K, Waxman A. Public-private health partnerships: a strategy for WHO. *Bulletin of WHO* 2001;79,748–54.
- Jennings B, Arras J. Ethical guidance for public health emergency preparedness and response: Highlighting ethics and values in a vital public health service. Prepared for the Ethics Subcommittee, Advisory Committee to the Director, Centers for Disease Control and Prevention, 2008.
- Michaelis AP. Priority-setting ethics in public health. Journal of Public Health Policy 2002;23:399-412.
- White DB, Katz MH, Luce JM, Lo B. Who should receive life support during a public health emergency? Using ethical principles to improve allocation decisions. Annals of Internal Medicine 2009;150:132-8.

Module 3: Protection of Underserved or Marginalized Populations

Introduction to the Topic

What special obligations does public health have to underserved and marginalized populations? Protecting the public's health is a core public health value. Because underserved and marginalized populations exhibit greater susceptibility to those factors that cause morbidity and mortality, protecting these populations requires greater care and vigilance. Well-intentioned efforts to help these populations often have unforeseen consequences that can result in greater harm to them.

Case: Enforcement of Lead Paint Standards in Marginalized Populations

Disclaimer: This case study is solely an educational exercise and does not necessarily reflect the position of Centers for Disease Control and Prevention on this issue.

Background

Lead poisoning remains one of the most prevalent environmental health conditions among U.S. children; approximately 500,000 children less than 6 years old have blood lead levels (BLLs) at or above the recently established reference value for lead of 5 µg/dL.[1] Elevated BLLs can lead to serious health consequences, including reduced IQ, hyperactivity and other behavioral problems, and rarely in the United States, death in the most serious cases.[2] Even though BLLs ≥ 10 µg/dL have fallen dramatically in the past fifteen years – from 8.6% of children tested in 1988-1991 to 1.4% of children in 1999-2004,[3] recent data has demonstrated adverse health effects at BLLs less than 10 µg/dl, including decreased IQ, risk for attention deficit disorder and behavioral problems.[4] Given that over 25% of U.S. children still live in housing with deteriorated lead-based paint, environmental lead exposure continues to be a serious health threat, with the burden of childhood lead exposure felt most keenly by the poor.[2, 5, 6]

While other sources of lead remain in the environment of children (e.g., water, imported products, and industrial and other emissions) and are of serious concern, the ingestion of lead paint chips and lead dust remains the greatest source of lead exposure for children.[7] Prior to 1978, lead-based paint was commonly used in home construction and maintenance. To remedy lead paint-related issues, property owners generally are required to hire a licensed contractor who typically completes interim control measures, such as repairing dry rot, re-painting or stabilizing paint, treating impact and friction surfaces, capping window sills, and removing and controlling dust. These measures

temporarily render dwellings safe, significantly reduce lead dust levels, and correlate with lower BLLs in children, but are not a permanent solution and require routine maintenance to remain effective.[8] Lead hazard remediation is the subject of several national rules and regulations, including, importantly, the 'HUD Lead Safe Housing Rule' (24 CFR 35).[9] Costs of lead hazard remediation can be substantial to homeowners.[10]

Case Description

Your community is a mid-sized city located in the northeastern United States. Like many other jurisdictions, the city is facing difficult financial times. More than 30% of homeowners owe more than their houses are worth and demands for social services are near all-time highs. The waiting time for public housing exceeds two years, and the proportion of families in the city without health insurance is above 15%.

Among minority groups, these issues are even more prevalent and profound. In several of the low-income African American and Latino neighborhoods in the city, high BLLs in children are common. The overall prevalence of children with BLLs≥ 10 µg/dL in the city has fallen from nine percent of children tested to less than one percent in the past decade. But among minority groups, the prevalence of BLLs ≥ 10µg/dL remains between four to five percent of children tested. Many in the African-American and Latino communities in the city attribute this to the generally poor quality and age of housing stock and a large number of rental properties.

One afternoon you receive a call from Dr. Jackie Smith, the head of your environmental health division. In your state, statute delegates many environmental health and safety issues to local health departments, including residential lead inspection and lead hazard remediation.

In the past several years, residential lead inspection in your city has largely been triggered when a child is diagnosed with a BLL ≥ 10 µg/dL. The home then undergoes extensive testing and, if lead is found, property owners have 30-60 days to address lead paint hazards in the house or face consequences as serious as fines or condemnation of the property. Dr. Smith notes what could be the start of a troubling trend in some of the poorer neighborhoods in the city. Dr. Smith says that a growing number of homeowners with a lead poisoned child have told her that they cannot afford to fix up their home and cannot qualify for state or federal support because the cost of lead hazard remediation outstrips the value of their home or it is in too poor a condition otherwise to qualify for grants. In addition, grants to homeowners have requirements that the owners often cannot meet, including being current on property tax and having homeowner's insurance. The state law that requires lead hazard remediation in these homes also created a fund to assist homeowners like these who "fall through the cracks," but no state funds have been appropriated.

Dr. Smith fears that many of these families will be forced into homelessness or have their children put into protective services if their homes are placarded and condemned. Dr. Smith has asked you, the local health director, to provide input on under what circumstances homeowners should be given extensions beyond the 30-60 day time frame to complete lead hazard remediation measures.

Scenario Shift

A coalition of community leaders, including leaders from the faith-based community request a meeting with your local health department to advocate for more extensions to lead hazard control orders. They argue that the current policies are adding to the community's homelessness problem and that this new influx of homeless persons is impacting their programs. What impact does this have on your thinking about the case?

Discussion Questions

1. Are there any legal considerations (e.g., laws or regulations mandating or prohibiting activity) that must be taken into account?
2. Who are the main stakeholders in this case, and what are their primary interests?
3. What obligation does the local health department have to protect families with a lead poisoned child who own and live in their own homes from potentially losing their homes due to lead hazard remediation regulations?
4. What are some of the implications for building trust between public health officials and underserved or marginalized populations if the local health department allows or does not allow more time to complete lead hazard remediation measures? What are the implications for the health department's ability to work with the child's family to remediate the lead hazards if the health department reports the family to child protective services?
5. What are the ethical implications of allowing children to continue to live in a house with lead exposures if an extension is granted for completion of lead hazard remediation measures? Would your decision change if the children in the home were found to have a blood lead level that was increasing?
6. What should be the criteria for granting an extension?

Case References

1. Centers for Disease Control and Prevention. Unpublished data, 2012.
2. Department of Health and Human Services. National Toxicology Program Monograph on Health Effects of Low Level Lead, 2012. Available at: http://ntp.niehs.nih.gov/go/36443.
3. Jones R, Homa D, Meyer P, et al. Trends in blood lead levels and blood lead testing among U. S. children aged 1 to 5 years: 1998-2004. Pediatrics 2009;123:e376-e385.
4. Canfield RL, Henderson CR Jr, Cory-Slechta DA, et al. Intellectual impairment in children with blood lead concentrations below 10 μg per deciliter. New England Journal of Medicine 2003;348:1517–26.
5. Committee on Environmental Health. Lead exposure in children: Prevention, detection, and management. Pediatrics. 2005;116(4):1036-1046.
6. Evans GW. The environment of childhood poverty. American Psychologist 2004;59:77-92.
7. Levin R, Brown MJ, Kashtock ME, et al. U.S. children's lead exposures, 2008: Implications for prevention. Environmental Health Perspectives 2008;116:1285-93.
8. Clark S, Galke W, Succop P, et al. Effects of HUD-supported lead hazard control interventions in housing on children's blood lead. Environmental Research 2011;111:301-11.
9. Department of Housing and Urban Development. Interpretive guidance on HUD's lead safe housing rule: The HUD regulation on controlling lead-based paint hazards in housing receiving federal assistance and federally owned housing being sold (24 CFR 35), 2004. Available at: http://portal.hud.gov/hudportal/documents/huddoc?id=DOC_25476.pdf
10. Brown MJ. Costs and benefits of enforcing housing policies to prevent childhood lead poisoning. Medical Decision Making 2002;22:482-92.

Additional Resources for Module 3 –

- Bayer R. Stigma and the ethics of public health: Not can we but should we. Social Science & Medicine, 2008;67(3):463-72.
- Centers for Disease Control and Prevention. Identifying vulnerable older adults and legal options for increasing their protection during all-hazards emergencies: A cross-sector guide for states and communities. Atlanta, GA: U.S. Department of Health and Human Services, 2012.
- Eisenman DP, Cordasco KM, Asch S, Golden JF, Glik D. Disaster planning and risk communication with vulnerable communities: Lessons from Hurricane Katrina. American Journal of Public Health 2007;97:S109–S115.
- Hartman C, Squires GD. There is no such thing as a natural disaster: Race, class, and Hurricane Katrina. New York, NY: Routledge, 2006.
- Hoffman S. Preparing for disaster: Protecting the most vulnerable in emergencies. UC Davis Law Review 2009;42:1491.
- Macklin R. Bioethics, vulnerability, and protection. Bioethics 2003;17:472–86.
- Ruger JP. Health and social justice. Lancet 2004;364:1075–80.
- Wingate MS, Perry EC, Campbell PH, David P, Weist EM. Identifying and protecting vulnerable populations in public health emergencies: Addressing gaps in education and training. Public Health Reports 2007;122(3):422–26.

Module 4: Protection of Individual Privacy and Data Confidentiality

Introduction to the Topic

Data collection is a fundamental activity of public health practice. Public health has a duty both to act on evidence it collects and to protect data confidentiality. These duties, which sometimes come into tension, play out against a backdrop of information technology advances and complicated privacy laws. The ethical challenge in this area is often to find ways to use data innovatively to address disease burden, while ensuring privacy and protecting confidentiality.

Case: New Uses of Public Health Surveillance Data to Improve HIV Care and Reduce Transmission

Disclaimer: This case study is solely an educational exercise and does not necessarily reflect the position of Centers for Disease Control and Prevention on this issue.

Background

The Centers for Disease Control and Prevention (CDC) estimates 1.2 million people in the United States are living with HIV infection and one in five (20%) of those people are unaware of their infection. Each year, about 50,000 people get infected with HIV in the United States. Getting people tested, aware of their HIV infection, and into medical care is critical for stopping the spread of HIV. Medicines (antiretroviral therapy or ART) can lower the level of virus in the body, helping people live longer healthier lives, and lower the chances of passing HIV on to others. However, CDC estimates that only 28% of people living with HIV infection are getting the care they need to manage the disease and keep the virus under control.[1-3]

The White House Office of National AIDS Policy (ONAP), a component of the Domestic Policy Council, is leading the effort to develop a national strategy to address the epidemic. To develop the strategy, ONAP engaged many experts from the public and private sectors, as well as thousands of Americans. These efforts led to the development of the National HIV/AIDS Strategy (NHAS) for the United States.[4]

The three primary NHAS goals are: 1) reducing new HIV infections, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. One of the recommendations is to establish a seamless system to immediately link people

to continuous and coordinated quality care when they learn they are infected with HIV. Monitoring linkage, retention, and success of care with HIV surveillance data is critical to public health efforts to prevent HIV in the United States and to monitor progress toward meeting the NHAS goals. In particular, laboratory test results, such as CD4 t-lymphocyte counts and percentages and viral load, reported to HIV surveillance can be used as indicators of entry and maintenance of care and the extent of viral suppression. Currently 33 states, Washington D.C., Puerto Rico and Guam require reporting of all CD4 and viral load test results to health departments and have the means to identify those needing but not connected to care.[5]

Traditionally, surveillance data have been used to monitor incidence and prevalence of disease, describe demographic and risk characteristics of affected populations, and guide program planning and evaluation. For some conditions, such as HIV and other sexually transmitted diseases (STDs), health departments use surveillance data to facilitate provision of partner services.[6] However, the use of surveillance data for case management and referral to care, particularly to private health care providers outside of the public health system, has not been widely implemented. Innovative public health activities have been proposed, including the expanded use of laboratory indicators from HIV surveillance data, to follow-up with individuals outside of the public health system, either directly or through their health care provider.[7]

Case Description

The State Health Department (SHD) in your state is considering various ways to implement the national strategy at the local level. The SHD has contacted you, the local health department (LHD) Director, for your input on the following proposed options for implementation:

1. Provider referral: LHD staff will monitor CD4 cell counts and viral load test results reported through routine HIV case surveillance (e.g., notifiable disease case reporting) over time. For persons with low CD4 counts or high viral loads, LHD staff will inform the individual's health care provider, if known to the LHD, so that the provider can initiate follow up with the patient.

2. Individual referral: LHD staff will monitor CD4 cell counts and viral load test results reported through routine HIV case surveillance (e.g. notifiable disease case reporting) over time. For persons with low CD4 counts or high viral loads, LHD staff will contact the individuals directly to inform them of the results and recommend/ offer treatment options.

3. Electronic Medical Record (EMR) referral: Your LHD will have the opportunity to be part of a pilot linkage project between an EMR system (e.g., in a managed care organization or a private health care system) and the SHD. If a patient needs follow up related to HIV, the EMR system will send an alert to the provider EMR, offering the provider the opportunity to discuss needed follow up with the patient.

Discussion Questions

1. Are there any legal considerations (e.g., laws or regulations mandating or prohibiting the activity) that must be taken into account?
2. Who are the stakeholders in this case and what values and perspectives do they bring to the issue about the implementation of the national strategy?
3. What are some of the arguments in favor or against the expanded use of surveillance data to improve HIV care and reduce transmission?
4. How does your understanding of the scientific findings regarding the effectiveness of antiretroviral treatment factor into your decision?
5. What type of engagement might be necessary with providers, infected individuals and their communities to implement these types of follow-up activities?
6. How should you consider the obligation to use surveillance data in making your decision? What might be the long term impact of your decision on public trust?
7. Are there financial, personnel, training, and operational challenges associated with notifiable disease surveillance activities in local health departments that should be considered?
8. What decision would you make in this case?

Scenario Shift

1. Laboratory indicators from HIV surveillance data indicate that a large percentage of persons in a demographic or risk group (e.g., low income, African American, Hispanic or young men who have sex with men) in one part of the county are not receiving needed care. The SHD is considering implementation in this targeted area for case management and referral to care. Does this change your thinking? Why or why not?

2. Instead of using HIV surveillance data, your LHD is considering similar implementation options using body mass index (BMI) surveillance data to address the high levels of obesity in the county. Does this change your thinking? Why or why not?

Case References

1. Centers for Disease Control and Prevention. Vital signs: HIV prevention through care and treatment – United States. Morbidity and Mortality Weekly Report 2011:60(47);1618-23.

2. Prejean J, Song R, Hernandez A, et al. Estimated HIV incidence in the United States, 2006–2009. PLoS One 2011;6:e17502.

3. Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. New England Journal of Medicine 2011;365:493–505.

4. Office of National AIDS Policy. National HIV/AIDS strategy for the United States, 2010. Available at: http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf

5. Centers for Disease Control and Prevention. Status of CD4 and viral load reporting by HIV surveillance reporting areas, as of June 7, 2012—50 states, funded cities, District of Columbia, and U.S. dependent areas. Unpublished report, June 2012.

6. Centers for Disease Control and Prevention. Recommendations for partner services programs for HIV infection, syphilis, gonorrhea, and chlamydial infection. Morbidity and Mortality Weekly Report 2008;57(RR-9):1-63.

7. Herwehe J, Wilbright W, Abrams A, et al. Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS. Journal of the American Medical Information Association 2012; 19(3):448-52.

Additional Resources Related to this Case

1. Centers for Disease Control and Prevention. Data security and confidentiality guidelines for HIV, viral hepatitis, sexually transmitted disease, and tuberculosis programs: Standards to facilitate sharing and use of surveillance data for public health action. Atlanta (GA): U.S. Department of Health and Human Services, 2011. Available at: http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf

2. Fairchild AL, Alkon A. Back to the future? Diabetes, HIV, and the boundaries of public health. Journal of Health Politics, Policy, and Law 2007;32(4):561-593.

3. Fairchild AL, Bayer R. HIV surveillance, public health, and clinical medicine: Will the walls come tumbling down? New England Journal of Medicine 2011;365:685-687.

4. Maiorana A, Steward WT, Koester K, et al. Trust, confidentiality, and the acceptability of sharing HIV-related patient data: Lessons learned from a mixed methods study about Health Information Exchanges. Implementation Science 2012;7:34.

Additional Resources for Module 4:

- Bayer R, Fairchild AL. The limits of privacy: Surveillance and the control of disease. Health Care Analysis 2002;10:19–35.
- Fairchild A, Bayer R. Ethics and the conduct of public health surveillance. Science 2004;303(5658):631-32.
- Fairchild AL, Gable L, Gostin LO, Bayer R, Sweeney P, Janssen RS. Public goods, private data: HIV and the history, ethics, and uses of identifiable public health information. Public Health Reports 2007;122(Suppl 1):7–15.
- Gostin L. Health care information and the protection of personal privacy: Ethical and legal considerations. Annals of Internal Medicine 1997;127(Supplement 2):683-90.
- Hodge JG. Health information privacy and public health. The Journal of Law, Medicine and Ethics 2003;31:663–71.
- Lee LM, Gostin LO. Ethical collection, storage, and use of public health data: A proposal for a national privacy protection. Journal of the American Medical Association 2009;302:82–4.
- Lurie N, Fremont A. Building bridges between medical care and public health. Journal of the American Medical Association 2009;302(1):84-6.
- Wartenberg D, Thompson WD. Privacy versus public health: The impact of current confidentiality rules. American Journal of Public Health 2010;100(3):407-12.

Module 5: Community Engagement and Information Sharing

Introduction to the Topic

The obligation to engage with the community arises out of public health's population focus and is the public health version of the informed consent procedure. Engaging with the community involves information sharing but also gathering input from the community. Providing input and having the sense that it is being given a fair hearing is crucial for the community to develop a sense of shared responsibility and to support programs. Input should not end with the implementation of a program, but should be ongoing. In the case of emergency preparation and response, it is essential to engage the community in advance and establish strong relationships. Democratic process depends on an informed community, while any relevant data obtained by public health should be made available to the public. When programs contain potential risks and benefits, the public should be informed and in some way give its consent to their implementation. Transparency and clear communication expedite this democratic process, help build and maintain trust, and facilitate accountability.

Case: Childhood Obesity Educational Campaign

Disclaimer: This case study is solely an educational exercise and does not necessarily reflect the position of Centers for Disease Control and Prevention on this issue.

Background

Childhood obesity is a serious problem in the United States. Nearly one-third (31.7%) of children in this country are overweight or obese. Childhood obesity rates across the nation have more than tripled since 1980, increasing from 5% to 17%.[1]

Obesity poses numerous challenges for childhood health. Excess weight impacts children's mental and physical wellbeing and is associated with numerous conditions: breathing conditions such as asthma and sleep apnea, joint problems and musculoskeletal discomfort, risk factors for heart disease including high cholesterol and high blood pressure, and type 2 diabetes.[2] In addition, obese children are more likely than normal weight children to become obese adults, leading to continued risk factors and disease.

Awareness of the magnitude and severity of childhood obesity has been increasing in recent years. By 2010, 80% of Americans recognized that childhood obesity is a significant and growing

challenge.[3] However, many parents still have difficulty determining whether or not their child is at a healthy weight. While nearly one-third of children and teens are overweight or obese, over 80% of parents think that their child is at a healthy weight.[3] This problem is particularly pronounced for overweight parents. They are both more likely to have an at-risk or overweight child, and less likely to accurately assess their child's weight--which limits their ability to take action to promote their child's health.[4] Cultural influences also may affect parents' perceptions of children's weight, reflecting differences in values or beliefs about body size among various ethnic groups.[4]

Health officials are particularly concerned that parents may lack the knowledge and skills necessary to help their children maintain a healthy weight. This may indicate a broader issue of health literacy in the population, described by the Institute of Medicine as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[5-6] Limited health literacy has broad implications for health. It increases barriers to managing chronic illnesses, accessing care, and receiving preventative services.[7] Furthermore, while limited health literacy affects Americans of all backgrounds, it disproportionately affects vulnerable populations, most notably, ethnic minorities, some of those disproportionately affected by childhood obesity, and those with lower socioeconomic status. To advance health literacy, the Institute of Medicine recommends collaboration with the population of interest through the four Es: Engage, Educate, Empower, and Enable. Collaborations to build the skills of health literacy can support population health across a wide range of conditions.

Case Description

State health officials in State X have become particularly concerned about the impact of childhood obesity on their communities. The state's adult obesity rates are average with respect to the rest of the country. However, the level of childhood obesity in the state far exceeds the national average, suggesting not only problems for the health of today's children and teens, but also the future health of the broader population. One in five children in the state are obese, ranking it in the top five states for childhood obesity. Furthermore, obesity disproportionately affects minority populations in the state. While whites have an obesity rate of just over 25%, rates for Latinos and African-Americans are substantially higher, at 31% and 40%, respectively.

The state health department has been asked to provide input on a health education campaign being developed by an alliance of health advocates. The campaign has two goals: first, to use social marketing to change social norms about healthy weight, the social desirability of physical activity,

and making healthy food choices; and second, to improve health literacy, particularly in minority and lower socioeconomic populations.

The alliance is concerned that in today's crowded media market, other media sources will overshadow health promotion messages. The alliance wants to ensure that the childhood obesity campaign not only captures the attention of the public, but also motivates individuals to change behavior. To do this, the alliance is considering launching a public awareness campaign focused around attention-grabbing advertisements that put a face to the health hazards associated with childhood obesity.

Advertisements will depict overweight and obese children from the community engaging in activities linked to obesity, such as consumption of less healthy foods (such as soda or other sugar sweetened beverages) and sedentary activities such as playing videogames and watching TV. A billboard, for example, might feature an overweight, sedentary child playing videogames, surrounded by "junk foods", with the tagline: "Childhood obesity—a game no one wins." An internet or TV video clip might offer testimonials from children about the ways obesity keeps them from enjoying life, such as being picked on by their peers or playing in games at recess or on sports teams.

The head of the alliance has contacted you, the local health director of the state's largest city, for your thoughts about whether to conduct the health education campaign.

Discussion Questions

1. Are there any legal considerations (e.g., laws or regulations mandating or prohibiting the activity) that must be taken into account?
2. Who are the stakeholders that should be considered in deciding whether this health education campaign should be put into place? What are the values and perspectives of each of these stakeholders in this decision?
3. As a local health director, what are some of the advantages and disadvantages of the proposed social marketing strategy that you would consider in advising the alliance?
4. Should "shock messaging" be used to draw attention to health issues? What might be some of the unintended consequences of these messages?
5. What level of evidence of potential impact is necessary to justify the campaign?

6. What would be your recommendation to the alliance?

Scenario Shift

How might the following policy provisions change your view?

- Parallel advertisements will also be run which depict healthy-weight children engaging in health-promoting behaviors, such as being physically active and eating fruits and vegetables.
- The health department will launch a new program to promote healthy eating and physical activity within the community (increased funding/access to safe places for play, cooking demonstrations and discounted or free fruits and vegetables, etc.).

Case References

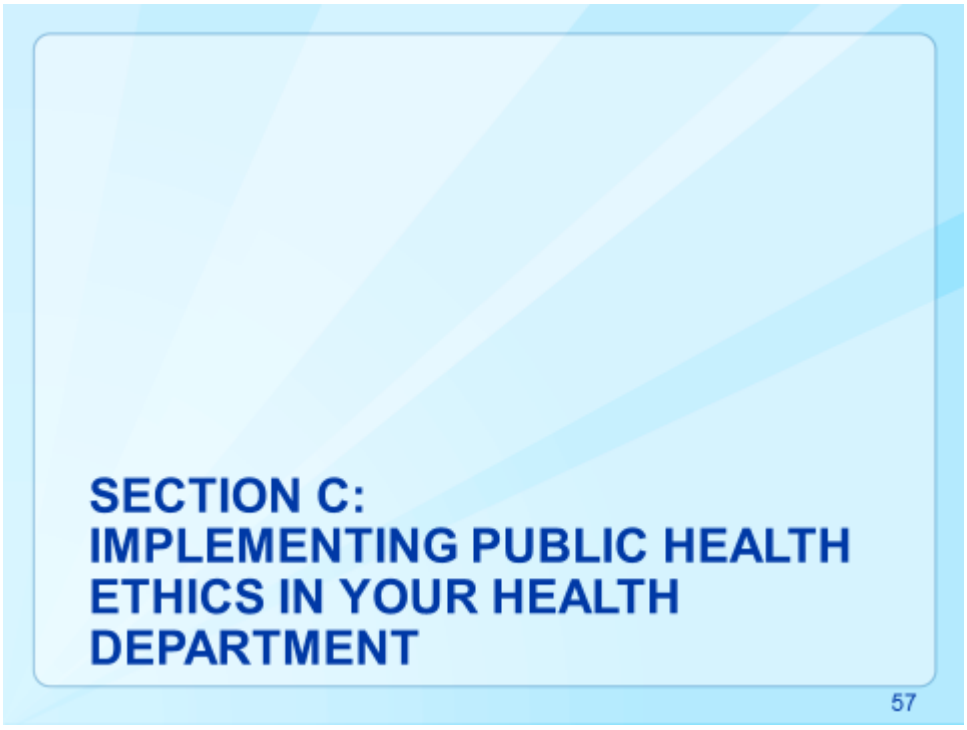
1. Centers for Disease Control and Prevention. National Center for Health Statistics (NCHS). National Health and Nutrition Examination Survey Data. Hyattsville, MD: U.S. Department of Health and Human Services,2007.
2. Centers for Disease Control and Prevention. Basics about childhood obesity. Available at: http://www.cdc.gov/obesity/childhood/basics.html
3. Robert Wood Johnson Foundation's Trust for America's Health. F as in fat: How obesity threatens America's future, 2010. Available at: http://healthyamericans.org/reports/obesity2010/
4. Doolen J, Alpert PT, Miller SK. Parental disconnect between perceived and actual weight status of children: A metasynthesis of the current research. Journal of the American Academy of Nurse Practitioners 2009;21(3):160-6.
5. Institute of Medicine. Health literacy: A prescription to end confusion. Washington, DC : The National Academy Press , 2004. Available at: http://www.iom.edu/Reports/2004/Health-Literacy-A-Prescription-to-End-Confusion.aspx
6. National Center for Education Statistics. The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy. Washington DC: US Department of Education, 2006. Available at: http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483

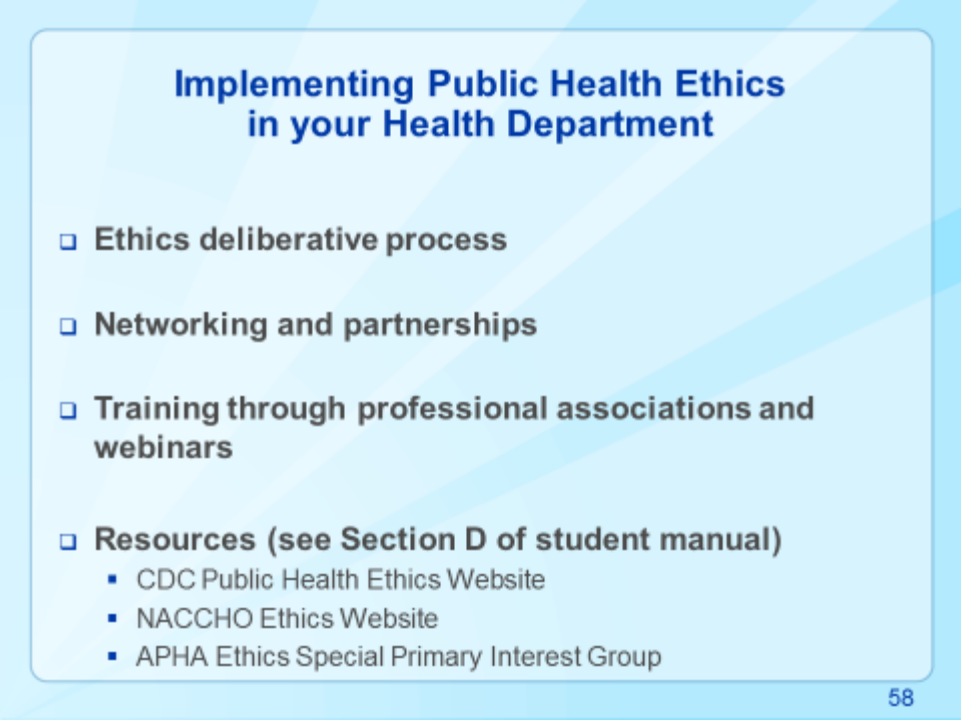
7. Schillinger D, Keller D. The other side of the coin: Attributes of a health literate healthcare organization. Commissioned Paper for the Institute of Medicine Roundtable on Health Literacy. 2011. Available at: http://www.iom.edu/Activities/PublicHealth/HealthLiteracy.aspx

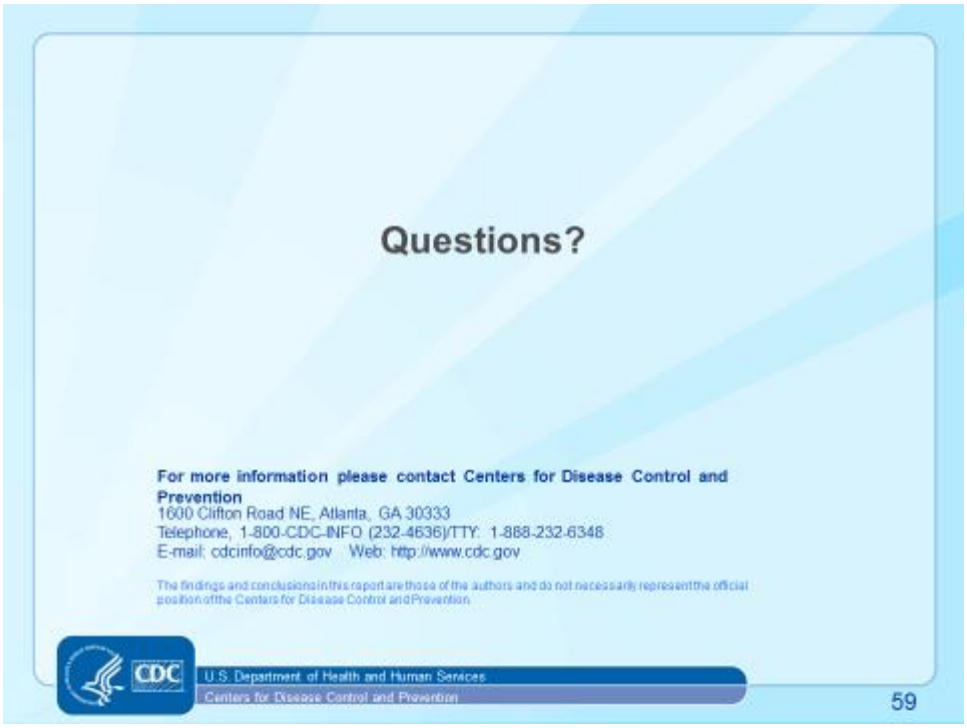
Additional Resources for Module 5:

- Blendon RJ, Koonin LM, Benson JM, et al. Public response to community mitigation measures for pandemic influenza. Emerging Infectious Diseases, 2008;14(5)778-86.
- Bruni RA, Laupacis A, Martin DK. Medicine and society: Public engagement in setting priorities in health care. Canadian Medical Association Journal 2008;179:15-8.
- Dickert N, Sugarman J. Ethical goals of community consultation in research. American Journal of Public Health 2005;95:1123-27.
- French PE. Enhancing the legitimacy of local government pandemic influenza planning through transparency and public engagement. Public Administration Review 2011;71(2):253-64.
- Gazmararian JA, Curran JW, Parker RM, Bernhardt, Debuono BA. Public health literacy in America: An ethical imperative. American Journal of Preventive Medicine 2005;28:317–22.
- Hanks CA. Community empowerment: A partnership approach to public health program implementation. Policy, Politics, & Nursing Practice 2006;7(4):297-306.
- Laverack G. Improving health outcomes through community empowerment: A review of the literature. Journal of Health, Population and Nutrition 2006;24(1):113-20.
- Roberts N. Public deliberation in an age of direct citizen participation. The American Review of Public Administration 2004;34;315.
- Tindana PO, Singh JA, Tracy CS, Upshur REG, Daar AS, et al. Grand Challenges in global health: Community engagement in research in developing countries. PLoS Medicine 2007;4(9):e273.

Section C: Implementing Public Health Ethics in Your Health Department




Implementing Public Health Ethics in your Health Department
Ethics deliberative process
Networking and partnerships
Training through professional associations and webinars
Resources (see Section D of student manual)
CDC Public Health Ethics Website
NACCHO Ethics Website
APHA Ethics Special Primary Interest Group
58


Questions?
For more information please contact Centers for Disease Control and Prevention
1600 Clifton Road NE, Atlanta, GA 30333
Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: http://www.cdc.gov
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention
CDC
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
59

Section D: Student Handouts and Selected Additional Resources on Public Health Ethics

List of Contents

Student Handouts

Ethical Analysis Framework[1]

1. Analyze the Ethical Issues in the Situation

   - What are the public health *risks and harms of concern*?
   - What are the public health *goals*?
   - Who are the *stakeholders*? 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?

2. Evaluate the Ethical Dimensions of the Alternate Courses of Public Health Action

   - *Utility:* Does a particular public health action produce a balance of benefits over harms?
   - *Justice:* Are the benefits and burdens distributed fairly (distributive justice)? Do legitimate representatives of affected groups have the opportunity to participate in making decisions (procedural justice)?
   - *Respect for individual interests and social value:* Does the public health action respect individual choices and interests (autonomy, liberty, privacy)?
   - *Respect for legitimate public institutions:* Does the public health action respect professional and civic roles and values, such as transparency, honesty, trustworthiness, consensus-building, promise-keeping, protection of confidentiality, and protection of vulnerable individuals and communities from undue stigmatization?

[1] Gaare-Bernheim R, Neiburg P, Bonnie R. Ethics and the practice of public health. In Goodman R, et al (eds). **Law in Public Health Practice**. Oxford University Press, 2002, 2007

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 overriding the conflicting ethical claims necessary 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, on the basis of principles in the Code of Ethics or general public health principles, that citizens–in particular, those most affected–could find acceptable in principle?

Principles of the Ethical Practice of Public Health

1. Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.

2. Public health should achieve community health in a way that respects the rights of individuals in the community.

3. Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.

4. Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.

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

6. Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.

7. Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.

8. Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.

9. Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.

10. Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.

11. Public health institutions should ensure the professional competence of their employees.

12. Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Sample Case Ethical Analysis (to be distributed by the facilitator)

Selected Additional Resources on Public Health Ethics

Journal Articles:

- Bayer R, Fairchild AL. The genesis of public health ethics. Bioethics 2004;18(6)473-92.
- Callahan D, Jennings, B. Ethics and public health: Forging a strong relationship. American Journal of Public Health 2002;92(2):169-76.
- Childress JF, Faden RR, Gaare RD, et al. Public health ethics: Mapping the terrain. Journal of Law, Medicine & Ethics 2002;30:170-8.
- Howard DE, Lothen-Kline C, Boekeloo BO. Using the case-study methodology to teach ethics to public health students. *Health Promotion Practice* 2004;5:151-9.
- Kass NE. An ethics framework for public health. American Journal of Public Health 2001;91:1776-82.
- Lee LM. Public health ethics theory: Review and path to convergence. Journal of Law, Medicine & Ethics 2012;40:85-98.
- Marckmann G, Schmidt H, Sofaer N, Strech D. Putting public health ethics into practice: A systematic framework. *Frontiers in Public Health* 2015; 3:23. doi:10.3389/fpubh.2015.00023.
- Thomas JC, Sage M, Dillenberg J, Guillory VJ. A code of ethics for public health. American Journal of Public Health 2002;92(7):1057-9.

Books:

- Balint J, Philpott S, Baker R, Strosberg M (Eds). *Advances in bioethics, volume 9: Ethics and epidemics*. Amesterdam, NL:Elsevier/JAI, 2006.
- Barrett D, Ortmann L, Dawson A, Saenz C, Reis A, Bolan G (Eds). *Public Health Ethics: Cases Spanning the Globe: A Casebook*. Springer Press, 2016.
- Bayer R, Gostin LO, Jennings B, Steinbock B (Eds). Public health ethics: Theory, policy, and practice. New York: Oxford University Press, 2007.
- Boylan M (Ed). *Public health policy and ethics*. Dordrecht, NL: Kluwer Academic Publishers, 2004.
- Coughlin S. Case studies in public health ethics (second edition). Washington DC: American Public Health Association, 2009.
- Dawson A, Verweij M (Eds). Ethics, prevention, and public health. Oxford, UK: Oxford University Press, 2007.
- Holland S. Public health ethics. Cambridge, UK: Polity Press, 2007.
- Jennings B. Arras JD, Barrett DH, Ellis BA (Eds). *Emergency Ethics: Public Health Preparedness and Response*. Oxford University Press, 2016.

Other:

- American Public Health Association. Website for Ethics Section. - https://www.apha.org/apha-communities/member-sections/ethics.
- Centers for Disease Control and Prevention. Website for Public Health Ethics Unit, Office of Scientific Integrity, Office of the Associate Director for Science - http://www.cdc.gov/od/science/integrity/phethics/.
- Jennings B, Kahn J, Mastroianni A, Parker L (Eds). Ethics and public health model curriculum, 2004 - https://repository.library.georgetown.edu/handle/10822/556779.
- National Association of County and city Health Officials. Website for Information on Public Health Ethics) - http://www.naccho.org/programs/public-health-infrastructure/ethics.
- North Carolina Institute for Public Health (on line training modules on public health ethics) - http://nciph.sph.unc.edu/tws/training_list/?mode=view_kw_detail&keyword_id=2641.
- Public Health Leadership Society. Principles of the ethical practice of public health, 2002 - https://www.apha.org/~/media/files/pdf/membergroups/ethics_brochure.ashx.