

Ethical Guidance for Public Health Emergency Preparedness and Response: Highlighting
Ethics and Values in a Vital Public Health Service

Prepared by

Bruce Jennings, MA
Center for Humans and Nature, New York, NY and
Yale University, New Haven, CT

and

John Arras, PhD
University of Virginia, Charlottesville, VA

For the Ethics Subcommittee, Advisory Committee to the Director,
Centers for Disease Control and Prevention

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Disclaimer: This document represents the recommendations of the Advisory Committee to the Director, Centers for Disease Control and Prevention and does not necessarily represent Centers for Disease Control and Prevention views or policy. The document was approved by the Ethics Subcommittee on October 9, 2008* and by the Advisory Committee to the Director on October 30, 2008.

* Members of the Ethics Subcommittee at the time that the document was approved include John Arras, PhD; Ronald Bayer, PhD, Columbia University; Vivian Berryhill, National Coalition of Pastors' Spouses; Vanessa Northington Gamble, MD, PhD, George Washington University; Robert Hood, PhD, Florida Department of Health; Thomas Hooyman PhD, Regis University; Bruce Jennings, MA, Center for Humans and Nature; Nancy Kass, ScD, Johns Hopkins University; Kathy Kinlaw, MDiv, Emory University; Bernard Lo, MD, University of California, San Francisco; and Leslie Wolf, Georgia State University.

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This white paper grows out of the work of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC). This subcommittee is comprised of experts in ethics and related fields drawn from outside CDC who work closely with CDC officials responsible for public health ethics consultation within CDC, and with CDC experts from particular National Centers who advise on specific issue or content areas. The Ethics Subcommittee is charged with providing advice and ethics opinions as requested to the Director, the Director's Advisory Committee, and other CDC officials. It also undertakes study of issues of significant concern in public health ethics so as to produce publications and other educational materials useful to CDC staff and to the field of public health as a whole.

This white paper is the second publication written under the auspices of the Ethics Subcommittee. The first was "Ethical Guidelines in Pandemic Influenza," written by Kathy Kinlaw and Robert Levine. In 2006 the subcommittee determined that the entire field of all hazard emergency response and public health emergency preparedness and response would benefit from the development of a framework of ethical goals and concepts. It was decided that not only the role of CDC in such activities should be addressed, but also the role of public health professionals and officials at all levels. It was also determined that the focus of this white paper should not only be on specific decisions made by individuals developing and implementing emergency plans, but also on the ethical nature and mission of public health emergency planning itself.

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[‡] Titles and organizational names reflect those in place while this document was being developed. In 2009, CDC underwent reorganization and some of the titles and organizational names referred to in this document no longer apply.

Wooster. Moreover, in the course of our research we were privileged to talk with many people both within CDC and those working at the state and local levels in the trenches of emergency preparedness. Their perspective kept us grounded when the ethical analysis tended to become overly abstract. We are grateful to them for giving us their time and the benefit of their experience and expertise. These people included Nelson Arboleda, Steven Boedigheimer, Ralph Bryan, Bruce Burney, Christine Casey, James Cheek, Nathaniel Cobb, Roberta Erlwein, David Kennedy, Richard Klomp, Valerie Kokor, Brock Lamont, Lisa M. Lee, Ken Martinez, Elizabeth O'Mara, Bobbie Person, Harald Pietz, Mark White, and the members of the CDC Public Health Ethics Committee.

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Executive Summary

Introduction

Severe acute respiratory syndrome (SARS), the events of September 11, 2001, the post 9/11 anthrax attacks, Hurricane Katrina, avian influenza, global climate change—a mere listing such as this serves as a stark reminder of society’s vulnerability to a public health disaster and the need for emergency preparedness planning. Today at the federal level and in virtually every state and county, concerted attention is being paid to public health preparedness. Priority setting, rationing, and triage of health services are being discussed; protective measures that may override individual liberty and property rights are being contemplated.

All these events bring to the forefront the complex ethical and social values that are involved in the planning, response, and follow-up phases of public health emergencies. The purpose of this white paper is to provide an overview and a conceptual framework to promote further study and discussion of the ethical dimensions of public health emergency preparedness planning and response (PHEPR), both within the public health community and in society at large. The report was developed in conjunction with the Ethics Subcommittee of the Advisory Committee to the Director, CDC.

In discussions of emergency preparedness, attention is often focused exclusively on moral dilemmas and “tragic choices” (i.e., public choices involving life and death situations that pit irreconcilable values against one another) that arise during the response phase when time is scarce, decisions are pressing, essential resources must be rationed, and individual interests may be subordinated to the public interest. Reflection on ethics will not provide clear-cut rules or directives in such situations. This does not mean that ordinary morality

becomes irrelevant during emergency responses; it does mean that acting ethically and making ethically justified decisions will depend largely on specific and concrete circumstances that cannot be fully specified in advance. The best contribution of ethics is to inform advance planning and organization of emergency response so as to minimize the number of tragic choices that must be made. Therefore, while we acknowledge and attempt to shed some light on the ethical dilemmas that arise during the response phase of PHEPR, the main focus of this white paper is on the ethical orientation that should guide the planning and recovery phases.

What is Public Health Emergency Preparedness?

In the aftermath of the terrorist attacks of September 11, 2001, and the deliberate attempt to infect people with anthrax, the focus of public health emergency planning was on the threat of bioterrorism. After Hurricane Katrina and the flooding of New Orleans and other areas of the Gulf Coast, and amid concerns about pandemic influenza and other infectious diseases, the focus of public health preparedness has been broadened to an all-hazards orientation. This more comprehensive approach is now recognized as central to the public health mission. Yet at the same time, because a well-funded and thoughtfully designed public health infrastructure is necessary if society is to meet the wide array of currently unforeseeable threats and future disasters, PHEPR vitally depends upon non-emergency public health policies and programs.

In a similar vein, we believe that the ethical framework for public health provides the appropriate framework for PHEPR as well. The moral stakes are high in preparedness activities, but they are also high in ordinary public health practice. Different types of

hazards—epidemic, weather related, environmental, radiologic—present special circumstances for ethical decision making and reflection, but they do not require tailor-made ethical principles or goals.

A public health emergency exists when a situation arises whose health consequences have the potential to overwhelm routine community capabilities to address them. Public health emergency preparedness and response may be defined as the capability of the public health and health-care systems, communities, and individuals, to protect against, quickly respond to, and recover from health emergencies, particularly those whose scale, timing, or unpredictability threaten to overwhelm routine capabilities.

Public health preparedness activities include regulating environmental conditions and food and water safety to minimize disease threats, planning for emergency medical and public health response capabilities, detecting a disease outbreak, conducting epidemiologic investigations to ascertain the nature of a disease outbreak or epidemic, performing laboratory analyses to support surveillance and epidemiology, pursuing public health interventions to limit the spread of disease, ensuring the provision of emergency medical treatment and prophylaxis, remediating environmental conditions, and preventing secondary public health emergencies following a disaster.

Public health preparedness planning is a multidisciplinary endeavor, which draws on the traditional bodies of expertise within public health and on the experience and skills of the social and behavioral sciences, risk communication, architecture and planning, environmental science, engineering, and public safety.

Public health planners must work together with those responsible for disaster management who come from other fields and must negotiate a complicated web of

jurisdictional, bureaucratic, and organizational interests and boundaries. They must also be cognizant of the legal implications of their activities and must work effectively with policymakers, elected officials, the business community, civic leaders, and the press. As they undertake these myriad tasks, they must always conduct themselves in such a way as to maintain the confidence and trust of the public.

Ethical Goals of Public Health Emergency Preparedness and Response

To provide a framework of ethical and value concepts for PHEPR, we have formulated seven ethical goals that should orient both the content of preparedness plans and the process by which they are devised, updated, and implemented in an emergency situation and its aftermath.

- **Harm reduction and benefit promotion.** PHEPR activities should protect public safety, health, and well-being. They should minimize the extent of death, injury, disease, disability, and suffering during and after an emergency.
- **Equal liberty and human rights.** PHEPR activities should be designed so as to respect the equal liberty, autonomy and dignity of all persons.
- **Distributive justice.** PHEPR activities should be conducted so as to ensure that the benefits and burdens imposed on the population by emergency response measures and mitigations are shared equitably and fairly.
- **Public accountability and transparency.** PHEPR activities should be based on and incorporate decision-making processes that are inclusive, transparent and sustain public trust.

- **Community resiliency and empowerment.** A principal goal of PHEPR should be to develop resilient, as well as safe communities. PHEPR activities should strive towards the long-term goal of developing community resources that will make them more hazard-resistant and allow them to recover appropriately and effectively after emergencies. Resilient communities have robust internal support systems and networks of mutual assistance and solidarity. They also maintain sustainable and risk mitigating relationships with their local ecosystems and their natural environment.
- **Public health professionalism.** PHEPR activities should recognize the special obligations of certain public health professionals and promote competency of and coordination among these professionals.
- **Responsible civic response.** PHEPR activities should promote a sense of personal responsibility and citizenship.

The Importance of Ethical Analysis: Health and Liberty

The nature and complexity of emergency planning and response require ethical analysis at several different levels. The ethical goals of PHEPR must be clearly articulated and understood. There are several reasons for this. First, these goals are intrinsically important. They express the values of public health professional service and traditions, and they represent the nature of our moral ideals as a community. Moreover, clarification of these ethical goals of PHEPR is important because widespread public recognition of them reinforces public trust and the legitimacy of public health efforts. Finally, public health emergency preparedness is an activity conducted under the auspices of the state. It has an impact, not only on the health and safety of individuals, but also on their liberty, autonomy,

civil and human rights, property, and other fundamental interests. Public health emergency preparedness planning must address the actions people need to take to protect themselves and, by complying, to protect others using a community health and safety perspective. PHEPR inherently involves behavior modification and control on a large scale. It must inform and instruct people about how to behave during an emergency so as to promote their own best interests, even if they are inclined to behave in other ways. Sometimes this involves restricting people's liberty.

In the planning phase, the rationale and benefits of paternalistic and coercive measures must be publicly explained and understood. If the planning and its directives are deliberative, transparent, and accepted by the community at large, the restrictions imposed on some individuals will be more ethically acceptable than if such measures are planned in secret by a small group of officials.

A central theme of this white paper is that the ethical acceptability of an emergency plan is a function both of the substantive content of its provisions (what it requires people to do and what the consequences of that are) and of the process through which those provisions are discussed, formulated, argued about, and ultimately agreed to.

In the aftermath of the emergency or disaster event, experience shows that solidarity and self-sacrifice often give way over time to disillusionment, recrimination, and even litigation. To mitigate this kind of backlash, it is important to have ongoing monitoring of the use of authority and power during the implementation of emergency plans. This is to ensure that power and authority are not abused and that paternalistic or coercive measures are justified under the circumstances. It is also important to have ongoing and ex post facto

evaluation and assessment to gauge the effectiveness of emergency plans, to learn from mistakes, and to make improvements for the future.

Planning is by nature an ongoing activity, a work in progress. As they go forward, policymakers, public health professionals, and civic leaders should take steps to identify the ethical dilemmas and value conflicts that arise in the options and contingencies contained in planning at all levels. In this white paper, we offer general advice and recommendations concerning the conduct and approach that should be taken by public health emergency planners. These recommendations are summarized first in relation to the overall design of PHEPR and then in relation to specific policies and strategies.

General Features of the Ethical Design of PHEPR

- Emergency plans and mitigation activities should have clearly defined and realistic goals. Planners and the community should identify these goals. To the extent possible, consensus should be reached on them, and their rationales should be widely understood.
- Emergency preparedness goals should be pursued and implemented as effectively as possible, given existing resources and information. Ineffective, unduly burdensome, and wasteful policies and practices are not ethically justified.
- Public trust is key to the success of any emergency planning. Planning processes should be transparent, and multiple opportunities for deliberative citizen participation should be provided. Meaningful two-way communication, bottom-up as well as top-down communication, is essential. Deliberative planning that is broadly inclusive and participatory is not only the most effective means for creating well-informed and

successful emergency plans, it will also strengthen the ethical fabric of the open, pluralistic society we seek to protect.

- Preparing a community for a future emergency or disaster requires well-functioning institutions, not just simply an “emergency plan.” A community marked by just social practices and a commitment to social justice before an emergency is likely to carry that commitment through the emergency response and into the aftermath and recovery period. Such communities are likely to be better able to rebound quickly and recover effectively, and such communities will likely meet the benchmarks of both justice and resiliency in their recovery process and outcomes.
- To the extent possible, PHEPR should follow an approach that emphasizes the use of the least restrictive alternatives, community involvement, and transparent communication. The role of ethics, especially in the planning phase before a crisis event, is to define reasonably just, humane, and responsible guidelines for paternalistic and coercive measures during a crisis response.
- In PHEPR, planners and public health officials must always be prepared to be accountable for their conduct in terms of the good reasons they had for deciding and acting as they did. Accountability means being able to provide good reasons, or rationales that are reasonable under the circumstances, for actions and decisions, even if in retrospect it appears that mistakes were made.
- PHEPR planning and conduct should inspire civic responsibility, a sense of justice, and concern for others in need. Fear and self-interest will no doubt be strongly in evidence during any public health emergency. Unless public health leadership can, in conjunction with elected officials and other community leaders, move communities

beyond these motivations to a sense of common purpose and solidarity, public health will have failed in its professional obligations and will most likely fail in its practical efforts as well.

Specific Recommendations Concerning PHEPR Policy and Practice

Justice and Fairness

- Officials and planners should attempt to identify in advance the known or potential burdens of the mitigation activity and identify the segments of the population upon whom those burdens are likely to fall. Planners and policymakers should attempt to minimize the burdens of the mitigation activity. They should consider alternative approaches to achieve the same goals and should avoid imposing undue burden on groups unfairly or inequitably.
- Policies and decisions should not place an undue burden on any one segment of the population in the recovery phase and should aim to bring about as even-handed and uniform a pattern of assistance and recovery as possible. Measures taken during the immediate response to an emergency essentially have the effect of distributing risk. This must be done in an equitable and nondiscriminatory manner, balancing individual interests and social well-being. During the recovery phase, generally speaking, priority in recovery efforts should be provided on the basis of greatest need and greatest impact. Those who will be otherwise homeless, for example, might be given priority for temporary housing. Those at greatest health risk due to the dislocation of their ordinary routines and modes of living should be given special attention.

- A clear societal consensus is lacking regarding the proper weight that should be attributed to certain conflicting values during public health emergencies. No one conception of justice, such as an emphasis on aggregate well-being and efficiency or an emphasis on equity, provides the necessary solution to ethical dilemmas in practice. Therefore, lacking ethical certainty on the right outcomes, planners should seek ethical consensus on fair and appropriate procedures for setting priorities and allocating scarce resources.
- Fairness should be a feature not only of the outcome of mitigation activities but also of the way in which they are conducted and carried out. Planners should attempt to make the public health benefits and the accompanying social, economic, and personal burdens balanced and proportionate.

Respect for Persons with Special Needs or Vulnerabilities

- Persons and groups with special susceptibility to harm or injustice during public health emergencies exist in virtually every community and should be carefully identified and assessed during the planning process prior to emergency events. Without such pre-disaster event preparation, it is unlikely that their special needs will be met on an ad hoc basis in the course of an actual emergency.
- Auditing and mapping community assets (e.g., individuals with particular local knowledge or groups accorded special trust and loyalty in the community) should be an integral part of PHEPR. To acknowledge that certain individuals, groups, neighborhoods, or communities are vulnerable to severe risk and disruption during a public health emergency is not to say that such communities are lacking in all assets or resources, but they do need special advance planning and accommodations in order

to help and sustain themselves. This is an example of the sense in which PHEPR is and must be a community effort actively involving all strata of civil society and not simply a centrally planned and top-down effort.

- To facilitate good planning, persons with special needs or their representatives should have an opportunity to participate actively and directly in the PHEPR process. When many needs are calling for attention, the voice of the vulnerable and those who have been socially or culturally marginalized is most likely to be drowned out unless it has been heard in advance and special provisions have been made.

Accountability and Transparency

- Monitoring of the use of authority and power should be ongoing during the implementation of emergency plans. This is to ensure that power and authority are not abused and that paternalistic or coercive measures are justified under the circumstances.
- Evaluation and assessment of emergency plans and their implementation should be ongoing during and after a disaster. This is necessary in order to gauge the effectiveness of emergency plans, to learn from mistakes, and to make improvements for the future.
- The lesson to be drawn from the existence of pervasive uncertainty is that whatever conclusions are reached about the justice of any proposed mitigation activities must be considered provisional and subject to revision over time as the disaster unfolds. Flexibility in response to changing conditions and evolving knowledge will be crucial to successful disaster planning and mitigation activity.

- Good communication goes both up and down. It is more than simply providing factual information and transparency and requires more than simply telling people what has already been decided. Communication should involve a two-way form of exchange and provide the resources necessary for the public to reflect on and come to accept planning decisions rationally, and not just to be told what they are. If this is to happen, communication must be both linguistically and culturally appropriate.

Transparent public health communications follows these rules of thumb:

- Acknowledge uncertainty.
- Provide follow-up information as quickly as possible.
- Advise patience and flexibility.
- Admit mistakes and move on.
- Provide advice that can realistically be acted upon.
- Do not abandon the community, and do not appear to be doing so.

Professional Responsibility

- Confronting some degree of personal risk comes with the job of being a health professional. Health professionals have an ethical contract with the society at large. But while health professionals may have an obligation to submit themselves to risk for the sake of others, society (and the specific organizations that employ health professionals) has a corresponding obligation to protect them from known hazards while they are fulfilling their professional duties.
- Society has an obligation to provide health-care workers with the training and tools they need. It is ethically wrong for society to put health professionals in harm's way while failing to provide them with needed resources. Society should strive adequately

to provide needed care to all health workers who become ill or disabled in the line of duty, and to provide compensation to their families should they die.

Conducting Public Health Research During Emergencies

- Systematic observation and data collection to enhance understanding of the epidemiologic, medical, and behavioral aspects of PHEPR may ethically be undertaken during the response phase of an emergency as well as during the planning and recovery phases. At all times, it is important to protect and respect the fundamental rights and interests of individuals. Whether or not these activities are viewed as “research,” they should only be conducted with appropriate ethical oversight and review. Appropriate oversight in a public health emergency context does not necessarily involve the same review mechanisms (e.g., institutional review boards) that have been developed to protect human subjects participating in research in other settings.

CDC Deployment During Emergency Situations

- The ethical obligations of individual CDC professionals and the ethical obligations of the CDC leadership and organizational support systems go hand in hand. During an emergency deployment, the consequences of poor performance can be extremely serious. Many other persons, including those who are in positions of great need and vulnerability, put their trust in CDC expertise and skill.
- An individual professional has an obligation to ensure that he or she is adequately prepared to meet the requirements of a deployment.

- As an agency and an employer, CDC also has an obligation to provide the required and appropriate training, preparation, equipment, and support to the personnel CDC utilizes for PHEPR.
- The process of selecting individuals for deployment should be orderly, transparent, and fair. If an individual believes that an assignment is inappropriate or has been wrongly motivated, an orderly and confidential review and appeals process should be in place for that person. Considerations of undue family burden and personal hardship should also be taken into account.
- Clear, but reasonably flexible standards of performance and discretion should be established and clearly understood by everyone on the deployment team and along the chain of command. If appropriate training is the organizational responsibility of CDC in the preparedness phase, ensuring an appropriate and effective support system and reasonable expectations is CDC's responsibility during the deployment phase.
- When they are deployed during an emergency event, CDC personnel have an ethical obligation to provide clear and timely information to relevant governmental authorities within their field-based chains of command. They also must assist in making decisions even under conditions of uncertainty or limited and possibly unreliable information. The ethical responsibilities of the public health professional in emergency situations are complex in terms of their responsibility to scientific standards and to practical necessity. On one hand, the deployed CDC professional is one of the principal voices of scientific rationality in public health emergencies and if within the scope of duties, should tailor his or her communication activities to ensuring that this voice is heard. On the other hand, especially in the response period

when CDC personnel are most likely to be deployed, public health professionals are obligated to use their best judgment and to provide analysis and advice under conditions of uncertainty and time pressure.

- Scientific uncertainty should not be a rationale for inaction. Sound factual information is a foundation for ethically justified decision making, but decisions must be made and actions taken even in the face of imperfect information. CDC as an agency should support its personnel and the mission of public health by resisting unwarranted limits others may place on the gathering of relevant scientific information, the analysis of that information, or communicating the results of that analysis to the appropriate officials and decision makers.

The following guidelines should inform the communication and relationships between deployed CDC personnel and other state and local public health and emergency management officials:

- CDC personnel should be candid about the limitations of their findings at the time of communication.
- They should offer perspectives on the ranges of potential risk or harm and, to the extent possible, estimates of the probabilities involved.
- They should indicate what further investigation would be necessary to provide greater certainty, and how long it would take to acquire more information.
- They should be candid about the likelihood that greater certainty or more reliable information will not be forthcoming before decisions have to be made.

Public health professionals cannot perform their mission or fulfill the ethical goals of their activities without the cooperation of other professionals and specialists. Disagreements may arise among the various professional cultures and perspectives in emergency preparedness and response; for example, public health priorities and law enforcement priorities may sometimes be in tension. However, cooperation is essential. At the same time, the ethical integrity of all the professionals and agencies involved should be preserved and respected. To achieve this balance, there must be mechanisms of integrity-preserving compromise, review, and appeal.

Conclusion

PHEPR is a vital public health function. As such, it is both a governmental responsibility and a civic endeavor. This white paper, therefore, presents a broad overview of its subject, as opposed to a focused look at one aspect of PHEPR, such as the response to pandemic influenza, bioterrorism, or weather-related emergencies.

PHEPR is ultimately about protecting a community, but it is also about embodying the traditions and values of a community and a vision of how the community can be made a better environment for all its members in the future. Successful emergency planning must rely on and tap into a preexisting fund of civic responsibility, a sense of justice, and concern for others in need, but it can, and should, be an occasion to foster these outlooks and impulses as well. Fear and self-interest will no doubt be strongly in evidence during any public health emergency. Public health leadership, in conjunction with elected officials and other community leaders, can move communities beyond these motivations to a sense of

common purpose and solidarity. If it does this, PHEPR will succeed in meeting its professional ethical obligations and will most likely succeed in its practical efforts as well.

Ethical Guidance for Public Health Emergency Preparedness and Response:
Highlighting Ethics and Values in a Vital Public Health Service

Introduction

“All partners who can contribute to action as a public health system should be encouraged to assess their roles and responsibilities, consider changes, and devise ways to better collaborate with other partners. They can transform the way they ‘do business’ to better act to achieve a healthy population on their own and position themselves to be part of an effective partnership in assuring the health of the population (*I*).” --[Institute of Medicine 2003: 32]

The purpose of this white paper is to identify the various ethical principles and values that are germane to public health emergency preparedness and response (PHEPR), to provide guidance on cogent, rigorous processes of ethical reasoning and decision making in the context of PHEPR, and to propose, where possible, ethical considerations that should inform federal, tribal, state, and local policies, practices, and training as they support local PHEPR efforts.[§]

[§] There is no short or perfect term in use to refer to the activities we focus on in this paper. We will be concerned with the public health dimension of emergency planning, and not so much with law enforcement and public safety dimensions, although we recognize that the boundaries here are often indistinct and overlapping. We also intend the term to cover pre-event planning and preparation, event response, and post-event recovery.

Public Health Emergency Preparedness and Response

Key Points

A public health emergency exists when a situation arises for which the health consequences have the potential to overwhelm routine community capabilities to address them. Public health emergency preparedness and response may be defined as “the capability of the public health and health-care systems, communities, and individuals, to prevent, protect against, quickly respond to, and recover from health emergencies, particularly those whose scale, timing, or unpredictability threatens to overwhelm routine capabilities.”

The conception of PHEPR followed here includes the following elements:

- ❖ A narrow focus on bioterrorism or weapons of mass destruction is less appropriate than an “all hazards” approach to planning.
- ❖ A robust, well-functioning infrastructure is necessary for the success of both everyday public health and public health in a time of crisis. PHEPR and the rest of public health supplement, rather than supplant, one another.
- ❖ Preparedness is understood to encompass more than adequate equipment, deployment of health professionals, training, and supplies; preparedness requires the involvement, education, and support of the entire community.
- ❖ Public trust and confidence are essential in PHEPR, and public health decision making will be most effective when it is transparent and has direct links to the communities it serves.

Ongoing monitoring of the use of authority and power is important during the implementation of emergency plans. This is to ensure that power and authority are not abused and that paternalistic or coercive measures, if used, were justified under the circumstances. Ongoing and ex-post facto evaluation and assessment are also important to gauge the effectiveness of emergency plans, to learn from mistakes, and to make improvements for the future.

The Reemergence of Public Health

In 1988 the Institute of Medicine called attention to a serious decline in the public health infrastructure of communications, laboratories, surveillance systems, trained personnel, and capacity to respond quickly and adequately to a sudden large-scale threat to population health (2). This state of affairs had come about after years of inadequate funding and lack of public attention to public health. Ironically, public health was the victim of its own historic successes:

vastly improved sanitation, vaccination and the control of infectious diseases, and improvements in air and water quality. The focus of population health, at least in the United States and other developed nations, seemed to be shifting toward the prevention and control of chronic illness and addressing behavioral and lifestyle risk factors. Systems to sustain public health were shifting from traditional public health functions to individual-based clinical care and health insurance coverage to support such care (3,4).

The threat of sudden disruption in the health-care system and serious danger to life and health on a large scale came to the fore again in the 1990s as increasing attention was focused on terrorism, spurred by the bombings in a parking garage at the World Trade Center and at the federal office building in Oklahoma City, as well as the poison gas release in the Tokyo subway system. The 1996 Defense Against Weapons of Mass Destruction Act (P.L. 104-201), commonly known as the Nunn-Lugar-Domenici Act, established a domestic preparedness program and broadened the mandate of the Federal Emergency Management Agency (FEMA) to include attacks by weapons of mass destruction as well as natural disasters. In addition, Congress also passed another significant law, the Antiterrorism and Effective Death Penalty Act of 1996, which provided for additional government controls to deter terrorism. In 1998, CDC established the Bioterrorism Preparedness and Response Program, which improved laboratory, surveillance and emergency response communication capabilities. In addition, in this same year, CDC was authorized by Congress to establish a national stockpile of pharmaceuticals and vaccines (5). In 2000 and early 2001, simulation exercises (TOPOFF 1 and “Dark Winter”) revealed many remaining shortcomings in emergency preparedness and the ability to respond—poor interagency and intergovernmental communication and coordination, lack of local planning, and inadequate surge capacity (6).

Such concerns increased exponentially in the aftermath of the terrorist attacks of September 11, 2001, and the use of anthrax as a means of bioterrorism shortly thereafter. PHEPR was placed squarely at the center of the public health mission and has been a focal point of funding, personnel, training, and other resources at the federal, tribal, state, and local levels. Improvements have been made in many states and locales in their capacity to respond to epidemic or environmental contamination events. Much work remains to be done (7–10). Conditions such as West Nile virus, severe acute respiratory syndrome (SARS), multidrug-resistant tuberculosis (MDR-TB), and *Escherichia coli* contamination in the food supply have required public health responses. Some initiatives, such as the national smallpox vaccination plan of 2003, which aimed to immunize the nation’s health-care workers and first responders, did not succeed because of disagreements over risk-benefit considerations and lack of trust and cooperation among target populations. The devastation of Hurricane Katrina demonstrated the social and political complexity of emergency planning, response, and recovery (11–18).

Additional public health challenges loom on the horizon, including avian influenza, possible future instances of bioterrorism, and the prospect of long-term climate change with its multiple threats to public health and well-being (heat waves; flash flooding, violent storms, drought, malnutrition, and large-scale human migration with attendant sanitation and epidemic side-effects)(19). These and other threats to the usual systems of disease prevention, health-care delivery, and public safety ensure that PHEPR will remain a vital public health responsibility in the 21st century and will be integral to the mission of CDC and other public health entities.

Despite the anticipated continuing importance of PHEPR, during the last few years serious debates and disagreements have arisen within public health concerning the funding of PHEPR, the proper responsibilities of federal, tribal, state, and local governments, and questions

about whether giving priority to PHEPR undermines other important public health functions and services. There has also been debate about the cultural implications of PHEPR and whether a focus on PHEPR could be perceived as undermining public health's openness and its close working relationship with poor and marginalized groups. This could arise because of an allocation of public health funding and other resources away from community-level activities, or because of an identification (whether warranted or not) of public health with other institutions of government authority, which many marginalized communities mistrust. Finally, some have been concerned that PHEPR will refocus public health back on its historical tradition as an instrument of social control and on the “police powers” of the state, and will cause public health to lose sight of its broader social outlook (3, 20-21). In this broader outlook “health” is not simply the absence of disease, it comprises the conditions and capabilities—material, environmental, social, and political—that enable populations to avoid disease and to experience good health in the context of other elements of well-being and human flourishing (22).

A full discussion of debates such as these is beyond the scope of this report. We believe that consensus is emerging among public health officials and practitioners regarding the appropriate place of PHEPR within public health and its proper scope. This consensus is built around the following points:

- A narrow focus on bioterrorism or weapons of mass destruction is less appropriate than an “all-hazards” approach to planning. Indeed, in 2003, a presidential directive mandated that the U.S. government adopt an all-hazards approach to emergency preparedness and response (23).
- Preparedness is now understood to encompass more than adequate equipment, deployment of health professionals, training, and supplies. Preparedness also involves the

community. A well-prepared community is a community in which the population is medically well served, a strong public health infrastructure is in place, and community-based public health services are not neglected but are robust and well integrated into everyday life. If political and budgetary decisions are made that put PHEPR in a zero-sum relationship with other public health programs, such as prenatal and infant nutrition or childhood vaccination programs, it should not be assumed that such decisions genuinely strengthen preparedness.

- A robust, well-functioning infrastructure is necessary for the success of both everyday public health and public health in a time of crisis. PHEPR and the rest of public health supplement, rather than supplant, one another.
- Public trust and confidence are essential in PHEPR, and public health decision making will be most effective generally when it is transparent and has direct links to the communities it serves.

We embrace these emerging points of agreement and attempt to build upon them with the approach to ethics taken here. PHEPR goes hand in hand with non-emergency public health policies and programs because a well-funded and thoughtfully designed public health infrastructure is necessary if society to meet the wide array of currently unforeseeable threats and future disasters. In a similar vein, we believe that the ethical framework for public health generally provides the appropriate framework for PHEPR as well. The moral stakes are high in preparedness activities, but they are also high in ordinary public health practice. Different types of hazard—epidemic, weather-related, environmental, and radiologic—present special circumstances for ethical decision making and reflection but do not require tailor-made ethical principles or values.

Public Health Emergency Preparedness and Response

A public health emergency exists when a situation arises for which the health consequences have the potential to overwhelm routine community capabilities to address them. PHEPR may be defined as “the capability of the public health and health-care systems, communities, and individuals, to prevent, protect against, quickly respond to, and recover from health emergencies, particularly those whose scale, timing, or unpredictability threatens to overwhelm routine capabilities (24).” Public health preparedness activities include regulating environmental conditions and food and water safety to minimize disease threats, planning for emergency medical and public health response capabilities, detecting a disease outbreak, conducting epidemiologic investigations to ascertain the nature of a disease epidemic, performing laboratory analyses to inform surveillance and epidemiology, pursuing public health interventions to limit the spread of disease, ensuring the provision of emergency medical treatment and prophylaxis, remediating environmental conditions, and preventing secondary public health emergencies following a disaster (25).

PHEPR is a multidisciplinary endeavor that draws on the traditional bodies of expertise within public health, such as surveillance, epidemiologic analysis, laboratory analysis, and deployment of measures known to be effective in limiting the spread of infection and minimizing human morbidity and mortality. It also draws on the

Components of Effective PHEPR

- ❖ Capacity to assess health risk
- ❖ Necessary legal authority in place
- ❖ Roles and responsibilities clearly defined
- ❖ Incident command system in place
- ❖ Public engagement
- ❖ Epidemiology functions
- ❖ Laboratory functions
- ❖ Countermeasures and mitigation strategies (e.g., vaccination, quarantine, social distancing)
- ❖ Mass health care access and delivery
- ❖ Public information and communication
- ❖ Robust supply chain
- ❖ Trained and staffed workforce

experience and skills of the social and behavioral sciences, risk communication, architecture and planning, environmental science, engineering, and public safety. It must also work together with those responsible for disaster management who come from other fields, and it must negotiate a complicated web of jurisdictional, bureaucratic, and organizational interests and boundaries (26–29). PHEPR must be cognizant of the legal implications of its functions, and it must work effectively with policymakers, elected officials, the business community, civic leaders, and the press. It must operate in such a way as to maintain the confidence and trust of the public.

The nature and complexity of the task of PHEPR suggest that it requires ethical analysis at several different levels. First, it falls within the general domain of public health ethics, a field that has developed substantially in recent years (30–41). Moreover, the ethics of PHEPR have thus far been neglected. For example, a recent review of federal and state influenza pandemic plans showed that, with few exceptions, there was no explicit reference to ethical issues and concepts in these documents (42).

The ethical goals of PHEPR are multiple, difficult to prioritize in any systematic or philosophically grounded way, and may give rise to practical ethical dilemmas when they conflict. They must be clearly articulated and understood for several reasons. These goals are intrinsically important, they express the values of public health professional service and traditions, and they represent the nature of a community's moral ideals. The clarification of these ethical goals of PHEPR is important also because widespread public recognition of them reinforces public trust and the legitimacy of public health efforts.

Public health emergency preparedness is conducted under the auspices of the state, local or tribal jurisdiction. It has an impact, not only on the health and safety of individuals, but also on their liberty, autonomy, civil and human rights, property, and other fundamental interests

(41,43–45). Public health emergency preparedness planning must face the occasional necessity of directing people to behave in a certain way during an emergency to protect the health interests of the population and to promote their own best interests, even if they are inclined to behave in other ways.

“Paternalism” is the term in ethics used to convey the notion of a restriction of an individual’s freedom of choice for the sake of protecting or promoting that individual’s best interests. PHEPR is inherently prone to paternalism, since one of its basic missions is to guide behavior during an emergency. In many instances, the inclination of some, perhaps large numbers of people, will be to behave differently than the PHEPR process calls for. People may want to be together with others when they should isolate themselves. They may want to leave their homes when they should stay off the roads. Or some may want to stay home, which feels safe and familiar, in order to protect their belongings when the safest course is to evacuate. People may seek medicines that are inappropriate for them to take or unjust for them to hoard. They may act on the basis of rumor or unreliable, even false information, or on the basis of irrational thinking concerning risk. PHEPR must foresee these understandable, but nonetheless counterproductive behaviors, and it must somehow prevent, or at least discourage them (46,47).

These unavoidable paternalistic aspects of PHEPR alone would be enough to make it a subject of ethical discussion. American culture has strongly antipaternalistic currents within it. Americans value individual freedom of choice and self-reliance. They are suspicious of authority, not deferential to it or cowed by it. In the last generation, the American public has come to the point where they no longer believe that “father knows best,” much less that doctor knows best, and even less that health commissioner knows best. In addition, many Americans are

skeptical of uses of power that claim to be in the best interests of the powerless or in the public interest but all too often seem to serve the interests of the powerful.

This is not to say that during an emergency most people will not comply with emergency regulations and directives, that they will not turn to their leaders, experts, and other authorities for protection and guidance, or that they will not be willing to forgo significant personal liberty in return for a promise of greater protection and safety. When their community is threatened, people even in a privacy-oriented and individualistic culture will volunteer, feel a sense of solidarity, and make sacrifices for the common good. This was the experience of the World War II generation, and it was demonstrated again for a time after the events of September 11, 2001. Public engagement activities dealing with community mitigation interventions have indicated that there is a willingness at the grassroots level to forgo or temporarily suspend certain ordinary civil liberties and freedoms in the face of a pandemic (48).

However, this individualism of American culture, reinforced by ethical systems that stress autonomy, rights and civil liberties, will have an impact especially on the planning and recovery phases of PHEPR. In the planning phase, directives that restrict liberty must be fully explained and justified. That notion suggests an important theme, namely, that the ethical acceptability of an emergency plan is a function both of the substantive content of its provisions (what it tells people to do and what the consequences of that are) and of the process through which those provisions are discussed, formulated, argued about, and ultimately agreed to. In the aftermath or recovery phase of a public health emergency, experience shows that solidarity and self-sacrifice often give way to disillusionment, recrimination, and even litigation (49). It is probably in the nature of any emergency plan that it cannot protect (or please) all of the people all of the time. To mitigate this, it is important to have ongoing monitoring of the use of authority

and power during the implementation of emergency plans. This is to ensure that power and authority are not abused (“Who watches the guardians?”) and that coercive measures were justified under the circumstances. Ongoing and postcrisis evaluation and assessment are also important to gauge the effectiveness of emergency plans, to learn from mistakes, and to make improvements for the future.

Throughout this white paper we argue in favor of public health approaches that employ the least restrictive alternatives, community involvement, and transparent communication. Nonetheless, the use of coercion or secrecy or deliberately withholding information from the public cannot be ruled out a priori. It is important that public health planners not wait for disaster to strike before trying to work out a viable scheme of priorities. The role of ethics in the planning phase before, and in the recovery phase after, a crisis event is to define reasonably just, humane, and responsible parameters for action and decision making. Even within those parameters, there is no way to be sure that moral mistakes will not be made, but one must always be prepared to be accountable for one’s conduct in terms of the good reasons that one had for deciding and acting as one did (50).

Overview

This white paper aims to address two dimensions that are interrelated. First, it seeks to provide an ethical conception of PHEPR as a whole, as a complex activity blending the coordination of many groups, disciplines, and interests and drawing on numerous bodies of knowledge and expertise. This may be seen as an account of the “ethics of PHEPR;” that is, an account of its moral point and human value; an account of why it is an activity that should be engaged in at all.

The second dimension explores what might be called the "ethics in PHEPR," that is, the specific moral dilemmas, choices, and quandaries that arise in the course of actually doing PHEPR. It addresses particular aspects of preparedness and response plans, particular decisions that planners and communities have to make, decisions that require balancing many diverse, and sometimes conflicting values. Both these dimensions are important because specific decisions and policies (the ethics in) would lack conviction and direction if they were not placed in the context of a guiding vision of ethically informed planning as a whole (the ethics of).

The white paper is divided into three parts. Part I is devoted to a formulation and brief commentary on the main ethical goals or objectives of PHEPR. It also presents a framework for ethical reasoning and decision making oriented toward the types of situations and decisions likely to arise in the context of PHEPR. Part II contains a series of sections devoted to ethics in the practice of PHEPR. Topics discussed in the first sections are the broad mandate of preventing death and disease, the problem of justifying the limitation of individual liberty, questions of justice and the allocation of scarce resources, and accommodation of persons with special needs and vulnerabilities. The remaining sections turn to aspects of PHEPR that may seem more political and social in character but are of significant ethical concern as well: the relationship between experts, leadership, and elected representatives on one hand, and democratic citizens on the other, and the role of the press and other forms of mass communication in mediating this relationship during emergencies; the obligations and duties of individuals who play important roles in the PHEPR process, particularly health professionals and their conduct during the response phase of a public health emergency; and the sense of responsibility and cooperation on the part of private citizens that will facilitate effective and ethically sound preparation, response, and recovery in a community.

Part III is devoted to aspects of PHEPR that have a direct bearing on the activities and responsibilities of CDC personnel. These discussions focus on 1) the problem of using the response and/or recovery phase of PHEPR as an opportunity to conduct research for the purpose of better understanding behaviors and biological conditions that manifest themselves during such periods so as to be better prepared to plan and respond in the future, and 2) the special ethical questions that pertain to the role of CDC and CDC personnel who are deployed to assist in emergency situations.

At the conclusion of each section, a summary of key points to consider is provided which distill the central ethical perspectives offered in that section.

PHEPR in each of its phases—the pre-event planning phase, the response phase, and the post-event recovery phase—is a complex ethical undertaking, just as it is a complex managerial and scientific one. This white paper cannot reduce that ethical complexity, and it does not pretend to offer a decision-making or policy-making algorithm. However, it does provide conceptual tools and perhaps sufficient discussion to orient and to clarify one’s understanding of that complexity; hence, it may serve to enhance public health’s capacity to manage that ethical complexity and to respond to it competently and reasonably.

PART I

Ethical Goals and Ethical Decision Making

Two frameworks provide the ethical and conceptual grounding for the remainder of this report. The first framework consists of the general ethical goals that are most pertinent to PHEPR. This framework is based on the notion that the emergency preparedness and response process ought to be used to respect and promote the basic values of harm reduction/health

promotion, equal liberty and human rights, distributive justice, public accountability, creating strong and vital communities as well as safe ones, public health professionalism, and the recognition of civic and personal responsibility.

The second framework presents guidelines for careful ethical reasoning in practical decision making and policy making. This is not a formula or an algorithm for arriving at ethically correct decisions. That is not its purpose. It does offer a general orientation and mode of thinking that will increase the likelihood that decision makers will be alert to a broad range of values, be attentive to the types of factual information that bear on ethical decisions or value judgments, and remain open and flexible concerning diverse points of view, while still confident and decisive enough in their judgments to meet the challenges of advance planning and emergency response situations.

Ethical Goals and Ethical Decision Making

Key Points

The emergency preparedness and response process ought to be used to respect and promote the basic values of health, liberty and rights, justice and equity, efficiency and effectiveness, accountability, community, professionalism and scientific integrity, and civic and personal responsibility.

Decision makers should

- ❖ Be alert to a broad range of values;
- ❖ Be attentive to the types of factual information that bear on ethical decisions or value judgments;
- ❖ Remain open and flexible concerning diverse points of view; and
- ❖ Remain confident and decisive enough to meet the challenges of advance planning and emergency response situations.

The basic ethical goals of public health emergency preparedness and response are

- ❖ Harm reduction and benefit promotion;
- ❖ Equal liberty and human rights;
- ❖ Distributive justice;
- ❖ Community resiliency and empowerment;
- ❖ Public accountability and transparency;
- ❖ Public health professionalism; and
- ❖ Responsible civic response.

Ethically responsible public health decision makers will

- ❖ Be clear about the goals of a public health mitigation activity;
- ❖ Be sure that a public health mitigation activity is based on the most reliable factual information that is reasonably available to decision makers under the circumstances;
- ❖ Be aware of the ethical values that are affected (promoted or undermined) by the mitigation activity, both by the effects the mitigation activity produces and by the ways in which the mitigation activity must be implemented and carried out;
- ❖ Be concrete rather than abstract in ethical thinking; put a face on the individuals and groups who will be most directly affected by a mitigation activity; and
- ❖ Be aware that the process of decision making leading up to the selection of a mitigation activity can raise important ethical considerations in its own right.

Ethical Goals of Public Health Emergency Preparedness and Response

1. Harm reduction and benefit promotion

PHEPR activities should protect public safety, health, and well-being. They should minimize the extent of death, injury, disease, disability, and suffering during and after an emergency.

2 Equal liberty and human rights

PHEPR activities should be designed so as to respect the equal liberty, autonomy and dignity of all persons.

3 Distributive justice

PHEPR activities should be conducted so as to ensure that the benefits and burdens imposed on the population by the emergency and by the need to cope with its effects are shared equitably and fairly.

4 Public accountability and transparency

PHEPR activities should be based on and incorporate decision-making processes that are inclusive, transparent, and sustain public trust.

5 Community resiliency and empowerment

A principal goal of PHEPR should be to develop resilient, as well as safe communities. PHEPR activities should strive towards the long-term goal of developing community resources that will make them more hazard-resistant and allow them to recover appropriately and effectively after emergencies.

Resilience is the capacity of a community (and of the individuals who comprise it) to respond creatively, preventatively, and proactively to change or extreme events, thus mitigating crisis or disaster. In the PHEPR context, we focus especially on the social or community dimension of the concept. Social resilience is defined by Adger as “the ability of groups or

communities to cope with external stresses and disturbances as a result of social, political and environmental change. This definition highlights social resilience in relation to the concept of ecological resilience which is a characteristic of ecosystems to maintain themselves in the face of disturbance (51).” Resilient communities have robust internal support systems and networks of mutual assistance and solidarity. They also maintain sustainable and risk mitigating relationships with their local ecosystems and their natural environment (52-54).

Public health professionals and other leaders should use the preparedness planning process to empower communities by strengthening their social capital and to make them more resilient, so that they can weather all hazards and emergencies—which are now inevitable throughout the globe and no community is immune from them—with as little damage as possible, recover from disasters effectively, and return to civic health (55-59).

What is the conceptual import of the concept of “resilience” and what are its implications for public health preparedness? A resilient community is not simply one that is able to “bounce back” or “rebound” to the status quo ante. This is the sense of resiliency prevalent in psychology and medicine. However, in ecology and related fields, resiliency is the capacity of a (natural or social) system to absorb external disturbances without losing its essential continuity and coherence (51, 53, 60). Building the second conception of resiliency capacity into public health, emergency planning opens up new possibilities for linking the underlying vitality and integrity of communities and systems of social capital with the concepts of “preparedness” and “security.”

6 Public health professionalism

PHEPR activities should recognize the special obligations of certain public health professionals, and promote competency of and coordination among these professionals.

7 Responsible civic response

PHEPR activities should promote a sense of personal responsibility and citizenship.

Fulfilling These Goals: Aspects of Ethical Reasoning and Decision Making

When considering particular aspects of an emergency plan or policies that will govern the response to emergency situations, public health officials and other stakeholders should consider the following aspects of sound ethical analysis and decision making (33–35). Doing so in light of the goals defined previously will provide a mode of ethical reasoning that is practical and should be considered in the development of policy directives and training materials by CDC and other public health authorities at the state and local levels. Ethically responsible public health decision makers will adopt the following practices:

- *Be clear about the goals of a public health mitigation activity.* Identify the goals to be accomplished by the mitigation activity and ascertain that these goals are consonant with the widely accepted goals and objectives of the public health profession. For example, a proposed mitigation activity that gives priority to protection of property over protection of human life and health would be subject to special scrutiny and would require special justification because it presumably would not be consonant with the standard goals of public health.
- *Be sure that a public health mitigation activity is based on the most reliable factual information that is reasonably available to decision makers under the circumstances.* Identify and assess the available factual information. In making this assessment, decision makers 1) should be careful to weigh the evidence indicating that the proposed mitigation activity will be effective in attaining its goals; and 2) should not jump to conclusions, but

should consider alternatives, i.e., is the proposed mitigation activity the only practical alternative? Emergency public health decision making will always have to wrestle with the reliability, the completeness, and the timeliness of the information available to it.

There is no such thing as perfect information, but that does not mean that decision makers do not have a responsibility to use the best information they have. Arbitrary and ill-informed decisions are not ethically acceptable, even in emergency situations.

- *Be aware of the ethical values that are affected (promoted or undermined) by the mitigation activity, both by the effects the mitigation activity produces and by the ways in which the mitigation activity must be carried out.* Identify the values at stake in the decision. Values are significant human rights, goods, interests, or states of affairs that affect human flourishing. Almost by definition, public health will promote the values of human life, safety, and health. However, public health activities encroach into an ethical domain that is broader than specific public health values alone. Therefore, in an ethical assessment of a mitigation activity, it is important to be aware of values concerning liberty, justice and equality, dignity, respect, responsible stewardship of scarce resources, transparency and accountability, maintaining public trust, and professional integrity (40).

Taking such values seriously involves asking the following kinds of questions: How can we best achieve public health effectiveness with minimal coercion? Among available alternatives, which mitigation activity is most efficient? Which is the least harmful and burdensome? Are important individual rights or interests at stake in the decision? Will the mitigation activity have effects that are fair and equitable; in other words, will the benefits and burdens caused by the mitigation activity be distributed justly

across the affected population? Can the mitigation activity be implemented in a respectful and nondiscriminatory fashion?

- *Be concrete rather than abstract in ethical thinking; put a face on the individuals and groups who will be most directly affected by a mitigation activity.* One way to do this is to perform an assessment that will identify the “stakeholders” in a decision. Stakeholders may be defined as those whose rights or interests are significantly affected by a decision. Special efforts should be made to include and to consider the interests of vulnerable or marginalized stakeholders, who may not have the power to influence the decision unless special provision is made to ensure their participation. For example, stakeholder assessment asks, "Who will benefit from the proposed mitigation activity? Who will be burdened by it? Who should have a voice in making the decision?"
- *Be aware that the process of decision making leading up to the selection of a mitigation activity can raise important ethical considerations in its own right.* Many times people are so focused on content that they do not become self-consciously analytic and critical about process. They focus on what is to be decided and forget the ethical importance of how it is decided. Decision making process is as much an ethical issue as is the content or the effects of that mitigation activity.

It is ethically important, therefore, to consider the process for making the decision and the values that pertain to the process—participation, inclusiveness, public and open deliberation, fair hearings, adequate technical support and expertise. It is also important for public health emergency preparedness planners to consider the properties of the decision-making process itself; it should be designed with checks and balances, redundancy, feedback loops for learning from mistakes and for making mid-course

corrections, and an appeals process to review decisions that come under challenge. The types of questions that should be asked are, "Is the decision-making process fairly representative and inclusive? Is it open and transparent? Is it intelligently responsive: that is, does the implementation process include the capacity to monitor and evaluate progress and to learn from mistakes or unanticipated consequences?"

- *Take steps to enable careful evaluation of the mitigation activity later.* How will public health planners know if a mitigation activity is successful, has met its goals, has been implemented ethically, and has had good ethical effects? This brings the process full circle, since having clearly defined and stated goals at the outset is a prerequisite for proper evaluation later on. For example, ask such questions as, "What are our criteria of evaluation? Are data being gathered, or records being kept such that it will be possible to conduct an evaluation and assessment of the mitigation activity later?"
- *Be aware of and resist unwarranted urgency in implementing a mitigation activity.* Consider the timing of the mitigation activity in an analytic way. Avoid the exaggeration of risk and worst-case scenarios. Resist precipitous action. This is particularly important if one feels that the ethical analysis of a proposed mitigation activity is inadequate or incomplete. Of course, excessive caution, weak resolve, and procrastination are undesirable and often harmful as well. Leaders and decision makers have difficult judgments to make, and what is needed is perhaps the ethical equivalent of "due diligence." For example, ask questions such as the following, "Why exactly does this decision have to be made immediately? Is there time for the collection of additional information or data without taking undue risk? Is there time for broader community

consultation before a final decision has to be made, particularly if very difficult and consequential ethical decisions have to be made?"

PART II

Saving Lives and Preventing Illness: A Broad Mandate

Saving Lives and Preventing Illness

Key Points

- ❖ The ethical objective of PHEPR is not only to minimize morbidity and mortality, it also includes protecting the common good, and the objective of reducing morbidity and mortality may sometimes have to be subordinated to other objectives.
- ❖ It is not the resulting “emergency plan” or document per se that matters so much as the planning process and activity itself, stretching over several years, and revisited and exercised periodically.

PHEPR activities should protect public safety, health, and well-being. They should minimize the extent of death, injury, disease, and suffering during and after an emergency. It is important to notice the difference between the public health perspective on this objective and the perspective traditionally adopted by clinical medicine. What

has been termed the “rule of rescue” is very powerful in social and medical morality. Saving lives has a very high, sometimes the highest, priority. “Above all, do no harm” is an enduring tenet of medical ethics. However, the public health ethical objective of PHEPR is not only to minimize morbidity and mortality; it also includes protecting the common good, and the objective of reducing morbidity and mortality may sometimes have to be subordinated to other objectives. Faced with a pandemic, infection control may take precedence over protecting those most at risk of death. This will have a direct bearing on how vaccines and life-sustaining treatment (ventilators, or intensive care units) are used (61).

Minimizing psychological harm and trauma is equally important. In addition, even public health emergency planning, and not just simply emergency planning from other perspectives, must be concerned with minimizing economic loss, destruction of property, and the disruption of basic social services. However, the scope of emergency planning does not stop there. It includes environmental damage, loss of biodiversity and ecosystemic degradation. Such matters have both short- and long-term effects on public health (8,19,62,63). PHEPR should be conceived and practiced in such a way that it casts a very broad net. The importance of this has been demonstrated repeatedly.

As horrible and deadly as it was, the injury and loss of life from the fire and smoke of the exploding airplanes or the falling buildings were not the only public health disaster on September 11, 2001. The other, ongoing disaster was environmental: the effects of the collapse of the massive twin towers and the subsequent human exposure to toxic materials during the event and for months thereafter (64-66). Similarly, it was not so much Hurricane Katrina itself as the collapse of the levies that brought New Orleans into a public health crisis, while underlying social, economic and cultural conditions exacerbated it (14,15,67-73). PHEPR must include not only planning for a catastrophic event per se but also must include upstream assessment and preventive measures and downstream recovery and mitigation. Building codes and their enforcement, as well as the proper maintenance of the aging infrastructure of U.S. cities, are also components of PHEPR, for they too protect lives and defend health. The connection between these upstream environmental and infrastructure issues and public health should be explicitly recognized and acknowledged because their importance is often forgotten, and other factors like cost savings and political expediency often overshadow them (74).

It is not the resulting “emergency plan” or document per se that matters so much as the planning process and activity itself, stretching over several years and revisited periodically. Plans should not only be reviewed at regular intervals for currency, but they should also be evaluated, using exercises or drills. Emergency planning produces much more than just a document; it sets in motion a whole social complex—discussions, large meetings, small meetings, networks among officials and professionals, local organizing and educational activity, creation of new communication channels, and recruitment of specialized personnel or retraining of existing personnel.

Moreover, the goal of harm reduction must be broad enough to encompass the social and cultural dimensions of catastrophic events and how they are planned for and responded to in both the immediate event and in the long term (75). PHEPR should strive to minimize long-term loss of social capital, cultural disintegration, and social suffering. Both the bio-psycho-social model of health that is widely accepted within the public health field and a growing body of epidemiologic research indicate that the destruction of webs of supporting relationships and of civic institutions can have significant effects on population health and well-being. All-hazard emergency planning and response must protect not only the whole person (i.e., both body and mind), but also organizations, systems of social functioning, and culturally meaningful ways of life.

The paradigm of PHEPR that provides the most latitude for achieving high ethical standards and ideals is a broad social model of emergency planning. It brings public health into contact with similarly oriented perspectives and movements in cognate fields. It draws orientation from social epidemiology and “place-based” (ecosystem landscape and built environment) public health, community-based participatory research, deliberative planning, and

the building of learning communities and learning organizations in management and leadership science (76-78). It may even have an analog in law enforcement and criminal justice theories of community policing (79).

This is an exceedingly broad mandate and a daunting task for PHEPR. Nonetheless, from an ethical as well as from a public health point of view, nothing less than this broad mandate and mission for planners will be truly adequate.

Placing Constraints on Individual Liberty

"The defense of liberty consists in the 'negative' goal of warding off interference. To threaten a man with persecution unless he submits to a life in which he exercises no choices of his goals; to block before him every door but one, no matter how noble the prospect upon which it opens, or how benevolent the motives of those who arrange this, is to sin against the truth that he is a man, a being with a life of his own to live..." "I wish to be the instrument of my own, not of other men's, acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside (80)." [Berlin 1969: 127; 131]

Placing Constraints on Individual Liberty

Key Points

- ❖ The maxim of using the “least restrictive alternative” is a way of simultaneously minimizing harm and respecting freedom in an emergency.
- ❖ Restrictions of liberty are most readily justified when the restrictions are short-lived and the damage done to the person thereby is reparable or compensable. Material interests, such as confiscated or destroyed property or lost wages due to mandatory social distancing measures are compensable; loss of dignity, failure to be treated as an equal and with respect, or suffering, stigmatization and loss of privacy may not be.
- ❖ The infringement on liberty will not be as severe if the person being restricted perceives that the restriction has been determined in a fair and reasonable way. Many times, it is not the restriction of freedom of movement or freedom of choice per se that is offensive, but the suspicion that it represents a discounting of the worth of the person being restricted.
- ❖ Emergency plans should respect the privacy and confidentiality of individuals who have to be restricted, and should protect them from undue social stigma and humiliation.
- ❖ For the most part, a voluntary compliance approach is ethically superior to mandatory compliance, assuming that the necessary behaviors can be achieved.
- ❖ When it is clear that individuals pose a serious risk to others by their unwillingness to comply with behavioral restrictions, there is clear ethical justification for compelling them to do so.
- ❖ Attempts at correcting misinformation and at rational persuasion should be made before more punitive or physical measures are used.
- ❖ If mandatory restrictions on liberty are ever chosen by public health planners and policy makers, they have a responsibility to ensure that adequate resources are available to enforce those requirements fairly and humanely.

Emergency situations and personal liberty are rather like oil and water. There is a long tradition of civil liberties in this country, but ethics and the law have always recognized that rights and liberties can be temporarily overridden during an emergency situation when substantial harm to others is impending. Such temporary power has the potential for being extended in unjust ways and abused. A sensitivity to past abuses within public health itself has grown, and public health planners are, or should be, acutely aware of past restrictive measures

that were justified on grounds of public health necessity but were later revealed to be instances of outright racism, social animosity, and invidious discrimination (30,81). Medical or epidemiologic necessity often seems more objective and clear-cut than it really is. It can lead to premature closure in considering policy options. It is an ethical mistake to be underinclusive in imposing restrictive measures because excess harm will result, but it is also ethically wrong to be overinclusive, for then the important values of liberty and rights have been sacrificed to no purpose of corresponding moral weight.

In 2001–2002 these difficult issues were brought out in the open and made the subject of a wide-ranging debate by a joint project between CDC and a team of legal scholars from Johns Hopkins University. This project produced the Model State Emergency Health Powers Act (82). A review of existing state laws found much inconsistency and many instances in which state authorities might not have a legal basis for taking the steps necessary in a public health emergency. The Model Act identified a wide range of powers to be granted to state governors, for a limited time, in the event of a properly declared emergency. Involuntary quarantine, invasive medical treatment without patient consent; commandeering and destruction of private property by the state—all of these legally extraordinary practices and more were proposed for debate.

One of the principal authors of the Model Act argues that its measures are in keeping with a long-standing legal and ethical framework in the liberal democratic tradition in which personal liberty is balanced against preventing harm to others, and the interests of particular individuals are balanced against the public interest (82). Central to this analysis is the notion of a threshold restriction on individual liberty. Policy and public health authority should calibrate the

lowest threshold of restriction that is compatible with meeting the public health and safety objective in question.

Similar notions are in fact widespread in public health ethics and in ethics generally. The maxim of utilizing the “least restrictive alternative” is a way of simultaneously minimizing harm and respecting freedom in an emergency (41,83). However, this idea is limited by the fact that it seems to presuppose that it is known where the objective threshold of liberty restriction lies (e.g., what subset of persons to quarantine because they pose the true risk of spreading disease when it is not necessary to quarantine the entire group) (41,84,85).

Over inclusive restriction of liberty is problematic, of course, because it has untoward side effects (20,86). It wastes scarce resources to maintain a large restricted population and to ensure compliance. It takes persons who have been unnecessarily restricted away from more productive activities. The core of the problem raised by the use of liberty-limiting public health mitigation activities, however, is that they override something that arguably is of intrinsic value and something that we all have a duty to respect. That is the value of individual liberty and respect for the right of adults to make judgments for themselves concerning precautions, prudence, and balancing safety and risk reduction against other personal values and priorities (21). The noted British political philosopher, Sir Isaiah Berlin, gave one of the best expressions to the core value of liberty in the words quoted as the epigraph of this section.

It is easy to say that when protecting life and respecting liberty conflict, one must err on the side of life. Public health professionals may feel that the protection of health justifies the restriction of liberty as well. Restrictions of liberty are most readily justified when the restrictions are short-lived and the damage done to the person thereby is reparable or compensable. Material interests, such as confiscated or destroyed property or lost wages due to

mandatory social distancing measures, are compensable; loss of dignity, failure to be treated as an equal and with respect, or suffering stigmatization and loss of privacy might not be. It is always important for those in authority, and this applies as well to those with benevolent motives, to recognize the fallibility of their judgment and their ability to foresee all the results and consequences of public health policies that restrict individual self-direction, liberty, and freedom of choice. The balance between preventing harm and respecting liberty is not as easily struck as it may first appear, particularly in the context of public health emergency planning.

Like the idea of using the least restrictive alternative means to achieve a public health objective, the moral equivalent of the judicial notion of due process is a guide for striking the right balance under conditions of uncertainty. PHEPR should respect the right of persons not to be denied liberty or property in an arbitrary, discriminatory, or unnecessarily restrictive way. The infringement on liberty will not be as severe if the person being restricted perceives that the restriction has been determined in a fair and reasonable way. Many times, it is not the restriction of freedom of movement or freedom of choice per se that is offensive but the suspicion that it represents a discounting of the worth of the person being restricted.

Similarly, when a person's liberty is restricted, the manner in which that person is treated has a large impact on the underlying value of respect for persons. Emergency plans should respect the privacy and confidentiality of individuals who have to be restricted, and should protect them from undue social stigma and humiliation. Also, the balancing of liberty against other values so that respect for persons is not undermined can be achieved when plans make special accommodation and provision for those with special needs or impairments who will suffer disproportionate burdens or be denied rightful benefits if their impairments are not compensated for by environmental mitigations, special equipment, resources, or services.

Voluntary versus Mandatory Compliance Policies

The issue of voluntary versus mandatory compliance policies has a specific bearing on the problem of ethically justified limitations on liberty. Public health emergency plans are replete with features that essentially tell individuals what they should do under specific circumstances. Not only in emergency situations but in all of public health, behavior modification is one of the principal tools for limiting disease and promoting health. In emergency situations, and therefore also in emergency planning, the stakes are higher and noncompliance has more serious and immediate consequences.

For the most part, a voluntary compliance approach is ethically superior to mandatory compliance, assuming that the necessary behaviors can be achieved. Self-imposed quarantine in one's home rather than in a supervised facility is one example. Social distancing orders without too much in the way of surveillance and enforcement are another. Voluntary compliance has a strong role in public health emergencies because people are fearful for their own lives and health and see that the restrictions are beneficial; people also feel in their conscience the importance of not putting others at risk by failure to comply with the emergency plans requirements.

Nonetheless, when it is clear that individuals pose a serious risk to others by their unwillingness to comply with behavioral restrictions, there is clear ethical justification for compelling them to do so. Similarly, when it is believed on the basis of sound evidence that large numbers of people in the population are unlikely to comply with various restrictions voluntarily (a curfew or home quarantine, for example), mandatory policies backed up by law enforcement are justified, although they should be used with the utmost restraint and judiciousness.

Mechanisms for individual hardship appeals should be readily available.

Situations of justifiable coercion exist, but they should be arrived at gradually. Attempts at correcting misinformation and at rational persuasion should be made before more punitive or physical measures are used. This standard applies both in cases of harm to others, where ethical justification is relatively straightforward, and in the more difficult cases of noncompliance involving only harm to self (87,88).

In the PHEPR context, it is unlikely that too much time or energy will be expended on those whose behavioral limitations (or noncompliant behavior) poses only a risk to themselves (89-92). Rescue workers during a flood will not linger too long to persuade a person to leave their home when there are still many other people up the street awaiting rescue. Also, the scarcity of time and human resources raises the question of whether it is fair to others to take the additional time necessary to gradually work through the steps along the spectrum from persuasion to coercion. Moreover, attempts to use physical coercion by those not properly trained in such techniques will put both themselves and the noncompliant individual at risk.

If mandatory restrictions on liberty are ever chosen by public health planners and policy makers, they have a responsibility to ensure that adequate resources are available to enforce those requirements fairly and humanely. This is but one example of the general proposition that a part of ethically responsible PHEPR is to provide adequate training and materials to public health workers and other public safety officials and first responders so that they can do their jobs effectively and safely. Risk inherent in the situation does have to be accepted by those who volunteer to serve, but risks that are artifacts of poor planning and policy are unjust and should not be imposed on anyone. One can easily realize how much PHEPR involves matters of ethics by remembering the consequences of not doing it well.

Allocation of Resources

Perhaps the most pressing, difficult, and anxiety-provoking ethical issues prompted by disaster preparedness and mitigation activity concern the problem of distributive justice. If a pandemic of avian influenza were to strike the United States, who should be given priority in the distribution of scarce vaccines, antiviral medications, and ventilators? When the next devastating hurricane overwhelms coastal communities, which affected neighborhoods or population groups should be evacuated first? Should society invest significant resources to try to rescue those who have chosen to remain in place? If the United States experiences another anthrax attack, should antibiotics first be given to politicians or postal workers? In the face of death and scarcity of resources, the old questions remain as relevant and disturbing as ever: Who shall live when not all can live? How shall we choose who lives and who dies?

Allocation of Resources

Key Points

- ❖ Thinking about just allocation of resources in the context of a public health disaster is complicated by chaos during the response phase, pervasive uncertainty, lack of consensus on the relative merits of stockpiling or building up basic infrastructure, and pervasive value conflicts, such as maximizing public welfare versus fairness or equity.
- ❖ It is important to think about, and try to reach consensus on, allocation issues well in advance of a crisis.
- ❖ In addition to traditional utilitarian goals of public health, e.g., maximizing the number of lives saved or the number of quality-adjusted life years, public health should seek to achieve fairness or equity by focusing efforts on the most vulnerable sectors of the population, e.g., the poor, racial minorities, and people living with disabilities.
- ❖ Since there does not appear to be a single right answer to the question of how efficiency and equity should be balanced in responses to public health crises, it is crucially important to develop a fair process that will both effectively engage the public in planning and lend moral legitimacy to the results of deliberation. Even if there is no consensus on a single correct way to balance efficiency and equity, it might be possible to achieve a greater degree of consensus on what would be a fair process for coming to a decision.

The elements of fair process include:

- ❖ Transparency and publicity;
- ❖ An appeals process;
- ❖ Resorting to publicly available, nonsectarian reasons in attempting to justify policies, and;
- ❖ Active engagement with stakeholders.

In addition to these urgent questions posed at the point of distribution in the trenches, society faces equally difficult policy choices concerning how much to spend on the production and stockpiling of medicines and materials in anticipation of a crisis, particularly when those resources will go to waste if a crisis does not occur as feared. Suppose policy makers take the seemingly prudent course and decide to stockpile vaccines, antiviral drugs, antibiotics, ventilators, hospital beds and other life-sustaining resources. How large a stockpile should they

create, and at what cost? As the richest nation on earth, perhaps we should attempt to create a cache of goods so massive that it might preclude the necessity of rationing should disaster strike. However, given the equally massive opportunity costs^{**} involved in such an undertaking, the low likelihood of disasters actually striking at any particular place and time, and the need to constantly replenish aging stockpiles of dated drugs, perhaps it would be better to deemphasize the importance of stockpiling in favor of building up a basic public health infrastructure and hospital overflow capacity. If it is decided to stockpile, how much of current public health and national budgets should be devoted to this enterprise, and what sorts of items constitute the best candidates for this purpose?^{††}

Questions of justice often achieve special saliency in the course of disasters because disasters often feed upon and exacerbate deep-seated, chronic, and pervasive patterns of social injustice that precede them. Hurricane Katrina provides perhaps the most graphic illustration of this phenomenon. Although that natural disaster wreaked havoc upon rich and poor alike, the poor and marginalized, neglected for so long, bore the brunt of the catastrophe (12). The faces of the displaced and desperate survivors in the New Orleans Superdome were by and large the faces of poor and middle-class African-Americans who lacked the money or the means to escape from the rising waters. Many of the medically and socially worst off citizens of that city, e.g., those with physical and mental disabilities and their families, never even made it to the Superdome, victims of drowning in their own homes or on the lower floors of abandoned facilities. Disasters thus tend to highlight and exacerbate the deep social fissures and chronic social injustices that haunt our society.

^{**} Here we follow the standard meaning of this term in economics, where the “opportunity cost” of any given public expenditure, x , is the value of those alternative opportunities society must forego because of a decision to spend money on x rather than on those other things.

^{††} For information on current stockpiling goals and procedures, see: <http://www.bt.cdc.gov/stockpile/>.

Why Deliberating about Disasters and Justice is So Difficult

Even under the best of conditions, thinking about the nature and demands of justice is difficult and contentious. As with any area of philosophy, fundamental questions of justice generate conflicting answers and rival “-isms”— e.g., utilitarianism, egalitarianism, libertarianism, and communitarianism. Even beyond the usual problems posed by the essentially contested nature of philosophical argument, there is ample reason to worry that thinking about justice in the context of disaster planning and response will face particularly vexing obstacles. First, some might argue that thinking about just responses to disasters is pointless precisely because disasters, by their very nature, tend to overwhelm a society's capacity for rational thought and planning. Large-scale disasters engender large-scale social chaos. Reliable information is scarce, resources are quickly tapped out, front-line responders are stretched to the breaking point, and the desperately needy in ever greater numbers cry out in anguish for rescue. In the fog of chaos, one might argue, thinking about justice is a distracting waste of time; the best we can do is rely on ad hoc, seat-of-the-pants judgments and muddle through as best we can. Although the chaotic aftermath of any given disaster is a context particularly ill-suited to measured deliberations bearing on distributive and procedural justice, this does not warrant mitigation activities guided exclusively by considerations of efficiency, the greatest good of the greatest number, or a kind of amoral realism in which might makes right. On the contrary, the ability to predict in advance the fog of chaos makes it all the more imperative to deliberate about just responses to disasters well before they occur.

A second, more significant difficulty is posed by a question at the very heart of disaster planning: What share of the health-related budget should be directed at future planning specifically for various kinds of disasters, and what share should be devoted instead to the

establishment and maintenance of a robust public health infrastructure capable of providing sturdy all-purpose defenses against a wide variety of both current and future threats? The danger here is that planners might be seduced into irrational thinking by the prospect of a bioterrorist attack that threatens catastrophic losses but whose probability of occurring is actually quite low. (For an analogous example of this kind of thinking, one prominent public official has opined that in the context of the post-9/11 world, "...if there's a one percent chance that Pakistani scientists are helping al Qaeda build or develop a nuclear weapon, we have to treat it as a certainty in terms of our response." [93]). Obviously, this way of approaching problems focusing narrowly on the worst possible scenario can often lead to counterproductive results.

The questions arise, then, regarding whether the national interest will be best served by insuring ourselves against such high-damage/low-probability future threats, or by investing in strengthening public health defenses against any and all present and future threats to the public's health. More concretely, should government spend the greater part of its preparedness budget on shoring up the capacity of biological and chemical laboratories, which are used every day, or should it also invest heavily in building laboratory capacity against future radiologic attacks that might never take place?

Unfortunately, there is no clear-cut theoretical solution to this problem. Rational prudence would dictate some form of social insurance against the prospect of catastrophic disasters, especially for a rich country like the United States. Once disaster strikes, the public will want to know whether its worst effects could have been foreseen; and if they could have been foreseen, why they were not prevented. In retrospect, spending additional millions of dollars in the year 2000 on shoring up the levees protecting New Orleans would have been the obviously prudent choice. On the other hand, spending millions or billions annually to prevent

potentially catastrophic events with an extremely low probability of occurring might turn out to be the public health equivalent of the Maginot Line.^{‡‡}

A third problem underscores the more general issue of uncertainty in disaster planning. That is that the inability to make accurate predictions extends not simply to whether or not a particular sort of disaster is going to occur, but also to the magnitude of all impending threats and to the particular populations or age cohorts that might be most threatened by them. Planning for a pandemic of influenza implicates many such uncertainties. Before a pandemic emerges from its incubator, health officials will not know what specific virus to target with a specially crafted vaccine, what range of effects antiviral drugs will have against it, and which age or population groups will be most severely affected (94). The lesson to be drawn from the existence of such pervasive uncertainty is that whatever conclusions we reach about the justice of any proposed mitigation activities must be considered provisional and subject to revision over time as the disaster unfolds. Flexibility in response to changing conditions and evolving knowledge will be crucial to successful disaster planning and mitigation activity.

A fourth difficulty for thinking about the justice of disaster responses stems from the existence of conflicting values at stake in such situations. The task would be considerably easier if disaster mitigation activity implicated only a single overarching value, such as saving as many lives as possible. In such a case, planners would simply have to identify the dominant value and then array resources so as to afford it maximal protection. Unfortunately, the fact of scarcity often throws into relief several conflicting values that vie for our attention and resources, both in normal everyday life and especially during disasters. In the example of pandemic influenza,

^{‡‡} The Maginot line was a chain of defensive fortifications built by France on its eastern border between World War I and World War II. It was designed to stop any future invasion by Germany, but in World War II, the Germans conquered France by going around the Maginot line to the north.

priority setting with regard to the deployment of scarce vaccines or antiviral drugs might well be directed at saving the most lives, but priority might also reasonably be given to preserving vital social and economic infrastructures, to safeguarding the young rather than the elderly, or the disabled rather than the able-bodied. Here too, there is no reliable societal consensus regarding the proper weight that should be attributed to some conflicting values, and this will make it difficult, if not impossible, to resolve rationally many disagreements over the justice of disaster mitigation activities. Many such conflicts involve tradeoffs between the maximization of certain values (e.g., lives saved or quality-adjusted life years [QALY] secured) and the equitable distribution of resources. That is, in many cases securing the “best possible” results, however defined, might conflict with exhibiting the sort of concern demanded by justice for every group potentially affected by these decisions. Such conflicts between achieving maximal efficiency and the equitable treatment of all concerned go right to the heart of just disaster planning and mitigation activity.

Conceiving Justice as Efficiency and Equity

For most of its long history, the field of public health has defined itself and its guiding orientation in opposition to the practice of clinical medicine. Whereas medicine’s focus is the individual patient, public health has focused on the health of entire populations; and whereas medical ethics has in large measure been guided by individualistic and deontological (duty-based and rights-based) norms of fidelity to the interests of individual patients, public health has gravitated towards a largely consequentialist and social welfare-oriented or utilitarian ethic focusing on maximizing population health. Traditionally, the norms animating the enterprise of public health have tended to place the safeguarding of public health and safety above the

concerns of individuals whose condition or behavior might threaten society's wellbeing. In many ways, this focus on the maximization of good consequences comes naturally to public health, as does a utilitarian conception of justice that holds that a pattern of distribution of benefits and burdens across a population is just (or ethically justified on grounds of justice) when that pattern maximizes aggregate net benefit or provides a greater aggregate net benefit than any other practical alternative. For utilitarians, the maximization of welfare is the very definition of justice (95).

However, the traditional ethical orientation of the field of public health has not defined justice only in terms of maximizing aggregate net benefit; public health is also deeply committed to a view of justice that is concerned with the fairness and human impact of the way benefits and burdens are distributed in society as well as the aggregate results of that distribution. This emphasis on the protection of basic needs of all individuals and groups and on the equity of distribution has no doubt accounted in large measure for public health's traditional focus on the poor and dispossessed within society. Given the historical and epidemiologic correlation between poverty and disease, it should not be surprising that public health has adopted a special concern for the health needs of the poor and marginalized sectors of society. Whether one is attempting to combat the HIV epidemic, drug-resistant tuberculosis, or the after-effects of a devastating hurricane, the surest route to achieving maximal health returns is to focus attention on the plight of the poor, whose living conditions create efficient transmission of infectious diseases and the most likely victims of natural disaster. Efficiency and health maximization are not the only reasons for a special focus on the poor and socially vulnerable, but they are powerful reasons nonetheless. In sum, the tension between efficiency and equity—bang for the buck and fairness—lies at the heart of the problem of distributive justice as it pertains to public health.

Conceiving of justice as efficiency or the maximization of results prompts the question: Maximization of what? Different answers to this question will yield different policy recommendations, both in public health and in disaster planning. First, one might view utility or general welfare as the maximand, which would lead to adopting a straightforwardly utilitarian theory of public health justice. In this view, actions and policies should be governed by social value criteria that include but transcend a concern for health outcomes. In the context of disaster mitigation activity, such a theory of justice would give priority not only to front-line public health workers but also to key political decision makers and to workers in industries critical to economic welfare. Pushed to a logical extreme, such a theory could countenance prioritizing young healthy workers for pandemic influenza vaccine on the grounds that the greatest economic cost exacted by an influenza pandemic would be attributable to massive loss of life in the healthy working population.

In general, utilitarian theories of such broad scope are not appropriate for decision making, either within health policy or public health, where the target of justice should remain focused upon health outcomes. This would still permit planners to prioritize front-line public health workers, vaccine manufacturers and transporters, and other personnel indispensable for maintaining vital infrastructures both in health care and public health. Still, focusing exclusively or primarily on health outcomes creates the task of determining which health outcomes are the most appropriate target for public health mitigation activities in time of crisis. Should the maximand be some sort of quantitative measure, such as quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs)? According to these methodologies, people rate various states of health and well-being ranging from 0 (death) to 1 (perfect health). Then a mitigation activity's likely effect on quality of life (e.g., moving a patient from .7 to .9) is multiplied by the

effect's duration and, finally, by the number of people thus affected. The cost per QALY can then be computed by dividing the estimated total bill by the number of QALYs promised by a particular mitigation activity. Formulas like this are intended to focus spending on those procedures that promise the most health-related bang for the buck.

Although methods of this sort have proved useful in setting priorities in health policy and public health, they remain highly controversial, primarily because of their tendency to obscure or preclude tradeoffs between the maximization of health and other important values. Critics charge, for example, that QALY/DALY approaches tend to give short shrift to the elderly and the disabled on the grounds that money spent on them will not generate as many QALYs as care given to younger people or to those who can be returned quickly to normalcy. The worry, then, is that such approaches are inherently discriminatory towards those who are often regarded as the most vulnerable or needy.

A third interpretation of the object to be maximized would simply target the number of lives saved with available resources, regardless of the number of QALYs those lives have to offer (96). This simple and clearly stated objective has intuitive appeal. It would give priority to those who are most at risk for death or serious morbidity, and to whose cure or rescue has the highest chance of success. Those whose rescue or cure would require extraordinary expense or who most likely would not respond to treatment (e.g., elderly, immunocompromised nursing home residents) would not be favored. A distributive principle framed in terms of saving the most lives would also avoid some of the problems inherent in more utilitarian views. For example, unlike some applications of utilitarianism that strive for maximal economic or social benefit, it would not give priority to politically and economically favored sectors of the society, and would thus be less likely to erode social trust among the population at large.

Although the “most lives saved” metric meshes nicely with the population-based approach of public health, and although it might provide reliable guidance in many contexts, it too is vulnerable to the criticism that it ignores or precludes other important values. Like the QALY method and all conceptions of justice as the maximization of some value or other, this approach can be faulted in some contexts for ignoring the fairness of its favored distributions (97). In addition to producing the greatest amount of overall welfare, the most QALYs per dollar, or the most lives saved, a theory of justice is also expected to “give everyone their due.” For some alternative approaches to justice, this will mean giving priority to the worst off or the most vulnerable, or ensuring that everyone has a fair chance at benefiting from a given distribution, or that everyone’s basic, human needs are satisfied—regardless of the impact of such prioritization on our ability to maximize anything. Such alternative approaches are referred to as theories of “justice as equity.”

According to this rival conception of justice, these equity concerns can function either as external checks and balances imposed upon the field of public health conceived as a health maximizing enterprise, or they can be embraced within an alternative, more capacious conception of public health as an enterprise at the service of social justice. With either interpretation, the traditional public health focus on the poor and marginalized can best be explained not simply as part of a health maximizing strategy, although it is surely at least that, but rather by viewing priority for the poor and marginalized as a demand of social justice (39). In this view, those whose basic needs have not been met by society, those whose fundamental human capacities have been systematically stunted by unjust social institutions, have the greatest claim on resources at the disposal of public health.

At the very least, justice as equity would mandate various checks on the achievement of greater population health at the expense of individual rights, e.g., through the precipitous isolation of infectious but compliant individuals. At most, it would claim that a concern for human rights is an integral aspect of the mission of public health. In the context of disaster mitigation activity, justice as equity might mandate priority for the poor, people living with disabilities, and the socially isolated. Moreover, a more controversial equity-based view might give priority to saving the young (e.g., in a context of pandemic influenza) before the elderly, not on the convenient ground of social utility, but rather because justice demands it. In this view, the elderly have already lived (most of) their lives; they have already played out their “fair innings” (98). Children and young adults, on the other hand, have yet to live out their allotted span of innings and thus have a greater claim to public health resources.

The equity perspective thus complicates the task of doing justice in the context of public health disasters. Whether equity concerns are viewed as externally imposed checks on the achievement of public health goals, as the traditional view would have it, or as internally articulated priorities of public health, the maximization of good consequences will have to be weighed and balanced against countervailing values. This tension poses a fundamental problem for a theory of public health justice because there is no consensus, either within society at large or within the ranks of philosophers, on exactly how such conflicts of value should be resolved. Most of us believe that equity concerns should temper the achievement of maximal health-related results, at least to some extent, but there is reasonable disagreement in many cases on how far the scales should tip in the direction of priority for the poor, the disabled, the vulnerable, or the young. What costs in terms of overall population health outcomes is a society willing to pay to safeguard the basic interests of various vulnerable groups? Even if we could all agree that

those who are worst off deserve some degree of priority, concentrating resources on the desperately sick might in some circumstances be terribly inefficient at saving the most lives (99).

Suppose, for the sake of argument, that vastly more people could be saved during an influenza pandemic by targeting vaccines at school-age children, who quite efficiently transmit infectious diseases to their families and, in turn, to the society at large. Would justice demand that priority be given instead to debilitated, immune-system-depleted, elderly nursing home patients, who might plausibly be defined as the most vulnerable group? It is not at all clear that justice would demand such a dramatic tradeoff with efficiency, defined as the ability to save the most lives. At this point, theories of justice appear unable to resolve such reasonable disagreements. Certain ethical principles might be clearly wrong (e.g., “Let the free market decide who shall live”) or unfair in application (e.g., a lottery), but many proposed trade-offs between the maximization of health and conflicting equity concerns appear to fall within a range of ethical acceptability, even if none may strike us as uniquely just or ethically correct.

From Substance to Process

Because theories of justice do not yield univocal solutions to such balancing problems, political philosophers are increasingly recommending processes of democratic deliberation as a crucial supplement to substantive theory (99,100). In this view, a number of possible trade-offs might be plausibly justified by conflicting sets of values, so the task is to formulate fair rules for a process that will serve to legitimate a particular social choice. The focus here is not on theoretical correctness, although it is often assumed that all the live policy options on the table will be “just enough” or not demonstrably unjust; rather, the focus is on legitimacy, or the question of why free and equal citizens should accept any given political decision, especially

those bearing on tragic choices of life against life. All persons believe that their life is of equal value to the lives of others, so if any particular tragic choice favors others over us or our loved ones—e.g., if a decision has been made to give a ventilator or vaccine to someone else, and if we are likely to die or suffer greatly because of that choice—we will certainly insist upon knowing who made the decision and what reasons have been given to justify it. Above all, we will seek reassurance that the decision was fair and that it was reached by a fair process.

Typical requirements for fair process include the following:

- **Publicity or transparency in decision making.** Contrary to those who believe that such tragic choices will prove socially toxic to a public unwilling or unable to contemplate them (*101*), the partisans of deliberative democracy hold that when it comes to matters of social justice, and especially to matters affecting who shall live and who shall die, publicity and transparency about the grounds for decisions is a prerequisite of their legitimacy. Those who might have to pay the ultimate price of rationing decisions have every right to know how those decisions were reached and on what grounds. Secrecy or the rule of experts behind closed doors is by nature an unaccountable decision procedure that can obscure all manner of stupidity and injustice, including favoritism for one's family or social group and discrimination against minorities or the socially marginalized. Thus, in addition to being a precondition of legitimacy, publicity can help guarantee that decisions will be as well informed as possible and, hence, will tend to be more substantively correct or just over time than decisions reached in secret. As an example, an economic study has been unable to document a single instance of large-scale famine in open, democratic societies with a free press. By contrast, examples of famines or horribly

managed natural disasters are depressingly easy to document among secretive military regimes (102).

- **An appeals process.** Those who disagree with a certain value ordering or who believe they or others have been unfairly disadvantaged by a social choice should be able to appeal the decision to responsible and responsive authorities. This will help ensure that principles are being fairly applied and that decision makers remain open to the lessons of new experiences and arguments. The existence of an appeals process testifies to belief that all persons are equal in moral status and have a right to have their grievances aired and addressed. When conjoined to the publicity condition, the appeals requirement can provide society with a public record of criticisms bearing on allocation criteria and of official responses to them. (Obviously, an appeals process without a publicity condition would be useless, as one would have no idea what exactly to protest.) This sort of record can function analogously to the body of appellate decisions in common law systems like that in the United States, where principles constantly undergo reinterpretation and specification in light of new fact patterns and fresh perspectives on value orderings. Public scrutiny of this public record of criticism and official response could help detect and rectify inconsistencies in past patterns of decision making, and public officials would have to either abandon or defend such choices (e.g., on the grounds of differing circumstances). Ideally, the result could be a growing body of increasingly sophisticated, morally justified and politically legitimate case judgments that could inform future policy.
- **The relevance condition.** Some defenders of deliberative democratic procedures have proposed that limits be placed on the kinds of reasons that might legitimately be

advanced in such public deliberations (99). The only reasons that should count in public allocation decisions in health care or public health are those that could be accepted as relevant by fair-minded people who are disposed to find mutually justifiable terms of cooperation. Perhaps more sharply put, this means that appeals to reasons, evidence or principles that could only be accepted by those already committed to some sectarian (i.e., religious) viewpoint will be ruled out of order.

This limitation on public deliberation is suggested for two reasons. First, coming to broadly acceptable social decisions on such morally and politically fraught issues is difficult enough without having to wade through fundamental and rationally irreconcilable religious commitments bearing on life, death, and our place in the universe. Second, the relevance condition is advanced in order to protect free and equal individuals from the imposition of public policies whose grounds (in sectarian religious doctrine) they could not freely accept. In the context of abortion and physician-assisted suicide, the imposition of sectarian religious beliefs upon the entire body politic has been said to amount to a kind of tyranny (103).

As opposed to the publicity and appeals conditions, this relevance condition is controversial and potentially problematic (104). Although designed to simplify public deliberation by bracketing highly contentious religious appeals, this condition leaves in place many equally contentious claims emanating from ethical or political theory on which many reasonable people can and do vehemently disagree. As a result, the process of deliberation is not likely to be substantially facilitated by automatically discounting certain beliefs or arguments because of their religious provenance. In addition, many if not most, persons' approaches to questions of ethics and public policy are no doubt in

large measure shaped by their own religious commitments. To officially rule out all such religious sources would thus have the effect of disenfranchising a large segment of the population from the deliberative process, and would no doubt be interpreted by those excluded as a kind of demeaning marginalization. This problem could, however, be ameliorated somewhat by interpreting the relevance condition as excluding only those religious arguments that could not be given a secular translation. For example, religious arguments for racial integration and against legal segregation could be stated either in the language of the Hebrew prophets used by Martin Luther King or in the language of justice and equality. King's biblically-based preaching for social and legal equality would thus not run afoul of the relevance condition.

- **Democratic participation/involvement of stakeholders.** A major theme in much commentary on democratic deliberation is the need for greater citizen participation in public policy decision making. For policies to achieve genuine legitimacy in the eyes of the public, more is needed than publicity and an appeals process. Notwithstanding their crucial importance, those two conditions cannot do much to allay the perception on the part of many that life and death policies in public health are imposed upon them from on high by distant bureaucrats.

The primary remedy for this perception is greater involvement of the public in public policy formation. The guiding idea is that those whose interests are affected by public health policies, and especially those who are negatively affected, will be more inclined to view such policies as legitimate and fair if they (or others like them) have had a voice in the development of such policies. So it behooves decision makers in government and public health to strive for enhanced public participation, not only

because such participation is a source of legitimation, but also because it is the best way to secure crucially important collaboration between public health officials and the public in a common, communal effort to secure the public's health (105). The Oregon Medicaid rationing experiment provides a good illustration of this point. Despite many warnings that the public could never accept transparent discussions bearing on the rationing of health care, Oregon seems to have been largely successful in its effort to solicit public engagement and support for explicit health-care rationing (106).

Although there is widespread agreement on the desirability of enhanced public participation in the policy formation process, it is less clear exactly what such participation would look like. There is, in fact, widespread disagreement on the exact form that such participation should take, who should be asked to participate, what should be the ground rules for discussion, what information should be provided, and how to judge the results. There is, moreover, some well-founded skepticism that inviting various stakeholders or community representatives will automatically ensure the democratic bona fides of deliberative outcomes. Great care must be taken to secure broad representation of affected populations, especially among those who are the least well off, most in need, and least politically connected.

Although grappling with the fine points of the democratic participation condition is a daunting task, and although we are nowhere near knowing enough about this process to advance confident practical conclusions in this white paper, we view this as a crucially important condition for the legitimacy and acceptability of public health decision making bearing on the allocation of scarce resources, and we encourage efforts on many fronts to experiment with different routes to greater and more effective democratic participation in

the deliberative process (48,105,107). Although a robust emphasis on establishing fair processes is unlikely to solve all problems in this area, and although vexing and divisive issues of moral principle may well resurface in debates over what exactly constitutes a fair process (108), we are confident that a process viewed by most citizens as fair will help lend legitimacy to public policy governing PHEPR and forge trust-engendering bonds of social solidarity between public health officials and the general public.

Justice in Stages

Several different sorts of justice/allocation issues might arise during the planning, response, and recovery phases of PHEPR, and these will be briefly discussed here. The planning phase is a crucially important period for integrating justice-based concerns into disaster preparedness. Because planners will not be able to deliberate in a serious or sustained way about justice in the thick of a disaster, they should be asking right now what sorts of responses are ideally (or at least adequately) just, and which processes for decision making are ideally or adequately fair and legitimate. This is the period during which crucial decisions will have to be made about what sorts of resources and how many of each should be stockpiled for eventual distribution in a public health emergency, whether natural or manmade. It is also a time to deliberate about the proper criteria for allocating scarce resources, to enlist the public's participation in this process, and to secure public support for whatever criteria are selected. This is the time for asking and grappling with the difficult questions, such as whether age should be a legitimate criterion for allocating ventilators or vaccines during a pandemic of influenza, and what percentage of the national wealth should be allocated to helping other nations cope with

threats that implicate all countries, such as pandemic influenza. This process should take place at all levels in society, from town councils to CDC and beyond.

If this job has been done adequately during the planning phase, substantive criteria for distribution and fair processes should already be in place awaiting deployment during the response phase. This is not to suggest that advance planning will obviate the need for thinking about justice in the thick of an emergency. Like war, public health emergencies have a way of foiling the best laid plans and wreaking havoc with carefully wrought protocols. Resources will be exhausted and personnel will be stretched to the breaking point, and no matter how much planning has taken place, health officials will no doubt be surprised and confounded by events at hand. Hard choices in the thick of disaster will have to be made.

In addition to the planning phase of PHEPR, the recovery phase is also a period when serious considerations of distributive justice, equity, and fairness should be factored into policy and decision making. Even as background social inequalities and special vulnerabilities may magnify the disruptive effects of a public health emergency on certain individuals or groups, so too will such background factors affect how readily certain segments of a community will be able to recover and rebuild following a disaster event or emergency situation.

Justice during the recovery phase involves allocation of scarce resources among individuals and groups in need, and it is closely tied to the notion of resilience at the level of entire communities. A community marked by just social practices and a commitment to social justice before an emergency is likely to carry that commitment through the emergency response and into the aftermath and recovery period. Such communities are likely to be better able to rebound quickly and recover effectively, and such communities will likely meet the benchmarks of both justice and resiliency in their recovery process and outcomes. Resources will normally be

scarce during the recovery phase, and the pace of rebuilding and recovery will not be the same for everyone who needs these resources and assistance. Priorities will have to be set concerning when and in what order people receive assistance, even if eventually there will be sufficient recovery resources to go around.

Policies and decisions that meet the ethical tests of justice will not place an undue burden on any one segment of the population in the recovery phase, and such policies will attempt to bring about as even-handed and uniform a pattern of assistance and recovery as possible. Generally speaking, priority in recovery efforts should be provided on the basis of greatest need and greatest impact. Those who will be otherwise homeless, for example, might be given priority on lists for temporary housing and shelters over those who have family or other private means of temporary housing assistance. Those at greatest health risk because of the dislocation of their ordinary routines and modes of living should be given special attention in preference to those who are experiencing inconvenience but are not being placed at serious risk. Those whose small businesses cannot survive a prolonged closure or period of inactivity might receive priority for available business recovery loans.

Not only the fact of recovery assistance per se, but also the nature and timing of that assistance are important factors in the distributive and priority-setting decisions in the response phase of PHEPR. An old saying in the criminal justice context, “Justice delayed is justice denied,” can be adapted to a similar maxim for PHEPR: “Assistance delayed is assistance denied.” This consideration bears especially on the mechanisms that are set up to handle the allocation and utilization of recovery assistance. Here considerations of justice and fairness cut two ways. On one hand, justice requires that waste, fraud, and abuse be prevented as much as possible so that assistance actually does arrive at its intended and appropriate destination.

Procedural and administrative safeguards should not be lightly dismissed as mere “red tape;” they have an important ethical function in any public service setting.

On the other hand, excessively restrictive, bureaucratic, and inflexible procedures during the response phase will also undermine the goal of justice. Health officials must not spend so much time determining whether a patient is eligible to receive a medicine that the patient deteriorates while waiting. They must not make it so onerous to restore business functioning, education, housing, environmental remediation and other elements of recovery that a community expires from outmigration, capital flight, and social despair.

Meeting the Special Needs of Vulnerable Populations

Previous sections have focused on the ethical values of life, safety, health, liberty, and justice (equity and welfare maximization) in the context of PHEPR. The theme that unites these various discussions is the reconciliation of respect for persons and individual dignity with service to the entire community and the common good. This theme can be deepened and explored more fully in the context of protection and service to those who, in an emergency event and its aftermath, will be especially vulnerable to harm and injustice—the loss of life, health, or dignity. “Vulnerability” is sometimes partly a function of the capabilities and personality of the individual. However, more frequently, and more relevant for the purposes of this report, vulnerability is a function of the social systems and resources that shape individuals' options and individuals' practical ability to utilize their own inner strength and intelligence to protect themselves in the face of danger or disruption. Moreover, vulnerability need not be a global condition that characterizes all facets of an individual's life. It is better understood as a notion that is specific to particular situations, problems, and tasks.

A concerted effort to anticipate and plan for special needs and cultural accommodation is an essential part of preparedness planning (109,110). During the planning phase, this effort most often involves direct consultation with and participation of those with special knowledge or lived experience pertinent to individuals and groups who have such special needs. Then, during the response phase, an equitable use of resources and a genuine commitment not to abandon those at special risk must inform the decisions and mitigation activities during the emergency response phase and its aftermath. Finally, the concept of vulnerability and special need should continue to be taken into consideration and recognized during the recovery phase (111).

Meeting the Special Needs of Vulnerable Populations

Key Points

- ❖ A concerted effort to anticipate and plan for special needs is an essential part of preparedness planning.
- ❖ “Vulnerability” is sometimes partly a function of the capabilities and personality of the individual. However, more frequently, and more relevant for the purposes of this report, vulnerability is a function of the social systems and resources that shape individuals' options and individuals' practical ability to utilize their own inner strength and native intelligence to protect themselves in the face of danger or disruption. Moreover, vulnerability need not be a global condition that characterizes all facets of an individual's life. It is better understood as a notion that is specific to particular situations, problems, and tasks.
- ❖ Emergency plans and response procedures should make special accommodation and provision for those with special needs or impairments who will suffer disproportionate burdens or be denied rightful benefits if their impairments are not compensated for by environmental mitigations, special equipment, resources, or services.
- ❖ PHEPR cannot be a substitute for a broad, progressive effort to improve services for those living with chronic illness and disability, for children, for the elderly, for poor and minority persons who are underserved, or for those who need long-term care. However, it can at least try to ensure that persons and groups with special needs are not forgotten or abandoned in times of crisis or emergency.
- ❖ Some persons and groups have background conditions and situations that compound their vulnerability during emergencies and expose them to special kinds and degrees of risk and disruption.
- ❖ Persons and groups with special susceptibility to harm or injustice during public health emergencies exist in virtually every community and should be carefully identified and assessed during the planning process prior to emergency events. It is unlikely that their special needs will be met on an ad hoc basis during an emergency in progress. Advance planning and preparation are vital to protect these individuals.
- ❖ General plans about contacting and providing services to people with special needs are important, but in emergencies when transportation is difficult and telecommunication unreliable, local emergency responders must have precise local knowledge concerning detailed special needs and precise physical locations. Advance registration programs and local neighborhood support networks can be helpful for this purpose.
- ❖ It is important not to overgeneralize or to base PHEPR on stereotypes or unexamined assumptions concerning those with special needs. Their attitudes, preferences, and resources are not all identical.

- ❖ Provide culturally and functionally appropriate informational and educational resources for individuals with disability, their family members, and others who care for them about what to expect in times of emergency.
- ❖ Public health measures designed to limit the spread of infectious diseases, such as social distancing, pose many problems for vulnerable populations.
- ❖ To facilitate good planning, persons with special needs or their representatives should have an opportunity to participate actively and directly in the PHEPR process.

PHEPR cannot be a substitute for a broad, progressive effort to improve services for those who are vulnerable or who have been pushed to the margins of society because of racial and ethnic discrimination, poverty, or the fact of living with chronic illness and disability or being in need of long-term care. However, it can at least try to ensure that persons and groups with special needs are not forgotten or abandoned in times of crisis or emergency; that they too will be rescued, protected, and provided for; and that they too may hope to survive an emergency and emerge on the other side to resume lives of dignity and meaning. PHEPR can also benefit from the strengths and assets present in the neighborhoods and communities where vulnerable persons live, for these communities often have the local knowledge, trust, and outreach capabilities that PHEPR needs in order to be successful.

The Concept of Vulnerability

During a public health emergency, all persons experience unusual and often urgent needs for rescue, protection, vaccination, medical treatment, and other public health support. To that extent, any emergency makes everyone “vulnerable;” no one is completely self-reliant, and serious and urgent needs call for an ethical response of mutual aid, caring, and attention.

Nonetheless, some persons and groups have background conditions and situations that compound

their vulnerability during emergencies and expose them to special kinds and degrees of risk and disruption (112,113).

These background conditions arguably call for a special ethical response and a heightened degree of concern and attention. As previously noted, disasters tend to highlight and exacerbate the deep social fissures and chronic social injustices that haunt a society. Shortcomings in emergency preparedness and response are often a function of pre-existing inadequacies in the public health infrastructure and in other service systems. The devastation of New Orleans and other areas along the Gulf Coast in 2005 after Hurricane Katrina vividly demonstrated that some individuals and groups are much less able than others to protect themselves and to take advantage of public health and public safety systems, even when those systems are functional and accessible (which they sometimes are not). It also revealed the moral shame of discrimination and unfairness that can easily arise when resources are scarce and systems are under unaccustomed stress (12,14,15,68,69,71).

As mentioned, the concept of vulnerably refers to social, economic, and cultural inequities as well as to biological impairments. Although difficult to define precisely or to enumerate exhaustively, various types of vulnerabilities and special needs exist that PHEPR must plan for and make special deliberate efforts in advance to accommodate. These vulnerabilities come from many different sources and situations, including the following:

- Chronic physical or psychiatric disease
- Physical, sensory, or motor impairments
- Cognitive or emotional impairments
- Developmental immaturity or disability
- Physical isolation

- Social isolation
- Poverty and lack of material resources
- Lack of support systems and other social resources (e.g., homelessness)
- Fear of contact with authorities (e.g., the reluctance of undocumented aliens to call official attention to themselves)
- Strong emotional reactions that inhibit or even paralyze effective personal responses, such as fear or a desire to maintain the status quo of normal life and everyday routine (“I will not leave my home!” “What is going to happen to my pet?”) (114-117).

Special needs and vulnerability do not come only from conditions that are usually thought of as “disabilities.” Vulnerability is not limited to states of special physical or emotional dependency on others, such as may characterize those with sensory or motor impairments, those with developmental or cognitive impairments, those with mental illness, children, or those who are frail and elderly. Vulnerability is also a function of social, cultural, racial, linguistic, and geographic disadvantage. Physically able-bodied and mentally capacitated persons may nonetheless be living in a condition of social vulnerability and precariousness. This form of vulnerability can be due to such factors as racial discrimination and stigma, poverty and lack of resources, lack of access to functioning and empowering social networks, or living in an area that has lack of access to services and resources or lack of access to transportation. These cultural and social components of vulnerability have often been overlooked or discounted in the field of public health emergency planning. That should change, and is changing, because the cultural and social components of vulnerability are significant in their own right, both for affected communities of class or color and for persons with disabilities, for whom social vulnerability,

perhaps as much or more than biological impairment, is a significant risk factor in their lives (110).

For these reasons, diverse types of special planning and accommodation are needed in PHEPR in order to meet the goals of justice, individual liberty and respect, and sustaining or rebuilding of resilient communities. Vulnerability does not necessarily mean helplessness. Vulnerable individuals and communities are often healthy and resilient, with many assets and resources, although those outside the community looking in often misjudge these factors. These communities simply need special advance planning and accommodations in order to help and sustain themselves.

To summarize, PHEPR activities need to be culturally as well as physically and medically appropriate. They need to take into consideration the existing memories, sentiments, and prevailing attitudes of the persons or communities in question, each of whom will have experienced their particular “vulnerability” in a distinctive way that must be acknowledged and honored if trust and cooperation are to be established. Much of this depends upon forging proper relationships, effective and trustworthy partnerships, and open, two-way lines of communication between emergency planning officials and distinct communities and neighborhoods during the planning process.

The question of how an emergency plan ought to account for and accommodate the special needs of vulnerable populations provides a kind of microcosm in which most of the ethical dimensions of PHEPR can be found. Thus far, the needs of special populations have not been systemically identified or addressed in many emergency plans at the state and local levels (11,68,109,116-119).

Key Factors in Addressing Special Needs

Persons with both physical and emotional vulnerabilities and those with social, cultural, and geographic vulnerability should be given special attention and recognition in the PHEPR process. These individuals should not be left to “fend for themselves,” even temporarily during an emergency. They may not be able to evacuate without special assistance; they may be particularly susceptible to infectious disease, which targets those whose immune systems are not only compromised by chronic illness or age but also by inadequate diet and other circumstances of poverty.

Several groups in particular will warrant more complex ethical considerations. First, research has demonstrated that racial and ethnic minorities suffer disproportionately in the wake of emergencies. They are more likely not to be adequately prepared and to experience more injuries, diseases, and deaths (*120*). Public health emergency planning must address these racial and ethnic disparities in preparedness.

Persons with some types of mental illness find it difficult to plan ahead, may be oblivious to warnings, and in some cases may be fearful or paranoid about participating in mass events, such as evacuations. Additionally, some people with mental health concerns do not consider themselves ill, will not self-identify beforehand and may resent being asked to participate because of the stigma associated with mental health problems. Some may refuse to evacuate and may place responders at risk when they are sent back into dangerous areas to provide rescue. Likewise, persons with certain intellectual disabilities may be particularly hard to reach (e.g., those with mild mental retardation who may be living independently in the community). These individuals often are very isolated, have jobs with few friends or close colleagues, and often find comfort in a very steady routine. In such cases, they will be less apt to leave a home and routine

they know well. They may be more likely to ignore warnings to leave the area and may be particularly fearful about evacuating because they are unable to figure out the complex set of instructions about where to go, whom to contact and what to take with them. The more stressful and confusing the circumstances, the more likely some individuals are to retreat to their home or apartment and try to stay put until the stressful situation is over. These persons in particular, will need special outreach long before an emergency occurs (11,68,121,122).

For example, consider the situation of a family trapped in their home by rapidly rising flood waters. In the family is a teenage boy with autism. When rescue personnel arrive, they find that a great deal of time and special communication skills are required to coax the boy into the waiting boat. The rest of the family will not leave without him. Is it feasible to deploy personnel with such skills, even if the location of families with autistic children is identified in advance as a part of the emergency plan? If many other families are waiting for assistance, is it justified to use coercion—physical restraints or medical sedation without informed consent—to remove this family more quickly? (72).

To attempt to give a general answer to such an ethical dilemma is difficult, and possibly misguided.^{§§} Difficult judgments will have to be made on the scene, taking very particular circumstances and assessments into account. It can be said in a general way, however, that with

^{§§} Generally speaking, during evacuation events, recalcitrant adults are permitted to make their own decisions to leave or to remain in place. If it is a toxic gas release, and an immediate threat to life was in the balance, perhaps no one would choose to stay, making coercive removal unnecessary; or arguably the imminent threat to life would more easily justify paternalistic coercion and forcible removal. Yet another dimension of complexity arises in the case of minor or incompetent adults. Should parents or guardians have the right to endanger such persons by refusing evacuation? Moreover, one's intuitions and judgments may vary as one considers infectious disease events and social distancing measures rather than evaluation events. This suggests that the specific context and circumstances matter in PHEPR ethics. Nonetheless, more research is needed on circumstances involving harm to children and other dependents and clearer standards on the limits of parental and guardian authority would be helpful. Here public health ethics and public health law overlap and might well work in collaboration to develop such standards.

appropriate advance planning and early identification of special needs, the number of ethical dilemmas of this kind arising during a response to emergency can probably be minimized.

It is important for PHEPR to take into account the population of isolated persons in a given area. This includes persons who, for cultural, geographic, or social reasons, generally do not fall into any other category. Examples are persons who travel from one area to another seeking seasonal work; those who are homeless and living on the streets; those who are part of religious or cultural groups who specifically avoid contact with the outside world; and individuals and groups that historically have avoided interactions with local or federal agencies.

Another example of particular vulnerability that should be factored into PHEPR, especially during the planning and recovery phases, is illustrated by the impact of Gulf Coast hurricanes on the resident Vietnamese communities. Many in these communities are dependent on the fishing industry and have difficulty accessing services for linguistic reasons. These and countless other examples are reminders that vulnerability takes many forms and manifests itself in many different ways. Personal health and safety may be put at risk; people may be displaced from their homes and supportive communities; people may be displaced from the broader economy; and people may, for linguistic or cultural reasons, be isolated from the mainstream sources of communication and social support services.

Those in charge of PHEPR during an emergency probably will need information concerning the number or location of isolated and otherwise vulnerable persons, but they must be able to retrieve it quickly and act upon it rapidly. Therefore it is crucial to collect such information in advance and to store it and keep it up-to-date in a form that will be accessible in an emergency. This may require close and culturally appropriate cooperation with established ethnic, religious, and minority groups in the community, and such special outreach measures

should be anticipated and planned. Links to such groups can be established beforehand by local emergency personnel, but in times of emergency, proactive contact will have to be arranged because it cannot be assumed that they will receive information through media or through outreach by community-based groups, such as faith-based organizations, existing social networks, or volunteer groups. In many communities, for example, a kind of census of special circumstances and needs (e.g., housebound individuals) is taken by volunteers on the neighborhood level. This information is then communicated to public health and other government agencies, such as volunteer fire departments, so that they are better able to plan in advance to meet those special needs during an emergency.

Communicating emergency information to geographically and socially isolated individuals and groups may be especially difficult (123). Some may avoid, or not have access to, mass media. Some may live in temporary quarters and not know the local area enough to be able to follow evacuation information or instructions. Those who are isolated from others—for example, someone living in a motel at the edge of town for a couple of weeks, or someone with a mental health problem living on the streets—may not interact with others on a daily basis or hear about a disaster or an upcoming emergency. Prior listing of where isolated individuals and groups exist in the community and advance identification of a specific person (perhaps with special training) assigned to follow up in times of emergency, may help reach out to these people. Those who work directly at the street level with isolated, displaced, or homeless persons probably have the most information and rapport with this population, and they can be a valuable resource for PHEPR planning.

Guidelines for Preparedness Planning for Vulnerable Populations

Addressing the concerns and planning to meet the special needs of vulnerable populations will require attention to the following guidelines:

- Persons and groups with special susceptibility to harm or injustice during public health emergencies exist in virtually every community and should be carefully identified and assessed during the planning process prior to emergency events. Without such pre-disaster event preparation, their special needs are unlikely to be met on an ad hoc basis during an emergency in progress. Advance planning and preparation are vital to protect these individuals. Moreover, general plans about contacting and providing services to persons with special needs are important, but in emergencies when transportation is difficult and telecommunication unreliable, local emergency responders must have precise local knowledge concerning detailed special needs and precise physical locations. Advance registration programs and local neighborhood support networks can be helpful for this purpose.
- Public health emergency preparedness planners should consider establishing a system whereby individuals with special needs and vulnerabilities can voluntarily register or otherwise identify themselves to local public health officials. Alternate mechanisms are important because the formal process of registration may deter many people from participating. Enlisting the aid of well trusted and respected community-based organizations is a key to PHEPR effectiveness. Such an approach begins with a general information and education effort to alert the community to the existence of the registry system and to answer their questions and concerns about it. In most communities, there will probably then be two additional phases. The first will be an initial (and ongoing)

voluntary phase during which individuals in the community take the initiative to put themselves into the registry. This should be accomplished in a variety of ways and made as convenient as possible. In the second phase, an effort is made to include those who do not voluntarily self-identify. One way to accomplish this is to enlist the cooperation of neighborhood and community groups, such as clinics; local physicians; senior centers; independent living centers; churches; trusted voluntary organizations in the community that offer special programs, shelters, and services; and local chapters of groups serving those with chronic diseases.

Public health officials should identify and work with community partners who have gained the trust of racial and ethnic minorities in order to identify at-risk persons. This should be a critical element of PHEPR because racial and ethnic minorities might be less likely to accept a risk or warning message as credible without confirmation of the message from their trusted interpersonal networks (124). Another barrier to PHEPR is that racial and ethnic minorities might distrust government officials and think that they are hostile, if not apathetic, to their well-being (125). Following Hurricane Katrina, for instance, undocumented immigrants avoided recovery assistance because they feared deportation (126). As part of the planning process, public health officials should work with churches, grassroots organizations, community-based organizations and voluntary associations to develop culturally and linguistically appropriate strategies to identify at-risk individuals. For example, many African-American churches maintain health ministries, and these may be a useful means to identify members of their churches who are at risk.

The creation of special needs databases for planning purposes raises a number of ethical questions. Should these lists be voluntary, as we recommend, or mandatory? What incentives to

register, if any, should be employed? Should individuals be permitted to designate themselves as in need of special assistance, or should some more objective basis for creating such databases be used? How can such lists be kept up-to-date? Who should have access to the database? How can databases be more effectively shared in a timely fashion? Should there be one central (i.e., regional or state) database? How should all of this be managed to balance privacy and emergency needs?

- Auditing and mapping community assets (i.e., individuals with particular local knowledge or groups with special trust and loyalty in the community) should be an integral part of PHEPR. To acknowledge that certain individuals, groups, neighborhoods, or communities are vulnerable to severe risk and disruption during a public health emergency is not to say that such communities are lacking in all assets or resources. On the contrary, vulnerable communities are not helpless. They simply need special advance planning and accommodations in order to help and sustain themselves. This reinforces the concept that PHEPR is and must be a community effort actively involving all strata of civil society, and not simply a centrally planned and top-down effort made on a service provision or public safety model.

An important element of auditing and mapping community assets is assessing the community's cultural diversity to make sure that preparedness efforts are conducted in a linguistically and culturally appropriate manner to ensure that all community members are included. A cultural assessment would answer such questions as what racial and ethnic groups make up the community, what languages do they speak, what are their cultural perceptions of risk and disaster, what are their preferences for warning dissemination, and what are the trusted organizations and institutions.

- Public health planners should not overgeneralize or base PHEPR on stereotypes or unexamined assumptions concerning those with special needs. The pitfall of stereotyping or overgeneralization of beliefs and attitudes should be avoided in PHEPR for all vulnerable groups, those who experience social and cultural marginality as well as those living with disability. Differences of cultural and geographic origin matter to people. Broad categories, such as “Hispanic,” “African-American,” and “Asian-American” are of limited value for PHEPR. A much more fine-grained understanding of local community and individual perspectives, values, concerns, and differences is required in this type of planning. Persons with disability are often ill-served by stereotypes and broad categories of classification as well, being often viewed, for example, as isolated individuals or as belonging only to special groups cut off from the mainstream. However, many people with disability do not see themselves as part of a single group, and this is particularly true for those who are chronically ill or disabled later in life. Most people with disabilities have family members or significant others who are not disabled and will not want to be separated from them (127).

How can resources currently available in the community for people with special needs be better used in planning? To date, the means of communication in the planning process have not been as open or as in as many languages as they should be. Better communication is needed in order to enable emergency planners to understand the special needs and concerns of vulnerable members of the community. This can in turn lead to more effective planning because they will be able to anticipate behavior and response to emergency situations (117,127). To better assist people with limited English proficiency, emergency planners might develop partnerships with

medical interpreters and learn how to work effectively with them or even integrate them as part of the preparedness team.

In considering emergency events that require rapid, large-scale evacuation measures, the events surrounding Hurricane Katrina showed that large numbers of people in low-income areas do not own cars and cannot be evacuated unless transportation was provided for them. Officials also discovered that emergency transportation arrangements that had been provided for in preexisting planning are not uniform but work differently in different parts of the city. In addition, they learned that many other circumstances faced by low-income persons can complicate evacuation planning. Those who do not have access to banking services, for instance, often keep their valuables at home and are reluctant to leave their homes for that reason. Individual family situations also complicate evacuation, and planning must aim toward keeping families together. Emergency shelters need to accept and accommodate pets, or their function will be undermined. Also, many persons with disabilities, those in wheelchairs for example, will refuse to be evacuated unless they are taken out with their families. Public health officials need to know in advance where persons with disabilities and other special needs are located and have appropriate transportation available to get them out of the area (accessible vans for example), and they must be willing to evacuate non-disabled family members at the same time. The challenges continue when persons using wheelchairs reach shelters, for whom mobility requires a reliable electric power source.

Another example is that of persons with cognitive or developmental disabilities, who often have very set routines and will refuse evacuation rather than disrupt that routine. They may fear, for example, that they will lose their job if they do not show up at work. A prior plan and prior discussion at work could alleviate this.

- Provide linguistically, culturally, and functionally appropriate informational and educational resources for vulnerable or dependent individuals, their family members, and others who care for them about what to expect in times of emergency. This can be done both as part of general public education in times of emergency and through targeted education. It is perfectly ethical to say “Mrs. Smith, you have a child who is ventilator-dependent and a wheelchair user. If you hear reports that the area will be evacuated in advance of the oncoming hurricane, please prepare to have your family ready to evacuate 24 hours before evacuation is expected to begin for the rest of the population.” Having someone aware of this for several months or even years beforehand—and not at the last minute—would certainly be an ethically acceptable approach.

The provision of culturally and linguistically appropriate information is critical to overcoming language and information barriers. According to 2005 US census data, nearly one-third of Spanish-speaking residents spoke English “less than well.” However, most warnings about Hurricane Katrina were provided in English only. Language barriers contributed to information delays about the path of the hurricane, delays in evacuations, and difficulties in understanding emergency messages (128). Dissemination of preparedness information in languages that reflect a community’s diversity is an essential ingredient for ethical planning and implementation of PHEPR.

- Public health measures, such as social distancing, designed to limit the spread of infectious disease pose special problems for those who rely on outside help. Persons with disability and working mothers with young children are often dependent on caretakers or others who come in and out of their households on a daily basis to do specific tasks or help with specific chores. When attendants or child care workers are too sick to show up,

or they are barred by their agencies from providing care because of fear of an infectious disease, the consequences can be very serious (129).

Family members and others who regularly check on someone with a disability may not heed warnings about not interacting with others. They must weigh the possibility of infection versus the concerns about the immediate needs of those for whom they care. Unless alternatives are put in place (such as some sort of visiting nurse service), these caretakers understandably may not heed warnings to stay away.

These and similar examples show the connection between foreseeing and accommodating special needs and circumstances in PHEPR planning and the type of behavioral response and compliance with the plan that an actual emergency event may elicit in the community.

- To facilitate good planning, individuals with special needs or their representatives should have an opportunity to participate actively and directly in the PHEPR process. Identifying those with special vulnerabilities and needs and setting up special services and accommodations for them in advance of an emergency is critical so that they will not be neglected or fall between the cracks (110,117). Once scarcities begin to emerge in an emergency situation and priorities begin to be set, vulnerable populations are likely to be lost in a general sea of trouble and need. When many needs are calling for attention, the voice of the vulnerable is most likely to be drowned out unless it has been heard in advance and special provisions have been made.

Response efficacy, promoting the general welfare, and adhering to the principles of justice are all involved in advance planning to meet the special needs of the vulnerable. Making special provisions for vulnerable populations will also have an effect on the behavior of

emergency responders and many able-bodied adults, so the overall success of emergency response plans is effected by the planning steps taken on behalf of the vulnerable.

Communication and Deliberative Participation for Emergency Planning

Two distinct but closely related facets of ethically sound PHEPR involve the relationship between planners and public health professionals (as well as other leaders, opinion shapers, and elected officials) and the general public—the community and citizenry whom PHEPR exists to protect and to serve. The first facet has to do with external communication and information moving from the planning organization to persons outside that process. The second concerns the internal conduct of the planning process. The first has to do with the content, style, and timing of public communications; the second with the active role of community members or representatives in the deliberations leading up to the plan itself. The first involves transparency,^{***} the second, inclusiveness.

^{***} There is some disagreement about the definition of the term, transparency. For some, open meeting and open records requirements are sufficient to provide transparency in the operation of some decision-making body. We understand transparency to require at least some measure of justification and explanation. Not just telling people after the fact what has been decided but attempting to explain why it has been decided. Transparency also requires that the public be provided with the necessary education, background information, and resources to intelligently assess what they are being told and what has been decided or proposed.

Communication and Deliberative Participation in Emergency Planning

Key Points

- ❖ Two distinct, but closely related facets of ethically sound PHEPR involve the relationship between the planners and the general public. The first has to do with public communications; the second with public participation. The first involves transparency; the second, inclusiveness.
- ❖ Community members have a right to be provided with truthful, complete information so that they in turn can fulfill their civic and personal obligations in the context of a public health emergency.
- ❖ Individuals have a right to deliberate about and give informed participatory consent to decisions and policies that materially affect their own safety, health, and well-being.
- ❖ Open, inclusive deliberative planning will build the necessary foundation of legitimacy and public trust required by a PHEPR effort and will also provide for feedback and self-correcting mechanisms that will improve the efficacy of preparedness measures.
- ❖ Sound factual information is a foundation for ethically justified decision making, but decisions must be made and actions taken even in the face of imperfect information.
- ❖ If public health planning without facts is like sailing in a fog, planning without judgment is like sailing without a rudder.
- ❖ Good communication is more than simply providing factual information, and transparency requires more than simply telling people what has already been decided. Communication should involve a two-way form of exchange and provide the resources necessary for the public to reflect on and come to accept planning decisions rationally, and not just to be told what they are.
- ❖ Inclusiveness and grassroots participation in the emergency preparedness planning process can have significant benefits. It can alert the planning process to concerns, cultural perspectives, and other vital factors that professional planners may overlook. It can create a sense of investment in the emergency plans that may lead to better community coordination and compliance later on.
- ❖ Transparent public health communications follows these rules of thumb:
 - Acknowledge uncertainty.
 - Provide follow-up information as quickly as possible.
 - Advise patience and flexibility.
 - Admit mistakes and move on.
 - Provide advice that fits the context and can realistically be acted upon.
- ❖ Do not abandon the community, and do not appear to be doing so.
- ❖ Planning should include the provision of resources to supervise, train, and use volunteers effectively.

Provision for both transparency and inclusiveness must be made in PHEPR; both are vital to ethically sound and practically effective preparedness and response. Ethical considerations push PHEPR toward transparent, respectful communication with community members because they have a right to be provided with truthful, complete information so that they in turn can fulfill their civic and personal obligations during a public health emergency. Ethical considerations also push PHEPR toward formal and meaningful inclusion of ordinary citizens in the planning process and decision making. There are both principled and practical reasons for this. Individuals have a right to deliberate about and give informed participatory consent to decisions and policies that materially affect their own safety, health, and well-being. In addition, open, inclusive deliberative planning will build the necessary foundation of legitimacy and public trust required by a PHEPR effort and will also provide for feedback and self-correcting mechanisms that will improve the efficacy of preparedness measures (105).

Communication, Evaluation, and Judgment

In discussing the ethical dimensions of PHEPR, decision making with incomplete or imperfect knowledge and under pressure of time is one of the main topics of ethical questions and dilemmas. Sound factual information is a foundation for ethically justified decision making. However, factual information, and the expertise that goes into discerning and collecting it, is not the complete picture; decisions and actions must be taken even in the face of imperfect information.

Facts in and of themselves rarely drive or compel decisions because factual information requires assessment and evaluation, and judgments of value inevitably enter into the interpretation of facts and their meaning. “Judgment,” as used here, is a general term covering

such things as assessment, estimation of risk and probability, conjecture, understanding of human motivation and behavior, sensitivity to cultural or symbolic meaning, discernment, taste, a sense of propriety, and the tacit knowledge (“intuition”) that comes from experience (78). Without judgment, facts are of limited use and provide little guidance. If public health planning without facts is like sailing in a fog, planning without judgment is like sailing without a rudder. In describing and analyzing facts, the notion of special training and expertise has an obvious application, and it can be strong enough to warrant granting special power and authority to those who possess it. In matters of judgment, however, the notion of expertise as the possession of a small and definable group of persons is much more dubious. This means that public health planning is always a compound of expertise and common sense— trained analytical knowledge and knowledge gained from experience; technical science, and “street science” (130).

Transparency and the Communication Spectrum

PHEPR communication may be thought of as a spectrum of message transmissions. At one end is the direct conveying of information alone, without embellishment. That information may be about environmental conditions (“A level-four hurricane is expected to make landfall in 12 hours at location X.”) or about instructions or commands (“When the alarm sounds, proceed to the nearest underground shelter. Do not bring your pets with you.”). Further along the spectrum is communication that conveys information but also conveys judgment, explanation, and rationale, particularly when instructions or commands are issued. This type of communication admits uncertainty and probability; it attempts to persuade rather than simply to instruct. These two types of communication are essentially one-way circuits, from leader to constituent, from authority to citizen.

However, good communication is more than simply providing factual information, and transparency requires more than simply telling people what has already been decided.

Communication should involve a two-way form of exchange and provide the resources necessary for the public to reflect on, and come to accept or reject, planning decisions rationally and not just to be told what they are. Communication about emergency planning should be like (very good) political campaigning—the Lincoln-Douglas debates, for example—not like listening to the weather report. Thus, further along the spectrum of communication are two-way communication and feedback loops. At one point the general public is enabled to comment on the communication and to ask questions in reaction to it. This “community consultation” or “public engagement” can make a significant contribution to planning communication as well as to the planning process. Properly done, it can promote both transparency and inclusiveness. Community consultation makes for more intelligent planning before an emergency and better compliance with the provisions of a plan during and after an emergency (48,131).

Even further along the spectrum is the area of communication in planning that involves more active and direct grassroots participation, wherein lay persons have an opportunity not only to react but to participate in forming the plan from an early stage. In this role, they contribute to the discovery of factual information and the making of evaluative judgments. This is where transparency in communication blends into inclusiveness in planning.

The special area of risk communication requires additional consideration. Public health information prior to and during an emergency is often complex, hard for some lay people to comprehend, and often uncertain or probabilistic in nature (93). Under these circumstances, communication is especially difficult because the message sent and the message received may be

quite different. Recognizing this problem, some in public health might argue for tight control of information and release of only minimal information during emergencies.

Another line of thought, which is growing in influence and which is more desirable, is to have confidence in the ability of the public to handle information and to appreciate frank admissions of uncertainty on the part of public health officials. The public, far from losing trust in officials due to such openness and candor, responds well to it, while responding quite negatively to secrecy and deception when it learns about them after the fact.

The days when public health mitigation activity consisted of removing the pump handle of the neighborhood well to keep unsuspecting people from drinking contaminated water are mostly behind us. Yet, many conceptions of PHEPR are built around benevolent authoritarianism and paternalism, and they draw upon models of public health communication that rest on more or less manipulative incentives and behavior modification approaches. This should, and will, change. In recent years, public health practice has moved from the command pole of the communication spectrum toward the deliberative and participatory pole. In ordinary programs, public health professionals do not direct the communities they serve toward better health; they cooperate and collaborate with communities that make themselves healthier.

Inclusiveness: Deliberative Planning and Civic Participation

The benefits of inclusiveness and direct participation in the planning process, at least by representatives of grassroots groups and engaged individual citizens, can be substantial. Such participation can alert the planning process to concerns, cultural perspectives, and other vital factors that professional planners may overlook (131,132). A sense of investment in the planning may lead to better community coordination, and ultimately compliance later on. One political

scientist has noted that, “Although few adhere to the view that deliberation inevitably leads to consensus, many believe that deliberation under the right conditions will have a tendency to broaden perspectives, promote toleration and understanding between groups, and generally encourage a public-spirited attitude (133).”

Well managed participation and inclusiveness can have the same effect as timely, honest, and candid communications in promoting public trust and legitimacy and, hence, a greater willingness to cooperate during an emergency. Indeed, without these things, public trust is unlikely in today's society. Normal channels of interest group bargaining and lobbying no longer enjoy public confidence; they have been discredited by spin, misinformation, and financial influence. Nothing will make cooperation and the maintenance of order during an emergency more difficult than widespread mistrust and suspicion of leaders and authorities.

In particular, making appropriate and equitable provision for vulnerable individuals and groups in emergency plans requires input from those with direct experience and with insight into the perspectives of those living under conditions of vulnerability, marginality, or discrimination (118). Avoidable mistakes and miscues will occur if good and well-established lines of communication have not been formed between the disability community and public health officials. The motto of the American disability rights movement right now is, “Nothing About Us Without Us,” and this could well be the aspiration of other vulnerable groups as well. It is an appropriate reminder and rule of thumb for PHEPR.

There is not a sharp line between community consultation or town hall meetings concerning PHEPR and the inclusion of official community representatives in the internal infrastructure of the planning process. This distinction has to do with the numbers of participants involved, recruiting them, and their qualifications for the task at hand. It also has to do with the

distinction between input that is advisory and input that has some more authoritative status. Community representatives are never given veto power over important decisions, but once they are accepted into the process, emergency planners must accommodate their wishes and needs to a great extent. Because these individuals will have access to information that is not generally publicly available, and because their roles and identities are known so they become points of attention by the media, they carry some influence. The political costs for elected officials of neglecting them or pushing measures through over their opposition can be substantial.

The personality and style of individual community representatives and the external pressures they are under will influence the role they play in the planning process. They can generate conflict and be a disruptive presence for experts and staff, which could have the unintentional beneficial effect of forcing staff to broaden their agenda and their ways of thinking. However, they also may want to play a disruptive role in the process in order to reinforce their power and standing with their constituency.

The converse of this type of conflict in professional–lay relationships is generally referred to by political scientists as “cooptation” (134). Here the community representative is led, usually by subtle psychological means, to identify more with the insider professionals than with the external constituency or community. Professional and bureaucratic interests seem to merge with community interests. The representative ceases to represent the grassroots in the sense of protecting their rights and giving them voice and internalizes the paternalist attitude toward them that many professionals have and so makes common cause with the professionals.

Neither conflict over hidden agendas nor cooptation are what the ethical values of inclusiveness require. These considerations point to the importance of the selection process for community representatives. In general we support inclusiveness and lay participation in PHEPR.

However, it is rarely desirable to politicize the planning process. Appointing community activists with their own independent agendas, therefore, is less desirable than appointing more independent, detached, individuals who are respected and trusted by broad sectors of the community. Such persons are more likely to be guided by the common good of the whole community and will work effectively with emergency planners to produce a planning process that is both effective and has ethical integrity (135).

The Response Phase

Thus far we have considered communication and participation largely in the planning and recovery phases of public health emergencies. The response phase requires a different kind of analysis (59). For effective communication and transparency, the prime imperative is to provide the most reliable information available in a timely manner. During an emergency response, the conditions are not auspicious for deliberation and consultation. Fear, insecurity, and uncertainty about the immediate future are not conducive to thoughtful deliberative participation by citizens in any case, and during an emergency fear and panic may lead people to undervalue the rights and interests of minorities or those who are stigmatized. Fear, blame, rumor, and stigma are normally rampant during a time of crisis, and public health planners should anticipate and attempt to minimize these outcomes.

Good communication during the response phase can dampen bigotry, extinguish rumor, and prevent or minimize panic. It is important for public health responders to have a good working relationship with the local press and, in all communication, to resist the urge toward benevolent deception or withholding of accurate information. Transparency, candor, and openness will serve both ethical and practical objectives. Communication during the response

phase will often have a direct bearing on the choices ordinary people make and the risks that they are subjected to, and public health responders should recognize the responsibility they have, often under very trying circumstances. Good advance planning, clear lines of responsibility and communication worked out in advance, and a carefully built and earned reservoir of public trust will help. Without them it is unlikely that any response effort will go well. Even with them, response-phase communications will be replete with hard choices.

Transparency counsels public health communicators to trust their audience even as they need the audience to trust them. The public does not expect infallibility from public health; it does expect fidelity. Transparent public health communications follows these rules of thumb:

- Acknowledge uncertainty.
- Provide follow-up information as quickly as possible.
- Advise patience and flexibility.
- Admit mistakes and move on.
- Provide advice that fits the context and can realistically be acted upon.
- Do not abandon the community and do not appear to be doing so.

Volunteers. The major aspect of participation that arises in the response phase is volunteer participation in the implementation of response plans and in providing services and staffing. Volunteerism is a double-edged sword. On one side, it is one of the most admirable aspects of any disaster situation and, as such, should be encouraged and applauded. On the other side, it can cause managerial and technical nightmares and reinforce the adage that the road to hell is paved with good intentions.

Sometimes the sheer number of volunteers can overwhelm the beleaguered professionals at a disaster site. The safety of the volunteers becomes a new issue to reckon with. This can be both immediate and long-term, as we are now discovering with the report of chronic health problems of those who spent time at or near Ground Zero in New York. The full dimensions of the public health emergency created by the events of September 11, 2001, are only beginning to be appreciated nearly a decade after the event.

Planning should include the provision of resources to supervise, train, and use volunteers effectively. How essential their function is will vary from one emergency situation to the next, but to actively discourage or restrict them from doing something to help is highly undesirable from the long-term point of view of community well-being and morale, no matter how expedient it may be in the short term. We are reminded of the conflict that almost broke out between the New York City police and firefighters at the World Trade Center debris pile when the former had been instructed to prevent the latter from joining the search for buried victims (136).

Altered standards of care. An interesting aspect of using volunteers during an emergency arises in the provision of medical care and in performing medical procedures. Many state laws restrict such activities to licensed physicians and nurses, but with some relatively simple training, others may reasonably be permitted to perform medical tasks, such as starting intravenous lines, performing tracheotomies, and setting broken bones. The performance of medics in the military during combat demonstrates that something less than a medical or nursing degree will suffice. However, statutory change will be necessary and the training resources are not currently in place. In addition, the question arises of altered standards of care and legal liability. If someone sustains a serious injury while being cared for in emergency settings that do not conform to the standard of practice of normal times, should they be able to recover damages? Will their ability to do so

make it impossible to set up a volunteer program as a part of an emergency plan? Should limits be placed on tort liability to protect those providing care and services in good faith during special emergency circumstances?

Many elected officials, policy makers and public health officials believe that lawsuits, to say nothing of litigious attitudes, are out of place in the context of public health emergencies and other disaster situations. Many existing state laws contain provisions limiting liability and access to the courts, and other states are considering adding such restrictions. The Model State Health Emergency Act contains such a provision, for example. Yet, the problem of responsible oversight and public accountability remains to be addressed. Officials should not be paralyzed by concerns about civil liability during emergency response, and volunteers should not be prevented from assisting by such concerns. However, what then would be the mechanism of quality control over the actions of volunteers and recent trainees? Tort liability is one such safeguard in the U.S. system. Partly this is a question of acceptable risk, and partly it is a question of a trade-off between the ethical objective of reducing mortality and morbidity and the ethical objective of protecting individual liberty, autonomy, and respect for persons. Liberty (in this case, the right to judicial relief when one has been injured or wronged) and respect for persons are not to be set aside lightly, even when a person's life is at risk. If liberty is limited in the name of protection, then it is contingent upon society to provide protection and not cause injuries due to improper management.

No doubt new laws and regulations will be developed that will balance the need for new standards of care during emergencies and the need to protect victims from neglect and incompetent treatment. This problem is not limited to nonprofessional volunteers. During emergencies, even physicians might have to do things that they would never do, in ways that

they would never do them, under ordinary circumstances (61,137). Further comment on the technical questions of how to achieve that balance in the law is not within the scope of this report. From an ethical point of view, although this remains controversial, we recommend that the balance be struck slightly in favor of limiting liability and encouraging the work of volunteers. Despite foreseeable individual injuries, this will be in the best interest of communities and of ethically sound PHEPR in the long run.

The role of civil lawsuits for health injuries against public health and government officials who do not adequately warn or protect citizens and volunteers is another difficult issue. This is not a discussion of the legal responsibilities of public health emergency planners and officials. We propose that high ethical standards be set for these officials and this activity, and it would seem to be appropriate to have corresponding legal accountability in place as well.

The Emergency Excuse

The legitimacy of public health officials is based on their objective qualifications and the objective outcomes they produce. (Note that during and after Hurricane Katrina, one problem was that some officials had not been adequately trained or prepared for the challenges they had to face.) Training and use of qualified staff are necessary but not sufficient conditions for legitimacy. Legitimate authority must also be accountable to the citizenry at large and to those most directly affected by decisions made by that authority.

Accountability also means transparency regarding the conduct of public health officials. Voluntary compliance with public health authority requires an understanding of the reasons and rationales for policies and a sense of trust that the public interest is motivating public health

officials in their activities. These general considerations apply to public health at all times, but they are no less important in the context of PHEPR.

It is sometimes argued that the time and resource constraints of an emergency situation make the ethical requirements of transparent authority impractical or even undesirable. This can be called the “emergency excuse” for using power in a style of benevolent authoritarianism and paternalism, for limiting liberty liberally, and for rejecting transparency and participation. The emergency excuse in fact has less traction in ethical analysis than many in public health believe. It does not provide good grounds for setting aside the kind of ethical objectives we have offered in this report, for at least two reasons.

First, whatever validity it may have during the response phase of an emergency, it does not apply to the pre-event planning process, when time constraints are not so stringent. The link between transparency and later compliance is an important consideration to bear in mind during PHEPR. Second, even during the emergency response phase, when decisions have to be made under conditions of imperfect information and rapid response is crucial, it is still ethically necessary to differentiate between the reasonable and justified exercise of authority and power and the arbitrary, improper exercise of authority and power. Time pressure should not be used as a general excuse or reason to give officials an ethical *carte blanche*; if it is, the emergency response effort will most likely lack of coordination and become a power struggle that will undermine effective response efforts. Adherence to the ordinary rules of morality and to the ethical objectives set forth here remains essential in emergency situations, not in spite of the fact that time is short and emotions are running high, but precisely because of these things.

Professional Obligations

“Society’s granting of power and privilege to the professions is premised on their willingness and ability to contribute to the social well-being and to conduct their affairs in a manner consistent with broader social values (138).”

Health-care workers and other health professionals play pivotal, front-line roles in disaster response, yet the risks they sometimes face in the line of duty can place severe strains on their willingness to stand their ground in the face of natural or bioterrorist catastrophes. Although the story of health-care workers and SARS was largely one of remarkable heroism and solidarity in the face of a deadly epidemic, hundreds of physicians in China refused to return to their posts (139). Many others around the world found themselves making anguished choices between serving the ill and protecting themselves and their own loved ones from the threat of deadly disease. While SARS was eventually contained by rigorous infection control measures, including widespread quarantine, an epidemic of avian influenza may place health workers at much greater risk of severe morbidity and death. Beyond the level of individual practitioners, individual hospitals might shut their doors to new patients because of fears that they might contaminate existing patients.

The threat of natural or manmade disasters thus poses the question of whether health-care providers have a moral obligation to risk illness and death in the line of duty. Do physicians, public health workers, nurses, and others have a moral duty to stay at their posts in the face of risk, or are such choices merely a matter of individual conscience for individual practitioners? If their conduct is governed by a moral or professional duty, how strenuous is this duty and what are its limits? Such questions were routinely faced by physicians and nurses before the advent of antibiotics, especially during times of plague and outbreaks of other infectious diseases.

Professional Obligations

Key Points

- ❖ Health professionals often put themselves at risk in responding to crises. It is crucially important to discern the nature, scope, and limits of their professional obligations to place themselves in harm's way.
- ❖ In addition to weighing their professional obligations against personal risks, health personnel often must also consider their competing obligations to family.
- ❖ In considering whether to stand their ground in the face of personal risks, health professionals must also consider their obligations to one another. A refusal to perform one's allotted duties will impose additional burdens on those professionals who are already doing their fair share.
- ❖ The services of nonprofessionals (e.g., orderlies, record keepers, food service and laundry personnel) are crucial for the success of public health interventions, but they too face personal risks and competing family obligations in times of crisis. Little thought has been devoted to the question of whether they also have heightened responsibilities and what the sources of their obligations might be (e.g., a heightened sense of civic responsibility). More thought should also be given to how such nonprofessionals should be compensated for serving in times of crisis.
- ❖ In the context of crises like SARS, pandemic influenza, or Hurricane Katrina, society has a solemn obligation to provide health workers with the protections and tools they need to subdue the epidemic or blunt the effects of natural disasters. These include adequate training, accurate information, and, perhaps most important, a robust public health infrastructure in which to do their jobs.
- ❖ Society should strive to provide needed care to all health workers who become ill or disabled in the line of duty, and to provide compensation to their families should they die in the line of duty.
- ❖ A willingness to face some additional risks is implied by undertaking the vocations of medicine and public health. There are, however, limits to a duty to assume personal risk, the exact contours of which are hard to discern at the outer edges. It should be noted, however, that professional medical ethics has long held the position that the physician ought to accept great personal risk, even some risk to life itself when that is unavoidable, for the sake of the patient.
- ❖ Provision of a robust public health infrastructure, including adequate personal protective equipment for health workers, not exhortations to heroism, should be the primary focus of disaster preparedness.

In 1912, the Code of the American Medical Association (AMA) stated that during such times, “a physician must continue his labors for the alleviation of suffering people, without

regard to the risk to his own health or to financial return (140).” This principled stand was greatly attenuated, however, both by the AMA’s increasing emphasis upon physicians’ untrammelled discretion in deciding whom to serve and, even more importantly, by the advent of the era of antibiotics, which gave the appearance of having forever vanquished life-threatening infectious diseases. During the brief period between the widespread dissemination of antibiotics and the rise of acquired immunodeficiency syndrome (AIDS), the notion of a strong professional duty to treat in the face of mortal threat no longer seemed relevant to the medical community. But as AIDS, SARS, and now the disturbing threat of pandemic influenza have amply demonstrated, the *pax antibiotica* was only a momentary reprieve, and the age-old questions about the duty to stand one’s ground in the face of risk press as urgently upon the medical community today as ever (141).

One standard way of thinking about these questions is available in the social contract tradition, i.e., health professions are forging a contract of sorts with the society at large. Those professions endorse and enforce a duty to provide care for the sick even in the face of personal risk, while society, for its part, grants to the health professions (and especially to physicians) social esteem, comfortable remuneration, and, perhaps most importantly, a great degree of professional autonomy, including the exclusive legal right to practice medicine. Perhaps the most powerful feature of this social contract argument is its recognition that if physicians, through licensure, are to be granted the exclusive legal prerogative of practicing medicine, then physicians must provide care to those in need even in the face of some personal risk. If they do not, and if the bargain physicians have struck with society denies to all other groups (e.g., herbalists, acupuncturists) the legal right to do so, no one will remain to care for the sick in times of great social need. It is difficult to imagine the effects, both for stricken individuals and for

society at large, if health workers and hospitals refused to accept gravely ill and highly infectious patients.

A corollary of this line of thinking stresses the obligations that health professionals bear toward one another. If a front-line public health worker, physician or nurse refuses to come into contact with sick and infectious patients, the latter will not simply disappear; they will inevitably become the charge of other health workers. The question, then, is not “Why me?”, but rather, “If not me, then who?” If failure to care for patients in the presence of risk merely shifts the burden onto one’s fellow health professionals, who must then shoulder even more than their fair share of risk, then such refusals amount to a serious injustice towards one’s own colleagues.

An alternative, yet mutually supportive approach to the duty to treat can be found in an ethic of virtue. According to this line of argument, the job of health workers is to attend to the needs of the sick. To do this job well, certain virtues are necessary, such as competence and courage in the face of adversity. Those who stress an appeal to the virtues as opposed to the social contract often respond, “This is who we are; this is what we do.” Those who fail to exhibit some degree of courage in the face of personal risk are like firefighters who refuse to rescue people trapped in burning buildings, or police officers who refuse to pursue suspected criminals down dark alleys. Confronting some degree of personal risk comes with the job of being a health worker. Those who refuse to run such risks arguably misunderstand what it means to be a doctor, nurse or public health worker. Thus, rather than focusing on some sort of contractual, quasi-legalistic, tit-for-tat exchange between the medical profession and society at large, the virtue orientation focuses attention squarely and directly on health professionals’ mission of caring for the needy. The fact that this mission places such professionals in the path of personal risk lends it the aura of a higher calling than other professions like law, teaching, or chartered accountancy.

This focus on the individual health worker's duty gives the virtue approach a distinct advantage over some versions of the social contract argument, which tends to focus on the duties of entire professions rather than on individual practitioners. Strictly speaking, the contractual duties of the medical profession to the larger society are theoretically compatible with a robust right of individual physicians to treat whomever they wish. So long as a sufficient number of physicians remain on the job to care for those in need, others could opt out as they see fit. Although medical history is replete with examples of such opting out during times of plague, the virtue approach would label such examples as deviations from what should be expected from all health professionals, notwithstanding their personal or idiosyncratic views about shouldering risks, and it would underscore the importance of inculcating the requisite virtues into each new generation of physicians, nurses and public health workers. According to this virtue orientation, students of medicine, nursing and public health should be aware that their chosen profession comes with various risks attached, so that one's eventual entry into such fields would presuppose a fully explicit acceptance of such hazards. While such an acceptance was merely implicit, at best, during the period of the *pax antibiotica*, it must be fully explicit in a world threatened by AIDS, SARS, and pandemic influenza (141,142).

Considered jointly, the social contract and virtue approaches support a robust duty on the part of health professionals to maintain their posts even in times of great social stress and threats of infectious disease. As elaborated so far, however, these complementary approaches may not be sufficient to account for three additional concerns: 1) What duties, if any, are owed by nonprofessionals working in the health-care and public health sectors? 2) What does the larger society owe to health workers beyond the legalities of licensure? and 3) Where lies the tipping

point between professional duty and what the philosophers call the realm of supererogation, i.e., conduct above and beyond the call of duty?

Regarding the first concern, one lesson of the recent SARS epidemic is that the burden of some infectious diseases might fall most heavily on hospitals, where the sickest and most infectious patients go for care and, in many cases, for isolation and quarantine. While public health and health-care professionals often heroically put themselves in harm's way, many nonprofessionals (including paramedics, radiographers, office workers, food service workers, and even janitorial staff) got sick, faced enormous psychological stress, and in some cases died during that epidemic. While the health professionals (eventually) enjoyed enhanced public esteem, and were in most cases provided with the requisite information and technical supports to protect themselves, the nonprofessionals faced similar risks without the luxury of choice or comparable access to social rewards, information, and protection (143). Now, assuming that the combined efforts of all these disparate professional and nonprofessional staff were necessary to keep the hospitals functioning in their battle against SARS, what can be said regarding the behavior of nonprofessionals during that crisis and possible future disasters?

The first thing to note is that neither the traditional social contract rationale nor the professional virtue approach sheds any light on this question. As a first step in the direction of fully addressing it, we suggest either a broadening of the typical social contract scenario or a renewed appreciation of the duties of ordinary citizens to contribute to the common good during times of crisis. One could, for example, include administrators, food services personnel, and radiology technicians in the social contract, but this would obviously call for a matching, broadened conception of the societal quid pro quo. Thus, in addition to the benefits of licensure, professional autonomy, and social esteem meted out to physicians, the equivalent of "battle pay,"

compensation for injury or death, and some appropriate form of public recognition could be envisioned for nonprofessional staffers. Alternatively, a society could explore the possibility that threats posed to the social fabric on the order of SARS or pandemic influenza should engage the moral sensibilities not just of health professionals, but also of ordinary citizens who happen to serve as office workers and orderlies in hospitals and clinics. In order to subdue such threats to society, it could be argued that every member of the community must contribute what she or he can to the common effort; every oar must be in the water. Here too, in order to avoid placing an undue burden on those members of the community who, because of their placement within the medical and public health infrastructures, face greater than average risks, public health planners would need to think of appropriate ways of honoring them and compensating them for their sacrifices.

The second concern questions what the larger society owes to health workers beyond the legalities of licensure. The suggestion of a broadened social contract applies with even greater force to the case of health professionals. In exchange for health workers' services and willingness to face considerable risk in the line of duty, society has a matching obligation to do more than provide them with licensure and enhanced esteem. Especially in the context of crises like SARS, pandemic influenza, or Hurricane Katrina, society has a solemn obligation to provide health workers with the protections and tools they need to subdue the epidemic or blunt the effects of natural disasters (141,144). This means, first, that they must be provided with the best available information and infection control measures. During the SARS outbreak, some of the physicians in China who refused to return to their hospitals did so precisely because they were outraged at what they perceived to be the government's ineptitude in handling the early stages of the epidemic, and because they were afraid to engage with this mysterious new and lethal disease

without adequate infection control protections (139,145). One thing is clear: both professional and nonprofessional health personnel must be given adequate support from their institutions and from society at large. Nonprofessionals should also have in place appropriate training, resources, protective equipment, and follow-up support to help perform their job safely. Society thus has no right to insist on heroism from health workers, either professional or nonprofessional, while failing to provide them with needed protections.

This expanded social contract should also include a social obligation to create and maintain an adequate infrastructure for public health. The focus here should not fall exclusively or even primarily on the virtues or expected sacrifices of individual health workers, but rather on the social, ethical, and legal obligations to provide such workers with an infrastructure conducive to their safety and the success of their present and future missions. A well-funded and thoughtfully designed public health infrastructure is by far the best way for society to meet the wide array of currently unforeseeable threats and future disasters. Narrowly targeted stockpiles and response plans for specific threats (e.g., hurricanes, anthrax, pandemic influenza) no doubt have their place; but they will most likely fail to achieve their objectives in the absence of a sound system of public health (146).

Finally, such a broadened social contract would encompass more appropriate forms of social recognition for the sacrifices made by health workers. At a minimum, health workers should not be socially shunned, as many were during the Toronto SARS crisis. (Once it became known that health workers were transmitting that deadly disease, they were often shunned by the general public as potential carriers. Nurses in Toronto's hospitals reported that taxi drivers often refused to take them home from work.) Beyond that, society should strive to provide needed care

to all health workers who become ill or disabled in the line of duty, and to provide compensation to their families should they die (147).

The final concern is the difficult question of how much risk health workers are morally and professionally obligated to accept, especially in a context of biological terrorism or natural disaster. The first thing to note is that any adequate accounting of the obligations borne by health-care and public health professionals must acknowledge and take seriously the full complexity of their moral situation. The moral challenge here stems not simply from a potential conflict between professional duty and individuals' interest in avoiding serious morbidity and mortality, but also from health workers' competing moral obligations to their spouses or partners and children who depend on their support. Therefore, this is not simply a test of moral will between self-interest and duty, where the right answer may be clear but difficult to follow, but a genuine moral dilemma between competing moral obligations. In many cases, health workers might fear becoming ill and losing the ability to provide for their families; in others, they may be tempted to stay home in order to provide much-needed care to their own family members already stricken by disease or natural disaster (148).

A second preliminary point is that different sorts of disaster pose different levels of risk to health professionals. An intentional anthrax attack, for example, may cause widespread fear and panic in the general population, particularly among those living and working in close proximity to the event(s). Fortunately, anthrax is not contagious from person to person, and those caring for the ill need not fear being directly infected. However, those handling patients and other material (e.g. clothes, personal effects) that may be contaminated with anthrax spores need to take precautions to avoid spore contact, inhalation or ingestion. A major hurricane on the scale of Katrina, on the other hand, may not expose health workers to especially high levels of

personal physical danger, but the psychosocial risks of working in such stressful conditions might pose a serious threat to their mental health (73). In certain extreme circumstances, such as the recent SARS epidemic or a predicted pandemic influenza crisis, health workers face very high risks of serious morbidity and mortality.

Unlike the human immunodeficiency virus (HIV), which can be transmitted from person to person in the absence of symptoms, SARS became highly communicable only after patients had become sufficiently sick to become hospitalized. As a result, hospitals became places of infection and death, and many physicians and nurses died caring for SARS patients. Although the mortality rate for SARS worldwide hovered at the alarming average rate of 15%, health workers constituted a disturbingly large percentage of its victims at epicenters in Hong Kong (25%), Vietnam (100%), and Canada (65%) (149). Those who did not become ill were nevertheless often quarantined in their hospitals for long periods of time, and many of these suffered greatly from the effects of isolation, including depression. Perhaps the most noteworthy thing about the SARS epidemic is that so many health workers showed up for work despite the alarming risks and the mysterious nature of the disease.

This third category of concern, then, poses the most difficult questions concerning the boundary between duty and heroism. A discussion can begin with two fairly uncontroversial observations. First, medicine, nursing, and public health are inherently risky professions to some extent, and always have been. Prior to heated debates over physicians' duty to treat HIV-infected patients during the late 1980s, health workers routinely treated, for example, psychiatry patients with violent tendencies and patients on tuberculosis wards. Indeed, one commentator argued at that time that physicians had a duty to treat AIDS patients because they had already accepted a certain level of risk by virtue of becoming physicians (150). Since the risks posed by HIV were

not significantly greater for physicians practicing adequate infection control than the background risks inherent in medical practice, the argument went that contemporary physicians can be assumed to have implicitly consented to treat patients with HIV.

Second, no credible morality of medicine, nursing, or public health would impose a duty of martyrdom. Did Russian physicians have a duty to lower themselves by helicopter into the Chernobyl nuclear reactor to treat technicians exposed to fatal doses of radiation? In cases such as this, marked by extremely high levels of risk and inadequate protection, health workers do not have a moral or professional duty to treat. The public can always hope for heroic deeds, for health workers giving the last full measure of devotion, but it cannot expect or demand these things of doctors, nurses or public health workers. Nor should health workers be expected to plunge into the fray without first having in place appropriate training, resources, protective equipment, and follow-up support to help perform their job safely. It is the duty of society at large (and health care institutions) to provide these resources. This is true, not only both because society cannot and should not expect health workers to accept possibly lethal but unnecessary risks, but also because such workers have a duty to keep themselves healthy so that they can continue to treat others. Again, the provision of a robust public health infrastructure, including adequate personal protective equipment for health workers, not exhortations to heroism, should be the primary focus of disaster preparedness (151).

However, after acknowledging these uncontroversial points, the truly hard cases remain. Were the health workers who fell ill or died while caring for SARS patients just doing their duty, or did they transcend the call of duty into the realm of heroism, wherein we can be grateful to those who stood their ground but cannot criticize or condemn those who fled? Several commentators have pointed out that the remarkable thing about the SARS epidemic was the

steadfastness of health professionals in the face of palpable and serious risk. A profession that dithered, not to its credit, over its obligations to treat much less risky HIV-infected patients during the 1980s and 1990s (152), by and large rose to the much more daunting challenge posed by SARS. While it remains philosophically dubious to infer an “ought” from an “is,” we conclude from the conduct of health professionals during the SARS outbreak that nurses, physicians, and public health workers considered such risks to be within the purview of their professional duties, especially when they were provided with adequate infection control protections. Does this mean that those who died in the line of duty were not also heroes? Hardly. It took genuine courage for those health workers to stand their ground, and they should be honored for it. Students of nursing, medicine, and public health should be taught their names and told their stories.

If the duty to treat in the context of natural and manmade disasters encompasses the levels of risk encountered during the SARS outbreak, the risks posed by most future events will likewise fit within the ambit of duty. Perhaps the most daunting of these future disasters would be a pandemic of virulent avian influenza, which, experts estimate, would most likely not exceed the risks posed to health workers by SARS.

Finally, the notion of professional duty should not be expected to do all the moral heavy lifting in this controversy. Health-care and public health professionals have serious moral duties to serve the public good, even at reasonable risk to their life and health. However, society would be remiss if it concentrated solely on such duties to the exclusion of offering various incentives for altruistic behavior, especially when the level of risk begins to rise beyond the level of duty. In past epidemics, for example, cities have bestowed additional privileges or remuneration on “plague doctors” who stood their ground instead of fleeing, or bestowed licensure or guild

privileges on practitioners who may not have been deemed eligible previously (152). Again the most basic foundation for health professionals to answer an extraordinary call of duty is to ensure that institutional support and resources are in place, including, as was mentioned earlier, appropriate training, resources, protective equipment, and follow-up support to help health personnel perform their job safely. Additional support to ensure that the health care workforce responds in an emergency might include such things as increased pay; the reliable backup of specialized hospital units well stocked with highly skilled practitioners, technology, and medications; giving first responders high priority in the distribution of scarce vaccines and prophylactic medications; and special supports for ill family members. If health-care and public health professionals can be reassured that their ill family members will be properly cared for, their moral dilemma will be attenuated, which will make it easier for them to assume their proper posts at the barricades.

Civic Obligations and Personal Responsibility

“What’s true of all the evils in the world is true of the plague as well. It helps men to rise above themselves (153).”

One important dimension of PHEPR is to foster a sense of civic obligation and a concern for the well-being of the community as a whole on the part of all citizens and community residents. A closely related goal is to prepare individuals and families to understand what their responsibilities will be during an emergency and to equip them with information and possibly other resources to react appropriately and responsibly at such a time. These goals are both ethical and practical. The discussion in this section relates to the ethical goal of promoting personal and civic responsibility (Goal 7), but it also relates to the goal of developing strong as well as safe

communities (Goal 5). Public health professionals and other leaders should use the planning process to strengthen the social capital of communities and to make them more resilient so that they can weather all hazards and emergencies—which are now inevitable throughout the globe and no community is immune from them—with as little damage as possible and bounce back from disasters quickly and return to civic health (55-59).

Civic Obligations and Personal Responsibility

Key Points

- ❖ Public health professionals and other leaders should use the planning process to strengthen the social capital of communities and to make them more resilient so that they can bounce back from disasters quickly and return to civic health.
- ❖ PHEPR is a civic activity. It is a public function, a part of the basic purpose of forming a political community in the first place, the security, life, liberty, and well-being of the people as a whole. It is an expression of the entire community about the value of the lives and health of its members.
- ❖ Civic renewal is a practical, not a theoretical task, and people will not become involved in their community unless they find the activities and issues meaningful in their own lives and believe that their involvement will actually make a difference.
- ❖ The capacity of individuals to respond and the capacity of communities to respond are interrelated.
- ❖ The fact that PHEPR is primarily a societal and a governmental responsibility does not obviate the fact that there are significant moral obligations incumbent on private citizens as well.
- ❖ Emergency planning will engage people in ways that renew or strengthen their own sense of civic responsibility and membership. It may also reinforce the health of those organizations of neighborhood and civil society that make up the infrastructure of civic life or ability to recover from disaster and dislocation.
- ❖ Plans tell individuals how to behave in the face of impending danger, but individuals must ultimately take responsibility for how prudently and responsibly they act to protect themselves and their families.
- ❖ Public health emergency planning should assume a measure of self-protection and personal responsibility on the part of ordinary people, and it should give them the information they need to make informed choices.
- ❖ Planning must also accommodate the reality of limited choices and resources that many people confront in their normal lives, for these will constrain them before, during, and after an emergency as well.

There are two different perspectives from which to view PHEPR. One is to view it through a professional lens and using a consumer model. Seen in this way, emergency planning is rather like medical or financial planning. Providers with specialized knowledge are preparing a product for clients who are using that product to promote their own interests as consumers.

An alternative way to look at the emergency planning process is to see it as a civic activity. It is not a commodity to be exchanged between a consumer with an interest and a provider with the expertise to fulfill that interest. It is a public function, a part of the basic purpose of forming a political community in the first place, the security, life, liberty, and well-being of the people as a whole (154). It is not the property of those who create it; it is not simply “used” by those who benefit from it. It is an expression of the entire community about the value of the lives and health of its members. It is less like a commodity to be bought and sold and more like a covenant, an agreement to be entered into by all that establishes commitments of responsibility for each.

If we view the activity of emergency planning as a civic activity, then citizens are parties to the plan, not consumers of it. In this view, it is entirely appropriate to emphasize broad, inclusive participation and community engagement in the planning process. PHEPR is one important aspect of the life of strong democratic communities.

In including civic considerations in this white paper we do not mean to suggest that emergency planning should wait until justice is achieved and broader social problems, like racism and poverty are solved. Planning must cope with society as it is, not as it could or should be. Nor does this suggest that PHEPR will be the main instrument of social reform. Many other activities must converge on the problem of civic renewal and resilience, although we believe that emergency planning, if structured and carried out in a participatory fashion, could make a contribution not only to the rather narrow health and safety goals of preparedness but also to the task of reinforcing civic life and liberal democratic values (44,105,,155,156).

Civic renewal is a practical, not a theoretical task, and people will not become involved in their community unless they find the activities and issues meaningful in their own lives and

believe that their involvement will actually make a difference. Otherwise, time is too precious in most people's lives to be wasted on activities that involve a lot of meetings and talk. Danger focuses attention, and public health matters are coming to the forefront of public awareness in ways that have not been seen in decades. This, despite all its negative aspects, also provides an opportunity. If we are going to engage in efforts to develop emergency response plans in communities throughout the country, why not get as much civic benefit out of the activity as we can?

Moreover, a growing body of public health and epidemiologic research is demonstrating that the health status of individuals is not merely a function of their genetic makeup, their biological functioning, and the toxic substances or microorganisms they are exposed to in their physical and biological environment. Physical health, to say nothing of mental health and psychological well-being, is affected by the sociocultural environment (22,74,76,157-159). Everyday health risk factors associated with the breakdown or absence of civic resources (so-called "social capital") are also risk factors pertinent to what will happen during emergency situations. The capacity of individuals to respond and the capacity of communities to respond are interrelated. Each factor separately, as well their interesting (if still poorly understood) interrelationship, should be of central interest and concern to the emergency planner.

Fostering Responsible Citizenship and Personal Responsibility through Planning

The fact that PHEPR is primarily a societal and a governmental responsibility does not obviate the fact that there are significant moral obligations incumbent on private citizens as well. The previous section addressed the special obligations attendant on the role of “professionals” in society, in particular health professionals. This section views each person in his or her dual identity as democratic citizen and as moral agent. By “citizen,” we mean not only or primarily a legal status, but an ethical and political status of being a responsible member of a political community of free and equal persons, a community of reciprocal rights and obligations, a community of shared vulnerability and risk, and a community of mutual concern and respect. By viewing persons as “moral agents,” we bring to the foreground their private, as distinct from their civic, lives: that is, their web of familial and kinship relationships, friendships, and personal associations. Among these, the most compelling moral obligations during a time of threat or crisis no doubt pertain to one’s role as parent, spouse, or family member. Finally, morality recognizes that individuals have rights and duties that pertain to themselves, in particular, the right to self-preservation.

We believe that a sense of citizen obligations, concern for the common good, and a sense of personal and familial responsibility generally reinforce one another. However, there may be times when a conflict of obligations seems to arise. In this section, we address such conflicts between civic and the personal duties: how to prevent, avoid, and mitigate them as much as possible through the pre-event planning process; and if they do arise, how to think through and resolve them.

Emergency Planning as Community Building

The importance of building active voice and involvement for citizens in the planning process has been discussed previously. Doing this is supported by considerations of rights and respect, ensuring justice and nondiscrimination, and making the plan more intelligent and effective by tapping into the kinds of local knowledge that experts may overlook. An added dimension of this process is that undertaking planning and the other activities that mitigate community vulnerability to hazards and that strengthen the community's resilience will engage people in ways that renew or strengthen their own sense of civic responsibility and membership. It may also reinforce the health of those organizations of neighborhood and civil society that make up the infrastructure of civic life and are integral to the ability to recover from disaster and dislocation (75,160,161).

An example of this was demonstrated in the village of Shang-An in Taiwan. In 2001, Taiwan, a country prone to recurrent public health and weather-related emergency events, began efforts to improve the country's emergency response capability and to explore ways in which people at the grassroots level can be integrated into the preparedness and planning process. In Shang-An, public engagement activities demonstrated how "street science" can be used, as residents shared their knowledge of local ecology, terrain, and other conditions. They became a part of a kind of surveillance and early warning system. They also formed effective community organizations to take an active role in problem solving and in undertaking hazard mitigation and disaster management tasks (162).

Having the opportunity to take part in such local community-based public health functions has an educational effect on citizens and helps to promote greater scientific and health literacy. This in turn spills over the line between peoples' sense of communal membership and

civic responsibility as citizens and their sense of responsibility for the health and safety of themselves and their families as moral agents (132). By taking part in public health emergency preparedness and hazard mitigation efforts, a person can bring closer together the civic and the personal realms of his or her life and conscience. Not only will vulnerability to various public health hazards be thereby mitigated, but also the radical privatization and the alienation from the civic realm that so many who bowl alone in America now apparently feel. (A study of the decline of civic engagement in America reports an increasing number of persons bowling by themselves rather than joining bowling leagues [158]). When large numbers of volunteers show up at a disaster site to help, we may always admire their expression of solidarity and mutual concern, but we need not forever be astounded by it.

Emergency Planning and Private Dilemmas

It is important not to carry the notion of fusion of public and private, civic responsibility and personal responsibility too far. When this is done, communal conformity can eclipse individuality, privacy, and the liberty that leads to diversity. Ethical conflicts and dilemmas will undoubtedly arise in the context of emergency planning (86,141,163). Plans tell people how to behave in the face of impending danger, but people ultimately have to take responsibility for how prudently and responsibly they act to protect themselves and their families. Private moral agency and personal responsibility wrestle with scarcities of various kinds, and these scarcities become dramatic in the emergency planning context.

Everyone should be informed about steps they can take to prepare for an emergency and what to do to find shelter, to evacuate, or to locate medical care. Much information regarding these things is now available, although some reports suggest that it is being conveyed in ways

that are not sensitive to ethnic or class differences (121,122). It is not obvious that prudence and private moral responsibility dictate that more immediate needs (rent, children's clothing, education) should be forgone so that one can stock up on 90 days' supply of canned goods. Public health emergency planning should assume a measure of self-protection and personal responsibility on the part of ordinary people, and it should give them the information they need to make informed choices. However, planning must also accommodate the reality of limited choices and resources that many people confront in their normal lives, for these will constrain them before, during, and after an emergency as well. Private morality should not require undue burden or self-sacrifice. New Orleans after Hurricane Katrina was replete with examples of this kind of inequality in options, choices, and consequences. A just society will provide adequate social provision so that mothers and fathers will be able to make prudent individual provision for the health and safety of their family without making tragic trade-offs (39).

No one can be in two places at the same time, and physical presence can take on an importance in times of crisis that it does not in everyday life. What do we say about the man who was in his office when the plane hit Tower 1 and who decided to search the floor for survivors rather than go immediately to the stairway to escape and protect himself? What does one say to his wife and children? Perhaps he had a special task in case of fire in the evacuation plan that his agency had prepared some time ago. Should he, or anyone have accepted that role and that responsibility? Yet if no one does, if no one should, how can there ever be any plan?

PART III

Conducting Public Health Research During or Immediately After Disaster Events

Public health officials often have an opportunity to conduct research on such things as medical and nursing techniques, logistical arrangements, and human behavioral responses during public health emergencies. CDC personnel may be called upon by local officials and others to do so because they have the training and experience necessary to organize and conduct research of this kind. Is it ethically acceptable to engage in research activities during the response phase of a public health emergency? If so, with what safeguards and oversight should such research be conducted? How should emergency response planning and implementation distinguish between “research” and other response activities?

At first glance, it might appear that doing research in the midst of a disaster constitutes a particularly inappropriate response to the urgent needs of a suffering population. A natural disaster or terrorist attack might leave thousands of people in desperate need of shelter, medical care, psychiatric services, food, and clothing. To suggest that public health research be conducted in a setting of such desperate need may give the appearance that health officials are more interested in expanding the horizons of knowledge than in the primary task of disaster intervention, which must be to safeguard the basic health interests of all individuals within the affected population. Although research in this context can generate worrisome ethical tensions, we believe that such a pessimistic conclusion is profoundly misguided. It misconstrues the fundamental social mandate of public health institutions while ignoring the strong ethical imperative to do research, even in the context of disaster intervention, in order to prevent further death and illness in present or future disasters.

Despite the many differences between public health and clinical medicine, the ethical case for research is equally powerful in both domains. Just as clinical research is necessary not only to develop new cures for dreaded diseases, but also to identify the many standard therapies in wide circulation that either do nothing or actually harm or kill those subjected to them, so public health research is necessary to determine which disaster interventions might most effectively promote health and combat disease in various populations. Since the mandate of public health institutions is to help create and sustain conditions in which people can be healthy, that mandate must include an ethical imperative to create the knowledge base necessary for effectively carrying out this important mission, both in the ordinary course of affairs and in disaster situations.

Conducting Public Health Research During or Immediately After Disaster Events

Key Points

- ❖ There is a strong ethical rationale to do research, even in the context of disaster, in order to prevent further death and illness in future disasters.
- ❖ The basic norm governing public health research is the equality and dignity of each individual subject. Research must be conducted during times of emergency, but it must not contravene the basic rights and interests of those asked to participate.
- ❖ We adopt a version of the so-called “equipoise requirement” for undertaking public health research. That is, participants must receive a level of care and protection that does not fall below what most reasonable public health practitioners would regard as the best practices of crisis response available.
- ❖ Under the rubric of “social value” we conclude that, if a particular research project properly targeted at finding better modes of disaster intervention should conflict with the effective provision of relief, e.g., by draining away funds or necessary personnel devoted to immediate disaster relief, then such research should either not be conducted in the present circumstance or additional funds or personnel should be devoted to the research in a way that would not threaten or undermine the primary goals of crisis response.
- ❖ Researchers must be attentive to the norm of fair subject selection. Some victims of disaster (and perhaps some public health professionals) might be considered to be “vulnerable” and in need of special protections. Researchers should avoid attempting to enroll subjects who have already been subjected to numerous studies or who have been traumatized by their experience of disaster.
- ❖ Declaring all or most traumatized disaster survivors as “vulnerable” and incapable of giving genuine consent would constitute an overreaction to a legitimate concern in some particular cases.
- ❖ Researchers need to guard against the so-called “therapeutic misconception” and take great care to inform potential research participants that their participation is strictly voluntary and that some interventions to which they are subjected might be undertaken primarily for the benefit of the research (and the victims of future disasters) rather than for their personal benefit.
- ❖ Given the limited window of opportunity for conducting research in disaster settings, the legal regulation of research in the emergency context must attempt to strike a judicious balance between protecting the rights of research subjects and avoiding the imposition of onerous and unnecessary administrative barriers to the conduct of important research.
- ❖ Two potentially helpful responses to the above difficulty include advance formulation of so-called “just-in-case protocols” and centralization and specialization of human subjects review for disaster-related research.

- ❖ Even when public health interventions can be properly demarcated as research, many such studies will fall into the category of minimal risk research and should, therefore, be subjected to expedited review.
- ❖ Certain public health research in this context might fall into the category of “quality improvement” research. Some such studies should be exempted from IRB review altogether, while others should be subjected to expedited review.

Types of Research in the Emergency Context

Two distinct kinds of research might be conducted in emergency settings. First is research whose purpose is to compare a standard mode of crisis intervention with one or more innovative or experimental approaches that researchers hope might achieve better results. For example, researchers might study the comparative advantages and disadvantages of providing various alternative mental health services to victims of a disaster. Here the primary motivation might be to diagnose and improve the mental health of survivors, but there would be a definite research component comparing established and innovative interventions in order to create new knowledge and assist the victims of future disasters. Second is the category of “opportunistic research,” i.e., research on some subject not related to the optimal management of emergency interventions but which might be available for study only in the context of an emergency such as the one at hand.

To focus precisely and concisely on the ethical tensions embedded in disaster-related public health research, the subject matter of this section must be delimited. First, it will not be concerned with standard public health interventions that might resemble research insofar as they depend upon various scientific or statistical methodologies but are conducted primarily for the purpose of disaster response rather than research. For example, we shall not discuss here the ethics of routine case-finding, surveillance, assessing environmental hazards, or laboratory studies of various strains of bacteria and viruses. Insofar as these standard public health

interventions are used in order to effectively respond to an immediate threat, they will be regarded as public health practice, not research.

Second, we will not address the related question of how to distinguish public health practice from public health research. Because of the complex nature of some public health interventions, which combine elements of traditional practice with methods of data collection and analysis that can often resemble the tools of research, decision makers are frequently perplexed about how to label such interventions. Are they public health practice or research? This is not a mere matter of semantics; major consequences, including the legal necessity of seeking costly and time-consuming Institutional Review Board (IRB) review, can flow from a determination that a contested intervention is research rather than practice. Although this is a crucial threshold question for decision makers in the field and a major cause of concern for contemporary policy makers at CDC, the Office for Human Research Protections (OHRP), the National Institutes of Health (NIH), and other concerned groups, it is sufficiently complex to merit a report of its own (164,165). If a particular public health intervention exhibits elements that qualify as bona fide research according to the norms embedded in public policy, those elements should receive IRB review of some sort (full or expedited) or be explicitly and officially exempted from such review.

Third, this discussion is an inquiry into the ethics of doing research in disaster settings, not biomedical or public health research in general. Therefore, most of the standard norms governing the conduct of biomedical or public health research are either assumed or at least as beyond the scope of this discussion.

Fourth, our focus is primarily on ethics as opposed to regulation. Many daunting regulatory challenges face the development and implementation of effective and ethical research

designs in the context of disaster response. By their very nature, disasters, whether natural or manmade, tend to occur without much notice, leaving little time for careful vetting of hastily designed research protocols by IRBs. While we acknowledge the urgency of developing adequate regulatory frameworks for disaster-related research and will refer occasionally to various regulatory issues, a full treatment of this set of issues is beyond our present scope.

Normative Starting Point: Equal Respect for Persons

Research in a disaster setting exposes persons here and now to various inconveniences and risks largely for the benefit of other people in the future. Whereas most individuals have no ethical problem with sacrificing one or more of their own interests so that other more important interests might flourish—e.g., eclipsing one's interest in avoiding the momentary pain of the dentist's drill in favor of a long-term interest in a healthy (and pain-free) molar—they have a serious ethical problem with sacrificing the well-being of some people in order to secure the well-being of others. The chief ethical task for research ethics in any sphere, then, whether in the realm of clinical medicine or public health, is to find a way to secure important benefits for individuals in the future without sacrificing the rights or basic interests of the subjects of the research.

This fundamental commitment to the rights and interests of each person appears to rule out most utilitarian solutions to this problem, since utilitarianism is primarily concerned with amassing the greatest amount of total welfare without worrying about how that welfare is produced or distributed. It is thus, at least theoretically, open to utilitarians to expose some research subjects to risks that might be viewed as excessive or unfairly distributed on the grounds that such a sacrifice would serve the greater public good. Given the vast numbers of

people who might be benefited in the future, one could easily justify the sacrifices of a few today for so many more tomorrow.^{†††} In the sphere of clinical research, this sort of utilitarian justification is precluded by what Benjamin Freedman referred to as the ethical requirement of “clinical equipoise” (166). According to this requirement, physicians owe a fiduciary duty of personal care to every patient, even to those enrolled in a clinical trial. This duty can only be reconciled with the impersonal demands of the randomized clinical trial—e.g., randomization, rigidly observed protocols, blinding of subjects and investigators—when, and only when, it can honestly be said that all of the various arms of the proposed study are in “equipoise.” That is, only when there is genuine disagreement within the expert clinical community concerning the best approach to a particular clinical problem, all things considered. This did not mean that all the arms of a study must weigh equally in the scales of clinical judgment, which would have been to set the bar way too high. It was enough for a respectable minority of the expert clinical community to believe that no agreement has been reached on the pivotal question of which treatment, available either inside or outside the study, was the best for patients with a particular condition. Given this sort of “equipoise,” Freedman believed physicians could invite their patients to join a clinical trial with a clear conscience and their fiduciary duties intact.

The lesson of this history for those grappling with the ethics of research in the domain of public health is that, unless health officials are willing to embrace publicly a frankly utilitarian justification for research in disaster settings, they must adopt some analog of Freedman’s

^{†††} Our reservations about embracing a utilitarian framework for assessing research within PHEPR are consistent with the Pandemic Influenza white paper developed for the CDC Ethics Subcommittee. See “Ethical guidelines in pandemic influenza” found at: http://www.cdc.gov/od/science/integrity/phethics/panFlu_Ethic_Guidelines.pdf. This report ranks the maintenance of social infrastructure higher than the principle of moral equality for purposes of vaccine distribution and other measures to contain transmission and reduce mortality. Research promises benefits to people in the future (or future people), and we believe it would be wrong to sacrifice the basic interests of existing people in the midst of a disaster to achieve such a goal. On the other hand, pandemic influenza could threaten basic social, medical, and public health institutions with truly catastrophic consequences for everyone. Given this different context, different principles might be more important, or the same principles might lead to different conclusions.

equipoise requirement (167,168). For example, researchers proposing to compare the effectiveness of a standard public health intervention against some innovative or nonstandard approach to disaster intervention would have to acknowledge the existence of reasonable disagreement or debate among expert public health practitioners as to the best approach, all things considered. Crucially, however, in the public health context this equipoise requirement cannot be based on the special fiduciary duties inherent in the physician–patient relationship. Since public health workers do not generally enjoy a pre-established clinician–patient relationship with the subjects of their research (i.e., the community), they cannot ground their fundamental ethical norm on this nonexistent relationship. Instead, it should be grounded on a commitment to regard each person as a free and equal member of society whose basic interests should not be sacrificed in the interests of maximizing the public’s health or welfare.^{†††} Thus, in the course of research, participants must receive a level of care and protection that does not fall below what most reasonable public health practitioners would regard as the best practices of crisis response available (167).

Insofar as both clinical and public health research are bounded by concerns for the protection of human subjects, they share a common commitment to the core values of human dignity and equality. In the area of clinical research, these values are expressed in the duty of personal care, also known as the therapeutic obligation, for each research participant. In the area of public health research, they are expressed in the analogous duty to honor the dignity and rights of all research subjects, in part by not subjecting them to interventions known to be inferior to others.

^{†††} Embracing the principle of moral equality in this context does not preclude the possibility that the principle of efficiency or achieving maximal utility might trump the principle of equality in other contexts, such as priority setting in the context of pandemic influenza. See “Ethical guidelines in pandemic influenza” found at: http://www.cdc.gov/od/science/integrity/phethics/panFlu_Ethic_Guidelines.pdf.

A Framework for Ethical Analysis

Our ethical analysis of research in disaster settings conforms to the grid developed at the National Institutes of Health for assessing the ethical acceptability of clinical research protocols (169). Instead of following the well-trod principles-based approach originally published in the influential *Belmont Report* and later developed in Beauchamp and Childress's various editions of the *Principles of Biomedical Ethics* (170), this grid sets out seven benchmarks, each of which must be satisfactorily addressed for a research project to be deemed sufficiently ethical. These benchmarks are social or scientific value, scientific validity, fair subject selection, favorable risk-benefit ratio, independent review, informed consent, and respect for potential and enrolled subjects. Since our analysis is narrowly focused on the ethics of disaster-related research, we shall only discuss those benchmarks that require additional commentary for this particular purpose. We also depart from this report and a subsequent article (171) in our insistence upon some form of equipoise requirement as opposed to the suggested substitute norm of nonexploitation, which we regard as excessively vague and utilitarian. Because the particular canons of scientific validity, risk-benefit analysis, and respect for potential and enrolled subjects apply equally to both clinical and disaster research, we shall not consider them further here.^{§§§}

Social value

Since all research requires the expenditure of scarce financial and human resources, and since most research in the biomedical and public health arenas exposes subjects to at least some

^{§§§} By "scientific validity," Emanuel has in mind the use of accepted scientific principles and methods to produce reliable data. By "respect for subjects" he means such behaviors as permitting subjects to withdraw from the research, protecting privacy through confidentiality, and informing subjects of the results of clinical research (p. 2703).

physical or psychological risks, the research must lead to valuable knowledge that makes the expense and risks worthwhile. In the area of disaster-related research, the expectation is the discovery of new interventions that will better shield the population from harm or speed their recovery from physical injury, psychological trauma, or environmental destruction. To be of social value in this sense, research protocols must be designed so as to add to the existing body of knowledge and (hopefully) dispel “equipoise” by demonstrating that some interventions are better or worse than others.

Estimates of social value are also important for resolving two different kinds of conflicts involving disaster-related research. The first sort of conflict arises between the overriding goal of disaster intervention, which is to save lives and restore people as soon as possible to healthy living conditions, and the objective of emergency research, which is to obtain knowledge that may save other lives in future emergency events. Since the victims of disaster are already in a highly vulnerable state and their basic interests are already under threat, they should have every reason to expect that, in cases of genuine conflict, the goal of crisis intervention should take priority over other goals.

Two practical directives follow from this conclusion. First, research that can be pursued in nonemergency contexts should, in general, not be conducted in the context of a public health emergency. The only conceivable exception to this rule might be research projects unrelated to the ends of disaster intervention that 1) nevertheless hold out the prospect of significant social value, and 2) can only be studied during a unique window of opportunity afforded by a given emergency. Even in such a case, however, the research should not be conducted if it would significantly impede delivery of relief to the victims of a disaster.

Second, if a particular research project properly targeted at finding better modes of disaster intervention should conflict with the effective provision of relief, e.g., by draining away funds or necessary personnel devoted to immediate disaster relief, then such research should either not be conducted in the present circumstance or additional funds or personnel should be devoted to the research in a way that would not threaten or undermine the primary goals of crisis response. Much will depend here on both the magnitude of the public health emergency and the extent to which research would actually impede the primary objective of disaster relief. In truly catastrophic situations, it might be hard to justify any research that conflicted in a serious way with the direct delivery of assistance to victims.

A second kind of conflict can arise at the level of priority setting. Some research projects might be largely duplication of previous studies, might focus on issues of only peripheral concern in the context of disaster planning or intervention, or might target crisis events of extremely low probability. Other projects might be very ambitious but would distract attention from the larger goal of establishing and sustaining a robust public health infrastructure. Although we cannot state categorically that such research should never be done, especially given the elasticity of the term “public health emergency,” it should definitely be assigned lower priority than research with greater social value.

Fair Subject Selection

Assuming that a research study promises adequate social value, the next question is which persons or groups should be asked to participate in it. Two different sorts of concerns occupy commentators on this question in the research ethics literature. The first is that the group of people selected to undergo the inconveniences and risks of a study should also stand to benefit

in some way from the results of a successfully conducted trial. Thus, if researchers decide to locate their study of an expensive drug in a poor country where people could never afford an approved version of it, commentators are likely to conclude that the proposed subject selection is unfair. It is unclear how this concern might surface in the context of disaster research, however, where the locus of a disaster is so often utterly unpredictable. This concern about subject selection is also attenuated by the fact that much disaster-related research will consist of epidemiologic studies, which generally pose fewer risks for the enrolled population than do typical clinical research studies.

The second concern focuses on the recruitment of so-called “vulnerable populations,” i.e., individuals or groups who might be more likely than others to be misled, mistreated or exploited in the course of research, and who might therefore require “special protection” in the course of IRB review. Historically, a wide variety of groups have been accorded this status, including prisoners, children, women, the cognitively impaired, elderly residents of nursing homes, patients with terminal illnesses, medical students, and illiterate citizens of poor countries. Although critics rightly worry that lumping these diverse groups of people into the category of “vulnerable research subject” often serves only to stereotype and disempower them (113), there may well be reason to worry that the victims of a disaster might be more easily abused or exploited than more typical subjects of biomedical research. They have presumably just undergone the trauma of living through a disaster. Their place of work may have been destroyed; their home may have been swept away; their loved ones may have died or suffered serious injuries. The toll of human suffering inflicted by a major disaster can leave its victims reeling, disoriented, and desperate for a helping hand. While the causes and potential cures for this

suffering are appropriate and important objects of study, including the victims of disaster in research has the potential merely to encumber them with additional burdens.

Similar concerns attend the enrollment of public health responders in research. Like the victims of disasters, they too can suffer from exhaustion, disorientation, or depression which simultaneously makes their own mental health needs appropriate objects of research while possibly rendering them vulnerable in similar ways to the additional burdens of participating in public health research.

While a detailed examination of exactly what kind of “special protections” should be accorded different categories of vulnerable subjects in disaster research is not within the scope of this report, researchers contemplating disaster-related studies should be attentive to the following issues:

- Are members of the population under scrutiny likely to be burdened with numerous requests for interviews and study participation from many different parties, including journalists, the police, the military, and public health workers? Including the same group of people in multiple studies could impose unfair burdens on them.
- Are potential subjects currently too disoriented from a recent traumatic experience to reach a reasoned and informed decision about participating?
- Are personnel and procedures in place to screen the targeted population for cognitive impairments and to provide psychological supports to those who experience difficulty during or immediately after a session with researchers (113)?

Informed consent

In addition to conformity with the usual criteria of informed consent as described in 45 CFR 46.116, researchers contemplating studies in the aftermath of a disaster will encounter two special consent-related problems. First is the question of whether recently traumatized individuals might lack the decision-making capacity to give genuine consent. Although little empirical research has addressed this question, it is likely that declaring all or most traumatized disaster survivors as “vulnerable” and declaring them incapable of giving genuine consent would constitute an overreaction to a legitimate concern in some particular cases (172). Since capacity to consent to research is a “task-specific” issue—i.e., is this particular person in this particular circumstance capable of understanding and consenting to this particular study?—focusing on broad, stereotypical categories (e.g., “psychiatric patient”) is usually bound to mislead. Still, given the real possibility that some trauma victims will indeed be so disoriented as to render them incapable of rational decision making, some commentators caution that investigators should take this into account in the design of their studies and perhaps provide additional safeguards, such as a time lag between an initial contact and eventual interview, or inviting local clinicians to assess any acute need for psychiatric intervention (172).

A second concern about informed consent in this setting involves the so-called “therapeutic misconception,” i.e., the subjects of clinical investigation often confuse their participation in research with therapy. Even when explicitly told that their treatment will be determined by chance and governed by a rigorous scientific protocol, patients often still mistakenly assume that their own treatment will, of course, be determined by their doctor, who is concerned only with each individual patient’s best interests (173). Patients with such a misconception inevitably develop a skewed conception of the risks and benefits at stake in any

particular study. Believing, or hoping, that their doctor is focused exclusively on their best medical interest rather than on the accumulation of scientific knowledge, patients fail to consider the risks inherent in the design of most clinical trials, risks that are due precisely to an array of methodological safeguards against bias, such as randomization, blinding, placebos, or crossover designs.

In the disaster setting, potential participants in research may harbor an analogous misconception, i.e., the belief that all their interactions with physicians, public health officers, social workers, and psychological researchers in the immediate aftermath of the disaster are primarily for their own benefit. Researchers need to guard against this ubiquitous misconception, taking great care to inform potential research participants that their participation is strictly voluntary and that the intended beneficiaries of the research are future victims of future disasters.

Institutional review

Numerous scandals involving biomedical research have led to the present system of rigorous oversight of clinical research based upon a country-wide network of local IRBs for the ethical vetting of all federally funded research with regard to informed consent, risk/benefit analysis, or confidentiality. This system represents a vast improvement in the protection of research participants vis-à-vis the era of unregulated physician/researcher discretion. On the other hand, many critics of the present system, some with vast experience in running IRBs (174), contend that the present system, including the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, has swung the pendulum too far in the opposite direction, toward a “hyperprotective” regime more interested in minutiae than in the protection of patients. An undue focus on dotting “i”s and crossing “t”s, the critics contend, has led to vast increases in the

costs of ethical surveillance without much evidence that those costs have secured increased human subjects protection. The regulation of research in the emergency context must, then, attempt to strike a judicious balance between protecting the rights of research subjects and avoiding the imposition of onerous and unnecessary bureaucratic barriers to the conduct of important research. In previous sections we discussed how the logistical demands of research can impinge upon the primary goal of assisting those caught up in an emergency; in this section the focus will be on how socially valuable research can be stymied by bureaucratic obstacles, and how this problem might be successfully resolved.

Although some critics of the current regulatory regime cite the onerous costs of full IRB review as the most serious problem, in the context of PHEPR, the primary threat to the conduct of research is the passage of time. Especially during the response phase of an emergency, researchers must seize a very small window of opportunity to conceive and conduct a study. If they are legally compelled to comply with onerous informed consent requirements and seek full IRB review of their proposed protocol, that window may well close before their research has even begun. It takes time to get individualized informed consent, and IRB review, even when it is supposedly “expedited,” can be enormously time-consuming.

We envision two main lines of constructive response to this concern. First, whenever possible, public health researchers should try to plan at least the general outline of their studies well in advance of the actual emergency event. If undertaken during the planning phase rather than in the midst of the chaotic response period, researchers might be able to develop a set of “just-in-case protocols” that could receive a full, leisurely vetting from IRBs. Another step that might be taken during the planning phase is the establishment of centralized IRBs (or

subcommittees of existing IRBs) whose dedicated function would be the prompt processing of pleas for expedited review that would arise during the response phase of emergencies.****

We recommend that CDC investigate the feasibility of establishing such a centralized clearinghouse for reviewing expedited protocols drafted in response to ongoing emergencies, and we encourage other IRBs to join efforts to coordinate review during declared public health emergencies. Establishment of such centralized loci of decision making—e.g., at CDC or within geographic proximity to the site of an emergency—could accomplish several important public health goals. Although we stress here their potential value in expediting the review of research projects in a maximally efficient and timely manner, such centralization would also reduce redundancy in the review process, which would secure both fiscal and ethical benefits. A centralized process would no doubt be less expensive than an archipelago of unrelated IRBs. Centralization would also help public health officials eliminate or greatly reduce the number of research studies targeting exactly the same problem and, importantly, involving the same group of subjects. The bombing of the Federal Building in Oklahoma in 1995 and the attack on the World Trade Center on September 11, 2001, represent two very different examples of the oversight of research following terror (175).†††† The norm of ethical subject selection dictates that care is taken not to impose excessive or unnecessary burdens on the participants of research. Whether or not institutions choose to participate in a centralized review process, IRBs

**** We are assuming here that risky, complex protocols requiring full IRB review would in all likelihood need to be drafted during the planning phase if they are to be successfully deployed during the brief window of opportunity available during emergencies.

†††† Research following the Oklahoma bombing was coordinated by and funneled through the IRB of the University of Oklahoma Health Sciences Center. This approach was motivated by the goals of protecting the survivors of the disaster, minimizing burdens on the research subjects, and to maximize the knowledge gained from each study. By contrast, research following the attack on the World Trade Center in New York was both massive in scale and largely uncoordinated (58,175).

should be included in PHEPR, and they should plan and exercise their ability to respond to requests for review of research in disaster settings with appropriate expertise in a timely manner.

A second, more complicated and controversial line of response to concerns about research review focuses on the likely characteristics of most PHEPR-related research and the need for better ways to categorize and subject it to ethical oversight. Much, if not most, of the research that will be proposed in this area is either epidemiologic or psychosocial. Researchers will want to document and analyze the incidence of mortality and morbidities, both physical and psychological, arising from various environmental factors. Most often, this documentation will take the form of standard public health practice activities, such as surveillance and contact tracing, which do not fall under 45 CFR 46 (also known as the Common Rule) and need not be scrutinized by an IRB. Sometimes, however, the quest for data will develop into full-blown research projects intended to benefit a much larger ambit of people than the victims of a current disaster. Even when such interventions can be clearly demarcated as research, a large proportion might fall into the category of minimal risk research, i.e., interventions that pose little or no physical, psychological, or social risk to subjects beyond those risks normally encountered in daily life. If and when this is the case, the review of such research not only may, but also should be expedited and free from bureaucratic, expensive, and time-consuming hurdles.

Another distinctive feature of much, but not all, PHEPR-related research is a familiar resemblance to quality improvement (QI) studies. Just as hospital chains currently do QI research to determine the best ways to reduce the incidence of catheter-related infections (*176*), so public health agencies will want to study the best ways to educate disaster victims about, for example, the importance of hand washing in refugee centers or the avoidance of carbon monoxide poisoning in homes recently reclaimed from flooding. Although federal regulators have recently

insisted, wrongly in our view, upon subjecting some vitally important QI investigations to the full brunt of IRB review, including informed consent from all affected patients and physicians (177), we believe that a good deal of QI research is primarily intended to assess and improve the provision of services to specific populations, and thus should fall outside the ambit of IRB review (178,179). Likewise, in the context of PHEPR we concur with CDC guidelines which hold that interventions should not be treated as research when the “intent of the project is to identify and control a health problem or improve a public health program or service;...data collected are needed to assess and/or improve the program or service, the health of the participants or the participants’ community;...and the project activities are not experimental”(164). We contend that interventions that meet the above criteria should not be defined as research, thus should be exempted from IRB scrutiny altogether.^{****}

Naturally, real situations will not always be this simple, and the fit between some proposed interventions and the above criteria for exemption from the Common Rule will not always be exact. Some proposed projects will exhibit hybrid or overlapping features between QI-like steps to improve service delivery to particular communities and research procedures involving sophisticated analyses and subject selection geared toward the generation of widely applicable knowledge. Projects falling into this borderland between program improvement and research should be subjected to formal ethical review, but the degree of scrutiny provided should correlate with the projects’ degree of risk to participants. If those risks are low, other conditions

^{****} This suggestion finds support in the Common Rule at 45 CFR 46.101b(5), where the criteria for exemption from the reach of the federal regulations are enumerated: “Research and demonstration projects which are conducted by or subject to the approval of department or agency heads (e.g., at CDC), and which are designed to study, evaluate, or otherwise examine: (i) Public benefit or service programs;... (iii) possible changes in or alternatives to those programs or procedures....”

are favorable (e.g., the data collected are not linked to names), and the window of opportunity is fleeting, we urge that such projects be candidates for expedited review.^{§§§§}

Special Ethical Considerations for CDC and CDC Personnel Deployed During an Emergency Response

“...what captures more of a sense of our primary purpose, being a partner with the community, a public servant, or an employee of the government? You’re in the middle, you’re a bridge, you’re a forced ambassador, trying to make peace (180).”

The ethical issues of PHEPR have thus far been discussed from a general point of view, encompassing in the analysis those parties that do (or should) play a role in planning, response, and follow-up—public health officials, medical and health professionals, government officials (local, state, and federal), technical experts, community leaders, and ordinary citizens. This section will focus on the more particular perspective of CDC and the public health professionals who make up its staff. These issues apply in similar ways to public health professionals in state and local health departments, although the ways different organizations manage these issues will vary. Describing CDC's perspective may serve as a guide to other jurisdictions. It not the purpose of this section to provide a full description or assessment of the policies, procedures, and programs that CDC follows in terms of staff deployment. When we suggest that, from an ethical point of view, deployment arrangements ought to have certain features, supports, and safeguards, for example, it is not to suggest that CDC does not have such policies or management systems.

^{§§§§} A similar analysis could be provided for the waiver of Common Rule-style informed consent in many PHEPR settings. Subpart A would approve the waiver of rigidly construed informed consent protocols when there is no more than minimal risk, when such waiver will not adversely affect the rights or welfare of subjects, and could not be practicably carried out without a waiver. This final proviso is crucially important for disaster-related research confronting a very brief window of opportunity. See 45 CFR 46.116 (d).

Indeed much of what we recommend is already in place. Our purpose in this section is to develop ethical benchmarks concerning some of the moral dilemmas and obligations inherent in field deployment during a public health emergency. Others may be able to use these benchmarks in further developing CDC policy in the future.

Special Ethical Considerations for CDC and CDC Personnel Deployed During an Emergency Response

Key Points

- ❖ CDC functions as a national resource for public health surveillance, scientific and technical guidance, and standard setting in the nation's largely decentralized public health system, in which the main legal and governmental authority resides in the states. CDC also provides direct technical advice and support on site during emergency situations.
- ❖ Just as an individual professional has an obligation to ensure that he or she is adequately prepared to meet the requirements of a deployment, CDC as an agency has an obligation to provide the required and appropriate training, preparation, equipment, and support.
- ❖ A facet of the deployment situation related to ethics is the discrepancy between what one knows ethically should be done and what one is in a position to do or to achieve.
- ❖ A public health emergency planning, response, and recovery effort is a complex social and administrative undertaking. Playing an advisory role as a federal official and a public health professional, with special technical or scientific expertise, in this complex undertaking often presents the CDC official with conflicting agendas.
- ❖ The scientific and advisory mission of deployed CDC personnel is made ethically difficult by the fact that the scientific knowledge to be brought to bear on decisions is incomplete or imperfect. Scientific advice must be given in an interpretive, and not simply a declarative fashion.
- ❖ The ethical obligations of individual CDC professionals and the ethical obligations of the CDC leadership and organizational support systems go hand in hand. During an emergency deployment, the consequences of poor performance can be extremely serious. Many other persons, including those who are in positions of great need and vulnerability, put their trust in CDC expertise and skill.
- ❖ Certain deployment assignments may be hazardous and require substantial individual sacrifice.
- ❖ The process of selecting individuals for deployment raises important ethical considerations and may be the cause of personal conflict and ethical dilemmas. This process should be orderly, transparent, and fair.
- ❖ If an individual believes that an assignment is inappropriate or has been wrongly motivated, an orderly and confidential review and appeals process should be in place for that person that is consistent with existing personnel or uniformed service procedures. Considerations of undue family burden and personal hardship should also be taken into account.

- ❖ Clear, but reasonably flexible, standards of performance and discretion should be established and be clearly understood by everyone in the deployment team and along the chain of command. If appropriate training is the organizational responsibility of CDC in the preparedness phase, ensuring an appropriate and effective support system and reasonable expectations is CDC's responsibility during the deployment phase.
- ❖ Disaster sites must not be allowed to be defined as places where moral limits do not apply. CDC personnel operating in these areas must be empowered and encouraged to retain their moral perspective and their sense of ethical propriety.
- ❖ Many situations will be open to conflicting interpretations concerning the right course of action. Procedures and protocols should be put in place that will enable CDC-deployed professionals to seek ethical assessment and guidance concerning value conflicts and uncertainties.
- ❖ Regarding designated authorities and decision makers, CDC personnel have a strong prima facie obligation to provide clear and timely information during the emergency event.
- ❖ The CDC-deployed professional is one of the principal voices of scientific rationality in public health emergencies and should tailor his or her communication activities to ensuring that this voice is heard.
- ❖ CDC as an agency should support its personnel by resisting unwarranted limits others may place on the gathering of relevant scientific information, analysis of that information, and communicating of the results of that analysis to appropriate officials and decision makers.
- ❖ The following guidelines should be used in communication:
 - CDC experts should be candid about the limitations of their findings at the time of communication.
 - They should offer perspectives on the ranges of potential risk or harm and, to the extent possible, estimates of the probabilities involved.
 - They should indicate what further investigation would be necessary to provide greater certainty and how long it will take to acquire more information.
 - They should also be candid about the likelihood that greater certainty or more reliable information will not be forthcoming in the time before decisions have to be made.
- ❖ CDC leadership should maintain the organizational capacity (an adequate trained workforce, adequate resources, adequate funding) to permit it to respond by deployment without compromising its other vital and ongoing agency functions.
- ❖ There should be a well-defined mechanism for the preparation of post-deployment reports and analyses by CDC personnel.

Part of the mission of CDC is to deploy its expert staff to locations throughout the United States and around the world to assist with the management and mitigation of public health emergencies. They are most often cast in the role of technical advisors; they do not typically converge on a location and take charge. Numerous special ethical questions and obligations arise for deployed CDC personnel during an emergency situation when they are engaged in public health functions such as surveillance, case-finding, virus characterization, assay development, health and infrastructure assessments, data collection, and other forms of technical support to state and local officials engaged in public health efforts.

The Role of CDC in Emergencies

Under normal circumstances CDC functions as a national resource for public health surveillance, scientific and technical guidance, and standard setting in the nation's largely decentralized public health system, in which the main legal and governmental authority resides in the states. CDC offers a centralized, uniform, and highly respected source of scientific and professional expertise to public health officials throughout the country. It provides epidemiologic information on a national and global scale; it provides laboratory assessment with technological sophistication that many localities cannot match, and upon which they have come to rely. In the preparedness and response field, CDC has been integrally involved in the development of national guidance and practice standard-setting documents, from which regional and local preparedness efforts have benefited. CDC is also involved in the federal policy-making process concerning the dissemination of federal public health resources, including the development and allocation of national stockpiles of vaccines, medications, and medical supplies to be used in emergency situations.

The public health systems in the various states, territories, and local jurisdictions vary sufficiently that it is not possible to discuss them except in general terms. However, one ethically relevant characteristic of state and local systems is that they are integrated into the communities in which they serve. Local public health agencies have detailed knowledge of communities—information that may be critical to successfully implementing the technical expertise provided by CDC. Although organizational structures vary, many of these ethical issues also apply to public health scientists and officials in the states, territories, and local jurisdictions. The public health system is decentralized; in some states the local organizational units draw upon state-level support in a manner similar to the way CDC responds to request for assistance from states and territories. Moreover, during a public health emergency the public health system becomes even more decentralized, involving a wider array of partners in other government agencies, and not-for-profit, and private sectors as well. Often these relationships are not based on formal authority, but state, territorial and local officials may be responsible for successfully coordinating the actions of different partners. Challenges CDC faces in preparing and protecting its workforce during a public health emergency also apply to other jurisdictions.

A public health emergency exists when a health threat or disruption occurs so widely or so rapidly that it overwhelms the capacity of the usual public health and medical infrastructure to respond effectively. Therefore, in addition to its role as a central clearinghouse and purveyor of public health information and knowledge, CDC also provides direct technical advice and on-site support during emergency situations.

A Typology of Ethical Issues in Deployment

To put the ethical challenges faced by deployed CDC personnel in perspective, three facets of the deployment situation in general should be highlighted. (Note that these challenges may also apply to public health professionals in states and territories, if they are deployed in other jurisdictions as advisors, or when public health professionals function as part of multidisciplinary emergency response teams.) The first may be called the problem of “many hands” (181). A public health emergency planning, response, and recovery effort is a remarkably complex social and administrative undertaking. It demands the coordination and cooperation of many agencies and individuals, with cross-cutting jurisdictions, constituencies, and interests. The structure of this arrangement makes it likely that issues of communication, decision making, and resource allocation (including allocation of the time and energy of CDC personnel) will arise. In this complex undertaking, playing an advisory role as a federal official and a public health professional with special technical or scientific expertise often presents the CDC official with conflicting agendas. The scientific and advisory mission of deployed CDC personnel (and indeed of all deployed public health personnel, from whatever agency) is made ethically difficult by the fact that the scientific agenda is not the only or the most important one in a given circumstance.

The second aspect of the deployment situation that fosters ethical challenges is the need for decision making in the face of incomplete information and scientific uncertainty. The scientific and advisory mission of deployed CDC personnel is made ethically difficult by the fact that the scientific knowledge to be brought to bear on decisions is incomplete or imperfect. Scientific advice must be given in an interpretive, and not simply a declarative fashion. Decision making under conditions of uncertainty and partial or unreliable information is compounded by

time pressure, fatigue, emotional stress, often a narrow margin for error, and very high stakes (151). Providing advice and consultation in this setting is more than difficult; this is an atmosphere in which ethical problems thrive.

The third facet of the deployment situation related to ethics is the discrepancy between what one knows ethically should be done and what one is in a position to do or to achieve. We call this the gap between “responsibility” and “authority.” It is a common occurrence, indeed a structural feature that leads not only to ethical conflict, but to serious ethical dilemmas as well. This is an important distinction and requires more definition and explanation.

Responsibility, as the term is used here, is an ethical notion. It exists whenever a person is in a position to make a difference in the lives of others, to prevent harm or promote health, or to affect the distribution of resources so that fairness is respected and better outcomes obtained. Authority is a more formal, legal or administrative notion. It refers to the official vesting of responsibility in a designated role, office, or person. Such official recognition carries with it the power to enlist the obedience and cooperation of others as matter of rule and position.

Responsibility does not necessarily carry with it such power. One may see what ethically needs to be done and see the means to achieve this end, but not command the deference or cooperation of others. Responsibility must persuade; authority can instruct. Responsibility flows from ability and expertise, not from position, role, or public recognition. If one is best able and most qualified to make a decision, then one is responsible for that decision. But being (ethically) responsible for a decision is not the same thing as having the power and authority to make it. In the real world, authority can flow along channels other than ability and expertise.

Responsibility and authority theoretically should overlap, and in practice they do often exist in the same person in any given situation. Those in a position to act on behalf of others’

interests are often those who have been designated to play this role and to have this responsibility; in other words, they are the ones who have the authority to so act. It is also true that the advisory role that deployed CDC personnel play in an emergency situation vis-à-vis state and local officials is officially recognized and does have some *de jure* authority attached to it. However, in that advisory role, CDC personnel always carry with them the burden of responsibility, and a gap can exist between the authority they have been granted and the responsibility they feel. Superiors expect the responsible use of expertise, time, and energy by deployed CDC personnel, while deployed CDC personnel know that the well-being of ordinary people who need and trust them is at stake. Ethical dilemmas for CDC personnel can arise in this gap between their responsibility and their authority or power.

The range of activities that CDC personnel may be called upon to undertake during the course of a deployment assignment is quite broad. The following functional categories can serve as an organizing schema for ethical issues faced by deployed CDC personnel and by CDC as an organization that carries out a deployment service and mission:

- Preparedness for deployment
- Carrying out particular assignments and functions during deployment
- Communication and the ethics of giving policy advice
- Policy and agency issues regarding the role of CDC in emergency deployments

Preparedness for Deployment

The ethical obligations of individual CDC professionals and the ethical obligations of the CDC leadership and organizational support systems go hand in hand. During an emergency deployment, the consequences of poor performance can be extremely serious. Many other

persons, including those who are in positions of great need and vulnerability, put their trust in CDC expertise and skill. The health and well-being of these persons, as well as their material and property interests and sometimes even their lives, can be at stake. For these reasons, competence and preparation are important not merely as instrumental means for achieving desired ends or outcomes; they are also ethically important, and their ethical significance has several different dimensions.

Certain deployment assignments may be hazardous and require substantial individual sacrifice (145). Professionals arguably do have more demanding role obligations than ordinary morality requires of all individuals. This is true of military and public safety professionals as well as health professionals, particularly the Commissioned Corps of the U.S. Public Health Service. ***** To do what society calls upon them to do, they must put themselves at risk and in harm's way. They therefore owe it to themselves and to their families to mitigate such risk by availing themselves of the proper training and by being given the proper support by others. Just as an individual professional has an obligation to ensure that he or she is adequately prepared to meet the requirements of a deployment, CDC as an agency has an obligation to provide the required and appropriate training, preparation, equipment, and support. The proper timing of such training is itself important; it should be conducted in advance and in fair anticipation of an upcoming deployment. So-called "just in time" approaches to such training, while thought to be an efficient use of scarce resources in an agency, run several serious ethical risks if such approaches are not properly managed and quality controlled (182–184). Of course,

***** CDC personnel who are in the Commissioned Corps of the U.S. Public Health Service have additional obligations relating to emergency response. In 2003, the Secretary of Health and Human Services recognized the Commissioned Corps' unique status to provide swift and effective responses to urgent health needs and directed that all active-duty officers meet readiness standards by 2005. Commissioned Officers are required to meet and continuously maintain force readiness standards relating to health and safety, physical readiness, and training and professional competency. Failure to meet these standards may result in disciplinary actions including denial of promotion, separation from active duty, and/or termination of an officer's commission.

the timing of emergencies is largely unpredictable and a state of readiness must be maintained, but the need for rapid response does not justify hasty or inadequate preparation. CDC has recognized the ethical importance of preparation and support of deployed staff and has in place a system of preparation, counseling, support services in the field, and programs addressing the needs and concerns of personnel when they return from a deployment assignment.

Professionals who are called upon to perform functions for which they have not been adequately prepared and trained will undergo unnecessary psychological stress as a result, which may undermine morale and, ultimately, performance in the field (145). They may also perceive this situation as an ethical conflict; a sort of moral double bind in which they recognize the need of others and at the same time recognize that they should not allow themselves to be placed into a situation that will overwhelm them, because they may then inadvertently do more harm than good.

The process of selecting individuals for deployment also raises important ethical considerations and may be the cause of personal conflict and ethical dilemmas. This process should be orderly, transparent, and fair. No CDC staff professional, no matter how well qualified and trained, should be made to feel that he or she is being chosen for deployment as a kind of bureaucratic punishment growing out of previous professional disagreements or personal relationships. By the same token, well-trained and prepared persons should not be passed over for deployment for extraneous organizational reasons. In either case, objective merit is the ethical touchstone. The deployment system and its underlying support systems should aim at selecting the best qualified personnel. CDC professionals should not be assigned to roles or duties for which they are not qualified unless the extreme workforce shortages in a very serious emergency demands that such extraordinary steps be taken.

Within reasonable limits, CDC staff should have the prerogative to decline a particular assignment if they are not properly qualified or trained for it; indeed, it might be argued that they have an ethical duty to refuse such an assignment. If an individual believes that an assignment is inappropriate or has been wrongly motivated, an orderly and confidential review and appeals process should be in place for that person that is consistent with existing personnel or uniformed service procedures. Considerations of undue family burden and personal hardship should also be taken into account. CDC should implement such a review process and maintain it with appropriate training and directives to supervisory personnel.

Individual and CDC Responsibilities During Deployment

Once CDC professionals arrive on site during an ongoing public health emergency, they should have clearly defined areas of responsibility and lines of authority and decision making to follow. The respective roles of the various agencies on the scene and the respective roles of CDC and other public health professionals from state and local jurisdictions should be clarified and effectively communicated to all parties. This is more easily stated than achieved, however, and even if achieved, it is not a panacea. It is in the nature of an emergency situation to be fluid, dynamic, and unpredictable; everyone caught up in it must remain flexible and able to adapt to unexpected demands and rapidly changing circumstances. Somewhere between an orderly workday with a manageable "to-do" list on one hand, and utter chaos on the other, lies the actual reality that CDC staff will experience. Too much rigidity will undermine the effective pursuit of the deployment mission and the ethical goals we have identified in this white paper. Too much flexibility will lead to what is sometimes called "mission creep," wasted and ineffective effort, confusion, exhaustion, and undue stress (28,72,185).

Sometimes, factors that pull a deployed CDC professional away from the initial mission and clearly defined functions do not grow out of disorganization but out of genuine need and scarcity of personnel. Examples of this include requests by local officials for CDC personnel to perform tasks other than those they were sent into the field to perform, such as providing direct medical care, counseling, helping with transportation, or distributing safety equipment. A different kind of request, but one that poses similar dilemmas, may come from superiors off site who demand certain kinds of recordkeeping or reporting functions, which are unduly time consuming and could lead CDC personnel to be unable to respond to more direct service provision and mitigating activities.

Public health professionals cannot perform their mission or fulfill the ethical goals of their activities without the cooperation of other professionals and specialists. Disagreements may arise among the various professional cultures and perspectives in emergency preparedness and response; for example, public health priorities and law enforcement priorities may sometimes be in tension. However, cooperation is essential. At the same time, the ethical integrity of all the professional and agencies involved should be preserved and respected. To achieve this balance, there must be mechanisms of integrity-preserving compromise, review, and appeal (154).

Perspectival conflicts are readily found in emergency situations. What may have priority from an upper echelon administrative point of view may not be a priority from the perspective of an individual surrounded by immediate compelling circumstances. It is probably impossible to avoid such conflicts of perspective, and no set of ethical goals or modes of ethical reasoning can definitively adjudicate them. Although appropriate management and supervision of field personnel is important and CDC staff must remain accountable, those on site must also have

discretion to assess the immediate situation, prioritize their time and energy, and act without continual fear of reprimand after the fact.

In lieu of a definitive ethical answer to these quandaries, the important point is that clear, but reasonably flexible, standards of performance and discretion be established and that they be clearly understood by everyone in the deployment team and along the chain of command. If appropriate training is the organizational responsibility of CDC in the preparedness phase, ensuring an appropriate and effective support system and reasonable expectations is CDC's responsibility during the deployment phase.

A second, and closely related organizational responsibility is to provide for the safety and security of CDC personnel deployed during an emergency. The individual public health professional has an obligation to expose himself or herself to risk when public health's ethical goals require it, but it is the organizational obligation of CDC (or any other public health agency) to ensure that those risks are reasonable and proportionate to the benefits being sought. Professional obligations do not cancel basic ethical requirements: CDC professionals must be treated with due concern, respect, and protection as befits persons whose lives and well-being are of intrinsic ethical value. In this instance, the ethically appropriate course is also psychologically and motivationally the most effective one. Emergency responders and their supporters, such as CDC deployed personnel, need to feel that they matter in the eyes of others and that they are being supported and protected to the extent possible under the circumstances. This is key to the success of an emergency mission.

CDC has already taken steps to provide such support, not only in predeployment training and equipping functions, but also in postdeployment support and counseling. For example, in response to increasing demands placed on CDC staff by investigations of dangerous infectious

diseases or grueling national or international relief work, a small group of CDC mental health professionals collaborated to create the Responder Resilience Program in 2004. Its main goal has been to support and safeguard the health and safety, both physical and emotional, of individuals deployed to the field or to support roles during a public health emergency (186-188).

CDC Responder Resilience Services

In 2004, in response to increasing demands placed on CDC staff by dangerous infectious disease investigations or grueling relief work (national or international), a small group of mental health professionals at CDC collaborated on the creation of the Responder Resilience Program (RRP). Its basic goal has been to support and safeguard the health and safety, both physical and emotional, of persons deployed to the field or to support roles during a public health emergency. RRP has sought to support responders and increase CDC's culture of preparedness in the following five areas:

- ❖ **Enhancing workforce development**—conducting disaster mental health portion of predeployment briefings; collecting and disseminating relevant support materials to responders; teaching the mental health portion of the Public Health Readiness Certificate Program; supporting development of field team leader training.
- ❖ **Advocating for deployees and expanding cross-cutting relationships within CDC and with external partners**—actively participating in numerous Emergency Operations Center (EOC)–sponsored exercises to assess responder emotional well-being; providing input to other CDC teams working on preparedness issues; interfacing with national/international subject matter experts on resilience and mental health.
- ❖ **Strengthening relationship with CDC's Employee Assistance Program (EAP)**—improving access to relevant services by arranging for training for EAP team members by professionals from organizations with extensive international relief worker experience; sharing relevant information and collaborating with EAP to provide needed services.
- ❖ **Providing leadership**—making evidence-informed recommendations about improving individual and organizational resilience based upon historical responses to agency assessments.
- ❖ **Supporting relevant research**—collaborating with external partners to publish findings in scientific journals (e.g., *Psychiatric Annals*, *Journal of Homeland Security and Emergency Management*, *Military Medicine*).

The RRP is developing a peer-based model of providing psychological first aid in the field, while expanding the training and educational services it provides to an increasing cross-section of CDC staff and managers.

Less dramatic than safety and security, but similar in that it bespeaks the respect being shown for CDC staff as persons and moral agents, is the need to facilitate ethical sensitivity and awareness during emergency deployment. In addition to their other special features, emergencies

are times and places of such unusual and extraordinary activities that they can seem to be beyond the reach of ethical norms. Public health and emergency necessity, like military necessity, is a powerful notion that can be used to justify conduct that would never be permitted under “normal” circumstances. Its compelling and persuasive power is precisely its danger.

Disaster sites must not be allowed to be defined as places where moral limits do not apply. CDC personnel operating in these areas must be empowered and encouraged to retain their moral perspective and their sense of ethical propriety. For instance, during an emergency, when data are being collected or various behavioral observations are being recorded, no supervisors may be on the scene telling investigators that they should obtain consent or protect individual medical confidentiality. This does not mean that these normal ethical requirements have disappeared. It does mean, though, that acting ethically falls back to an unusual degree on the conscience and discernment of individuals who have the power to decide and act on others. The fact that CDC or other health personnel can order the destruction of someone’s property without risk of penalty does not mean that they should do so as a matter of course, or simply because it is more convenient, without sufficient public health grounds for considering that property to be contaminated or that it poses an unacceptable risk.

Because of the continuing recognition of ethical restraints, and because many situations will be open to conflicting interpretations concerning the right course of action, procedures and protocols should be put in place that will enable CDC deployed professionals to seek ethical assessment and guidance concerning value conflicts and uncertainties. As mentioned previously, these conflicts may grow out of the gap between responsibility and authority. CDC deployed staff might observe inappropriate or even illegal behavior on the part of those over whom they have no authority. CDC personnel might also be put in a position to directly observe deficiencies

in the conduct of other public health or emergency management agencies. Looking the other way is not an ethical option. Often, the established chain of command (either at the local site, or within CDC off-site) will be sufficient to provide clarification and guidance, but at times it will not be, perhaps because the ethical conflict involves elements of the chain of command itself. At such times, alternative mechanisms should be available to CDC personnel to which they can report their concerns and through which they can obtain advice.

That function is served, at least in part, by CDC's Emergency Operation Center (EOC) Ethics Desk. The EOC Ethics Desk was established in 2006 to provide advice to the CDC Incident Manager on the ethical implications of major emergency response decisions and actions and to provide guidance and support to CDC staff involved in responding to an event if they should have questions or concerns about ethical issues. The ability to communicate in real time with a member of the Ethics Desk or consultation team at CDC headquarters or elsewhere may be one way to operationalize such a protocol. Ethics consultation mechanisms can also be anticipated and included in various CDC guidance documents so that this approach is considered by state and local PHEPR agencies as well.

Communication and the Ethics of Policy Advice

CDC-deployed personnel will have a major role in gathering, analyzing, and interpreting the significance of public health information. They will assist those decision makers and officials who are not health-care professionals in understanding the medical implications of particular findings, in understanding the power and limitation of existing information, and in understanding the risk/benefit analyses that pertain to emergency response policies and decisions. But while CDC personnel may have a large role and measure of responsibility in generating information,

despite the work of the CDC Joint Information Center, which is designed to coordinate various levels of public health expertise and authority, they often have much less authority concerning the communication of that information. Once more, this gap will be a source of ethical tension and questioning for CDC-deployed professionals. If they have an obligation to provide the most accurate, scientific, and reliable information possible under the circumstances to their state and local colleagues, do they have a cognate obligation to ensure that such information is communicated completely and truthfully and that it is disseminated widely within the affected community? The task of ethical guidance would be easier if one could simply answer yes to this question, but unfortunately, the reality of emergency situations makes the answer more complex.

As was done previously (see *Communication, and Deliberative Participation in Emergency Planning*), it is useful to distinguish between providing information to official decision makers and providing information to other stakeholders, the media, and the general public. Regarding the general public, it is not generally the role or the responsibility of CDC-deployed professionals to determine the communication plan in question. If the officials who are responsible for that plan are observed to be engaged in ethically questionable conduct or in conduct that is ethically troubling to a CDC staff member (an extreme and unlikely example would be lying to the public or deliberately falsifying or distorting information, particularly information provided by CDC), the response should generally be the same as described with regard to observed illegal or unethical conduct.

Regarding designated authorities and decision makers, CDC personnel have a strong *prima facie* obligation to provide clear and timely information during the emergency event. Without that information, officials cannot make rational decisions and choices; they cannot exercise their own ethical responsibilities properly. The problem is that any communication is

always somewhat selective and interpretive. This is not deception; it is built into the nature of communication and the nature of scientific information. Providing officials with complete technical information is often poor communication and results in misunderstanding and overload; such “information dumping” makes decision making harder, not easier. On the other hand, through selectivity and interpretation, the CDC expert can influence the course of the decision-making process. Advocacy can easily overtake objective scientific advice, especially if the public health expert anticipates that the official(s) in question will make a decision with which the expert disagrees.

Ethical responsibility, as we understand and present the concept here, does not permit frank and deliberate policy advocacy disguised as scientific advice on the part of CDC professionals deployed in emergency settings. At the same time, responsibility does not allow an expert to be indifferent or inattentive to the way in which scientific information is understood and assimilated. The responsible course of action is to walk a fine line between a deliberate attempt to direct the course of a decision and indifference toward the scientific warrant and rationality of a decision. The CDC-deployed professional is one of the principal voices of scientific rationality in public health emergencies and should tailor his or her communication activities to ensuring that this voice is heard. It is essential to have the relevant and appropriate information reach the right decision makers, and CDC staff should not permit that information be cut off or sequestered by subordinate officials who may have their own agendas. CDC as an agency should support its personnel in this regard by resisting unwarranted limits others may place on the gathering of relevant scientific information, analysis of that information, and communicating the results of that analysis to the appropriate officials and decision makers.

Thus far it has been assumed that the information to be communicated to officials has a clear scientific meaning and validity, as least in the eyes of the expert technical community. Matters become even more complex, and the ethical choices more difficult, when the validity of the information is in question among experts. What level of certainty should one have in an emergency event before information is relayed to others? For example, identification of environmental hazards is often intuitively clear to experienced experts before definitive test results are available. Waiting for the final data before acting will bring about increased exposure. How candid should one be about the uncertainty, when stressing it may cause decision makers to discount it more than is prudent or warranted? Decision makers, particularly at times of crisis, are notoriously intolerant of ambiguity. President Harry Truman once remarked that he wished he had a one-armed advisor who wouldn't say, "On the one hand, this, but on the other hand that..." A public health expert must often seem like an octopus.

What are the risks and lost opportunities in relaying less than certain information? What guidelines should be used in determining the level of certainty necessary before communicating with others? What should the communication strategy be in such situations?

Our recommendations in this situation are as follows:

- CDC experts should be candid about the limitations of their findings at the time of communication.
- They should offer perspectives on the ranges of potential risk or harm and, to the extent possible, estimates of the probabilities involved.
- They should indicate what further investigation would be necessary to provide greater certainty and how long it will take to acquire more information.

- They should also be candid about the likelihood that greater certainty or more reliable information will not be forthcoming in the time before decisions have to be made.

It is better to offer decision makers one's best educated and experienced guess about an important matter than to exaggerate either the certainty or uncertainty of the information one has available. In these difficult circumstances, a deployed CDC professional lives up to an acceptable level of ethical responsibility by communicating in accordance with the standard of transparency regarding his or her own thinking; certainty before the fact or accuracy after the fact are not the relevant ethical standards here.

Policy and Agency Issues Regarding the Role of CDC in PHEPR

At the outset, we noted that the historic role of CDC in deploying personnel to emergency locations has been to bring its scientific expertise to bear on the situation and to assist state and local authorities who have operational and policymaking authority over the conduct of the emergency response. Nonetheless, there are some broader structural and policy issues that CDC should acknowledge and to which it should develop appropriate responses. Important as they are, setting rigorous standards for preparedness and providing scientific advice during emergencies are not sufficient. CDC's leadership in the public health profession and field calls for the agency to play a multifaceted leadership role in developing a national system of PHEPR. These issues are of ethical concern to CDC personnel as well.

One important issue involves the type of assistance provided by CDC through deployment of expert personnel to an emergency location and the proper coordination and communication among different levels of jurisdiction and authority. As noted above, PHEPR is primarily a state and local responsibility and CDC deployment occurs in response to a request

from those authorities, not at the instigation of CDC itself. But what if a state or local authority does not request the appropriate level of assistance in a timely fashion? What is the obligation of CDC to advocate for a different type of response than has been requested of it, if in the professional judgment of CDC leadership the requested level or type of deployment is inappropriate? The relationship between the federal government and state governments is often a sensitive political issue. The aftermath of Hurricane Katrina in Louisiana demonstrated the difficulty of cooperation among some federal agencies, such as the Federal Emergency Management Agency (FEMA), the governor, and the mayor of a large affected city. Political considerations of this kind will be factored into decisions by higher federal authorities.

At the level of CDC, the ethically responsible policy is to advocate for emergency response that utilizes the best available public health capability and expertise. Only if this is done will the central ethical goals that have formed the core of this white paper be met. If the necessary expertise and resources are available at the state or local level, then all is well and good. But if not, if there is a clear need for federal involvement, CDC should advocate to play a role in the response, and it should resist being excluded. As a matter of principle, we would argue that all Americans, regardless of the state in which they live, have a right of equitable access to the assistance and expertise of this national public health resource.

Factors to be weighed at this point include the degree of scientific certainty, the amount of harm that would occur without federal involvement, and where various types of federal involvement may be indicated, whether the state's request for involvement is proportional to the risk posed by the emergency. An additional consideration is whether federal involvement can limit the emergency's impact to worsen inequality. These points, and others articulated in the public health ethics emergency framework above help identify the ethical challenges faced by

decision makers when there is a concern that effective collaboration does not exist. Moreover, CDC leadership should maintain the organizational capacity (an adequate, trained workforce, adequate resources, adequate funding) to permit it to respond by deployment without compromising its other vital and ongoing agency functions.

A second structural issue and agency responsibility grows out of the position in which CDC is placed by dint of its deployment operations during an emergency. The deployment experience puts CDC staff in a position to observe gaps in the public health infrastructure at state and local levels that are made particularly evident during an emergency response. In light of this, it is the ethical responsibility of CDC to record and document these observations. There should be a well-defined mechanism for the preparation of postdeployment reports and analyses by CDC personnel. They should be trained in techniques of observation and assessment for use during their deployment and given the support necessary upon their return to create a useful database containing such information.

This is an important part of the general policy that the public health system as a whole ought to use emergency preparedness and response as an opportunity for learning and improvement in response capabilities. It goes even further in that emergency deployment gives CDC an opportunity to detect and mitigate defects in the ongoing operations of public health in non-emergency situations. This is an opportunity that CDC should not overlook, nor fail to capitalize on.

Conclusion

PHEPR is a vital public health function. As such, it is both a governmental responsibility and a civic endeavor. This white paper therefore has presented a broad overview of its subject, as opposed to a focused look at one aspect of PHEPR, such as the response to pandemic influenza,

bioterrorism, or weather related emergencies. The purpose of this white paper has been to provide a substantive framework of values and ethical goals, a fairly rich ethical vocabulary, so to speak, with which continuing ethical research and debate on PHEPR can proceed. Its treatment of specific scientific and practical details of emergency planning is illustrative rather than comprehensive; it offers ethical orientation and food for thought rather than specific rules, standards, or guidelines.

We believe that there is considerable value in providing resources for ongoing, serious conversation and deliberation about ethics, even in the absence of definitive guidance or ethical directives. At times, premature guidance and conclusiveness can stifle ethical reflection and reasoning rather than promote it. There is much that is not yet understood about how to do emergency planning and disaster preparedness well. The epidemiologic, clinical, and behavioral sciences are still on a learning curve in the field of PHEPR. Likewise, there is still much to be learned about the ethics of preparedness.

Finally, PHEPR is ultimately less about protecting a community than it is about embodying the traditions and values of a community and a vision of how the community can be made a better environment for all its members in the future. Successful emergency planning must rely on and tap into a preexisting fund of civic responsibility, a sense of justice, and concern for others in need. Emergency planning can, and should, be an occasion to foster these outlooks and impulses as well. Fear and self-interest will no doubt be strongly in evidence during any public health emergency, but public health leadership, in conjunction with elected officials and other community leaders can move communities beyond these motivations to a sense of common purpose and solidarity. If it does this, PHEPR will succeed in meeting its professional ethical obligations and will most likely succeed in its practical efforts as well.

References

1. Institute of Medicine. The future of the public's health in the 21st century. Washington, DC: Academy Press; 2003.
2. Garrett L. Betrayal of trust: the collapse of global public health. New York: Hyperion; 2000.
3. Rosner D, Markovitz G. Are we ready? Public health since 9/11. Berkeley, CA: University of California Press; 2006.
4. Lurie N, Wasserman J, Nelson CD. Public health preparedness: evolution or revolution? Health Affairs 2006;25:935–45.
5. CDC. Biological and chemical terrorism: strategic plan for preparedness and response. Recommendations of the CDC Strategic Planning Workgroup. MMWR 2000;49(No. RR-04):1–14.
6. O'Toole T, Mair M, Inglesby TV. Shining light on "Dark Winter." Clin Infect Dis 2002;34:972–83.
7. Borden KA, Schmidlein MC, Emirch CT, Piegorsch WW, Cutter SL. Vulnerability of U.S. cities to environmental hazards. Journal of Homeland Security and Emergency Management 2007;4:Article 2.
8. Frickel S. Our toxic gumbo: recipe for a politics of environmental knowledge. In: Understanding Katrina: Perspectives from the Social Sciences. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Frickel/>.
9. Hearne SA, Segal LM, Earls MJ. Ready or not? Protecting the public's health from disease, disasters, and bioterrorism. Washington, DC: Trust for America's Health; 2005.

10. Lister SA. An overview of the U.S. public health system in the context of emergency preparedness. CRS Report for Congress. Washington, DC: Congressional Research Service, Library of Congress; 2005.
11. U.S. Department of Justice. Making community emergency preparedness and response programs accessible to people with disabilities; 2006. Available at <http://www.ada.gov/emergencyprep.htm>.
12. Cooper C, Block R. Disaster: Hurricane Katrina and the failure of Homeland Security. New York, NY: Times Books; 2006.
13. Abbott EB. Book review of Disaster: Hurricane Katrina and the failure of homeland security. *Journal of Homeland Security and Emergency Management* 2007;4(1):Article 5.
14. Daniels N, Kettl DF, Kunreuther H. On risk and disaster: lessons from Hurricane Katrina. Philadelphia, PA: University of Philadelphia Press; 2006.
15. Hartman C, Squires GD. There is no such thing as a natural disaster: race, class, and Hurricane Katrina. New York, NY: Routledge; 2006.
16. Rodriguez H, Dynes R. Finding and framing Katrina: the social construction of disaster. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at http://understandingkatrina.ssrc.org/Dynes_Rodriguez/.
17. Alexander D. Symbolic and practical interpretations of the Hurricane Katrina disaster in New Orleans. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Alexander/>.
18. Wachtendorf T, Kendra JM. Improvising disaster in the city of jazz: organizational response to Hurricane Katrina. In: *Understanding Katrina: perspectives from the social sciences*.

Social Science Research Council; 2006. Available at

http://understandingkatrina.ssrc.org/Wachtendorf_Kendra/.

19. Center for Health and the Global Environment. Climate change futures: health, ecological and economic dimensions. Boston: Harvard Medical School; 2005. Available at

<http://chge.med.harvard.edu/programs/ccf/index.html>.

20. Annas GJ. Bioterrorism, public health, and civil liberties. *N Engl J Med* 2002;346:1337–42.

21. Annas GJ, Mariner WK, Parmet WE. Pandemic preparedness: the need for a public health—not a law enforcement/national security approach. New York, NY: American Civil Liberties Union; 2008. Available at

<http://www.aclu.org/privacy/medical/33642pub20080114.html>.

22. Evans RG, Marer ML, Marmor TR. Why are some people healthy and others not? New York, NY: Aldine de Gruyter; 1994.

23. Executive Office of the President. Homeland Security Presidential Directive (HSPD)-8; 2003. Available at <http://www.fas.org/irp/offdocs/nspd/hspd-8.html>.

24. Nelson C, Lurie N, Wasserman J, Zakowski S. Conceptualizing and defining public health emergency preparedness. *Am J Public Health* 2007;97(Suppl 1):S9–S11.

25. Salinsky E. Public health emergency preparedness: fundamentals of the system. Washington, DC: George Washington University Press; 2002.

26. Lakoff A. From disaster to catastrophe: The limits of preparedness. In: Understanding Katrina: perspectives from the Social Sciences. Social Science Research Council; 2006.

Available at <http://understandingkatrina.ssrc.org/Lakoff/>.

27. de Waal A. An imperfect storm: narratives of calamity in a liberal-technocratic age. In: Understanding Katrina: perspectives from the social sciences. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/deWaal/>.
28. Perrow C. Using organizations: the case of FEMA. In: Understanding Katrina: Perspectives from the social sciences. Social Science Research Council. 2006. Available at <http://understandingkatrina.ssrc.org/Perrow/>.
29. Sturken M. Weather media and homeland security: selling preparedness in a volatile world. In: Understanding Katrina: perspectives from the social sciences. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Sturken/>.
30. Bayer R, Fairchild AL. The genesis of public health ethics. *Bioethics* 2004;18:473–92.
31. Callahan D, Jennings B. Ethics and public health: forging a strong relationship. *Am J Public Health* 2002 Feb;92:169–76.
32. Childress JF, Faden RR, Gaare RD, et al. Public health ethics: mapping the terrain. *J Law Med Ethics* 2002;30:170–8.
33. Kass N. An ethics framework for public health. *Am J Public Health* 2001;91:1776–82.
34. Kass NE. Public health ethics: from foundations and frameworks to justice and global public health. *J Law Med Ethics* 2004;32:232–42.
35. Kass N. An ethics framework for public health and avian influenza pandemic preparedness. *Yale Journal of Biology and Medicine* 2005;78:239–54.
36. Lappe M. Values and public health: value considerations in setting health policy. *Theor Med* 1983;4:71–92.
37. Lappe M. Ethics in public health. In: Last JM, ed. *Maxcy-Rosenau Public Health and Preventive Medicine: 1849-1865*, 12th edition. Norwalk, CT: Appleton-Century-Crofts; 1986.

38. Mann JM. Medicine and public health, ethics and human rights. *Hastings Cent Rep* 1997;27:6–13.
39. Powers M, Faden R. *Social justice: the moral foundations of public health and health policy*. Oxford, England: Oxford University Press; 2006.
40. Thomas JC, Sage M, Dillenberg J, Guillory VJ. A code of ethics for public health. *Am J Public Health* 2002;92:1057–9.
41. Holland S. *Public health ethics*. Cambridge: Polity Press; 2007.
42. Thomas JC, Dasgupta N, Martinot A. Ethics in a pandemic: a survey of the state pandemic influenza plans. *Am J Public Health* 2007;97(Suppl 1):S26–S31.
43. Gostin LO. When terrorism threatens health: how far are limitations on human rights justified? *Florida Law Review* 2003;55:1105–70.
44. Jennings B. On authority and justification in public health. *Florida Law Review* 2003;55:1241–56.
45. Lukes S. Questions about power: lessons from the Louisiana hurricane. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Lukes/>.
46. American Public Health Association. *National opinion survey to determine levels of preparedness for a public health crisis*. Washington, DC: American Public Health Association; 2007.
47. King's Fund. *Public attitudes to public health*. London, England: The King's Fund; 2004.
48. Keystone Center. *Pandemic influenza vaccine prioritization: public engagement meetings*. Keystone, CO: The Keystone Center; 2007. Available at http://www.keystone.org/Public_Policy/vaccine_prioritization_2007/public_engagement.html.

49. Myers D. Disaster response and recovery: a handbook for mental health professionals. Rockville, MD: Center for Mental Health Services, 1994.
50. Walzer M. Political action: The problem of dirty hands. *Philosophy and Public Affairs* 1973;2:160–80.
51. Adger WN, Social and ecological resilience: are they related? *Progress in Human Geography* 2000;24:347-364.
52. Schneider RO. Principles of ethics for emergency managers. *Journal of Emergency Management* 2006;4:56–62.
53. Walker B, Salt D. Resilience thinking: sustaining ecosystems and people in a changing world. Washington, DC: Island Press; 2006.
54. Muddaugh JP. Pandemic influenza preparedness and community resiliency. *JAMA* 2008;299:566–8.
55. Erikson KT. Everything in its path: destruction of community in the Buffalo Creek flood. New York, NY: Simon and Schuster; 1976.
56. Erikson KT. A new species of trouble: the human experience of modern disasters. New York, NY: W.W. Norton and Company; 1994.
57. Vale LJ, Campanella TJ. The resilient city: how modern cities recover from disaster. New York, NY: Oxford University Press; 2005.
58. Paton D, Johnston D. Disaster resilience: an integrated approach. Springfield, IL: Charles C. Thomas Publishers; 2006.
59. Barbee D. Disaster response and recovery: strategies and tactics for resilience. *Journal of Homeland Security and Emergency Management* 2007;4:Article 11.

60. Gunderson LH, Holling CS Eds. Panarchy: understanding transformation in human and natural systems. Washington: Island press; 2002.
61. NYS Workgroup on Ventilator Allocation in an Influenza Pandemic, and NYS DOH/NYS Task Force on Life and the Law. Allocation of ventilators in an influenza pandemic: planning document. New York State Department of Health; 2007. Available at http://www.health.state.ny.us/diseases/communicable/influenza/pandemic/ventilators/docs/ventilator_guidance.pdf.
62. United Nations. A more secure world: our shared responsibility. Report of the Secretary-General's high-level panel on threats, challenges and change. United Nations; 2004. Available at <http://www.un.org/secureworld/>.
63. Sze J. Toxic soup redux: why environmental racism and environmental justice matter after Katrina. In: Understanding Katrina: perspectives from the social sciences. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Sze/>.
64. Zimmerman R. Public infrastructure service flexibility for response and recovery in the September 11th, 2001, attacks at the World Trade Center. In: Natural Hazards Research and Applications Information Center, Public Entity Risk Institute, and Institute for Civil Infrastructure Systems. Beyond September 11th: an account of post-disaster research. Special Publication No. 39. Boulder, CO: Natural Hazards Research and Applications Information Center, University of Colorado; 2003.
65. World Trade Center Health Panel. Addressing the health impacts of 9/11: report and recommendations to Mayor Michael R. Bloomberg. New York City Government, Office of the Mayor; 2007. Available at http://www.nyc.gov/html/om/pdf/911_health_impacts_report.pdf.

66. World Trade Center Health Panel. 2008 annual report on 9/11 health. New York City Government, Office of the Mayor; 2008. Available at http://www.nyc.gov/html/om/pdf/911_health_impacts_report.pdf.
67. Leonard HB, Howitt AM. Katrina as prelude: preparing for and responding to Katrina-class disturbances in the United States—Testimony to US Senate Committee, March 8, 2006. *Journal of Homeland Security and Emergency Management* 2006;3:Article 5.
68. Eisenman DP, Cordasco KM, Asch S, Golden JF, Glik D. Disaster planning and risk communication with vulnerable communities: lessons from Hurricane Katrina. *Am J Public Health* 2007;97:S109–S115.
69. Strolovitch D, Warren D, Frymer P. Katrina's political roots and divisions: race, class, and federalism in American politics. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/FrymerStrolovitchWarren/>.
70. Graham S. Cities under siege: Katrina and the politics of metropolitan America. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Graham/>.
71. Gilman N. What Katrina teaches about the meaning of racism. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Gilman/>.
72. Molotch H. Death on the roof: race and bureaucratic failure. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Molotch/>.

73. Tracy L. Muddy waters: the legacy of Katrina and Rita. Washington, DC: American Public Health Association; 2007.
74. Frumkin H, Frank L, Jackson R. Urban sprawl and public health: designing, planning, and building for healthy communities. Washington, DC: Island Press; 2004.
75. Hoffman SM, Oliver-Smith A. Catastrophe and culture: the anthropology of disaster. Santa Fe, NM: School of American Research Press; 2002.
76. Berkman LF, Kawachi I. Social epidemiology. Oxford, England: Oxford University Press; 2000.
77. Forester J. The deliberative practitioner: encouraging participatory planning processes. Cambridge, MA: MIT Press; 1999.
78. Schon DA, Rein M. Frame reflection: toward the resolution of intractable policy controversies. New York, NY: Basic Books; 1997.
79. Friedmann RR, Cannon WJ. Homeland security and community policing: competing or complementing public safety policies. *Journal of Homeland Security and Emergency Management* 2007;4:Article 2.
80. Berlin I. Four essays on liberty. Oxford, England: Oxford University Press; 1969.
81. Gostin LO. Public health ethics: tradition, profession, and values. *Acta Bioethica* 2003;9:177–88.
82. Center for Law and the Public's Health. The Model State Emergency Health Powers Act. Georgetown University and Johns Hopkins University; 2001. Available at <http://www.publichealthlaw.net/MSEHPA/MSEHPA2.pdf>.
83. Upshur RE. Principles for the justification of public health intervention. *Can J Public Health* 2002;93:101–3.

84. Parmet WE. Legal power and legal rights. Isolation and quarantine in the case of drug-resistant tuberculosis. *N Engl J Med* 2007; 357:433–5.
85. Campion EW. Liberty and the control of tuberculosis. *N Engl J Med* 1999;340:385–6.
86. Fairchild AL, Colgrove J, Jones MM. The challenge of mandatory evacuation: providing for and deciding for. *Health Aff* 2006;25:958–67.
87. Trotter G. *The ethics of coercion in mass casualty medicine*. Baltimore: Johns Hopkins University Press; 2007.
88. Gaylin W, Jennings B. *The perversion of autonomy: coercion and community in a liberal society*. 2nd ed. Washington, DC: Georgetown University Press; 2003.
89. Bytheway B. The evacuation of older people: the case of Hurricane Katrina. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Bytheway/>.
90. Fussell E. Leaving New Orleans: social stratification, networks, and hurricane evacuation. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Fussell/>.
91. Scanlon J. Two cities, two evacuations: some thoughts on moving people out. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Scanlon/>.
92. Oliver-Smith A. Disasters and forced migration in the 21st century. In: *Understanding Katrina: perspectives from the social sciences*. Social Science Research Council; 2006. Available at <http://understandingkatrina.ssrc.org/Oliver-Smith/>.
93. Sunstein CR. *Worst-case scenarios*. Cambridge, MA: Harvard University Press; 2007.

94. Arras JD. Rationing vaccine during an avian influenza pandemic: why it won't be easy. *Yale J Biol Med* 2006;78:287–300.
95. Goodin R. *Utilitarianism as a public philosophy*. Cambridge, MA: Cambridge University Press; 1995.
96. Verweij M. Project on addressing ethical issues in pandemic influenza planning: equitable access to therapeutic and prophylactic measures. Geneva: World Health Organization; 2006.
97. Brock D. Ethical issues in the use of cost effectiveness analysis for the prioritization of health care resources. In: Anand S, Peter A, Sen A, eds. *Public health, ethics and equity*. Oxford, England: Oxford University Press; 2004.
98. Williams A. Intergenerational equity: an exploration of the 'fair innings' argument. *Health Econ* 1997;6:117–32.
99. Daniels N, Sabin J. *Setting limits fairly*. Oxford: Oxford University Press; 2002.
100. Gutmann A, Thompson D. *Democracy and disagreement*. Cambridge, MA: Harvard University Press; 1996.
101. Calabresi G, Bobbitt P. *Tragic choices*. New York, NY: W.W. Norton and Company; 1978.
102. Sen AK. *Poverty and famines: an essay on entitlement and deprivation*. New York, NY: Oxford University Press; 1983.
103. Dworkin R. *Life's dominion*. New York, NY: Knopf Publishers; 1993.
104. Friedman A. Beyond accountability for reasonableness. *Bioethics* 2008;22:101–12.
105. Bernheim RG. Public engagement in emergency preparedness and response (EPR): ethical perspectives in public health practice. Unpublished manuscript.

106. Bodenheimer T. The Oregon Health Plan — Lessons for the nation. *N Engl J Med* 1997;337:651–6.
107. Gould SD, Biddle AK, Klipp G, Hall CN, Danis M. Choosing health plans all together: a deliberative exercise for allocating limited health care resources. *J Health Polit Policy Law* 2005;30:563–601.
108. Sabik LM, Lie RK. Principles versus procedures in making health care coverage decisions: addressing inevitable conflicts. *Theor Med Bioeth* 2008;29:73–85.
109. Davis E, Mincin J. Incorporating special needs populations into emergency planning and exercises. *Nobody left behind: disaster preparedness for persons with mobility impairment*. Lawrence, KS: University of Kansas, Research and Training Center on Independent Living; 2006.
110. Drexel University Center for Health Equality. National consensus statement on integrating racially and ethnically diverse communities into public health emergency preparedness. Washington, DC: US Department of Health and Human Services, Office of Minority Health; 2008.
111. Powers M. Vulnerable populations in the context of public health emergency preparedness planning and response. Unpublished manuscript.
112. Kailes JI. Disaster services and "special needs": terms of art or meaningless term? Lawrence, KS: University of Kansas, Research and Training Center on Independent Living; 2005.
113. Levine C. The concept of vulnerability in disaster research. *J Trauma Stress* 2004;17:395–402.

114. Executive Office of the President. The federal response to Hurricane Katrina: lessons learned; 2006. Available at <http://library.stmarytx.edu/acadlib/edocs/katrinawh.pdf>.
115. Kailes JI. Why and how to include people with disabilities in your emergency planning process? Lawrence, KS: University of Kansas, Research and Training Center on Independent Living; 2005.
116. National Organization on Disability. Prepare yourself; disaster readiness tips for people with disabilities. Washington, DC: National Organization on Disability. 2008.
117. National Council on Disability. Saving lives: including people with disabilities in emergency planning. Washington, DC: National Press Club; 2008.
118. US Department of Homeland Security. Individuals with disabilities and emergency preparedness. Annual report, July 2005. Washington, DC: US Department of Homeland Security; 2005. Available at <http://www.icdr.us/documents/AnnualReport05.pdf>.
119. University of Florida. The disaster handbook. National edition. Disaster planning for elderly and disabled populations. Gainesville, FL: University of Florida; 1998. Available at <http://disaster.ifas.ufl.edu/chap2fr.htm>.
120. Pastor M, Bullard RD, Boyce JK, Fothergill A, Morello-Frosch R., Wright B. In the wake of the storm: environment, disaster and race after Katrina. New York, NY: Russell Sage Foundation; 2006.
121. Falkheimer J, Heide M. Multicultural crisis communication: toward a social constructionist perspective. *Journal of Contingencies and Crisis Management* 2006;14:180–9.
122. James X, Hawkins A, Rowel R. An assessment of the cultural appropriateness of emergency preparedness communication for low income minorities. *Journal of Homeland Security and Emergency Management* 2007;4:Article 13.

123. Wray R, Rivers J, Whitworth A, Jupka K, Clements B. Public perceptions about trust in emergency risk communication: qualitative research findings. *International Journal of Mass Emergencies and Disasters* 2006;24:45–75.
124. Spence PR, Lachlan KA, Griffin DR. Crisis communications, race, and natural disasters. *Journal of Black Studies* 2007;37:539–54.
125. Elder KA, Xirasagar S, Miller N, Bowen SA, Glover S, Piper C. African Americans' decisions not to evacuate New Orleans before Hurricane Katrina: A qualitative study. *American Public Health Association* 2007; 97(Suppl 1):S124-S129.
126. Carter-Pokras O, Zambrana RE, Mora SE, Aaby KA. Emergency preparedness: knowledge and perceptions of Latin American immigrants. *Journal of the Poor and Underserved* 2007;18:465–81.
127. Spence PR, Lachlan KA, Burke JM. Adjusting to uncertainty: coping strategies among the displaced after Hurricane Katrina. *Sociological Spectrum* 2007;27:653–78.
128. Messias DK, Lacy E. Katrina-related health concerns of Latino survivors and evacuees. *J Health Care Poor Underserved* 2007;18:443–64.
129. Uscher-Pines L, Duggan PS, Garoon JP, Karron RA, Faden RR. Planning for an influenza pandemic: social justice and disadvantaged groups. *Hastings Cent Rep* 2007;37:32–9.
130. Corburn J. *Community knowledge and environmental health justice*. Cambridge, MA: MIT Press; 2005.
131. Schoch-Spana M, Franco C, Nuzzo JB, Usenza C. Community engagement: leadership tool for catastrophic health events. *Biosecurity and Bioterrorism: Biodefense Strategy Practice and Science* 2007;5:8–25.

132. Schafer WA, Carroll JM, Haynes SR, Abrams S. Emergency management planning as collaborative community work. *Journal of Homeland Security and Emergency Management* 2008;5:Article 10.
133. Chambers S. Deliberative democratic theory. *Annual Review of Political Science* 2003;6:307–18.
134. Selznick P. *TVA and the grass roots*. Berkeley, CA: University of California Press; 1984.
135. Barnes MD, Novilla LMB, Meacham AT, McIntyre E, Erickson BC. Analysis of media agenda setting during and after Hurricane Katrina: implications for emergency preparedness, disaster response, and disaster policy. *Am J Public Health* 2008;98:604–10.
136. Langewiesche W. *American ground: unbuilding the World Trade Center*. New York, NY: North Point Press; 2002.
137. Health Systems Research Inc. *Altered standards of care in mass casualty events*. Washington, DC: Agency for Healthcare Research and Quality; 2005. Report No. 05-0043.
138. Frankel MS. Professional codes: why, how, and with what impact? *Journal of Business Ethics* 1989;8:109–15.
139. Brookes T. *Behind the mask: how the world survived SARS*. Washington, DC: American Public Health Association; 2005.
140. Baker RB, Caplan AL, Latham S. *The American medical ethics revolution: how the AMA's code of ethics has transformed physicians' relationships to patients, professionals and society*. Baltimore, MD: John Hopkins University Press; 1999.
141. Pandemic Influenza Working Group. *Stand on guard for thee: ethical considerations in preparedness planning for pandemic influenza*. Toronto, Canada: University of Toronto, Joint Centre for Bioethics; 2005.

142. World Health Organization. Ethical considerations in developing a public health response to pandemic influenza. Geneva: World Health Organization; 2007. Available at http://www.who.int/csr/resources/publications/WHO_CDS_EPR_GIP_2007_2/en/index.html.
143. Reid L. Diminishing returns? Risk and the duty to care in the SARS epidemic. *Bioethics* 2005;19:353.
144. Meslin EM, Alyea JM, Helft PR. Pandemic flu preparedness: ethical issues and recommendations to the Indiana State Department of Health. Technical Advisory Document (TAD-05-07). Indianapolis, IN: Indiana University Center for Bioethics; 2007.
145. Person B, Sy F, Holton K, Govert B, Liang A, NCID/SARS Community Outreach Team. Fear and stigma: the epidemic within the SARS outbreak. *Emerg Infect Dis* 2004;10:359–63.
146. Daniels N. Justice, resource allocation and emergency preparedness: Issues regarding stockpiling. Unpublished manuscript.
147. Huber SJ, Wynia MK. When pestilence prevails...physician responsibilities in epidemics. *Am J Bioeth* 2004;4:W5–W11.
148. Dawson A. Professional, civic and personal obligations in public health emergency planning and response. Unpublished manuscript.
149. Emanuel EJ. The lessons of SARS. *Ann Intern Med* 2003;139:589–91.
150. Daniels N. Duty to treat or right to refuse? *Hastings Cent Rep* 1991;21:36–46.
151. Antares Foundation. Managing stress in humanitarian workers: guidelines for good practice. Amsterdam, Netherlands: Antares Foundation; 2006.
152. Arras JD. The fragile web of responsibility: AIDS and the duty to treat. *Hastings Cent Rep* 1988;18:10–20.
153. Camus A. *The plague*. New York: Vintage Books; 1991.

154. Benjamin CG. Putting the public in public health: new approaches. *Health Affairs* 2006;25:1040–3.
155. Jennings B. Community in public health ethics. In: Ashcroft RE, Dawson A, Draper H, McMillan J, eds. *Principles of health care ethics*. West Sussex: John Wiley and Sons; 2007.
156. Jennings B. Public health and civic republicanism. In: Dawson A, Verweij M, eds. *Ethics, prevention, and public health*. Oxford, England: Oxford University Press; 2007.
157. Daniels N, Kennedy BP, Kawachi I. Why justice is good for our health: the social determinants of health inequalities. *Daedalus* 1999;128:215–51.
158. Putnam RD. *Bowling alone*. New York, NY: Simon and Schuster; 2000.
159. Wilkinson RG. *Unhealthy societies: the afflictions of inequality*. London, England: Routledge; 1996.
160. Pelling M. *The vulnerability of cities: natural disasters and social resilience*. Sterling, VA: Earthscan Publications; 2003.
161. Savitch HV. *Cities in a time of terror: space, territory, and local resilience*. Armonk, NY: M.E. Sharp, Inc; 2008.
162. Chen LC, Lui YC, Chan KC. Integrated community-based disaster management program in Taiwan: a case study of Shang-An Village. *Journal of Natural Hazards* 2006;37:209–23.
163. United Nations. *Disaster management ethics*. Department of Humanitarian Affairs of the General Secretariat of the United Nations for the Disaster Management Training Programme; 1997.
164. CDC. *Guidelines for defining public health research and public health non-research*; 1999. Available at <http://www.cdc.gov/od/science/regs/hrpp/researchdefinition.htm>.

165. Hodge J, Gostin L. Public health practice vs. research. A report for public health practitioners including cases and guidance for making distinctions. Council of State and Territorial Epidemiologists; 2004. Available at <http://www.cste.org/pdffiles/newpdffiles/CSTEPHResRptHodgeFinal.5.24.04.pdf>.
166. Freedman B. Equipoise and the ethics of clinical research. *N Engl J Med* 1987;317:141–5.
167. London AJ. Research in a public health crisis: the integrative approach to managing the moral tensions. Unpublished manuscript.
168. Kukla R. Resituating the principle of equipoise: justice and access to care in non-ideal conditions. *Kennedy Institute of Ethics Journal* 2007;17:171–202.
169. Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? *JAMA* 2000;283:2701–11.
170. Beauchamp T, Childress JF. *Principles of biomedical ethics*. 6th ed. New York, NY: Oxford University Press; 2008.
171. Miller F, Brody H. A critique of clinical equipoise: therapeutic misconception in the ethics of clinical trials. *Hastings Cent Rep* 2003;33:19–28.
172. Rosenstein DL. Decision-making capacity and disaster research. *J Trauma Stress* 2004;17:373–81.
173. Appelbaum PS, Roth LH, Lidz CW, Benson P, Winslade W. False hopes and best data: consent to research and the therapeutic misconception. *Hastings Cent Rep* 1987;17:20–4.
174. Fost N, Levine RJ. The dysregulation of human subjects research. *JAMA* 2007;298:2196–8.

175. Collogan LK, Tuma F, Dolan-Sewell R, Borja S, Fleischman AR. Ethical issues pertaining to research in the aftermath of disaster. *J Trauma Stress* 2004;17:363–72.
176. Wenzel RP, Edmond MB. Team-based prevention of catheter-related infections. *N Engl J Med* 2006;355:2781–3.
177. Gawande A. A lifesaving checklist. *New York Times* December 30, 2007. available at: <http://www.nytimes.com/2007/12/30/opinion/30gawande.html?scp=2&sq=A.+Gawande%2C+%22A+lifesaving+checklist%22&st=nyt>.
178. Lynn J, Baily MA, Bottrell M, et al. The ethics of using quality improvement methods in health care. *Ann Intern Med* 2007;146:666–73.
179. Nightingale S, Prasher J, Simonson S. Emergency use authorization (EUA) to enable use of needed products in civilian and military emergencies, United States. *Emerg Infect Dis* 2007;13:1046–51.
180. Bernheim RG. Public health ethics: the voices of practitioners. *J Law Med Ethics* 2003;31:104–9.
181. Thompson DF. Political ethics and public office. Cambridge, MA: Harvard University Press; 1987.
182. United Nations Office for the Coordination of Humanitarian Affairs. Guiding principles on internal displacement. 1998. Available at http://www.reliefweb.int/ocha_ol/pub/idp_gp/idp.html.
183. Tyshenko MG. Management of natural and bioterrorism induced pandemics. *Bioethics* 2007;21:364–9.
184. U.S. Department of Health and Human Services. Public health emergency response: a guide for leaders and responders. Washington, DC: U.S. Department of Health and Human

Services; 2007. Available at

<http://www.phe.gov/emergency/communication/guides/leaders/Pages/default.aspx>.

185. Quarantelli EL. Catastrophes are different from disasters: some implications for crisis planning and managing drawn from Katrina. In: Understanding Katrina: perspectives from the social sciences. Social Science Research Council; 2006. Available at

<http://understandingkatrina.ssrc.org/Quarantelli/>.

186. Reissman DB, Schreiber M, Klomp RW, Hoover M, Kowalski-Trakofler K, Perez J. The virtual network supporting the front lines: addressing emerging behavioral health problems following the tsunami of 2004. *Military Medicine* 2006;171(Suppl 1):40-3

187. Reissman DB, Schreiber MD, Shultz JM, & Ursano RJ. Disaster mental and behavioral health. In: Koenig KL, Schultz CH, eds. *Disaster medicine*. New York: Cambridge University Press; 2010.

188. Reissman DB, Kowalski-Trakofler KT, Katz CL. Disaster resilience and public health practice: a framework integrating resilience as a worker protection strategy. In: Southwick S, Charney D, Litz B, Friedman M, eds. *Comprehensive textbook on resilience*. New York: Cambridge Press; 2011.