Social Justice in Pandemic Preparedness

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Debra DeBruin, PhD, Joan Liaschenko, RN, PhD, and Mary Faith Marshall, PhD

Pandemic influenza planning in the United States violates the demands of social justice in 2 fundamental respects: it embraces the neutrality of procedural justice at the expense of more substantive concern with health disparities, thus perpetuating a predictable and preventable social injustice, and it fails to move beyond lament to practical planning for alleviating barriers to accessing care.

A pragmatic social justice approach, addressing both health disparities and access barriers, should inform pandemic preparedness.

Achieving social justice goals in pandemic response is challenging, but strategies are available to overcome the obstacles. The public engagement process of one state's pandemic ethics project influenced the development of these strategies. (*Am J Public Health.* 2012;102:586–591. doi:10.2105/AJPH.2011.300483)

HISTORICALLY, SOCIALLY DISadvantaged groups have fared the worst of any population during influenza pandemics.[1–3] They will most likely continue to do so; this certainly held true for the 2009 influenza A (H1N1) pandemic. Although that pandemic was relatively mild, its disparate impact on certain populations raises significant ethical concerns. The US Centers for Disease Control and Prevention (CDC) acknowledges,

> [I]t's clear that minority groups have consistently had higher rates of serious 2009 H1N1 disease, including hospitalizations, than non-minority groups. In fact, hospitalization rates among minority groups have consistently been more than double those of White, non Hispanics.[4]

Preliminary data analysis in Minnesota indicates that "nonwhites represented an astonishing 31% of hospitalized cases,"[5] although they consititute only 11% of the population of the state.[6] American Indian/Alaska Native populations in the United States had a death rate 4 times as high as all other racial/ethnic groups combined.[7] We focused on pandemic preparedness in the United States, but similar disparities span the globe. For example, in Australia, New Zealand, and Canada, rates of hospitalization and death for 2009 H1N1 were 3 to 8 times as high in indigenous as in general populations.[8] Murray et al. contend that if a severe (1918-type) pandemic occurred today, "96% (95% CI 95-98%) of the estimated number of deaths would take place in the developing world."[9(p2215)]

CDC maintains that the reasons for racial/ethnic differences in hospitalization rates are unknown but suggests they may be attributable to socioeconomic factors such as "access to care, preponderance of underlying health conditions among certain ethnic or minority groups, and self care or care seeking behaviors."[4] Blumenshine et al. suggest[1] and Quinn et al confirm[10] that differences in exposure, susceptibility, and access to health care account for influenza-related health disparities. Socially disadvantaged persons are more vulnerable to illness, less able to protect themselves through preventive strategies, and more burdened than relatively privileged populations by public health response interventions. Inadequate access to health care impedes effective intervention when members of underprivileged populations fall ill. Structural inequalities underlie all of these factors.

In the context of public health, Farmer et al.,[11] Parker,[12] Kelly,[13] Keshavjee and Becerra,[14] Mukherjee,[15] and others have identified large-scale social forces such as poverty, racism, gender inequality, and other social determinants of disease as components of what they call structural violence: "[S]tructural violence remains a high-ranking cause of premature death and disability."[11(p1690)] The paradigm of structural violence was introduced by Galtung in the context of peace studies in the 1960s.[16] He discriminates between tripartite forms of violence: personal, cultural, and structural. For Galtung, structural violence conveys a systemic inequitable social arrangement involving, for example, economic or political power. It is perpetuated by institutions and social structures that prevent individuals or populations from meeting their basic needs.

> There may not be any person who directly harms another person in the structure. The violence is built into the structure and shows up as unequal power and consequently as unequal life chances.[16(p171)]

These structural inequalities constitute the core of structural violence.

To counter the social injustice of structural inequalities and adequately meet the needs of vulnerable groups, pandemic preparedness efforts must address both health disparities and access barriers. Here we outline challenges inherent in eliminating injustice and delineate strategies to meet those challenges. These strategies offer pragmatic ethical guidance, moving beyond the identification of abstract moral principles or the creation of broad ethical frameworks for pandemic planning. In part, our analysis arose from our work on the Minnesota Pandemic Ethics Project (MPEP), the primary aim of which was to offer ethical guidance to the Minnesota Department of Health concerning the rationing of scarce health resources during influenza pandemics. MPEP's public engagement process involved representatives of several vulnerable communities and specifically sought guidance on meeting the needs of those groups.[17–19] We undertook further analysis, developed independently from MPEP, that focused on social justice—and not on the other concerns about fairness that garner a great deal of attention in the literature on pandemic preparedness, such as prioritization of key workers or of certain age groups for access to resources during pandemics.

UNDERSTANDING THE MORAL COMMITMENT TO JUSTICE

Even mild pandemics challenge our moral commitment to justice. Ethical guidance for pandemic planning is generally concerned with procedural notions of justice. The Ethics Subcommittee of the Advisory Committee to the Director of CDC

> recommend[s] an approach to justice that focuses on the procedures to be followed with the hope that good procedures will lead to fair outcomes.[20(p5)]

These procedures include applying guidance consistently ("treating like cases alike"[20[p5]]), relying on impartial decision-makers, and engaging the public in planning.[20] The Association of State and Territorial Health Officials highlights the Ethics Subcommittee's fair process characterization of justice in its guidance concerning at-risk populations in pandemics.[21]

Social justice requires the use of fair procedures, but fair procedures do not suffice to promote social justice, despite hopes that they will. Unless supplemented by a substantive understanding of justice and injustice, procedural notions of justice tend to rely on neutral decision-making. In other words, fairness is associated with lack of bias: decision-making strives to be blind to race, ethnicity, class, gender, and other social categories. The Ethics Subcommittee identifies "favoritism and discrimination" and "special consideration" for some groups as inimical to fairness; justice requires that "the same rules apply to all."[22(p11)] Ironically, when applied in a systematically unequal social context—one rife with health disparities—this approach disproportionately affects the already disadvantaged, perpetuating and exacerbating existing disparities. Gostin observes,

> [O]stensibly neutral pleas for people to stay home, or stock up on basic necessities, are meaningless for the poor or homeless—as we saw during the Gulf Coast hurricanes, when the poor and vulnerable lacked the means to follow public health advice to "evacuate" or "shelter in place."[23(p3)]

Common pandemic preparedness strategies to reduce transmission may be nominally fair and neutral but create disparities when applied in contexts beset with inequalities. Social-distancing strategies such as telecommuting or avoidance of public transit may not be realistic options for at-risk populations.[10] Preventive strategies may exacerbate risks for these populations, as when school closings interrupt critical meals programs, or parents must leave children unattended or risk job loss. Thus, rather than ameliorating structural inequalities, pandemic preparedness strategies sometimes contribute to them.

Focus on neutral decision-making has diverted attention from assessing specific needs of at-risk groups. Uscher-Pines et al. maintain that

> there is little evidence that national planning efforts are addressing the rights and interests of disadvantaged groups, despite the likelihood that these groups will be disproportionately affected should a pandemic occur.[24(p38)]

Such planning failures are morally unacceptable.

Occasional guidance acknowledges more substantive conceptions of justice. The World Health Organization suggests that considerations of equity may at times justify prioritizing vulnerable populations for access to resources. This suggestion represents a departure from the standard emphasis on the neutrality of procedural justice. The organization offers no rationale for this concern for vulnerable populations and states it tentatively, as perhaps justifying priority for their needs.[25]

MPEP understands justice from the perspective of procedural fairness and more broadly. Minnesota's ethical frameworks embrace the substantive objectives of reducing significant group differences in mortality and serious morbidity and making reasonable efforts to reduce access barriers.[18] Such objectives raise important questions. How significant must differences in morbidity and mortality be to justify special attention? When are efforts to reduce access barriers deemed sufficient? Still, these objectives acknowledge the ethical significance of health disparities and access barriers and recognize that in an unequal context, it is not enough to refrain from discrimination and to be guided exclusively by a procedural notion of justice and its focus on neutrality. Addressing structural inequality requires a substantive conception of justice that can ground positive steps to address health disparities and access barriers.

If ethical frameworks for pandemic preparedness are to be useful, attention must shift from abstract discussions of ethical commitments, principles, and goals to more concrete matters of implementation. Too often discussions of the ethical issues involved in pandemic preparedness provide only high-level normative analyses of abstract values and principles, which offer little concrete guidance. Such discussions provide insight into important moral issues, but they leave unanswered critical questions about how moral guidance can be practically implemented in the complex context of pandemic planning and response. To be truly practical, ethical frameworks for guiding pandemic planning and response should be supplemented with moral analyses of implementation issues and practices—analyses that contextualize the norms and thus guide the development of detailed logistical protocols that compose the pandemic plan. MPEP offers guidance about implementation issues, including concerns about health disparities and access barriers.[17] Because the guidance was developed as part of a state-based preparedness effort, it focuses on that particular context. However, these ideas could be expanded to apply to national and global contexts.

ADDRESSING HEALTH DISPARITIES

Although the mechanisms are not fully understood, ample evidence documents the role of social risk factors for disease: socially disadvantaged groups suffer a greater burden of disease than do more privileged groups. Poorer health outcomes correlate not only with poverty, but also with race, ethnicity, gender, and low social status (an individual's position in social hierarchies). Such disparities cannot simply be attributed to barriers in access to care; social conditions influence the risk of contracting disease and the ability to recover regardless of access to health care. Social factors include quality of nutrition, dependence on public transportation, prevalence of dignity-affirming or dignity-denying experiences, and resources sufficient to mitigate stress in daily life. Research on the relationship between social status and health has repeatedly demonstrated a positive correlation between them.[26–28] Existing patterns of material deprivation, social exclusion, and inequalities in power are modifiable risk factors for illness, although these structural inequalities are often overlooked as risk factors and are all too often explained narrowly as lifestyle choices.[29,30]

Partly in response to concerns about disparities, MPEP recommends that those who are at higher risk of dying from or becoming severely ill with influenza be prioritized for resources.[18] Of course, this recommendation does not stand alone. MPEP places it in the context of a much larger discussion about ethical stewardship of resources during pandemics,[18] which includes, for example, concerns about preservation of critical services and debates about the possible justifiability of age-based rationing, issues beyond the scope of this article. Moreover, this approach does not directly address underlying disparities; broader efforts must be undertaken to alleviate them. Nor does—or should—this approach attempt to redress historical wrongs associated with long-standing patterns of structural inequalities; in this context, historical patterns are relevant because they provide data on which the recommendation is grounded. However, this recommendation may offer some protection to at-risk populations during an influenza pandemic.

To implement this recommendation, public health and health care workers need to gather data so that groups who are at higher risk can be identified as promptly as possible during pandemics and resources can be targeted to at-risk populations. For example, it is widely documented that Canadian officials recognized that First Nations communities were suffering disproportionately from H1N1 early in the pandemic. Certain sources of data may fail to adequately reflect the burden of disease in at-risk populations. For example, hospitalization data may not capture rates of morbidity and mortality in populations lacking adequate access to care. Public health officials should consider the best approach to gathering data on at-risk populations; they are best positioned to understand what types of data can be collected and what resources may be available for data collection during pandemics.

Admittedly, the more severe the pandemic, the more strain on public health agencies' ability to collect data. Even in a mild pandemic, data will be gathered over time, and the picture they present will gradually emerge. When hard data cannot be acquired, the state can best approximate the information it needs through collaboration with local health departments and social service agencies because these organizations have the greatest knowledge of the communities they serve. Of course, sufficient historical and risk factor data exist to predict which groups are likely to be at particular risk, so that relevant preparations can be made. As Barker argues in an editorial on the First Nations experience with 2009 H1N1 in Canada,

> But how, in the face of overcrowded housing, lack of running water and disproportionate rates of chronic diseases, can we allow ourselves the excuse that what was seen during the first wave was not entirely predictable? We know that First Nations harbour rates of respiratory illnesses, such as tuberculosis, 29 times that of non-Aboriginal-born Canadians. We know that rates of the non-traditional use of tobacco are as high as 69%. The answer is simple. Predicting this would require mitigation. . . . [I]t requires the support and willingness of all Canadians to admit that the health disparities facing First Nations do have solutions.[31(p130)]

Ultimately, public health can alleviate health disparities only to the extent that it works to understand the risks confronting disadvantaged populations.

Once at-risk groups are identified, allocation of resources such as vaccines and antivirals to distribution sites could track these target groups. Prospective and strategic planning could direct more resources to communities with more eligible recipients so that those at highest priority have the best access to resources. If members of the public at high risk of death from influenza are prioritized for vaccination, then proportionate supplies of vaccine could be distributed according to incidence of risk factors such as certain chronic illnesses. By contrast, if vaccine is distributed in amounts proportional to area population rather than to risk, priority groups may not be reached as needed. The challenge with a prioritized distribution scheme relates to the need for data to guide distribution. Collaboration with local providers can enhance understanding of the needs of communities. Even with ideal amounts and types of information, efforts to target resources to at-risk populations can succeed only to the extent that the state makes reasonable efforts to remove barriers to access.

ADDRESSING ACCESS BARRIERS

Preparedness efforts must address 2 types of barriers to access: socioeconomic and geographical. Both types of barriers raise justice concerns. Both can block or delay access to care and thus worsen outcomes. Socioeconomic and geographic barriers to access are highly interdependent in that people of a particular economic and social class are likely to live in the same areas. Discussions of geographical barriers focus largely on disparities in availability of care that render particular areas vulnerable. For example, a recent analysis of US critical care beds per capita shows wide variation in distribution and concludes that

> pandemic or disaster affecting a small proportion of the population could quickly exceed critical care capacity in some areas while leaving resources idle in others.[32(p1372)]

Although these geographic barriers to access present critical issues, we focus on socioeconomic barriers at a more local level.

Working at the local level to address access barriers was a recurring theme in MPEP's public engagement process. As part of that process, the project team led 9 small-group community engagement meetings across Minnesota. Communities and local partners were chosen to foster inclusion of typically underrepresented groups, such as persons with disabilities, racial and ethnic minorities, and low-income persons. A total of 125 people participated in these meetings. More detail on public engagement methods and results can be found in project reports.[17–19]

Participants were asked to identify access barriers in their communities. Those frequently mentioned were

- Lack of accessible information about influenza or public health and health care services in their communities,
- Distrust of government and public health agencies and programming,
- Lack of insurance and inadequate insurance coverage,
- Poverty,
- Transportation and mobility issues, and
- Distance to care.

Participants felt that many access barriers could be alleviated through outreach efforts in communities and partnership with community organizations that understand and are trusted by their communities. Participants strongly emphasized the need to bring educational campaigns into individual communities to better inform residents about influenza, pandemic planning, and available community health services. They proposed that educational campaigns be offered in multiple languages with a variety of teaching strategies rather than consist merely of distribution of written materials. They also advised that information be disseminated in multiple venues—such as neighborhood hubs—rather than simply be posted to the Internet.

To improve trust, participants felt strongly that educators should be culturally competent and represent diverse groups found in the communities where the educational campaigns would be offered. Participants stressed that to address issues concerning trust, transportation, mobility, and distance to care, resources should be brought into local communities, easily accessible sites or mobile units should be used for distribution of resources, and collaborations with trusted community organizations should be developed for providing care.

Some strategies recommended by participants may be viewed as best practices for public health.[3] However, participants indicated that these strategies are far too often neglected—a lived experience reflected in long-standing patterns of data concerning the impact of illness in these populations. Thus, the input provided by participants supplements quantitative data in revealing failures to implement best practices.

Although local organizations play a critical role in pandemic response, responsibility to alleviate access barriers must be shared across levels. Only the state has aggregate data and thus the ability to compare mortality and morbidity across regions. Additional information will be acquired from surveillance at federal and global levels. Collaborative efforts between hospitals will require complex negotiations that are essential to removing access barriers and reducing group differences in mortality and serious morbidity. Regional hospital pandemic plans should attend specifically to efforts to alleviate health disparities and reduce access barriers. Justice requires that all hospitals, regardless of jurisdiction, accept patients who typically confront access barriers that block or delay care. Working toward strong, collaborative relationships between these entities promotes the development of mechanisms that allow for and facilitate the admission of patients and reimbursement for services. Federal guidance regarding hospital plans overlooks these concerns.[33]

Promoting equity of access requires vigilance and cooperation across all levels. Achieving equity will depend on the nature and quality of collective action, knowledge, interaction, and moral commitment between public health and public and private health care organizations at the local, regional, and state levels. Issues of lack of insurance and poverty involve structural inequalities. They are notoriously difficult to address and require systemic change in addition to and beyond pandemic preparedness efforts.

Still, public engagement participants felt that efforts should be made to provide free or low-cost services to disadvantaged communities, perhaps by targeting publicly subsidized resources from the Strategic National Stockpile to those communities and allowing more privileged communities to rely more heavily on privately held resources. Participants also strongly expressed the need for public health officials to offer credible assurance that immigration authorities will not be present or involved in the distribution of resources, both to allow undocumented immigrants to gain access to care and to prevent intimidation of citizens or documented immigrants who may seek care when not carrying documentation.

CONCLUSIONS

Pandemic influenza planning in the United States and most of the world violates the demands of social justice in 2 fundamental respects: it embraces the neutrality of procedural justice at the expense of more substantive concern with health disparities, thus perpetuating a predictable, preventable, historical social wrong, and it fails to move beyond lament to practical planning geared toward alleviating access barriers.

A substantive social justice approach should inform pandemic planning. Planners should partner with at-risk communities to ensure that their needs are met. Those who will suffer disparate effects of pandemics or other public health disasters should receive preference in the distribution or rationing of resources, so that they may be protected from further harm. Social vulnerabilities linked to race, ethnicity, gender, socioeconomic status, and other social stratifications should not carry a sentence of avoidable ill health and death from infectious disease. ■

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Contributors

D. DeBruin was a coleader of the Minnesota Pandemic Ethics Project (MPEP) and participated in the design, conduct, and analysis of input from public engagement activities. J. Liaschenko and M. F. Marshall partnered on MPEP. J. Liaschenko contributed to the design of public engagement activities. D. DeBruin led and J. Liaschenko and M. F. Marshall participated in the development of the content, drafting, editing, and review of the article.

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Human Participant Protection

No protocol was required because human research participants were not involved.

Note. Analyses here are the work of the authors and should not be understood to reflect the views of other MPEP participants.

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The Expert and the Lay Public: Reflections on Influenza A (H1N1) and the Risk Society

Charles Dupras, MSc, and Bryn Williams-Jones, PhD

Trust between the lay public and scientific experts is a key element to ensuring the efficient implementation of emergency public health measures.

In modern risk societies, the management and elimination of risk have become preeminent drivers of public policy. In this context, the protection of public trust is a complex task. Those actors involved in public health decision-making and implementation (e.g., mass vaccination for influenza A virus) are confronted with growing pressures and responsibility to act. However, they also need to accept the limits of their own expertise and recognize the ability of lay publics to understand and be responsible for public health.

Such a shared responsibility for risk management, if grounded in participative public debates, can arguably strengthen public trust in public health authorities and interventions.

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THE INFLUENZA A (H1N1) virus pandemic was not as devastating as expected, so the preventive health measures that were deployed to cope with the outbreak are now being challenged.[1,2] Questions remain about the appropriateness of large-scale population vaccination programs, such as those promoted as the best response to the expected influenza epidemic in spring 2009. Large-scale vaccination involves considerable financial (and other resource) costs for governments, and the political decision to make such an investment in public health is not without repercussions. In particular, if such decision-making processes are not fully transparent and well justified—for example, if accusations of conflict of interest arise, as was the case with World Health Organization (WHO) recommendations[2,3]—public trust in the resulting public health program or intervention can be threatened. Clearly, an erosion of public trust in the judgments of public health authorities (whether they be local, national, or international) can have serious negative consequences on the future implementation of other emergency response programs.[4]

To respond to this problem of a loss of (or weakened) public trust, we must understand its sociocultural and historical origins. The examination of past implementations of emergency programs can hopefully help us understand our strengths and faults and eventually serve as tools for continuously improving our management of public health in such emergency situations. Neustadt and Fineberg's book on the 1976 swine flu "affair" is a good example of how critical of ourselves we should be to react better to such crises in the future.[5] For this same purpose, and by placing a sociological macroscopic lens over a particular recent crisis, we are presenting a case analysis of the 2009 H1N1 flu pandemic.

Drawing on the literature in the social sciences, we have affirmed that the management of health crises is necessarily also the management of human crises. We integrate reflections from contemporary bioethics and political philosophy, in line with views about the responsibility of decision makers in democratic states. First, we argue that the concept of trust (e.g., by the public in health experts) should be situated in the context of modernity—namely, in