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## Participatory and Deliberative Practices in Health: Meanings, Distinctions, and Implications for Health Equity

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# Participatory and Deliberative Practices in Health: Meanings, Distinctions, and Implications for Health Equity

## **Abstract**

This paper examines the meanings of and distinctions between public deliberation and a tradition of participation in health committed to community empowerment, collective action, and social justice and their implications for health equity. Although participation (as empowerment) and public deliberation share fundamental democratic ideals, these democratic practices differ in basic respects. Whereas participation in health typically seeks to engage marginalized and minority groups in planning, research, and action on the social determinants of health and wellbeing, deliberative processes seek to create the conditions for reasoned and respectful public dialogue that can lead to well considered collective judgments about important social issues. Whereas the ultimate aim of participation in health is a redistribution of resources and power that will advance health equity and social justice, the ultimate aim of deliberation is a fair process that yields public decisions all will view as legitimate. Proponents of public deliberation often contend that decision-making subject to democratic deliberation will result in (more) just outcomes; yet, public deliberation has been criticized precisely for its inability to include marginalized perspectives and to challenge status quo institutional arrangements and power relations. This analysis concludes that the use of public deliberation to advance health equity and social justice in the U.S. context holds promise despite serious challenges.

## **Keywords**

public participation, participation in health, public deliberation, inequality, diversity, health equity, social justice

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A version of this paper was presented to a group of practitioners and scholars who participated in a symposium on public deliberation in health policy and bioethics at the University of Michigan in September 2010. This two-day symposium, organized by Julia Abelson, Susan Goold, and Erika Blacksher, asked the twenty-five researchers in attendance to reflect on questions about rationales, methods, uses, and impact of public deliberation in the health sector. The papers in this symposium set reflect some of the work, thought, and constructive criticism that resulted. I thank my colleagues for an intellectually invigorating and rewarding experience. I also thank the Canadian Institutes of Health Research (through a grant led by Julia Abelson) and the University of Michigan Center for Ethics in Public Life (through a grant led by Susan Goold) for supporting the endeavor. I also would like to thank a number of reviewers, including Julia Abelson, Ellie Garrett, Rosalina James, and Sue Brown Trinidad.

## Introduction

As participatory processes in public decision-making have become more common, so too have debates about what they are, why they matter, and whether they work. Answers to such questions tend to vary with the goals, topics, and contexts of participatory initiatives. As with the other papers in this symposium set, this paper's interest relates to participatory processes in the health sector and to deliberative processes in particular.<sup>1</sup> Public deliberation began to take root in the health sector in the 1990s and more recently has become the subject of systematic study and institutionalization (Abelson et al. 2013).

In contrast, public participation has a long history in public health and medicine. Participatory processes in some form have anchored social movements in health that stretch back at least 60 years, beginning with community-oriented primary care, subsequent notions of primary health care, and continuing through the decades with community participation in health promotion, healthy cities and communities movements, community-based participatory research, and human rights and health equity agendas. As with public deliberation, public participation in health is a heterogeneous concept whose meanings and practices have evolved over time in response to scholarly critique, practical experience, and social change (Morgan 1991, Robertson and Minkler 1994). This paper situates public deliberation, as colleagues and I define it (Blacksher et al. 2012, Abelson et al. 2013), in relation to a particular tradition of participation in health, which views participation in terms of community empowerment, collective action, and social justice.

Participation (as empowerment) and public deliberation share deep commitments to democratic ideals. They call for expanded citizen participation and claim numerous benefits, from the transformation of citizens to more legitimate public decisions and institutions. Yet, these democratic practices differ in fundamental respects. Whereas participation in health typically seeks to engage marginalized and minority groups in planning, research, and action on the social determinants of health and wellbeing, deliberative processes seek to create the conditions for reasoned and respectful public dialogue that can lead to well-considered collective judgments about important social issues. Whereas the ultimate aim of participation in health is a redistribution of resources and power that will advance health equity and social justice, the ultimate aim of deliberation is a fair process that yields public decisions all will view as legitimate. To be sure, proponents of public deliberation often contend that decision-making subject to

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<sup>1</sup> I do not address a related yet distinct movement toward lay participation in health *care* decision-making, which endorses greater participation of patients in treatment decisions and consumers in resource allocation planning. For an early discussion, see Charles C and DeMaio S . (1993) Lay Participation in Health Care Decision Making: A Conceptual Framework. *Journal of Health Politics, Policy and Law* 18;4:881-904.

democratic deliberation will result in (more) just outcomes. Yet, public deliberation has been criticized precisely for its inability to include marginalized perspectives and to challenge status quo institutional arrangements and power relations (Sanders 1997, Young 2001). These critiques raise an important question for deliberative democrats concerned about entrenched social inequalities in health: What role, if any, do deliberative processes have in the quest for health equity and social justice?

This paper takes up that question in the context of a broader analysis of the meanings of participation and deliberation in the health arena. This paper begins with a brief discussion of public participation in general, drawing on two oft-cited typologies. Against this background, I discuss the meanings of public deliberation and of participation in health and some of the debates that surround each, highlighting those concerned with diversity and inequality. A comprehensive review of both concepts is beyond the scope of this paper, but each idea is discussed in detail sufficient to draw basic contrasts. These discussions set the context for this paper's last section, which examines the limits and promises of public deliberation in efforts to advance health equity and social justice.

### Public Participation & Deliberation: Meanings

The first challenge to any assessment of the meaning of public engagement processes, whether in health or other social sectors, is the sheer volume and diversity of terminology. Public engagement strategies travel under a vast array of banners—citizen engagement, collaborative decision-making, public participation, public involvement, public deliberation, deliberative engagement, deliberative democracy, community engagement, community organizing, community empowerment, participatory research, participatory governance, and participatory budgeting, among others. Conceptual ambiguity regarding the meanings of these terms abounds, despite decades of analysis and discussion among scholars and practitioners (Rowe and Frewer 2005, Rifkin 1996, Robertson and Minkler 1994). Still, conceptual distinctions have been drawn that helpfully inform this paper's first aim to situate deliberation in relation to an empowerment model of participation in health.

In an early attempt to establish a typology of public involvement mechanisms, Arnstein distinguishes among a number of activities according to the directional flow of information and the distribution of power (1969). At the bottom of the ladder are forms of “non-participation” that seek to “educate” or “cure” participants. Rubberstamp advisory committees and community action agencies that dupe citizens or attempt to mollify their complaints rather than hearing and redressing them constitute mere “manipulation” and “therapy.” Next up on the ladder are activities that allow participants to have a voice, such as “informing” and “consultation,” but nonetheless represent “tokenism” because participant input is ultimately not taken into account.

Only when citizens have what Arnstein calls “decision-making clout” do public engagement activities qualify as genuine participation. They include “partnership” that enables participants to negotiate and engage in trade-offs with decision-makers as well as “delegated power” and “citizen control” that transfers decision-making power fully to citizens. Throughout her analysis, Arnstein casts participants as “have-nots,” which underscores the role of power in her definition of participation as:

a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future.... The have-nots join in determining how information is shared, goals and policies are set, tax resources are allocated, programs are operated, and benefits like contracts and patronage are parceled out. In short, it is the means by which they can induce significant social reform which enables them to share in the benefits of the affluent society. (1969, p. 216)

Rowe and Frewer’s (2005) more recent typology of public engagement mechanisms both draws on and departs from Arnstein’s. Their scheme turns on the directional flow of information, a criterion that serves to distinguish forms of public participation from public communication and consultation. Whereas public communication refers to mechanisms that convey information from sponsors (often government officials) to the public, and public consultation refers to mechanisms that convey public opinions to sponsors, public participation refers to processes that entail dialogue both among members of the public and between participants and initiative sponsors.

Like Arnstein, Rowe and Frewer exclude public communication and consultation from the category of public participation because they lack reciprocity in communication. Although Arnstein does not stress communication among participants, she does, like Rowe and Frewer, make communication between participants (members of the public) and decision-makers a defining feature of participation. But Rowe and Frewer’s analysis diverges from Arnstein’s in two important respects. First, they underscore the potentially transformational quality of participation. Whereas public consultation captures “raw opinions” currently held by the public, the dialogic character of participation creates the opportunity for all parties’ views and values to evolve. The positions of participants and decision-makers alike may be informed by and ultimately changed by the deliberative exchange. Second, their interpretation of participation lacks Arnstein’s emphasis on power. They neither define the zenith of participation in terms of full citizen control and a redistribution of resources nor characterize participation as a remedy solely for the poor and dispossessed.

**Public Deliberation.** Rowe and Frewer's emphasis on the dialogic character of participation reflects a "deliberative turn" in the purposes and methods of participatory processes (Rodela 2012, Abelson et al. 2003). In broad terms, public deliberation refers to "a process of public discussion in which participants offer proposals and justifications to support collective decisions" (Fung 2003, p. 343) or, more specifically, to "a particular sort of discussion—one that involves the careful and serious weighing of reasons for and against some proposition" (Fearon 1998, p. 63). Conceptions of public deliberation differ in many ways but share a focus on communicative processes that create the conditions under which the interests, opinions, and preferences of participants can evolve (Elster 1998). So central is the element of preference formation and transformation that some identify the "malleability of opinion" as a primary indicator of successful deliberation (Lehoux et al. 2012).

Early conceptions and definitions of public deliberation fell out of deliberative democratic theory and turned on unitary reason, consensus, and the common good (Mansbridge 2006). But a period of critical response and practical experimentation has led to definitions and models of deliberation that attempt to account for pluralism and practice. Chambers' synthesis of not only "what democratic theory is" but also of what it "is doing these days" (Chambers 2003) describes public deliberation as:

debate and discussion aimed at producing reasonable, well-informed opinions in which participants are willing to revise preferences in light of discussion, new information, and claims made by fellow participants. Although consensus need not be the ultimate aim of deliberation, and participants are expected to pursue their interests, an overarching interest in the legitimacy of outcomes (understood as justification to all affected) ideally characterizes deliberation. (p. 309)

Public deliberation, then, is a type of "democratic talk" that yields decisions all will view as legitimate. Their legitimacy derives from a process subject to a number of normative demands. Participants to the discussion should represent the full diversity of those affected by the decision under consideration, with an emphasis on marginalized and minority groups. All parties to the discussion should have an equal opportunity to contribute to discussion through a process of reflection and respectful exchange that entails articulating and justifying one's views. And, the deliberation is based on non-partisan information. In sum, deliberation should be inclusive, equal, reasoned, and voluntary (Button and Ryfe 2005).

A recently proposed "minimum definition" of public deliberation embodies these basic elements. Blacksher and colleagues argue that deliberation

is a form of public discussion about social issues that is, at a minimum, (1) based on balanced factual information that enhances participants' knowledge of the issue under consideration, (2) includes diverse perspectives of ordinary people to counter the disproportionate influence of experts and well-off citizens on public decision-making, and (3) creates the conditions under which all participants have an equal opportunity to articulate and justify their positions and weigh alternate views (Blacksher et al. 2012). The authors stress the deeply normative nature of public deliberation, describing it as a type of dialogue that is subject to norms of equal respect and reciprocity and that seeks considered collective judgments about what "we ought to do." The authors strongly endorse but do not require public deliberation to inform particular policy decisions, recognizing that deliberative processes might be usefully deployed for other purposes or at other stages of collective problem solving.

This minimum definition skirts a number of important questions. Basic among them are questions about the expectations and purposes of deliberation. One question concerns the forms of communication that qualify as reasons (or as reasoned). Are story-telling, testimony, greeting, or appeals to faith forms of reasoning and argument admissible in a deliberative context? A related question concerns the role of self-interest. If deliberations are ideally oriented toward collective judgments and common ground, is there any place for self-interested deliberation? Both questions hint at another: exactly *who* should deliberators be? The public deliberation literature typically describes participants as "ordinary citizens" who lack specialized expertise and vested interests, and who lend legitimacy to the deliberative process precisely for these reasons (Lehoux et al. 2012). But, as Lehoux and colleagues argue, doesn't everyone bring personal experience and expertise in some form to the discussion? Isn't that the point of ensuring diversity? And shouldn't deliberators have the opportunity to express that perspective, particularly if their views are rarely represented in the public square?

Concerns about diversity and inequality motivate many of these questions. Scholars and practitioners of deliberation argue that "the demands for reason, consensus, and the common good may marginalize or exclude members of disadvantaged groups" (Mansbridge et al. 2006, p. 5). Expectations that participants engage in highly rationalistic forms of communication may privilege those with more education or are otherwise practiced at this sort of communication (Sanders 1997). And, demands for consensus and the identification of a common good may frame the deliberative task in terms of dominant interests and silence minority perspectives (Karpowitz et al. 2009).

Creating the conditions of equality within a deliberative space, so that all perspectives are represented and can participate effectively with an equal voice, is a serious challenge (Chambers 2003). But it is not the only challenge deliberation scholars and practitioners face. Even when deliberative settings can effectively include minority perspectives and create the conditions for deliberative equality,

there remains the question of whether deliberation as such can challenge existing power structures and the structural inequalities they maintain and reinforce. How can a deliberative agenda that seeks to determine and legitimate policy decisions within existing institutional arrangements also criticize those institutions? “To the extent that [deliberation] must presuppose constrained alternatives that cannot question existing institutional priorities and social structures, deliberation is as likely to reinforce injustice as to undermine it” (Young 2001, p. 684).

One source of such criticism comes from a more activist participatory tradition of democracy, which some claim is neglected in this era of deliberative democracy (Hildreth 2012).<sup>2</sup> The ideals of participatory democracy—an empowered citizenry dedicated to eliminating structural inequalities through collective action—have, however, remained very much alive within the health sector.

**Participation in Health.** The idea of community participation in health has a long and storied history in public health and medicine (Rifkin 1996). A commitment to participation has anchored health movements over the last six (or more) decades, from community-oriented primary care founded in the 1940s in South Africa to more recent models of health promotion, community-based participatory research, and health equity. The 1978 Alma Ata Declaration formalized participation as a guiding principle in improving people’s health, embedding it in the definition of primary health care (World Health Organization 1978). The Declaration posited that people have both a right and a duty to participate individually and collectively in planning and implementing programs that affect their health. Since then the idea that people have a right to participate in health programs, planning, research, and implementation has been reaffirmed by high-level bodies and commissions, from the 1986 Ottawa Charter (World Health Organization 1986) to the 2008 report from Commission on the Social Determinants of Health (World Health Organization 2008).

Despite, or perhaps because of, the prevalence of participation as an ideal, its meaning is not univocal. Participation has taken on varied meanings against the backdrop of globalization, the rise of a neoconservative ideology, and the evolution of health movements, going by myriad names—community participation, community empowerment, community development, community organizing, community capacity building, popular participation, and participatory research, among other labels. As with public deliberation, efforts to define participation in health, distinguish it from related concepts, and measure it abound (Rifkin et al. 1988, Wallerstein and Bernstein 1994, Robertson and Minkler 1994, Rifkin and Kangere 2001, Laverack 2001, DeVos et al. 2009).

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<sup>2</sup> Some scholars, however, trace the roots of public deliberation to participatory democratic movements. See for example Kadlec A, Friedman W, “Deliberative Democracy and the Problem of Power,” *JPD* 3(2) 2007.

For purposes of this analysis, the most important conceptual distinction drawn by many commentators is between utilitarian and empowerment models of participation. Whereas the former model treats participation as a means to achieve a project's aims more effectively and efficiently, the latter treats participation as an end to empower people as individuals and communities (Morgan 2001). In the utilitarian model, participation takes the form of persuading people to collaborate with and contribute resources (labor or otherwise) to an externally developed initiative. In contrast, the empowerment model treats participation as a social process through which the community takes responsibility for diagnosing problems, identifying opportunities and strategies for change, and taking collective action to improve health and social wellbeing.

This "definitional divide" played out in the evolution of community-oriented primary care (COPC), a precursor to the idea of primary health care that anchors the 1978 Alma Ata Declaration. COPC founders deemed community participation an essential feature of the model (Tollman 1991) and practical experiences with it abroad and in the United States suggest a rich understanding of it. Communities are depicted as a resource "rich in potential" and "amply supplied with bright and creative people" (Geiger 2002); community members are to be provided with training (Tollman 1991) and treated as partners in the assessment, planning, implementation, and evaluation of health programs and community initiatives. Setting people free to seek their own destiny has been described as the "essence" of primary health care (Rifkin and Walt 1986).

This vision of primary health care has other defining features. Health is defined as social and mental wellbeing, not just the absence of disease; a function of social, economic, and political conditions, not just health care and technology; and about disease prevention and health promotion, not just treatment and cure (Tollman 1991, Declaration of Alma-Ata 1978). This view of health is integrally linked to notions of social justice in its demand that the structural conditions of health be secured for all people and that all people participate in decisions and collective action that produce and distribute health in a population.

A second and quite different model of primary health care developed in response to the Alma Ata Declaration, and with it, another interpretation of community participation. In contrast to community-oriented primary health care, "selective primary care" was rooted in a biomedical model of health, with goals of improving health status through technology and biomedicine, cost-efficiency, and cost-sharing (Rifkin 1996). Community members are beneficiaries of programs, and community participation means "getting large groups of people to accept the medical interventions the professionals have selected to use" (Rifkin 1986, p. 562). Consultation with community members seeks behavior change that improves health and ultimately promotes program sustainability.

Despite the utilitarian appeal of such an approach, the empowerment model gained prominence in the health promotion movement of the 1980s and 1990s (Robertson and Minkler 1994) and, some suggest, now dominates public

and global health (Wallerstein 2006). With roots in Paulo Friere's liberation education philosophy and participatory conceptions of democracy, community participation casts people as "actors in history, able to name their problems and their solutions to transform themselves in the process of changing oppressive circumstances" (Wallerstein and Bernstein 1994).

The 1986 Ottawa Charter made community participation central to its overarching goal of health promotion.

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities—their ownership and control of their own endeavours and destinies.

In the U.S. context, participatory approaches to health-related research in particular have received attention in the last decade (Minkler et al. 2003). A 2002 Institute of Medicine report included community-based participatory research (CBPR) among areas of essential training for public health professionals (Rosenstock and Hernandez 2002), and the Centers for Disease Control and Prevention, the National Institutes of Health, and many private foundations have begun providing substantial support for participatory research. Although focused on research, CBPR shares an empowerment model's core commitments to involve all stakeholders, particularly community members, in a research process that focuses on a topic of importance to the community and that seeks knowledge that can translate into collective action to improve community health and eliminate health disparities. Key features include the equitable involvement of a range of stakeholders and community members, mutual learning among all parties, reciprocal transfer of expertise, shared power and responsibility, mutual ownership of the processes and product, and an orientation toward collective action and social change (Israel et al. 1998).

The influence of an empowerment approach to health participation has been further bolstered in the 21<sup>st</sup> century by the rise of human rights perspectives in global health (DeVos et al. 2009). Human rights perspectives have influenced how participation and empowerment are conceived by highlighting the need for accessible, fair, and transparent processes that ensure an equal opportunity to participate and mechanisms of accountability whereby "governments explain and justify, to rights-holders and others, how they have fulfilled or failed to fulfill obligations regarding participation" (DeVos et al. 2009, p. 26).

Despite its prevalence as an idea and aspiration, participation as empowerment remains controversial and difficult to achieve in practice. That participation has failed to take root in health initiatives is widely noted (DeVos et al. 2009, Lawn et al. 2008, Morgan 2001). Moreover, some argue that the World

Bank's adoption of participation as a criterion of health and development initiatives, while helping to institutionalize it, also subverts it because of the way the bank defines participation. Stakeholders are defined as those who influence and share control over the development initiatives and include all those who affect the outcome, such as elected officials, agency staff, and non-governmental and private sector representatives (Morgan 2001). The poor and disadvantaged are noticeably missing from the list of stakeholders and "power" goes unmentioned.

### Public Participation and Deliberation in Health: Related Yet Distinct

This sketch of deliberative and participatory processes is by no means complete, but some basic comparisons and contrasts can be drawn. As already noted, these practices share a deep commitment to democratic values. Mutual respect and equality are among the core values that ground both practices. Deliberative theorists identify equality as an essential criterion of democratic deliberation and conceive of deliberators as "free and equal" citizens (Mansbridge et al. 2006). What this means in practice is that everyone should be given an equal opportunity to speak and diverse perspectives be represented in the room. It also requires the facilitator to keep a low profile so discussion can achieve a "free flow" and participants can begin to direct themselves according to ground rules they all agree to (Mansbridge et al. 2006). Expectations of experts, when they are involved, are also highly circumscribed to ensure that discussion does not revolve around them.

Empowerment models of participation in health express the value of equality in at least two ways. As with public deliberation, community members are considered equals to the experts and organizers who typically initiate health research and programs. Cast as experts with lived local knowledge about barriers to health and opportunities for improvement, community members are deemed essential to making positive change in their community. Just as the facilitator's role is critical to achieving equality in deliberative settings, so too is the role of health researcher or community organizer in participatory ones. The organizer must not dominate the process but rather conduct her work with sensitivity and humility to facilitate community empowerment and mobilization (Morgan 2001).

The relevance of equality in participatory initiatives, however, extends beyond the interpersonal relations of participants and organizers. The stated aim of empowerment approaches to participation in health is to reduce structural and material inequalities in the lives of community members. This commitment to a fair distribution of resources and power can itself be traced to the idea that all persons are moral equals, deserving of equal respect (Fleischacker 2004). Deliberative theorists often argue that decisions subject to democratic deliberation will be more public-spirited and perhaps more just, but the primary work to date has been to neutralize the detrimental effects of structural inequalities *within the deliberative space*, not outside it.

Related to the values of equality and respect is a commitment to shared learning. Proponents of both deliberative and participatory practices posit the potential for people to learn from one another and, importantly, for experts and decision-makers to learn from “the people.” Participatory forms of research cast community members as “inside experts ... who live with the problems being studied” and whose knowledge and experience is essential to research and action on health disparities, the roots of which lie in the social, economic, environmental, and political features of the community (Horowitz et al. 2009, p. 2633). In deliberative settings, co-learning is supposed to occur at two levels, among participants and between participants and decision-makers. Deliberators’ contribution to the discussion is typically characterized, however, not as a form of expertise, but rather as something all persons possess, social values. Because all public policymaking entails normative judgment, the public’s social values are considered an essential counter-balance to the interests and (rarely explicitly identified) values of experts and activists. In both cases, better decisions and solutions are claimed to be the result.

These democratic practices also lay claim to personal and civic learning. The learning may be personal in the sense of experiencing new levels of agency, efficacy, and empowerment, and a deeper understanding of one’s values or their transformation in light of newly acquired information (Alkire 2002). As people learn more about the world around them and refine their views and values in response, participatory processes shape their personal identities. Deliberation theorists tend to stress the cultivation of civic identities. Citizens who participate in deliberative forums can “see things from different points of view and that enables individuals to come to see themselves as equal, capable and responsible members in a shared political life” (Button and Ryfe 2005, p. 30). In learning better the virtues and skills of citizenship, nothing less than “a more fully democratic kind of life” and a more robust democracy becomes possible (Button and Ryfe 2005, p. 30).

Proponents of deliberative and participatory initiatives promise a better democracy, though through different routes. In the case of deliberation, an enhanced democracy derives from fair *processes* that produce decisions all will view as legitimate. For proponents of participation, an enhanced democracy follows on the heels of collective action that will yield more just substantive *outcomes*. Both practices are thus described as solution-oriented, though their respective solutions take different forms: decisions about public policy in the case of public deliberation, and action on the social determinants of health and wellbeing in the case of participation in health. Thus, critics sometimes contend that democratic deliberation is “all talk and no action” and unable to produce the social and institutional changes needed to counter structural inequalities (Hilbreth 2012). This raises the question: Do deliberative processes have a role in an agenda that seeks greater health equity and social justice? Or, are they a distraction from the more immediate demands of community empowerment and social action?

### Promises and Limits of Deliberation for Health Equity and Social Justice

Some view the question about how deliberative theory and practice connect to concerns about structural inequalities as among the field's most pressing questions (Kadlec and Friedman 2011, Fung 2005, Chambers 2003). Yet, in a recent account of assumptions academics make about public deliberation, Lee describes this assumption as accurate for only a small subset of practitioners and theorists (Lee 2011). For many deliberation practitioners, discussions of inequality and social justice threaten to “torpedo” productive deliberation and the field of public deliberation more generally (Lee 2011, p.17).

Those who do take seriously activist challenges to deliberative democracy have re-imagined the terms of deliberation. Some theorists and practitioners have, for example, enlarged conceptions of reason-giving, making room for other forms of discourse such as story-telling, testimony, greeting, and other modes of communication that use emotion and symbolism to convey meaning (Mansbridge et al. 2006). In addition, they have stressed the importance of participants' expressions of self-interest, particularly on questions of fair distribution (Mansbridge et al. 2010). Expressions of self-interest can function both as information, clarifying and establishing people's preferences and needs, and, in some circumstances, as justification of one's preferences.

Related to the role of self-interest, some have underscored the role of contestation and conflict in establishing the range of issues at stake. Whether conflict is compatible with deliberation is, however, an open question. As Coelho discusses in this symposium set, her study of citizen participation in Brazil shows that in districts with strong histories of citizen mobilization and activism, participatory processes were characterized by more confrontation and conflict, precluding more deliberative styles of interaction (Coelho 2013).

Practitioners have also experimented with “enclave deliberation” to ensure minority perspectives get voiced (Karpowitz et al. 2009). This approach gives disempowered groups the opportunity to deliberate among themselves to explore and forge their own ideas and interests. Proponents argue that when enclave deliberation is built into broader processes of deliberation, such that enclave deliberators also take part in more heterogeneous representative forums, concerns about diversity can be addressed and the criteria for legitimate deliberation can be met.

All this sounds promising, but the activist can still ask, so what? Even if deliberative processes can equally and effectively include minority and marginalized voices (and limited evidence suggests they can (see p. 578 in Karpowitz), what relevance might this “deliberative equality” within the forum have for addressing questions of structural inequality outside of it? This question has two parts. First, how might deliberative output differ (in ways relevant to addressing structural inequalities) when hammered out under ideal deliberative

conditions? Second, how might such deliberative output be connected to processes of social and political change that can remedy entrenched structural inequalities associated with class, race, and other markers of social disadvantage?

Deliberative democrats have plenty to say in response to the first question. Theorists and practitioners often claim that well-designed and implemented deliberative forums will produce fairer outcomes and more democratic citizens. Studies suggest, for example, that participants subject to inclusive deliberative conditions become more tolerant and more committed to long-term social and political participation (Ryfe 2005), make more public-spirited decisions by forgoing benefits on behalf of others (Goold et al. 2005), and become less polarized in their views (Coehlo 2013). It has also been suggested that the civic learning cultivated by deliberation can enhance personal and political efficacy, social trust and social capital, and empathy (Button and Ryfe 2005). Others have suggested that deliberation can foster “social intelligence”—habits of thought and action that can produce “very real forms and processes of democratic change” (Kadlec and Friedman 2011).

It is not a stretch to imagine that such effects would work in favor of a more just world. Whether deliberation actually does transform citizens and tilt their policy positions in these ways are empirical questions that merit ongoing investigation. But even if more just decisions result from deliberative processes, how might they enter the political system or inform processes of social and political change? Deliberative democrats acknowledge that policy makers rarely are bound by the decisions of deliberative groups (Ryfe 2005, Kadlec and Friedman 2011). More typically, decision-makers take the results of deliberation under consideration but are not bound to use them directly.<sup>3</sup> Indeed, some deliberative forums avoid an explicit policy connection, positing instead the goal of citizen education. So, the question remains, Can deliberative processes inform social change processes that can remedy structural inequalities?

Deliberative democrats are not completely silent on this question. A few theorists have developed approaches that view deliberative and participatory practices as complementary phases within a larger “circuit of cooperative inquiry” (Hildreth 2012) and forms of “deliberative activism” that act (e.g., sit-ins and protest marches) in a deliberative spirit (Fung 2005) or that sandwich deliberation in between more activist pursuits that prime a problem for deliberation and then connect deliberative output to social change (Kadlec and Friedman 2011).

Such responses suggest a number of ways that deliberation might be very useful to participatory initiatives seeking to promote health equity. Participatory

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<sup>3</sup> This raises the question of whether all forms of public deliberation qualify as a form of participation as Arnstein and Rowe and Frewer define it. The answer depends in part on what it means for decision-makers to take account of deliberative results or for the latter to inform policy decisions.

processes in health typically entail stages of interaction and decision-making for which deliberation is ideally suited. Prior to taking action, the actors involved often need to make decisions about the community's most pressing needs, priorities, and promising opportunities for change. The number of people involved can be considerable, sometimes taking the form of coalitions comprised of researchers, planners, community organizers, community members, and other community representatives (e.g., faith leaders, businesses).

While all involved might be committed to the same overarching goal to improve community health and wellbeing, the multiplicity of perspectives and interests is likely to translate into different perspectives and priorities for the types of action that should be taken. Public deliberation is particularly well suited to priority-setting exercises, because the conditions under which a diversity of views can be identified and justified are created, yet with an orientation toward coming to a collective judgment about "what we ought to do." Because people are given the time to identify not only what they think should be done but also *why*, people's underlying rationales and values can be identified, which can form the basis of a broader sense of mission and collective purpose. In addition, given the reality of power differentials among the actors involved, enclave deliberation might be fruitfully used with more disempowered community members to give them an opportunity to identify their range of interests and needs at some point within a broader series of deliberations.

Despite these potential benefits to the health equity enterprise, the use of public deliberation in U.S. public health—which prioritizes the elimination of health inequities—is rare. Deliberative processes have been used to engage citizens in setting priorities in *health care* in the United States and abroad (Abelson et al. 2013, Goold 2005, Ginsburg et al. 2006), but not in the public health sector. Scutchfield notes that none of the main approaches to community engagement in public health incorporate public deliberation (Scutchfield et al. 2004). Moreover, he suggests that the community engagement models that do exist (e.g., Mobilizing for Action Through Planning and Partnership, or MAPP) severely limit the role of public judgment in public health planning. Incorporating public deliberation into such models, he argues, would expand the role of the public in public health decision-making, providing officials with a reliable source of information about the community's values and priorities. It could also create more transparency in decision-making, which in turn could promote community trust in public health institutions, an important public health value.

Despite the potential benefits of incorporating public deliberation into U.S. public health decision-making processes, there are a number of challenges to using them to advance health equity, a top U.S. public health priority. One challenge relates to framing deliberations in ways that free them from existing institutional constraints on public health (the very criticism Young waged against public deliberation generally). Two such constraints are particularly relevant in the context of U.S. public health. First, spending on public health constitutes a

mere 5 percent of all health spending (McGinnis et al. 2002). Widely recognized as woefully inadequate to make headway on improving population health and reducing health disparities, a 2012 Institute of Medicine report recommends doubling the current federal appropriation for public health (IOM 2012). Second, although aware of the need to incorporate and act on a broad array social determinants of health to reduce health disparities, the U.S. public health system is in the nascent stages of developing strategies and networks for collaboration with other social sectors, such as education, labor, transportation, law enforcement (Scutchfield and Howard 2011).

Those who wish to use public deliberation to advance health equity would need to frame the deliberative exercise in ways that overcome such institutional constraints. For example, communities convened to deliberate priorities for strategies to reduce health disparities will need to include not only public health-oriented health care interventions (e.g., vaccinations, safety net services) but also strategies for acting on the built and physical environment, housing, neighborhood safety, early childhood education, and lifelong opportunities for job training and education and employment, among other social determinants. Although a number of existing health planning models (e.g., ReThink Health; Health Bound; County Health Rankings) include an array of social determinants, they lack a deliberative decision-making process to help citizens identify their collective priorities for action. An opportunity exists to incorporate these models into deliberative processes and vice versa.

Another potential limitation of deliberation for advancing health equity relates to its appropriateness in different cultural settings. Public deliberation's emphasis on the inclusion of all voices and conflict might not fit the values and communication styles of all cultural communities, particularly minority groups. It has been suggested, for example, that focus groups, which like deliberative forums stress the inclusion of all voices, might be inappropriate for use in some Native American and American Indian communities (Strickland 1999). Whether or not these communities or other non-dominant groups would find deliberation an acceptable form of communication for decision-making or, more broadly, what deliberation and priority-setting look like in these communities, are unexplored empirical questions. Yet, given the disproportionate incidence of illness and disease among minority and marginalized groups, determining what sort of deliberative processes might work in such communities will be imperative. The recent call for greater use of public deliberation in the health sector generally (IOM 2011) further underscores the importance of investigating such questions.

These challenges to using deliberation models to advance health equity are nontrivial and, no doubt, others remain to be identified and examined. Yet, the promises of public deliberation for a health equity agenda are also great. If we can imagine models of deliberation developed for use with diverse and disenfranchised communities, framed to overcome existing institutional constraints that compromise a new public health agenda that acts on the social

determinants, and is directly connected to social and political processes that have long belonged to an empowerment tradition of participation in health, then perhaps we can make real progress on reducing health disparities and advancing the larger cause of social justice.

#### REFERENCES

Abelson J, Blacksher E, Boesveld S, Goold SD, Li K. (2013) “Public Deliberation in Health Policy and Bioethics: Mapping an Emerging, Interdisciplinary Field.” *Journal of Public Deliberation* 9;1.

Abelson J, Forest PG, Eyles J, Smith P, Martin E, Gauvin FP. (2003) “Deliberations about Deliberative Methods: Issues in the Design and Evaluation of Public Participation Processes.” *Social Science & Method* 57:239-251.

Alkire S. (2002) *Valuing Freedoms: Sen’s Capability Approach and Poverty Reduction*. Oxford: Oxford University Press.

Arnstein S. (1969) “A Ladder of Participation.” *Journal of the American Institute of Planners* 35:216-224.

Blacksher E, Diebel A, Forest PG, Goold SD, Abelson J. (2012) “What Is Public Deliberation?” *Hastings Center Report* 42;2:14-17.

Button M, Ryfe DM. (2005) “What Can We Learn from the Practice of Deliberative Democracy?” In J. Gastil, P. Levine (eds.) *The Deliberative Democracy Handbook: Strategies for Effective Civic Engagement in the 21<sup>st</sup> Century*. San Francisco, CA: Jossey-Bass.

Chambers S. (2003) “Deliberative Democratic Theory.” *Annual Review of Political Science* 6:307-326.

Coelho V. (2013) “What Did We Learn about Citizen Involvement in the Health Policy Process: Lessons from Brazil.” *Journal of Public Deliberation* 9;1.

De Vos P, De Ceukelaire W, Malaise G, Pérez D, Lefèvre P, Van der Stuyft P. (2009) “Health through People’s Empowerment: A Rights-Based Approach to Participation.” *Health and Human Rights* 11;1:23-35.

Elster J. (1998) “Introduction.” In J. Elster (ed.) *Deliberative Democracy*. Cambridge: Cambridge University Press.

Fearon J. (1998) "Deliberation As Discussion." In J. Elster (ed.) *Deliberative Democracy* Cambridge: Cambridge University Press.

Fleischacker S. (2004) *A Short History of Distributive Justice*. Cambridge, Mass.: Harvard University Press.

Fung A. (2003) "Survey Article: Recipes for Public Spheres: Eight Institutional Design Choices and Their Consequences." *The Journal of Political Philosophy* 11;3:338-367.

Fung A. (2005) "Deliberation Before Revolution: Toward an Ethics of Deliberative Democracy in an Unjust World." *Political Theory* 33;2:397-419.

Geiger HJ. (2002) "Community-Oriented Primary Care: A Path to Community Development." *American Journal of Public Health* 92:1713-1716.

Ginsburg M, Goold SD, Danis M. (2006) "(De)constructing 'Basic' Benefits: Citizens Define the Limits of Coverage." *Health Affairs* 25;6:1648-1655.

Goold SD, Biddle AK, Klipp G, Hall CN, Danis M. (2005) "Choosing Healthplans All Together: A Deliberative Exercise for Allocating Limited Health Care Resources." *Journal of Health Politics, Policy & Law* 30;4:563-601.

Hildreth R. (2012) "Word and Deed: A Deweyan Integration of Deliberative and Participatory Democracy." *New Political Science* 34;3:295-320.

Horowitz CR, Robinson M, Seifer S. (2009) "Community-Based Participatory Research from the Margin to the Mainstream: Are Researchers Prepared?" *Circulation* 119:2633-2642.

Institute of Medicine. (2011) Ulmer C, Ball J, McGlynn E, Bel Hamdounia S (eds.) *Essential Health Benefits: Balancing Coverage and Cost*. Washington, D.C.: The National Academies Press 2011.

Institute of Medicine. (2012) *For the Public's Health: Investing in a Healthier Future* Washington, D.C.: The National Academies Press 2012.

Israel B, Schultz A, Parker E, Becker A. (1998) "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health." *Annual Review of Public Health* 19:173-202.

Kadlec A, Friedman W. (2011) "Deliberative Democracy and the Problem of Power." *Journal of Public Deliberation* 3;2, Article 8.

Karpowitz C, Raphael C, Hammond A. (2009) "Deliberative Democracy and Inequality: Two Cheers for Enclave Deliberation among the Disempowered." *Politics & Society* 37;4:576-615.

Laverack G. (2001) "An Identification and Interpretation of the organizational aspects of Community Empowerment." *Community Development Journal* 36:134-145.

Lawn J, Rohde J, Rifkin S, Were M, Paul V, Chopra M. (2008) "Alma-Ata 30 Years On: Revolutionary, Relevant, and Time to Revitalise." *Lancet* 372:917-927.

Lee C. (2011) "Five Assumptions Academics Make About Public Deliberation, and Why They Deserve Rethinking." *Journal of Public Deliberation* 7;1, Article 7.

Lehoux P, Daudelin G, Abelson J. (2012) "The Unbearable Lightness of Citizens within Public Deliberation Processes." *Social Science & Medicine* 74;12:1843-1850.

Mansbridge J, Hartz-Karp J, Amengual M, Gastil J. (2006) "Norms of Deliberation: An Inductive Study." *Journal of Public Deliberation* 2;1:1-47.

Mansbridge J, Bohman J, Chambers S, Estlund D, Føllesdai A, Fung A, LaFont C, Manin B, Martí JL. (2010) "The Place of Self-Interest and the Role of Power in Deliberative Democracy." *The Journal of Political Philosophy* 18;1:64-100.

McGinnis JM, Williams-Russo P, Knickman J. (2002) "The Case for More Active Policy Attention to Health Promotion." *Health Affairs* 21;2:78-93.

Minkler M, Blackwell AG, Thompson M, Tamir H. (2003) "Community-based participatory research: Implications for funding." *American Journal of Public Health* 2003;93(12):1984-5.

Morgan L. (2001) "Community Participation in Health: Perpetual Allure, Persistent Challenge." *Health Policy and Planning* 16;3:221-230.

Rifkin S. (1986) "Health Planning and Community Participation." *World Health Forum* 7;2:156-162.

-- (1996) "Paradigms Lost: Toward a New Understanding of Community Participation in Health Programmes." *Acta Tropica* 61:79-92.

Rifkin S, Walt G. (1986) "Why Health Improves: Defining Issues Concerning Comprehensive Primary Health Care and Selective Primary Care." *Social Science & Medicine* 23;6:559-566.

Rifkin S, Muller F, Bichmann W. (1988) "Primary Health Care: On Measuring Participation." *Social Science & Medicine* 26;9:931-940.

Rifkin S, Kangere M. (2001) "What Is Participation?" In S. Hartley (ed.) *CBR: A Participatory in Africa*. London: University College, 37-49.

Robertson A, Minkler M. (1994) "New Health Promotion Movement: A Critical Examination." *Health Education Quarterly* 21;3:295-312.

Rodela R. (2012) "Advancing the Deliberative Turn in Natural Resource Management: An Analysis of Discourses on the Use of Local Resources." *Journal of Environmental Management* 96:26-34.

Rosenstock G, Hernandez L. 2002. *Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21<sup>st</sup> Century*. Washington: D.C.: Institute of Medicine, National Academy of Sciences.

Rowe G, Frewer L. (2005) "A Typology of Public Engagement Mechanisms." *Science, Technology, & Human Values* 30;2:251-290.

Ryfe D. (2005) "Does Deliberative Democracy Work?" *Annual Review of Political Science* 8:49-71.

Sanders L. (1997) "Against Deliberation." *Political Theory* 25;3:347-376.

Scutchfield FD, Ireson C, Hall L. (2004) "The Voice of the Public in Public Health Policy and Planning: The Role of Public Judgment." *Journal of Public Health Policy* 25;2:197-205.

Scutchfield FD, Howard A. (2011) "Moving on Upstream: The Role of Health Departments in Addressing Socioecologic Determinants of Disease." *American Journal of Preventive Medicine* 40;1S1:S80-S83.

Strickland CJ. (1999) "Conducting Focus Groups Cross-Culturally: Experiences with Pacific Northwest Indian People." *Public Health Nursing* 16;3:190-197.

Tollman S. (1991) "Community Oriented Primary Care: Origins, Evolution, Applications." *Social Science & Medicine* 32;6:633-642.

Turnock B (2004) *Public Health: What It Is and How It Works*. Sudbury, MA: Jones & Bartlett.

Wallerstein N, Bernstein E. (1994) "Introduction to Community Empowerment, Participatory Education and Health." *Health Education Quarterly* 21;2:141-148.

Wallerstein N. (2006) "What Is the Evidence on Effectiveness of Empowerment to Improve Health?"  
[http://www.euro.who.int/\\_data/assets/pdf\\_file/0010/74656/E88086.pdf](http://www.euro.who.int/_data/assets/pdf_file/0010/74656/E88086.pdf), accessed 2/18/2-13.

World Health Organization. Declaration of Alma-Ata. 1978.  
[www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf), accessed 1/4/2013.

World Health Organization. Ottawa Charter for Health Promotion. 1986.  
<http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>, accessed 1/4/2013.

World Health Organization. Commission on the Social Determinants of Health. (2008) Closing the Gap in a Generation.  
[www.who.int/social\\_determinants/thecommission/en/](http://www.who.int/social_determinants/thecommission/en/), accessed 1/4/2013.

Young IM. (2001) "Activist Challenges to Deliberative Democracy." *Political Theory* 29;5:670-6.

