Health Reform and Health Equity: Sharing Responsibility for Health in the United States

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INTRODUCTION

Two failings of U.S. health care have defined recent reform efforts. The escalating cost of health care, estimated to have reached \$2.5 trillion in 2009¹, and the swelling ranks of un- and underinsured Americans, now totaling some 75 million.² They share company with a third, however, that has attracted little attention. Tens of millions of poor and minority Americans experience levels of health typical of middle- or low-income countries.³ Differences in health status by social class, race and ethnicity, and geographic region are large and persistent in the United States.⁴ Guaranteed access to timely, quality, primary care could improve our nation's health, but no amount of health care can remedy social disparities in health. Health reform that made health equity a goal would demand a bolder agenda that acts on the social, economic, environmental, and cultural factors, or "social determinants of health," implicated in the disproportionate incidence of disease among poor and minority groups.⁵

While other countries have pioneered promising national health equity initiatives from which the United States might learn, the prospect of a comprehensive, government-led agenda faces significant barriers. They include an idea with a long history in this nation—personal responsibility for health.⁶ It is thus notable that the language of "shared responsibility for health" increasingly has found its way into the American vernacular, and at the highest levels of government. President Barack Obama and secretary of health and human services Kathleen Sebelius, among others, have declared health a collaborative enterprise. This paper takes up the question of why health should be treated as a shared responsibility, what that entails for the subjects of responsibility, and what it might look like in practice. I will propose a notion of shared responsibility for health that

takes seriously the social determinants of health, yet also underscores the role for individual agency and I will use it to evaluate a range of health reform and health promotion activities proposed or underway in the United States. I begin with a brief description of the nature and extent of U.S. health disparities and the notable efforts of England and Canada to achieve health equity in their respective populations.

BACKGROUND

U.S. population health has improved markedly in the last 100 years. People live substantially longer, from 47 years in 1900 to 77 years in 2000, and report feeling significantly healthier throughout their later years. These gains in health, however, have not been shared equally among social groups. Public health research has documented significant and enduring social inequalities in health within the United States, and by some accounts these inequalities are growing.

Studies show disparities by social class, race and ethnicity, and geographic region. For example: a blue-collar worker is 2.8 times more likely to die from a heart condition than is a businessman⁹; African American males in the District of Columbia have a life expectancy 17 years less than a white male in Montgomery County, Maryland¹⁰; and males in southwest South Dakota have a life expectancy 22.5 years lower than females in Stearns County, Minnesota.¹¹ Some regional groups have experienced absolute declines in health, as illustrated by the decline in life expectancy between 1982 and 2001 among low-income white women in Appalachia and Mississippi Valley.¹²

In addition to these intra-country disparities, America's health fares poorly relative to other countries. Among 192 nations, the United States ranks 46th in average

life expectancy from birth and 42nd in infant mortality. ¹³ The United States also fares poorly in terms of morbidity. A 2006 study that compared morbidity among older individuals in England and the United States, for example, concluded that U.S. residents are "much less healthy than their English counterparts and these differences exist at all points of the [socioeconomic] distribution." ¹⁴

Health care reform that guaranteed all Americans access to timely, quality primary care could improve our nation's health¹⁵ and help reduce inequalities in health status. ¹⁶ But health care is not the primary determinant of health. Reforms that aim to produce a more equitable distribution of health must act on the root causes or "social determinants" of health. ¹⁷

Such initiatives have grown in number and scale over the past decade. The World Health Organization's (WHO) Commission on Social Determinants of Health identifies eighteen initiatives from high, middle, and low-income countries advancing comprehensive government-wide health equity agendas. A recent review of health equity efforts throughout Europe describes reforms implemented in England as the most advanced for their degree of comprehension and coordination across policy sectors. That nation's process began with the landmark Black Report on health inequalities, commissioned by the Labour government in 1977 and published (reluctantly) by the Conservative government in 1980. Although the report spurred action in countries such as the Netherlands and Italy long before gaining traction in England the government-commissioned Acheson Report published in 1998 set into motion a bold series of initiatives. The report proposed both new policies for reducing health inequalities and that existing policies in non-health sectors be assessed for their impact on health

inequalities.²¹ Current policies range from those focused on reducing childhood poverty and investing in early childhood development to health action zones that aim to reduce poverty in deeply deprived areas to tax credits for working families.²² And, disparity reductions goals have been set for 2010.²³

Canada's efforts are also noteworthy, in part for their early beginnings. A 1974 report from then Canadian health minister, Marc Lalonde, criticized the focus on health care delivery as a means to promote health and called for the development of a conceptual framework that addressed the non-medical health determinants.²⁴ Although criticized for failing to adequately address the impact of environment on lifestyle and for unleashing a focus on individual responsibility for health²⁵, the report became the first in a long series of documents and initiatives to promote health for all Canadians. Not until 1986, however, did Canada publish a document that embodied principles and policies that took seriously the social determinants of health. Achieving Health for All: A Framework for Health Promotion, developed alongside the World Health Organization's Ottawa Charter, frames the pursuit of health equity as a societal responsibility and addresses both institutional and environmental determinants of health.²⁶ Canada has continued to produce high level policy documents addressing health equity and has restructured data collection and health research to address health equity and the non-medical determinants of health.²⁷

Recent reviews of both countries' efforts nonetheless identify lingering challenges. In the United Kingdom, pitfalls include: limited evidence about effective interventions and of change in intermediate outcomes and poor integration of health inequality initiatives in mainstream systems²⁸ as well as the government's rejection of

income redistribution through taxation as a remedial strategy.²⁹ Research has shown that Canadian initiatives have failed to penetrate across government sectors, a weakness attributed to a lack of research that could inform policy tradeoffs among sectors, and that the non-medical determinants of health message has neither penetrated nor persuaded policy advisors in the finance sector.³⁰

England's and Canada's respective achievements and challenges may be attributed to any number of forces. But, these nations' values are no doubt at work. The values held by policy makers and polities influence which social issues become defined as problems, how those problems are framed, and whether they are acted on. It is significant that their official documents and initiatives cast health inequalities as inequities or disparities—which connote their moral unacceptability—and justify government action on grounds of social justice and social responsibility. The theme of personal responsibility for health has not been absent in these political contexts 33,34, but it appears not to have dominated health promotion and disease prevention policy.

The same cannot be said for the United States. Personal responsibility is a core American value and its prominence in the context of health has a long history.³⁵ Over the past few decades the health responsibility debate has intensified and within political discourse often plays out in predictable* and unproductive terms. In its barest form, proponents of personal responsibility deny any role for structure in health and proponents of social responsibility downplay the role of health-related behaviors in poor health. This debate, long deemed a straw man by some³⁶, has begun to give way to calls for "placing

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This debate has not, however, played out in predictable ways within moral philosophy. As philosopher Dan Wikler explains, generally left leaning philosophers have developed responsibility-sensitive theories of egalitarian justice whose implications for health policy fall far to the right of those typically proposed by political conservatives. Dan Wikler, "Personal and Social Responsibility for Health," in *Public Health, Ethics, and Equity*, eds. Anand S, Peter F, and Sen A. (Oxford University Press 2004).

individual within a social determinants approach to health inequity."³⁷ This exchange, which I treat in the next section, will set the stage for exploring the meaning and implications of a commitment to share responsibility for health.

SHARING RESPONSIBILITY FOR HEALTH IN THE U.S. CONTEXT

Mounting evidence of the contribution of personal behaviors to chronic disease and the increasing incidence of such diseases have intensified the debate over health responsibility. That debate has generated a number of helpful analyses that illuminate the meaning of health responsibility and its many implications for health policy. ^{38,39} An analysis by Schmidt reveals considerable variation in the concept's meaning ⁴⁰, though three senses of responsibility are thematic. Role responsibility refers to those actions that follow from personal identity and role, which in the context of health can simply refer to the fact that a person should take better care of herself because only she can. Causal responsibility refers to the contribution individuals behaviors make to health outcomes. And, liability responsibility refers to the idea that individuals should be held liable for the adverse consequences of their voluntary health-related actions.

Causal and liability responsibility figure pivotally in personal responsibility proposals. Recommendations to, for example, lower the treatment priority of individuals whose disease is deemed the product of free choice or for disease prevention programs to target only those diseases deemed not the product of free choice turn on a view that people who freely cause their poor health should be held accountable for it in some way. Although such proposals can be rejected on a number of grounds⁴¹, much of the rebuttal

has attempted to establish the primacy of social structure in the production of health and thus diminish the role of individual agency.

To that end, rebuttals can draw on ample epidemiological data establishing social factors as causes of illness to make at least two sorts of arguments. First, social conditions can exert health-harming properties regardless of individual behavior, as evidenced by studies showing that significant health differences between advantaged and disadvantaged groups remain after controlling for behaviors related to diet, exercise, and smoking.⁴² Thus it can be shown that contexts, such as poor neighborhoods, are associated with different risk profiles that harm health independently of any behavior directly associated with health.

Second, social conditions can directly shape health behaviors. Explanations of the disproportionate incidence of poor health behaviors exhibited by low income groups may argue that low socioeconomic position truncates the range of (health-promoting) options available to them⁴³ or otherwise impinges individual agency by limiting opportunities for control over health-consequential circumstances⁴⁴, by undermining the development and exercise of health-related agency⁴⁵, or by rendering people "victims" of their environment. Explanations of the better health of more advantaged groups may argue that individuals use their socioeconomic resources—money, knowledge, power, prestige, and social support—to protect their health and to minimize the consequences of injury and disease. Link and Phelan frame the resources that shape health behavior and access to contexts with different risk profiles as "fundamental causes" of disease because they exert their causal properties reliably over time, even as diseases, treatments, and health risks have changed dramatically from one historical period to the next. As humanity

exerts more and more control over disease, advantaged groups become better situated to protect and promote their health and generate new disparities in health.⁴⁹

None of these arguments removes the individual from the scene, but each attempts to relocate responsibility for poor health from the individual to some form of social structure or process. "The locus of blame is key, for if blame is placed on the individual, social structure is exculpated, and the resulting suffering and premature death will not be counted as a social injustice." This view taps the moral intuition that justice demands the remedy of inequalities (in health or other important goods) generated by unjust social institutions and policies⁵¹, and provides moral support for exhortations to identify and remedy the "causes of the causes" of poor health or the conditions that "put people at risk of risks." ⁵³

Friends of health equity have nonetheless expressed concerns about an agenda oriented exclusively toward structural reforms. Noting the shift toward a broad and integrative epidemiology that resists binary models, Forde and Raine, for example, point out the artifice of trying to disentangle social and individual factors and the contention that dogs efforts to prove the primacy of either.⁵⁴ "[T]he causes of the causes cannot, and so should not, be separated from the causes of poor health."⁵⁵

The fact is individual attributes make a non-trivial contribution to health, can be identified, and can be modified. Indeed, they often must be modified in order for structural interventions to have their intended effect. Although the health benefits of some structural reforms are virtually unavoidable (e.g., as when public sources of water are fluoridated or automobile airbags mandated) and thereby universal in their impact regardless of personal effort or resources, many population-based interventions do not so

seamlessly translate into health improvements at the individual level. Many interventions still require individuals to take action and thus are subject to some of the same barriers that limit the uptake of more individualistic health interventions, especially among socially disadvantaged groups. Just as cultural beliefs, low income and educational attainment, chronic socioeconomic stress, or fatalist attitudes may impede one from acting on, say, information about health risks, these same attributes may work to erode the benefits of a population-based intervention, such as smoking ban. ^{56,57}

The implication is not only that population-based measures may be less effective than they could be, but that they, like their more individualistic counterparts, may generate health disparities. Even if the maldistributive potential of population-based interventions is less than that of individualistic interventions—a question that depends in part on how one defines equity —the concern about socioeconomic constraints on health agency stands. And it can be used to advocate both for interventions that improve health independent of individual effort and socioeconomic level on the life- and health-enhancing opportunities such reforms make available.

An exclusive focus on the structural determinants of health may not only forgo the constructive potential of individual agency, it may telegraph a negative message about the agency of those who bear the brunt of disease. To the extent that a health promotion agenda casts those with poor health as victims of their circumstances or unable

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[†] Health interventions may raise the absolute level of health of disadvantaged groups even as the exacerbate inequalities between better and worse off groups. No consensus exists as to whether health equity should be defined in terms of achieving an absolute minimum of health, equality *per se*, or some other measure. For a detailed discussion of standards of equity see, Powers M, Faden R. *Social Justice: The Moral Foundations of Public Health and Health Policy* (Oxford University Press 2006), chapter 3.

to make positive life changes risks further undermining or perhaps stigmatizing those already marginalized by race, ethnicity, poverty, or other markers of disadvantage.

If structure and agency are both implicated in the production of health, and if the pursuit of health equity might be enhanced by a strategy that attends to both, what implications for health responsibility follow? The overarching, if obvious, implication is that health is a shared responsibility. The phrase might seem to dilute accountability, but the language of *responsibility* requires that we get specific about actors and their obligations. We have to ask, Who is responsible for what action toward whom and on what normative grounds?⁶¹ So, in the pursuit of health equity, who are the subjects of responsibility and what are they obligated to do? The question is best answered in the context of ground-level knowledge of the populations of interest, barriers to health, and the resources and opportunities available within particular social and political contexts. But as a general response to the question, two sets of actors and actions can be identified.

One set of actors, call them agents of population health, are bodies of collective action that can work effectively to create the social, material, and environmental conditions for health. The recent report from WHO's Commission on the Social Determinants of Health identified a list of such bodies that include: global institutions and agencies, national and local governments, civil society, research and academic communities, and the private sector. What, in the name of health equity, should they do? The WHO report details six categories of action, many of which can also be found in the recommendations of other documents and commissions who have addressed the social determinants of health, including the national initiatives already described. They include investing in children's development and health, creating communities and work

places that promote physical and psychological health, securing social protection and universal health care across the life course, and other activities aimed at achieving a more equitable distribution of resources that include gender equity, market responsibility, and the political empowerment of marginalized groups. The overarching responsibility is to create fair conditions and opportunities for a healthy life and normal lifespan. Noting the powerful and entrenched interests arrayed against this goal, others have underscored the necessity of another, less official, form of collective action—the political struggle that historically has been the product of social movements. 63,64

This important reminder about how social change happens, from and by the people whose interests are most dearly at stake, points to a second set of actors implicated in the project of health equity. Individuals who are sick, at risk of illness, or otherwise the targets of health promotion and health equity reforms also have responsibility, though not the sort associated with bare-knuckled calls for personal responsibility. Schmidt's conception of "co-responsibility" goes some distance in describing the responsibility that might apply. Recognizing that personal control over health admits of degrees, Schmidt proposes a "more nuanced and less punitive" notion that assigns responsibility yet withholds blame. This conception prohibits punishments such as higher premiums for illness or lower priority for treatment of illnesses to which individual behaviors contribute and endorses more positive strategies such as health education programs and campaigns that raise individuals' awareness and capacity for positive change.

Fine as far as it goes, this conception of responsibility overlooks a form of action particularly relevant in the context of health equity. Where universal policies cannot be implemented and targeting must apply, communities and populations of interest should

be treated as 'full partners and peers' in the project of better health. Their knowledge and input should be sought out, participation recruited, and promising interventions supported. In this, agents' capacity for positive change potentially expands to their communities and perhaps to larger social units. Public health and development experts have long recognized that recruiting community members as agents of change can leverage the empowerment potential of such initiatives and improve their effectiveness. ^{67,68} It may also cultivate respect and recognition among parties.

With these ethical criteria in mind, we can ask this paper's last question: how do health promotion experiments proposed or underway in United States fit the bill? The current ferment in health reform and health promotion activities reveals signs of progress and stubborn tendencies. I begin by looking at two policy experiments, one underway and one proposed, that reveal regressive tendencies and conclude on a note of measured optimism, describing a number of activities and initiatives that suggest a shift in the right direction.

West Virginia Medicaid Reform and the Safeway 'Wellness' Amendment.

Made possible by the 2005 Deficit Reduction Act that gave states new options for reducing Medicaid benefits, West Virginia in 2006 implemented a plan in which benefits vary depending on client behavior. An 'enhanced' package of services is reserved for clients who sign a contract (on behalf of themselves and their children if they have them) in which they agree to undergo screening exams, follow the doctor's prescribed regimen, show up on time for appointments, and otherwise try to stay healthy. Failure to meet expectations relegates clients and their children to a 'basic' plan that excludes benefits once standard.⁶⁹ Children in the basic plan are no longer eligible for skilled nursing care,

prosthetics, nutrition education, diabetes care, and mental health services, among other services. Adults in the basic plan face similar restrictions.

The demerits of the plan are numerous and have been well chronicled. ^{70,71} Three speak to this paper's interests. The plan makes no attempt to alter the social conditions that influence clients' ability to adopt healthier behaviors or the contexts in which they live and work. The plan structure is punitive, eliminating essential services, even those such as nutrition education that could enhance clients' knowledge and capacity for health. And, the plan went into place with no opportunity for public input or comment. Not surprisingly, analysts suggest the plan will worsen, not improve, the health of those subject to these policies. ⁷²

A proposed amendment in the Senate health care reform bill, known as the Safeway Amendment, is less draconian but fails on similar grounds. The amendment expands existing rules for workplace wellness programs that offer incentives, including premium discounts, for participation in health promotion programs and attainment of weight-, cholesterol-, and tobacco-related goals. Currently, most wellness programs refrain from punitive measures[‡] and instead encourage healthy habits by offering employees helpful resources (e.g., on-site fitness centers, online meal planning guidance) and relatively small rewards (e.g., coupons, prizes) for meeting behavioral and/or biomarker goals. Analysts have shown that as amended by the Senate bill the rules for these programs allow for potentially significant cost increases for employees who fail to meet goals.⁷³ Given the social gradient in health behaviors and the difficulty of making behavior change, the plan is likely to penalize employees on the low end of the pay scale

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[‡] Exceptions include Scotts Lawn's program that, while offering a rich set of tools to improve health behaviors, such as an on-site clinic, fitness center, and personal health coaches, exacts heavy penalties for not complying with the plan, including firing employees for smoking, on or off site. A lawsuit is pending in Massachusetts.

"who are generally less healthy than their higher-paid counterparts and thus in greater need of health care, less likely to meet the targets, and least likely to be able to afford higher costs."⁷⁴

Promising Activities. Forces for a progressive health agenda have been gathering strength in the last decade. Institutes dedicated to health equity, health promotion, and community development have been established⁷⁵; national commissions and bodies have issued reports on health inequalities and the social determinants of health⁷⁶; states and communities have begun to invest in and transform their communities; and proposed health reforms include some enlightened recommendations. The five activities described below represent national, state, and local initiatives that signal progress.

- The Robert Wood Johnson Foundation's Commission to Build a Healthier America published a report in early 2008 that laid out the case for the social determinants of health. Although the report was neither government commissioned, as was the UK's Black and Acheson reports, nor well received by all health equity advocates due to the perceived timidity of its recommendations⁷⁷, it was the first commission of its kind in the United states and the product of bipartisan commissioners.
- RWJF and The Pew Charitable Trusts have established a national initiative to promote policy makers' use of Health Impact Assessments (HIAs)⁷⁸, tools that identify the health consequences of policies in non-health sectors. The philanthropies created a national center of excellence to coordinate the effort, funds demonstration projects, provides training and technical assistance, and conducted two federal-level HIAs. HIAs enable the kind of inter-sectoral government action endorsed by the UK's Acheson Commission and WHO's Commission on the Social Determinants of Health and generate data necessary for evidence-based decisionmaking across policy sectors.
- The current health reform legislation, precarious as it is, contains considerable dollars directed at prevention, including community transformation grants to fund infrastructure changes that facilitate healthier living, such as walking and biking paths, lighted sidewalks and playgrounds, and farmers' markets⁷⁹ and a defined benefit package that waives cost-sharing for basic preventive services and well-baby and well-child visits,⁸⁰ among many other efforts to elevate and empower the voice of public health.
- In 2001 Minnesota's Department of Health published A Call to Action: Advancing Health for All Through Social and Economic Change that urged the promotion of

Minnesotans health through social and economic change. ⁸¹ The Blue Cross Blue Shield of Minnesota Foundation embraced the message and has developed and support projects to improve the social and economic conditions of vulnerable communities. ⁸² Its Growing Up Healthy project provides children at risk with early learning opportunities, safe and affordable housing, and a clean environment. Investing in children's development is the signal activity endorsed by WHO's Commission on the Social Determinants of Health, UK's Acheson Commission, and RWJF's Commission to Build a Healthier America, and is a policy recommendation that has garnered bipartisan support in the United States. ⁸³

• New York City, under the reign of Mayor Michael Bloomberg and public health commissioner Thomas Freiden, now director of the Centers for Disease Control, instituted an array of policies and initiatives to promote health in New York City's neighborhoods, from requiring restaurants to post calorie counts, to banning trans fats in public restaurants, to planting trees in low-income, high asthma neighborhoods. The city's plan to plant a million trees over a decade to create shade and beauty and cleanse and filter neighborhood air, is notable for creating jobs for at-risk teens and young adults. Some twenty 16 to 24 year-olds will be earn \$12 an hour to learn about horticulture, plant, and care for trees. 84

In different ways, these activities express a commitment to sharing responsibility for health. They aim to create environments that enable and support healthful living and to collaborate with individuals as agents of change in their own lives and their communities. I have also noted, where appropriate, when these initiatives might have appeal across the political spectrum, an important practical consideration in a political context as polarized as the United States. A Congress splintered among left-leaning Democrats who deem the proposed health care reforms too conservative, right-leaning Democrats who declare them too liberal, and right-wing Republicans who condemn them as "socialist" stands as a sharp reminder of the challenge that lies ahead. The pursuit of a truly comprehensive health equity agenda will require more than the official actions of commissions, institutions, researchers, policy leaders, and civic organizations. It will require the political commitment, and struggle, of ordinary Americans.

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