

Chapter 2

Mobilizing for the Right to Health and Health Care

We really need to stop thinking of health care as a for-profit venture and start treating it as a right and a public good.

—Franzen, as cited in NESRI (2010, p. 9)

Human rights advocates, like Peg Franzen of the Vermont Workers' Center, view corporate profit-making in the health sector and realizing the human right to health care as fundamentally incompatible. This is especially relevant in the United States when the success of health policy is measured predominantly in terms of profitability and cost-benefit analyses rather than positive health outcomes for all people. Since the early 1990s local and national efforts in the United States have sought to redefine health care not as a commodity, but as a human right (McGill, 2012; Soohoo & Goldberg, 2010). Labor organizers, public interest lawyers, community leaders, and social workers have increasingly challenged the commodification of health through grassroots advocacy, with an aim to change state and federal health policy. Their fundamental goal is to address the lack of universal access to affordable, quality health care.

The US health care system is often touted as offering a level of care unsurpassed by any other country. Indeed, the United States spends over twice as much per capita on health care as the average developed country.¹ Others suggest that the *quality* of health goods and services in the United States is also superior. Yet the National Research Council and Institute of Medicine of the National Academies (Woolf & Aron, 2013) recently acknowledged that the United States falls far short of having the world's best health care system. Indeed, a growing body of evidence points to another way in which the United States is "exceptional" among its peers, but in this instance it is in terms of "health disadvantage" (2013, p. 4). Health outcomes and access to health care highlight pervasive inequality and health disparities in the United States. In 2010, for example, a record 50 million people (approximately 16 % of the US population) lacked health insurance (US Census Bureau, 2012).

¹ Per capita health care expenditures in 2011 were \$8,508 in the United States, compared to \$3,322 on average for Organisation for Economic Co-Operation and Development (OECD) countries (Organisation for Economic Co-Operation and Development, n.d.).

The number without health coverage was significantly higher among non-whites/racial minorities, lower-income workers, and those who worked less than full-time (and non-workers). Access to health insurance in the United States is also determined by geography: the percent of the (non-elderly) population lacking health insurance is highest in the South and Southwest (Solomon, 2013). Despite improvements in access to health insurance in 2011 and 2012, the period from 1999–2010 witnessed a marked decline in health insurance coverage for most groups (US Census Bureau, 2012; Center on Budget and Policy Priorities, 2013c). Tyler (2013) notes that while the Patient Protection and Affordable Care Act of 2010 (hereafter ACA) is intended to significantly expand coverage to the uninsured and underinsured, its passage “will not end the debate in America about the need for the realization of the right to health care” (pp. 80–81). Expanding health care insurance alone will not be sufficient to overcome decades-long legacies of disparities in access health care services and health outcomes.

Data on health insurance finds a direct connection between social class—and often, poverty—and health coverage. In the United States, the intersections with race and ethnicity and gender are crucial to consider; health disparities are systemic, affecting people of color disproportionately on major measures of health and well-being. In general, individuals and those living in households with higher incomes have better health outcomes and live longer. The United States Centers for Disease Control and Prevention (2013) reports that health disparities persist throughout the country in numerous domains. As one example, they illustrate the importance of poverty status or membership in an ethnic group as a determinant of access to health care (United States Centers for Disease Control and Prevention, 2013). According to Wolfe (2012), “those with low incomes also tend to have relatively poor outcomes for health and mortality, compared to those with higher incomes. The gap appears to begin prior to birth, and then increase throughout childhood” (p. 25).

As troubling, a 2013 study found inferior health outcomes in the United States compared to 16 comparable or “peer” high-income countries (Woolf & Aron, 2013). Examining data from the 1990s–2008, compared with the average of peer countries, the United States fared worse in nine health domains:

- adverse birth outcomes; injuries and homicides
- adolescent pregnancy and sexually transmitted infections
- HIV and AIDS
- drug-related mortality
- obesity and diabetes
- heart disease
- chronic lung disease
- disability status related to aging.

The US health disadvantage affects all groups, and while it is “more pronounced among socioeconomically disadvantaged groups ... even advantaged Americans appear to fare worse than their counterparts in England and some other countries” (Woolf & Aron 2013, p. 3). The authors underscore that the “health disadvantage is particularly striking given the wealth and assets of the United States and the

country's enormous level of per capita spending on health care, which far exceeds that of any other country" (p. 4).

A particular challenge in the United States is the patchwork of policies and programs to provide health care insurance coverage and health services access. This includes employer-based insurance programs which have significant variability in levels of coverage and costs. Public programs, including Medicaid, Medicare, the Children's Health Insurance Program (CHIP), and health programs for some veterans available through the American Veteran's Alliance, also address health needs of targeted individuals. Medicaid is a federal-state public insurance program providing health coverage to nearly 65 million low-income Americans (including children, adults, the elderly, and persons with disabilities) (Center on Budget and Policy Priorities, n.d.). The Children's Health Insurance Program (CHIP) gives states matching federal funds to provide health coverage to nearly 8 million children in families whose income is typically up to 200 % of the poverty line. Medicare is a federal program providing health coverage to about 47 million Americans (in general, over 65 years old and including several million younger adults with disabilities). It is estimated that the Affordable Care Act of 2010 will help nearly 32 million uninsured Americans obtain quality, affordable health coverage in both the private and public markets.

Despite these numerous programs, the health sector is fragmented and still excludes many Americans (both low and medium income) from quality health services. The US health care system includes profit-based insurance and health service delivery and non-profit and/or "charity care" (Goodnough, 2014). It is in this context that we argue that addressing US health disadvantage is a matter of human rights. Tyler (2013) claims to "successfully frame a health and human rights strategy in the US, it is essential that the health care, public health, and legal communities unite to effect change at the community as well as the state and national levels" (81). Social workers can play a central role in such a mobilization as well. Local, state, and national organizing for the right to health and health care has revitalized earlier efforts in US history to achieve universal health care. During the same period in which the Universal Declaration of Human Rights was adopted by the United Nations and the UN Commission for Human Rights worked to further define a right to health and health care, in the United States the Roosevelt, Truman and Johnson administrations sought to implement a universal health insurance program (Rudiger & Meier, 2003). Though President Johnson failed to articulate health care as a right, his policies "advanced the principle of government responsibility to actualize social and economic rights through his comprehensive efforts to address poverty, improve educational opportunity, expand affordable housing, and provide improved social services to disadvantaged American citizens through his War on Poverty and Great Society programs" (Schimmel, 2013, p. 5).

Despite presidential support for enacting a universal health care plan, the American Medical Association (AMA), representing interests of physicians, argued that universal health care schemes being implemented in Europe threatened core values of "personal freedom." Using the specter of Cold War-era politics, the AMA claimed the Truman administration's recognition of "access to the means for the

attainment and preservation of health” as a “basic human right” would lead to “socialized medicine” and was contradictory to core American norms about choice (President’s Commission on the Health Needs of the Nation as cited in Rudiger and Meier (2003), p. 72).² Contemporary debates about health care access still mirror these cleavages.

In the following pages, we highlight prominent examples of efforts to challenge the dominant framework of health care-as-commodity to illustrate how local, community-based mobilization can contribute to a broader national dialogue on health justice. This chapter depicts the importance of community practice to the realization of the human right to health and health care. Community practitioners can help assure the participation of vulnerable and affected groups in mobilizing for rights-based approaches to health care, develop programs and policies responsive to local communities, and promote accountability and transparency in health care provision through broad public engagement. We link the conceptual framework of community practice, focusing on political and social action outlined by Gamble and Weil (2010), with human rights-based mobilization for health and health services. Emphasis is placed on the importance of fostering broad participation in social and political campaigns to affect policy change.

Defining the Right to Health and Health Care: International Standards and Practices

The “right to enjoyment of the highest attainable standard of physical and mental health” was established in international law in the 1946 Constitution of the World Health Organization (WHO) (World Health Organization, 2005 [1946]), even before the adoption of the Universal Declaration of Human Rights (1948). According to the WHO Constitution, health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The Preamble of this Constitution further asserts that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition” (World Health Organization, 2005 [1946]). The right to health was also invoked as part of the right to an adequate standard of living in the UDHR (Art. 25) and was recognized as a human right in the International Covenant on Economic, Social and Cultural Rights (ICESCR) in 1966. It is also referenced in all the other major human rights treaties.

Since the founding of the United Nations in 1945, the meaning of the right to the highest attainable standard of health has gradually been elaborated. In particular, the

² Today the American Medical Association (n.d.) invokes the responsibility of medical professionals to “advocate for social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being” and highlights that these “responsibilities confer on physicians an active obligation to respect and advocate for the human rights of their patients and society, as a means to promoting good health.”

Committee on Economic, Social, and Cultural Rights (which monitors the treaty) and a UN Special Rapporteur on the right to health have helped define the obligations of governments and other non-governmental organizations in respecting, protecting, and fulfilling the right to health. In 2000, the UN Committee on Economic, Social, and Cultural Rights issued General Comment No. 14 on the right to the highest attainable standard of health, providing important depth to understanding the right to health. While the United States has yet to join the ICESCR (1966), and thus is not bound to its provisions in international human rights law, the guidelines provided in General Comment No. 14 and in other human rights documentation provide a strong basis for advocacy and policy-making.

The ICESCR establishes that parties to the treaty “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (1966, paragraph 12.1). Moreover, governments are to formulate and implement policies that include efforts to reduce infant mortality and promote child development; improve “environmental and industrial hygiene”; prevent, treat, and control disease; and create conditions to “assure to all medical service and medical attention in the event of an illness” (paragraph 12.2a–d). This articulation of the right to health also includes a right to the “enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health” (UN CESCR, 2000, paragraph 9).

Core Principles of the Right to Health and Health Care

International human rights law establishes that the right to health is an “inclusive right” that contains both freedoms and entitlements (Office of the United Nations High Commissioner for Human Rights and the World Health Organisation, n.d.). The right to health is expansive—broader than a right to health care—as it is predicated on the realization of other human rights, including adequate housing, food, water, education, and a range of civil and political rights (Hunt & Backman, 2008).

Securing the right to health, which has been criticized by some as overly broad³ is firmly entwined with a subset of this right to access a “variety of facilities, goods, services” (CESCR, 2000, paragraph 9). This entails addressing the right to access health care and a system of health care delivery that is based upon four essential components: the availability, accessibility, acceptability, and quality of health services (CESCR, 2000, paragraph 12). Access to these elements can be assessed through several questions. First, in terms of *availability*, does a functioning public health and health care system exist, including goods and services, plentiful enough to assure that all individuals can make use of them on a basis of non-discrimination? Second, are the existing health facilities, goods, and services accessible to everyone? This notion of *accessibility* includes four aspects: (1) non-discrimination; (2) physical

³ See Wolff (2012) for a helpful overview of this critique.

accessibility; (3) economic accessibility or affordability; and (4) information accessibility (World Health Organisation, 2008). Third, the right to health care also requires attention to whether or not health facilities, goods, and services meet the standard of *acceptability*. Thus, are they “respectful of medical ethics and culturally appropriate, i.e., respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements” (UN CESCR, 2000, paragraph 12c)? Fourth, the right to health care requires that health facilities, goods, and services must be “scientifically and medically appropriate and of good quality.” In other words, in assessing *quality* are there “skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation” (paragraph 12d)?

The right to health embodies all the above principles in terms of health care facilities, goods, and services, but it also has a more expansive dimension that recognizes that health is affected by underlying social determinants. The social determinants of health have been defined as “the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics” (World Health Organization, n.d., p. 1). These social determinants of health are defined in human rights terms as being secured by the realization of social, economic, cultural, civil and political rights which are understood as *interdependent*. Thus, as the UN Committee on Economic, Social, and Cultural Rights (2000) suggests:

The right to health is closely related to and dependent upon the realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health (paragraph 3).

International human rights law recognizes that realizing economic and social rights requires the input of resources to fulfill the government’s obligations in these domains. Human rights, in short, involve not only the *claims* of rights-holders, but also the *obligations* of duty-bearers (in this instance, the government).

A number of other dimensions of the right to health and health care must be understood in order to develop effective advocacy. The first is that the right to health is to be progressively realized, which means that governments must demonstrate that they are taking steps toward the full achievement of the right. Some governments may not be able to immediately foster the realization of all dimensions of the right to adequate health due to weaknesses in existing health care systems, insufficient economic resources, and/or inadequate capacity. Nonetheless, the Committee on Economic and Social Rights in recent years has underscored that the notion of “progressive realization” of the right to health should not be taken as a license for states to act slowly in prioritizing policies and programs. In addition, countries not facing serious resource constraints are held to a higher standard for implementing the right expediently. Thus, under international law, the United States is understood to

have adequate resources and expertise to design and implement health care systems to fulfill a universal right to health and health care (MacNaughton, 2012).

Governments, regardless of resources, must also demonstrate that they are “taking steps” to realize the right to health. This means, at a minimum, governments must:

- (1) Adopt a “national strategy to ensure to all the enjoyment of the right to health, based on human rights principles which define the objectives of the strategy”;
- (2) Set indicators and benchmarks for the “formulation and implementation” of the strategy; and
- (3) Address the “core minimum obligation” which includes: (a) “[A]ccess to health facilities, goods and services *on a non-discriminatory basis*, especially for vulnerable or marginalized groups”; (b) “Access to the *minimal essential food* which is nutritiously adequate and safe”; (c) “Access to *shelter, housing and sanitation* and an adequate supply of safe drinking water”; (d) “The provision of *essential drugs*”; and (e) “*Equitable distribution* of all health facilities, goods and services” (World Health Organisation, 2008, pp. 24–25).

The latter set of core minimum obligations illustrates the notion of interdependence of rights, suggesting that access to health care by itself is no guarantee of good health if individuals and groups face barriers to housing, food, or income. In international law, governments are obliged to “take steps towards the realization of rights, including the right to health, which should be *concrete, deliberate, and targeted*” (Emphasis ours, WHO, 2008, p. 24).

The progressive realization principle affords government time to implement programs and policies to realize the right to health or other economic and social rights. But, when discrimination on the basis of factors, such as race, ethnicity, sex, sexual orientation, language, religion, political or other opinion, national or social origin, or ability status, has the “intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health” then government must take affirmative steps to end such discrimination immediately (UN Committee on Social and Economic Rights, 2000, paragraph 18). The UN Committee on Social and Economic Rights further underscores that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds” (2000, paragraph 12c).

The question of discrimination is particularly profound in the United States, where health disparities on the basis of race and gender are well documented (CERD Working Group on Health and Environmental Health, 2008). The US government’s latest report to the Committee on the Elimination of Racial Discrimination openly admitted that despite efforts to enforce the laws such as the Civil Rights Act of 1964, which prohibits discrimination in federally funded hospitals and health care centers, health disparities “based on race and ethnicity, socioeconomic status and other factors persist at unacceptably high levels” (United States Department of State, 2013, paragraph 133).

Rights-based mobilization for health in the United States also entails the broad-based *participation* of multiple stakeholders, but especially of individuals and

groups affected by exclusion from the “core minimum obligations” above. Moreover, human rights law mandates that when racial and ethnic disparities are present, governments, such as the United States, are to implement laws and practices that redress these inequalities immediately. In the face of undeniable racial and ethnic health disparities—which the US government itself admits—the role for grassroots involvement in formulation and implementation of the right to health care is crucial. Only through such participation can accountability for realizing the right health and health care be fostered.

U.S. Obligations for Securing the Right to Health and Health Care

The United States has failed to ratify several key human rights treaties that articulate a right to health and health care services.⁴ These include the International Covenant on Economic, Social, and Cultural Rights (ICESCR) (1966), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979), the Convention on the Rights of the Child (CRC) (1989), the Convention on the Protection of Rights of All Migrant Workers and Members of Their Families (1990), and the Convention on the Rights of Persons with Disabilities (2006).⁵ However, the United States has signed the ICESCR, CEDAW, and the CRC, which obligates the government to “refrain from acts that would defeat the object and purpose” of the treaties (MacNaughton, 2011, p. 212). Furthermore, the United States has joined several human rights treaties which outline the intersection of civil and political rights and rights to health and health care services, especially with respect to special or minority populations, or individuals under the guardianship of the state (prisoners, migrants held in detention, refugees, youth in state care).⁶ The US government has also acknowledged economic and

⁴ Joining an international human rights treaty in the case of the United States entails a process whereby the President signs a treaty, signaling endorsement of its principles. Lawyers for the State Department then analyze the treaty. Following that review, the administration forwards recommendations to the Senate Foreign Relations Committee concerning any aspects of the treaty to which the government claims reservations or understandings. If ratified, the United States may officially file such reservations with the treaty body (Venit, 2011). The Senate Foreign Relations Committee determines whether or not to advance a treaty to the full body of the Senate for debate and a vote. A two-thirds vote of the Senate is necessary to approve a treaty, followed by the President’s final signature.

⁵ In late 2013, the Senate Foreign Relations Committee pushed for a second vote in the Senate to ratify the Convention on the Rights of Persons with Disabilities, which was defeated by just six votes earlier in the year (Cox & Pequet, 2012). This is the first human rights treaty that has been seriously considered for ratification in the United States since 1994.

⁶ These include the International Covenant on Civil and Political Rights (1966), the Convention Against Torture (1984), and, importantly, the Convention on the Elimination of All Forms of Racial Discrimination (1965).

social rights by inviting UN Special Rapporteurs on education, housing, water, and extreme poverty to the United States to investigate claims of human rights violations in these areas. And, in 2010, the United States highlighted the Patient Protection and Affordable Care act in its Universal Periodic Review report to the Human Rights Council, signaling its belief that this policy addressed health care as a human right (United States Department of State, 2010).

Greater receptivity in the United States to engaging on social and economic rights issues, despite the legacy of weak constitutional supports for such rights, is due largely to growing social and political pressure. In the past 20 years, civil society organizations have begun to invoke the right to health and health care services in advocacy campaigns. Local groups have creatively used international human rights monitoring processes linked to reporting on key global treaties to address some aspects of the right to health and health care (as noted in the discussion of CERD above). Advocates have focused on issues that intersect with civil and political rights, particularly related to obligations of the government to refrain from violating the right to health in terms of torture, and inhumane or degrading treatment and punishment within the military and criminal justice system (CUNY School of Law and American Civil Liberties Union, n.d.; International Human Rights Law Clinic University of Chicago Law, Chicago Legal Advocacy for Incarcerated Mothers, and American Civil Liberties Union 2013). Activists have also used provisions of the right to health and health care on the basis of equality under the International Convention on the Elimination of All Forms of Racial Discrimination, drawing attention to disparate health outcomes on the basis of race and ethnicity as a human rights concern (CERD Working Group on Health and Environmental Health, 2008; Human Rights Project of the Urban Justice Center, 2007).

Despite the US failure to ratify key treaties that involve the right to health care, advocates have used the moral weight of human rights framing, as well as the standards set by the Committee for Social, Economic, and Cultural Rights and the Special Rapporteur on the right to health, to make rights-based claims. Such efforts have taken place in varied contexts: at local levels in terms of seeking to influence municipal policy (King County/Seattle or Baltimore, MD), at the state level (Vermont, Maine, Maryland, and Pennsylvania) and to a lesser degree nationally (McGill, 2012; Rudiger, 2011; Solomon, 2009).

A major impediment to realizing robust, universal rights-based standards for health care is the fact that there is no constitutional right to health in the United States outside of efforts to address discrimination on the basis of being in a protected class (Carmalt, Zaidi, & Yamin, 2011; Swendiman, 2012). While there has been some interest in Congress in a Constitutional amendment to make health and health care a matter of rights enforceable on the basis of the US Constitution, these efforts have had little practical impact. The Congressional Research Service recently commissioned an analysis of Supreme Court decisions related to health care in an effort to outline the relationship between health care and the Constitution (Swendiman, 2012). The first sentence of the study invokes many of the principles of a rights-based approach to health care. It states: “The health care reform debate raises many complex issues including those of coverage, accessibility, cost, accountability, and

quality of health care. Underlying these policy considerations are issues regarding the status of health or health care as a moral, legal, or constitutional right” (2012, p. 1). At stake is the issue of whether or not the court would find an “implicit fundamental right to health care for poor persons under the Constitution” (p. 2). The authors of the report pose the following questions: “If each individual has a right to health care, how much care does a person have a right to and from whom? Would equality of access be a component of such a right? Do federal or state governments have a duty to provide health care services to the large numbers of medically uninsured persons? What kind of health care system would fulfill a duty to provide health care? How should this duty be enforced?” (2012, p. 2).

That these questions have been posed for a Congressional audience suggests that social mobilization for a rights-based approach to health care has gained influence in the United States.⁷ However, the framing of any duty or obligation to health care is narrow, at least to date. The Congressional report argues that though the United States Constitution “does not explicitly set forth a right to health care, the Supreme Court’s decisions in the areas of right to privacy and bodily integrity suggest the Constitution implicitly provides an individual the right to access health care services at *one’s own expense* from willing medical providers” (emphasis ours, Swendiman, 2012, p. 2). It also asserts, however, that if the Supreme Court in the future were to find an “implicit right to health care for persons unable to pay for such care, it might do so either by finding that the Constitution implicitly guarantees such a right, or that a law which treats persons differently based on financial need creates a ‘suspect classification’” (p. 2). The report underscores that either of these pathways to legal recognition of a fundamental right to health care for those who cannot afford such services is possible, but does not speculate on whether or not the current Supreme Court would make such a finding.

Despite the lack of constitutional protections and Supreme Court interpretations that recognize a right to health care, the United States has enacted policies in the past 50 years that are consonant with some of the values of the right to the highest attainable standard of health. These include statutes such as Title VI of the Civil Rights Act of 1964 (42 U.S.C. section 2000d) and the creation of social policies providing more accessibility to health care goods and services. In 1965, Congress created Medicare (a program addressing older adult health care) and Medicaid (to provide basic health services to people with very low incomes). The Civil Rights Act of 1964 meant that hospitals receiving federal Medicare funds must integrate and demonstrate that they were not discriminating against patients (Bonastia, 2006). Other laws also sought to expand access to health care, including the Mental Health Parity Act of 1996 and the State Children’s Health Insurance Program (SCHIP) of 1997. While

⁷ MacNaughton and McGill (2012) point to a trend in the United States to implement economic and social rights without ratification of international treaties. We argue that rights-based concepts and benchmarks, such as accessibility and affordability, as well as quality health care, have made their way into *the practice* of health care policy-making. While the duties to fulfill or realize these dimensions for all remain unmet, key norms have begun to shift where such claims are made in varied settings (in Congress, at the state level, and in local organizing).

these were important legislative steps, they often devolved responsibility for implementation of programs to the state level and failed to meet human rights standards which entailed universal coverage and access to quality health care. Further, despite the much-touted reforms of the 2010 Patient Protection and Affordable Care Act (ACA), designed to provide greater access to health insurance and health care benefits, the law fails to meet human rights-based standards (Carmalt et al., 2011; Tyler, 2013; Schimmel, 2013).

The United States is the only wealthy, industrialized country in the world that does not provide a plan for universal health care coverage and does not recognize a legal right to care, except in emergency situations (Yamin, 2005). Even passage of the ACA will not provide universal health coverage to all people in the United States. The law's provisions favor "expansion of the market-based health insurance system over universal coverage, failing to fully address the existing problems with access to health care for the underserved" (Tyler, 2013, p. 84). The Supreme Court's decision in *National Federation of Independent Business v. Sebelius* (2012) permits states to determine Medicaid eligibility standards and whether or not to participate in Medicaid expansion. The "flexibility" given to states as a result of this ruling has resulted in the exclusion of an estimated 6 million of potential beneficiaries in states that did not elect for Medicaid expansion (Kaiser Commission on the Medicaid and the Uninsured, 2013).

The Central Role of Community Practice in Securing the Right to Health Care

Realizing the human right to health care presents challenges in any national context, but in the United States this dilemma is amplified by longstanding practices of administering health policy at the state level. The federal system presents barriers to achieving universal access to affordable, quality health care services on a basis of equality and non-discrimination. While a large percentage of US citizens realize a high standard of access to health services, the US health care system is inherently unequal and millions of people have limited access to even the most basic health care services (Carmalt et al., 2011; Hoffman, 2012). Even experts who have lauded the 2010 health care reform recognize that its effects could be limited and not achieve universal goals that are required from a right to health approach (Gable, 2011).

The Affordable Care Act does establish a "legal infrastructure that seeks to achieve universal health insurance coverage" and "targets some of the major impediments to accessing needed health care for millions of Americans" (Gable, 2011, p. 340). These include not only health insurance exchanges and efforts to control costs of health care services, but also an expansion of public health infrastructure, clinical and community preventative services, and efforts to educate the public in preventative health measures, particularly linked to diet, obesity, and prevention of chronic disease. Addressing each of these domains of the ACA from a rights-based approach to health requires *participation* of individuals. Arguably the

“affected population” in this context is a large proportion of society which has limited access to health care services for either prevention or treatment. Community practitioners thus have a substantial role to play in helping communities to assess changes being wrought under the law, the effects of this policy on individuals, families and communities, and in developing local and national responses to limitations in the implementation of the ACA in the future.

Beyond the ACA: State-Level Advocacy for the Human Right to Health Care

Community or “macro” practice is one of the oldest methods of social work in the United States. This includes different forms of practice in communities (community organizing, community development, and community building), as well as policy advocacy and policy practice, planning, and activities performed within organizations. Despite a variety of possible practice roles and modes of engagement, community practice is generally viewed as focused on efforts to address social problems and promote social change. Until recently, linking community practice to human rights in the United States was rare (e.g., Androff, 2012; Jewell, Collins, Gargotto, & Dishon, 2009; Pyles, 2006). Drawing upon the model for social and political action developed by Gamble and Weil (2010), we highlight cases of rights-based mobilization for health and health services in the United States and illustrate the potential of infusing core principles of the right to health care within community practice. These examples suggest both the opportunities and challenges of “grass-roots” campaigning for the right to health services in the United States.

An important mode of community practice is grounded in political and social action; the aim of this form of community organizing is to mobilize various constituencies for broad social and political aims (Gamble & Weil, 2010). Such engagement is evident in the work of the Vermont Workers’ Center (VWC) in its efforts to create the first state law “for a universal, publicly financed health care system” (Rudiger, 2011).⁸ The VWC initiated its “Healthcare Is a Human Right” campaign in 2008. By 2011, in collaboration with other community groups, they secured the adoption of Act 128 and Act 48, which incorporated human rights principles into Vermont law and provided a framework for creating a state-funded health care program that assures all Vermont residents access to quality health care (McGill, 2012).

The VWC’s campaign used an explicit human rights frame, drawing upon the principles of universality, equity, transparency, accountability, and participation. According to McGill, the campaign emphasized that:

⁸ The group started out in 1996 as the Central Vermonters for a Livable Wage and officially became the Vermont Workers’ Center in 1998. They first established a Workers’ Rights Hotline and devoted much of the first decade of work to workers’ rights. By 2008, the VWC shifted to health care as a primary campaign out of recognition that health care access was a key concern for many members of the Center (<http://www.workerscenter.org/about-vermont-workers-center/history>).

health care should be available to all Vermonters regardless of their ability to pay; that the cost of the health care system should be shared fairly; that Vermonters should participate in the design and implementation of the health care system; that the system should be transparent, efficient, and accountable to the people it serves; and that the government should be responsible for ensuring that the health care system complies with these principles (2012, p. 108).

Organizers for the Health is Human Right Campaign held public meetings throughout the state between 2008 and 2010, raising awareness about the failures of the Vermont health care system and principles of a human rights-based approach to health care. Supporters believed that mobilizing local residents was crucial to any substantive health policy reform. They focused on engaging a broad group of supporters, due a failed attempt to pass single-payer health care in 2005, when Republican Governor James Douglas vetoed the legislation. As one organizer noted, “We figured the reason why we don’t have a health care system that works and treats it as a basic right is not because it doesn’t make the most sense or politicians don’t understand how to make it work It’s because there’s not the right political pressure making them do it. So our strategy was just to show them that this is what we wanted over and over again” (as cited in McGill, 2012, p. 109).

The campaign’s success was based upon its ability to engage Vermont residents in a variety of locales using multiple strategies. It relied upon volunteers to staff information tables at grocery stores, farmers’ markets, participate in local parades and write letters to the editor in local newspapers. The VWC created relationships with unions, religious communities, businesses, and health care reform groups and received endorsements from influential organizations such as Vermont Health Care for All and the Vermont Nurses’ Union. They crafted a “People’s Toolkit” to use in public education and outreach. McGill (2012) notes that one of the most influential tactics was hosting state-wide human rights hearings and, later in the campaign, public forums. In public hearings and “People’s Forums,” community members provided testimony to local leaders, including legislators, about challenges they faced in accessing affordable and quality health care. The campaign also compiled some 1,500 surveys in which respondents provided personal stories about their challenges in accessing health care. Such stories, when shared in a 2008 report to elected officials, “humanized the health care crisis and helped ... explain the connection between human rights principles and the suffering of individual residents” (2012, p. 110). Once legislation was introduced in 2010, a “People’s Team” of volunteers were active at the state legislature, attending all hearings related to health care legislation. Through these efforts, they were able to show broad-based support for the campaign, even as they fostered capacity among local residents to participate in political advocacy. In one innovation, organizers developed a series of questions to analyze three health care bills that had been introduced on the basis of how well each proposal met human rights standards (see [Class Exercises and Additional Resources](#)).

In 2010, the proposed legislation (H.100/S.88) was passed by both the Vermont House and Senate and became law. Notably, Act 128 (2010) does not say explicitly that there is a human right to health care. However, the law uses all the major human rights principles outlined in the UN Committee on Economic and Social

Right's General Comment No. 14 (2000). This is immediately apparent when examining the language of the legislation: It is "the policy of the state of Vermont to ensure *universal access* to and coverage for essential health services for all Vermonters. All Vermonters must have access to comprehensive, quality health care. Systemic barriers must not prevent people from accessing necessary health care" (section [Defining the Right to Health and Health Care: International Standards and Practices](#)). Moreover, "The health care system must be *transparent* in design, efficient in operation, and *accountable* to the people it serves. The state must ensure public *participation* in the design, implementation, evaluation, and *accountability* mechanisms in the health care system" (section [Core Principles of the Right to Health and Health Care](#)).

The passage of Act 128 was just the first step in the campaign to realize universal health care in Vermont. A second Bill, H.202, was introduced and passed in 2011 as Act 48. It "creates a framework for implementing a comprehensive, publicly financed universal health care system" called Green Mountain Care (McGill, 2012, p. 112). At the time of writing, Vermont is seeking to be exempted from federal requirements that would challenge the state's abilities to implement a publicly financed universal health care system. The case remains exemplary in terms of its achievements and potential, but the law has yet to be implemented. Notably, the Vermont model of organizing for health care reform at the state level has been so successful that other states such as Maryland and Maine have initiated similar campaigns. The fact that these efforts are expanding, even in the wake of the enactment of the federal law on health care reform, illustrates that access to health care remains a fundamental public concern.

Grassroots Mobilization—Fostering Meaningful Participation

Fostering community participation has been a central aim of community practice since its inception in the United States. As Gamble and Weil (2010) note, community may be defined by geographic locale or by those who share a common interest or goals but live and work in varied locations. They note that the principle that undergirds community organizing "derives from the democratic value that emphasizes how important it is that people be involved in decisions affecting their lives" (2010, p. 11). While human rights campaigning for justice both globally and in the United States has frequently relied upon "grassroots mobilization," fostering participation of groups whose economic and social rights have not been fulfilled is still in its early stages. Often the focus on human rights mobilization has been on civil and political rights violations (Becker, 2013). Efforts to articulate and demonstrate community involvement in campaigning for economic and social rights, as well as implementing and monitoring progress on achieving such rights, merit greater attention.

The model advanced by the National Economic and Social Rights Initiative (NESRI) in New York City is promising for rights-based community practice in the

United States. NESRI partners with grassroots and local organizations such as the Vermont Workers' Center to help define community interests, develop campaign goals, collaborate in drafting legislation, and provide training on human rights law and practices. Though NESRI is little more than 10 years old, it has already partnered with numerous organizations on a variety of economic and social rights campaigns and is a key facilitator in the Vermont, Maryland, and Maine efforts to implement rights-based approaches to health care. Lawyers and health care practitioners increasingly acknowledge the importance of community mobilization as well. Tyler (2013), a lawyer and clinical professor in health sciences, argued that “case-by-case advocacy” will not realize a health and human rights agenda. “The ultimate goal is systems accountability and change. This will only come with lawyers and health care providers partnering with and empowering communities to enforce and articulate their rights as human rights” (p. 88). The role of the community-based social work practitioner is central to this process.

Among the lessons learned from these local efforts to introduce a human rights framework for health and health care is that broad participation is vital to the success of shifting public discourse. This empowerment approach to participation seeks to mobilize community members for involvement in decision making, planning, implementation, and monitoring and evaluating health programming. Health practitioners have underscored that the participation process itself is important. But the more fundamental aims are to redistribute “resources and power in the political process” and increase the “ability of marginalized communities to control key processes that influence their lives” (De Vos, De Ceukelaire, Malaise, Pérez, Lefèvre, & Van der Stuyft, 2009, p. 25). It is too early to assess whether or not the Vermont campaign to realize universal health care defined in terms of human rights will result in such redistribution of resources and more equitable health outcomes. But the tools for such evaluation already have been defined by groups like the Vermont Workers' Center. Community social work practitioners should play important roles in assessing progress under the new legislation as a model to be considered in other parts of the United States.

Class Exercises and Additional Resources

For Discussion: The Core Minimum Obligations to the Right to Health in the US Context

According to the UN Committee on Economic, Social, and Cultural Rights, the core minimum obligations to the right to health include:

- (a) “[A]ccess to health facilities, goods and services *on a non-discriminatory basis*, especially for vulnerable or marginalized groups”;
- (b) “Access to the *minimal essential food* which is nutritiously adequate and safe”;

- (c) “Access to *shelter, housing and sanitation* and an adequate supply of safe drinking water”;
- (d) “The provision of *essential drugs*”; and
- (e) “*Equitable distribution* of all health facilities, goods and services”

(WHO, 2008, pp. 24–25).

Questions for Discussion

- Which of the core minimum obligations to the right to health exist in your community?
- Which of these core minimum obligations to the right to health would you prioritize in your community and why?
- What are the benefits and/or limitations of using a rights-based approach to health and health care in advocacy efforts?

For Discussion: Illustrating the Interdependence of Human Rights Through the Child’s Right to Health and Health Care

Read the excerpt from a recent general comment of the Committee on the Rights of the Child (2013) concerning the child’s right to the highest attainable standard of health. In small groups discuss the questions below.

28. Article 24, paragraph 1, imposes a strong duty of action by States parties to ensure that health and other relevant services are available and accessible to all children, with special attention to under-served areas and populations. It requires a comprehensive primary health-care system, an adequate legal framework and sustained attention to the underlying determinants of children’s health.

29. Barriers to children’s access to health services, including financial, institutional and cultural barriers, should be identified and eliminated. Universal free birth registration is a prerequisite and social protection interventions, including social security such as child grants or subsidies, cash transfers and paid parental leave, should be implemented and seen as complementary investments.

Questions for Discussion

- Have the barriers to children’s access to health services (identified above) been eliminated in your community?
- How would you frame the issue of children’s access to health care to generate public support to realize children’s right to health and health care?
- What groups in your community and professional organizations (state, local) should be involved in efforts to address this human rights concern?

For Discussion: Does the United States Need a Constitutional Amendment on the Right to Health?

Over the past decade a number of Congressional representatives have introduced a proposed amendment to the US Constitution that would provide an entitlement to health care. Read the text of the proposed amendment introduced by Rep. Jesse Jackson, Jr. to the 108th Congress. Then discuss the questions that follow.

HJ 30 IH

108th CONGRESS

1st Session

H. J. RES. 30

Proposing an amendment to the Constitution of the United States regarding the right of citizens of the United States to health care of equal high quality.

IN THE HOUSE OF REPRESENTATIVES

March 4, 2003

Mr. JACKSON of Illinois introduced the following joint resolution; which was referred to the Committee on the Judiciary

JOINT RESOLUTION

Proposing an amendment to the Constitution of the United States regarding the right of citizens of the United States to health care of equal high quality.

Resolved by the Senate and House of Representatives of the United States of America in Congress assembled (two-thirds of each House concurring therein), That the following article is proposed as an amendment to the Constitution of the United States, which shall be valid to all intents and purposes as part of the Constitution when ratified by the legislatures of three-fourths of the several States:

‘Article--

‘SECTION 1. All citizens of the United States shall enjoy the right to health care of equal high quality.

‘SECTION 2. The Congress shall have power to implement this article by appropriate legislation.’

Questions for Discussion

- How would a federal Constitutional Amendment help advance a right to health care?
- What actions could lead to the adoption of such an amendment?
- What short-term and mid-term goals would be necessary to develop a campaign to amend the Constitution for a right to health care?
- What other approaches to ensure the human right to health care would likely generate public support?

Human Rights-Based Guidelines for Analyzing Vermont's Legislation

The following questions were used to analyze the state of Vermont's proposed legislation on health care in the late 2000s. They were directly tied to human rights principles for health care. Consider how these questions could be used in advocacy for health care in your community.

- Does the system provide health care for all?
- Does the system provide equal access to comprehensive health care services?
- Does the system treat health care as a public good?
- Does the system eliminate barriers to use needed health care services?
- Is the system financed equitably?
- Do people pay for their health care on their ability to pay without regard to unrelated factors such as age, gender, employment, or health status?
- Does the system use money effectively and efficiently?
- Does the system allocate resources equitably, according to health needs?
- Does the system improve the quality of health care by rewarding providers who utilize best practices and provide excellent outcomes?
- Does the system enable meaningful community participation?
- Is the system accountable to the people it serves?

Sources Adapted from McGill (2012, p. 111); see also more detailed guidelines with links to specific aspects of the right to health care on the Vermont Workers' Center website at: http://www.workerscenter.org/sites/default/files/hchr_hsjiao_assessment.pdf.

Organizations in the United States Using a Health and Human Rights Perspective

Listed Below are Organizations that Advocate for Access to Health Care from a Human Rights Framework

- Healthcare is a Human Right: Accessible healing for all: <http://healthcareisa-humanright.com/>
- Healthcare NOW! Organizing for a National Single-Payer Healthcare System: <http://www.healthcare-now.org/>
- Montana Human Rights Network: <http://www.mhrn.org>
- National Economic and Social Rights Initiative: <http://www.nesri.org/>
- National Health Law Program: <http://www.healthlaw.org/>
- South L.A. Coalition for Health and Human Rights: <http://www.southlahealthand-humanrights.org/about.html>
- Vermont Workers Center-Healthcare is a Human Right Campaign: <http://www.workerscenter.org/healthcare>



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