

EDITORIAL

Deepening the Relationship between Human Rights and the Social Determinants of Health: A Focus on Indivisibility and Power

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The social determinants of health and human rights describe where and how we live and thrive. They express our actual and optimal conditions of housing and nutrition; our social, cultural, and spiritual connections; our access to education, health, and social services; and our ability to be fully involved in our societies through expression, mobility, association, work, and engagement with the formal political process. Ultimately, they are different yet overlapping measures and languages of human well-being and self-actualization. The connection between these deeply related but, until recently, rarely linked conceptual frameworks was made explicit in the 2008 report of the WHO Commission on the Social Determinants of Health (CSDH). This seminal report comprehensively outlined the imperative to scale up the global focus on the social determinants as a matter of social justice, the absence of which was “killing people on a grand scale.”¹

The CSDH report prompted a special issue in *Health and Human Rights* in 2010 exploring the relationship between human rights and the social determinants of health.² Since then, there have been several critical global policy initiatives, including the Rio Declaration on the Social Determinants of Health (2011) and the Sustainable Development Goals (SDGs) (2015), which affirmed the links made by the CSDH locating the social determinants of health in relation to human rights and the right to health.³ These complimentary frames are at last connected in rhetoric and policy, but what does this linkage mean in practice, and what progress has been made since 2009?⁴

As three human rights and right to health scholars, we are deeply engaged with the theoretical and practical implications of these concepts and their linkages. Yet none of us exists outside concepts or theory when it comes to human rights and the social determinants of health. This was made clear when one of us experienced a health crisis in the lead up to this special issue. A long night in the emergency room highlights how power is mediated through variables like place, race, age, class, gender, ethnicity, and disability to determine health care, and indeed health: watching nurses brush off valid questions from an older male patient of color; hearing a white male patient interrupt his female doctor repeatedly. While

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such actions are small and subtle, they suggest the broader dynamics that underlie inequitable disparities in health care treatment and health outcomes not only in low- and middle-income countries, but in high-income countries like Canada, the United States, and Australia.

Newspaper reports from 2018 exemplify these trends and their complexities: in April, *The New York Times* reported a CDC finding that black women in the United States are three to four times more likely than white women to die from pregnancy-related health issues.⁵ In October, *The Sydney Morning Herald* reported on systematic and widespread bullying and harassment of public health workers in the Australian state of New South Wales, and the ensuing impact this has on quality of patient care and health worker mental health and well-being.⁶ And in November, the Canadian Broadcast Corporation reported on a class-action lawsuit brought by almost 60 Indigenous women alleging a prolonged period of forced sterilizations over a 25-year period, including as recently as 2017.⁷ No person, no community, and no country is exempt from the interaction of the social, economic, and political factors that determine health and health care.

This is the context from which this special section proceeds in its effort to deepen exploration of the relationship in theory and practice between human rights and the social determinants of health. It is inspired by and builds on a diverse series of conversations that took place at an international conference held in May 2017 at the University of Toronto. The conference, sponsored by the Lupina Foundation, the Dalla Lana School of Public Health, and the Canada Research Chair Program, began with a special keynote address on health and human rights by Amartya Sen.⁸

Unsurprisingly, the conference discussions were deeply influenced by Professor Sen's capabilities approach that considers the societal conditions in which individuals can become active agents of change rather than "passive recipients of dispensed benefit."⁹ Conference discussions identified two key areas particularly in need of deeper scholarly and practitioner engagement: (1) expansions of

the theoretical and evidence-based links between human rights and the social determinants of health, encapsulated in the human rights framing of "indivisibility," and (2) analyses that deepen our understanding of the constitutive role of power in the broader determination of health. We used these key areas to anchor this special issue. In our call for papers for this issue, we drew on these conference discussions to offer guiding questions elaborating on both themes. With regard to the indivisibility of human rights and the social determinants of health, we asked researchers to consider how to move beyond calling for access to health and related services only, towards health and health related policy capable of realizing the fuller vision of dignity and equal worth that underpins human rights. In this respect, health could be understood in line with its definition in international law not simply as the absence of disease, but as physical, mental, emotional, social, and cultural well-being. We asked whether this comprehensive vision of human rights could provide an alternative conceptualization of the social determinants of health, that moved beyond exclusively outcomes-based top-down measures towards process-oriented, agency-based empowerment that broaden the scope of health interventions. We asked whether and how social science research on the social determinants of health in areas such as intersectionality, anthropology, sociology, communications, and political science could help build the concept of the indivisibility of human rights into a richer operational concept in relation to the social determinants of health. Finally, we asked how we could build an evidence base to buttress the interdependence of human rights and the social determinants of health and show how systematic attention to rights could promote population health? And which disciplines and institutions should decide what constitutes such evidence?

With regard to our second key theme, we asked contributors to consider how the human rights community could better focus on structural drivers of health, including neoliberal policies that impact realization of the right to health and systematically enacted power differentials around

race, gender, sexuality, disability, and ethnicity.

How could human rights practitioners and health workers be more attentive to the way power consciously and unconsciously shapes both the definition and realization of human rights and the social determinants of health? And how does power influence the full vision of human rights as incorporating social, economic, civil, and cultural domains?

We are gratified to present six papers that responded to various aspects of this ambitious call. In our analysis, these papers highlighted four key themes in relation to the indivisibility of human rights and the social determinants of health, and the constitutive role of power therein.

(1) Participation as a determinant of health: Recognizing knowledge in communities. Linking practitioner experience and scholarly reflection, Mulumba et al., Trout et al., and Aczel and Makuch present case study analyses that highlight the importance of community involvement in the development and implementation of effective health systems and health protections. The right to participation is codified in Article 21 of the Universal Declaration of Human Rights and Article 25 of the International Covenant on Civil and Political Rights, which guarantee a right to participate in governance, public affairs, and access to services. Building on Human Rights Committee General Comment No. 25 and the Rio Political Declaration on Social Determinants of Health, Mulumba, London, Nantaba, and Ngwena argue that participation is not only an independent right but also an underlying positive determinant of the right to health. Recognizing the critical importance of participation, both South Africa and Uganda have developed specific structures to integrate community participation and represent their interests within the health care system. Drawing on a three-year study aiming to “develop and test models of good practice for Health Committees in South Africa and Uganda,” Mulumba et al. examine the fora, structures, and timing of participation in this practice-oriented piece. They interrogate how to leverage community participation in a meaningful

rather than perfunctory manner. They ask: if participation is essential, how do we do it right? One of their key findings is that the level of participation is critical. They note that community participation is too often limited to “the lowest rung of the health system,” a strategy which is “manifestly disabling to community agency” because few possibilities exist at this level to address health system determinants. Conversely, forms of community participation that include “a voice that is able to articulate all the way up the system” can strengthen community engagement, provide meaningful substantive input, and allow it to be communicated at levels where it can have an impact.

Trout, Kramer, and Fisher examine a series of paradoxes in “Social Medicine in Practice: Realizing the American Indian and Alaska Native Right to Health.” While Indigenous peoples in the United States were some of the first people to “hold an unambiguous state-conferred right to health,” this recognition has not demonstrably improved the health of American Indian and Alaska Natives (AIAN). They identify two key obstacles. First, there has been “socialization for scarcity in tribal health” wherein deprivation of resources has become normalized and consequently not served as a catalyst for action. They ask if it is “possible to disrupt” community expectations of inferior infrastructure, care, and health outcomes. Is it possible to disrupt the American public’s expectation of these disparities as “inevitable, immovable, and allowed”? Second, they highlight the lengthy delay by both health care workers and academics in linking social determinants of health and human rights. Trout et al. argue that existing literature articulating these links “tends towards historicized notions of social determinants” that rightly acknowledges the impact of colonialism as “social forces shaping the inequitable burden of disease in Indigenous communities” but neglects contemporary, concrete, and immediate conditions. Despite the lack of resources and a high burden of disease, Trout et al. recognize Alaskan Indigenous communities not as places of deficit, but of knowledge and opportunity. They recognize that while AIAN communities may benefit from support from global networks, “AIAN

health organizations, tribes, and community activists have much to offer the global movement toward health as a human right.” They offer a detailed case study as one such example.

Trout et al. examine the Maniilaq Social Medicine center and their attempts to align the care they offer with a rights-based approach to health acknowledging social determinants. Using an integrated approach—connecting governance, social services, primary care, local knowledge, academic research, and policy advocacy around social determinants and human rights—Maniilaq Social Medicine aims not only to treat illness and injury but “ultimately to play a role in redressing structures of inequality that both produce and are propagated by poor health.” In doing so, this project understands health as a broader social, cultural, and economic mandate of strength, health and resilience. This detailed case study concludes with concrete recommendations and “scalable strategies” for other AIAN communities.

Aczel and Makuch’s paper considers the human rights dimensions of hydraulic fracturing (“fracking”) —a method of natural gas extraction—arguing for a “human rights-based, participatory approach to regulation.” This topical paper examines the intersection of politics, power, and participatory governance through the vehicle of an international People’s Tribunal vis-à-vis the environmental determinants of health. Reflecting on findings from the May 2018 Permanent People’s Tribunal on Human Rights, Fracking, and Climate Change, they examine how such a mechanism can support advocacy against the commencement of fracking activities in the north of England. They highlight international participatory governance mechanisms as key tools advocates can leverage to challenge a government’s decision to begin fracking—particularly in the absence of compelling domestic laws and regulatory environments. Aczel and Makuch argue that the tribunal demonstrates “*why* human rights mechanisms are key in regulation of a new technology” and “*how* international human rights law and providing an open forum to present testimony can be an important tool to protect citizens’ basic human rights.” Although the

paper is more nuanced in its thematic connection to the social determinants of health, it no less contributes to an important conversation around the role people’s tribunals play in terms of implicitly promoting the right to health alongside social and environmental determinants in national and global landscapes.

Mulumba et al., Trout et al., and Aczel and Makuch each emphasize the importance of substantive and meaningful participation. Mulumba et al. and Trout et al. both highlight the expertise that lies in populations typically depicted as “service recipients” rather than policy contributors. Their papers speak to Sen’s capability approach as they examine how people can engage with health care systems as active agents of change rather than “passive recipients of dispensed benefits.” Aczel and Makuch identify participation as a critical advocacy tool through which to actively combat “dispensed harm.” All three papers identify agency at a collective rather than individual level. Mulumba et al. and Trout et al. recognize local communities as assets and sites of expertise, while Aczel and Makuch identify local communities as agents of accountability. In different ways, Mulumba et al. and Trout et al. make the critical point that recipients can and should be participants, and that participation is not a nicety but an efficient and effective strategy to improve health care systems and services. In doing so, they challenge structures of power as well as prevalent assumptions of who is an expert, recognizing that community members are valuable resources and, unsurprisingly, experts on their own lives. Mulumba et al. and Aczel and Makuch highlight mechanisms and structures of participation. Mulumba et al. argue that structures of participation must be carefully considered for maximum impact, while Aczel and Makuch examine ways in which participatory mechanisms can provide alternatives to weak legal and regulatory structures.

(2) **Power, neoliberalism, and economics as structural determinants of health.** How do we negotiate the relationship between state-guaranteed human rights, underlying social determinants of health, and the economic systems in which we

work and through which we finance these systems? MacNaughton and Frey, and O'Hare address this question at different levels, examining the relationship between work and health, and the role of taxation in supporting health rights.

MacNaughton and Frey compare three frameworks addressing decent work: the CSDH, the Decent Work Agenda of the International Labour Organization, and the right to decent work in international human rights law. They argue that while the CSDH acknowledges fair employment and decent work as "components of daily living conditions that have powerful effects on health and health equity," it missed important opportunities to link to and strengthen existing frameworks and, in doing so, affirm decent work as a human right. This gap is one, they argue, that has been perpetuated at several junctures. The Millennium Development Goals "failed to include a goal or target on full employment and decent work for all until 2007" and the subsequent SDGs feature work only in Goal 8, a goal aimed at "economic growth, full and productive employment and decent work for all." MacNaughton and Frey argue that the SDG contextualization of work is problematic. In Goal 8, it is articulated not as a social determinant that could alleviate poverty (SDG 1) or hunger (SDG3), or provide a path to a healthy life (SDG3), but as a "means to or ends of economic growth unlinked to human rights of well-being." They note, "the resulting paradigm [...] is that full employment and decent work are not recognized as human rights or social determinants of health but merely components of the neoliberal economy." MacNaughton and Frey argue that the CSDH "could have helped to ensure that full employment and decent work were recognized as human rights or health equity goals in the SDG framework." MacNaughton and Frey are concerned with how to build a strong and protective structure for decent work as a human right. Their piece is a conceptual analysis of how to place floors and walls upon foundations, which building blocks to place where, and which walls can bear weight. In this complex project, they note gaps in construction and the failure to capitalize on past investments, often resulting from an inability to

learn across different fields of study and practice. MacNaughton and Frey posit that interdisciplinary and cross-institutional collaboration "may be the key to achieving the rights to decent work and health for all."

While social determinants of health are increasingly recognized as necessarily interdisciplinary, there continue to be dangerous blind spots. O'Hare shines light on one such gap examining the role of tax abuses on the right to health. She argues that while such abuses have a negative impact on core human rights obligations, including those under the right to health, outside of the ground-breaking work of scholars like Attiya Warris, "human rights scholars have largely ignored the need for revenue and tax scholars have not analyzed laws and policies through the lens of human rights." She observes that while human rights are extensively codified, less attention is paid to the practical financial mechanics of their fulfillment. O'Hare explains that the "pathways between government revenue, government expenditure, public services, and fundamental rights is known," as she traces the link from a 10% increase in tax revenue through increases in public health spending to decreases in under five mortality. Although there are sufficient global resources to meet shortfalls in low-income countries, O'Hare argues that meeting this gap domestically is preferable, as this is where the human rights obligation lies, the funding is more stable, there is an opportunity for greater citizen engagement, and priorities can be set locally. She examines the lower tax contribution in low-income countries, with a focus on domestic and international "tax avoidance," including waivers granted to international corporations.

Exploring the worlds of work and taxation, MacNaughton and Frey, and O'Hare bring new language into these fields while stretching the concept of social determinants of health to engage with new disciplines and sectors. Both pieces highlight the need for real, boundless interdisciplinarity in addressing these complex questions, including systematically interdisciplinary policy development processes to ensure that knowledge across fields is incorporated and reflected in new policies and laws.

These two pieces also illuminate the underexplored intersection of neoliberal economics, human rights, and social determinants.

(3) Law as a determinant of health: Learning from practice, improving research. The final paper, by Footer et al., aims to improve both research and practice through a systematic review of a particular mode of engagement. Legal empowerment holds real promise in improving the well-being of vulnerable people with respect to both social determinants of health and human rights. Footer et al. note that this approach, consisting of “the use of laws, legal systems/institutions and services for socio-structural change,” has “gained prominence as a framework for strengthening individuals capacity to exercise their rights, with implications for their health and well-being.” They argue however, that while significant literature explores how law can inhibit the right to health, particularly for vulnerable peoples, less research empirically examines the ways in which engagement with law can facilitate improved health. With a view to identifying patterns, gaps, and the evidence base supporting legal empowerment, Footer et al. undertake a meta-narrative literature review and synthesis. In doing so, they ask: How has legal empowerment been practiced in relation to health? How has it been studied? What is its impact? They find that there is a lack of “robust conceptualization,” measurement, and analysis of the contexts in which legal empowerment initiatives function alongside insufficient study of interventions themselves, particularly those operating at the grassroots level. They identify a need for more thorough assessment of legal empowerment interventions drawing on a variety of methodological tools and approaches, noting, for example, that none of the examined studies follow a single cohort through time. The task of assessing the impact of legal empowerment either at the community, structural, or individual level is a complex and difficult one. Acknowledging these challenges and aiming to provide a structure to assist future research, they propose a framework that aims to clarify the different forms legal empowerment can

take, the level of intervention, and suggest variables that can be measured.

(4) Reflections on context and categorization. The six papers in this special section draw on the experience of practitioners and the insights of scholars in the Global North and Global South, stretching the concept of social determinants to include new sectors and actors. While diverse in their focus and approach, the importance of context emerges in each. When we discuss and address social determinants and human rights in relation to health, what ideational and practical categories are we placing them in? Trout et al. note that an obstacle to improved health in AIAN communities is the context of expectations. Communities, providers, and the public anticipate substandard health care, health infrastructure, and health outcomes. Insufficient expectations can be self-perpetuating and can normalize the inequitable and unacceptable. Mulumba et al. argue that the context of participation—when, why, and at what level—is critical. The way participation is incorporated into policy development and consultative processes reflects beliefs about the value and utility of community participation and its expected impact on health systems and outcomes. Aczel and Makuch re-contextualize fracking by examining it through a human rights lens. In doing so, they also question the limits of the categories of human rights and health, blurring the lines between humans and their natural environment. MacNaughton and Frey critique the contextual placement of decent work in the SDGs, underlining the ways in which framing a right as an economic good undermines its content and positions it as a component in an economic equation rather than of a fulfilling life. O’Hare pushes for tax evasion to be considered a human rights abuse in addition to a financial crime, connecting the dots between lost revenue and investments in health. Footer et al. note that understanding of context is currently lacking from analysis on legal empowerment. Context and categorization are ways of structuring and understanding, guiding us in how to think about and act on particular topics. They are also, however,

actions of power that indicate priorities, urgency, and importance, that place ideas within institutions, ministries, and disciplines, and that shape who is (and who is not) expected to act.

Way forward

The papers in this special section illustrate ways in which the intersection of the social determinants of health and human rights can assist us to better understand and respond to the breadth of deeply embedded power differentials and structural disparities that persist in impacting health, even in settings of relative wealth. These papers outline some of the ways that these conceptual tools, when operationalized through their legal, policy, and advocacy dimensions, could enable effective action to realize a meaningful holistic right to health in many settings. However, we note that *de facto* realization of the transformative power of the social determinants and human rights nexus will depend on four key factors.

First, complex health issues and their political, economic, socio-cultural, environmental, and transboundary intricacies cannot continue to be addressed in silos. Multi-stakeholder partnerships that advance game-changing interdisciplinary, cross-sectoral right to health research and advocacy approaches will need to be leveraged, and a Health in All Policies approach persistently pushed.¹⁰ Interdisciplinary teams and approaches must become standard practice, and education and training must be developed with this in mind.

Second, the social determinants and human rights nexus will need to be purposively advanced through formal integration of participatory governance mechanisms into policy and planning for health at national and subnational levels. The diversity of community and local actors, civil society, and the private sector that are causally impacted by health-related resources and investment should be an official part of interconnected decision-making and policy implementation, monitoring, and review processes. This is consistent with the international disability rights' mantra, "nothing about us without

us." Certainly, the necessity to critically interrogate presumptions of expertise on both global and local scales was recognized by UN Member States in both the formulation and finalization of SDG content.¹¹ This is made clear in SDG 16 ("Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels") and its target 6 ("Develop effective, accountable and transparent institutions at all levels") and target 7 ("Ensure responsive, inclusive, participatory and representative decision-making at all levels").¹²

Indeed, when it comes to participatory governance and the social determinants, Article 4 of the landmark Alma-Ata Declaration (1978) is unequivocal: "people have a right and duty to participate individually and collectively in the planning and implementation of their health care."¹³ The Ottawa Charter for Health Promotion (1986) and the Bangkok Charter for Health Promotion in a Globalized World (2005) also emphasize that communities and civil society organizations must play a central role in health promotion for achieving better health for all and for community empowerment.¹⁴ The UN Committee on Economic, Social and Cultural Rights is similarly unequivocal in its 2000 General Comment No. 14, The Right to the Highest Attainable Standard of Health:

[T]he right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under [the right to health]... Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people's participation is secured by States.¹⁵

The third factor that will bring to life the overlap between the social determinants of health and human rights is overt commitment on the part of countries to the realization of intergenerational health equity. Populist, polarizing politics and bigoted policy-making, often cobbled together

on the fly and without a sound scientific evidence base, is surely undermining the health of future generations across all five global regions. There is an urgent need for many countries to acknowledge and redress intergenerational trauma and its destructive health and well-being consequences among disenfranchised populations. This includes intergenerational trauma exacerbated by environmental abuse, degradation, and climate change, which can perniciously and disproportionately impact Indigenous communities.¹⁶

Countries should therefore formally commit to intergenerational health and well-being through regulatory measures that cut across short-term electoral cycles and partisan political divides. Such actions both complement and strengthen countries' SDG commitments, which are non-binding. For example, we commend the Welsh government's introduction of a Well-Being of Future Generations (Wales) Act (2015) that requires public bodies in Wales "to think about the long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change."¹⁷ In fact, the Welsh Assembly is the "first legislature in the world to enshrine in law a duty, falling on public bodies, to safeguard the well-being of future generations."¹⁸

Fourth, while it is imperative to pay keen attention to funding, policy frameworks, and legal structures, we must not ignore the amorphous power of attitudes and beliefs, and the ways in which these intangible ideas yield concrete impacts on health. Attitudes and beliefs that reflect and perpetuate dominant structures of power such as economic and political systems, as well as forms of racial, cultural, gender, and class domination, systematically damage the health of marginalized communities. Such beliefs led to the shooting of multiple unarmed black men and boys in the United States and allowed Brian Sinclair, an Indigenous man, to be "ignored to death" in a Canadian hospital emergency waiting room because he was presumed to be drunk rather than suffering from a treatable bladder infection.¹⁹ Beliefs rooted in inequality perpetuate violence against LGBT com-

munities and promote violence against women worldwide. Fear-fuelled beliefs perpetuate stigma around health conditions as varied as HIV, mental illness, addiction, and lymphatic filariasis, which can in turn lead to social isolation, depression, and hesitation in seeking care. These intangible ideas are determinants of health that are as real as the lack of access to safe drinking water. We need to pay attention not only to perceptions and attitudes that result in overtly violent structures, but also "structures of indifference" that bring injury, illness, and death by neglect.²⁰ Finally, we must be alert to the ways in which attitudes, beliefs, and biases shape where and to whom we look for solutions, what expertise we recognize, which disciplines, professions and lived experience we deem relevant, and which parts of the world (and parts of town) we think we can learn from.

Conclusion

One of the most powerful contributions of research into the social determinants of health is that it can enable us to identify consistent patterns of inequality and their impact on health. At the same time, research into the social determinants of health can elucidate the complex, bidirectional association between health and education or health and the environment so as to bring weight to cross-disciplinary advocacy for health. Human rights enables us to name and frame these issues and patterns as violations with clear legal obligations for state action. We are glad to offer this special section as an important contribution to the ongoing effort to elaborate the links between human rights and the social determinants of health, and to dig deeply into key aspects of this relationship. We hope that the research presented in this section offers answers, provocation, and inspiration in what we anticipate will be an ongoing dialogue between these areas of scholarship and practice.

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