

EDITORIAL

Making the Case: What Is the Evidence of Impact of Applying Human Rights-Based Approaches to Health?

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Context for the special issue

This special issue of the *Health and Human Rights Journal* constitutes another step on the path toward making the case for human rights-based approaches (HRBAs) to health. In 2003, the United Nations (UN) outlined the pillars of an HRBA to development, which include universality and inalienability, indivisibility, interdependence and interrelatedness, non-discrimination and equality, participation and inclusion, and accountability and the rule of law.¹ Since then, leaders from national governments and UN agencies have repeatedly emphasized the need to operationalize human rights and incorporate them into the implementation of policies, programs, projects, and other health-related interventions with a view to enhancing effectiveness.² Nevertheless, implementation efforts regarding HRBAs to health and development have faced, and continue to face, multiple challenges, including some degree of miscommunication and polarization between different fields, where the imperatives of health and human rights are not always seen as complementary and rights imperatives are misconstrued to ignore all concerns regarding cost-effectiveness. Even for sympathetic actors and institutions, there is a need to gather sufficient evidence of the impact of human rights to be persuasive to policy makers, donors, and the public alike.³

Measuring evidence of impact is far from simple in an HRBA. It challenges three fields—human rights, public health, and medicine (as well as related communities and disciplines)—to bridge epistemological differences about the nature of what constitutes evidence and impact, as well as how to establish those truths. To begin with, the outcome of interest is not necessarily just the health outcome, or output, measured by such indicators as “deaths averted”; rather, HRBAs require both conventional health indicators and new measures for assessing effects. These effects include changes in legal and policy frameworks, as well as other qualitative changes. It may also be necessary to consider symbolic or ideational effects of HRBAs, such as transformations in public attitudes and perceptions, and the appropriation of a sense of entitlement, as some authors in this issue note. Standards of evidence also present challenges. As the experiences described in Mexico, Peru, India, and elsewhere underscore, HRBAs are inherently multi-level and multi-factorial, deeply embedded in social contexts and relationships. Standard medical and public health tools that rely

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on isolating variables and abstracting them from context, such as randomized controlled trials, will generally not be possible, nor will they often be the most apposite way to establish convincing associations; other disciplinary approaches need to be explored. For example, standards and methods for demonstrating associations and “impact” in law and social sciences often reflect quite different presumptions than in medicine and public health, as well as different theories of knowledge and social change, yet adopting—and adapting—these for use in evaluating HRBAs to health requires interdisciplinary collaboration and agreement regarding the objectives of the measurement exercise.

In 2013, the World Health Organization (WHO) published a monograph analyzing the evidence of impact of an HRBA on aspects of women’s and children’s health. The study, the first of its kind, focuses on the evidence of impact of *governments’* human rights-shaped health interventions, with particular attention to the initiatives of countries’ executive branches, such as ministries of health, for two reasons. First, governments have the primary legal responsibility for implementing human rights; and, second, very little attention has been given to the impact of governmental human rights-shaped initiatives on women’s and children’s health. This has resulted in a critical gap in knowledge, which the WHO monograph highlights and addresses.⁴

The monograph includes a number of examples from Brazil, Italy, Malawi, and Nepal. However, it also underscores the scarcity of research and evaluation on the impact of HRBAs in relation to women’s and children’s health and suggests that, among other reasons, there is a “lack of clarity and agreement about the methods and tools needed to carry out research and evaluation” of the impact of HRBAs.⁵ The monograph proposes a platform for policy makers seeking to implement an HRBA to women’s and children’s health, as well as an agenda-setting process to strengthen research on and evaluation of the impact of HRBAs.

Several follow-up meetings to the monograph have been held in different countries, under the auspices of diverse institutions, demonstrating a high level of interest in the topic. One expert consultation

was held at Harvard University’s FXB Center for Health and Human Rights in 2014, with the explicit objective of continuing the discussions raised in the WHO monograph in relation to refining research methods for assessing evidence of impact and linking them with initiatives from other UN agencies, the World Bank Institute, academics, and civil society organizations. Out of that Harvard meeting, a consensus emerged about the usefulness of drawing together the evolving and sometimes fragmented research and practice examples in this area—leading to the birth of the idea for this special issue.

The articles in this issue address a number of overlapping themes. First, a number of them contribute to further “making the case” for more and better evidence of impact. Although HRBAs are being supported more than ever before, support for HRBAs will hinge on illustrations of their efficacy and their specific contribution to this new agenda.

Second, several papers note that human rights-shaped interventions are increasingly being applied by nongovernmental actors. While the implications of this diversification are many, it presents a particular challenge in terms of expanding the way we understand, and therefore monitor, the impact of HRBAs. In addition, the actors that are taking on this role do so with a view to addressing barriers that are not otherwise addressed by conventional public health, but yet often hold themselves accountable to conventional measures of public health, demonstrating an urgent need to update our methods to suit our purpose.

Lastly, a number of articles look at the types of structural change that occur as a result of HRBAs—be it in law and policy, organizational design and programming, agenda setting, power relations, or specific program design—providing insight into and illustrations of how human rights are making a difference for health, the ways these changes can be measured, and important lessons for their transferability to other contexts.

The questions posed in this special issue

The thrust of this special issue is not how to measure the extent of noncompliance with human

rights standards, although that remains a crucially important task. Instead, the issue focuses on a new challenge: how to capture the effects of applying an HRBA to health. This challenge has become important in light of recent developments in, and the growing maturity of, the health and human rights movement. Of course, the movement continues to monitor the failure of duty-bearers to comply with their human rights obligations. But, additionally, in recent years, it has increasingly looked at how to operationalize an HRBA in communities, clinics, hospitals, and beyond. This additional (not alternative) focus on the meaningful, practical operationalization of health rights gives rise to new questions—the most pertinent of which for our purposes is, what is the effect of this increasing operationalization, and how do we measure it?

Measuring the impact of the increased “operationalization” of human rights-based approaches. In the issue’s introductory piece, Rebekah Thomas and WHO colleagues, including this issue’s co-editor Flavia Bustreo, identify and discuss some of these questions and propose “a new frame of reference for monitoring evidence of the impact of human rights-based approaches.” They suggest that human rights-shaped interventions have impacts at different points along “a spectrum of change.” The spectrum ranges from individuals and households to structures (for example, the legal environment) to programs (for example, service delivery) to society (for example, gender dynamics and health outcomes). The authors emphasize that “the different points [on the spectrum] are overlapping and interdependent” and that the same human rights-shaped intervention may have an impact at several points along the spectrum. Their framework recognizes that “different types of change can occur at a number of points on a spectrum of time and place, and that these changes are determined by a variety of actors, including individuals, communities, policy makers, health workers, lawmakers, and law enforcers.” In line with what many of the authors in this issue also assert, Thomas et al. note that a variety of methods are needed to assess different impacts at different points along the spectrum of

change. As they put it, a “mix of methods will enable the production of a broader array of evidence for understanding the contributory and cumulative effects of human rights interventions on the health of women, children, and adolescents.”

Other contributions in this issue raise additional questions, such as the level of evidence needed to establish impact. For example, Maya Unnithan proposes a “plausibility approach,” which WHO also suggests in its 2013 monograph. Alternatively, the level of evidence might depend on the method of evaluation used to assess a particular impact, as implied by a number of other papers in this issue. Thus, the same human rights-shaped intervention may generate different impacts that demand different evaluative methods requiring different levels of evidence.

Yet through the array of approaches and examples set out in this special issue, it becomes clear that there is much to commend the “new frame of reference” suggested by Thomas et al. because it provides “a more nuanced understanding of the impact of rights-based approaches and their complexity, as well as their contextual, multi-sectoral, and evolving nature.”

Other points to highlight from the diverse contributions in this issue include the following:

There is now high-level buy-in regarding the significance and usefulness of human rights-based approaches in building political support and framing services to benefit disadvantaged populations. This was hardly the case 15 years ago, at the beginning of the Millennium Development Goals. But today, human rights aspirations and language are a part of development and health discourse, and are informing new global health strategies, as noted by contributors to the Invited Commentaries section of this special issue.

Human rights (but not evidence of impact) are being integrated into health policies and programs. In addition to UN offices and agencies, many national governments are attempting to put their human rights commitments into practice. Using examples from Cambodia, India, Kenya, and Nepal, Thomas

Silberhorn, Parliamentary State Secretary of Germany's Federal Ministry for Economic Cooperation and Development, describes the German government's implementation of an HRBA to health and asserts that Germany, in spite of the challenges faced, has enjoyed successes in demonstrating impact on health outcomes. Silberhorn writes that "applying an HRBA effectively helps enhance the access of poor, vulnerable, and marginalized groups to health-related services, and helps improve the quality of health care." The examples show that "it is important to systematically integrate an HRBA at all levels of development cooperation in the health sector and to further develop the capacity of government and civil society actors to include a human rights focus in their planning, implementation, and evaluation of health strategies and programs. Not only will human rights be strengthened as a result, but health programs will also provide better health outcomes."

In their commentary, former Mexican health minister Julio Frenk and Octavio Gómez-Dantés describe the political utility that the normative discourse of HRBAs can lend: "movement toward universal health coverage ... can be aided by the use of an ethical platform in the design, negotiation, and implementation of health policies." Using Mexico's health reform as a case study, they demonstrate that although the use of technical evidence and effective political strategies were important, these elements were "strongly aided by the use of a solid ethical platform." Moreover, the authors explain that this "solid ethical platform" was explicitly informed by human rights. They conclude, "Mexico's recent health reform demonstrates that a rights-based approach to health care can produce significant policy results."

Human rights must be explicit from the outset. In an interview for this special issue, former Mozambican health minister Francisco Songane confirms that the lack of evidence of impact of an HRBA constrained his ministerial policy options. Reviewing the role of human rights in the HIV movement (for example, around the right to treatment) and, more recently, the women's and children's health movement (for example, around the rights to safe

delivery and survival), he underscores three key factors that contributed to these movements' success: "champions' who led advocacy efforts and who enjoyed strong support from civil society," political leadership, and international frameworks. Songane notes that "an HRBA—to be effective and truly rights based—must be explicit from the very beginning of health strategy development and project planning." This is an important insight not only for the implementation of human rights in health but for research on and the evaluation of human rights impact more broadly.

As the papers in this issue demonstrate, human rights are unlikely to be integrated across the health sector in one sweeping initiative; progress is more likely to be incremental. However, it is very difficult, if not impossible, to conduct research and evaluation suitably designed to capture the various impacts of human rights across multiple dimensions of change unless the initiatives being evaluated are located within organizations that have a minimum threshold of familiarity with, and acceptance of, an HRBA. Attempts to graft human rights impact evaluations onto organizations that have made little or no conceptual and institutional accommodations or adjustments for human rights are unlikely to succeed. There are signs of this difficulty in Sara Davis's contribution on human rights in global health financing.

Various methodological approaches are being used and refined, although substantial challenges remain in defining HRBAs and assessing impact. The unique contribution of human rights requires tailored measurement approaches. Just a few years ago, virtually no one was discussing how to measure the impact of HRBAs in an empirical fashion. As demonstrated by the articles in this special issue, that has changed. Most of the contributions reflect on some of the methodological challenges and contrast suggested approaches with more traditional methods in medicine and public health. In her piece, Unnithan explores "evidence" and "causation" (or attribution) and the relationship between them. She critiques evidence-based medicine for its reliance on "a strict hierarchy of ac-

ceptable evidence linked to clinical effectiveness.” Unnithan encourages practitioners to consider the different uses to which evidence can be put—for example, *evidence for use* in clinical interventions and *evidence of* the impact of rights. She suggests that “[a]longside evidence gathered on the basis of observation and controlled experimentation (as in evidence-based medicine), a ‘subject-near’ approach is necessary to ascertain what a human rights-based framework means and achieves.” She favors “pluralist, epistemological interpretations of evidence and methodological diversity.” Because of the “importance of ‘context’ in evaluating the effects of rights-based approaches to health,” she emphasizes the value of “[c]ertain kinds of qualitative” methods, including ethnographic ones. The importance of context in relation to human rights impact evaluation is a recurring theme throughout the special issue. As for causation, Unnithan suggests that “a plausibility approach offers the means to capture the effects of co-occurrence of multiple factors” and thus is more appropriate than a probability approach for evaluating human rights-based interventions. WHO’s 2013 monograph also favors this approach: “when assessing the impact of a human rights-based approach ... it will often be most compelling and feasible for evaluators to use the plausible level of evidence.”⁶

Measuring impact requires mixed methods of evaluation—quantitative and qualitative, subjective and objective. The paper by María-Luisa Escobar et al. describes SaluDerecho, a World Bank Institute initiative on priority setting, equity, and constitutional mandates for the legal enforcement of health rights that was first implemented in Latin America. The authors assert that “[a]lthough the ultimate goal of an HRBA is to achieve health outcomes, this impact is not direct.” They argue that the impact of human rights-based initiatives should be measured by changes in relation to the availability, accessibility, acceptability, and quality (AAAQ) of health services, “which—all other things being equal—might improve health outcomes.” They observe that a “mix of qualitative and quantitative evaluation methods seems appropriate for determining the impact of

policy decisions on AAAQ.” The authors then evaluate SaluDerecho’s impact using a process-focused results framework and methodology, which they applied in the course of the project, and conclude that “SaluDerecho has increased participation, transparency, and accountability among stakeholders, influencing institutional and organizational changes and policy innovation at the national and regional levels.” Other work assessing the impact of the legal enforcement of health rights has similarly emphasized the need to see the judiciary’s role in HRBAs in the context of broader efforts at policy-making and program implementation.⁷

The Belgian nongovernmental organization Third World Health Aid (TWHa) focuses on social mobilization around the right to health. With its partners, TWHa addresses barriers to the right to health and aims to help communities “increase their potential to organize and to collectively improve living conditions.” In their paper, Fanny Polet et al. explain how TWHa and its partners have endeavored to gauge the impact of their interventions through the “most significant change” methodology, which seeks to capture the subjective and ideational components of change, along with objective observations. As the authors write, the “main attraction of the method, which is based on stories of significant personal change, lies in the fact that it is fundamentally participatory in the data-collection phase and in the analytical process.” They report that, “[r]emarkably, we have observed an increased level of awareness and commitment among the participants, which we had not observed or measured using the standard evaluations” and conclude that participants, in telling their stories, were able “to emphasize the impact of any individual or organizational support they received and the role that it played in these changes.”

Without a doubt, much work remains to be done to further refine the meaning of HRBAs, as well as methodologies to assess the evidence of impact. Moreover, different disciplinary and ideological approaches would posit differing responses to how universal versus context-driven the definition and application of an HRBA in relation to a specific health problem should be. However, we

are no longer asking the same questions that we were five to ten years ago. That is, we are now at a stage where we can begin to ask more complicated questions—not whether accountability or participation are fundamental, but instead, how should those concepts be defined if we are drawing the contours of what a meaningful HRBA includes? And what counts in terms of measuring empowering participation, for example? Many of the pieces in this special issue grapple with the difficult questions of how to capture indirect impacts in addition to direct ones, and symbolic impacts in addition to material ones. And some papers even go beyond strict focuses on “evaluations of impact”—looking, for example, at how we can more systematically understand the meanings of processes of change in other forms, such as the personal narratives proposed by Polet et al. to capture “most significant change.”

Looking at case studies, it is possible to draw out common themes and key messages in HRBAs. Rights-driven changes are increasingly being adopted but may falter unless we also ensure an empowered and enabling environment. HRBAs are understandably concerned with an enabling legal and policy framework. Gillian MacNaughton et al. argue that their study of state-level health care reform in 2010 “demonstrates that an HRBA to health has the potential to positively shape laws and policies on health care, and may be implemented at the subnational level even where the national government has not recognized the right to health.”

But the need to go beyond laws and policies to incorporate human rights principles into financing and organizational aspects of programs also comes through clearly. In her paper on human rights in global health financing, Davis argues that when testing and treatment for infectious diseases are “fast-tracked” for global scaling up, “the work of assessing and addressing the impact of human rights” is sometimes sidelined.

Where HRBAs are used to address challenges that other sectors cannot, they should be measured against criteria that reflect both this difference and the type of change effected: organizational, agenda setting, power relations, and program design.

The overarching importance of context for understanding the political role that health systems play, as well as how to assess impact, comes across clearly in many of the papers. Lindsey Dyer introduces the Human Rights in Healthcare Programme, which was established in England in 2005 as part of a government-led initiative to embed human rights into public services. Designed “to integrate human rights into [National Health Service, or NHS] processes and use an HRBA to health,” the Programme encompassed several NHS organizations. Dyer focuses on one of these organizations, the Mersey Care NHS Trust. As she reports, “there is evidence that Mersey Care was using human rights to improve both the quality of services and health outcomes.” Dyer reflects on the sort of evidence needed for human rights impact, accepting that there may be a place for “randomized controlled trials as an evidence base for a particular intervention or drug treatment” but adding that “an important lesson from the Programme is that a wider definition of evidence needs to be used.” Answers, she notes, “cannot be provided by one discipline alone.” Her conclusion echoes the views of Songane and other contributors: “NHS England ... may be persuaded to pay due regard to human rights only if it can be proven that investing in human rights-based services and interventions meets legal obligations while also delivering health impacts—better quality services and health improvements that are equally, if not more, cost-effective compared to other interventions.”

In a very different setting, Jeannie Samuel and Ariel Frisancho discuss findings from an HRBA initiative in rural Peru showing the impact that social accountability can have on attitudes and empowerment in a setting of deep social disparities and marginalization of indigenous people, particularly women. Based on the experience of this initiative, the authors conclude that “citizen monitoring can lead to important changes at a health facility level ... [and] can also provide key information that can be used to put previously neglected concerns onto local and national health policy agendas.”

Similarly, when Jashodhara Dasgupta et al. explore a pilot project in India that used mobile health

technology to promote women's rights to free maternal health care, they assert that the project not only improved health services but also enabled women to claim their entitlements to these services and to report health workers' demands for informal payments. The authors conclude that "meaningful changes in the way that women were able to take an active role in monitoring informal payments and transparently share this information, as well as a shift in the power dynamics between these women and the health system, were described and documented."

Using case studies from India, Kenya, and Ukraine, Diederik Lohman and Joseph Amon evaluate the results of a human rights-based advocacy approach to expanding access to pain medicines and palliative care. They also evaluate the impact of their global advocacy efforts around this issue. The authors find that all three countries "have made significant progress, and global institutions and norms have increasingly recognized and supported expanded access to palliative care as a human right." Like other contributors, they recognize that "attributing impact is often difficult because of complex policy environments and the wide range of influences on government policies and practices." Moreover, "[e]ven in the cases where we believe attribution is fairly straightforward, it was not always possible to identify which component of the human rights-based advocacy approach or which specific interventions were decisive." They also accept that "it is difficult to assert that specific strategies or interventions are generalizable, geographically or temporally."

Lohman and Amon recognize that not all their efforts were successful. For example, their engagement with the UN's Universal Periodic Review (UPR) and human rights treaty bodies "had little impact, either because the review process in the end did not consider the issue of palliative care, the resulting recommendation was too vague to be meaningful, or the government did not follow up on the recommendation." This is especially interesting in light of the more positive experiences of UNFPA, as described by Kate Gilmore et al.

The contribution of Gilmore et al. is unlike any other in this issue because its focus is not on the impact of a human rights-shaped intervention

per se but on an international human rights process. Recently established, the UPR is a form of peer review or mutual accountability—in other words, a process whereby states review the human rights record of other states. We include it here for a number of reasons, not least that certain features of the process—such as accountability and, to a certain degree, participation—are part of an HRBA. Drawing from a recent UNFPA study, the authors argue that a number of the recommendations on sexual and reproductive health that were adopted during the first cycle of the UPR (2008–2012) have led to new laws, policies, strategies, and other interventions. They recognize the difficulty of establishing causation and accept that "moving from commitment to effective action cannot be attributed solely to the UPR." Rather, "the UPR builds political momentum and complements other international, regional, and national dynamics, such as electoral and social mobilization processes."

It will be interesting and important, first, to examine subsequent UPR cycles and see the degree to which earlier UPR recommendations have been implemented (Gilmore et al. begin this examination) and, second, to evaluate the impact of new laws, policies, and other interventions arising from UPR recommendations. Further, the way that we develop and refine methodologies that adequately capture the impacts will itself generate a demand for them. The UPR and other human rights processes should be urging states and others to routinely include suitably designed impact evaluations in their human rights-shaped interventions.

Looking ahead in the era of the Sustainable Development Goals

This special issue by no means pretends to present a comprehensive review of interventions where HRBAs have had an impact. Rather, it surveys a wide range of initiatives at multiple levels—laws and policies, programs, social accountability and monitoring, and remedies. Based on this survey and on other experience, it is fair to say that there is an increased awareness of the need to measure impact in financing and policymaking, program design,

monitoring and evaluation, and other accountability mechanisms, including the courts. Clearly, challenges remain to addressing the multiple social, cultural, economic, and legal factors that shape health access and outcomes in ways that do not attempt to decontextualize evaluation. However, as Flavia Bustreo and Paul Hunt have written previously:

*When examining the possible link—or attribution—between human rights-shaped interventions and health gains, there must be no double standards. Attribution between public health interventions and health gains is commonly established. This is also true for attribution between overseas development assistance and impact. Human rights-shaped interventions should not be subject to a stricter test of attribution than is commonly accepted elsewhere in public health or when considering the impact of overseas development assistance.*⁸

One clear issue emerging is the lack of a common definition of what constitutes an HRBA. The gulf between the human rights community and the health community still exists and requires work. One suggested way forward is for WHO and the Office of the United Nations High Commissioner for Human Rights to work together in trying to ensure that discussions within human rights mechanisms such as the UPR reflect health concerns and dimensions. This could advance action to protect and fulfill the right to health of every individual, wherever he or she lives. Similarly, the World Health Assembly could discuss the human rights dimensions of health. Such efforts will need a clear measuring and monitoring plan, and their impact will be crucial.

Further, although there is some skepticism in mainstream public health and medical circles about the effectiveness and efficiency of HRBAs, at the same time many “mainstream” evaluations of health are increasingly concerned with the need to understand the gaps in people’s aspirations and expectations regarding health and in the functioning of governmental systems—and, in this way, they acknowledge the need to go beyond conventional trend measurement. Moreover, transdisciplinary approaches are increasingly being used to assess the effects of laws and policies relating to health.⁹

The emphasis of this special issue is on the use of interdisciplinary expertise and methods to evaluate HRBAs. However, harnessing and collaborating in the construction of a combination of eco-social, epidemiological, demographic, economic, anthropological, and other social science tools to better evaluate how complex systems evolve and incorporate changes will both benefit the enterprise of human rights and enrich the development of these new methodologies in public health.

We, as the editors of this special issue, endorse the idea originally presented in the WHO monograph that this field would benefit greatly from a multidisciplinary research network—which bridges the global South and North—where the methodologies used to evaluate HRBAs could be subjected to peer critique and refined in an iterative way. We are convinced that moving toward more rigorous evaluation is key to ensuring the effective integration of HRBAs into health and development practice. Moreover, we endorse the need to find international, national, and subnational mechanisms to institutionalize the measurement of impact of human rights-shaped health-related interventions.

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