

# **Process Is the Point**

# Justice and Human Rights: Priority Setting and Fair Deliberative Process

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Most people responsible for setting priorities in health have considerable expertise relevant to deciding how to use resources effectively and the kinds of improvements that should be emphasized. Most are also concerned with distributing improvements equitably. Accordingly, they often invoke human rights or principles of distributive justice to legitimize choices that create winners and losers.

We propose an approach that draws on the strengths of both perspectives as a way to add legitimacy to efforts to set priorities in health. Our proposal provides a process for setting priorities but is not a formula or an algorithm for generating particular priorities. We propose an approach that would do away with the process through which priorities are set and decisions made, and suggest the value of a focus on the process of legitimizing these decisions. (Am J Public Health. 2008;98:1573-1577. doi:10.2105/AJPH.2007. 123182)

### PEOPLE RESPONSIBLE FOR

setting priorities in health generally have considerable training and expertise in the empirical

assessment of the complex epidemiological, economic, management, and other information relevant to deciding how resources can be used most effectively and the kinds of improvements in population health that should be emphasized. Most are also concerned with distributing the improvements they strive for equitably, but few are confident that they know how to reconcile their expertise in improving population health with the goal of doing so fairly. Understandably, they, and the institutions they work for, search for established normative frameworks to help them sort through this information, make acceptable decisions, and justify the decisions made. Accordingly, human rights or principles of distributive justice are often invoked by decisionmakers to legitimize choices that create winners and losers. Despite their strengths, neither framework is sufficient to truly guide these pervasive and pressing policy decisions.

On the basis of the internationally recognized legal framework, a human rights approach to health emphasizes that health rests on the satisfaction of a broad nexus of rights, including the rights

to health, nondiscrimination, education, information, basic liberties, and political participation. For a characterization of what we mean by human rights approach, see the box on this page. A human rights approach gives good guidance as to the economic, social, cultural, and political factors that need to be addressed and highlights government accountability for progressively improving the satisfaction of rights to improve population health. However, human rights

give little assistance—except by ruling out discrimination and calling for the participation of affected communities in relevant decisionmaking—about how to select winners and losers and how best to determine which claimants should have priority. Even if attention is given to the philosophical foundations attached to relevant rights recognized under international law, this does not provide guidance as to how these rights help to determine priorities among claimants.

### A Human Rights Approach to Setting Priorities in Health

A moral and legal imperative exists to respect, protect, and fulfill human rights in relation to the delivery of health services and for health more generally. Based on international norms and standards, we suggest the following to be key elements of a human rights based approach:

- 1. Direct concern with equity in the utilization of resources
- Examination of the factors that may constrain or support planned interventions, including the legal, policy, economic, social, and cultural context.
- 3. Participants and negotiation between all stakeholders, even as primary responsibility rests with government officials to facilitate these processes and to determine which interventions may have the biggest impacts on health
- 4. Government responsibility and accountability for the manner in which decisions are made, resources are allocated, and programs implemented and evaluated, including the impact of these decisions on health and well-being.



Most general theories of justice similarly fail to give adequate guidance. For example, a prominent liberal egalitarian theory of justice for health builds on the fact that maintaining normal functioning protects the range of exercizable opportunities (or capabilities) that people have. Because there are social obligations to protect opportunity, there also are obligations to promote health and to distribute it equitably.3 This theory of justice gives reasonably good guidance about some aspects of health system design and resource allocation regarding some determinants of health. Nevertheless, taken on its own, it is too general to yield determinate answers to the key distributive questions required in setting priorities. For example, the theory supports giving some priority to those who are worse off-but how much? Giving complete priority and giving no priority are implausible answers. It also fails to tell us when to aggregate less important benefits to many so that they outweigh significant benefits to a few. Similarly, the theory fails to tell us how we should balance achieving best outcomes against giving people fair chances at some benefit.<sup>4</sup> Other general theories of justice face similar problems. Classical versions of utilitarianism fail to give adequate weight to the goals of equity or fairness in addressing these unsolved rationing problems and, thus, fail to match widely held attitudes toward these issues.5

Those faced with pressing practical decisions about priorities need an approach that both gives guidance and enhances the perception

of legitimacy and fairness. We propose a general approach that draws on both perspectives as a first step in joint work to strengthen the approaches used to set priorities in health. Specifically, we suggest that a deliberative fair process ("accountability for reasonableness"), developed as a form of procedural justice for setting limits under resource constraints, should be supplemented with measures to ensure appropriate stakeholder involvement and government accountability that derive from a human rightsbased approach to health programming.<sup>6,7</sup> This account of fair process provides a coherent rationale for emphasizing the key components of a human rightsbased approach; at the same time, the emphasis on government accountability operationalizes the outcome of appealing to fair process. The combined approach makes clearer the content and rationale for progressive improvement or "realization" of a human right to health and is an issue we shall return to in future work.

To illustrate better the potential value of this approach, we examined how the setting of priorities can be considered from both human rights and distributive justice perspectives in a typical, albeit hypothetical, situation. We explain why both perspectives give inadequate guidance to set priorities among available options. We then propose conditions that should be met if the procedure is to yield fair and legitimate decisions and suggest how this approach both adds to and draws strength from a human rightsbased approach to health. We

believe the result is generally politically feasible and can give proper guidance to planners and implementers concerned with improving population health fairly.

### THE SHARED PRIORITY-SETTING PROBLEM

Imagine a government, sensitive to rights and ethical concerns, that wants to improve its efforts in the area of maternal health. The task is large and complex and requires building on programs already in place as well as evaluating new proposals to determine the extent and ways in which the proposal would contribute to reaching these goals. Five options are up for discussion.

- Outreach to married women to deliver family planning services, including education about the advantages of using trained birth attendants.
- Heavier investment in emergency obstetric facilities in urban and semiurban areas, siting them in ways that address the most underserved populations.
- Investment in training and supporting the placement of attendants at all peripheral centers.
- Advocacy to change the marriage and family law that allows girls to marry at very early ages.
- Outreach to families and communities to increase the enrollment of girls in secondary school.

We assume existence of the evidence of the effectiveness and cost-effectiveness of the different

options and suggest some areas of concern with respect to these options, regardless of which approach is taken to set priorities.

The first option builds on existing efforts and would address both relatively high fertility rates and the cultural barriers to using skilled attendants. On its own, however, it would do nothing about the relative lack of skilled birth personnel, and it will favor older married women, because the lack of autonomy of adolescents, whether married or unmarried, means they will not be reached through this program.

The second option is expensive and would require taking funds away from existing programs. However, it is likely to show immediate and tangible results in maternal mortality reduction. Because these facilities would necessarily be built in places with decent infrastructure, this option does not address geographical barriers, poor roads, or missing transportation services, nor does it locate services in more rural areas that lack appropriate transportation and other infrastructure.

The third option addresses the gap in the existence of services for women living outside of urban areas; however, it will be expensive and on its own will not guarantee that pregnant women will be able to make use of the services offered. In addition, it is not clear whether these services should be offered free or whether user fees should be applied.

The fourth option has low economic costs but potentially high political costs. It would require



working with sectors beyond the health system and addressing cultural traditions that disempower women. Securing the political commitment needed to confront these cultural forces will be difficult, even as the struggle itself may be valuable for raising community awareness.

The program to increase the enrollment of girls in secondary school would work to change the broader cultural context. It would benefit girls who completed school by delaying the age of marriage and hence first childbirth, and it would have positive benefits over the next generations. However, it is expensive, lacking in evidence as to the best approach, and does little to benefit maternal health in the short term.

Both human rights and principles of distributive justice offer grounds for supporting each of the options, therefore we focus on the value disagreements that underlie how best to set priorities in this case.

### Analysis of a Human Rights Approach

A human rights approach sets out a process but does not determine a preordained result. It requires analyzing which rights and which populations would be positively or negatively affected by each intervention. Specific attention must be paid to who would benefit most, and in what ways, from each intervention, and who would be left out.

A human rights approach requires assessing the relative impact of each option on maternal health for the population as a

whole and with specific attention to vulnerable populations but does not determine which option should take priority. Thus, option 5 would be attractive in that it satisfies the right to education for girls into the future and has the potential for long-term impact in reducing early-adolescent birth rates and the attendant birth complications. Likewise, the value inherent in the effort to change the law in option 4 would, in the long term, help to improve maternal health at a population level. Neither of these options, however, addresses the immediate needs of women at greatest short-term risk of complications from unattended child-

The issues raised by the second and third options, although focused on immediate needs, raise conflicts as to which women should be prioritized in accessing health care: locating services in urban or rural areas will help different people, all of whom will have reasonable rights-based claims to have their health care needs met. Attention to human rights identifies these claimants and some of the issues to be considered but does not establish priorities among them. Noting that more people might be helped with one program than another does not solve concerns about inequality in the distribution of services or the satisfaction of these rights claims. The strength of a rights framework in establishing accountability for meeting the goals and targets that such programs aim to achieve does not itself show that giving priority to one or another is the preferred

solution. In short, attention to rights leaves unresolved the priorities that must be established among programs competing for resources, each of which arguably would improve health and the satisfaction of relevant rights.

### Analysis of the Opportunity-Based Approach

The opportunity-based account of justice and health referred to earlier, similar to a rights-based approach, gives some reason to support each of the proposed options, whether in the health or nonhealth sector, because each has an effect on health and, thus, opportunity. (Some, like the education program or the program on family and property law, also affect the opportunity of women in other, nonhealth-related ways). The first program results in favoring older, married women who are less at risk but easier to reach than younger women. People can reasonably disagree about how much priority should be given to help those who are hardest to reach given that this would mean giving up real benefits for those who are easier to access.

The second option offers significant benefits to some women at the time of delivery, but it is not clear these benefits outweigh the lesser benefits to larger numbers that might result from the third option. Reasonable people will disagree. Similarly, concentrating complex obstetrical services in urban areas is a "best outcomes" solution, because more people can easily get to them, but it denies people in rural areas a "fair chance" at any

benefit. Conversely, changing the law and improving education for girls gives the largest number a chance at some benefit, but it fails to help those most in need in the short term. As noted earlier, a classical utilitarian approach simply ignores all concerns about equity in these examples, maximizing instead some aggregate measure of health; as a result, it yields priorities that many would, for good reason, find objectionable.

The winners and losers created by priority-setting choices all have rights claims and claims of distributive fairness on their side. As clear from this discussion, neither human rights nor the appeal to general principles of distributive justice suffices to resolve disagreements about how to decide among these claims in setting priorities. Any legitimate solution must be a way of arriving at priorities that ensures all concerned see the decision as having been made fairly.

# ACCOUNTABILITY FOR REASONABLENESS

Where, as in the example, fundamental aspects of individual and population well-being are affected by decisions that limit access to scarce resources and perceived entitlements, those responsible for making these decisions know that affected populations have a fundamental interest in understanding why and how decisions were made. An approach to fair deliberative process, called "accountability for reasonableness," which is grounded in democratic theory, allows for



careful deliberation that highlights underlying value disagreements.6 The main idea behind this approach is that "fair-minded" people, who seek mutually justifiable terms of cooperation, should be able to agree on and justify, even when resources are constrained, the reasons for the priorities they determine necessary to meet health needs fairly.

The following four conditions make more precise this notion of accountability for reasonableness:

- 1. Publicity condition: Decisions that establish priorities in meeting health needs and their rationales must be publicly accessible.
- 2. Relevance condition: The rationales for priority-setting decisions should aim to provide a reasonable explanation of why the priorities selected were determined to be the best approach. Specifically, a rationale is reasonable if it appeals to evidence, reasons, and principles accepted as relevant by fair-minded people. Closely linked to this condition is the inclusion of a broad range of stakeholders in decisionmaking.
- 3. Revision and appeals condition: There must be mechanisms for challenge and dispute and, more broadly, opportunities for revision and improvement of policies in light of new evidence or arguments.
- 4. Regulative condition: There must be public regulation of the process to ensure that conditions 1, 2, and 3 are met.

The publicity condition exposes the rationales of decisionmakers

to broader forms of public review and, thus, helps to establish broad accountability for the decisions made. As the rationales for any changes to the decisions made are made public, the coherence of the underlying rationales for how priorities are set can be assessed. By forming a public record of decisions and the reasons behind them, the reasoning applied to setting priorities can be improved over time. The involvement of multiple stakeholders in the process not only is useful for ensuring that a range of relevant arguments and interests are considered but also allows for buy-in and enhances legitimacy, even as the difficulties inherent in ensuring vulnerable groups are present and heard is acknowledged. All of these conditions fit well with key elements of a human rights approach. In addition, they have been embraced by researchers in Canada and elsewhere as a framework for evaluating priority setting and processes in various  $countries.^{8-12} \\$ 

### **FAIR PROCESS IN A HUMAN RIGHTS APPROACH**

Accountability for reasonableness provides a systematic rationale for application of key elements of a human rightsbased approach. Unfortunately, in both the literature and in practice, when human rights are invoked, it is often assumed that simply by invoking its key components, the appropriate solution to setting priorities will present itself. 13 We have illustrated why

this approach is insufficient. Adapting accountability for reasonableness to the context in which human rights are brought into priority-setting deliberations thus appears to be a natural way to advance efforts to promote health and well-being.

The account of fair process presented here is not in any way alien to human rights efforts. Its publicity condition, calling for public access to the rationales for priority-setting decisions, simply makes concrete a form of transparency and accountability already acknowledged as key to a human rights approach. It requires transparency about what interventions are on the table for discussion, the rationale used to give priority to a particular area of focus, the need to directly inform affected communities of the criteria used in selecting goals and targets, and the mechanisms in place to ensure government accountability over time. 14,15

The requirement of relevance in ensuring agreement among stakeholders on what kinds of evidence will be used and how it will be analyzed and evaluated in setting priorities brings into play several elements of a human rights approach. Further, the vetting of various arguments and the inclusion of all affected by a decision, with particular attention to vulnerable groups whose rights are most threatened, is familiar ground and, even as they can only be defined in context, includes populations such as the children, elderly, or migrants for example. Human rights have much to offer to supplement this condition through the practice of

setting out specific criteria that must be considered. For example, determination of the accessibility, availability, acceptability, and quality of the proposed intervention, as well as a focus on nondiscrimination, may help bring to the fore specific criteria important for determining relevance.2

Although the key elements of accountability for reasonableness may be present in typical human rights efforts to improve health, they have not been explicitly integrated into priority-setting processes. Accountability for reasonableness provides the justification for integrating these elements into an explicit, fair process for setting priorities, and human rights contribute legal accountability and established criteria to be debated within the process itself.

#### **COMING TOGETHER**

Advocates often complain that governments can hide their unwillingness to improve health behind the cloak of resource constraints. Accountability for reasonableness helps shed light on whether improvements are slow because of government incapacity or unwillingness. By making explicit the process through which priorities are set and decisions are made, it becomes much harder to disguise unwillingness. This in turn allows accountability for reasonableness to defend the human rights concept of progressive realization against two frequently raised objections. Advocates and critics of human rights alike complain that progressive



realization can seem vague because it lacks clear standards governing which alternatives are more appropriate. <sup>16</sup> Even as resource constraints may not permit a completely deliberative and equitable process in every instance, accountability for reasonableness helps eliminate much of this vagueness by yielding an explicit record of why and how alternatives are chosen. Over time, such a record may reveal the true commitments to change that a government is able and willing to make.

The political aspects of introducing fair process are also worth highlighting. Some political cultures are likely to be more antithetical to fair process as well as to its related elements in human rights approaches. In addition, because this process strengthens accountability for the decisions made, some decisionmakers may be uncomfortable and resist its implementation. One protection against this resistance is the broader involvement of stakeholders in priority setting and their adequate preparation for the task, with special care to ensure vulnerable groups are present and heard. Recognizing that an inclusive approach to stakeholder involvement is always preferable, even as it is difficult, a central political issue, then, will be the selection of these participants and the support they are given. Ideally, transparency about the decisionmaking process will facilitate broader social learning in the society as a whole.

Some people may worry that, just as two juries may come to different verdicts, different groups participating in a fair process may decide on different priorities. We conclude by emphasizing that joining accountability for reasonableness with a human rights approach provides a process for setting priorities relevant to our hypothetical case and beyond, but we are not proposing a formula or algorithm for generating particular priorities. An algorithm would do away with the process, and it is precisely the process that is the point.

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Sofia Gruskin and Norman Daniels jointly conceptualized, wrote, edited, and revised the article.

#### **Human Participant Protection**

No protocol approval was needed for this study.

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