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ETHICAL CONSIDERATIONS FOR THE CREATION OF A NATIONAL NEGLECTED TROPICAL DISEASE POLICY

ABSTRACT

The term "neglected tropical diseases" (NTDs) refers to a group of parasitic, viral, and bacterial diseases that cause substantial and often debilitating illnesses, affecting more than one billion people globally. In the United States, addressing NTDs focuses largely on developing safe and effective mechanisms to prevent and treat NTDs. Furthermore, new or existing treatments must be made available to those in need—often people living in poverty or extreme poverty (less than $2 a day). But research, development, and delivery of these interventions is costly and relies mostly on funding from the federal government. With pressure to limit government expenditures, decisions regarding the allocation of limited resources entail balancing priorities, which involve many, often unarticulated or implicit, ethical judgments. This report highlights some of the central ethical issues pertaining to NTD policy development and argues that ethical considerations should be included in the policy development process. We conclude that the United States should develop an NTD policy to further reduce the prevalence and impact of NTDs both within and outside our borders.

INTRODUCTION

More than one billion people in the world suffer from one or more NTDs (World Health Organization 2013). NTDs are a collection of disparate diseases that predominately impact the poor (Hotez 2013a). These diseases are not new. In fact, many have affected humans for centuries, earning them the label "biblical diseases." NTDs are most commonly chronic infections, affecting people over many years. While they generally do not cause death, they often can cause disfiguration and disability, leading to the social ostracism of affected individuals.

NTDs are found primarily in rural areas, although some appear in urban areas, and they principally affect the poor. They also condemn the poor to a lifetime of poverty because often they render people unable to work or unemployable due to cognitive effects, stigma, or other factors. Numerous attempts to monitor and address NTDs have yielded some progress (Hotez 2013a; Molyneaux 2013; Hotez, Raff, Fenwich, Richards, and Molyneaux 2007; WHO 2013; WHO 2010). Yet many still suffer, and current efforts alone will not eliminate NTDs even over a long period of time (Hotez 2013a).

Bioethics involves a multidisciplinary approach to examine ethical issues in health care, health policy and law, science, public health, and human research. Applying a normative lens to NTD public policy development allows us to focus on ethical considerations of what ought to be done. In exploring these issues in terms of right and wrong and good and bad, we recognize the many ways in which ethical judgments are made implicitly in policy development. These efforts should acknowledge and address the

ethical questions that emerge regarding NTD response. Failure to do so puts the long-term sustainability of policy at risk. For instance, a policy that ignores ethical considerations that are important to some stakeholders might not be well-supported and could adversely affect resources available in future funding cycles, undermining efforts to effect change. Failure to address ethical considerations in policy development also could undermine trust among affected communities and hinder efforts to fight disease.

Crafting coherent and consistent national NTD policy that will be widely supported requires an awareness of when normative assumptions and judgments are being made and the range of positions that might be held regarding a particular decision. Since NTDs affect people from different moral and geopolitical communities, and since people within the United States disagree about how much money ought to be spent on aid and how to allocate it, we expect disagreement about what ought to be done and how to determine what ought to be done. While we lack a privileged position from which to resolve disputes about normative questions, these questions remain salient. Ignoring them will not make them irrelevant (Engelhardt 1996). In this report, we introduce a select number of relevant disputes to help policymakers understand the differences of opinion on these issues to foster a more informed and effective policymaking process.

Policy work often involves compromises among different parties to develop and advance shared goals. In this report, we will discuss normative judgments associated with naming NTDs as "neglected" and how these judgments direct us as a society to address these diseases more effectively. Next, we will explore some of the moral appeals that might inform discussions on whether additional efforts to combat NTDs should be undertaken. Because of deep moral differences, an important consideration in policy development is how to build a broadly accessible case for responding to NTDs and measuring success. Framing the discussion in terms of different moral appeals facilitates this goal and guides policymakers to understand the different reasons for concluding that "something more ought to be done" to combat NTDs. Finally, we will examine additional normative questions that emerge after we conclude that "something more" ought to be done to combat NTDs. These include questions about how to prioritize efforts to combat NTDs and how to conduct NTD research.

These normative questions are important for NTD policy development and should not be ignored. Instead, these issues should be acknowledged and incorporated into policy development to improve the likelihood that a national plan can have a long-term impact.

What's in a name?

The term "neglected tropical diseases" involves a normative claim—a claim about what someone "ought to do" or "ought to have done." The word "neglected" has two senses: moralized and non-moralized. The non-moralized sense describes facts that have no moral implications, as in: "We have neglected our garden and the weeds are terrible." This statement is a non-moralized use of "neglected" because there was no moral obligation to weed the garden (unless, for example, the failure reflects slothfulness or a broken promise). "Neglected" in the moralized sense refers to a failure to do something that one morally ought to have done. For example, "The doctor neglected to tell the patient the truth about her diagnosis in hopes of avoiding a lengthy appointment late in the day." The difference between the moralized and non-moralized senses of "neglected" hinges on the existence of agents who have duties, obligations, or responsibilities, and of entities toward whom those obligations, responsibilities, or

duties exist. The moralized sense of "neglect" indicates that there is something someone ought to have done but did not do, and that there is someone for whom it ought to have been done.

The term "NTDs" invokes the moralized sense of neglect as evident in the NTD literature. Molyneaux argued:

> "Policymakers are ignoring scientific and operational evidence that interventions against 'other diseases' are effective. By concentrating on so few agents, current policies could perpetuate inequity, disrupt health financing policies, divert human resources from achievable goals, and deny opportunities for impoverished health systems to improve. Current policy also raises ethical issues. Resources are being transferred to interventions against the big three [HIV/AIDS, tuberculosis, and malaria] that, realistically, have only a limited chance of success as they are reactive and do not adequately control transmission—a prerequisite for any public health impact." (Molyneaux 2004)

The claim here is clear—policymakers could have and should have attended to NTDs but have not. Policymakers are being poor stewards of resources because they fail to ensure that their choices with regard to NTDs will have positive effects on public health. This constitutes a failure to fulfill duties toward persons with (or at risk for) NTDs. Thus, when we use the term NTDs, we are already in the realm of normative claims. The first ethical judgment lies in the name itself.

Acknowledging this leads to additional questions. Who had a duty and to whom? What did the duty entail? Moving forward, the most relevant questions include: who has obligations now, and what are those obligations? Ought "something more" be done about NTDs now? If so, why? What ought to be done, in what order, and how?

Ought "something more" be done about NTDs now and, if so, why?

Although many observers will say "yes," some might reject the claim that "something more" ought to be done altogether. Someone who takes a Malthusian view, which promotes the need for global population control, might see NTDs as one way of avoiding over-population. Those who argued that it was unwise to prevent mother-to-child transmission of HIV because it would lead to more orphans who had to be supported by the state might support such a view. They might think treating NTDs will lead to more population problems and more people who need assistance.[1] While demographic studies have disproven this view—in fact the longer a population lives, the lower its overall birth rate—there are people who advocate for this approach regardless of reality (Bongaarts 2009).

Even among the majority who we expect would reject the claim that we may or even ought to ignore NTDs, we find different accounts of why "something more" ought to be done. We should expect this, given that there is no single shared account of morality and no means to resolve such differences through reason alone (Engelhardt 1996). Baruch Brody has developed a framework to acknowledge the legitimacy of different moral appeals (Brody 1988 and 2003). The moral considerations are appeals to the consequences of our actions, rights, virtues, deontological constraints (actions we ought not to do regardless of the consequences), special obligations, and justice (Brody 1988 and 2003). All of these are grounded in the canon of Western philosophical ethics, especially the works of Plato, Aristotle, Kant, Locke, Mill, and Ross (Brody 1988 and 2003). These competing appeals, Brody argues, provide us with appropriate ways of examining moral questions, and they should frame our evaluation of such questions. In analyzing specific cases, such as what NTD policy should look like, the model requires that we consider the different

appeals and judge their significance to evaluate what ought to be done given the circumstances (Brody 1988).

We use the model of competing appeals as a heuristic approach to frame the discussion around the question of whether "something more" ought to be done about NTDs now and why. Such a framework can be helpful in the policy setting, where the goal is to understand and incorporate different points of view to build consensus. By considering ways in which parties who hold different moral positions might evaluate the question of whether "something more" ought to be done to combat NTDs, we identify areas where there might be consensus as well as disagreements. Finding a path forward for NTD policy is an important goal, even if a compromise policy is not what some consider ideal. Understanding different accounts of what ought to be done can help policymakers identify suitable paths likely to have broad support and be effective over time.

What does justice require with respect to NTDs? Do people have a right to NTD treatment?

Often, NTD advocates use a justice or rights plea to encourage the adoption of a more robust policy to help end NTDs. The appeal to justice is a broad call that concerns the distribution of benefits and burdens and the allocation of resources, compensation for harms, fairness of transactions, and retribution for wrongdoing (Brody 1988). Justice often is described as the duty to treat equals equally. For NTD policy, this is framed sometimes as redistributing materials and resources equitably to prevent or treat curable NTDs.

The appeal to rights refers to the obligation, all things being equal, to acknowledge both the positive and negative rights of persons. Negative rights include forbearance rights—rights not to be subject to the interference of others. They obligate others to leave us alone. Positive rights refer to rights against other persons to access material goods, opportunities, or other resources (McCullough, Jones, and Brody 1998). Sometimes, the obligation to treat equals equally is understood in terms of a right to equitable treatment. Because justice and rights claims often are invoked jointly, we consider the appeals together here.

A note of caution in examining justice and rights claims: The terms "justice" and "social justice" often are used to capture a series of different intuitions about what rights and obligations individuals have with respect to the distribution of resources and opportunities. The terms often are used without justification of what some owe to others or careful specification of what is owed. Yet the terms often are invoked as if they, in and of themselves, justify particular obligations or outcomes. Frederich Hayek was acutely aware of this, referring to the use of "social justice" as intellectually dishonest because it claims particular needs must be met without further justification (1976). Announcing that it is a requirement of "social justice" that the federal government fund NTD research, for instance, is unlikely to advance the policy discussion of NTDs and should be avoided. Competing accounts of justice and rights must be acknowledged.

The complexity of the seemingly simple obligation to treat equals equally becomes clear when we ask how to determine who is equal and what does it mean to treat them equally, or what constitutes fair treatment. Different theories of justice interpret and apply the requirements of justice differently. Thus, the appeal to justice will have different implications for NTD policy depending on the substantive theory of justice policymakers hold. Similarly, different accounts of what rights people have, including whether or not they have any positive rights to resources belonging to others and against whom they have them, entail different directions for NTD policy.

Many of the differences between accounts of justice and rights can be described by recognizing the categories of variations among them. We consider four categories here, defined

by four questions: What is the scope of justice? What distribution pattern does justice require? What role ought the state play in securing justice? Toward whom do we have obligations of justice? These are not the only differences, but they highlight how appeals to justice and rights may lead to different approaches to NTD policy, depending on the substantive moral theory grounding the appeals.

What is the scope of justice?

The first category concerns the scope of justice: does justice entail a right to particular material goods or resources, or access to particular opportunities or liberties (or some combination)? Related to NTDs, do people have a right to treatments, preventive measures, or even research and development of new therapies? Or does justice entail an obligation not to take away a person's opportunities and liberties but no obligation to provide them with the goods or resources needed to pursue opportunities or execute their choices? Do they have a right to a fair opportunity to be free of NTDs? If so, what is required to have a fair opportunity? For example, fair opportunity might require an initial equal distribution of resources after which people may do as they will and the outcomes, however unequal, will be deemed fair (Dworkin 1981a and 1981b). Differences in outcomes are tolerated insofar as they are the result of the choices people make and not bad luck (such as being born with a disease). Fair opportunity also could be understood as merely requiring that no resources, rights, or opportunities be taken away from someone unjustifiably.

Norman Daniels applied John Rawls' well-known account of justice to argue that because justice requires fair opportunity, it requires access to (some) health care (Daniels 1985).[2] Daniels contends that disease and disability impair one's opportunity range—a case we see with several chronic NTDs which can make it difficult or impossible for children to learn, grow, and attend school and which can render adults unable to work (Hotez 2013a). As a result, to have a fair opportunity requires access to the resources to overcome the limitations disease and disability impose. Health care serves an important role in helping people maintain or achieve species-typical functioning, and hence in helping give them equal opportunities. Even when people cannot achieve normal or typical functioning through health care, health care can improve their opportunity range and help them have as close to a fair opportunity as possible. Hence, Daniels believes, as do others such as Allen Buchanan, that health care is among the goods subject to justice claims (Buchanan 1984). These accounts would call for policy that actively redistributes resources to combat NTDs.

More complex accounts invoke well-being or liberty as the currency for measuring justice. Madison Powers and Ruth Faden (2006) hold that social institutions are just insofar as they facilitate and support well-being, as measured across six dimensions: health, security, reasoning, respect, attachment, and self-determination. Such an account will require access to the goods and services that support well-being, including health. For NTDs, this would require access to treatment and preventive measures. We also find accounts of justice that focus not on specific opportunities or resources but on liberty and the obligation not to interfere with others without their permission (Nozick 1974; Engelhardt 1996).

Different accounts of the scope of justice have significant implications for NTD public policy development. Some will require material support for NTD research and development as well as the dissemination of effective interventions. Others call for a policy that protects liberties and the right of noninterference. The latter will not recognize a justice-based obligation to redistribute resources to provide treatment, though defenders of this view might offer other reasons to support efforts to combat NTDs. They also

might call for the removal of many or all barriers to the rapid development of safe and effective interventions to combat NTDs, such as regulations that hinder research.

What distribution pattern does justice require?

A second category reflects differences over what pattern of distribution is required to enact justice. Although many say justice requires fairness, fairness may denote equal access, equitable access, access based on desert (what one deserves), access based on need, or the outcomes of fair exchange, among others.[3] Egalitarians argue for equal or equitable distribution of whatever goods, resources, or opportunities are relevant. For example, G.A. Cohen argues (against Rawls) that inequalities in the distribution of not only basic liberties but also of goods based on "myriad forms of lucky and unlucky circumstances" are unjust and should not be tolerated (Cohen 2008). Richard Arneson offers a different egalitarian response to Rawls, arguing instead for "equality of opportunity for welfare" (1989).

On other accounts, justice calls for a distribution pattern that meets a particular threshold for all, even though some will have more. This threshold often is referred to as a decent minimum. Tom Beauchamp and James Childress describe it this way: "The right to a decent minimum of health care...requires equal access only to fundamental health care and health-related resources...It guarantees basic health care for all on a premise of equal access while allowing unequal additional purchases by individual initiative" (2009). Inequality is tolerated as long as all have "basic health care." Defining "fundamental health care" and "basic health care" is no simple matter, as we have seen in the debates related to the Affordable Care Act.

Alternatively, a utilitarian might evaluate outcomes by judging patterns of distribution to determine which one yields the most overall good or maximizes welfare overall. Utilitarian claims ultimately require empirical evidence about what will maximize good outcomes. They could demand grave inequalities and even that some people be extremely poor off if such a pattern maximized overall welfare.

Others might hold that the just pattern of distribution is the one that reflects merit or desert, or just exchange. Nozick, for example, focuses on the mechanisms of acquisition and transfer of property. Fairness requires just transfer, and as long as property is acquired and transferred justly, no one else is entitled to it. Nozick sees property and other resources as already being owned. They do not exist in the world waiting to be allocated: "Things come into the world already attached to people having entitlements over them" (1974). We should not begin with a sense of what kind of pattern of distribution we think ought to exist and work backwards to justify reallocations. Instead, we must begin with the rightful owners and ask their permission to use their resources. To be sure, it might be morally good to give away what one rightfully owns to save the lives of others, but no one has a right to that aid. Just transfers require permission or authorization of the rightful owner of the resource. In the context of NTDs, this means that we may not forcibly take resources from some, as through taxation, merely to make other people better off.

A distinction may be drawn between patterns of distribution that are unfair—in the sense that someone ought to be compensated for them or the situation ought to be rectified—and patterns that merely are unfortunate (Engelhardt 1996). Unfortunate circumstances might call on us to be compassionate, charitable, or in some other way render aid voluntarily, while unfair circumstances allow for coercive redistribution aimed at righting the wrong. Theories of justice draw the line between the unfortunate and the unfair in different places. For example, one might hold that "[i]njuries, disabilities, and diseases due to the forces of nature are unfortunate," while those "due to the unconsented-to actions

of others are unfair" (Engelhardt 1996). In the case of unfair injuries, disabilities, and diseases, there remains a question as to who must compensate the wronged party. Some might argue that the party who performed the unconsented-to action is responsible, since that is the locus of the unfairness; with respect to society, the situation simply reflects unfortunate circumstances (Engelhardt 1996). In other words, even where there is unfairness, there remains another question about who is obligated to right the wrong. Do persons facing unfair circumstances with respect to other individuals have a claim against uninvolved members of society who are not at fault for their suffering? The substantive theory of justice one adopts will affect where we draw the line between the unfair and the unfortunate, and who we think ought to compensate those experiencing unfairness. It might be morally good or even obligatory to render aid, but that is different from saying that we may coercively redistribute resources to right the wrongs of others.

NTD policies framed around different distributions patterns will look different. To distribute resources based on need may lead to a significant shift in resources away from the United States to meet very basic needs among the poor in developing and underdeveloped countries. It also will entail significant redistribution within the United States to combat NTDs found domestically. A policy based on just transfers or merit may lead to very different outcomes. In developing policy, ignoring either of these views is likely to lead to a policy that someone will find objectionable. Acknowledging these differences and attempting to forge a compromise position may yield more support even if no one sees the policy as ideal.

These differences do not tell us how the pattern of distribution is to be achieved, something we turn to examining in the third and fourth categories.

What role ought the state play in securing justice?

Third, accounts of justice differ on the role of the state or the use of other coercive force in securing justice. Some see the state as authorized or even obligated to use its coercive force to secure a particular outcome or pattern of distribution, to ensure access to opportunities and so on. Others do not. These differences have implications for NTD policy development. For example, Nozick holds that we may not use coercive force to take away resources an individual is entitled to, even if doing so would serve someone else well. To be permissible, redistribution requires the authorization or permission of the parties rightfully in possession of the good or resource in question. In regards to NTD policy, two people could believe the United States has robust moral obligations to help meet the basic needs of the world's poorest people as a fundamental matter of justice. One person might argue that this is precisely the kind of moral obligation the government should enforce. States may or even ought to use coercive force to redistribute wealth to fulfill this obligation (Blake 2001). In thinking about NTDs, this might include aggressive taxation and redistribution of resources to support research, development, and dissemination of treatments and preventive interventions.

In contrast, another individual might hold that the US government has limited authority to enforce moral obligations to render aid. While the government might enforce obligations not to harm others, requiring people to fulfill a moral obligation to aid others—even others in dire need—is not a proper function of the state. States should not use their coercive force for this purpose or, if they may do so, it is only with careful justification (Novick 1974; Gaus 2010). Under this view, the government may not aggressively tax people to redistribute resources to combat NTDs. Coerced redistribution might be permissible if it is required to fulfill one of the legitimate functions of the state, such as self-defense. If, for example, an epidemic

of NTDs sufficiently threatened to put public welfare at risk, then the state might coercively redistribute resources to facilitate self-defense. But the mere fact that redistribution is necessary for the well-being of others or that we have a moral obligation to help those in desperate need would not justify coerced redistribution. The state would not, for example, be permitted to impose a tax to provide funding to help combat NTDs in another country that posed no apparent threat to us.

Yet others might hold that the government should "nudge" or create incentives to promote particular behaviors, including redistributive actions (Leonard, Thaler and Sunstein 2008).[4] One might, for instance, offer special tax incentives to people who donate money to combat NTDs or to pharmaceutical companies doing research on diseases of the poor. US policy has incorporated such "nudges" for rare or "orphan" diseases and conditions and some tropical diseases (U.S. Food and Drug Administration 2015 and 2008), though some have challenged the efficacy of these strategies in combatting NTDs (Kesselheim 2015). One's account of the authority of the state in enforcing matters of justice and securing particular patterns of distribution will affect policy development.

Toward whom do we have obligations of justice?

A fourth category on which accounts of justice and rights vary concerns identifying the equals who ought to be treated equally. Toward whom do we have obligations of justice? Against whom do we hold rights associated with justice? Do we have the same obligations to all humans, regardless of where they live? Or do we have obligations to people who live in the same community or country that do not apply to people in other countries? Does it matter whether they legally live in that community or country? How should we define communities? Answers to these questions will have a strong impact on US NTD public policy, as they will define whom we reach within and outside our borders. Should we focus on only US citizens with these diseases living in the United States or also those abroad? Or should we include anyone living within our borders? Are we obligated as a First World and developed country to help others in underdeveloped nations and living in extreme poverty across the globe? Do all people with NTDs merit equal assistance, or do we have greater obligations to some groups rather than others? Should public policy privilege assistance to some people or populations over others?

Discussions of international distributive justice concern obligations between nations, societies, or groups, whereas global distributive justice focuses on the obligations of individuals in one society to persons in other societies. There is much overlap among these discussions, such as concerns about the significance or insignificance of things like citizenship, residency in the same state, or some sense of membership in the same political community. The contrast here primarily is between "statists," who argue that principles or claims of justice only apply within one's state, and "cosmopolitans," who think principles and claims of justice function internationally (Valentini 2011).

Among the cosmopolitan views, we find Peter Singer and Thomas Pogge. In the 1970s, Singer argued that obligations of beneficence require us to address the needs of the poor through famine relief (1972). Since then, he has continued to argue that in a global community, we have obligations to individuals in need even when they are distant and unknown to us (Singer 2004). Regardless of borders—political, ethnic, or otherwise—the demands of global justice require sacrifice from the well-off for the benefit of the less well-off.

Thomas Pogge maintains, with Singer, that wealthy societies are obligated to work to eliminate global poverty and that all of us who live in such societies are morally obligated to work for structures and institutions that

fight poverty. Our failure to do so, including our acceptance of trade deals and other political maneuverings that condemn people to poverty, is morally culpable and constitutes a form of killing. We are "hunger's willing executioners" and we contribute to the problem of global poverty and all that follows from it (Pogge 2008). Unlike Singer, who focuses on the obligation of individuals to render aid and give of their resources, Pogge focuses on the obligation of wealthy states to eliminate tariffs and subsidies that disadvantage poor countries. If necessary, wealthy states should tax natural resource sales and distribute funds to the global poor. Both Singer and Pogge take a cosmopolitan view of justice, holding us responsible for meeting the needs of the poor everywhere, regardless of where they live. In keeping with Singer and Pogge's reasoning, as a wealthy nation and as wealthy individuals, the United States and its citizens are obligated to help those outside the country's borders combat NTDs.

Others hold that membership in a community such as a nation does matter for understanding justice and the obligations that follow from it. One view is that justice claims that support obligations to redistribute aid make sense only within political communities. Thomas Nagel describes the position this way:

> "Socioeconomic justice...is fully associative. It depends on positive rights that we do not have against all other persons or groups, rights that arise only because we are joined together with certain others in a political society under strong centralized control. It is only from such a system, and from our fellow members through its institutions, that we can claim a right to democracy, equal citizenship, nondiscrimination, equality of opportunity, and the amelioration through public policy of unfairness in the distribution of social and economic goods" (Nagel 2005).

The political legitimacy of the state gives rise to the obligations of those within the state and to the legitimate use of state force to promote justice and enforce obligations. In the absence of a legitimate global state, Nagel argues that claims of distributive justice do not apply (2005). We have humanitarian obligations to render aid, but claims of justice and rights secured through distributive justice collapse (2005). It is only through shared participation in a coercive political institution—the state—that we have "associative responsibility" to each other and that claims of distributive justice make sense. This view rejects the proposal that justice requires that people in wealthy countries be coerced to render aid to poor countries, though this account often holds that there are other reasons we are obligated to assist.

Other accounts focus on the degree of social interaction among groups. A higher degree of social interaction yields a greater obligation to redistribute wealth and render aid. The degree of social interaction might follow national or other political borders, but it might not (Cohen and Sabel 2006). On these accounts, it is plausible that ordinarily we will have greater obligations within our communities or nations than outside them. In relation to NTDs, the United States might have more obligations to assist its neighbors, such as Mexico, which shares its southern border, or the United Kingdom, which shares a similar culture, versus other nations such as China or African countries, which are located on the other side of the world and have differing cultures and histories.

Different accounts of the extent to which we have obligations, whether as individuals or societies and whether to individuals within versus outside our communities, affect our thinking about whether and how to respond to NTDs. We might, for example, have an obligation to combat NTDs within our borders and to prevent the introduction of NTDs into our borders, but not an obligation to combat them in other countries, except insofar as it serves our

interests. Others disagree and think that if there is an obligation to those who live in our nation and that the obligation justifies use of state force to redistribute wealth to meet the need, then the same applies to those living in other countries. At this point in time, US federal and state policy aimed at preventing and treating NTDs is minimal; funding for these efforts approximately totals only $100 million (1%) of the $8.5 billion federal global health budget (USAID; KFF).

Appeals to justice and rights are important in discussions of what ought to be done with respect to NTDs. Recognizing competing claims about what appeals to justice and rights require can help bring clarity to policy discussions. Two people might agree on the role of the US government in securing justice, believing that the government ought to use force, such as taxation, to secure a just distribution of resources. One individual could view justice as requiring an equitable distribution of health care resources—everyone should have access to the same treatments based on need regardless of cost. The other could believe that people must have access to a decent minimum level of health care but are free to purchase what they can and want beyond that level. Both share the view that the state ought to use coercive force to secure a just distribution of health care resources, but they believe it should aim at different ends. Thus, the pattern of distribution one seeks to achieve also affects how we answer questions about what the state ought to do.

Despite differences, most accounts of justice and rights will support some effort to combat NTDs, though policymakers should be aware of underlying differences that may lead to policy disagreements and decisions that are likely to be controversial. Development of a substantive and long-term NTD policy in the United States undoubtedly will result from a compromise between these different views on justice and rights. There is no consensus on which substantive theory of justice should be adopted or how it should be applied in developing policy. Nor is it possible to secure consensus through sound rational argument (Engelhardt 1996). If policymakers fail to acknowledge and discuss these disagreements while crafting policy and fail to identify ways in which compromises can generate agreement, they ultimately risk creating policies that cannot be implemented successfully over time due to lack of support.

Do we have special obligations to combat NTDs?

The appeal to special obligations recognizes that certain people stand in special relation to each other, such as parents and children. Relationships generate special obligations that we either do not have to others at all or that are less extensive. Much has been written on special obligations that exist in relationships among family members, especially parents and children (Brakman 1994; Baier 1993). In the context of NTDs, the discussion of special obligations is more likely to focus on questions about obligations within and between communities than on obligations within families, a point addressed already in the discussion of justice. Special obligations are treated separately here because such obligations might exist independent of discussions of justice and rights. One might hold that some populations have special obligations to others that are not grounded in justice or rights but rather in virtue of their relationship. Much like we might hold that parents have special obligations to their children not as a matter of justice or children's rights but by virtue of being parents, we might find other grounds for special obligations to render aid.

One could argue that states have an obligation to their own residents to ensure that basic health needs are met, or that states have an obligation to ensure that their residents or citizens have a fair opportunity to meet their basic health needs. In other words, one could hold that countries in which NTDs are prevalent are responsible for combating

them within their borders. A challenge here is that many countries facing NTDs are too poor to do this. If one accepts the view that "ought" implies "can," then in some cases it is implausible to say that these countries are responsible and ought to combat NTDs on their own (Kant 1934 and 1998). Although the maxim that "ought implies can" is the subject of much philosophical debate, many would argue that it makes no sense to ascribe duties to agents who cannot fulfill them. One might argue that states that cannot afford to combat NTDs ought to facilitate legitimate interventions and cooperate with those who can help.

We often appeal to community boundaries in describing obligations, such as the obligation of public school districts to educate children who live within their boundaries but typically not to educate children who reside in other districts. Others might hold that countries with past relationships, such as former colonial powers, have special obligations to poor countries that were their former colonies (Ypi, Goodin, and Barry 2009). These past relationships generate special obligations to combat NTDs. Some might argue that community membership is not special, since we belong to a global human community (Nussbaum 1994). Pragmatic considerations about the global spread of disease might motivate even those who do not recognize special obligations to others, since meeting their needs regarding NTDs might help us as well. It might even be critical to our own welfare over time. In particular, we might look to all developed nations, or all developed nations deemed "geographically close," as having a special obligation to address NTDs.

There are other ways in which someone might invoke special obligations in the context of NTDs. Different substantive views about whether there are any special obligations pertinent to the discussion of NTDs and, if so, what they are and what they entail are plausible. They are important for policy development insofar as they shape views about who ought to help combat NTDs or who ought to do more to address NTDs. Failure to account for different understandings of special obligations could lead to failed policy, because there will be deep disagreement about the relationships that ground such duties. If promoting a policy that assumes that the global community as a whole has an obligation to address NTDs, as many NTD advocates propose, policymakers must be aware of the objections they might face. It is possible that some efforts to combat NTDs can be justified by an account of special obligations, but efforts in other places will require a different justification.

What would the virtuous person do in the face of NTDs?

An appeal to virtues leads us to evaluate actions or assess what ought to be done through the framework of what a virtuous person would do and how particular virtues would guide decision-making under specific circumstances (Pellegrino 1993; Hursthouse 1999; Annas 2004). The virtues of charity and compassion are particularly important here, given that NTDs affect the poorest of the poor and have significant adverse consequences for individuals, families, and communities.

What would a virtuous person do in the face of NTDs? What would a charitable and compassionate person do? The focus is not on what justice requires and who has rights against whom. Rather, the focus is on the type of person one ought to be and the actions such a person would undertake under the given circumstances. Different substantive accounts of charity, compassion, and other virtues are plausible. For example, some believe that compassion requires that physicians assist patients in ending their lives under some circumstances, while others think assisting in suicide never could be compassionate because it involves participation in something immoral. It is difficult to imagine

accounts of compassion and charity that would suggest we ought to do nothing about NTDs. However, we should expect disagreement about how much effort ought to be put forth and what compassion and charity call for. Do charity and compassion imply only that individuals ought to render some aid, e.g., by giving money or, in the case of some health care professionals, through occasional direct service? Or do they require much more sacrifice?

The appeal to virtue might generate support for a more robust NTD policy from people who otherwise reject government involvement in funding research and treatment. In the context of NTDs, someone who advocates for "smaller government" and believes that the federal government should have a limited role in health care but also has a commitment to virtues such as charity or compassion might support policy efforts to combat NTDs on those grounds.

For many people, their understanding of virtue is informed by religious commitments. Many of the world's major religions recognize a commitment to help the poor, to be charitable, and to be compassionate.[5] It would be impossible and unwise to attempt to summarize the views of the world's religions regarding obligations to help the poor or any other topic. Focusing on three major monotheistic religions, we offer a few cursory examples.

For Christians, Christ's explicit commands and parables highlight the call to compassion and charity. Consider Jesus' commandment to Christians that they show to one another the love Christ has shown to them: "A new commandment I give to you, that you love one another; as I have loved you, that you also love one another" (John 13:34).[6] Jesus also commanded that, "You shall love your neighbor as yourself" (Mark 12: 31). Christians learn about what these commandments mean in part through biblical parables. For example, in the parable of the Good Samaritan, Jesus teaches that we must love strangers in need (Luke 10: 25–37). Great variations exist among Christians, but in general, scriptures provide a basis for Christians to see themselves as having obligations to render aid to others beyond only their friends and family. For Christians, almsgiving is obligatory (Matthew 6: 19–20). Moreover, the care of the poor is a central part of the work of the Church (Acts 6:1–6). This is different from saying that the state should coercively redistribute wealth. Rendering aid through taxation is not almsgiving. Much like the appeal to virtues described above, this may be a personal appeal to Christians.

The Jewish tradition recognizes an obligation of both individuals and communities to be charitable (to render aid to the poor) as well as a duty to rescue (Nahmod 1999). The command to not "stand by idly when your fellow's life is at stake" (Leviticus 19:16 as cited in Nahmod 1999) and rabbinical interpretations of this command form the basis of the individual duty to rescue. Maimonides developed a series of rules that specify this duty, and they include an obligation to warn of and protect from future harm (Nahmod 1999). The duty to rescue refers not only to rescue from imminent danger but also to protect from predictable future harm. Both of these might shape a Jewish approach to responding to NTDs. Within the Jewish tradition there may be a greater obligation to some than others, e.g., relatives over strangers, but the overall appeal to such duties could inform responses to NTDs from Jewish perspectives.

Islam obligates Muslims to render humanitarian aid just as it requires fasting during Ramadan, daily prayer, and a pilgrimage to Mecca (Krafess 2005). The individual obligation to render aid (*zakat*) must be supplemented by communities when individual contributions fail to fulfill needs (Krafess 2005). Not only must individuals give, but the poor are seen as having a right to aid. This obligation to help the poor includes an obligation to help in the event of an emergency, as well as an obligation to provide for long-term needs. Although details vary on how to understand

obligations of charity and toward whom there is such an obligation, the basic tenet that one must support the poor is found in Islam (Kochuyt 2009). Other major world religions, such as Hinduism and Buddhism, similarly recognize an obligation to help alleviate poverty (Galston and Hoffenberg 2010).

A different form of religious appeal is the notion to "take care of your own." This concept of taking care of one's own when it comes to basic needs and significant poverty is controversial and perhaps inappropriate (Brody 2009). Nevertheless, it is plausible that it could motivate some individuals or groups committed only to taking care of members of particular religious communities. To this end, it is worth noting that the vast majority of the people who suffer from NTDs live in Roman Catholic–majority, Muslim–majority, and Hindu–majority countries (Hotez and Aksoy 2011).

In the context of policy, some might object to an appeal to virtues because the obligations that follow sound weak. To say that a virtuous person would render aid implies that "it would be a good thing for you to render aid" rather than "you must render aid." Some might see this as insufficient. People must give, they claim; it is not merely the case that it would be good for them to give. They want an account that might even justify the use of force to fulfill the obligation. This objection points to several issues. First, appeals to virtue are not the only relevant appeals. The appeal to virtue in conjunction with one or more other appeals might yield the more powerful claim desired. Second, it might not be possible to justify the more forceful claim. That we desire a conclusion does not mean we can offer a justified argument for it. Finally, others worry that virtues focus too much on the obligations of individuals and not of communities. In the context of large-scale problems such as NTDs, we need an account of the obligations of communities or states and not merely those pertaining to individuals:

> "Virtue accounts most clearly identify individuals as responsible because only individuals are capable of possessing virtues, and of moral feelings like humanitarian concern and caring. All individuals who are capable should cultivate and act upon these dispositions in order to be good people. The particular duties that individuals have depend on what actions are right for a person to do in exhibiting her virtue. In other words, they are contextual, relative to the particular individual in the particular situation. Exclusively virtue accounts are also exclusively moral, focused on individualized rather than political action, and unable to accommodate collective agents into their framework." (Gosselin 2009)

An account of virtue that emphasizes the importance of charity and compassion might motivate the claim that "something more" ought to be done to combat NTDs. Despite different accounts of virtue, many accounts, including those shaped by some of the major world religions, will support some obligation to help the poorest of the poor who suffer from NTDs. Whether the obligation is enforceable is a different matter.

What will happen if we don't do more to combat NTDs?

The appeal to consequences dictates that "[a]ll other things being equal, the favorable consequences of an action are good reasons for performing that action, even if not always conclusive reasons, and the bad consequences of an action are good reasons for not performing the action, even if one nevertheless might in some cases have better reasons for doing it anyway" (Brody 1988). Because an account of the good is necessary to distinguish between positive and negative consequences, different people may judge the same consequences differently (Engelhardt 1996). Is it worse that children die young, or that adults live long lives in poverty, suffering and shunned?

Differences also emerge when we ask which consequences should concern us. Should we be concerned about the consequences for only certain people or groups? Must we be concerned about the consequences for everyone? Do the consequences for some matter more than the consequences for others?

Decisions both to act and not to act have consequences, both for others and ourselves. On many accounts of the good consequences, an appeal supports the claim that "something more" ought to be done to combat NTDs. The consequences of perpetual poverty and instability for poor countries with significant NTD burden certainly suggest that more ought to be done, especially when these conditions lend themselves to political instabilities. In addition to the consequences for poor countries where many people are affected by NTDs, decisions about combating NTDs also affect us. First, although NTDs largely affect people in poor, less developed nations, there are people in the United States and other developed nations who suffer from NTDs. This is particularly true in the southern part of the country (Hotez 2013b). NTDs are a domestic problem already in the United States, and given the extent to which travelers and soldiers may bring back NTDs as well as the northern migration of vectors carrying the diseases (such as mosquitos) due to climate change, we expect to see more NTDs in the United States in the future (Hotez 2009a).

Wealthy countries already spend funds on development assistance such as food aid and education aid. Given the extent to which NTDs harm productivity, create food insecurity, and make it impossible for people to get out of poverty, it is short-sighted to ignore NTDs (Conteh, Engels, and Molyneux 2010; Hotez 2009b; Hotez and Pecoul 2010). Wealthy countries could look at efforts to develop and provide measures to combat NTDs as a form of development assistance, given the extent to which eliminating NTDs would improve the very conditions other development efforts seek to address (Hotez 2013b). Some have suggested that focusing resources on NTDs might be more appropriate than some other programs that currently receive more support because doing so would have better consequences: "Resources are being transferred to interventions against the big three [tuberculosis, malaria, and HIV/AIDS] that, realistically, have only a limited chance of success as they are reactive and do not adequately control transmission…" (Molyneaux 2004).

Third, NTDs "destabilize communities" by perpetuating poverty, which itself contributes to political instability. In addition, debilitated health infrastructures that result from prolonged conflicts can lead to increased NTDs that can in turn exacerbate the original conflicts (Hotez 2011; Hotez and Thompson 2009). The consequences often spill over to other countries by creating health and political instabilities, especially when dealing with refugees from countries burdened by NTDs. More efforts to combat NTDs could have the good consequence of greater stability in a region.

Some of these considerations may be especially compelling when we consider efforts to address NTDs in the United States and Mexico. Several NTDs that are endemic in one country are shared with the other. For instance, insect vectors carrying the parasite that causes Chagas are common in many areas of South and Central America and through the US–Mexico border states, including Texas and Arizona (Matthews and Herricks 2015). Mosquitos with West Nile Virus are prevalent in the United States and many are worried they will migrate to Mexico, while Dengue and Chikungunya are now being transmitted within the United States (Matthews and Herricks 2015).

Looking at the consequences of NTDs, particularly on the poorest of the poor, we see the harms for those who have or are at risk of developing NTDs. The high prevalence of NTDs also has serious consequences for the rest of the world. An appeal to consequences can support

claims that "something more" ought to be done to combat NTDs. We should expect variation in judgments about how much and what ought to be done as well as where to focus our efforts.

How should we address NTDs?

The appeal to deontological constraints calls for consideration of moral rules that restrict our actions. For example, deontological constraints might prohibit the use of people as research subjects without their informed consent. This appeal perhaps is the one least likely to be invoked in asking whether we ought to do "something more" about NTDs. It is likely to play a greater role in discussions about how to address NTDs. Deontological constraints may be important when we consider the kinds of research that may be conducted on people and under what circumstances.

Different philosophical and religious positions may shape how we answer questions of whether "something more" ought to be done to combat NTDs. Many of these will support the claim that "something more" ought to be done. Once we move beyond the claim that "something more" ought to be done, we face questions about what ought to be done, in what order, by whom, and how.

What Ought to Be Done About NTDs?

Many people will hold that "something" ought to be done to combat NTDs. The focus now turns to further defining the "something." Additional questions that should be addressed include: Where ought something to be done? How much ought to be done? Which priorities should guide decisions about what ought to be done? How ought we pursue research to combat NTDs? The issues are not merely questions of science, economics, and policy. Answering these questions involves making normative judgments. For example, different views about how to prioritize treatment and prevention, or about what risk-benefit tradeoffs are appropriate in conducting research on NTDs, may lead to different approaches to combating NTDs. Decisions on these and other issues will have to be made in crafting and implementing policy to address NTDs. Thus, a range of ethical questions is pertinent in developing policies regarding NTDs beyond the initial problem of what ought to be done. We explore a few examples of the ways in which these issues might be pertinent to policy development. There are numerous other questions and answers that will emerge in policy discussions as well. Our goal here is to highlight some examples and demonstrate the importance of including these questions in the policy process.

Where ought we combat NTDs?

Policy regarding NTDs will have to address the important question of where to focus efforts. The reasons we hold for doing "something more" can affect our views about where to allocate resources, as mentioned in the discussion of justice and rights. Pragmatic, self-interested reasons for addressing NTDs will justify only or primarily those efforts that serve our interests. For example, one might argue that the Unites States can justify special attention to efforts to combat NTDs along the US-Mexico border because of the economic importance of this region for the United States and because of the increased likelihood that diseases found along the border will be spread to other parts of the country. One might justify focusing attention on NTDs that could destabilize countries in which we have strategic interests. NTDs in parts of the world we find to be of little importance to our own objectives—such as underdeveloped countries where we have no economic trade—might be of less concern. Others could argue that increasing globalization means there is no country with which the United States will not have a connection. The notion of the flat world, where global economic and supply chains cross all previous boundaries, means that what happens in far-away places is of great

consequence for the United States (Friedman 2006). The interests of developed industrial economies are bound up with emerging markets. Nevertheless, certain areas still might be more important than others for reasons of self interest.

Individuals who argue that NTDs should be combatted for the sake of addressing global inequities will support much broader efforts. Yet others might focus on combatting NTDs within national borders because they hold that people within particular communities have obligations or special rights to each other, a claim others reject. If we think former colonial powers have special obligations to their former colonies, we might argue that the NTDs prevalent in those former colonies merit greater attention. If we think we have greater special obligations to neighbors rather than to communities far away, we might focus on NTDs in countries that share our borders or are otherwise close by.

Policy scholars should not ignore questions about where to focus efforts to combat NTDs. Different accounts of justice and rights, different accounts of the consequences that matter most, and different understandings of special obligations that might exist shape our assessments of where we ought to combat NTDs. Decisions about where to combat NTDs are bound up with how the United States answers the question of whether and why "something more" ought to be done to combat NTDs.

How much ought to be done to combat NTDs? What will count as success?

Once we conclude that "something more" ought to be done to combat NTDs and where to focus efforts, we face additional questions: How much must be done to satisfy the obligation to do "something more"? How will efforts be evaluated and what will count as success? These questions must be addressed as part of the policy development process so that policies have clear and consistent goals.

Policies without clear and consistent targets are problematic. For example, a general call to eliminate NTDs does not hold the same power as an international mandate to reduce infection rates by a specific number on a specific date. A good example is the United Nations Millennium Development Goals (MDG). They set specific goals, a deadline, and specific metrics by which to measure progress for each goal. Some the MDGs were met by the 2015 deadline, but many were not. The unmet MDGs were used to help develop the follow-up United Nations guidelines—the Sustainable Development Goals—although this set of goals has been criticized as being less focused (Gostin and Friedman 2015).

The reasons for which we think "something more" ought to be done affect the policy goals, measures, and thresholds we choose. For example, someone concerned about inequity might call efforts successful only when inequities are significantly reduced and ultimately eliminated. This requires much more than merely treating and preventing NTDs. It requires attention to many other health disparities. Someone else might conclude that we ought to address NTDs only to the extent necessary to provide a decent minimum level of care. In the context of NTDs, it might mean a reasonable opportunity to receive treatment for a specific condition rather than access to a full spectrum of health services necessary to be healthy. Someone who advocates for doing more to combat NTDs because it is in the country's self-interest to do so might claim success when our strategic interests are protected, such as when NTDs are eliminated or significantly reduced along the US-Mexico border and in the United States. Even where pragmatic considerations such as money limit the goals that can be adopted, prioritizing within the constraints that arise involves normative judgments. These judgments are essential to policy development efforts.

Ultimately, NTD policy development efforts have to set goals and establish metrics if they are to be successful. If the goals are not chosen

intentionally, they are unlikely to be met or to lead to coherent and effective policy. Without goals, the initiative will lose power and support will be harder to maintain long-term.

What priorities will govern NTD efforts?

Even when goals and targets have been established, a number of decisions must be made in setting priorities and establishing an NTD agenda, such as: on which diseases will we focus? Will we focus on certain populations, such as children or individuals living in extreme poverty? Will we focus on disease diagnosis, prevention, or treatment? How much attention will be given to building local capacity to prevent and treat NTDs? Even if we think NTDs should be addressed globally, will efforts be prioritized in certain regions? Is it more important to eradicate or radically decrease the prevalence of disease in a few places or to have a modest impact in many places? Health diplomacy refers to the provision of health care and health services to advance strategic foreign policy goals (Katz, et al. 2011). Should opportunities to exercise health diplomacy influence priorities, such as choosing what to treat and where? In contrast, should poor governmental relationships disincentive collaboration with certain countries, such as Russia or China? Would the possibility of using efforts to address NTDs to serve diplomatic goals lead us to focus on one region over another? Is this permissible? Judgments about where we ought to focus our efforts also affect priority setting.

The moral appeals we use as the basis for claiming that we ought to do "something more" to combat NTDs and the moral theory that informs our description and application of the appeal will shape our priorities. Even if we acknowledge multiple appeals, we must assign them significance for them to serve as action guides (Brody 1988). The significance we attribute to specific appeals affects policy recommendations. For example, imagine someone who recognizes that the consequences of leaving NTDs untreated are grave and that we ought to render aid to combat NTDs. This person also holds, following Nozick, that individuals, as rightful owners of their property must authorize its transfer. Property rights are a type of deontological constraint on our actions. The appeal to consequences and the appeal to deontological constraints are competing appeals. Depending on the significance attached to each appeal, the person in question might conclude that it is justifiable to take property forcibly to achieve good consequences.

The warning here to policymakers is to not ignore the normative questions necessarily involved in priority setting. Nor should they assume that parties will agree on policy priorities; policy is crafted against a background of deep moral disagreement (MacIntyre 1984; Engelhardt 1996). Failure to acknowledge the assumptions at work in policymaking or to recognize areas of conflict can lead to problems adopting or applying a policy. Ignoring critical normative questions might lead to very weak and vague policy that has broad appeal but limited impact. This can occur when the focus on achieving consensus and agreement is bought at the expense of content. Ignoring the questions means that at some point, someone or some group will set priorities, perhaps without carefully assessing the ethical issues at stake. Priority setting is an important and necessary part of policy development, and priority setting involves normative judgments.

How should research on NTDs be conducted?

An important factor in NTD policy development is establishing a research agenda. Should research focus on improving ways to disseminate existing technologies and treatments to make a quick impact, or should it instead focus on developing new therapeutic or preventive measures? Choosing the goals

and priorities that will shape what research is conducted, when, and for what areas involves normative judgments. And these goals and priorities will lead research and funding in different directions. For example, emphasizing treatment versus prevention leads to different research priorities, as do considerations about which diseases and which populations will be addressed and in what order. Research agendas reflect normative judgments.

A range of ethical issues emerges after research priorities are set. How can research be conducted ethically? A simple answer is this: by applying many of the standard research ethics guidelines and regulations to particular settings (Emanuel et al. 2004; Council for International Organizations of Medical Sciences 2002; World Medical Association 2013). For example, researchers must ensure that studies have value and are scientifically valid. Research participants must be selected fairly, and studies must have a favorable risk-benefit ratio. Research also must be reviewed independently. Participants or their representatives must give informed consent, and investigators must show respect for participants and communities. Research also must be a collaborative partnership among investigators, the community, and healthy policy partners in the area (Emanuel et al. 2004).

Determining what each of these obligations means and how to fulfill each one involves normative judgments made in the light of particular circumstances. Specifying the obligations involves answering questions such as: who should conduct the independent review? Who should be part of the collaborative partnership? How will these decisions be made? What does it mean for the risk-benefit ratio to be favorable? How will risks and benefits be assessed? What risks will be tolerated? What potential benefits will be required? What potential benefits help to justify research? What kinds of trials and study designs are acceptable? For example, is it permissible to use placebo or the locally available standard of care as the control? Are challenge studies, in which participants are exposed intentionally to a disease-causing agent, such as a virus, permissible?[7] How will findings be judged and what will count as success? Is it better to have a less effective intervention that can reach more people quickly, or is it preferable to take more time to find a more effective intervention that will be available to fewer people?

To appreciate how significant and controversial these types of questions can be, consider the debate that emerged regarding Ebola vaccine and treatment trials. Randomized controlled trials (RCT), whether they use an active control (ACT) or a placebo control (PCT), often are considered the gold standard in biomedical research. Some argued that all Ebola vaccines and medications should be tested in RCTs because they are best suited to evaluate safety and efficacy quickly (Rid and Emanuel 2014; Joffe 2014). Others advocate for different designs, such as stepped-wedge design or single arm studies that grant at risk populations access to the vaccines. These designs, some argued, could answer the relevant research questions, but also satisfy ethical obligations to participants and communities and maintain community trust (Caplan, Plunkett and Levin 2015; Adebamowo et al. 2014). Others disagreed and thought RCTs, including trials using placebo, were essential in order to get accurate information regarding safety and efficacy.

A wide range of normative questions emerges when we think comprehensively about NTD research. No policy on NTDs could or should answer all of these questions in detail, but the mechanism for addressing them must be in place. Policymakers also must be careful not to assume answers to these questions inadvertently in policy development. Insofar as a policy imposes a particular research agenda, for example, that agenda should be justified; agenda setting involves normative judgments. To the extent that a policy restricts or calls for particular types of research, or insofar as it calls for certain stakeholders to be involved and excludes others, these decisions should reflect a thoughtful assessment of the ethical issues.

It might be appropriate for the policy development process itself to include stakeholder views earlier rather than later to ensure that the relevant issues are identified and addressed prior to adopting and implementing a policy. Where policy recommendations require particular research practices or prohibit others, the policy development process should recognize that these are normative judgments and should be treated as such. To the extent that policy can be crafted to promote ethical research conduct, it should do so. Merely stating that research should be conducted ethically is unhelpful. Some thought to what that means and the structures that must be in place to achieve that goal will be important.

Failure to anticipate the types of normative questions pertinent to NTD research in the process of policy development could lead to policies that cannot be implemented. Or, it could lead to policies that promote unethical practices. Alternatively, the policies developed could be so controversial that they undermine trust in the research process.

Conclusion

Policy development is normative work—it involves repeatedly asking and answering the question: what ought to be done? Policy development regarding NTDs involves a wide range of ethical issues. The claim that NTDs are "neglected" and the claim that "something more" ought to be done to combat NTDs are both normative judgments. Competing moral appeals lead to different accounts of what that "something more" is and how to achieve it. Policy goals need to be established clearly at the outset. These goals will give direction to policy efforts and guide evaluation. To gloss over these questions puts policymakers at risk for ignoring important questions and assuming consensus where there is none, both of which can adversely affect the long-term sustainability of policy recommendations. NTD policy must address questions about what ought to be done, by whom, when, in what order, and how. These normative questions should not be ignored as part of policy development efforts. It is not always appropriate for public policy to address them in detail. Nevertheless, policymakers must be careful that they do not assume answers or pretend that these questions can be side-stepped. Without an appreciation that this process involves making normative judgments, policymakers risk inadvertently making unethical choices. And without taking these questions seriously, we risk developing weak policies that have little substantive impact.

Endnotes

1. For a discussion of the opposition to preventing vertical transmission of HIV, see Mbali 2004. Despite the view that early death contributes to population control, the demographic data suggest the opposite. With longer life expectancy, we see a lower fertility rate (see Lutz and Qiang 2002).

2. John Rawls' *A Theory of Justice* is one of the most widely discussed contributions to contemporary social and political philosophy in the west. He articulates two requirements, invoking both fair opportunity and resource distribution:

- "First: each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others." (Rawls 1971, 60)
- Second: "Social and economic inequalities are to be arranged so that (a) they are to be of the greatest benefit to the least-advantaged members of society, consistent with the just savings principle (the difference principle); and (b) offices and positions must be open to everyone under conditions of fair equality of opportunity." (Rawls 1971, 302)

3. Although the terms "equal" and "equitable" often are used interchangeably, they refer to different patterns of distribution. "Equal" refers to distributing the same amount to everyone. "Equitable" refers to distributing the resource in question proportionally or appropriately given the circumstances. How we think we ought to determine what is proportional or appropriate

varies based on our conception of fairness. For example, equitable distribution might lead to giving some people significant support to reduce the mosquito population and prevent mosquito-borne diseases, while others receive very little or no support because they do not have a mosquito problem in their area. The goal of equitable distribution often is to achieve comparable results for all, recognizing that what is required for different groups or individuals to have comparable outcomes varies.

4. For a critique of "nudge" approaches, see Epstein 2003.

5. See Galston and Hoffenberg 2010 for more detailed discussion.

6. All quotes to Christian scripture are from The Orthodox Study Bible (2008).

7. For discussion of the ethical issues associated with challenge studies, see Miller and Grady 2001; Hope and McMillan 2004.

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