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Reply

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Reply

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I am grateful to those who commented on my book, *Health and Social Justice* (Ruger, 2010b).¹ Due to space limits, I cannot address every point, especially those on which there is agreement, but I will respond to select points of divergence.

I commence with Anita Allen's paper, with which I have very little disagreement. Her elucidation of key ideas and arguments in the book is cogent and discerning. I have learned a great deal from her commentary, and her insights have pushed me to move even further. Her concern about 'a bit' of a 'struggle' to see the 'connection' between two strands of thought in Chapter 5 (relevance of international humans rights to domestic health and positive right to health) is helpful as it relates to some of my global work,² in which I focus on these connections in a theory of global health justice and governance (Ruger, forthcoming). I thank Paul Hunt and Joo-Young Lee for their positive assessment of my scholarship's contribution to 'an important, complex and continuing process that examines the theoretical and operational relationships between development, poverty reduction, health and human rights.' I am delighted to hear that this work has 'enriched' the 'health and human rights communities' and that, as Hunt and Lee observe, my scholarship on non-judicial and judicial accountability (Ruger, 2006, 2008), central health capabilities, and equality and prioritization³ can enhance the work of the United Nations (UN) community. I welcome the continued and deeper 'connections' between my scholarship and the UN community that Hunt and Lee call for in their commentary.

I thank Keerty Nakray for her concerns about institutionalized power relations, which I share. She notes: 'institutional power impedes the "equitable distribution" of resources within and across households ... This applies ... to the healthcare women typically provide.' Nakray wonders how such power relates to 'health capability', 'a unique analytical concept proposed by Ruger.' I agree this relationship is important and requires further investigation (Ruger, 2010a), which is why colleagues and I are currently studying women's health capability and maternal and child health in India. In that study we aim to better understand women's health capability in the context of a participatory community maternal and child health project in Uttar Pradesh, focusing on power and inequality within and outside households.

I also thank Powers and Faden for their pointed critique, which has led me to respond and reiterate some key ideas from the book. Powers and

Faden ‘find the language of capabilities and functioning confusing’ (2006, p. 37); it seems they not only misunderstood some of the basic claims in my approach, but they differ significantly in their interpretation from other symposium commentators – particularly Allen, Hunt and Lee, and Reinhardt – so I will draw on the latter at times for clarification.

First, Powers and Faden claim my approach is not built on a pluralistic teleological theory. This claim necessitates a re-statement of at least two aspects of my theory: plurality of focal variables (primary and secondary) in domains of public policy, and plurality of interests (consequentialist [outcome oriented] and deontological [agency oriented]) incorporated in my ‘health capability’ idea (neither Sen nor Nussbaum has this idea in their work, so relying on their interpretations of other aspects of capability will not suffice.) There are numerous interests (various capabilities, components of well-being or quality-of-life) we value in different aspects of our lives. My approach, of course, recognizes this: ‘[t]he capability approach offers the entire capability set as the focal variable for decisions about macro resource allocation for a theory of social justice’ (Ruger, 2010b, p. 175), and I add that in the overall set of capabilities, health capabilities must be valued *vis-à-vis* other types of capabilities. The harder theoretical issues for questions of justice and health, however, center around what society owes us, if anything, in various domains of our lives, for example, domains of public policy, like health policy, in light of other important concepts, such as opportunity costs. This guiding query helps us understand the contours of what a theory of justice and health might seek to offer. Simply noting that we value multiple aspects of well-being or quality-of-life and should guarantee minimal or threshold levels is well-trodden territory. The conflict and tension: among different aspects of well-being and various institutions and domains of policy focused on ensuring them, and between individual and social goals, require scrutiny. Mine is not a purely ‘separate spheres of justice’ argument; rather, I argue for the need: to distinguish between supplementing and replacing domain-specific criteria in policy assessment, and to keep the domain of health policy related but distinct from other policy domains (Ruger, 1998, 2010b). This avoids ‘health imperialism’ as a single end for all of public policy, as well as irreconcilable plurality leading to ‘discordant positions, irresolution and an exhausted uncertainty’ (Emanuel, 1991, p. 6) in bioethics and health policy.

Second, Powers and Faden assert my approach involves a ‘wholesale displacement of outcomes,’ mis-describing the health capability concept. Rather, the idea of ‘health capability’ includes both health (health outcomes) and health agency as part of its conceptual focal space, including a societal obligation to, as Reinhardt notes, ‘meet health needs.’ Health capability as I define it, is ‘a person’s ability to be healthy,’ and ‘includes health functioning and health agency’ (Ruger, 2010b, p. 3). There is nothing in my theory that excludes health outcomes. The move is not a reductionist one of ‘shifting’ the political end or ‘downgrading’ the status of health. Quite the opposite, my theory ‘broadens the scope of social justice and health policy to include

health functioning and health agency' (2010b, p. 3). If we want a valuable outcome (e.g. health), we want the ability to have it, not just the autonomy not to have it or not to be interfered with having it. Two distinctions are helpful here: the difference between negative and positive freedoms, and the 'vitaly important distinction' that Allen observed in my work:

between arguments for a right to health, construed as a right to equal access or entitlement to health services versus arguments for a right to health, itself ... focus[ing] on whether all persons have what they need to flourish as human beings.

Third, Powers and Faden allege that my theory cannot accommodate concerns of justice and health over the 'full life-course.' They mistakenly suggest that my theory would somehow leave children out of the scope of justice and in a lurch; 'the health needs of children find no place within such a schema.' As a 'cradle to grave' concept, my approach includes the health outcomes and health agency of children as fundamental. Moreover, the book is chock full of concrete examples of ways in which society and children's parents should and can better meet the health needs of children (a few specific examples from the book include: autism spectrum disorders; asthma; maple syrup urine disease; pneumonia; patent ductus arteriosus; children's nutritional requirements; immunizations and vaccine-preventable childhood diseases; special sociolinguistic needs of Hispanic children of non-English speakers; preventing child rape; maternal and infant diseases; public health and healthcare [including preventative measures] for pregnant women and children; prenatal and chronic iodine deficiency). I would part company with Nussbaum (or at least with the interpretation that Powers and Faden ascribe to Nussbaum, and perhaps to Sen, too) on the view that children may be some sort of 'exception to the general appropriateness of a capabilities metric,' a statement I find entirely inconsistent with my own views on the importance of children's health in the health capability paradigm. (This, by the way, is but one of many examples of how my approach moves in different directions from its Aristotelian and capability roots and does not automatically or mechanically 'inherit many of the most persuasive and most contested features of the theories on which [it] relies.') In contrast to Powers and Faden, my focus in the paradigm is on a temporal notion of cumulatively building the ability to be healthy through health and health agency at any given moment and over time, which is why the scope of my project is 'cradle to grave.' In this way, as Reinhardt notes, my approach has something in common with the 'human health capital' perspective found in health economics. However, as Reinhardt points out in distinguishing my theory from that of human health capital, the latter 'merely depicts consumer choice at the level of the individual. It is not a treatise on the just distribution of health-care among individuals.'

Fourth, Powers and Faden's claims about the role of individual responsibility and choices in my theory are imbalanced. They misread my theory as

'insufficient in its application to the diverse range of threats to health other than ones posed by individual choices.' Individual choice and responsibility are but one aspect of the ability to be healthy. They are by no means the whole or even the 'bulk of the story when it comes to justice and health'; neither is 'offering more and better options for choice.' Rather, shared health governance 'means shared responsibility - individuals, providers and institutions have respective roles and responsibilities in achieving health goals' (Ruger, 2010b, p. 9). As Allen asserts, in sharp contrast to Powers and Faden, 'Ruger's theory ... seeks "to enhance individual responsibility through improving health agency". She does not, however, assume that individual choices as such should rule the health system - quite the contrary.' Allen further recognizes my defense of:

a role for government that goes beyond a minimal one. ... Health is not and cannot be something that comes about (or fails to come about) as a 'natural' consequence of atomistic individuals pursuing their wants and needs with whatever resources individual effort can muster.

Powers and Faden's interpretation is also in sharp contrast to Allen's (above) with respect to my distinction on the right to health.

Fifth, Powers and Faden's assertion that my theory does not account for protection from 'health threats in our food, water, and pharmaceuticals, in the healthcare system ...' again, contrasts with other commentaries, and misstates my view. Allen notes the active role I assign to government:

Under a right to health theory grounded in human flourishing, the state - including its agencies like the Food and Drug Administration, the National Institutes of Health and the Department of Health and Human Services - has a moral duty to provide the resources and scientifically grounded evidence-basis necessary for good health "as well as a legislative mandate to provide benefits for health".

I stipulate an active role for 'the state and its entities', which 'hav[e] not only a legislative mandate but also a moral duty' (2010b, p.127) to offer 'significant direction, oversight, regulation, financing, and, in some cases, provision of care' (p. 11). The book is filled with examples of the application of my theory to these areas, including a strong government role in regulation, oversight and provision.

Ruhi Saith has two main concerns. She alleges the book does not 'engage adequately' with either social epidemiology or health economics. Her assertion that 'Ruger's book does not refer explicitly to the discussions taking place in health economics' is incorrect. There is too little space here to enumerate the voluminous discussions in the book, and in my scholarship over the years,⁴ of key concepts in health economics (e.g. quality-adjusted

life years (QALYs), disability-adjusted life years (DALYs), save young life equivalent (SAVE), preferences, utilities, maximization, aggregation problem, contingent valuation [willingness to pay and willingness to accept], risk pooling and economic evaluations in the form of cost-minimization, cost-effectiveness, cost-benefit and cost-utility analysis, just to name a few) and social epidemiology (including the social determinants of health [see for just one example, Berkman and Kawachi, 2000] and application to specific examples, like tobacco and smoking). What is more, I have conducted numerous health economic studies that employ these techniques, not to mention having taught health economics and health measurement in both academic and policy venues. A careful read of the book and its origins would have made clear my long-running concern with the application of the capability approach and health economics.

Finally, I thank Uwe Reinhardt for his critiques, which are in four general areas: communication with laity; policy uptake; theoretical and abstract focus; and policy and political naïveté. His first concern is what he sees as a flaw in the book, the failure to 'communicate with the laity,' to make it accessible to 'lay readers,' even 'health policy analysts outside Ruger's circle of professional peers.' He adds that in addition to my glossary of acronyms, a dictionary that 'bridge[d] the gap' between the languages of the academy and of policy would have helped. His ideal? '[A] shorter, crisper, more reader friendly version aimed at a wider audience' that could 'change the course of health policy in [the USA].' I take his suggestions as a kindly invitation to create a more user-friendly version, and, as he writes, 'perhaps such an effort is yet to come.'

Even without that effort, ample connections already exist between the ideas and arguments in my book and the real-world health policy and legal debates currently taking place in America and across the globe. For instance, the arguments I lay out in Chapter 7, offering a moral framework for analyzing health insurance, have become increasingly important to the current health reform debate around the Patient Protection and Affordable Care Act. They have been cited in support of the Act during legal proceedings in California, Florida, Virginia and Michigan.⁵ Most recently in California and Michigan, the US government cited this work in its appellee brief to the 9th Circuit Court of Appeals and appellee brief to the 6th Circuit Court of Appeals, respectively. Moreover, as Hunt and Lee note, a number of other ideas and arguments in the book, and my scholarship more broadly, have been employed by United Nations organizations such as the United Nations High Commissioner for Refugees, United Nations Children's Fund, United Nations Human Rights Council, World Bank, and World Health Organization, to name a few.

Reinhardt has some complaints about my use of the theoretical framework and method of incompletely theorized agreements to analyze values and principles in health policy decision-making, which had not previously been done: too much theory, too abstract. This approach was first introduced in my 1994/95 Harvard term paper during the unraveling of Clinton's health reform (Ruger, 1995); it was later called 'a new perspective on failed efforts to enact universal health insurance in the United States' by the *Journal of Health*

Politics, Policy and Law (Schlesinger, 2007, p. 3). The excitement about the approach was not in the existence of ethical precepts of equality or equity, which as Reinhardt notes, are not new, but in the approach's spatial analysis of the horizontal and vertical dimensions of the connections or lack thereof (which I called high, mid and lower levels in my analysis) among values and principles in health policy reform. I argued that, from a social agreement perspective, the lack of agreement on a high-level conception or on low-level principles left the mid-level consensus on universal coverage vulnerable to dissolution. While Reinhardt is right that this is a theoretical and abstract academic study, its application was informed, in part, by the lessons I learned as a non-partisan health policy analyst for then-Governor William Weld's Task Force on the Health Care Industry (which sought to achieve universal healthcare coverage in Massachusetts in 1993/94; Safran and Ruger, 1994). My analysis linking theory to policy was described by the *Journal of Health Politics, Policy and Law* as 'lay[ing] the groundwork for policy advocates to take value-based arguments more seriously and for political analysts to explore more carefully how unarticulated value conflicts alter American political discourse' (Schlesinger, 2007, p. 5).

Notes

- 1 References and commentary relates to symposium papers unless otherwise indicated.
- 2 See, for example, publications online [<http://medicine.yale.edu/labs/ruger/publications.htm>].
- 3 See, for example, Ruger (1997, 1998) and publications on the aforementioned website (note 2).
- 4 See, for example, Ruger (1997, 1998) and publications on the aforementioned website (note 2).
- 5 For more information and links to key legal documents, see online [<http://publichealth.yale.edu/news/news/2011/reform.aspx>].

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