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Health, Disability and the Capability Approach: An Introduction[†]

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This special issue of the *Journal of Human Development and Capabilities* focuses on two areas of substantial and growing importance to the human development and capability approach: disability and health. The research on disability, health and the capability approach has been diverse in the topics it covers, and the conceptual frameworks and methodologies it uses, beginning over a decade and a half ago in health (Ruger 1998) and more than a decade ago in disability (Baylies 2002). We are pleased to share a set of articles in these two areas. The first set of articles focuses on disability, while the second set of articles focuses on health and the health capability paradigm (HCP), in particular.

Disability

This special issue starts with three articles on disability. Disability has figured in a number of the writings of both Martha Nussbaum and Amartya Sen (e.g. Nussbaum 2006; Sen 2009a). For example, Sen has used disability in numerous examples while exposing the capability approach (e.g. Sen 1985, 5). Later, Sen stressed the relevance of disability "for the understanding of deprivation in the world" and as "one of the most important arguments for paying attention to the capability perspective" (Sen 2009b, 258). Starting more than a decade ago, the capability approach has been used by other scholars in different disciplines to study various disability issues. For instance, it has been used to consider the relationship between disability and human development (Baylies 2002). It has been used to conceptualize disability in general as capability deprivation among persons with impairments (e.g. Burchardt 2004; Mitra 2006) or in specific contexts, such as education (Terzi 2005) or public policy (Trani et al. 2011). It has also been used to analyze the economic well-being of persons with disabilities, especially with respect to what Sen calls the "earnings handicap" and the "conversion handicap" experienced by persons with disabilities (e.g.

[†]Ruger was guest editor on health and wrote the introduction section on health. Mitra was guest editor on disability and wrote the introduction section on disability.

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Kuklys 2005). The literature at the intersection of the capability approach and disability has grown since and continues to grow, as shown by the disability articles in this special issue.

The Diaz et al. (2015) article analyzes the intentions of a disability policy in Chile. In recent years, increasing emphasis has been placed on program evaluations in development for purposes of learning or accountability by various stakeholders (international organizations, national actors, and donors). The stress has been placed on impact evaluations, and in some disciplines, certain methodologies have become dominant such as randomized controlled trials in development economics. The Diaz et al. article conducts an evaluation of a different kind, nonetheless ripe with insights. It focuses on the intentions of a disability program: the Ministry of Health's home-based care program for persons with severe disabilities aged 65 years and above. The idea is simple: if the intentions of the program are not in line with enhancing justice as per the capability approach, then the program in practice is unlikely to improve the situation of this group and is in need for reform. The authors conduct a content analysis of the official text of the program on underlying intentions of achievement, agency, freedom and well-being. They find that the program's intentions fall short on all accounts, and especially with respect to agency and freedom. This important finding makes us want to ask: Are the intentions of other disability programs in Chile and elsewhere also not justice-enhancing? This could be found by conducting similar studies for other disability programs, run by government or non-governmental organizations. Of course, such an analysis could be applied to policies beyond disability, including in health and poverty reduction. This article shows that, with relatively limited resources, content analysis can provide insights to uncover policies and programs that, in their intentions, do not enhance justice and therefore need reforms. It is thus a useful tool in the researcher and policy analyst's toolbox.

The Mutanga and Walker (2015) article analyzes the capabilities of students with disabilities in higher education in South Africa. While the rights to education for persons with disabilities is recognized under the 2006 United Nations Convention on the Rights of Persons with Disabilities (Article 24), students with disabilities continue to face serious challenges accessing schools or in schools. Efforts to make education more inclusive are hampered by a lack of data and research on these challenges and how to solve them. Mutanga and Walker contribute to fill this gap in the literature by collecting qualitative data from students with disabilities in two universities in South Africa. They identify 11 capabilities valued by the students: aspiration, cultural value, choice of identity, educational resilience, knowledge and imagination, language, mobility, religious affiliation, respect dignity and recognition, social relation and social networks, and voice. Students with disabilities often report lacking these capabilities, so the authors show for students with disabilities, the gap between their lived experiences and what they value in higher education. Their deprivations and valued capabilities have implications for policy. Education policy outcomes typically focus on few quantifiable achievements such as student graduation rates and exam performance. Yet, this study shows that the capabilities students with disabilities value and the deprivations they face are broad and multifaceted. The authors argue that these capabilities valued by students with disabilities can be secured by embedding them in curriculum and in higher education institutions. The authors find that individual agency and choice is important in these students' lives. They conclude that this highlights a contribution of the capability approach compared to other disability models, in that it places individual agency at the center stage.

The Trani et al. (2015) article is a study of multidimensional poverty and disability for Morocco and Tunisia. Unlike earlier such studies in low- and middle-income countries (Mitra, Posarac, and Vick 2013; Trani and Cunnings 2013), the authors have data for all age groups and measure functionings in a wide range of dimensions. They find a significant

association between disability and multidimensional poverty and thus demonstrate the need to include disability in poverty reduction policy, research, and data collection. Studies on multidimensional poverty have multiplied in recent years. The Multidimensional Poverty Index (MPI) (Alkire and Santos 2014), based on the capability approach, is increasingly used in research and policy. In brief, it is a measure of the experience of simultaneous multiple deprivations for households. This article offers a complementary way of implementing a multidimensional poverty analysis in that it uses the individual as a unit of analysis, compared to the household in the MPI. This is suitable for the analysis of potential patterns of disadvantage based on individual characteristics, such as age, sex, and disability status. As a matter of fact, the authors end up finding that persons with disabilities, and especially women with disabilities, are more likely to experience multiple deprivations than persons without disabilities. Such an analysis therefore shows the need for complementary analysis of multidimensional poverty at the individual level. Overall, this article offers the type of comparative assessments that, Sen argues, are essential to develop justice-enhancing reforms (2009a, 401).

Together, these articles, framed in the context of the capability approach, highlight the importance of disability in human development. They show that if development policies are going to positively impact the lives of persons with disabilities, these policies need to enhance the capabilities of persons with disabilities in a wide range of dimensions, including education (Mutanga et al. 2015), health-care services (Diaz et al. 2015), employment, social participation, psychological well-being and physical safety (Trani et al. 2015). Broadly, these articles have implications for assessing capabilities and public policies in human development in general, and for persons with disabilities and other groups, in particular.²

Health

The health articles address a number of themes at the intersection of health and capability. The article by Moczadlo et al. (2015) focuses on an important and understudied pillar the private sector—of the health economy. In the transition from international to global health, the dominance of United Nations agencies and bilateral arrangements has been replaced with a greater focus on private sector development and public-private partnerships. The contemporary global health architecture consists of a plurality of global and domestic health actors, many of which stem from private entities. Some of this transformation has been spurred by government failures and some by advances in technology and science, couched in the recognition that narrow medical interventions are inadequate to the challenge of the social and economic determinants of health. And in terms of human development, a corporation's investment in its employees and consumers' well-being has benefits that accrue in the short and long term, both for companies and for society overall. While a healthier and more productive workforce and clientele mean a greater return on investment for companies, the enhancement of individuals' substantive freedoms benefits all. The resources, innovation, and expertise that corporations can bring to global health is auspicious, for example, Merck & Company, Inc., helped control and eliminate river blindness in affected regions through the donation of Mectizan. Can the distribution networks and supply chain systems of Coca-Cola, for example, be leveraged to deliver condoms or oral rehydration therapy? Despite this promise, more often than not, multilateral corporations succumb to short-term inducements from investors over long-term improvement of societal well-being. Who then holds the private sector accountable?

It is in this context that the article by Moczadlo et al. invites our attention on assessing the corporate impacts on capabilities and sustainable human development. In independently

evaluating health initiatives in the Bayer CropScience's Model Village Project (MVP) this study estimates both the corporate potential and risks. Through a mixed-methods analysis, employing both quantitative and qualitative techniques, of two model and two control villages, researchers concentrate on health and health capabilities and offer results on trust, a vital ingredient to understanding both the process and outcomes of sustainable human development. A key distinction between subjective health perceptions and objective health and nutrition is made and data are collected and analyzed to better understand this gap. Trust is described by the authors as depending upon positive expectations about an individual or organization's motivation or behavior that allows a person to be vulnerable to that entity's actions. Corporate health initiatives, in this context, are seen as "corporate benevolence" that creates the kind of positive experience required to build trust in the asymmetric business relationship between multinational corporations and individuals, in this case farmers, in resource-constrained settings. The asymmetry in resources and power are important dimensions of the context within which private sector organizations either facilitate or thwart capability expansion.

In their results, Moczadlo et al. found a gap between subjective health perceptions and objective health status, demonstrating a significant lack of health awareness, possibly reflecting adaptation, apathy, and insufficient health knowledge. This was particularly acute in assessments of food quality and intake and malnutrition. Malnutrition is one of the most vexing health problems in India, where 39% of Indian children are stunted and 42% of Indian women are underweight before pregnancy due to poor nutrition. Villagers also indicated that health was one of the most important dimensions of their well-being and underscored health agency and responsibility. Half of the population distrusted multinational corporations.

Among the Bayer CropScience initiatives, the health camps served over 850 people, primarily diagnosing the difference between the objective health situation and subjective health perceptions. The water purification plant installation and dissemination had mixed results due to a lack of awareness of the benefits of purified water, and the dental camp treated children who had major dental problems and all children received tooth paste and a tooth brush and planned check-ups every six months. These activities improved villagers' access to health care and to health risk mitigation; the majority of participants saw improvements in their well-being as a result of the health-related activities. There are risks, however, that corporate strategies neglect significant parts of the population and do not replace the role of a strong and reliable public sector. This study underscores the important differentiation between health capabilities and health preferences (affected by habits, traditions, culture, and accepted customs).

The article by Chakraborty et al. (2015) focuses on the health system as a major institution in a health society. This article fits well with the global and national movement for universal health coverage as a sustainable development goal. The post-2015 development agenda is focused on well-being for all and universal health coverage in terms of health promotion, prevention, treatment, and financial risk protection. In their article, Chakraborty et al. analyze the Indian health-care system from a health capability perspective and argue that to address health inequalities, the Indian health-care system should reform the vision of health underlying the national health policy, focus on delivering health services to all, and employ key concepts of the HCP as guiding principles for providing universal health coverage.

Health inequalities in India vary across social and economic groups, yet characteristics of the public health-care system contribute to inequities in the HCP central health capabilities, the capability to avoid escapable diseases and premature death. Many limiting factors of the health-care system exist that include low public health disbursements (4% of GDP) and

very high out of pocket health-care expenditures, both of which create vulnerabilities and insecurities among the population. Additionally, applying the HCP concept of shortfall sufficiency, the allocation, and capacity of health resources in India exhibits a significant underperformance, making it impossible for all to access necessary and appropriate care. Finally, human resources for health are significantly compromised, large proportions of health positions are vacant and rural populations, in particular, lack sufficient information and well-trained and equipped expert personnel and diagnostic and treatment equipment and facilities. Health system deficiencies affect groups' and individuals' actual and potential health.

In order to address these social problems, Chakraborty et al. propose a social justice framework based on the HCP as the basis for public policy for health in India. The authors advance the principle of special moral importance for health capability. With a focus on the central health capabilities, the Indian framework emphasizes the freedom to achieve health functionings and health agency, the ability of the group or individual to pursue valuable health goals. Even if society guarantees equal access to high-quality medically necessary and appropriate health care, individuals must exercise their health agency to translate these resources into good health. The authors argue that the public health-care system and individuals have a shared obligation to create conditions where all can exercise health agency and effectuate health capability and they are especially concerned about individuals' exposure to risk and their ability to adequately manage it. They provide a vision to guide the health system reform in India and policy recommendations for addressing health inequalities.

The next article by Ruger (2015) advances a new interdisciplinary field of study, health capability economics. Health capability economics combines theory and research methods from ethics and economics, using a combination of concepts and techniques from these fields in order to avoid the deficiencies that result from a single-perspective approach. In neoclassical health economics, expected utility, strict rationality, and consumer theory are still used despite their limitations in explanatory power and in providing guiding principles for difficult social problems. The same is true for welfare health economics, which, despite a shift from the microeconomic tools of supply and demand analysis based in consumer theory to the use of the social welfare function to select the "best" social option, is limited in its ability to explain the behavior of individuals and institutions in relation to health, particularly the role of equity and need. While extra-welfarist analysis was an effective move away from both neoclassical and welfare health economics by incorporating nonwelfarist evaluations, such as health in its calculations, extra-welfarism, too, falls short of explaining human behavior and developing guiding principles for public policy, particularly collective choice grounded in social justice. On the ethics side, bioethics and medical ethics, have failed to fully consider opportunity costs and cost functions, efficiency, uncertainty and risk, asymmetric information and other market failures, and health production and health system reform.

Health capability economics emerges to account for these incongruities by integrating ethical and economic factors in understanding individual and societal health decision-making. A predominant issue in health capability economics involves understanding several strata of individual and collective choice in health and health-care. One branch relates to recognizing the major deviations from the conditions of perfect competition — and thus the falsity of the First and Second Theorems of Welfare Economics—of the health and health-care sectors—concerned particularly with uncertainty, information, public goods, and externalities. Economists would argue that violations of the principles of Pareto efficiency and competitive markets put us in a second best world where the best social scientific theory and methods (economic) are compromised. But the Pareto

principle does not include important ethical values, for example, distributional concerns, nor is it necessarily based on people's interests, which can diverge from their preferences (Fleurbaey 2007).

Health capability economics takes a different tack, highlighting three prevalent themes: need, equity, and efficiency. It conveys normative judgments about the fairness of markets for health and health-care and what the goals of health policy and public policy for health ought to be. Health capability economics does not, however, eschew positive economics rather this interdisciplinary field re-orientates positive economics toward the empirical consequences of policies focused on ethically important issues that have normative conclusions. It analyzes—and the founding branch of it advances a particular view of—the normative foundations of criteria for comparing advantage and disadvantage and their distribution across society. What is a fair way in which to allocate resources? How would changes in health policy and health system reform impact health equity? How can equitable public policies affecting health be implemented? What are the implications of public moral norms of equity in health for collective choice and social organization? How should the worst-off be treated by society?

The HCP is the founding branch of health capability economics. The HCP has sought a thorough understanding of the properties of a health society, of ethical principles and empirical methods (quantitative and qualitative) and the allocation of resources in terms of health equity criteria. Its focus has been on individuals' health capabilities in terms of their health functioning, health agency, and health needs. The HCP cross-fertilizes between ethics and economics; a focus on health equity and the shortfall sufficiency principle including priority to the worst-off; justifying a theory of fair allocation in terms of equality in health capabilities as an intrinsically and instrumentally valued component of the capability set. The HCP rejects incommensurable health preferences and utilities and their interpersonal comparisons across individuals and shifts the focus from resources and liberties to capabilities and functionings. The HCP seeks individual achievement and the freedom for achievement, along with equality in capability sets, sets of functionings accessible to individuals, and their health agency. By focusing on capabilities rather than achievements alone, the HCP accounts for both individual and societal responsibility for health equity.

Health capability economics focuses on criteria for evaluating social states and social policies, both at the individual and societal levels. The HCP holds that personal preferences about health and health-care should not be the basis for rank ordering social states, rather individuals' well-considered interests should be the indicator. The HCP provides better resources than neoclassical or standard welfare health economics or extra-welfarism, for normatively grasping individual vis-à-vis social responsibility. At the same time, the HCP incorporates positive economic methods of empirically examining the consequences of policy choices and integrates procedures and consequences in describing and evaluating social states. It broadens the analysis scope beyond the narrow consequentialism found in neoclassical and standard welfare health economics and extra-welfarism. Through a multistage process drawing on insights from ethics, economics, and public health and medical sciences, the HCP offers a way out of the dilemma of providing a small gain to many individuals at the cost of providing a large gain to a person who is badly off and of the dilemma of providing a small gain to the worst-off with exorbitant costs to society and losses in the central health capabilities of others. The HCP also weakens the neoclassical assumption of perfect selfishness in cooperation and social choice and includes studies of fairness, altruism, and inequity aversion.

Starting about a decade and a half ago, capability theory began to be applied to health and health-care (Ruger 1998; Sen 2009b) and subsequent interpretations of the capability

approach have emerged in this growing field of theoretical and empirical scholarship. The article by Kinghorn (2015) takes stock of four applications of the capability approach to health and health-care: the HCP, the OCAP/OxCAP instruments (Lorgelly et al. 2008), ICECAP instruments (Coast et al. 2008), and the assessment of patients with chronic pain. (Kinghorn 2010) The article then discusses a possible path, including issues to be addressed, for future research in this field in the future. The article identifies two key motivations in this field: (1) facilitating agreement on a core concept of health and (2) capability as an alternative to utilitarian health maximization. Kinghorn argues that extra-welfarism, using the Quality-Adjusted-Life-Year (QALY), is an alternative to a strict welfarist approach, but does not constitute an application of the capability approach due to its focus on health maximization and exclusion of capabilities and equity. The article analyzes these four strands in the field in terms, respectively, of the capability set, valuing objects within the capability set, and decision-making.

The scope of and methods used to define the capability set differs across the four approaches. The OCAP/OxCAP instruments (Lorgelly et al. 2008) refine an existing survey, from the British Household Panel Survey based on Nussbaum's 10 central capabilities. Some questions are phrased in terms of functionings while others ask about ability, all are combined into an index of 18 questions. The ICECAP instruments (Coast et al. 2008) are used for different populations: older people, the general adult population (Al-Janabi, Flynn, and Coast 2012), and supportive care at the end of life. The patients with chronic pain assessment (Kinghorn 2010) is participatory and focuses on identifying capabilities important to patients with chronic pain. It has been developed into a questionnaire for such patients. The HCP focuses on two central health capabilities (Ruger 2004). Quantitative research has been conducted with this approach to understand the impact of health insurance reforms, the effect of health expenses on household capabilities and coping mechanism among poor households in Vietnam (Nguyen et al. 2012a, 2012b, 2012c). Health agency has been studied qualitatively in India (Feldman et al. 2015).

Kinghorn (2015) also compares and contrasts the different approaches in valuing objects in the capability set. For example, for the OxCAP-MH (Simon, Anand et al. 2013), equal weights were assigned to each dimension, combined into an index, and for the ICECAP instruments best—worst scaling is used, whereas researchers and policy-makers can employ the health capability profile with scales and subscales (Ruger 2010). Health capability profile constructs have been developed for studies in Vietnam, and empirical health systems and medical research in low- and middle-income countries have employed the HCP. Central health capabilities can be determined through a process of incompletely theorized agreements with priority for central, above non-central, health capabilities. Like the HCP before, the ICECAP constitutes life as a prerequisite for other capabilities and thus absence of life is equal to absence of capability. The chronic pain instrument treats physical and mental well-being as a central capability such that the overall well-being score is reduced to zero where no capability exists in these dimensions.

For decision-making, the article argues that the ICECAP (Coast et al. 2008) uses preference-type information to create a common index and completely ordered states, while the chronic pain instrument (Kinghorn 2010) explores relative values but does not provide a general rule. The HCP advances shortfall sufficiency to determine need and priority for which a partial ordering of health capabilities or health functionings is what is required for analysis. A minimal threshold, as a minimum obligation to society, sets a constraint on redistribution. In the HCP, efficiency is also an important consideration in addition to equity; resources are used efficiently toward those in need as opposed to increasing the greatest general overall societal welfare. Applications of the HCP have conducted empirical

and ethical work on adult and child mortality, employing cluster analytical techniques, to establish a global norm or threshold of achievable health (Ruger and Kim 2006; Ruger 2006). Adopting shortfall sufficiency with equity and efficiency criteria would result in substantial policy and research shifts as compared to other allocation schemes. For example, the HCP would prioritize areas such as rare diseases with a smaller demographic but a greater share of resources. The article endorses shortfall sufficiency and gives it "monopoly-like status" because the author argues that it is the only suggestion found in the four approaches.

Kinghorn (2015) then goes on to discuss the implications of taking health as the sole objective for analysis as compared with, or even in addition to, evaluating health within the broader capability set. The HCP addresses this empirically and theoretically with health capabilities as part of the broader set of capabilities in allocating resources and extends beyond the QALY metric to include the ability to pursue health as well as health outcomes. The HCP also extends the determinants and sectors influencing health beyond health care alone. The HCP and extra-welfarism share the position that health deprivations below the threshold cannot be compensated by expansions elsewhere in the capability set and the HCP identifies the intrinsic and interrelated importance of health capabilities. By contrast, the ICECAP-O/A has no dimensions directly related to health and would need to be used in conjunction with a health-related instrument. From the ICECAP-O/A perspective the relevant endpoint is a broad concept of well-being. The patient with chronic pain assessment includes measures related to life expectancy and attention-seeking symptoms, such as physical discomfort, pain, and depression. For the patients with chronic pain assessment, both symptoms and broader well-being are important. While directly assessing capability is not possible, research on health agency focused on "perceived abilities" as well as "abilities", whereas other approaches have attempted to ask people about their functioning levels and their freedoms to function in terms of self-reported functionings and self-perceived capability.

The articles in this special issue on disability and health all attempt to develop or apply conceptual frameworks related to the capability approach to develop better policies and assess their impacts. While these articles are not necessarily representative of the scholarship on disability and health through the lens of the capability approach, they show part of a diverse and rich body of research that has been developing in these areas.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes

- The bibliography published as an online addendum to this issue provides a compendium of works on health, disability and the capability approach.
- 2. It should be noted that the health articles in this issue are not unrelated to disability and may well have implications for the analysis of disability issues through the capability approach. For instance, the Health Capability Paradigm and its consideration of needs is pertinent to the analysis of the conversion handicap mentioned above. In addition, the three interpretations of the capability approach in a health-care context that focus on assessing well-being overall (OCAP/OxCAP, ICECAP, chronic pain assessment), as reviewed in the article by Kinghorn, can be considered as assessments of disability conceptualized as capability deprivation among persons with impairments or health conditions (Burchardt 2004; Mitra 2006, Forthcoming).

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Jennifer Prah Ruger is Associate Professor of Medical Ethics and Health Policy and Senior Fellow of the Leonard Davis Institute of Health Economics at the University of Pennsylvania. She is the author of over 100 publications, including her book, Health and Social Justice (Oxford, 2009), about which a 2011 book symposium was published in the Journal of Human Development and Capabilities (JHDC). She was the founding coordinator of the Health and Disability Thematic Group of the Human Development and Capability Association (HDCA). In 1998 she completed her PhD Dissertation at Harvard University under the supervision of Amartya K. Sen and committee members, Joseph Newhouse and Jerry Green, entitled, Aristotelian Justice and Health Policy: Capability and Incompletely Theorized Agreements. In 2011, she received a Guggenheim Fellowship and in 2014 she was elected a lifetime member of the Council on Foreign Relations. Her research is conducted internationally and nationally, including work in Ghana, India, Indonesia, Malawi, Malaysia, Morocco, South Korea, South Africa, the United States and Vietnam.