HUMAN RIGHTS LAW IN PERSPECTIVE

Health and Human Rights

THÉRÈSE MURPHY

HEALTH AND HUMAN RIGHTS

This book aims to bolster the burgeoning discourse of health and human rights. In so doing, it charts the history of the linkage between health and human rights. It also pinpoints the sense of imperative that surrounds this relationship. More importantly, the book identifies a series of threats and challenges facing attempts to link health and human rights and proposes how these might be addressed. Amongst other things, it asks: is conflict between risk and rights inevitable in the context of infectious disease control? Is reproductive choice a bad argument in the context of reproductive technologies? Is it sensible for human rights to make use of measurement tools such as indicators? Is the 'cost of human rights' an argument that can and should be used by proponents of human rights? The answers it gives to these questions are original and engaging and will be of great interest to a diverse audience, including scholars and policy-makers in these areas.

Volume 18: Human Rights Law in Perspective

Human Rights Law in Perspective

General Editor: Colin Harvey
Professor of Human Rights Law
School of Law
Queen's University Belfast

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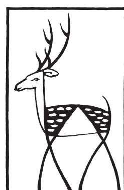

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Thérèse Murphy

Series Editor's Preface

2013 marks the 10th anniversary of *Human Rights Law in Perspective*. Since the publication of the first book in 2003, the Series has provided a forum for critical voices in human rights law. It has surpassed expectations, in terms of the depth, range and quality of the contributions. *Health and Human Rights* by Professor Murphy rests within the best traditions of the Series and legal scholarship in general.

It would be easy to be overwhelmed by the scale of doctrinal materials on human rights. The risk of thoughtless forms of legal scholarship and legal practice is always there. This work stands firmly against such trends, by constantly asking the searching questions about human rights, and human rights legal method in particular. It is a book that falls squarely within the *in perspective* spirit of the Series. In this sustained and original analysis of health and human rights, Professor Murphy notes the problem of human rights becoming buried within 'legalism', and provides convincing evidence why human rights scholars must 'think within and against' human rights law. The critical perspective adopted flows consistently throughout this work. There is a strong desire here to keep the critical conversation about human rights going, to resist closure, by subjecting health and human rights to a critique that places legal method 'centre stage'. This impressive and significant book will inform critical thinking about human rights law and practice now and in the future; it is a privilege and pleasure to welcome Professor Murphy to the Series.

Colin Harvey
Belfast, June 2013

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Introduction

I STARTED WORK on this book in order to solve a puzzle. This chapter introduces that puzzle; it also describes the broader aim of the book and previews what follows. The puzzle itself is simple enough. Put briefly, can my optimism about what is known as 'health and human rights' be reconciled with the fact that human rights and human rights advocates are being attacked from various quarters, and crucially, at least some of the criticisms strike a chord with me? Getting past this puzzle—finding a way to combine hopefulness and critique—is not so simple, however. In part this is because health and human rights is an extraordinary mix. In places it is akin to a manifesto, elsewhere it promotes management and technical intervention, and elsewhere again it is highly reflexive—and all the while, elaboration of legal rules affecting health is on-going. In part, too, scepticism about rights gets in the way: are human rights a hollow hope? Do they really have dark sides, and is paradox ever present?[1] There is also, frankly, too much advice. Ranging from good practice primers to interrogations of human rights, this advice counsels everything from more law, more institution-building and more regime coherence, to tackling conceptual doubts and changing habits.

Above all, however, nothing feels simple because the book that follows is not one I expected to write. Its topic—health and human rights—drew me in, but it is not a long-time interest of mine. The same is true of the right to the highest attainable standard of physical and mental health,[2] one of the book's key sub-topics. At the outset, the health rights with which I was familiar seemed very different to the right to health. The right to respect for private life, for example, insofar as it gives patients the right to refuse necessary medical intervention—including for bizarre or irrational reasons or for no reason at all—felt nothing like the sort of entitlement claim that

[1] See W Brown, 'Suffering the Paradoxes of Rights' in W Brown and J Halley (eds), *Left Legalism/Left Critique* (Duke University Press 2002); D Kennedy, *The Dark Sides of Virtue: Reassessing International Humanitarianism* (Princeton University Press 2004); O O'Neill, 'The Dark Side of Human Rights' (2005) 81 International Affairs 427; G Rosenberg, *The Hollow Hope: Can Courts Bring about Social Change?* (2nd edn, Chicago University Press 2008).

[2] See, eg, International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR') art 12.

might fall under the right to health. True, the right to health encompasses both entitlements and freedoms, but where, I wondered, was the common ground between such apparently different types of rights; between positive rights, on the one hand, and their allegedly negative counterparts, rights to be left alone, on the other? Surely it would not be enough to gesture towards the Universal Declaration of Human Rights, which contains human rights of all kinds, as some sort of totem?[3] In any event, the Declaration in turn raises the question of how we are to relate health to matters that have an effect on health (housing, education, food and the like), many of which have their own independent standing as human rights, without also conflating the two?

There is one obvious answer to these questions: rights of all kinds face criticism and praise alike. That, in short, is the common ground. Given the book's aim, however, such a broad answer is not helpful. Less helpful still is the array of criticism levelled, largely by philosophers, at the right to the highest attainable standard of health. Some of that criticism is devastating: this right, absent a theoretical account of its foundations, is apparently 'not an appropriate starting point for an inquiry into just health'.[4] More than this, it is a 'vacuous concept', best demoted from the list of rights recognised under international law.[5]

The problems multiply when public health enters the picture. True, its status as a limit on rights is apparent and seems sensible; relatedly, in recent years, its status as a limit on intellectual property rights has been widely promoted as a way to increase access to essential medicines, most of all antiretrovirals. Public health also seems central both to the origins of the health and human rights field (the AIDS pandemic is widely seen as the crucible from which the movement grew) and to its future. Public health, to be frank, seems to be sparking some of the freshest thinking in the field, ranging from proposals for a global health law convention and a Health Impact Fund, to population-based legal analysis.[6] Yet public health, ever a creature of eras and paradigms, can also be no friend of human rights. Balance is widely invoked, but in practice, a zero-sum—compelling a choice, 'public health *or* rights?'—is just as likely. In this context, synergy between human

[3] Universal Declaration of Human Rights (10 December 1948) UNGA Res 217A (III), UN Doc A/810 (hereafter 'UDHR').

[4] N Daniels, *Just Health: Meeting Health Needs Fairly* (Cambridge University Press 2008) 15.

[5] J Griffin, *On Human Rights* (Oxford University Press 2008) 209. *Cf* C Fabre, *Social Rights Under the Constitution: Government and the Decent Life* (Oxford University Press 2001); JP Ruger, *Health and Social Justice* (Oxford University Press 2010); J Wolff, *The Human Right to Health* (Norton Press 2012).

[6] See respectively LO Gostin and AL Taylor, 'Global Health Law: A Definition and Grand Challenges' (2008) 1 Public Health Ethics 53; A Hollis and T Pogge, *The Health Impact Fund: Making New Medicines Available for All* (Incentives for Global Health 2008); W Parmet, *Populations, Public Health, and the Law* (Georgetown University Press 2009).

rights and public health (or between human rights and global health, public health's newer international counterpart) looks like a pipe dream. And it does not help that judges have sometimes been credulous with regard to those who claim to act in the name of public health.[7] Or that the history of public health, in particular the history of state interventions in response to outbreaks of infectious disease, is replete with instances of discrimination.

Public health's many different eras and paradigms also make it hard to be clear-headed about new ideas, whether state stewardship, health security or even global health. Newness, it seems, can go unseen for long periods. Consider the range of non-state actors at the cutting edge of public health interventions today—from philanthropists to humanitarian and human rights non-governmental organisations (NGOs), from religious groups to the public–private partnership of the Global Fund to Fight AIDS, Tuberculosis and Malaria. In places these actors are almost substitute states—by which I mean they act as or instead of the state, and with budgets that many states cannot even dream of. Yet to what extent are these actors accountable under human rights law? And recognising that civil society can be as much derided as acclaimed, to what extent does human rights law protect non-state actors from interventions dressed up as accountability?

There is, of course, a duty on states to protect human rights (not just to respect and fulfil them), which means that measures have to be taken to prevent third parties from interfering with rights, including the right to the highest attainable standard of health.[8] But what is—and what should be the scope of this duty? And in practice, how often will it be feasible for an individual state to take on a powerful non-state actor, one that could well be a global economic player able to call upon the support of other states?

These questions lead in turn to the following one: how sensible is it for human rights to pursue non-state actors as *direct* duty-bearers at a time when shrinking the state and promoting personal responsibility are orthodoxy in parts of the world? I appreciate it does not have to be a case of 'either/or'. Still, under current circumstances, might it be better for human rights to focus on states—on, say, the obligation to protect and on states' extraterritorial obligations (both global ones, such the obligation of international cooperation, and those arising from the exercise of control, power or authority over people or situations outside a state's territory)?

In similar vein, it has to be asked: to what extent does the humanitarian biomedicine practised by at least some of today's non-state actors accord

[7] *Cf Toonen v Australia* (31 March 1994) UN Doc CCPR/C/50/D/488/1992, discussed below ch 1; *Minister of Health and Others v Treatment Action Campaign and Others* 2002 (5) SA 721 (CC), discussed below ch 3.

[8] See, eg, Committee on Economic, Social and Cultural Rights (CESCR), 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/49, para 35.

with either the enthusiasm for health security that has taken hold in both international organisations and a range of wealthy states in the wake of SARS and other pandemics, or the broader turn towards a more belligerent humanitarianism focused on individual criminal accountability for human rights violations and military intervention in support of that goal? And relatedly, but more generally, who or what prevents commitments such as global health security and humanitarian biomedicine from working at cross purposes, and who or what facilitates collaboration—collaboration that is infused by human rights obligations vis-à-vis both outcome and process?[9]

Soon the questions seem unstoppable. Has there been a pharmaceuticalisation of public health such that attention and resources are now flowing towards drugs and away from health systems, and will this produce a turning towards courts by individuals and groups seeking access to expensive medicines? Also, is public health on the verge of a neuro turn?[10] The neurosciences have certainly commanded considerable attention from a range of states and others too. And the World Health Organization (WHO) estimates that by 2020 depression will be the second leading cause of morbidity worldwide.[11] But what will emerge from this increasing centrality of neurology and mental health care? And crucially, is human rights prepared?[12] The WHO, for its part, has declared that ethics is 'the basis for its Health For All (HFA) policies and practices', guiding all aspects of planning and implementation, and that equity is 'the foundation of HFA in the 21st century'.[13] Is human rights prepared for this: in particular, what place is there for human rights in a line-up focused on equity and ethics? Moreover, how prepared is human rights for today's inequities in health, for 'the huge and remediable differences in health between and within countries … [the] [s]ocial injustice [that] is killing people on a grand scale'?[14]

[9] 'Interaction'—eg, how institutions and legal orders interact—is an area of growing interest for legal scholars: see, eg, N Krisch, *Beyond Constitutionalism: The Pluralist Structure of Postnational Law* (Oxford University Press 2012). For an interactional account of law, see J Brunée and S Toope, *Legitimacy and Legality in International Law: An Interactional Account* (Cambridge University Press 2010).

[10] On this turn see, eg, N Rose and JM Abi-Rached, *Neuro: The New Brain Sciences and the Management of the Mind* (Princeton University Press 2013).

[11] See www.who.int/mental_health/advocacy/en/Call_for_Action_MoH_Intro.pdf.

[12] Rights-based approaches to mental health have long provoked contrasting views: compare, eg, LO Gostin, 'Beyond Moral Claims: A Human Rights Based Approach in Mental Health' (2001) 10 Cambridge Quarterly of Healthcare Ethics 264, with N Rose, 'Unreasonable Rights: Mental Illness and the Limits of Law' (1985) 12 Journal of Law and Society 199. See further B McSherry and P Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart Publishing 2010); M Dudley et al (eds), *Mental Health and Human Rights* (Oxford University Press 2012).

[13] WHO, 'Health for All in the Twenty-First Century' (1998) WHO Doc A51/5, boxes 6, 7.

[14] Commission on Social Determinants of Health (CSDH), Final Report: 'Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health' (WHO 2008), executive summary.

Thinking about the neurosciences leads to science and technology more generally—to nanotechnologies, biotechnologies and so on. This, however, makes the health and human rights puzzle more complex still. True, there is an emergent international law of life sciences, including both a clutch of UNESCO declarations and a UN Declaration on Human Cloning, which calls on member states to 'prohibit all forms of human cloning inasmuch as they are incompatible with human dignity and the protection of human life'.[15] Equally, the relationship between human rights and new technologies in general has been drawing attention. In *S and Marper v UK*, for instance, the European Court of Human Rights (ECtHR) issued a warning to technology-hungry states that any take-up of new technologies in the criminal justice sphere must not lead to article 8 of the European Convention on Human Rights (ECHR) becoming 'unacceptably weakened'.[16] Moreover, even the long neglected right to enjoy the benefits of scientific progress and its applications, as found in article 27 of the UDHR and article 15(1)(b) of the International Covenant on Economic, Social and Cultural Rights,[17] has begun to draw human rights attention.[18]

Why then do matters seem worse? Because, quite simply, new questions pile up. For instance, if poverty is the biggest killer—almost a third of all human deaths, 18 million annually, are due to poverty-related causes such as malnutrition or diarrhoea[19]—is it right for the health and human rights law agenda to be alert to new technologies? Or is this in fact a bad case of wrong priorities? The attempt a few years back to produce an international treaty to ban the reproductive cloning of human beings certainly seemed both peculiar and peculiarly wasteful of both state and UN resources. Indeed, as Laurence Gostin and Allyn Taylor have asked, 'How precisely did human cloning become a global health issue?'[20]

On the other hand, there are also reasons to *encourage* human rights engagement with new technology questions—partly because of the potential of particular technologies, partly because it is unclear what the risks are and partly because as health technologies explode in number, reach and

[15] See also the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (4 April 1997, entered into force 1 December 1999), ETS 164 (hereafter 'Oviedo Convention') and its additional protocols.

[16] *S and Marper v United Kingdom* [GC] (2009) 48 EHRR 50, para 112. See generally T Murphy and G Ó Cuinn, 'Works in Progress: New Technologies and the European Court of Human Rights' (2010) 10 Human Rights Law Review 601.

[17] ICESCR (n 2) art 15(1)(b).

[18] On art 15(1)(b) see, eg, Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and Its Applications (2009), www.shr.aaas.org/article15/Reference_Materials/VeniceStatement_July2009.pdf; UN Human Rights Council (UNHRC), 'Report of the Special Rapporteur on Cultural Rights, Farida Shaheed' (14 May 2012) UN Doc A/HRC/20/26.

[19] WHO, 'The Global Burden of Disease: 2004 Update' (WHO 2008) 54–59, table A1.

[20] Gostin and Taylor (n 6) 58.

significance, their very availability challenges people's understandings of health and health care needs. These latter challenges in turn produce deep challenges for health rights, whether we see such rights as grounded in a minimum core focused on survival needs, in dignity or relatedly in freedom, or simply in the growing consensus regarding the scope and content of these rights.

New health technologies also produce non-health questions for human rights. One such question that is important from a non-discrimination perspective even if it isn't currently a question of global relevance concerns the almost simultaneous rise of both biobanking and forensic databases. The latter, promoted for their utility in crime control, tend to be run by states; the former, by contrast, are often run by universities or private companies and are promoted for their research benefits and hence their alleged benefits for the health of 'all of us'. A further contrast between the two is that biobanks generally invite 'giving' via a gift relationship, whereas with forensic databases, an individual might have no choice at all even if she has been acquitted or if her case has been discontinued. These basic differences produce questions that should be drawing attention from human rights—including who exactly is expected to give altruistically to biobanks, and who is in a biobank versus who is in a state's forensic database?[21]

The human rights/bioethics relationship is another issue thrown into sharp relief by the hope, hype and fear that envelops emerging technologies. Law and lawyers have of course often been found 'cheek-by-jowl'[22] with bioethics and bioethicists: the rise of patient autonomy is perhaps the prime example of this. Yet on the really interesting question—which isn't 'Has bioethics mixed with law?' but rather 'How have they mixed and with what effects?'[23]—human rights lawyers have said remarkably little.[24] Indeed, at one point during European law-making on xenotransplantation, representatives of the European Court of Human Rights advised that the ECHR 'should be understood as a legal instrument aimed at securing

[21] See, eg, *S and Marper* (n 16) para 44 wherein the ECtHR emphasised that, as applied, the UK's retention policy had led to the overrepresentation in the national DNA database of 'young persons and ethnic minorities, who have not been convicted of any crime'.

[22] SM Wolf, 'Law & Bioethics: From Values to Violence' (2004) 32 Journal of Law, Medicine and Ethics 293, 294.

[23] Ibid.

[24] The arrival of UNESCO's Universal Declaration on Bioethics and Human Rights (2005) did not change this, though it did prompt engagement by bioethicists, some of whom were concerned that human rights might subsume their field. See further RA Ashcroft, 'The Troubled Relationship between Human Rights and Bioethics' in MDA Freeman (ed), *Law and Bioethics* (Oxford University Press 2008).

individual rights and as such it may be of limited relevance to policy issues in the field of bioethics'.[25] That, to be blunt, cannot be correct.[26]

Human rights lawyers have also said little about the enthusiasm for public bioethics and, relatedly, citizen participation in science and technology decision-making,[27] which have been developing apace in certain settings. There is a real need to engage both empirically and conceptually with these developments. On the other hand, the right to health in international law encompasses an obligation to abolish traditional practices prejudicial to the health of children, and that hasn't really been engaged with either—at least not in ways that are clear of cultural and gender bias, and with imagination that reaches beyond the criminal law.[28] So that too could be described as a pressing matter.

Another matter marked by under-engagement (allied, at times, with unthinking evangelism) is the relationship between dignity and rights.[29] Often one finds them listed together, sometimes alongside 'fundamental freedoms',[30] implying both a connection between them and at least some degree of difference. How, then, should we see these connections and differences? Is dignity best conceived as, say, the ground of rights? Or as the content of rights?[31] And as regards health rights, does the growing body of case law suggest a judicial preference for dignity over freedom, equality, societal or international consensus, or a focus on what is needed for survival in giving effect to these rights?

[25] Explanatory Report on Draft Recommendation Rec (2003) 10 on Xenotransplantation (19 June 2003), wcd.coe.int/ViewDoc.jsp?id=39603&Site=CM.

[26] A point that seems now to be recognised: see Research Division of the European Court of Human Rights, 'Research Report: Bioethics and the Case-law of the Court' (Council of Europe/European Court of Human Rights 2012).

[27] *Cf* DJ Galligan, 'Citizens' Rights and Participation in the Regulation of Biotechnology' in F Francioni (ed), *Biotechnologies and International Human Rights* (Hart Publishing 2007); R O'Connell and S Gevers, 'Fixed Points in a Changing Age: The Council of Europe, Human Rights and New Health Technologies' in M Flear et al (eds), *European Law and New Health Technologies* (Oxford University Press 2013).

[28] *Cf* M Sabatello, *Children's Bioethics: The International Biopolitical Discourse on Harmful Traditional Practices and the Right of the Child to Cultural Identity* (Martinus Nijhoff 2009); J Tobin, *The Right to Health in International Law* (Oxford University Press 2012) 303–24. For the obligation itself, see Convention on the Rights of the Child (20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (CRC) art 24(3).

[29] *Cf* S Liebenberg, 'The Value of Human Dignity in Interpreting Socio-Economic Rights' (2005) 21 South African Journal of Human Rights 1; C McCrudden, 'Human Dignity and the Judicial Interpretation of Human Rights' (2008) 19 European Journal of International Law 655; KG Young, *Constituting Economic and Social Rights* (Oxford University Press 2012) 33–65. See more generally D Beyleveld and R Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press 2001); C Foster, *Human Dignity in Bioethics and Law* (Hart Publishing 2011).

[30] See, eg, UN Educational, Scientific and Cultural Organization (UNESCO), Universal Declaration on Bioethics and Human Rights (19 October 2005) arts 2(c) and (d).

[31] On these options, see J Waldron, *Dignity, Rank, and Rights (The Berkeley Tanner Lectures)* (Oxford University Press 2012).

There has also been less human rights law engagement than might have been expected on the relationship between cures, scientific research and markets. Access to essential medicines has of course drawn extraordinary state and non-state activism, at least as regards antiretrovirals. But what it means to spend so much on medicines and, more generally, what it means to be so focused on cures and interventions have drawn far less attention.[32] Is human rights activism on access helping to grow the drug market, for instance? Is it, as a consequence, shrinking opportunities to ask 'Are there things that should not be cured?' And is it sufficiently alert to the deep equality and justice challenges involved?[33]

To summarise: this book's content was not just new to me, it was also challenging—and that challenge proved deep and persistent. There was yet another hurdle, however, which seemed more challenging again. Strange though it may sound, the argument at the core of this book is not one I had in mind when I started to write. The argument concerns human rights method—specifically, the *legal* version of that method and, more specifically still, the *legal scholars'* version of it. Stated simply, what this book proposes is that engagement with human rights legal method is essential.

Yet legal method is dull-sounding; human rights legal method more so. Who would choose method when human rights provide opportunities to examine and, more importantly, to affect both power and empowerment? Also, given that the point of the book is to solve a puzzle and, in so doing, bolster the field of health and human rights, there is clearly a lot of pressure to make the right sort of argument. There is, for instance, a sense of imperative coursing through health and human rights in both its activist and its scholarly forms.[34] It drives the relationship and is engendered by it, and it is striking and, to be honest, quite captivating. Consider maternal mortality: seeing the problem of maternal mortality as a matter of rights—not as a twist of fate, as a question of individual behaviour or indeed as a

[32] CESCR, 'General Comment No 14' (n 8) para 19: 'Inappropriate health resource allocation can lead to discrimination that may not be overt. For example, investments should not disproportionately favour expensive curative health services which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population.'

[33] To what extent, for example, has human rights responded to the call by A Buchanan et al, *Chance to Choice: Genetics and Justice* (Cambridge University Press 2000) for a 'genetic decent minimum' for all?

[34] See, eg, JM Mann et al (eds), *Health and Human Rights: A Reader* (Routledge 1999); P Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (University of California Press 2005); S Gruskin et al (eds), *Perspectives on Health and Human Rights* (Routledge 2005); RJ Cook and CG Ngwena (eds), *Health and Human Rights* (Ashgate Publishing 2007); A Clapham et al (eds), *Realising the Right to Health* (Rüffer & Rub 2009); J Harrington and M Stuttaford (eds), *Global Health and Human Rights* (Routledge 2010); AE Yamin and S Gloppen (eds), *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Harvard University Press 2011); Tobin (n 28); B Toebes et al (eds), *Health and Human Rights in Europe* (Intersentia 2012).

tragedy—facilitates a critical change of frame. In the rights-based frame, suffering has to be taken seriously.[35] The problem of maternal mortality gets broken down, the challenge of *avoidable* maternal mortality emerges and, crucially, meeting that challenge becomes a duty, not an option—a duty for which those responsible can and must be held accountable.

But if that is the power of health and human rights, am I wrong to be writing a book that puts human rights legal method at centre stage? Isn't it the case that, whether one comes to health and human rights out of conscience, necessity or both, there are matters more pressing and more important than method? Put bluntly, isn't method a marginal matter? I had no trouble with these questions at the outset; method, for me, was marginal—so marginal I bypassed it. But as work progressed, my stance changed. It is true that human rights method has been a non-topic (at least in legal circles)—a matter more disregarded than studied.[36] But does that mean it is lacking in worth or utility, or that it is boring? Perhaps it has been misunderstood.

I. AN ARGUMENT FOR METHOD

To explore this, let's consider human rights legal method beginning with Robert Jennings' oft-quoted claim that the interpretation of treaties is an art, 'though it is part of the art that it should have the appearance of a science'.[37] If Jennings is right, method is straightaway a more interesting endeavour. What is more, treaties—either standing alone or alongside other acknowledged sources of international law[38]—are not the whole story of human rights law. There is also increasingly a constitutionalisation or, more broadly, a domestication of rights—forming part of what some see as a global model of rights, with its own distinctive modes of reasoning, and others see as the 'democratic iteration' or 'vernacularisation' of international human rights law.[39] Alongside this, there is also, and increasingly,

[35] See AE Yamin, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care' (2008) 10(1) Health and Human Rights: An International Journal 45. On the importance of frames, see also JN Shklar, *Faces of Injustice* (Yale University Press 1990); KG Young, 'Freedom, Want, and Economic and Social Rights: Frame and Law' (2009) 24 Maryland Journal of International Law 191.

[36] *Cf* F Coomans, F Grünfeld and M Kamminga (eds), *Methods of Human Rights Research* (Intersentia 2009).

[37] RY Jennings, 'General Course on Principles of International Law' (1967) 121 Recueil des Cours de l'Académie de Droit International 327, 544.

[38] On non-treaty sources of human rights law see, eg, B Simma and P Alston, 'The Sources of Human Rights Law: Custom, *Jus Cogens* and General Principles' (1992) Australian Yearbook of International Law 82.

[39] See respectively K Möller, *The Global Model of Constitutional Rights* (Oxford University Press 2012); S Benhabib, *Dignity in Adversity: Human Rights in Troubled Times* (Polity Press

what has been called a 'common law of human rights'.[40] This body of law is produced mostly by domestic judges—typically by national constitutional courts choosing to draw, in different ways, on international and foreign human rights judgments and norms as they determine the human rights questions coming before them. This common law is controversial, to be sure. It is nonetheless a mode of practice that is now adopted by an array of judges and by activists and academics too.[41]

A second reason to be interested in human rights legal method is as follows: there is more to human rights than human rights law. The point I am making here is not that rights 'as law' are dispensable. Seeing, having and arguing with and for rights as law are crucial moves. They take us from need, charity, 'doing good', humanitarianism and the like towards freedom, entitlement and obligation. In so doing, they establish both claimants and duty-bearers, giving agency to both. Just as importantly, they neither promote a hollowed-out state nor acclaim personal responsibility as a cure-all, and they also keep attention focused on law (and not just law as litigation) as a resource or tool. In saying this, I am not suggesting that law is synonymous with justice; I appreciate that at times law's technicalities seem to leave it 'trapped in a prison house of irrelevance'.[42] At times, too, law is no more than a distraction—a form of magical thinking. However, because rights as law shift us to the terrain of freedom, entitlement and obligation, they are not nothing either. Put differently, they might not be the last word,[43] but they are not dispensable either.

My overall point, instead, is that rights are *more than* a legal construct; they are more than formal entitlements and freedoms, no matter how important those entitlements and freedoms are in practice. Human rights legal method, if it is to be plausible, has to be able to accommodate this. Some use a distinction between human rights 'as law' and human rights 'as discourse' to capture the point. Others distinguish 'human rights law' from 'human rights talk'. Others again prefer to see rights 'from below'. But whatever we call it, seeing rights in this way opens up human rights legal

2011); SE Merry, *Human Rights and Gender Violence: Translating International Law into Local Justice* (University of Chicago Press 2006). *Cf* Krisch (n 9), emphasising pluralism; Young, *Constituting Economic and Social Rights* (n 29), emphasising that the focus should be on how ES rights are 'constituted', not just how they are constitutionalised.

[40] See C McCrudden, 'A Common Law of Human Rights' (2000) 20 Oxford Journal of Legal Studies 499. See also J Waldron, *Partly Laws Common to All Mankind: Foreign Law in American Courts* (Yale University Press 2012).

[41] See, eg, O De Schutter, *International Human Rights Law* (Cambridge University Press 2010) 1, noting that his book's content was chosen so as to reflect the 'hybrid character of human rights'.

[42] M Koskenniemi, *From Apology to Utopia: The Structure of International Legal Argument* (Cambridge University Press 2005) 4.

[43] Explaining why not having the 'last word' might be a good thing, see J Waldron, *Law and Disagreement* (Oxford University Press 1999).

method so that it includes the practices of NGOs and social movements more generally, and of the very many individuals and populations who adopt rights talk today.

In this way, we begin to see that human rights as law cannot succeed without *social processes*—that rights should never be cabined within a 'juridical cage'.[44] Attention is also drawn to the importance of a law 'of everyday life',[45] a form of law that does not shirk structural injustice or assume that law and legalisation lead only to justice, never to unintended, unwanted or unexpected side-effects. It also becomes easier to see that those who oppose rights are also engaged in rights talk. Odd though it might sound, opposing rights is a mode of rights mobilisation—not least because 'it draws legitimate and appropriate boundaries of rights use, thereby affirming some rights at the same time as it opposes others'.[46]

There is at least one further reason to be interested in human rights legal method. Today, human rights methods—how lawyers and non-lawyers respectively do human rights—are an object of enquiry and innovation. Anthropologists in particular seem very engaged by the question of method: specifically, by legal forms of human rights practice (including the ways in which these forms enrol anthropologists) and by what it would mean to have an anthropology of human rights or, more broadly, a focus on human rights studies.[47]

Neither the enquiry into method nor the production of new methods is limited to anthropology, however. Today, across a range of disciplines and arenas, institutionalisation of rights is on-going. Consider the rise of rights-based approaches to both development and humanitarianism or, perhaps, the new 'humanity's law',[48] which blends human rights, humanitarian law and international criminal justice. There are also on-going efforts to get beyond the frame of inter-regime interaction when thinking about human rights and the World Trade Organization (WTO) or human rights and intellectual property.[49] I accept that few if any of these examples of institutionalisation are smooth-running. Yet each of them forges new ways of doing

[44] A Sen, 'Elements of a Theory of Human Rights' (2004) 32 Philosophy and Public Affairs 315, 319.

[45] H Charlesworth, 'International Law: A Discipline of Crisis' (2002) 65 Modern Law Review 377, 391.

[46] J Goldberg-Hiller and N Milner, 'Rights as Excess: Understanding the Politics of Special Rights' (2003) 28 Law & Social Inquiry 1075, 1076.

[47] See, eg, A Riles, *The Network Inside Out* (University of Michigan Press 2000); SE Merry, *Human Rights and Gender Violence: Translating International Law into Local Justice* (University of Chicago Press 2006); M Goodale, *Surrendering to Utopia: An Anthropology of Human Rights* (Stanford University Press 2009); RA Wilson, *Writing History in International Criminal Trials* (Cambridge University Press 2011).

[48] RG Teitel, *Humanity's Law* (Oxford University Press 2011).

[49] See, eg, D Kinley, *Civilising Globalisation: Human Rights and the Global Economy* (Cambridge University Press 2009); A Lang, *World Trade Law after Neoliberalism: Reimagining the Global Economic Order* (Oxford University Press 2011).

human rights—new forms, in other words, of human rights method. That makes method not only more interesting but more challenging too. What, for instance, is to become of *legal* forms of human rights method in this pluralising environment?

I am not saying that these different sorts of institutionalisation are necessarily anti-rights, anti-'rights as law' or anti-legal practices around rights. The issue, simply, is that these disciplines and fields do rights *differently*. There is today more human rights 'talk', and that alone is likely to affect human rights law and human rights legal method. Moreover, in doing rights differently, at least some of these non-legal disciplines and fields bounce off the legal. As I mentioned earlier, within anthropology, there is already a descriptive approach that 'radically decenters international human rights law', opting instead for the idea of social practice as constitutive, at least in part, of human rights.[50] This isn't exactly a case of 'knowing who you are by knowing what you are not'.[51] It is nonetheless hard to avoid the feeling that human rights legal method is an *anti-model* of sorts.

So how should we, the 'legal', respond? We could redouble any and all efforts to be distinctively legal, deciding that human rights cannot safely be left to the care of others. But that, like all of the options that follow, means we have to be able to say what is 'distinctively legal'. We could also be centaur-like, part legal and part something else. Alternatively, we could tack between the legal and the non-legal. Equally, we could choose to raid the non-legal.[52] Law, it is fair to say, does have a penchant for appropriation: at the international criminal tribunals, for instance, historical evidence has become part of both prosecution and defence cases—'historical discussions are [now] a permanent feature of international criminal justice'.[53] But appropriation will produce follow-on questions, such as 'What happens when non-legal knowledges or questions make their way into legal settings?'[54] To answer this, we need to study actual legal settings. Moreover, any such studies need to be alert to legal moves that distinguish law from non-law, in particular the purposes that are served by such moves. Is the

[50] M Goodale, 'Introduction: Locating Rights, Envisioning Law between the Global and the Local' in M Goodale and SE Merry (eds), *The Practice of Human Rights: Tracking between the Global and the Local* (Cambridge University Press 2007) 7. See further M Goodale, *Surrendering to Utopia: An Anthropology of Human Rights* (Stanford University Press 2009).

[51] A phrase taken from KL Scheppele, 'Aspirational and Aversive Constitutionalism: The Case for Studying Cross-Cultural Influence through Negative Models' (2003) 1 International Journal of Constitutional Law 296, 300 where it is used to describe a particular comparative method of law reform.

[52] See relatedly C Geertz, *Local Knowledge: Further Essays in Interpretive Anthropology* (Basic Books 1983), canvassing these ideas in considering the relationship between law and anthropology.

[53] Wilson (n 47) 218.

[54] See relatedly M-A Jacob, 'Knowledge Games, Truthfulness and Organ Transplants Regulation' (2011) 6 Biosocieties 243, examining legal knowledge in a non-legal setting.

law/politics distinction, for instance—a distinction that is widely invoked by judges who insist that professional legal reason is what allows them to tell law from non-law—part of what produces the *authority* of law? Is it, in other words, crucial to our willingness to allow judges to declare the law (even if some quibble about democratic legitimacy or, more bluntly, judicial disregard for the will of the majority)? Moreover, is this authority what both NGO reports and forms of 'soft, soft law' are invoking when they envelop themselves in legal discourse? Relatedly, if law has this authority, why is it that in certain settings—the World Bank for instance—employees committed to human rights opt to pursue them using alternative terms (such as social justice) or to support particular interpretations while avoiding others?[55]

II. MAKING CHOICES

To sum up: there is much more to human rights legal method than meets the eye. In line with this I give it centre stage in the chapters that follow, using it to interrogate and navigate aspects of health and human rights today and to negotiate the puzzle that prompted this book in the first place.

Some will be disappointed by the choices I make. There will undoubtedly be a wish list of missing chapters, featuring both emergent frames, such as human dignity, and health law classics, such as patient autonomy, as well as a range of right-to-health issues that need urgent attention (from maternal mortality to corruption, neglected diseases, health financing, mental health, palliative care, health systems, the relationship between human rights and humanitarianism, or that between transitional justice and the right to health). Others will criticise the absence of a specific site. Why, they will ask, isn't the focus either international human rights law or its regional counterpart, or the health and human rights pedigree of a single state or organisation—South Africa, Brazil, the WHO or Human Rights Watch, for instance? In similar vein, others will ask: why isn't the focus public health or the right to the highest attainable standard of health, or perhaps the right to respect for private life (in particular, how the latter relates to consent to medical treatment—what some have called the '"quandary ethics" of individual

[55] See GA Sarfaty, 'Why Culture Matters in International Institutions: The Marginality of Human Rights at the World Bank' (2009) 103 American Journal of International Law 647. See more generally Y Dezalay and BG Garth, *The Internationalization of Palace Wars: Lawyers, Economists, and the Contest to Transform Latin American States* (University of Chicago Press 2002); M Fourcade, *Economists and Societies: Discipline and Profession in the United States, Britain, and France, 1890s to 1990s* (Princeton University Press 2009).

patients'[56])? There will also be those who take the view that poverty, not health, ought to have been my starting point.

I choose what follows for three reasons. First, I write as a human rights lawyer, and I see other human rights lawyers—principally human rights law scholars—as a key audience. The proposals I make concerning human rights legal method look at what lawyers do and at what they could and should do. In this setup of diagnosis and prescription, law (and human rights law in particular) will be both a central concern and a relevant resource.

Second, viewing health and human rights through a conventional law lens makes little sense to me. On positive versus negative rights, for instance, I am bored of the back and forth that can surround the matter. I prefer the stance of those such as Henry Shue and Asbjørn Eide, who choose to foreground obligations, thereby demonstrating that *all* rights require positive action.[57] That stance has also been adopted by the UN Committee on Economic, Social and Cultural Rights (CESCR), the body responsible for clarifying the meaning of the ICESCR and encouraging its implementation:[58] it can be seen, for example, in the CESCR's work on 'core obligations' of economic, social and cultural (ESC) rights, which draws out both positive and negative duties.[59]

I also reject strong distinctions between rights based on enforceability. I am tired of debates that treat enforceability as synonymous with justiciability, before going on to argue over little more than two options—either non-justiciability for ESC rights or courts with 'last-word' powers of judicial review that can be used to strike down legislation. Such debates neglect the range of possibilities for judicial enforcement of rights, both amongst different courts and inside an individual court. They also neglect the ways in which ESC rights play a part even where they are not judicially enforceable: they neglect, in other words, non-judicial forms of engagement with these rights.[60]

[56] P Farmer and N Gastineau Campos, 'New Malaise: Bioethics and Human Rights in the Global Era' (2004) 32 Journal of Law, Medicine and Ethics 243, 246.

[57] H Shue, *Basic Rights: Subsistence, Affluence, and US Foreign Policy* (2nd edn, Princeton University Press 1996); UN Commission on Human Rights (UNCHR), Sub-Commission on the Prevention of Discrimination and Protection of Minorities, 'The Right to Adequate Food as a Human Right', report prepared by Special Rapporteur Asbjørn Eide (7 July 1987) UN Doc E/CN.4/Sub.2/1987/23. See also P Alston and K Tomaševski (eds), *The Right to Food* (Martinus Nijhoff 1985), especially the chapters by Shue and by Van Hoof.

[58] The CESCR, which became operative in 1987, comprises a group of independent experts who engage with states parties, delivering concluding observations on state reports and offering analyses of treaty rights via general comments. A complaints mechanism, adopted in 2008, entered into force on 5 May 2013 having received10 ratifications, thereby bringing the CESCR into line with fellow UN treaty bodies.

[59] See below ch 1, text to nn 71–79 and 91–99.

[60] *Cf* J Bueno de Mesquita, P Hunt and G Sander, 'Administrative Reparations Programmes and the Right to the Highest Attainable Standard of Health: Peaceful Coexistence or Unavoidable Tension?' in L McGregor and C Sandoval-Villalba (eds), *The Law and Practice of Rehabilitation as a Form of Reparation* (Brill, forthcoming), exploring how harm to health is and should be recognised in transitional justice processes.

I would also like to see less talk about generations of rights, in particular less use of chronologies that place ESC rights as latecomers. Chronologies tend to mask the ways that civil and political rights strengthen ESC rights and can be used to develop them.[61] Equally, I would like more attention to be paid to seeing law 'from below'. This does not mean I am more serious about human rights talk than about human rights law: it simply means I give short shrift to accounts that obsess about legalisation or juridification and close their eyes to what can be learned from human rights in practice.[62] To be clear: it is not that I am discounting legal doctrine or legal institutions such as courts and legislatures. It is just that I am rarely convinced by accounts that neglect how doctrine emerges or how legal institutions can and do work with NGOs and others.

Still, convention as regards human rights law does have a place. I may advocate 'seeing from below', but that does not mean I am for the state in retreat, for the idea that we are best governed 'through the non-governmental'. Engaging with states—more than that, having expectations of states—is central to the form of human rights method I am proposing here. In part this is because I treat human rights law as a central plank in human rights method: states are the principal duty-bearers in the international human rights law regime. In larger part, however, it is because I see states as *human rights actors*. States can, to be sure, have too much power: equally, international law has been hobbled by state-centricity (even if international human rights law with its focus on individuals and their rights professes to be different[63]). Yet a stateless—or 'state-light'—version of human rights is not an attractive prospect either. States are part and parcel of human rights; more than this, they are central to positive, sustainable change.[64]

Human rights law has, I accept, largely neglected non-state actors. Related to this, it has failed to engage the full range of duty-bearers, from foreign states and international organisations to transnational corporations. But these omissions are now being addressed.[65] In so doing, we must

[61] See, eg, International Covenant on Civil and Political Rights (16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (hereafter 'ICCPR') art 26, a provision on equality and non-discrimination which extends beyond the rights enumerated in the ICCPR.

[62] For an optimum balance see, eg, LE White and J Perelman (eds), *Stones of Hope: How African Activists Reclaim Human Rights to Challenge Global Poverty* (Stanford University Press 2011); Young, *Constituting Economic and Social Rights* (n 29).

[63] *Cf* S Marks, 'Human Rights in Disastrous Times' in J Crawford and M Koskenniemi, assisted by S Ranganathan (eds), *The Cambridge Companion to International Law* (Cambridge University Press 2012) 319: 'This idea of human rights as "incursions into" state sovereignty presupposes that power gained by individuals is power lost by states … [I]n reality, things are not so simple; rights empower right-holders, but they also empower states to order and control the social environment in which right-holding arises and becomes consequential.'

[64] See similarly A Vincent, *The Politics of Human Rights* (Oxford University Press 2010).

[65] Examining four efforts to elaborate frameworks for such duty-bearers, see W Vandenhole, 'Emerging Normative Frameworks on Transnational Human Rights Obligations', EUI Working Papers, RSCAS 2012-17.

ensure that we do not dismiss the relationship between individuals and the domestic state, or the role of states as the principal duty-bearers under international human rights law.

I think we could venture further too. Should we be willing to talk, for instance, about states as *human rights activists*? Is Brazil, for instance, an activist state given that it helped to secure both the development agenda at the World Intellectual Property Organization (WIPO) and the creation of a 'special procedure' on the right to health at the UN; pushed for recognition of sexual rights at the UN; and gives its backing to UNITAID, the international drug purchase facility launched in 2006? And is its National AIDS Programme—recipient of the Gates Award for Global Health and named by the UN as the best in the developing world[66]—further evidence of 'activism'?

Calling Brazil an 'activist' could of course lead us to neglect the intra-country inequities that survive or are produced by its 'policy of biotechnology for the people'.[67] It could also obscure the range of actors that was required to craft Brazil's HIV/AIDS policy: international agencies such as the World Bank, national and multinational pharmaceutical companies, NGOs and grassroots organisations, and the media all played a part, coming together with the Brazilian state to forge a policy of universal access to treatment. Other things helped too, including the existence of a constitutional right to health[68] and an infrastructure for the production of generic drugs. More broadly, it might be objected that when we describe Brazil or any other state as an 'activist', we underplay the fact that when states ratify or accede to treaties, they make a commitment that comes with obligations—they create, in other words, an expectation that there will be state action to respect, protect and fulfil human rights.

The activist state is not, then, a problem-free idea. But perhaps we can agree that there is still good reason to look closely at state behaviour. In so doing, we are looking not just for 'best practice' or for indications of

[66] It was also singled out by the first Special Rapporteur on the right to health: see UNGA, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (10 October 2003) UN Doc A/58/427, para 59 noting that it 'may be an example of a right to health good practice that enhances the *availability* and *economic accessibility* of essential medicines, *active and informed participation* in health programmes, and *non-discrimination*'.

[67] J Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton University Press 2007) 8. Biehl goes on to describe Brazil's model policy as 'convoluted, dynamic, and filled with gaps' (10).

[68] Right-to-health litigation in Brazil is not uniformly seen as a good thing: see further OL Motta Ferraz, 'Health Inequalities, Rights, and Courts: The Social Impact of the Judicialization of Health' in Yamin and Gloppen (eds) (n 34); J Biehl et al, 'Between the Court and the Clinic: Lawsuits for Medicines and the Right to Health in Brazil' (2012) 14(1) Health and Human Rights: An International Journal 36.

'unforced consensus'[69] concerning rights but for the *full range* of rights practices. The reasons why a state ratifies a human rights treaty are interesting, but so too are its reasons for wanting to limit such commitments via, say, reservations, renunciations or derogations. For what reasons do states want to place these sorts of limits, to be part but not fully part? Is it, for instance, international reciprocity, risk of retaliation, standing or the 'home audience' that determines state behaviour on such matters?[70] We also need to know more about how domestic, regional and international courts and quasi-courts treat limitations upon rights, and how, too, NGOs see such limitations. This detail is crucial if we are to understand the proper role of different limitation devices and, relatedly, negotiate the often destructive competition between universalism and localism. It is also crucial to the central question of how to allocate resources fairly. For example, taking due account of contextual factors such as access to courts, political corruption and the like, where and how have particular courts helped to boost accountability in political decision-making and fuller participation? And which of the various grounds for protecting the right to health or health care—dignity or freedom, consensus or the need to secure basic survival—have been most powerful in shaping such judgments?[71]

The third and final factor that influences my choice of chapters is a commitment to rights 'made whole'. A book on health and human rights has to discuss the right to health, but it also has to discuss more than that. It has to be what we might call 'right-to-health plus'. In this way, civil and political rights can be brought into the fold, including the rights to life, to be free from torture, to respect for private life and to freedom of expression. This in turn should ease pressure on the right to health which, according to the CESCR in General Comment No 14, encompasses not just entitlements but freedoms too, including 'the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation'.[72]

[69] C Taylor, *Dilemmas and Connections: Selected Essays* (Harvard University Press 2011) 105–23.

[70] Studies by IR scholars point to the influence of domestic politics: see, eg, BA Simmons, *Mobilizing for Human Rights: International Law in Domestic Politics* (Cambridge University Press 2009); E Hafner-Burton, LR Helfer and CJ Fariss, 'Emergency and Escape: Explaining Derogations from Human Rights Treaties' (2011) 65 International Organization 673.

[71] On these questions, see K Syrett, *Law, Legitimacy and the Rationing of Health Care: A Contextual and Comparative Perspective* (Cambridge University Press 2007); Daniels (n 4); Ruger (n 5).

[72] CESCR, 'General Comment No 14' (n 8) para 8. Note the different language in Committee on the Rights of the Child (CRC Comm), 'General Comment No 15: The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art 24)' (17 April 2013) UN Doc CRC/C/GC/15 para 24: 'Children's right to health contains a set of freedoms and entitlements. The freedoms, which are of increasing importance in accordance with growing

Taking a 'right-to-health plus' approach should also ease pressure to subsume rights relevant to housing, education, work and so on within the right to health. Such rights are relevant to health, and overlaps with the right to health can and should be identified: the interdependence and indivisibility of rights mandate this, as does our growing awareness of the central role played by the social determinants of health.[73] At the same time, however, under the 'right-to-health plus' approach, it is easier for these other rights to flourish in their own right, and the right to health is also less likely to be stretched beyond sense.[74]

A further advantage of 'right-to-health plus' is that it does not blanket the field with the right to health or health-related rights. To do that neglects other rights. It also ducks—and may even produce—regime clashes within the international legal system. Equally, 'right-to-health-plus' does not push non-rights approaches (such as social justice or the health concept of equity[75]) out of view. It also leaves space for strategic choices. By this I mean it recognises that different rights play out in different, possibly unexpected ways on the ground, and that for these and other reasons, some will prefer to make claims under rights other than or in addition to health, or indeed without any reference whatsoever to rights.[76]

Finally, with 'right-to-health plus', we have to attend openly to the prospect of limits on rights (including in the interests of public health;[77] in order to promote the general welfare in a democratic society;[78] or because a case is before a court that uses a tool like the margin of appreciation). In so doing, the aim is to make actual practices of limiting rights less about rights-derision and dismissal, and more about rights-based processes. Steering the general sense of human rights away from freedoms and entitlements

capacity and maturity, include the right to control one's health and body, including sexual and reproductive freedom to make responsible choices.'

[73] See CSDH (n 14); WHO, Rio Political Declaration on Social Determinants of Health (21 October 2011), endorsed by Res WHA62.14 (26 May 2012) of the World Health Assembly, and by Res WHA65.8 of the Outcome Documents of the UN World Conference on Social Determinants of Health (June 2012). See relatedly AR Chapman, 'The Social Determinants of Health, Health Equity, and Human Rights' (2010) 12(2) Health and Human Rights: An International Journal 17.

[74] *Cf* CESCR, 'General Comment No 14' (n 8) para 4 which includes the underlying determinants of health *within* art 12 ICESCR.

[75] See, eg, A Sen, *Development as Freedom* (Oxford University Press 1999); A Sen, 'Why Health Equity?' in Cook and Ngwena (eds) (n 34); MC Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard University Press 2011).

[76] See, eg, MJ Roseman and AM Miller, 'Normalizing Sex and Its Discontents: Establishing Sexual Rights in International Law' (2011) 34 Harvard Journal of Law & Gender 313, 359 explaining why organising under the right to health is not always a preferred choice or even an option in the context of claims for sexual rights.

[77] See, eg, ICCPR (n 61) art 12(3). See also the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights (28 September 1984) UN Doc E/CN.4/1985/4.

[78] See, eg, ICESCR (n 2) art 4.

towards a set of often qualified freedoms and entitlements, and the processes for justifying those qualifications, could of course bring other broader benefits too.

III. THE STRUCTURE OF THE BOOK

To round out this Introduction, I want to explain the structure of the rest of the book. Chapter one offers the back story, providing a history of health and human rights. This history is both limited and idiosyncratic, but it will augment what I have been able to say here about the sense of imperative that courses through the field of health and human rights and about the threats the field faces today. As I have already explained, my response to these threats is to call for open and on-going engagement with human rights legal method. My response calls, in other words, for attention to legal craft—to what might be called the 'law way' of doing health and human rights. I suggest that we ask: what precisely is human rights legal method here and now? In particular, when we look at its detail, with due recognition of the diversity therein, what are its qualities and its weaknesses? And what is its value-added if human rights, as well as human rights methods, are now widely adopted, widely hyped and also widely denounced?

Chapters two to five build on the book's basic call. In these chapters I engage directly with human rights legal method: I assess, adapt and augment this way of doing rights, always staying rooted in law and in what human rights lawyers have done or have failed to do with law. To draw out the argument, I concentrate on one type of human rights lawyer, the one I know best: the human rights legal scholar. I want to persuade this scholar that she or he needs to think both widely and deeply about health and human rights challenges. To facilitate this, I use chapters two to five to offer a quartet of ideas for new or enhanced methods.

Chapter two looks at 'public health preparedness', also known as 'public health security' or, in its international mode, as 'global health security'. Whatever the term, the focus is the same: namely, the threat of emerging infectious diseases—from SARS and virulent new forms of influenza, to bioterrorism and both multi- and extensively drug-resistant forms of tuberculosis. Over the last decade or so, this threat has had a profound impact, immersing states, international organisations and others in the need for 'preparedness', the pull of 'action now' and the importance of governing the 'exceptional'. In so doing, it has shaped and been shaped by a new lexicon, one that features not just variations on 'preparedness' but also 'risk' and 'resilience', as well as a series of takes on 'security' (including 'biosecurity', 'human security' and what the WHO calls 'global public health security').

In chapter two I ask: is human rights prepared for public health preparedness? I argue that the answer is no, but I also propose two ways in which we

might change that. I suggest, first, that human rights needs to draw out risk *within* rights. That is, we need to explain the ways in which human rights law and practice already accommodate risk, and to maintain a watching brief vis-à-vis the use of such accommodations by states and others. We need, in other words, to explain, evaluate and monitor the array of opportunities to place limits on rights in the name of public health—opportunities such as derogations and general and particular limitations clauses, as well as judicial devices such as the ECtHR's margin of appreciation doctrine.[79]

My second suggestion is that we draw out rights *as* risk—namely, the ways in which human rights can be a risk for state and non-state actors alike, and the opportunities this produces for human rights claims-making. I accept these are limited, even danger-laden, opportunities: those who engage with human rights in order to avoid risk are doing so exclusively for reasons of reputational interest, keen to do the least possible for the biggest publicity. Still, the 'civilising force of hypocrisy'[80] is cause for some optimism. Moreover, amidst the popular tendency to see risk and rights in a zero-sum relation, human rights desperately needs alternative accounts of the risk/rights relationship. In the absence of these, human rights preparedness is a pipedream, and human rights are poorly understood and thus poorly defended.

Chapter three re-engages public health, looking at the human rights success story of access to HIV/AIDS medicines. It does this, for the most part, by 'seeing from below'—that is, from the perspective of human rights activism and in particular from the perspective of the Treatment Action Campaign (TAC), a South African NGO. Chapter three charts what has been achieved both by the TAC and by the broader human rights campaign on access to antiretrovirals. In so doing, it explains how law has been seen and has been used by the TAC. It also explains how South Africa's Constitutional Court and a range of others have responded to the TAC's claims-making and how that claims-making has affected both the TAC itself and the broader field of health and human rights.

The chapter's principal aim lies elsewhere, however. The chapter proposes that the 'cost of human rights'—which sounds of course like an argument *against* rights—can and should be developed in a pro-human rights way. It begins that development process, drawing on both the tenets of international

[79] See, eg, *Chapman v United Kingdom*, App no 27238/95 (Judgment of 18 January 2001) para 91: '[A] margin of appreciation must, inevitably, be left to the national authorities, who by reason of their direct and continuous contact with the vital forces of their countries are in principle better placed than an international court to evaluate local needs and conditions. This margin will vary according to the nature of the Convention right in issue, its importance for the individual and the nature of the activities restricted, as well as the nature of the aim pursued by the restrictions.'

[80] J Elster, 'Deliberation and Constitution Making' in J Elster (ed), *Deliberative Democracy* (Cambridge University Press 1998) 111.

human rights law and the practices of the TAC. Overall, its argument is that via the 'cost of human rights' we are better able both to see the cost to human rights of human rights success and to tackle the actual financial cost of human rights, such as the right to access essential medicines or the broader right to health.

Chapter four takes up the theme of numbers in a very different way. It explores the turn towards measurement and, specifically, towards quantitative indicators, placing this as one of the more prominent responses to the threats that now face both rights in general and health and human rights in particular. Quantitative indicators, along with their qualitative counterpart, are seen as a useful way to identify human rights violations, to assess the enjoyment of rights and progress thereto, and to improve human rights advocacy. They are, in short, seen as a way to move beyond standard-setting towards *implementation* of rights and there is, not surprisingly, considerable enthusiasm for them both within and outwith the human rights community.

In chapter four I interrogate this turn towards indicators. I do not dismiss it as a form of human rights legal method; doing so would be foolish given that indicators prioritise implementation and provide advocacy-opportunities too.[81] I do, however, propose that we think carefully about who is producing rights and rights-related indicators, who is using them, for what reasons and with what effects. And I go on to suggest that in the absence of due care and attention, numbers—and perhaps images too—could easily speak louder than words. Is human rights legal method prepared for this challenge? If not, how might it prepare itself?

Chapter five, which is about the right to reproductive choice, develops my interest in words. It outlines why, today, choice feels like a bad argument, laying part (though certainly not all) of the blame on for-or-against framings. Two routes out of the rising unspeakability of choice are suggested: first, bolstering reproductive rights via law, paying due regard to the implementation of any such laws and also to the differences between sexual, maternal and reproductive rights; second, adding texture to reproductive rights via ethnography—specifically, adding texture that draws out the *dignity* of choice.

The first route has already been undertaken by health and human rights. That is not a reason for complacency: recent history at the UN and elsewhere demonstrates that as regards reproductive rights and whether we are

[81] See, relatedly, the overarching recommendation 3 from the CSDH (n 14) 2: 'Acknowledging that there is a problem, and ensuring that health inequity is measured—within countries and globally—is a vital platform for action. National governments and international organizations, supported by WHO, should set up national and global health equity surveillance systems for routine monitoring of health inequity and the social determinants of health and should evaluate the health equity impact of policy and action.'

looking at these rights via health, liberty, life or equality, there is little that is secure. On the other hand, maternal mortality and HIV/AIDS are both Millennium Development Goals, and a general comment on reproductive and sexual health and rights is expected from the CESCR in the near future. Attention is also being paid to the decriminalisation and liberalisation of access to abortion, partly to address the problem of unsafe abortion. Related to this, there are notable instances—Nepal and Colombia, to name two—of effective collaboration on abortion law reform between governments, health professionals and NGOs. There is also a small body of jurisprudence and quasi-jurisprudence which emphasises to states that abortion must be available to the fullest extent of the law; that is, it must be available in practice, not simply on paper.[82] Moreover, these and other cases have sometimes linked access to abortion to the idea of human dignity—at least as regards a woman's physical and psychological health or integrity.[83]

But reproductive rights are also assailed. The right to reproductive choice, for instance, is endlessly on the defensive and widely cast as audacious. It is, some contend, a threat to life, to the family, to health professionals and indeed to women themselves. In this climate, it seems to me that the dignity of choice is at risk of being lost from view. To change that, I propose adding texture to reproductive choice via ethnographic method: listening, in other words, to actual decision-makers—not the judges, advocates, campaigners or philosophers with whom we are familiar, but rather the individuals and couples who are making or want the opportunity to make reproductive choices. In so doing, the aim is not to find some truth of reproductive choice or to push for all-out celebration of choice. The dignity of choice is about drawing out the complexity of choice and about why, in human rights, that complexity matters and has to be defended.

Chapter six is the final chapter in the book, so it will be no surprise that it opens by asking, 'Did I solve the puzzle, then?' Did I find a way to accommodate hopefulness and critique? To be specific, did I find a way to navigate not just the sense of imperative enveloping health and human rights but also the trenchant criticism, even derision, that is ever present too? It is of course tempting to have a preview of the answer here. But to do that would be to get ahead of the story, so let's move instead to the task of making a history of the field of health and human rights. What produced this field, what has it achieved and what pressures is it facing today? With this history in place, we shall be in a better position to identify both the need for and the focus of new human rights legal methods.

[82] See, eg, *KL v Peru*, Communication no 1153/2003, UN Doc CCPR/C/85/D/1153/2003 (22 November 2005); *Tysiąc v Poland* (2007) 45 EHRR 42; *RR v Poland* (2011) 53 EHRR 31; *P and S v Poland*, App no 57375/08 (Judgment of 30 October 2012, ECtHR).

[83] See, eg, *KL* (ibid). See relatedly R Dixon and MC Nussbaum, 'Abortion, Dignity, and a Capabilities Approach' in B Baines et al (eds), *Feminist Constitutionalism: Global Perspectives* (Cambridge University Press 2012), calling for a theoretical account of dignity and its potential relationship to rights to abortion.

1

Health and Human Rights

IN THIS CHAPTER, the aim is to introduce the field of health and human rights, the sense of imperative surrounding it and some of the threats that it faces today. This detail supplements the sketch in the Introduction; together these chapters set the scene for the upcoming case studies, each of which probes, pushes and pulls the human rights legal imagination in one or more ways. To get from here to there, however, I need a beginning point. So where exactly is it best to start the story of health and human rights?

I. STARTING POINTS

Would the Universal Declaration of Human Rights (UDHR)[1] be a good choice, for instance? Some will object that I am limiting my perspective, that I am taking my ambition to prioritise human rights legal method too seriously too soon and that I am at risk of missing non-legal starting points. There is though a case to be made for the UDHR, not least because in article 25(1) it clusters health together with other economic and social (ES) rights: every person, it says, 'has the right to a standard of living adequate for the health of himself and his family, including food, clothing, housing and medical care, and necessary social services'.[2] And zooming out from this article, another attraction of the UDHR comes immediately into view: this international human rights instrument features human rights of all kinds—economic, civil, social, political and cultural—making it a pioneer

[1] Universal Declaration of Human Rights (10 December 1948) UNGA Res 217A (III), UN Doc A/810 (hereafter 'UDHR').

[2] On the drafting history of art 25(1), see J Morsink, *The Universal Declaration of Human Rights: Origins, Drafting, & Intent* (University of Pennsylvania Press 2000). For a recent assessment, see J Zuniga, SP Marks and LO Gostin (eds), *Advancing the Human Right to Health* (Oxford University Press 2013). In the same year, the American Declaration of the Rights and Duties of Man (2 May 1948) OAS Res XXX, reprinted in Basic Documents Pertaining to Human Rights in the Inter-American System, OAS/Ser.L/V/I.4 Rev.9 (2003), art XI provided: 'Every person has the right to the preservation of his health through sanitary and social measures relating to food, clothing, housing and medical care, to the extent permitted by public and community resources.'

as regards the claim, popular today, that human rights are indivisible, interdependent and interrelated.

Obligations-wise, the UDHR was farsighted too. Today as we grapple with questions concerning who should be a human rights duty-bearer and in what manner, the Declaration seems quietly prescient in its assertion that 'every individual and every organ of society' has responsibility for rights and that both 'national effort and international co-operation' are needed for rights realisation.[3] What is also appealing about the UDHR is its apparent sturdiness in the face of rights evangelism and the expansionism that tends to go hand in hand with that evangelism. In the Declaration the realisation of economic, social and cultural (ESC) rights is conditional on the resources available; all rights, moreover, are subject to limitations necessary for securing the rights and freedoms of others, and meeting the just requirements of public order, morality and the general welfare in a democratic society.[4] This forces us to focus on rights *and* on justifiable limits to rights, the latter being just as much a part of human rights law as the former. There is promise too in the UDHR's inclusion of both a non-discrimination clause and entitlements to 'equality before the law' and 'equal protection of the law'.[5] The latter could be used, for instance, to break away from the near-singular focus on status-based discrimination within human rights; and the former, because it references 'property' (that is, economic status) as one of the prohibited grounds of discrimination, points to the possibility of putting a brake on distinctions based on wealth.[6]

The case for the UDHR as the starting point is not watertight, however. There are other international instruments, for instance, that offer more detail on the right to health. There is also the obvious objection that as a declaration, not a treaty, the UDHR is non-binding. For some, though, this latter objection plays out differently: it boosts the Declaration's credentials, illustrating its ability to draw us towards the 'disorder of orders'[7] that characterises the present day, wherein what is law and what is politics seem to be reshaping amidst an array of pressures, and legal bindingness is not

[3] UDHR (n 1) preamble, art 22.

[4] Ibid, arts 22 and 29(2).

[5] Ibid, arts 2 and 7. See also International Covenant on Civil and Political Rights (16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (hereafter 'ICCPR'), arts 2 and 26. *Cf* the absence of a general equality provision in the International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR').

[6] See further Morsink (n 2) 113–14; G MacNaughton, 'Untangling Equality and Non-Discrimination to Promote the Right to Health Care for All' (2009) 11(2) Health and Human Rights: An International Journal 47. *Cf* Committee on Economic, Social and Cultural Rights (CESCR), 'General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights (art 2(2))' (2 July 2009) UN Doc E/C.12/GC/20, recognising 'economic status' under the umbrella category 'other status' rather than under 'property'.

[7] N Walker, 'Beyond Boundary Disputes and Basic Grids: Mapping the Global Disorder of Normative Orders' (2008) 6 International Journal of Constitutional Law 373.

necessarily synonymous with influence. Others, moreover, will dismiss the bindingness claim as inaccurate, emphasising that for many international lawyers, large parts of the UDHR do now enjoy the status of binding rules of customary international law or can be considered to be part of the 'general principles of law recognised by civilized nations' that are acknowledged by article 38(1)(c) of the Statute of the International Court of Justice[8] as a source of international law. There is no agreement, to be fair, on how much of the UDHR does count as binding law. Still, as regards ESC rights, the argument does seem strong: in part because a substantial number of written constitutions make reference to these rights and in part too because amongst UN member states, there is almost universal adherence to international human rights treaties that protect ESC rights. Moreover, a complaints mechanism for the flagship instrument on these rights, the International Covenant on Economic, Social and Cultural Rights (ICESCR),[9] entered into force in spring 2013, having gained the requisite 10 ratifications.[10]

Are we ready then to settle on the UDHR as a decent starting point for health and human rights? Not quite. There are further objections that are much harder to dismiss. One is that the UDHR simply arrived too late to make it the optimum starting point; another is that a health-specific starting point seems more apt—one that acknowledges the underlying determinants of health, such as sanitation, but ultimately is more of a platform for the right to health than article 25 UDHR's umbrella provision. Let's now look at these objections in turn, beginning with the question: if this history of health and human rights is to commence prior to the UDHR, where exactly should it begin?

For some, the answer is likely to be article 55 of the UN Charter, which declares that the United Nations 'shall promote':

> a. higher standards of living … b. solutions of international economic, social health, and related problems … and c. universal respect for and observance of human rights and fundamental freedoms for all without distinction as to race, sex, language or religion.[11]

[8] Statute of the International Court of Justice (26 June 1945) UNTS 993.

[9] ICESCR (n 5). For an introduction to the ICESCR see, eg, M Craven, *The International Covenant on Economic, Social and Cultural Rights: A Perspective on its Development* (Clarendon Press 1995); M Ssenyonjo, *Economic, Social and Cultural Rights in International Law* (Hart Publishing 2009); B Saul, D Kinley and J Mowbray (eds), *The International Covenant on Economic, Social and Cultural Rights: Cases, Materials, and Commentary* (Oxford University Press, forthcoming).

[10] Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (10 December 2008, entered into force 5 May 2013) UN Doc A/RES/63/117 (hereafter 'OP-ICESCR').

[11] UN Charter (26 June 1945, entered into force 24 October 1945) TS 993. See also art 56: 'All Members pledge themselves to take joint and separate action in co-operation with the Organization for the achievement of the purposes set forth in Article 55.'

Others, I imagine, will argue for Franklin D Roosevelt's 'Four Freedoms' speech from 1941, either standing alone or in combination with his State of the Union Address of 1944, in which he insisted that 'necessitous men are not free men'.[12] For President Roosevelt, the United States needed a 'second bill of rights', a constitutional document that would recognise a range of ES rights, including the right to 'adequate medical care and the opportunity to achieve and enjoy good health' and to 'adequate protection from the economic fears of old age, sickness, accident, and unemployment'.

Interestingly, given the influence of Eleanor Roosevelt, Roosevelt's widow, on the drafting of the UDHR in her role as chair of the UN Commission on Human Rights,[13] we could also combine this state-based starting point with the UDHR, perhaps with the goal of drawing out the hybrid or pluralist character of human rights law—the ways, that is, in which human rights law is neither national nor international but rather a mercurial mix. And if we pursue this idea of a mix as the best way to start the story of health and human rights, we could also reach back past the 1940s—perhaps to what Mary Ann Glendon has called the 'forgotten crucible',[14] namely, the Latin American influence on both the UDHR and, more broadly, the universal human rights idea. There are lots of traces of Latin America's distinctiveness vis-à-vis rights, including Mexico's Constitution of 1917, which granted entitlements to medicines and medical attention for workers' families. The distinctiveness is palpable today too. In the Introduction, I alluded to the idea of the 'activist state': if we were to follow through on that from a health and human rights perspective, Brazil would be a leading contender. Equally, courts in Brazil and in other Latin American states—Colombia, Argentina and Costa Rica—have been spearheading health rights decision-making that now attracts supporters and detractors alike, including more and more who are using these cases to shake off the staleness of ESC rights justiciability debates. The upshot is a raft of new and frankly refreshingly interesting questions, including who is bringing these cases and for what reason, as well as whether and how implementation is taking place and with what effects on health and, more broadly, social equity and equality.[15] Interesting differences are emerging too, not least how the characteristics of a state—is it incompetent, is it neglectful, is it a new democracy working

[12] For these, see CR Sunstein, *The Second Bill of Rights* (Basic Books 2004). See more generally D Whelan and J Donnelly, 'The West, Economic and Social Rights, and the Global Human Rights Regime: Setting the Record Straight' (2007) 29 Human Rights Quarterly 908.

[13] See further MA Glendon, *A World Made New: Eleanor Roosevelt and the Universal Declaration of Human Rights* (Random House 2002).

[14] MA Glendon, 'The Forgotten Crucible: The Latin American Influence on the Universal Human Rights Idea' (2003) 16 Harvard Human Rights Journal 27.

[15] See, eg, AE Yamin and S Gloppen (eds), *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Harvard University Press 2011).

hard in difficult circumstances?—may well influence both the decision to go to court and the judgment handed down.

For some, courts and instruments will be no more than bit-part players in the history of health and human rights. For these history-writers, organisations—formal international organisations, non-governmental ones (NGOs) or both—are the core concern. If we adopt their approach, either the League of Nations[16] or the International Labour Organization (ILO), both founded in 1919, might be a plausible starting point. Or we might begin with the World Trade Organization (WTO), pitching its extension of intellectual property protections as a force that galvanised state and non-state opposition—with at least some of that opposition coalescing around human rights. There is also the option of starting with the World Health Organization (WHO), which describes itself as the 'world's health advocate'.[17] One attraction of the WHO, however, must be its Constitution: dating from 1946, this instrument offered the first affirmation of the right to the highest attainable standard of health,[18] a stance reaffirmed in the WHO's 1978 Declaration of Alma-Ata, which emphasised that health is a 'fundamental human right' and that governments 'have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures'.[19]

More recently, in 2003 the WHO made its first (and, to date, only) use of another constitutional provision, one that allows it to elaborate and adopt international conventions. Using that power to adopt the Framework Convention on Tobacco Control, the Organization signalled its potential as a law-maker and its interest in chronic diseases too.[20] Moreover, although some claim to be irritated by the WHO's paltry use of its law-making power, that gap has generated greater interest in tools of governance or 'global health diplomacy' that have been used by the Organization, notably its pioneering work with codes of conduct such as the International Code of Marketing of Breast-milk Substitutes, on which it partnered with

[16] See, eg, the Covenant of the League of Nations, 225 Consolidated Treaty Series (CTS) 195, art 25 whereby members agreed: 'to encourage and promote the establishment and co-operation of duly authorised voluntary national Red Cross organisations having as purposes the improvement of health, the prevention of disease and the mitigation of suffering throughout the world.'

[17] WHO, 'Health for All in the Twenty-First Century' (1998) WHO Doc A51/5, vi.

[18] Constitution of the World Health Organization (22 July 1946, entered into force 7 April 1948) 14 UNTS 185, preamble.

[19] WHO, Declaration of Alma-Ata (International Conference on Primary Health Care, Alma Ata, USSR 6–12 September 1978) paras I and V. This Declaration is also notable for its guidance on what constitutes an effective health system.

[20] WHO Framework Convention on Tobacco Control (21 May 2003, entered into force 27 February 2005) 2302 UNTS 166. There have been moves to encourage the WHO to back a Framework Convention on Global Health: see further Joint Action and Learning Initiative on National and Global Responsibilities for Health (JALI), details available at www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001031.

UNICEF,[21] and the more recent Global Code of Practice on the International Recruitment of Health Personnel,[22] which addresses the serious problem of health worker migration from the global South to the wealthy North.[23]

Starting our history with the WHO might not, however, be the most popular choice. The WHO's Constitution, lauded by some, is a problem for others. It focuses, they say, not just on the right to health of individuals but also on the security and well-being of states. Equally, as more than one commentator has complained, its definition of health—'a state of complete physical, mental and social well-being'—does risk 'turning all of social philosophy and social policy into health care'.[24] The WHO also has a pretty mixed record on rights. Initially it was very involved in shaping what became the right to the highest attainable standard of health in article 12 ICESCR; then, however, it entered a protracted period wherein engagement with human rights was actively avoided.[25] Moreover, although the Organization has adopted both the Declaration of Alma-Ata and, more recently, a revised set of International Health Regulations that take account of human rights,[26] during the 1990s amidst the health system reforms demanded of many states by the World Bank, it was widely seen as an inept counter-voice, quite unable to communicate the central importance of primary health systems.

Rejecting the WHO does not, of course, mean we have to revert to either courts or instruments as our starting point. Other international organisations remain viable contenders. Alternatively we could choose an NGO. Or we could choose a branch of health. By foregrounding public health, for instance, we would be taken back to state practices in the eighteenth century and earlier, or to the first international conferences on sanitation that took place at the start of the nineteenth century, or perhaps to the mid-nineteenth century when the first international meetings to coordinate the fight against infectious diseases were organised. Any one of these would be a useful lens through which the surveillance, reporting and vaccine-sharing difficulties of today's post-SARS world could be viewed. The instrumentalism

[21] WHO/UNICEF, 'International Code of Marketing of Breast-Milk Substitutes (23 May 1981) WHO Doc A34/x.

[22] WHO, 'Global Code of Practice on the International Recruitment of Health Personnel' (15 April 2010) WHO Doc A63/8.

[23] For details, see respectively S Shubber, *The International Code of Marketing of Breast-Milk Substitutes* (Kluwer 1998); AL Taylor and IS Dhillon, 'The WHO Global Code of Practice on the International Recruitment of Health Personnel: The Evolution of Global Health Diplomacy' (2011) 5 Global Health Governance 2.

[24] N Daniels, *Just Health: Meeting Health Needs Fairly* (Cambridge University Press 2008) 37.

[25] See BM Meier, 'The World Health Organization, The Evolution of Human Rights, and the Failure to Achieve Health for All' in J Harrington and M Stuttaford (eds), *Global Health and Human Rights: Legal and Philosophical Perspectives* (Routledge 2010).

[26] International Health Regulations (2005) (23 May 2005) WHA58/2005/REC/1. For details, see below ch 2.

that has long been one of the motivations for law-making around public health[27] might also move to centre stage; equally, we would be reminded again of the centrality of public health both to the modern state and, following Michel Foucault, to modern forms of governance.[28]

Another option would be to prioritise international humanitarian law, pitching it as perhaps the first attempt to 'humanise'[29] international law and citing, say, the Geneva Convention of 1864—its initial codification in treaty form—as an optimal starting point. One advantage of this choice would be its ability to focus attention on the forms, reach and significance of humanitarian biomedicine today. Is, for instance, public health preparedness, with its emphasis on management of emerging infectious diseases, a form of 'advance' humanitarianism? Or is it an anti-humanitarian move that diverts attention and, crucially, resources from people who are dying today? In a further variation again, this time honing in on the ascent of bioethics and bioethicists in the governance of health and new health technologies, we might also flag the 1947 Nuremberg Trials of Nazi physicians as a starting point—not least because these trials are widely seen as the juncture at which free and informed consent became the preferred mode of autonomy-protection for patients and research subjects alike.[30]

To sum up: with an expanding list that already includes instruments, courts and organisations, as well as particular branches of law and health, a Latin American influence and both Eleanor and Franklin D Roosevelt—we seem to have an array of starting points. Making a choice is daunting—a project in and of itself, and one that is not just intriguing but important too. But I can leave that task to others, given that history-writing is not my prime concern here: my goal is a more limited scene-setting one. To move ahead, then, I am going to shift focus to *pathways* to the field of health and human rights as it is today. These seem as important and certainly less troublesome than starting points. What is more, two strongly overlapping ones come immediately to mind. The first, detailed next, concerns public health; the second, detailed in section IV, concerns the right to health in the ICESCR and other health and health-related rights. For each of these pathways, I shall also provide a follow-on section that I call 'a view from

[27] See J Tobin, *The Right to Health in International Law* (Oxford University Press 2012) 14–43.

[28] M Foucault, *The History of Sexuality, Vol 1: The Will to Knowledge* (Penguin 1978). See also G Rosen, *A History of Public Health* (Johns Hopkins University Press 1993); D Porter, *Civilisation and the State: A History of Public Health from Ancient to Modern Times* (Routledge 1999).

[29] Adapted from T Meron, 'The Humanization of Humanitarian Law' (2000) 94 American Journal of International Law 239.

[30] See, eg, DJ Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (Basic Books 1991); GJ Annas and MA Grodin (eds), *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (Oxford University Press 1995).

here and now', in which I detail some of the more obvious threats to health and human rights that are in play today. In places these develop points I raised in the Introduction; elsewhere they add to the list provided there. Once they are in place, we shall be in a better position to drill down to the diagnosis and prescription offered in the case studies that follow in chapters two to five.

II. PUBLIC HEALTH

The earliest advocates of health and human rights were heavily focused on public health. For them, health and human rights was not simply about the right to the highest attainable standard of health in the ICESCR or about litigation involving this or other health or health-related rights. It was far broader: it was about the full range of rights and, above all, about the power of a *rights-based approach to health*—in particular the power of this approach to tackle and ultimately to reverse and end the HIV/AIDS pandemic. For Jonathan Mann, for instance, former head of the AIDS Programme at the WHO, human rights offered public health 'a more coherent, comprehensive and practical framework of analysis and action on the societal root causes of vulnerability to HIV/AIDS than any framework inherited from traditional health or biomedical science'.[31] Mann popularised a trilogy that today sounds strikingly simple: human rights abuses can dramatically affect health; health can be dramatically worsened when human rights are ignored; and health and human rights can operate in synergy with each other for global human betterment. For Mann and fellow pioneers in the field of health and human rights, one fact above all was clear: the 'promotion and protection of rights and health are inextricably linked'.[32]

The pioneers would readily have accepted that the links were complex, that teasing them out and arguing over them were on-going matters.[33] The game-changer, though, was the initial, broad linkage between health and human rights. Making that link ushered in a new language of claims-making around health, one rooted in dignity, freedom or basic needs (and increasingly in consensus), which had a degree of urgency and priority

[31] JM Mann, 'Human Rights and AIDS: The Future of the Pandemic' in JM Mann et al (eds), *Health and Human Rights: A Reader* (Routledge 1999) 223. See also LO Gostin and Z Lazzarini, *Human Rights and Public Health in the AIDS Pandemic* (Oxford University Press 1997).

[32] JM Mann, 'Health and Human Rights: If Not Now, Then When?' (1997) 2(3) Health and Human Rights 113.

[33] See relatedly GM Oppenheimer et al, 'Health and Human Rights: Old Wine in New Bottles?' (2002) 30 Journal of Law, Medicine and Ethics 522, assessing whether the health and human rights perspective had accurately characterised prior efforts to understand social inequality, disease and death.

over other claims and came with a set of local, regional and international fora wherein states as duty-bearers could be held to account, and new or underdeveloped duty-bearers, such as pharmaceutical companies, could be considered. And looking just at HIV/AIDS, that new language in turn proved transformative.

Access to antiretrovirals (ARVs) is now framed not just as a public good but as a human right. Related to this, individual states, pharmaceutical companies and, more broadly, the WTO intellectual property regime have been scrutinised in unprecedented ways and declared wanting where their actions or omissions are seen to be blocking price reductions on essential medications. Public health has also been a powerful counter-argument against the structural adjustment programmes (SAPs) that were until recently the standard prescription from the World Bank and others for damaged economies, mainly in Latin America but elsewhere too.[34] It is, of course, true that none of these transformations is secure or free from controversy; nonetheless, each bears the imprint of human rights—in particular, of human rights as a game-changer in how we think about health.

We need to acknowledge domestic courts too as key public health actors in this period, prompted in places by another equally important actor: highly networked NGOs, which have shown themselves to be crucial both to strategic litigation and to the success of remedies prescribed by the courts. So, for example, as I discuss in chapter three, faced with intransigence and denial on the part of the South African state, the NGO Treatment Action Campaign successfully invoked constitutional provisions on access to health care to secure a nationwide programme on prevention of mother-to-child transmission.[35] There are similar stories elsewhere: in Colombia, for instance, courts and other actors have used the law to hold government accountable for promises made concerning functioning health systems.[36] In places, managerial judging has been part of the accountability mix, with detailed remedies involving close supervision by courts. This burst of litigation has also meant that standards for limiting the right to health and health-related rights, including proportionality, reasonableness and necessity, have been fleshed out. The craft of justiciability, we might say, is now

[34] www.who.int/trade/glossary/story084/en/: 'Studies have shown that SAPs policies have slowed down improvements in, or worsened, the health status of people in countries implementing them. The results reported include worse nutritional status of children, increased incidence of infectious diseases, and higher infant and maternal mortality rates.'

[35] *Minister of Health and Others v Treatment Action Campaign and Others* 2002 (5) SA 721 (South African Constitutional Ct). See further below ch 3; WE Forbath et al, 'Cultural Transformation, Deep Institutional Reform, and ESR Practice: South Africa's Treatment Action Campaign' in LE White and J Perelman (eds), *Stones of Hope: How African Activists Reclaim Human Rights to Challenge Global Poverty* (Stanford University Press 2011).

[36] *Corte Constitutional de la República de Colombia*, *Sala Segundo de Revisión*, Case no T-760/08 (Colombian Constitutional Ct).

ascendant.[37] This a major about-turn, one I shall come back to below in sections IV and V, and in a number of the case studies too. For now, we can simply note that managerialism and experimentalism have also been pursued elsewhere. Access-to-medicines targets, for instance, were set in a number of UN declarations on HIV/AIDS; the Millennium Development Goals centre on targets too. New funding mechanisms, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, have emerged recently, and there has also been a surge of scholarly interest in structures to incentivise research and development and improve access to medicines for HIV/AIDS and for neglected diseases.[38]

Seeing and arguing for access to ARVs as a human right has also brought changes for individuals, NGOs, international organisations and an array of states, producing new understandings of identity, obligation and, of course, law itself. I shall say more about this in chapter three. Here, by way of illustration, we can consider Médecins Sans Frontières (MSF), a very well-known humanitarian NGO but not perhaps an obvious participant in health and human rights. The organisation, to be clear, has not made any public shift towards human rights; indeed, at MSF there is 'continued avoidance of human rights rhetoric'.[39] At the same time, MSF does seem an increasingly unconventional humanitarian group: it is heavily invested in the provision of HIV/AIDS treatment, for instance, and also in campaigns on access to essential medicines. Each of these is far more akin to a rights-based approach to health than to conventional humanitarian biomedicine. Moreover, given that HIV/AIDS treatment requires more than access to medicines—who can live on medicines alone?—MSF may find it hard to avoid going deeper into human rights terrain, where it will find challenging and on-going questions of justice that are rather different to the temporary, crisis-focused humanitarianism to which it has been accustomed.

Looking back at the public health pathway, it is also clear that although access to ARVs was the pre-eminent organising goal, it was not the exclusive focus of the fledgling field of health and human rights. Discrimination against people living with HIV was another central albeit related concern: damaging forms of criminalisation were one target; the gap between laws

[37] See further KL Scheppele, 'A Realpolitik Defense of Social Rights' (2004) 82 Texas Law Review 1922 (comparing role conceptions as between courts in Hungary and Russia in response to market reforms affecting ES rights); D Landau, 'Political Institutions and Judicial Role in Comparative Constitutional Law' (2010) 51 Harvard International Law Journal 319; KG Young, *Constituting Economic and Social Rights* (Oxford University Press 2012) esp pt II (outlining five forms of judicial review and four role conceptions of courts in ES rights adjudication).

[38] See, eg, A Hollis and T Pogge, *The Health Impact Fund: Making New Medicines Available for All* (Incentives for Global Health 2008); N Hassoun, *Globalization and Global Justice: Shrinking Distance, Expanding Obligations* (Cambridge University Press 2012).

[39] P Redfield, 'Doctors without Borders and the Moral Economy of Pharmaceuticals' in A Bullard (ed), *Human Rights in Crisis* (Ashgate Publishing 2008) 139–40.

prohibiting discrimination and the lived experience of discrimination, stigma and exclusion was another.[40] *Toonen v Australia*, decided in 1994 by the Human Rights Committee, the treaty body responsible for the International Covenant on Civil and Political Rights (ICCPR), resonated strongly with this concern about damaging laws. The Committee made its view clear: criminalisation of homosexual practices cannot be considered 'a reasonable means or proportionate measure to achieve the aim of preventing the spread of HIV/AIDS'.[41] Another treaty body, the Committee on Economic, Social and Cultural Rights (CESCR), addressed the question in 2000. In its general comment on the right to health, which I discuss below, it emphasised that where a state party to the ICESCR 'restricts the movement of, or incarcerates, persons with transmissible diseases such as HIV/AIDS … on grounds such as national security or the preservation of public order', that state will have to justify such measures as Covenant-compliant.[42] More recently, criminalisation has been addressed by Anand Grover, the UN Special Rapporteur on the right to health,[43] which suggests on-going problems of discrimination but, equally, on-going human rights attention focused upon them. We come back to the treaty bodies and the Special Rapporteur below in sections IV and V, examining their contribution to the second key pathway to health and human rights today: namely, the right to health in the ICESCR and other health and health-related rights.

III. VIEWS FROM HERE AND NOW

Say we were to start from here and now, how would we rate the success of the public health pathway just described? It is not an easy question to answer. My own initial worries about public health, detailed in the Introduction, seem in some ways misplaced. Public health appears to be radically different—it appears to be a force *for* human rights—if we look at it through lives saved through access to ARVs. Still, caution is not entirely misplaced. Has access, for instance, steered attention away from prevention?

[40] More recently, attention has been paid to how the Global Fund might better reconcile its focus on a country-driven model of funding with the need to reach sex workers, lesbians, gays, bisexuals, transgender people, and men who have sex with men: see further A Seale et al, 'Partnership, Sex, and Marginalization' (2010) 12(1) Health and Human Rights: An International Journal 123.

[41] *Toonen v Australia*, Communication No 488/1992, UN Doc CCPR/C/50/D/488/1992 (31 March 1994) para 8.5.

[42] CESCR, 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/4, para 28 (referring to the CESCR's art 4 limitation clause).

[43] UN Human Rights Council (UNHRC), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (27 April 2010) UN Doc A/HRC/14/20.

Has HIV/AIDS steered attention away from other illnesses and from health systems, gathering up more than its fair share of resources? And is the success of access litigation steering others towards litigation, creating not just misplaced expectations of courts but also misplaced court orders that give an apparent win to individual claimants whilst also skewering health and other budgets? Moreover, recall the turn towards public health preparedness, which I outlined in the Introduction: where does that fit? Also, going forward, how might it affect extant understandings of public health?

These questions point to the need to measure the success of the public health pathway; what they also point to, however, is the difficulty of knowing what and how to measure. It may be too soon to speak of net results from the public health pathway. On the other hand, it does seem important to make some sort of assessment, however hedged and conditional. That is the task to which we now turn, examining concerns about inequity and inequality, and about 'managerial' human rights.

A. Inequality and Inequity

The most challenging present-day concerns for health and human rights centre on inequality and inequity. Do we understand, for instance, how inequality and inequity relate to one another? And how rights-based approaches to health affect them? The answer to these questions is 'no'. Equality remains an underdeveloped commitment as regards ESC rights. Status-based discrimination has been the pre-eminent focus of international human rights law, and for the most part, equality is still seen as synonymous with non-discrimination, which means that positive equality continues to be neglected.[44] Status-based discrimination on the ground of economic status also seems neglected by comparison with fellow prohibited grounds, which means that human rights has yet to give serious consideration to the rights-credentials of two-tier health systems that allow individuals who can afford it to opt out of the public system.[45]

Equity in health does not seem to have had much penetration in human rights either.[46] And the same could be said of an array of related matters, such as health corruption, the relationship between health and social inequality, and the principles of procedural justice that are said to be

[44] *Cf* MacNaughton, 'Untangling Equality and Non-Discrimination' (n 6); AE Yamin, 'Shades of Dignity: Exploring the Demands of Equality in Applying Human Rights Frameworks to Health' (2009) 11(2) Health and Human Rights: An International Journal 1.

[45] *Cf Chaoulli v Quebec Attorney General* [2005] 1 SCR 791 (Canadian SCt).

[46] See AR Chapman, 'The Social Determinants of Health, Health Equity, and Human Rights' (2010) 12(2) Health and Human Rights: An International Journal 17.

essential to setting limits fairly.[47] And these gaps are all the more striking now that critics are asking, 'Are human rights *causing* inequity in health?' These critics point out that HIV/AIDS—specifically, access to treatment—is widely claimed as a human rights success; what they want to know, however, is 'What of other illnesses?' There is, they emphasise, no similar level of litigation elsewhere, no equivalent price reductions on medications and no comparable range of targets for individual states. Furthermore, looking only at HIV/AIDS, prevention is clearly not a success story akin to access to treatment, and this has led at least one commentator to denounce the apparent partiality of rights in trenchant terms: those who are HIV-positive 'advocate effectively for their right to treatment, while those who will get AIDS in the future cannot organise a lobby for a "right to prevention"'.[48]

How then are we to position access to HIV/AIDS treatment, the outstanding success story of health and human rights? Is it a 'transformative corrective to exclusionary and inequitable HIV/AIDS policies', as well as a template for 'increasing attention to other global health inequities and assuring realization of the right to the highest attainable standard of health'?[49] Or is it an inequity-producing one-off, an anomaly produced by factors such as the scale and effects of the pandemic, the arrival of effective ARVs, and the opportunities in AIDS activist circles for learning from elsewhere and building global alliances? Were the following factors significant too: the presence of discrimination and stigma against particular groups, price reductions, clear duties and duty-bearers, and rights-holders facing certain death? I shall be addressing these questions in detail in chapter three.

But whether it is an anomaly or not, what is clear is that access to treatment is now less secure than in the recent past. International funding, as the Joint United Nations Programme on HIV and AIDS (UNAIDS) has recently pointed out, 'has stagnated with the onset of the global economic downturn'.[50] The Global Fund, for instance, had to cancel a funding round. Moreover, although human rights attention to states' extra-territorial obligations has increased, and the question of benefit-sharing has also been attracting unprecedented levels of attention (partly because of the turn towards pandemic preparedness and the centrality thereto of sample and vaccine sharing), disputes concerning what is an obligation rather than a moral responsibility run deep. So too do disputes over intellectual property rights. The upshot is that robust measures remain by and large off the

[47] See further K Syrett, *Law, Legitimacy and the Rationing of Health Care: A Contextual and Comparative Perspective* (Cambridge University Press 2007); Daniels (n 24).

[48] W Easterly, 'Human Rights are the Wrong Basis for Health Care', *Financial Times* (12 October 2009).

[49] L Forman, 'Global AIDS Funding and the Re-emergence of AIDS "Exceptionalism"' (2011) 6 Social Medicine 45, 45.

[50] Joint United Nations Programme on HIV/AIDS (UNAIDS), 'Global Report: UNAIDS Report on the Global AIDS Epidemic 2012' (UNAIDS 2012) 62.

table. There is also a creeping sense that broader practices of global health governance have a loose relationship to global health justice. Again, I take up these questions in chapter three, and there is also some pertinent material in chapter two.

B. Managerial Human Rights

There is though more than one present-day pressure point within the public health pathway: as I explain in chapter four and make brief reference to in chapter five in the context of reproduction, programming tools, notably benchmarks and their companion indicators, are a further cause for concern. These tools, to be clear, are crucial: the Millennium Taskforce on Child and Maternal Health was right to counsel that 'human rights initiatives fixated on and bound by chapter and verse of human rights treaties often miss the mark'.[51] Problems can arise, however, if rights-based approaches to public health are reduced to such tools and if due care is not taken over their design and effects.

Vertical interventions tend to dominate, for instance, which means that primary health systems can be neglected. Further, in an effort to meet targets, individual vertical interventions can be so focused that they produce their own distortions. Most problematic of all is the supposed non-politics of benchmarks, indicators and the like. Thus, if we turn towards these forms of measurement, we will need first of all to stay alert to the politics of the tools we select; as others have pointed out, indicators *are* interventions.[52] Secondly, we need to recognise that rights-based approaches to public health inevitably involve political questions: these questions are not easy, but they have to be faced, not blunted or dulled down through management or other allegedly conflict-reducing practices.

The rise in proceduralisation raises related questions. Later in section V I shall be looking briefly at proceduralisation in health rights litigation, asking when it is a sign of undue deference, of a cowed court attempting a retreat from the sometimes overheated politics of substantive review, and when by contrast is it a means by which participatory democracy might flourish? Here, picking up on the claims I made in the Introduction concerning

[51] LP Freedman et al, UN Millennium Project Task Force on Child Health and Maternal Health, *Who's Got the Power? Transforming Health Systems for Women and Children* (Earthscan 2005) 34. See also P Alston, 'Ships Passing in the Night: The Current State of the Human Rights and Development Debate Seen through the Lens of the Millennium Development Goals' (2005) 27 Human Rights Quarterly 755, 826: 'Actors of the human rights community share a responsibility for the lack of integration of the MDG and human rights agendas.'

[52] See KE Davis and B Kingsbury, 'Indicators as Interventions: Pitfalls and Prospects in Supporting Development Initiatives' (Rockefeller Foundation 2011).

the gap in human rights scholarship on the question of, first, the law/bioethics relationship and, second, participation in health and health-technology policymaking, I want simply to note an allegation levelled at an apparently procedural turn in public health ethics. In a provocative 2008 article, the bioethicist Richard Ashcroft denounced an 'intellectual failure of nerve'[53] on the part of fellow bioethicists operating in a consultative or advisory role on matters of pandemic preparedness. They were moving almost immediately, he argued, to 'turn ethical problems into problems of deliberative politics'.[54] Labelling this a 'presumption of undecidability', Ashcroft insisted upon its opposite: a presumption *against* undecidability.

> If we act on a presumption that the ethical problems of resource allocation, pandemic response and so on are too complex or controversial for us to illuminate other than by listing principles and describing once again principles of procedural justice, then we are abrogating our responsibilities—or admitting our redundancy.[55]

Ashcroft, to be clear, was not against principles of procedural justice. His argument was only that something is awry if bioethicists—scholars and practitioners who specialise in argument about difficult issues—are heading straight for process in their deliberations on public health. Is there, I wonder, a risk that this phenomenon might yet spread from bioethics to human rights?

At this point I should say that tools can of course produce too much politics too. I am thinking particularly of the phenomenon sometimes described as 'managerial judging'—cases, that is, where a court following review of state action prescribes a detailed remedy that involves the court in close, on-going supervision. This form of judging is not common in health rights cases, but it does have at least one notable practitioner, the Colombian Constitutional Court.[56] Speaking of the string of judgments by which the Constitutional Court ordered a restructuring of the state's approach to health financing,[57] one former justice has emphasised that the Court really had no option other than a detailed remedy and detailed supervision thereof. Circumstances were, he has said, so bad both in Congress and amongst the insurance companies and providers that '[the judges] were the bureaucracy'.[58] Time will tell whether the Constitutional Court was right

[53] RA Ashcroft, 'Fair Process and the Redundancy of Bioethics: A Polemic' (2008) 1 Public Health Ethics 3, 7.

[54] Ibid.

[55] Ibid, 6–7.

[56] The South African Constitutional Court, moreover, has endorsed the 'managerial role of courts': *Port Elizabeth Municipality v Various Occupiers* 2005(1) SA 217 para 39.

[57] See esp case no T-760/08 (n 36).

[58] D Landau, 'The Reality of Social Rights Enforcement' (2012) 53 Harvard International Law Journal 189, 223–24, citing Manuel José Cepeda Espinosa, a former justice of the Court.

to do as it did;[59] but a broader bureaucratisation would surely be worrying. How would courts handle the inevitable extra workload, for instance? How would they cope with allegations that their decisions allow successful claimants to queue-jump? And who would be held responsible for the unintended, unexpected and unwanted consequences of such detailed court orders? The risks of disarray, discontent and disrepute seem high indeed.

I turn now to other present-day threats to courts and, more broadly, to health and human rights. To do this, I begin by drawing out the field's second related pathway: the right to health in the ICESCR and other health and health-related rights. Once I have sketched the astonishing rise of these rights in recent years, I detail what I see as three important foci for human rights legal method going forward: namely, health rights litigation; patient and research-subject autonomy and the overweening emphasis on consent and consent forms; and the need for health and human rights law engagement with new health technologies.

IV. THE RIGHT TO HEALTH AND OTHER HEALTH AND HEALTH-RELATED RIGHTS

Echoing what I said in the Introduction about the importance of taking an approach that is 'right-to-health plus', the first and perhaps most important point I want to make here is that the rights at the heart of this second pathway range across the spectrum; we are not talking simply about the right to health but about that right and other health and health-related rights that span a range of civil, cultural, social, economic and political rights. Today, moreover, these rights are recognised in international human rights law, in its regional counterpart and in an ever wider range of new and amended constitutions. There is also dialogue, as well as an expanding sense of interdependence, between and within these legal orders. Bodies of law that seem far from human rights—intellectual property law, say, or private law more broadly—are also being pulled in amidst ever closer rights-based scrutiny of their positive and negative use, effect and potential. The upshot is that for human rights legal method, health and human rights is a mercurial mix. Thus, we will need to see it in its totality but also to understand the particularities. International human rights law-making, for instance, is not identical to decision-making by constitutional courts, and constitutional courts are not identical to one another either. In similar vein, NGOs may

[59] For recent assessments see Landau, 'The Reality of Social Rights Enforcement' (ibid); AE Yamin, O Parra-Verra and C Gianella, 'Judicial Protection of the Right to Health: An Elusive Promise?' in Yamin and Gloppen (eds) (n 15); KG Young and J Lemaitre, 'The Comparative Fortunes of the Right to Health: Two Tales of Justiciability in Colombia and South Africa' (2013) 26 Harvard Human Rights Journal 801.

be linked nationally and internationally more than in the past, but NGO practices vis-à-vis law are certainly not identical. The same can be said of other notable actors, including national human rights institutions.

The next key point to make is that once we draw down to the right to health, what we find is that sometimes recognition of this right is explicit; elsewhere it emerges from other rights—the right to life, for instance, or the right not to be subject to cruel or inhuman treatment, or the prohibition on arbitrary detention.[60] In places it is the right of access to health care rather than the right to health that is recognised or implied. In places, too, mention is made of particular forms of health care (emergency treatment, for instance) or particular groups (the right of, say, every child to basic health care services[61]). Equally, in places health rights are judicially enforceable; elsewhere they appear as aspirational guarantees. Where they are enforceable, almost all of them appear alongside modes by which it is legitimate to impose limits upon them. Judges, moreover, have the power to craft further limitations through, say, judicially-fashioned principles of restraint, such as the margin of appreciation used by the European Court of Human Rights (ECtHR)[62] or simply through under-enforcement. Again, as I emphasised in the Introduction, the challenge going forward for human rights legal method is to track and ultimately to build a rights-based account of legitimate limitations on health rights. This is an important topic to which I shall return in several of the case studies that follow.

For a very long time, of course, and even when compared against fellow ESC rights, little or nothing seemed to happen with the right to health: it had legal form in a range of places, but it was a paper right and a controversial one at that.[63] So the question is: what led to the radical improvement in its standing as a right in the world (accepting of course that many remain to be convinced that this change is a good thing)? We have already examined one key influence: the HIV/AIDS pandemic, more particularly the arrival of ARVs and the consensus that was forged around access to treatment as a way to stop the loss of life. Health rights litigation helped forge that

[60] See, eg, Human Rights Committee (HRC), 'General Comment No 6: The Right to Life (art 6)' (30 April 1982) para 5; *Parmanand Katara v Union of India* (1989) 4 SCC 42 (Indian SCt); *Paschim Bana Khet Mazdoor Samity v State of West Bengal* (1996) 4 SCC 37 (Indian SCt); the *Zakari* case from Ghana, discussed in Young (n 37) 225–45; *D v UK* (1997) 24 EHRR 423 (ECtHR) (*cf N v UK* [GC] (2008) 47 EHRR 39).

[61] Constitution of the Republic of South Africa 1996, art 28(1)(c).

[62] For explanation and analysis of this doctrine see, eg, S Greer, *The European Convention on Human Rights: Achievements, Problems and Prospects* (Cambridge University Press 2006); DJ Harris et al, *Harris, O'Boyle and Warbrick: Law of The European Convention on Human Rights* (2nd edn, Oxford University Press 2009).

[63] *Cf* the following early attempts to flesh out the right to health in international law: V Leary, 'The Right to Health in International Human Rights Law' (1994) 1 Health and Human Rights 24; K Tomaševski, 'Health' in O Schachter and CC Joyner (eds), *United Nations Legal Order* vol 2 (Cambridge University Press 1995); B Toebes, *The Right to Health as a Human Right in International Law* (Intersentia 1999).

consensus: aided by highly networked NGOs, a bout of constitution-making, an array of chronic failures on the part of governments and, in places, wider standing and access to the courts, cases on HIV/AIDS medicines seemed almost to cascade from one state to another (albeit that success in court did not always produce access on the ground). This access cascade prompted in turn broader interest in rights litigation around health, albeit no other claim for medicines has experienced success akin to that for ARVs. It also eased some age-old anxieties about enforcement of ESC rights via justiciability. Having actual cases, whose detail and effects can be studied, makes it easier to divide legitimate concerns from hot air and from straightforwardly ideological opposition. Equally, and paradoxically, having actual cases seems also to have freed up space for more active consideration of non-judicial forms of ESC-rights enforcement.

The shift in status of the right to health can also be sourced to international law and policy-making. At times, to be sure, these sources functioned more as adversary-galvanising forces than as allies. Particularly strong aversions flowed both from the SAPs that were demanded by the international financial institutions during the 1980s and 1990s and from the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights,[64] which inaugurated an intellectual property regime for all WTO Members that seemed initially to wipe out the production of generics, thereby threatening access to medicines, especially in the global South.

Elsewhere, however, the signals from international law and policy-making were more promising. The issue of ESC-rights justiciability, for instance, gained a new forum and a new champion in 1987 when the ICESCR secured its own specialised expert committee, the CESCR.[65] It took, to be sure, more than 20 years to gain agreement on a complaints procedure for the CESCR,[66] yet justiciability still wove its way in—notably through the CESCR's scrutiny of reports from state parties and through its General Comments.

Two early Comments from the Committee, one in 1990 and the other in 1998, addressed justiciability. In the second of these, General Comment No 9, the Committee took on the claim that courts must be kept away from matters that concern resources. It was, the CESCR pointed out, not just

[64] Agreement establishing the World Trade Organization (15 April 1994, entered into force 1 January 1995) 1869 UNTS 299, annex 1C (Agreement on Trade-Related Aspects of Intellectual Property Rights) (hereafter 'TRIPS'). Adherence to TRIPS is required of all WTO members (bar least developed countries (LDCs) who do not have to implement it until 2016) and is enforceable via the WTO's Understanding on Dispute Settlement.

[65] See generally P Alston, 'The Committee on Economic, Social and Cultural Rights' in P Alston (ed), *The United Nations and Human Rights: A Critical Appraisal* (Oxford University Press 1992); M Odello and F Seatzu, *The UN Committee on Economic, Social and Cultural Rights: The Law, Process and Practice* (Routledge 2012).

[66] OP-ICESCR (n 10).

arbitrary but also incompatible with the interdependence and indivisibility of rights to put ESC rights 'beyond the reach of the courts'.[67] Clustering of rights into the justiciable and non-justiciable would also 'drastically curtail the capacity of the courts to protect the rights of the most vulnerable and disadvantaged groups in society'.[68] And, crucially, given that courts were 'generally already involved in a considerable range of matters which have important resource implications',[69] why precisely was there a resource problem particular to ESC rights justiciability? Separation of powers, the CESCR acknowledged, was to be respected; but cherry-picking between ICESCR rights and other rights, or between ICESCR rights themselves, had to be ruled out.[70]

In its earlier General Comment No 3, the CESCR had already made clear that it considered many ICESCR provisions 'capable of immediate application by judicial and other organs in many national legal systems':[71] it listed the freedom for scientific research[72] as one such provision. Much more significantly, General Comment No 3 punctured the notion that all obligations under the ICESCR were subject to a duty of a 'progressive realisation'.[73] There were, the CESCR pointed out, 'various obligations of immediate effect'. Avoiding discrimination was one such obligation; 'taking steps'—'deliberate, concrete and clearly targeted ones'—towards the full realisation of ICESCR rights was another.[74] There was also a 'minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights'.[75] Without this, the CESCR emphasised, the Covenant 'would be largely deprived of its raison d'être':[76]

> A state party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant.[77]

[67] CESCR, 'General Comment No 9: The Domestic Application of the Covenant' (3 December 1998) UN Doc E/C.12/1998/24, para 10.

[68] Ibid.

[69] Ibid.

[70] Ibid, noting that 'there is no Covenant right which could not, in the great majority of systems, be considered to possess at least some significant justiciable dimensions'.

[71] CESCR, 'General Comment No 3: The Nature of States' Parties Obligations (art 2, para 1)' (14 December 1990) UN Doc E/1991/23.

[72] ICESCR (n 5) art 15(3).

[73] Ibid, art 2(1): 'Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.'

[74] CESCR, 'General Comment No 3' (n 71) paras 1–2.

[75] Ibid, para 10.

[76] Ibid.

[77] Ibid.

Recognising the inevitable counter-claim from states parties—lack of resources—the CESCR continued in the following vein:

> In order for a state party to be able to attribute its failure to meet at least its minimum core obligations to a lack of available resources it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.[78]

Ten years later the CESCR used General Comment No 14 to elaborate on this admittedly controversial concept of minimum, or core, obligations. The context was the right to the enjoyment of the highest attainable standard of physical and mental health, established by article 12 ICESCR. Let's now look at this influential General Comment in more detail.[79]

A. General Comment No 14 on the Right to Health

General Comment No 14 dispensed almost immediately with one misconception: article 12 ICESCR is 'not to be understood as a right to be *healthy*'.[80] Good health, it pointed out, 'cannot be ensured by a State, nor can States provide protection against every possible cause of ill health'.[81] On the other hand, however, article 12 is not merely a right to timely and appropriate health care: it extends beyond this to the underlying determinants of health, such as access to safe and potable water and adequate sanitation.[82] It encompasses, moreover, both entitlements and freedoms, including the 'right to control one's health and body, including sexual and reproductive freedom' and the 'right to be free from interference', such as the right to be free from torture, experimentation and non-consensual medical treatment.[83] And it also requires the 'participation of the population in all health-related decision-making at the community, national and international levels'.[84]

[78] Ibid.

[79] CESCR, 'General Comment No 14' (n 42).

[80] Ibid, para 8 (original emphasis).

[81] Ibid, para 9.

[82] Ibid, paras 4 and 11.

[83] Ibid, para 8. See Tobin (n 27) 132–58, exploring the legitimacy of this move in the absence of an explicit textual reference to such freedoms in the right to health in international law, and concluding that it is justifiable.

[84] CESCR, 'General Comment No 14' (n 42) para 11. See also UN European Economic Commission (UNECE), Aarhus Convention on Access to Information, Public Participation in Decision-Making and Access to Justice in Environmental Matters (25 June 1998, entered into force 30 October 2001) 2161 UNTS 447; Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (4 April 1997, entered into force 1 December 1999) ETS 164 (hereafter 'Oviedo Convention') art 28; ICCPR (n 5) art 25. See generally H Potts, 'Participation and the Right to the Highest Attainable Standard of Health' (University of Essex Human Rights Centre 2009); AE Yamin, 'Suffering and Powerlessness: The Significance of Participation in Rights-Based Approaches to Health' (2009) 11(1) Health and Human Rights: An International Journal 5.

How then is state compliance with this right to be implemented, and how does the CESCR approach the task of assessing state compliance? In article 12(2) ICESCR there is a list of illustrative examples of states parties' obligations: these include the creation of 'conditions which would assure to all medical service and medical attention in the event of sickness'. Article 2(1), moreover, speaks of using 'all appropriate means, including particularly the adoption of legislative measures' to realise the Covenant's rights.

General Comment No 14 added considerably to this guidance by providing, first, four standards vis-à-vis health facilities, goods and services: availability, accessibility, acceptability and quality.[85] Secondly, it deployed the now standard tripartite typology of state obligations[86] to respect, protect and fulfil human rights, extending the latter obligation to encompass obligations to facilitate and to provide—a move familiar from earlier general comments on food and education—as well as an obligation to promote.[87] States parties, in other words, have both positive and negative obligations.[88] They must not only abstain from violating the right to health but also prevent third parties from violating it, and they must take measures to ensure that the right is enjoyed in practice and to further provide, promote and facilitate access to it.

General Comment No 14 also affirmed that states parties have what it calls 'international obligations'.[89] Article 2(1) ICESCR, for instance, imposes responsibilities in relation to others, obliging states parties to take steps 'individually and through international assistance and cooperation, especially economic and technical'. One consequence of this is that a state, in giving effect to its own obligation to deploy 'maximum available resources' under article 2(1), is expected to look not just to resources

[85] CESCR, 'General Comment No 14' (n 42) para 12, noting also that how these elements are to be applied 'will depend on the conditions prevailing in a particular State party'. See also Convention on the Rights of the Child (20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (hereafter 'CRC') art 24, making explicit reference to availability and accessibility; Committee on the Rights of the Child (CRC Committee), 'General Comment No 4: Adolescent Health and Development' (1 July 2003) UN Doc CRC/GC/2003/4, para 41.

[86] See, eg, the deployment of this typology in the Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, adopted by a Group of Experts, Maastricht 22–26 January 1997 (2 October 2000) UN Doc E/C.12/2000/13, para 6 (reprinted in (1998) 20 Human Rights Quarterly 691). For criticism of it, see IE Koch, 'Dichotomies, Trichotomies or Waves of Duties?' (2005) 5 Human Rights Law Review 81.

[87] CESCR, 'General Comment No 14' (n 42) paras 33–37. See also CEDAW Committee, 'General Recommendation No 24: Women and Health (art 12)' (5 February 1999) UN Doc A/54/38/Rev.1, paras 14–17.

[88] See relatedly HRC, 'General Comment No 6' (n 60): 'The expression "inherent right to life" cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures. In this connection, the Committee considers that it would be desirable for States parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics.'

[89] CESCR, 'General Comment No 14' (n 42) paras 38–42.

existing within the state itself but also to those that might be available through international assistance and cooperation.[90]

Article 2(1) also attracted attention elsewhere in General Comment No 14. Dealing with the question of limits on article 12, the CESCR acknowledged that the obligation to realise the right to health was a progressive one. Realisation, in other words, can happen over a period of time.[91] Crucially, however, and in line with its remarks in earlier general comments, the CESCR went on to caution that progressive realisation 'should not be interpreted as depriving States parties' obligations of all meaningful content'.[92] There are, it emphasised, various obligations of *immediate* effect: states parties must take deliberate, concrete and targeted steps towards full realisation of the right to health;[93] they must ensure freedom from discrimination in health-related matters;[94] and they must give effect to what the CESCR calls the 'core obligations' concerning the right to health.[95] So, for example, there must be a national strategy to ensure to all the enjoyment of the right to health, and indicators and benchmarks, designed to measure progress over time, must be identified.[96] There is also a principle of non-retrogression—in essence, a rebuttable presumption that a state party is not free to backslide.[97] Moreover, according to General Comment No 14, a state party to the ICESCR 'cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations set out in [General Comment No 14], which are non-derogable'; 'situations of conflict, emergency and natural disaster' are no exception to this.[98] More recently, the CESCR has added that core obligations produce not just 'national responsibilities for all

[90] See, eg, CESCR, 'General Comment No 3' (n 71) para 10, emphasising the need to use 'all resources that are at [the state's] disposal'; CESCR, 'General Comment No 12: The Right to Adequate Food (art 11)' (12 May 1999) UN Doc E/C.12/1999/5, para 17.

[91] *Cf* African Charter on Human and Peoples' Rights (ACHPR) (27 June 1981, entered into force 21 October 1986) 1520 UNTS 217, arts 15–16.

[92] CESCR, 'General Comment No 14' (n 42) para 31: 'Rather, progressive realization means that States parties have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of the right to health.'

[93] Ibid, para 30.

[94] See also ibid, paras 18–19, wherein the CESCR 'recalls general comment No 3, para 12, which states that even in times of severe resource constraints, the vulnerable members of society must be protected by the adoption of relatively low-cost targeted programmes'.

[95] CESCR, 'General Comment No 14' (n 42) para 43, providing a non-exhaustive list of six such obligations. In para 44, the CESCR lists five 'obligations of comparable priority'; these obligations, however, are not singled out for the same treatment as core obligations later in the General Comment. See also CESCR, 'General Comment No 8: The Relationship between Economic Sanctions and Respect for Economic, Social and Cultural Rights' (12 December 1997) UN Doc E/C.12/1997/8, para 7 emphasising that punitive measures must leave room for the protection of the minimum core of ES rights of vulnerable populations, in areas such as essential medicines and food.

[96] CESCR, 'General Comment No 14' (n 42) paras 53–58.

[97] Ibid, para 32.

[98] Ibid, paras 45 and 47.

States' but also 'international responsibilities for developed States, as well as others that are "in a position to assist"'.[99]

B. Beyond General Comment No 14

In issuing General Comment No 14, the CESCR emphasised that its elaboration of the right to health in the ICESCR was 'based on the Committee's experience in examining States parties' reports over many years'.[100] That presumably struck the right note—lacking an enforceability mechanism, the CESCR has had to craft its authority with care—but it could also be misleading. To put it bluntly, General Comment No 14 does rather more than reflect state practice. For instance, when a national constitutional court or an international organisation reaches for the General Comment as part of its reasoning, that may well bring about new rights-protective practices.[101] The same is true of a campaigning NGO that reaches for the General Comment. There is also of course a Special Rapporteur on the right to health—one of the UN Special Procedures—who is charged with elaborating upon General Comment No 14 via thematic reports, country reports and letters of complaints (which go by the term 'communications').[102] The first Rapporteur, Paul Hunt, produced 30 reports over a six-year term of office, tackling focused issues (such as maternal mortality, mental disability, access to medicines, the skills drain and neglected diseases) and far broader ones (such as the right-to-health features of health systems).[103] His successor, Anand Grover, has already looked at issues ranging from patent protection to informed consent, as well as describing both a right to health approach to health financing and the obstacles to health that are created by criminalisation. For each of these Rapporteurs, *operationalising* both the right to health and General Comment No 14 is what has been most important. And for them, achieving this means not merely judicial and quasi-judicial forms of accountability[104] but also rights-based policy approaches

[99] CESCR, 'Statement on Poverty and the International Covenant on Economic, Social and Cultural Rights' (10 May 2001) UN Doc E/C.12/2001/10, para 16.

[100] CESCR, 'General Comment No 14' (n 42) para 6.

[101] See, eg, case T-760/08 (n 36).

[102] Establishing the mandate, see UN Commission on Human Rights (UNCHR), 'The Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (22 April 2002) UN Doc E/CN.4/RES/2002/31.

[103] For his reflections on this work, see P Hunt and S Leader, 'Developing and Applying the Right to the Highest Attainable Standard of Health: The Role of the UN Special Rapporteur (2002–2008) in Harrington and Stuttaford (eds) (n 25).

[104] Accountability, like non-discrimination, equality and transparency, is a cross-cutting principle of international human rights law. See further AE Yamin, 'Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health' (2008) 10(2) Health and Human Rights: An International Journal 1.

with implementation, supervision and enforcement mechanisms. Hunt has explained this dual stance in the following way:

> The right to health requires both approaches, and if this fundamental human right is not brought to bear upon local, national and international policymaking, it runs the risk of marginal relevance, surfacing only when, as a last resort, it is argued in courts—institutions that are often inaccessible to the disadvantaged and impoverished.[105]

In terms of accountability, the Optional Protocol to the ICESCR has been welcomed by many. It gives the CESCR an entirely new form of authority, which may in turn ease the pressure on this body to present itself as reflective of state practice. Decisions will not, of course, be binding as a matter of treaty law; however, the potential for reach and significance is there. Here, for instance, is how the Office of the UN High Commissioner for Human Rights (OHCHR) explains the power of the UN treaty body complaints process:

> It is through individual complaints that human rights are given concrete meaning. In the adjudication of individual cases, international norms that may otherwise seem general and abstract are put into practical effect. When applied to a person's real-life situation, the standards contained in international human rights treaties find their most direct application. The resulting body of decisions may guide States, non-governmental organizations (NGOs) and individuals in interpreting the contemporary meaning of the texts concerned.[106]

These claims receive some support from practice as regards health rights amongst those UN treaty bodies where complaints procedures have been in place for some time. Thus we saw earlier that the Human Rights Committee has decried criminalisation as a public health tool in the context of the HIV/AIDS pandemic.[107] More recently, in *LH v Peru*, this Committee established that states parties can be held accountable for failing to ensure that, where abortion is lawful, it can in fact be accessed in practice.[108] The Committee on the Elimination of Discrimination against Women (CEDAW), for its part, has tackled non-consensual sterilisation and maternal mortality; it has also done considerable work on both violence against women and gender stereotyping.[109]

[105] Hunt and Leader (n 103) 33.

[106] OHCHR, 'Human Rights Treaty Bodies: Individual Communications', www2.ohchr.org/English/bodies/petitions/individual.htm.

[107] *Toonen* (n 41).

[108] *KL v Peru* (22 November 2005) UN Doc CCPR/C/85/D/1153/2003.

[109] See in particular *AS v Hungary* (14 August 2006) UN Doc CEDAW/C/36/D/4/2004; *Alyne da Silva Pimental Teixeira v Brazil* (10 August 2011) UN Doc CEDAW/C/49/D/17/2008. On stereotyping, see S Cusack and RJ Cook, 'Stereotyping Women in the Health Sector: Lessons from CEDAW' (2010) 16 Journal of Civil Rights and Social Justice 47.

Accountability has been promoted by regional bodies and instruments as well. In the European region, for instance, both the European Union and the Council of Europe have been active,[110] and we could include others too, such as WHO Europe or the European Patent Office. Moreover, although the obvious sites for health rights within the Council of Europe seem to be the European Social Charter system[111] and the Oviedo Convention,[112] the ECtHR can claim to be a health-rights actor too.[113] The Court has already heard several cases asking it to determine what constitutes rights-based regulation of new health technologies, such as pre-implantation genetic diagnosis.[114] Furthermore, like the Human Rights Committee, it has held that contracting states are accountable for securing access to abortion where it is lawful: rights in law must, the ECtHR insists, be rights in practice too.[115] The Court's 'greening'[116] of the ECHR is also pertinent. Violations of articles 2 and 8 ECHR have been found where threats to health had their source in environmental problems; the Court has also crafted an array of positive obligations on the contracting states in the environmental area—states have duties to carry out studies and to provide information to those affected,[117] to install legislative and administrative structures to prevent harm and to make provision for remedies.[118]

[110] See O De Schutter (ed), *The European Social Charter: A Social Constitution for Europe* (Bruylant 2010); B Toebes et al (eds), *Health and Human Rights in Europe* (Intersentia 2012); TK Hervey and JV McHale, *Health Law and the European Union* (Cambridge University Press 2004).

[111] European Social Charter (18 October 1961, entered into force 26 February 1965) ETS 35 (hereafter 'ESC'); European Social Charter (Revised) (revised 3 May 1996, entered into force 1 July 1999) ETS 163 (hereafter 'rev ESC'). The aim is for the latter eventually to replace the former.

[112] Oviedo Convention (n 84).

[113] See further I Koch, *Human Rights as Indivisible Rights: The Protection of Socio-economic Demands under the European Convention on Human Rights* (Martinus Nijhoff 2009); R O'Connell and S Gevers, 'Fixed Points in a Changing Age: The Council of Europe, Human Rights and New Health Technologies' in M Flear et al (eds), *European Law and New Health Technologies* (Oxford University Press 2013).

[114] See *Evans v United Kingdom* [GC] (2008) 46 EHRR 34; *SH and Others v Austria* [GC], App no 57813/00 (Judgment of 3 November 2011); *Costa and Pavan v Italy*, App no 54270/10 (Judgment of 28 August 2012).

[115] *Tysiąc v Poland* (2007) 45 EHRR 42; *P and S v Poland*, App no 57375/08 (Judgment of 30 October 2012, ECtHR); *RR v Poland* (2011) 53 EHRR 31.

[116] See A Boyle, 'Human Rights or Environmental Rights: A Reassessment' (2007) 18 Fordham Environmental Law Review 471.

[117] This emphasis on the right to information in environmental cases has in turn been picked up by the ECtHR in particular health contexts. See, eg, *Roche v UK* [GC] (2006) 42 EHRR 30; *I v Finland* (2009) 48 EHRR 31; *KH v Slovakia* (2009) 49 EHRR 34; *RR v Poland* (n 115).

[118] See, eg, *Guerra v Italy* (1998) 26 EHRR 357; *Hatton v UK* [GC] (2003) 37 EHRR 28; *Taşkın v Turkey* (2004) 42 EHRR 50; *Öneryildiz v Turkey* [GC] (2005) 41 EHRR 20.

The Court's 'health rights' case law is, I accept, challenging. For some, indirect protection of ESC rights is unsatisfactory.[119] Equally, for those who dislike the notion of ESC-rights justiciability, evidence suggesting that civil and political rights strengthen social rights or that social rights can be developed by a court charged with giving effect to an instrument focused on civil and political rights, will be unappealing and unwelcome. There will also be those who criticise particular aspects of the ECtHR case law. The Court's understanding of autonomy, for instance, protected through the rights to respect for private and family life in article 8 ECHR, and its enthusiasm for informed consent and, more recently, for proceduralisation will not be applauded by all. Questions have also been raised about its forays into rights-based regulation of new health technologies. A more rigorous approach to the relationship between human rights law and bioethics would also be helpful,[120] given that the Council of Europe is also home to the Oviedo Convention, UNESCO has already championed the Universal Declaration on Bioethics and Human Rights and, in health and health technology policy-making, enthusiasm for 'public bioethics' continues to grow.

Still, the following is incontrovertible. The ECtHR case law, along with that of other courts and quasi-courts—international, regional and national—has disrupted an array of longstanding assumptions about health rights and, more particularly, about health rights justiciability. Instead of assumptions, we can now have scrutiny and comparison vis-à-vis both actually existing forms of justiciability and the effects of other rights, including civil and political ones, on health and health care. The evidence base, concentrated for so long on the apex courts in India and South Africa, seems to be growing steadily. And styles of scrutiny, both judicial and scholarly, seem to be growing too.

Today's health and human rights law scholars, for example, do not tend to ask 'Are economic and social rights justiciable?' or 'How can there be such a thing as a right to health?' Their questions have 'grown up', and what they are now asking is: what prompted particular cases? What forms of review and remedy are being deployed, with what underlying role conceptions on the part of the courts and what justifications for the rights in play? What factors produce enforcement of judgments? And what are the effects of both judgment and enforcement, for individual claimants and beyond? Some of the scrutiny focuses on theoretical accounts;[121] elsewhere

[119] E Brems, 'Indirect Protection of Social Rights by the European Court of Human Rights' in D Barak-Erez and AM Gross (eds), *Exploring Social Rights: Between Theory and Practice* (Hart Publishing 2007).

[120] See *Gillberg v Sweden* [GC], App no 41723/06 (Judgment of 3 April 2012).

[121] See, eg, D Bilchitz, *Poverty and Fundamental Rights: The Justification and Enforcement of Socio-Economic Rights* (Oxford University Press 2007); S Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford University Press 2008); J King, *Judging Social Rights* (Cambridge University Press 2012).

the commitment is to empirical work. Equally, some studies are health specific,[122] whereas others range across ESC rights.[123] Courts, moreover, are not always centre stage. Today a growing number of legal scholars start with NGO practices, asking 'What part did litigation play in broader NGO work focused on contestation and on consensus-building?'[124]

V. MORE VIEWS FROM THE PRESENT

Once again, it is time to stand back and make an admittedly preliminary and provisional assessment. Having tracked the tremendous growth of the right to health and health and health-related rights, as well as the range of actors involved, and with an apparent breakthrough as regards classic claims both of non- and anti-justiciability, can health and human rights take a break? I think not. Rising levels of justiciability mean that both the forms and the detail of this justiciability need to be scrutinised closely.

A. Health Rights Litigation

There is, moreover, a challenging array of health rights-recognising courts and quasi-courts that need to be scrutinised. The list includes the obvious—constitutional courts, international human rights courts and quasi-courts—and the not so obvious, including not just ordinary appellate courts but also specialised tribunals such as the Competition Commission in South Africa, with whom the NGO Treatment Action Campaign engaged as part of efforts to bring down the price of ARVs. Of course, the challenge runs deeper still. We need to analyse the reasoning at the heart of the decisions made by these bodies. We need to build comparisons between different forms of rights-based reasoning around health. And we need to construct, almost from scratch, an account of the on-the-ground prompts for and effects of such decisions. We need, in short, to understand what it means to

[122] V Gauri and D Brinks (eds), *Courting Social Justice: Judicial Enforcement of Social and Economic Rights in the Developing World* (Cambridge University Press 2008); Yamin and Gloppen (eds) (n 15); Tobin (n 27).

[123] See, eg, R Gargarella et al (eds), *Courts and Social Transformation in New Democracies: An Institutional Voice for the Poor?* (Ashgate Publishing 2006); International Commission of Jurists, 'Courts and the Legal Enforcement of Economic, Social and Cultural Rights: Comparative Experiences of Justiciability', Human Rights and Rule of Law Series No 2 (2008), www.unhcr.org/refworld/docid/4a7840562.html; M Langford (ed), *Social Rights Jurisprudence: Emerging Trends in International and Comparative Law* (Cambridge University Press 2008); Young (n 37); E Riedel et al (eds), *Contemporary Issues in Economic, Social and Cultural Rights* (Oxford University Press, forthcoming).

[124] See, eg, A Clapham et al (eds), *Realising the Right to Health* (Rüffer & Rub 2009); White and Perelman (eds) (n 35); Young (n 37).

see, argue about and secure health through rights litigation. This is complex, on-going work that is only just beginning, but we should expect that it will become more complex still.

To start with, the arrival of new health technologies—indeed, even the promise of them—is broadening the sense of what it means to be healthy. Equally, reports of success with right to health claims will surely forge new expectations, new identities and new practices. That has already been the experience with rights-based access to ARVs. Looking ahead, individuals may try to combine together so as to be seen by and make claims upon the state and upon others too (including both new health super-philanthropists and international NGOs). The claims made by these individuals will of course emphasise *their* disease, *their* drugs, *their* treatment. They may also be strongly encouraged to make such claims by pharmaceutical companies keen to secure new or stronger markets for their products. We already know, for instance, that early proponents of patient autonomy in the United States provided an unintended opening for companies to push direct-to-consumer medicines. These companies, as David Rothman has pointed out, were 'at once reacting to a new patient rights paradigm, and just as clearly, promoting it'. And once commerce joined with ideology in this way, there was 'a powerful engine for promoting change', one that made it hard to raise concerns about the distorting effects of advertising.[125] This phenomenon—sometimes described as 'selling sickness'—is widespread. Amidst rising levels of health rights litigation, we clearly need to ask: will it be joined by what might be called 'courting sickness' as pharmaceutical companies look to exploit a new opportunity?

Complexity is also inevitable given the challenge of inequality and inequity. For some, the rising number of health rights cases simply sharpens the fear that a justiciable right to health, rather than addressing the social injustice that is 'killing people on a grand scale',[126] will instead compound it. If those who are able to access the courts turn to law in increasing numbers in order to secure 'their' drugs, 'their' treatment and, more broadly, 'their' right to health, this—the critics point out—will simply distort health budgets and presumably a range of other budgets too. We have seen that this sort of criticism is already being levelled at the alleged privileging of ARVs.

There are several other reasons to prepare for complexity. One is the traditional deference of most courts to medicine and science: as health rights justiciability blossoms and as the vogue for public participation in health and technology policy-making increases, how will this deference play

[125] DJ Rothman, 'The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective' (2001) 9 Health Care Analysis 255, 261.

[126] Commission on Social Determinants of Health (CSDH), 'Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health' (WHO 2008) executive summary.

out? Unevenness seems the most likely outcome. The deference tradition may be strong, but proportionality review is a growing force; and patient and research-subject autonomy are powerful commitments within human rights law. On the other hand, we should also recall that in *Soobramoney v Minister of Health, Kwazulu-Natal*, the first ESC rights decision of South Africa's Constitutional Court, the majority deferred to both medical and political judgement, emphasising that medical rationing was an arena where 'institutional incapacity and appropriate constitutional modesty require [the Court] to be especially cautious'.[127]

The increasing cosmopolitanism of courts and quasi-courts brings challenges too. We need to see what translates from one site to another, as well as what does not. Different source documents, different mandates and different organisational cultures generate a need for immense detail. The entry of new actors, not least the CESCR, which now has a petitions power, adds to the task. One sticking-point will be the concept of minimum, or core, obligations, which as we saw earlier has been promoted by the CESCR as a means to direct attention and priority in law-making and policy-making on the right to health.[128] The core concept is disliked by many. In what is it grounded, they ask? If the answer is basic needs or mere survival, the core concept could underperform in practice, leaving disadvantage undisturbed; yet if the concept is grounded in human dignity, achieving it could become an undue burden upon states. And as Katharine Young has explained, the problems with the core concept run deeper still. For instance, what if the claim for this core 'is made in order to increase the bundles of commodities or consumption share of the disadvantaged, while failing to challenge the underlying economic institutions that have produced the disadvantage in the first place'?[129] She rightly concludes that the 'language of rights-claiming matters—it requires critical analysis, rather than mere acceptance, especially when misrecognition and stigma are so quick to accompany the claims of the poor'.[130]

[127] *Soobramoney v Minister of Health, Kwazulu-Natal* 1998 (1) SA 765 (CC), para 30. The case, which concerned a denial of access to renal dialysis in a public hospital, provoked widespread anger and criticism for its failure to provide an appropriate remedy. See further C Scott and P Alston, 'Adjudicating Constitutional Priorities in a Transnational Context: A Comment on *Soobramoney's* Legacy and *Grootboom's* Promise' (2000) 16 South African Journal of Human Rights 206.

[128] See above, text to nn 71–79 and 91–99.

[129] Young (n 37) 98. See more generally LE White, '"If You Don't Pay, You Die": Exploring Death and Desire in the Postcolony' in Barak-Erez and Gross (eds) (n 119) 57, emphasising that the language of social rights must be embedded in ways that promote social accessibility and practical equality.

[130] Young (n 37). See also G MacNaughton, 'Beyond a Minimum Threshold: The Right to Social Equality' in L Minkler (ed), *The State of Economic and Social Human Rights: A Global Overview* (Cambridge University Press 2012).

Another trend that divides commentators is the proceduralisation of rights. Procedural justice is, on the one hand, an integral part of justice and, more narrowly, of rights-based approaches. Hence a turn to it by courts and quasi-courts can be welcomed as a way to reverse the widespread neglect it has experienced in both health and human rights scholarship and health policy-making.[131] On the other hand, however, when courts and quasi-courts turn towards procedure, it does raise the question: are they looking for a way out, a way to signal deference to political decision-making and a turn away from the alleged intrusiveness of substantive review, or at least from the complaints of judicial overreaching that tend to accompany this form of review?

There is, to be fair, no inevitable sharp line between procedural and substantive justice. Nonetheless, we do need urgently to engage with procedural justice; we need, for instance, to have a better sense of the difference between proceduralism (in essence, the attempt to manage away the unavoidable politics of health rights), on the one hand, and procedural justice or legitimacy, on the other. Significantly, meaningful engagement, crafted by the Constitutional Court of South Africa, is already caught in these crosswinds. It was pioneered as both a remedy where insufficient engagement occurred prior to litigation and a characteristic of 'reasonable' government policy-making on ESC rights.[132] Nonetheless, commentators are already lining up to ask: is it an innovation that opens up possibilities in cases where administrative law and ESC rights intersect, or is it an indication of shifting sentiments on the Court? More worryingly again, is it a sign of the collapse of human rights into a set of administrative law principles? I turn next to another arena—patient autonomy—where commentators have been lining up to express both deep enthusiasm and deep concern.

B. Patient Autonomy: Friend or Foe?

Some years back, two English lawyers, Ian Kennedy and Andrew Grubb, who were looking to establish medical law as an area of law in its own right, insisted that medical law had 'some conceptual unity'.[133] Medical law, they claimed, was best seen as 'a subset of human rights law'.[134] Kennedy had made related claims in earlier work: 'To argue that patients have rights ensures that they will be taken seriously as partners in the enterprise of

[131] Noting this neglect, see L London, 'What is a Human Rights-Based Approach to Health and Does It Matter?' (2008) 10(1) Health and Human Rights: An International Journal 65, 72.

[132] See, eg, *Port Elizabeth Municipality* (n 56); *Occupiers of 51 Olivia Road v City of Johannesburg* 2008 (3) SA 208 (CC).

[133] I Kennedy and A Grubb, *Medical Law: Text and Materials* (2nd edn, Butterworths 1994) 3.

[134] Ibid.

health.'[135] For Kennedy and Grubb, then, taking patients seriously meant that law had to be serious about tackling the power of doctors; law had to be on the patient's side, using the language of rights to bolster the patient's position in the otherwise imbalanced doctor–patient relationship.

Today, autonomy, as protected and promoted through consent and typically through the consent form, is at the heart of human rights approaches to health care, research and public health;[136] moreover, according to one expert giving evidence to the UK House of Lords Science and Technology Committee, today's practices of public participation in science and technology decision-making are often the 'social equivalent of informed consent'.[137] For some lawyers and philosophers, however, the rights-based power of the patient—patient autonomy—is out of control. Extant understandings of autonomy are also said to be of little use in contemporary health-related research settings. Onora O'Neill, for instance, has noted that 'amid widespread and energetic efforts to respect persons and their autonomy and to improve regulatory structures, public trust in medicine, science and biotechnology has seemingly faltered'.[138] And for Jonathan Montgomery, the 'moral basis of medical practice' has been put at risk.[139] Choice and consumerism have, he says, produced a 'demoralisation of medicine', a form of medicine in which technical skill and moral reasoning are divisible, and the health professional is reduced to being the technician. What is desperately needed, he has argued, is 'a legal context in which professional morality could flourish', and to achieve this, lawyers must stop advising lawmakers that the best way to bolster the rights and choices of patients is to remove ethical issues from the province of health professionals to that of the law. For Montgomery, law should facilitate the determination of ethical issues; it should not seek to take them over.

[135] I Kennedy, *Treat Me Right* (Oxford University Press 1988) vii. See also Kennedy's 1981 Reith Lectures, published as *The Unmasking of Medicine* (Allen and Unwin 1981).

[136] See, eg, UNGA, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (10 August 2009) UN Doc A/64/272, emphasising the 'importance of prioritizing informed consent as a critical element of a voluntary counselling, testing and treatment continuum in the development of guidance for clinical practice, public health evidence, and medical research protocols, with special attention to the needs of vulnerable groups'.

[137] House of Lords Select Committee on Science and Technology, 'Science and Society' (2000) para 5.2 (Peter Healey), quoted in R Brownsword and M Goodwin, *Law and the Technologies of the Twenty-First Century* (Cambridge University Press 2012) 252.

[138] O O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2001) 3. See also AI Tauber, *Patient Autonomy and the Ethics of Responsibility* (MIT Press 2005); C Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart Publishing 2009); SAM McLean, *Autonomy, Consent and the Law* (Routledge-Cavendish 2009); J Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press 2011).

[139] J Montgomery, 'Law and the Demoralisation of Medicine' (2006) 26 Legal Studies 185.

Others have pointed out that patient autonomy, as currently conceived by the law, is not always positive for patients either. It can leave them prey to aggressive practices of direct-to-consumer advertising of medicines. Equally, patients living with, say, the stigma of childlessness may find autonomy a particular burden: absent careful regulation, they may fall prey to clinics marketing potentially low-success services they cannot actually afford.[140]

There is also evidence that informed consent, the vehicle of choice for respecting autonomy and evidencing that respect, can be sought and given in a thoroughly pro forma fashion. In places, practices are worse still. The CEDAW Committee, for instance, heard a case wherein a patient was given a form she literally could not read (because part of it was in Latin, a language she did not understand) in an emergency context where delay and doubt were out of the question; the patient signed the form and later found that she had been sterilised.[141] Elsewhere, however, away from such egregious violations, 'getting through' and 'being moved along' have been reported as the lived experiences of consent.[142] More broadly, amidst the pain, relentlessness, even chaos of serious illness, autonomy may not be what a patient wants or, in any event, all that she wants.[143] But in the human rights enthusiasm for informed consent, do we find recognition of this latter way of being ill, of feeling scared and miserable and not in the slightest bit robust, heroic or in control?[144] Building on this, human rights legal method needs to ask: exactly how good is the broader fit between law's understanding of autonomy and what it is to experience autonomy? I shall be developing this idea in chapter five, where I look at the autonomy experiences of individuals and couples in the context of assisted reproductive technologies, and I ask whether human rights law should work harder to reflect such experiences.

C. New Technologies, New and Not so New Questions

I turn finally to new health technologies, which is an arena where human rights legal scholarship seems to be behind the curve. I accept that

[140] See relatedly M Strathern, *Reproducing the Future: Essays on Anthropology, Kinship and the New Reproductive Technologies* (Manchester University Press 1992) 177: '[G]iven the choice, not choosing to do so is somehow to be less of a person.'

[141] *AS v Hungary* (n 109).

[142] M-A Jacob, 'Form-Made Persons: Consent Forms as Consent's Blind Spot' (2007) 30 Political and Legal Anthropology Review 249, 260. Discussing the consent form in the context of research, see G Laurie and E Postan, 'Rhetoric or Reality: What is the Legal Status of the Consent Form in Health Related Research?' (2013) 21 Medical Law Review.

[143] L Diedrich, 'A Bioethics of Failure: Antiheroic Cancer Narratives' in M Shildrick and R Mykitiuk (eds), *Ethics of the Body: Postconventional Challenges* (MIT Press 2005) 135. See relatedly A Moll, *The Logic of Care: Health and the Problem of Patient Choice* (Routledge 2008), which draws on fieldwork in a diabetes clinic to argue that patient choice is not as liberating as it held up to be and that it risks eroding 'good care'.

[144] *Cf* World Medical Association (WMA), Declaration of Helsinki (1964, amended by the 59th WMA General Assembly, October 2008), para 26 emphasising dependency.

technology as a threat to human rights, and rights to technology as both a route to greater global justice and, equally, a threat to human dignity, are popular themes in the media and beyond. I accept too that benefit-sharing has attracted unprecedented levels of attention, and there has been a minor flurry of international human rights law-making on new health technologies.[145] And as I have already acknowledged and will develop further in chapter three, access to medicines—most of all, access to antiretrovirals—is in many ways the human rights success story of recent years.[146] Yet access to medicines apart, it also seems that the really interesting work on new health technologies has been happening elsewhere.

So, for example, feminist scholarship, governmentality studies, law and society, medical anthropology, science and technology studies (STS) and scholarship in the field of technology regulation appear a great deal more engaged—and engaging—than their human rights law counterpart.[147] The latter, by contrast, is in short supply, and where it is present, it can be mired in grand expectations. It seems to focus above all on law being applied to technology; on the force of law, as prohibiting or enabling, on law's capacity to protect and, equally, to promote. There is lots of talk of freedoms and of limits—of law acting as a limit and of the limits of law—but by and large, there is little else.

Where, for example, are the human rights lawyers writing on what sociologists, anthropologists and STS scholars call 'biological citizenship'[148] and how, if at all, human rights—as law and as discourse or 'talk'—is part of what produces such citizens? In other contexts, human rights have been cast as the sole approved discourse of resistance,[149] but is that true of these new biological citizens too? Biological citizenship is not, of course, produced by human rights cases alone. The small number of new health technology cases that have come before courts and quasi-courts drives home

[145] Notably the UNESCO trilogy (Universal Declaration on the Human Genome and Human Rights (11 November 1997), International Declaration on Human Genetic Data (16 October 2003), and Universal Declaration on Bioethics and Human Rights (19 October 2005)); but also the Council of Europe's Oviedo Convention (n 84) and the UN Declaration on Human Cloning (8 March 2005).

[146] See further below ch 3.

[147] Examples of such work by legal scholars include SS Silbey and P Ewick, 'The Architecture of Authority: The Place of Law in the Space of Science' in A Sarat, L Douglas and M Umphrey (eds), *The Place of Law* (University of Michigan Press 2003); I Karpin, 'The Uncanny Embryos: Legal Limits to the Human and Reproduction without Women' (2006) 28 Sydney Law Review 599; A Pottage, 'The Socio-Legal Implications of the New Biotechnologies' (2007) 3 Annual Review of Law and Social Science 321; Brownsword and Goodwin (n 137).

[148] See, eg, P Rabinow, *Essays on the Anthropology of Reason* (Princeton University Press 1996); R Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (Routledge 2000); A Petryna, *Life Exposed: Biological Citizenship after Chernobyl* (Princeton University Press 2002, reissued with a new introduction 2013); N Rose and C Novas, 'Biological Citizenship' in A Ong and SJ Collier (eds), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems* (Blackwell Publishing 2005).

[149] B Rajagopal, *International Law from Below: Development, Social Movements and Third World Resistance* (Cambridge University Press 2003).

this point; though the presence of three NGO interveners in a recent ECtHR case on access to donor gametes for IVF[150] also suggests that it is not just individual biocitizens but what might be called 'organised biocitizenship' that needs to be tracked. Still, the small number of cases suggests we should also be asking: are biocitizens political actors rather than litigious ones? Or is it the branch of law that is influential? Relatedly, within human rights law, to what extent does the right at issue—or the rights that are actually available in legal form—influence the decision to go to court?

I also think that we need to pay more attention to the law/bioethics nexus.[151] Formulations such as 'ethics and rights' (as in UNESCO's 2005 Universal Declaration on Bioethics and Human Rights), 'ELSI' (ethical, legal, and social implications) and 'sensitive moral or ethical issues' (as used by the ECtHR) are popular. What precisely is being captured and enacted by these connections and divisions? I am also intrigued by the following claim: 'Bioethics—it is everything that Europe is about.'[152] Schooled in the idea that the ECtHR is the premier international human rights court and that the European Union is a fascinating, unfolding illustration of both the power and the limits of law, I would not reach first for bioethics if asked to explain 'Europe'. But I can see that these different stances point to the need to ask: what is the standing of human rights—as law and as a discourse—amidst an array of legal and non-legal ways by which new health technologies might be governed?

Some of these questions call out for empirical work. Some of them, moreover, call for such work in non-legal fora. This will be new terrain for human rights legal method; yet health and human rights law is made not just by lawyers but by non-lawyers too—not least by organisations and advisory groups charged with 'public bioethics'[153] and by health professionals, pharmaceutical corporations and scientists,[154] as they make choices about how to understand what law is, what it is not and what it requires. So, for example, as part of human rights legal method we might ask: how

[150] *SH and Others* (n 114).

[151] See, however, T Faunce, 'Will International Human Rights Subsume Medical Ethics?' (2004) 31 Journal of Medical Ethics 173; GJ Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries* (Oxford University Press 2005); F Francioni (ed), *Biotechnologies and International Human Rights* (Hart Publishing 2007); T Murphy (ed), *New Technologies and Human Rights* (Oxford University Press 2009).

[152] N Lenoir, 'Biotechnology, Bioethics and Law: Europe's 21st Century Challenge' (2006) 69 Modern Law Review 1, 1.

[153] Exploring what it is legitimate to expect from such bodies, see J Montgomery, 'Reflections on the Nature of Public Bioethics' (2013) 22 Cambridge Quarterly of Health Care Ethics 9.

[154] See relatedly C Rhéaume, 'Western Scientists' Reactions to Andrei Sakharov's Human Rights Struggle in the Soviet Union, 1968–1989' (2008) 30 Human Rights Quarterly 1; R Goodman and MJ Roseman (eds), *Interrogations, Forced Feedings, and the Role of Health Professionals: New Perspectives on International Humanitarian Law, Human Rights and Ethics* (Human Rights Program Practice Series, Harvard Law School 2009).

does a bioethically-managed advisory group treat legal knowledge and, indeed, legal experts, where they form part of its membership? Is there a sense in which law is called upon merely for red-light prohibitions and green-light permissions, which limits its regulatory range and may even set it up to fail? Equally, is the treatment of human rights similar across the range of 'regulatory ethics',[155] including academic, clinical, corporate and public bioethics? Or are there important and interesting differences that we need to understand and track?

VI. CONCLUSION

There is, to be honest, no conclusion to this chapter. In part this is because there are many other questions about health and human rights today that could and should be raised. In larger part, it is because I did not set out to reach a conclusion. Instead, this chapter, together with the Introduction, puts in place a platform from which the four case studies that follow will make more sense, and from which other case studies might well be produced by others. I turn now to the first of my own choices, where I ask: is human rights prepared for the phenomenon widely described as 'public health preparedness'?

[155] D Callahan, 'Why America Accepted Bioethics' (1993) 23 Hastings Center Report 8, 8.

2

Is Human Rights Prepared?

A NEW FORCE seems to be at work in public health law and practice. Take, for example, the proliferation of references to 'preparedness'—from 'public health emergency preparedness' to more specialised variants such as 'public health emergency legal preparedness' and 'international legal preparedness'. 'Global public health security' seems increasingly popular too. A cluster of terms is not, of course, robust evidence that something is afoot: language shifts all the time, and individual changes are sometimes no more than a short-lived trend. Yet public health emergency preparedness does not feel like a passing fashion: it seems, in fact, the exact opposite. Indeed, as David Fidler and Laurence Gostin have argued, a 'policy revolution' seems to have taken place—a revolution brought about by the collision of public health and security.[1]

This chapter examines that collision. It does this by asking, 'Is human rights prepared for public health emergency preparedness?' I am not confident that human rights is prepared, but I believe it needs to be: human rights needs what might be called *human rights preparedness*. In this chapter, I suggest that there are resources within human rights law and practice which will take us towards this. I look at two such resources, labelling them 'risk within rights' and 'rights as risk'. The argument overall will be that these should be developed as supplements to the popular but rights-damaging notion of 'risk versus rights'.

To set the stage, we need to establish some basics—in particular, definitions of key terms such as 'public health security', 'global public health security' and 'public health emergency legal preparedness'. In the World Health Report 2007, the World Health Organization (WHO) described 'global public health security' as 'the reduced vulnerability of populations to acute threats to health'.[2] Later in the same report, more detailed definitions were provided:

> *Public health security* is … the activities required, both proactive and reactive, to minimize vulnerability to acute public health events that endanger the collective

[1] DP Fidler and LO Gostin, *Biosecurity in the Global Age: Biological Weapons, Public Health, and the Rule of Law* (Stanford Law and Politics 2007) 145.

[2] WHO, 'The World Health Report 2007: A Safer Future—Global Public Health Security in the 21st Century' (WHO 2007) vii.

> health of national populations. *Global public health security* widens this definition to include acute public health events that endanger the collective health of populations living across geographical regions and international boundaries … [G]lobal health security, or lack of it, may also have an impact on economic or political stability, trade, tourism, access to goods and services and, if [such events] occur repeatedly, on demographic stability.[3]

'Public health emergency legal preparedness', the third key term, is best seen as a part of public health security and of its counterpart, global public health security. It is in essence about having the right laws in place, and then using them in the right way in a time of public health emergency.[4] It is therefore both proactive and reactive; it is about legal preparedness for and response to public health emergencies.

I. SECURITY AND HEALTH THROUGH A NEW LENS

One response to all of the above would be to dismiss it as new terminology for old challenges. The impact of infectious disease on military might is undoubtedly an age-old concern. Disease has also long been seen as a source of indirect harm, in large part because of its potential to cause 'political and economic damage in countries in which a state has vital security, foreign policy, and trade interests'.[5] Moreover, if we turn from national security to economic security, other longstanding links between security and health come to light. Indeed, the first International Health Regulations (1969) and their predecessor, the International Sanitary Regulations (1951), were explicit on this matter: they aimed to 'ensure the maximum security against the international spread of diseases with a minimum interference with world traffic'.[6] Finally, from a political perspective, securitising health has also had particular appeal: infectious diseases have the capacity to compromise not just governing power but also trust in those who have been given such power.[7]

Longstanding connections between health and security do not, however, mean that the *contemporary* linkage is nothing new. We need to look at more recent history, in particular the recent history of international law and policy, if we want to determine whether public health is now 'looked

[3] Ibid, 1. It also describes pandemic flu as 'the most feared security threat' in the world (45).

[4] See B Kamoie et al, 'Assessing Laws and Legal Authorities for Public Health Emergency Legal Preparedness' (2008) 36 Journal of Law, Medicine and Ethics 23, defining it as 'attainment of legal benchmarks within a public health system' and identifying its four 'core elements' as effective legal authorities, competency in their use, coordination of their implementation across sectors and jurisdictions, and information to guide their design.

[5] Fidler and Gostin, *Biosecurity in the Global Age* (n 1) 139–40.

[6] International Health Regulations (1969) (WHO 1983) Foreword.

[7] Fidler and Gostin, *Biosecurity in the Global Age* (n 1) 139.

at through a new lens'.[8] 1994 offers a useful starting point: it was the year in which the United Nations Development Programme (UNDP) called attention to the achievement of human security, 'an idea … likely to revolutionize society in the 21st century'.[9] For the UNDP, traditional concepts of security were too focused on protecting states from external aggression, protecting national interests in foreign policy and protecting global security from the threat of nuclear war. Equally, they were not focused enough on 'the legitimate concerns of ordinary people who sought security in their daily lives'.[10] For the UNDP, human security was a way to address the imbalance. Human security, it argued, would help to protect people from chronic threats such as hunger and also from sudden, harmful disruptions of their daily lives.

Six years later, there was another less than conventional definition of security. This time it came from a more surprising source: the UN Security Council, which held a session in January 2000 on peace, security and HIV/AIDS, focusing in particular on the impact of AIDS in Africa.[11] The conjunction of peace, security and HIV/AIDS was novel, a point emphasised by the Security Council itself: we are, it said, 'exploring a brand-new definition of world security' and establishing 'a precedent for Security Council concern and action on a broader security agenda'.[12]

11 September 2001 ('9/11') is the next date in this short history, mostly because there is widespread agreement that 'The events of that day alter[ed] the landscape of security irrevocably.'[13] Very shortly thereafter, anthrax letters sent using the US Postal Service affected 22 people, of whom five died. The United States responded to these events in a range of ways, including via action to improve the preparedness of its public health law. Within weeks of September 11, the Centers for Disease Control and Prevention (CDC) had commissioned a draft Model State Emergency Health Powers Act and, as of 2009, the United States had its first National Health Security Strategy.[14]

At times, strongly-worded rhetoric ran alongside this reform agenda. The rhetoric invoked the importance of public health preparedness amidst a

[8] WHO, 'World Health Day: International Health Security—Invest in Health, Build a Safer Future' (WHO 2007) 14.

[9] UNDP, *Human Development Report 1994* (Oxford University Press 1994) 22.

[10] Ibid.

[11] UN Security Council, 'The Impact of AIDS on Peace and Security in Africa' (10 January 2000) UN Doc S/PV.4087.

[12] Ibid, 2.

[13] L Zedner, 'The Concept of Security: An Agenda for Comparative Analysis' (2003) 23 Legal Studies 153, 153.

[14] The requirement for a National Health Security Strategy by 2009, and then every four years thereafter, was set down by Pandemic and All-Hazards Preparedness Act (PAHPA) 2006.

'war on terrorism that is being fought on many fronts'. And it emphasised that public health, just 'like our system of national military preparedness', had to be in a 'constant state of readiness': 'Because health threats know no boundaries, we can afford no weaknesses in our public-health line of defence. Either we are all protected or we are all at risk.'[15]

The United States is not the only jurisdiction, to be sure, that is pursuing public health emergency preparedness. In recent years numerous governments have engaged in preparedness projects. Indeed, in the words of the Director-General of the WHO, 'vulnerability is universal'.[16] That is true, of course, yet there are also local understandings of vulnerability and local choices as regards how it should be addressed. For the United States, for example, it is not just 9/11 and its aftermath that have been shaping preparedness. There is also Hurricane Katrina, which devastated a large part of the Gulf Coast in 2005. Katrina affected preparedness-thinking via, first, the media's focus on an alleged epidemic of criminality in the wake of the hurricane and, second, the sense that people were let down very badly by the emergency services when they most needed help.[17] There is now, some say, a sense of preparedness through a Katrina lens—the drawing of a parallel between pandemic preparedness and hurricane preparedness.

In 2003, another global health security concern emerged. It came from the Severe Acute Respiratory Syndrome (SARS), a new and serious infectious disease. This disease started to spread internationally in February 2003, approximately two months after the Global Outbreak Alert and Response Network (GOARN)—a multi-partner network of agencies and technical institutions established by the WHO—had detected a confirmed influenza outbreak in the Guangdong Province of China. On 12 March 2003, the WHO issued a global alert. Three days later, it issued a second alert, naming the new disease, alerting international travellers to its spread and offering guidance to health professionals and public health authorities. In less than four months, however, transmission had been interrupted in the affected countries, and on 5 July 2003, the WHO was able to announce that the outbreak had been contained. In total, 8,098 cases of SARS had

[15] Jeffrey Koplan (then director of the CDC) speaking in 2001, cited in P Jackson, 'Funding Biodefense: Public Health, Bioterrorism, and the Emerging Infrastructure of Biosecurity Research' in JC Cohen-Kohler and MB Seaton (eds), *Comparative Program on Health and Security, Lupina Foundation, Working Papers Series, 2006–2007* (Munk Center for International Studies 2007) 2.

[16] WHO, 'The World Health Report 2007' (n 2) vii.

[17] On Katrina, see JS Simon, 'Wake of the Flood: Crime, Disaster, and the American Risk Imaginary after Katrina' (2007) Issues in Legal Scholarship 1. On vernacularisations of vulnerability, see A Lakoff and S Collier (eds), *Biosecurity Interventions: Global Health and Security in Question* (Columbia University Press 2008).

been recorded in 26 countries, with 774 documented deaths. (Hospital staff were most affected.) There were also serious financial costs as a result of disruption to travel, tourism, trade and production; for instance, the WHO estimated that for the Asian countries affected, the outbreak had cost US$12.3 billion.[18]

The outbreak and its containment produced a range of responses.[19] China, for example, was criticised for delay in reporting cases and an initial lack of cooperation with the WHO. The WHO meanwhile was criticised by Canada for its unilateral issuance of a travel advisory to persons proposing to travel to Toronto, the city outside Asia that was most affected by the outbreak.[20] In Canada, it was suggested that delays and wrangling between the Ontario government and its federal counterpart on the question of compensation had put the quarantine scheme at risk because it had given people financial incentives to break quarantine.[21] More broadly, as part of quarantine and isolation measures, a number of countries had adopted policies involving heavy limitations on individual rights.[22] The WHO claimed that these schemes had helped to interrupt transmission within just four months of the announcement of the outbreak; however, the use of measures that severely restricted individual freedoms was also deeply controversial.

2003 is notable for more than the SARS outbreak. It was also the year in which the Commission on Human Security, co-chaired by Sadako Ogata and Amartya Sen, issued its final report.[23] In that report, the Commission labelled illness, disability and avoidable death as 'critical pervasive threats' to human security. It also used this new variant on security to highlight the on-going neglect of economic and social rights.

One year later, 'comprehensive collective security'—described as a 'new and broader understanding' of international security—provided the overall vision behind the report of the UN Secretary-General's High-Level Panel on

[18] WHO, 'Severe Acute Respiratory Syndrome (SARS)' (WHO 2003).

[19] See generally DP Fidler, *SARS, Governance and the Globalization of Disease* (Palgrave Macmillan 2004).

[20] National Advisory Committee on SARS and Public Health, 'Learning from SARS: Renewal of Public Health in Canada' ('The Naylor Report') (Public Health Agency of Canada 2003) 205.

[21] See CM Flood and A Williams, 'A Tale of Toronto: National and International Lessons in Public Health Governance from the SARS Crisis' (2003/4) 12 Michigan State Journal of International Law 229, 240.

[22] Nuffield Council on Bioethics (NCOB), 'Public Health: Ethical Issues' (NCOB 2007) 52: 'News reports suggested that in Toronto … over 2,000 people who showed no symptoms of SARS were in quarantine at one point … [Q]uarantine officers at ports of entry and exit in Canada were given the authority to ask a person suspected of having the disease to undergo a medical examination and to detain that person if necessary for up to 20 days (the maximum incubation period set out for SARS).'

[23] S Ogata and A Sen, 'Human Security Now: Protecting and Empowering People' (Commission on Human Security 2003).

Threats, Challenges and Change.[24] The report prescribed an improvement in public health systems, arguing that the 'emergence of new infectious diseases, a resurgence of older diseases and a spread of resistance to a growing number of mainstay antibiotic drugs … signify a dramatic decay in local and global public health capacity'.[25] It also warned that 'the security of the most affluent State can be held hostage to the ability of the poorest State to contain an emerging disease'.[26] More controversially, it proposed a new role for the UN Security Council: in 'extreme cases of threat posed by a new emerging infectious disease or intentional release of an infectious agent',[27] it would be appropriate, the report stated, for the Security Council to help with the implementation of control measures.

The threat of biological terrorism resurfaced in 2005 in a UN reform strategy issued by Kofi Annan, then Secretary General of the organisation. In Annan's view, strengthening public health was the 'best defence' against biological terrorism. He, too, seemed to support an expanded role for the UN Security Council in the event of an 'overwhelming outbreak of infectious disease that threatens international peace and security'.[28]

Later that same year, the World Health Assembly, the legislative policy-making body of the WHO, comprising representatives from each member state, adopted a revised set of International Health Regulations (IHR (2005)).[29] These regulations, which bind member states on an opt-out basis,[30] were welcomed as a 'major step forward for international health'.[31] They contain 66 articles and nine annexes, and crucially they are very different to their predecessors, the International Health Regulations (1969). Notably, the new regulations take what has been described as an '"all risks" approach',[32] encompassing any emergency with repercussions for international health security, including outbreaks of emerging and epidemic-prone diseases; outbreaks of food borne disease; natural disasters; and the

[24] UN General Assembly (UNGA), 'A More Secure World: Our Shared Responsibility', Report of the High-Level Panel on Threats, Challenges and Change transmitted to the UN Secretary-General (2 December 2004) UN Doc A/59/565.

[25] Ibid, para 47.

[26] Ibid, para 19.

[27] Ibid, para 70.

[28] UNGA, 'In Larger Freedom: Towards Development, Security and Human Rights for All', Report of the Secretary-General (21 March 2005) UN Doc A/59/2005, para 29.

[29] International Health Regulations (2005) (23 May 2005) WHO Doc WHA58/2005/REC/1.

[30] Constitution of the World Health Organization (22 July 1946, entered into force 7 April 1948) 14 UNTS 185, art 22.

[31] See WHO, 'World Health Assembly Adopts New International Health Regulations', press release available at www.who.int/mediacentre/news/releases/2005/pr_wha03. The IHR took effect in June 2007.

[32] DP Fidler and LO Gostin, 'The New International Health Regulations: An Historic Development for International Law and Public Health' (2006) 34 Journal of Law, Medicine and Ethics 85, 86.

accidental or deliberate release of pathogens, or chemical or radio-nuclear materials.[33] The purpose of the new regulations is to 'prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks, and which avoid unnecessary interference with international traffic and trade'.[34] To give effect to this, states are assigned obligations with respect to surveillance and response—including an obligation to notify the WHO of events within their territories that may constitute a 'public health emergency of international concern'.[35]

But what of human rights? Do they feature in the new IHR? The answer, in short, is yes. The first reference is in article 3(1), which states that the implementation of the IHR (2005) is to be 'with full respect for the dignity, human rights and fundamental freedoms of persons'. Thereafter, human rights crop up in a number of articles. Article 42, for example, provides that all health measures must be applied in a transparent and non-discriminatory way. There are also several articles that make reference to informed consent, including article 23, which provides that states parties must not apply health measures such as vaccination, medical examination or isolation to international travellers without 'prior express informed consent', bar in circumstances where there is 'evidence of an imminent public health risk'.[36] And information privacy features too: article 45(1), for example, provides that states parties must treat personal health information in a confidential manner 'as required by national law'.

As regards limitations on rights, the new IHR impose requirements that are familiar from international human rights law. So, for example, both WHO recommendations to states parties and health measures implemented by states parties in response to identifiable risks must be 'no more invasive or intrusive to persons than reasonably available alternatives that would achieve the appropriate level of health protection'.[37] The IHR (2005) also grant power to the WHO to use information about disease outbreaks provided by unofficial sources (for example, non-governmental organisations

[33] See art 1 for definitions of 'public health risk' and 'public health emergency of international concern'.

[34] Art 2. Art 3(4), however, emphasises that states parties have 'the sovereign right to legislate and to implement legislation in pursuance of their health policies', noting that in so doing they should uphold the IHR.

[35] See respectively arts 5, 13 and annex 1, and art 6 and annex 2. To assist states and to encourage global implementation of the IHR, the WHO has turned to indicators: the 'IHR Core Capacity Monitoring Framework: Checklist and Indicators for Monitoring Progress in the Development of IHR Core Capacities in States Parties' (WHO 2011) provides 28 indicators for use in the state reporting process.

[36] If there is such evidence, then international travellers may be advised or compelled to submit to control measures such as vaccination, quarantine and isolation.

[37] Art 43(1) re states parties; see also arts 23 and 31. As regards WHO recommendations, see art 17.

(NGOs) or individual scientists).[38] Significantly, the WHO has described this power as a 'revolutionary departure from previous international conventions and regulations'.[39]

In practice, specialist public health surveillance networks and institutions (such as GOARN) are far more likely than NGOs to be in a position to provide relevant information on outbreaks.[40] Nonetheless, the shift away from states as the sole voice on public health matters does help to establish the legitimacy of non-state perspectives, including those of human rights NGOs. More generally, rising global interest in public health emergencies, of which the new IHR are one sign, offers NGOs a means by which they may be able to lift particular public health problems from obscurity or neglect to the international stage—a means perhaps to emulate the widely-envied success of the HIV/AIDS campaign for universal access to treatment.[41]

The new IHR experienced their first test in late 2006 when Indonesia temporarily stopped sharing samples of H5N1 avian influenza with the WHO.[42] Indonesia's decision seems to have been prompted by the announcement that an Australian pharmaceutical company had developed a patented vaccine for this form of influenza. The company had received Indonesian virus samples from the WHO, but it was disclaiming any benefit-sharing responsibilities: it said it would provide neither compensation nor a guarantee of access to the vaccine in the event of a pandemic. If a pandemic did break out, most Indonesians had no hope of affording the new vaccine.

For some, Indonesia's refusal to share samples amounted to a violation of the IHR; it was denounced as 'viral sovereignty',[43] an improper claim of ownership that was placing the global early warning system in peril. But for others, Indonesia was entirely justified in its complaint that the sample-sharing scheme facilitated commercial exploitation of developing countries.

[38] See arts 9, 10 and 11. The WHO is required to seek official verification from the state concerned before taking action, but if that state does not cooperate with verification and control efforts, the WHO can share the information with other states 'when justified by the magnitude of the public health risk'.

[39] WHO, 'The World Health Report 2007' (n 2) xv.

[40] On the responsible use of technology in public health and conflict early warning, see PN Pham and P Vinck, 'Technology, Conflict Early Warning Systems, Public Health, and Human Rights' (2012) 14(2) Health and Human Rights: An International Journal 106.

[41] On access to antiretrovirals, see below ch 3.

[42] See also the treatment of US national Andrew Speaker, who was in Europe when he was told by US officials that he had been diagnosed with XDR-TB and then disregarded a CDC direction that he should remain in Europe or hire a private plane to return to the US. Speaker flew to Canada on a commercial flight and then drove into the US. His actions might not be defensible, but neither was the reaction of officials who asked for him to be placed on the US 'no-fly' list, made his personal medical information public and compared him to a terrorist. See further WE Parmet, 'Dangerous Perspectives: The Perils of Individualizing Public Health Problems' (2009) 30 Journal of Legal Medicine 83.

[43] L Garrett and R Holbrooke, '"Sovereignty" that Risks Global Health', *Washington Post* (10 August 2008).

Why shouldn't there be a discussion, they asked, about rights of ownership over virus samples—perhaps following the template set by the Convention on Biological Diversity in relation to ownership over indigenous agricultural resources? More generally, where was the justice in a situation whereby poorer states were priced out of access to life-saving vaccines which had been developed via samples shared by those very same states?[44]

At a minimum, global health diplomacy was desperately needed: the WHO sought to broker this. In 2007, the World Health Assembly gave a guarantee that it would explore ways of helping poorer countries to develop the capacity for vaccine-production. Negotiations did not prove easy. The 2009 influenza A (H1N1) pandemic complicated matters further: developing countries emphasised that yet again vaccines were not shared in an equitable way. One year later, a Protocol to the Convention on Biological Diversity was adopted wherein states parties reasserted sovereignty over biological materials within their territories.[45] In the same year, the World Health Assembly passed another resolution, recognising the need to implement a fair and transparent, equitable, efficient and effective system both for the sharing of the H5N1 and other influenza viruses with human pandemic potential and for the sharing of access to vaccines and other benefits on an equal footing.[46] Finally, after four years of negotiation, the Assembly approved a Pandemic Influenza Preparedness Framework in the late spring of 2011.[47] How this framework will fare in practice is an open question. Whilst some private sector contributions have been secured, the intellectual property disputes that permeated the negotiations were not resolved; it seems they had to be avoided in order for agreement from the private sector and developed states to be secured.

II. HUMANISING SECURITY, SECURITISING HEALTH: VIEWS FROM HUMAN RIGHTS

How should a human rights lawyer respond both to this array of new linkages between health and security and to the rise of public health emergency

[44] See further C Hayden, 'Taking as Giving: Bioscience, Exchange, and the Politics of Benefit-Sharing' (2007) 37 Social Studies of Science 729.

[45] Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the Convention on Biological Diversity (29 October 2010, not yet in force).

[46] WHO, 'Pandemic Influenza Preparedness: Sharing of Influenza Viruses and Access to Vaccines and Other Benefits' (19 May 2010) WHO Doc WHA63.1.

[47] WHO, 'Pandemic Influenza Preparedness Framework' (24 May 2011) WHO Doc WHA 64.5 (PIP Framework). See further WHO, 'Report by Open-Ended Working Group of Member States on Pandemic Influenza Preparedness: Sharing of Influenza Viruses and Access to Vaccines and Other Benefits: Pandemic Influenza Preparedness Framework' (5 May 2011) WHO Doc A64/8.

preparedness? In what follows, I outline two possible responses. I use broad strokes, not close detail: the aim is to give a sense of the most likely human rights responses and, crucially, to flag why they point towards human rights preparedness as a key task.

A. The Optimist's Response

One possible human rights response to public health emergency preparedness is to embrace it, or even to acclaim it. We might call this the optimist's response. For the optimist, the new health and security relationship means that public health is being brought 'in from the cold'. Its profile is being raised, and increased resources are being directed towards it. Preparedness is, in short, a 'win-win'. Investment in countering bio-threats, the optimist will say, offers not just protection against bioterrorism but also enhanced public health: 'the more research in weaponized diseases that takes place, the more innovations for disease prevention will be found.'[48] Investment in hospitals will be improved too, for the simple reason that 'if a bio-weapon is released and people get sick, they will go to hospital first'.[49] Moreover, when confronted with details of abuses committed in the past in the name of public health,[50] the optimist will counter-claim that 'what's past is past' and that human rights and other limits on state power are now built into the IHR.[51]

The optimist may also argue that the HIV/AIDS pandemic shows that a health and human rights way of thinking is now accepted and embedded as best practice.[52] She might even invoke the ascent of human rights in the popular imagination and in national and international orders as evidence of a broader institutionalisation of rights. She might also invoke the SARS outbreak of 2003 as evidence of what can be achieved both when the WHO is proactive and when states, the WHO and others adopt a cooperative stance.[53] Stated shortly, the optimist's argument will be that 'The outbreak

[48] Jackson (n 15) 8.

[49] Ibid, 17.

[50] For the US see, eg, LO Gostin, *Public Health Law: Power, Duty, Restraint* (2nd edn, California University Press 2008).

[51] See, eg, House of Lords Select Committee on Intergovernmental Organisations, 'Diseases Know No Frontiers: How Effective Are Intergovernmental Organisations in Controlling Their Spread?' vol II: Evidence, HL 143–II (Stationery Office 2008) 38: 'Except for the Security Council's authority under Chapter VII of the UN Charter, I cannot think of any other international organisation the States Parties of which have granted to the Director-General material power in this way, to do countries severe economic and political damage, over their objection' (David Fidler).

[52] On the HIV/AIDS pandemic and health and human rights, see below ch 3.

[53] Canada might have been unhappy about the WHO's unilateral issuance of a travel advisory, yet according to a WHO official quoted in Flood and Williams (n 21) 244, it was nonetheless 'a model of transparency in its reporting and public information, of determination in its contact tracing'.

of SARS in 2003 and its successful global containment are testimony to a new way of working internationally for the public good'.[54] Linked to this, the optimist may point not just to the emergent right to human security but also to evidence that non-state actors (including pharmaceutical companies) cannot afford to ignore human rights. She will claim that today rights are concern for state and non-state actors alike and that public health will be one beneficiary of this.

B. The Sceptic's Response

There can be a second, very different human rights response to public health emergency preparedness. This response ranges from anxiety to outright opposition, which means that adherents to it can be described as 'linkage sceptics'. For these sceptics, seeing health through a security lens is not a positive development: it distorts public health priorities, causing bad consequences everywhere but especially in least developed states. Securitisation, in short, compromises the public's health. Moreover, even if preparedness is desirable in principle, extant preparedness projects are seen as inappropriate. Why, for example, is investment in neglected diseases still losing out so heavily in terms of funding? And if hospital surge capacity is a core issue, why isn't there more investment in public hospitals? Above all, why isn't there more investment in public health-care systems and, more generally, in healthy populations, which are 'resilient and able to resist infection or respond well if it arrives'?[55] In fact, when precisely did public health become so much about national security, essential services and personal responsibility? And whatever became of the tradition of social medicine, which dates back to Rudolph Virchow's famous 1848 'Report on the Typhus Epidemic in Upper Silesia',[56] or of the primary health care movement of the 1970s, as evidenced by the WHO's own Declaration of Alma-Ata?[57]

The optimist's claims about a new, cooperative world order are met with incredulity by the sceptic, who asks: how precisely does the WHO/Indonesia sample-sharing debacle evidence a new order? The sceptic also has a different take on the standing of human rights in infectious disease control. Rights might be built into the new IHR, but article 3 of those

[54] David Heymann, quoted in Fidler (n 19) xi.

[55] WK Mariner, GJ Annas and WE Parmet, 'Pandemic Preparedness: A Return to the Rule of Law' (2009) 1 Drexel Law Review 341, 343. The authors conclude that 'effective emergency preparedness depends on prevention and the availability of appropriate resources and planning, not on laws specially designed for emergencies' (343).

[56] R Virchow, 'Report on the Typhus Epidemic in Upper Silesia' in LJ Rather (ed), *Collected Essays on Public Health and Epidemiology*, vol 1 (Watson Publishing 1985).

[57] WHO, Declaration of Alma-Ata (International Conference on Primary Health Care, Alma Ata, USSR 6–12 September 1978).

regulations protects the sovereign right of states parties to legislate for the public good, upholding the purpose of the IHR and sound science. In addition, the sceptic will say, the rights provisions of the IHR have 'little to say about protection of livelihoods and food security, or potential health impacts that might result from the distortion of public health priorities towards global surveillance'.[58]

The sceptic is also not a cheerleader for 'global health', the newest addition to the public health lexicon. For her, it is host to rival practices (from global health security to rights-based humanitarianism and health and human rights), and as things stand, she sees no guarantee that human rights will hold its own in this company.[59] The sceptic may well be wary of other developments too, including the so-called 'explanatory turn' in international human rights law, which prioritises root causes—that is to say, the actual underlying causes of human rights violations—causes such as poverty and discrimination. Root causes should, of course, move us beyond the lists of violations that have long preoccupied human rights defenders. But can the explanatory turn live up to expectations? Take natural disasters: is there a risk with such disasters that discussion of root causes will be displaced by the need for 'action now' and by the tendency to think of natural disasters as just that—*natural*?[60]

The sceptic may see the health and human rights movement as a problem too. The movement has always been home to two very different approaches to public health and human rights. One approach forthrightly acknowledges the potential tension between public health necessity and human rights; the other does not—and this has produced vigorous intra-movement debate about conflicts and trade-offs between public health and liberty.[61] This, the sceptic will argue, is highly dangerous: in the 'age of preparedness', robust debate amongst rights advocates about the pros and cons of trade-offs could easily be read in a way that puts rights-claims at a disadvantage. And if we combine this with the low level of debate concerning how human rights relate to non-rights ideas such as equity, solidarity, social justice and the capabilities approach, rights seem more vulnerable again.

Threats to human rights are of course nothing new. Lately, however, an especially dangerous way of thinking seems to have emerged, partly as a

[58] B Von Tigerstrom, *Human Security and International Law: Prospects and Problems* (Hart Publishing 2007) 207.

[59] See further A Lakoff, 'Two Regimes of Global Health' (2010) Humanity 59; T Murphy, 'Public Health *Sans Frontières*: Human Rights NGOs and "Stewardship on a Global Scale"' (2011) 62 Northern Ireland Legal Quarterly 659.

[60] See S Marks, 'Human Rights and Root Causes' (2011) 74 Modern Law Review 57.

[61] Compare LO Gostin, 'When Terrorism Threatens Health: How Far are Limitations on Personal and Economic Liberties Justified?' (2003) 55 Florida Law Review 1105, with GJ Annas, *American Bioethics: Crossing Human Rights and Health Law Boundaries* (Oxford University Press 2005).

result of post-9/11 rhetoric about life in a 'time of crisis'. The position, in crude terms, is that exceptional times mandate exceptional measures. Indeed, as Liora Lazarus and Benjamin Goold have pointed out, 'the idea that certain human rights can be "turned off" when necessary' has acquired remarkable power; it is now widely regarded as a 'thoroughly reasonable reaction to the dangers allegedly faced by democratic societies'.[62] And as they go on to emphasise:

> The exceptionalism argument has become pivotal, so much so that liberals and human rights organisations must either rebut claims that our conditions are unique, or respond to these supposedly exceptional conditions by adjusting our institutions, practices, procedures and laws.[63]

In this environment, human rights advocates debating the relationship between public health and human rights need to be careful indeed.[64]

For the linkage sceptic, the new exceptionalism is one very good reason to be cautious about upbeat assessments of security and human rights. The sceptic's position is that hope in the idea of a 'right to security' is misplaced, not least because any such right can readily become an argument *against* other human rights. Think, for example, of the claim that human rights are no more than a tool used and abused by 'minorities', especially 'dangerous, violent minorities'. Or of its counterpart which claims that the right to security of 'law-abiding, decent people' to live safe and secure from crime and violence has been neglected.[65] Such claims are also not limited to the context of terrorism. Indeed, discussions on the criminalisation of disease transmission have been fed by metaphors of disease carriers 'as markedly different from "normal" members of society', which encourages 'people to think of the transmission of disease as the province of evil criminals, not people like them'[66] or, at a minimum, as the province of those who are socially irresponsible and thus in need of surveillance and control by the state.

[62] L Lazarus and BJ Goold, 'Security and Human Rights: The Search for a Language of Reconciliation' in BJ Goold and L Lazarus (eds), *Security and Human Rights* (Hart Publishing 2007) 4.

[63] Ibid.

[64] See relatedly N Hunter, '"Public-Private" Health Law: Multiple Directions in Public Health' (2007) 10 Journal of Health Care Law & Policy 101, 106: 'Command and control, in some form, is surely an indispensable mode for governmental response to an emergency … But in a form of mission creep and professional norm migration, all aspects of health emergency policy have shifted towards the framework of enhanced executive authority.'

[65] See further I Loader, 'The Cultural Lives of Security and Rights' in Goold and Lazarus (eds) (n 62).

[66] J Montgomery, 'Medicalizing Crime–Criminalizing Health? The Role of Law' in CA Erin and S Ost (eds), *The Criminal Justice System and Health Care* (Oxford University Press 2007) 267. See generally M Weait, *Intimacy and Responsibility: The Criminalisation of HIV Transmission* (Routledge/Cavendish 2007); UN Human Rights Council (UNHRC), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (27 April 2010) UN Doc A/HRC/14/20.

C. A Third Way

The sceptic's argument makes a lot of sense. History is replete with terrible abuses that happened in the name of public health.[67] History also points not only to the widely acclaimed 'rights revolution' but to the arrival of what might be called 'human rights lite'. The latter is not exactly an anti-rights revolution; however, it is not far off either. As we have seen, the legitimacy of rights in a time of crisis is now widely assailed. And the rise of rights-based approaches in humanitarian biomedicine—whether that humanitarianism is practised by NGOs, by states or by partnerships of some sort—is also proving difficult to handle in that it tends to emphasise individual suffering, which means that compassion, not justice, is seen as the most appropriate response.[68] Public health ethics, which is on the rise after a long history during which the discipline of bioethics seemed largely unconcerned with the topic of infectious disease,[69] is another development that is difficult to gauge. It could progress hand in hand with human rights approaches; equally, the two approaches may come into direct conflict; or they may pass one another like ships in the night, which in turn could lead to unintended, unexpected and unwanted consequences.[70]

Yet I am not as sceptical as the sceptic as regards the linkage between human rights and security. Parts of the optimist's argument make sense, and other parts of it are deeply appealing. I cannot see how being *against* security can be a viable human rights stance in responding to the trends outlined above and, more generally, in the context of millions worldwide who face insecure lives. Frankly, who would want to support human rights if they were seen to promote insecurity and risk, and to be against public protection?[71]

[67] See, eg, JD Moreno, *Undue Risk: Secret State Experiments on Humans* (Routledge 2001). Today in some states there is the additional complication that public health is being deployed as a tool of crime control: see N Rose, *The Politics of Life Itself* (Princeton University Press 2007) 241–51.

[68] See further M Ticktin, 'Medical Humanitarianism in and beyond France: Breaking Down or Patrolling Borders' in A Bashford (ed), *Medicine at the Border: Disease, Globalization and Security, 1850 to the Present* (Palgrave Macmillan 2006).

[69] MJ Selgelid, 'Ethics and Infectious Disease' (2005) 19 Bioethics 272; MP Battin et al, *The Patient as Victim and Vector: Ethics and Infectious Disease* (Oxford University Press 2009).

[70] Solidarity, social justice and equity, for instance, are core concepts within ethics. For discussion, see respectively B Prainsack and A Buyx, 'A Solidarity-Based Approach to the Governance of Research Biobanks' (2013) 21 Medical Law Review 71; M Powers and R Faden, *Social Justice: The Moral Foundations of Public Health and Health Policy* (Oxford University Press 2006); S Anand et al (eds), *Public Health, Ethics and Equity* (Oxford University Press 2004).

[71] For an analysis of the value commitments of ESR activists in Africa, see LE White and J Perelman (eds), *Stones of Hope*: *How African Activists Reclaim Human Rights to Challenge Global Poverty* (Stanford University Press 2011) 175, where White and Perelman nominate 'four foundational norms': one is security; the others are inclusion, equality and participation. See more generally I Loader and N Walker, *Civilising Security* (Cambridge University Press 2007).

III. TOWARDS HUMAN RIGHTS PREPAREDNESS: RISK WITHIN RIGHTS; RIGHTS AS RISK

To address my own split reaction and the broader divide within human rights, I propose two frames of enquiry: first, risk within rights and, second, rights as risk. I argue that these have the capacity to move us towards *human rights preparedness*—a mode of human rights practice that better fits the 'age of preparedness'. The power of the frames lies mostly in their ability to supplement a now conventional mode of reasoning about risk and rights. That mode fixates on risk *versus* rights, which, I suggest, places both rights and human rights advocates at a serious disadvantage from the outset.

To fixate on risk versus rights is also to place public health at risk. It could lead to people being treated as enemies of public health. Wendy Mariner et al are entirely right when they remind us that 'People do not want to get sick, and they do not want to make other people sick. Given accurate information and the means to protect themselves from disease, almost everyone will take appropriate precautions.'[72] They are also right when they respond to those who say that there will always be those who either refuse or cannot control their own behaviour, by arguing that such people are the exception and that public policy, if it is to be successful, should not be based on the exception.

My first frame—risk within rights—emphasises risk as a *component of human rights law*; that is to say, it emphasises risk as something that is already accommodated within the framework of human rights law.[73] The second frame—rights as risk—emphasises a now dominant feature of governance: namely, the assessment and management of risk. Today, governments and organisations alike are expected to identify and handle the risks (financial, legal, political, reputational and so on) to which they are exposed. But managing the risk of *rights* is part of managing risk, so there could be a way in here for human rights. And because human rights reach beyond human rights law, managing the risk of rights stretches beyond legal risk—beyond, that is, claims and litigation concerning human rights violations. Rights as risk encompasses, for instance, the potential for human rights activism to disrupt the interests and overall standing of a government or organisation—a potential that may be entirely detached from actual legal liability.[74] In what follows, I examine both rights as risk and risk within rights in more detail, starting with the latter.

[72] Mariner et al (n 55) 357.

[73] See relatedly JF Childress and R Gaare Bernheim, 'Beyond the Liberal and Communitarian Impasse: A Framework and Vision for Public Health' (2003) 55 Florida Law Review 1191, 1218: 'What is required is an alternative that moves beyond the liberal-communitarian impasse and beyond balancing liberty against public health/security. In our judgment, such a framework must recognize that liberty is part of our communal interests, along with public health…'

[74] See further N Whitty, 'Human Rights as Risk: UK Prisons and the Management of Risk and Rights' (2011) 13 Punishment and Society 123, highlighting both legal risk and 'legal risk+'.

A. Risk within Rights

Risk is not, I would argue, entirely new ground for human rights lawyers. It is of course true that neither the present terminology of risk nor today's risk consciousness were there in the past; yet analysing how threats to national security, to the rights and freedoms of others, or to public health could be dealt with as part of a *human-rights-based approach* has long been familiar to human rights lawyers. Part of the reason for this is that international and regional instruments on civil and political rights, including both the International Covenant on Civil and Political Rights (ICCPR) and the European Convention on Human Rights (ECHR), enable a state party to derogate on a temporary basis from most human rights[75] in the event of a public emergency that threatens 'the life of the nation'.[76] There is a similar provision in both the European Social Charter and the Revised Charter, indicating the possibility of derogation from the economic and social rights protected therein.[77] And as I explain below, although the International Covenant on Economic, Social and Cultural Rights (ICESCR) does not contain a similar clause, this does not mean that temporary derogation when necessitated by a public health emergency threatening the life of the nation is never possible.

Human rights instruments—whether they deal with economic, social and cultural (ESC) rights or with civil and political rights, or with both—also make explicit provision for limitations on certain rights. For example, interference with article 8 ECHR on the right to respect for private and family life, home and correspondence is justified if it is prescribed by law, pursues a legitimate aim and can be shown to be 'necessary in a democratic society'.[78]

[75] Under the International Covenant on Civil and Political Rights (16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (hereafter 'ICCPR'), certain rights are non-derogable, eg, the right to life (art 6). That list has been extended by the ICCPR's treaty body, the Human Rights Committee (HRC): see HRC, 'General Comment No 29: States of Emergency (art 4)' (31 August 2001) UN Doc CCPR/C/21/Rev.1/Add.11. See also the Siracusa Principles on the Limitation and Derogation Provisions in the ICCPR (28 September 1984) UN Doc E/CN.4/1985/4.

[76] ICCPR, ibid, art 4; European Convention for the Protection of Human Rights and Fundamental Freedoms (4 November 1950, entered into force 3 September 1953) ETS 5 (hereafter 'ECHR') art 15. The American Convention on Human Rights (ACHR) also has a derogation clause: ACHR (22 November 1969, entered into force 18 July 1978) 1144 UNTS 123 (ACHR) art 27. The principles of proportionality and non-discrimination are additional requirements for a valid derogation, and measures should not be inconsistent with other obligations under international law.

[77] European Social Charter (18 October 1961, entered into force 26 February 1965) ETS 35 (hereafter 'ESC') art 30; European Social Charter (Revised) (3 May 1996, entered into force 1 July 1999) ETS 163 (hereafter 'Rev ESC') art F. The revised ESC is intended eventually to replace the ESC.

[78] See also art 5 ECHR, protecting the rights to liberty and security but permitting 'the lawful detention of persons for the prevention of the spreading of infectious disease, of persons of

As I explain below, the principle of proportionality forms a key part of the test of justification, not just under the ECHR but more broadly too—indeed, although there is debate about the steps or stages of proportionality review,[79] it is fair to say that today proportionality is a global constitutional practice.[80] What proportionality demands, in essence, is that where several types of restrictions upon rights are available, 'the least restrictive alternative must be adopted'.[81] Moreover, this demand applies to derogations, not just to limitations. Thus it is not enough for a state to declare a grave and catastrophic event, such as a serious natural disaster, that threatens the life of the nation. In addition, as the text of the ICCPR makes clear, derogations are justified only 'to the extent strictly required by the exigencies of the situation'.[82]

Protection of health is one of the aims listed as a basis for limitations in the ECHR; another is the 'protection of the rights and freedoms of others'. In similar vein, the ICCPR includes both the 'rights and freedoms of others' and 'public health'. Following up on the latter, the Siracusa Principles explain:

> Public health may be invoked as a ground for limiting certain rights [in the ICCPR] in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.[83]

The International Covenant on Economic, Social and Cultural Rights (ICESCR), by contrast, makes no mention of public health. It focuses instead on what it calls 'the general welfare'. The relevant provision, article 4, runs as follows:

unsound mind, alcoholics or drug addicts or vagrants'. For an exploration of 'arbitrary' detention under art 5 in the context of PLHIV, see *Enhorn v Sweden*, App no 56529/00 (Judgment of 25 January 2005) esp para 44. See also the discussion of this case in R Martin, 'The Exercise of Public Health Powers in Cases of Infectious Disease: Human Rights Implications' (2006) 14 Medical Law Review 132.

[79] Domestic human rights law, perhaps most notably that from Canada, often identifies more steps or 'stages' to the proportionality test, drawing inter alia on the nature of the right subject to interference, whether there is a rational connection between the measure to be taken and the intended benefit, and whether less restrictive measures might be available. See, eg, *R v Oakes* [1986] 1 SCR 103.

[80] See R Alexy, *A Theory of Constitutional Rights* (J Rivers (trans), Oxford University Press 2002); M Klatt and M Meister, *The Constitutional Structure of Proportionality* (Oxford University Press 2012); K Möller, *The Global Model of Constitutional Rights* (Oxford University Press 2012).

[81] Committee on Economic, Social and Cultural Rights (CESCR), 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/49, para 29.

[82] ICCPR (n 75) art 4(1).

[83] Siracusa Principles (n 75) para 25. Para 26 provides, 'Due regard shall be had to the international health regulations of the World Health Organization.'

> [T]he State may subject [ICESCR] rights only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.[84]

This formulation may seem more restrictive of state action limiting rights than, say, its counterpart in the ECHR or in the European Social Charter:[85] the ICESCR requires that any limitation must be not just in accordance with law but 'compatible with the nature of [ICESCR] rights' and *solely* for the purpose of 'promoting general welfare'.[86] Yet it still grants very considerable leeway to states—albeit limitations must also be proportional if they are to be seen as legitimate by the Committee on Economic, Social and Cultural Rights (CESCR), the treaty body responsible for the ICESCR.[87] Overall then, whether the limitation is on a civil or political right, or an economic, social or cultural one, the question is: can the limitation be said to be justified? Generally speaking, this means a court will ask the following: is the limitation prescribed, or determined, by law?[88] Does it pursue a legitimate aim? And is it necessary in a democratic society (with proportionality forming a key part of 'necessity')?[89]

Typically, it is for the state to show that the limitation is justified.[90] Knowing that a justification may be sought by a court should 'improve the quality of government': 'any decision-maker who is aware in advance of the risk of being required to justify a decision will always consider it more closely than if there were no risk'.[91] Thus, as Liora Lazarus et al have emphasised, 'Demanding justification for permissible limitations of

[84] International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR') art 4. See also the Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights (8 January 1987) UN Doc E/CN.4/1987/17 Annex, paras 46–56, where it is suggested that 'promoting the general welfare' means 'furthering the well-being of the people as whole' (para 52).

[85] ESC (n 77) art 31(1); Rev ESC (n 77) art G.

[86] See further P Alston and G Quinn, 'The Nature and Scope of States Parties' Obligations under the International Covenant on Economic, Social and Cultural Rights' (1987) 9 Human Rights Quarterly 156, 192–206; A Müller, 'Limitations to and Derogations from Economic, Social and Cultural Rights' (2009) 9 Human Rights Law Review 557.

[87] CESCR, 'General Comment No 14' (n 81) para 29, making reference to art 5(1) ICESCR.

[88] On occasion the ECtHR has insisted that this requirement demands more than compliance with domestic law; it relates also to 'the quality of the "law", requiring [the relevant law] to be compatible with the rule of law'. See, eg, *Rotaru v Romania* [GC], App no 28341/95 (Judgment of 4 May 2000) para 55.

[89] See, eg, CESCR, 'General Comment No 14' (n 81) para 29, emphasising also that even legitimate public health limitations 'should be of limited duration and subject to review'.

[90] See, eg, Siracusa Principles (n 75) para 10; CESCR, 'General Comment No 14' (n 81) paras 28–29.

[91] E Mureinik, 'Beyond a Charter of Luxuries: Economic Rights in the Constitution' (1992) 8 South African Journal of Human Rights 464, 471.

human rights is central to their protection'.[92] And because the process of justification applies to ESC rights just as much as to their civil and political counterparts, it is also central to seeing rights as indivisible.

The key point, however, is that both derogation and limitation clauses, however they are phrased, are a means—*provided by human rights law itself*—for resolving conflicts between rights, managing the balance between rights and protected interests, and temporarily suspending particular rights where an exceptional crisis has affected the population. By way of further illustration, consider *Soering v United Kingdom*, where the stance of the European Court of Human Rights (ECtHR) makes it very clear that, even though rights are 'trumps'[93] (that is, they are accorded special or heightened protection), this does not mean restrictions on them can never be justified:

> Inherent in the whole of the Convention is a search for a fair balance between the demands of the general interests of the community and the requirements of the protection of the individual's fundamental rights.[94]

It is therefore quite wrong to say that human rights law does not recognise or deal with risk, or that a choice always has to be made between risk and rights. The text of human rights law, in both derogation and limitation clauses, makes it clear that risk *versus* rights is a misleading frame. So, too, do the interpretive principles of human rights law—from proportionality (with its various local expressions, including the reasonableness review favoured by the Constitutional Court of South Africa[95]) to particular modes of judicial restraint, such as the ECtHR's use of a margin of appreciation.[96] Stated shortly, text and interpretive principles alike offer a means to mediate risk and rights.[97] Or putting that another way, the framework of human rights law can and already does address issues of risk.[98] But has sufficient effort been made to explain this? I am not sure that it has.

[92] L Lazarus et al, 'The Evolution of Fundamental Rights Charters and Case Law: A Comparison of the United Nations, Council of Europe and European Union Systems of Human Rights Protection' (European Parliament 2011) 41.

[93] See R Dworkin, *Taking Rights Seriously* (Duckworth 1977); R Dworkin, *Justice for Hedgehogs* (Harvard University Press 2011).

[94] *Soering v United Kingdom* (1989) Series A no 161, para 89.

[95] See further below ch 3, section IV.

[96] This doctrine gives contracting states a measure of discretion in implementing the ECHR. Arguing for its broader application, see Y Shany, 'Toward a General Margin of Appreciation Doctrine in International Law? (2005) 16 European Journal of International Law 912.

[97] For a related argument, identifying six legal modes of limitation, see KG Young, *Constituting Economic and Social Rights* (Oxford University Press 2012) 99–129.

[98] Of course, this raises once again the question of the relationship between human rights law and public health ethics, given that the latter also includes the principle of proportionality, as well as principles of effectiveness, necessity, transparency, reciprocity and least restriction, and the harm principle. On these see, eg, S Benatar, 'Facing Ethical Challenges in Rolling Out Antiretroviral Treatment in Resources Poor Countries: Comment on "They Call It 'Patient Selection' in Khayelitsa"' (2006) 15 Cambridge Quarterly of Healthcare Ethics 322.

Derogations and Limitations

Three tasks are pressing. The first concerns derogations and limitations under the ICESCR, as well as derogations and limitations more generally. There is no derogation clause in the Covenant. Moreover, as we saw in chapter one, the CESCR has insisted on what it describes as core obligations.[99] The Committee has also sought state compliance with the obligation of progressive realisation of ESC rights, and related to this, it has been developing assessment criteria for retrogressive measures taken by states parties. Furthermore, each of the treaties that has a derogation clause—the ICCPR, the ECHR and the ACHR—says that derogations will be allowed only to the extent they are not inconsistent with a state's other obligations under international law.[100] These 'other obligations' could of course include ESC rights.[101] Furthermore, if derogation occurs during armed conflict, international humanitarian law imposes duties upon the state to ensure 'the food and medical supplies of the population' and to allow humanitarian aid organisations to be active.[102] Finally, the right to life under the ICCPR, one of the non-derogable rights under that treaty, seems to render at least part of the right to health non-derogable. The Human Rights Committee has emphasised that the right to life 'cannot properly be understood in a restrictive manner' and that its protection requires states parties to adopt positive measures. Related to this, it has called upon states to 'take all possible measures' to increase life expectancy, 'especially in adopting measures to eliminate malnutrition and epidemics'.[103]

So all of this leaves us with the question: derogation-wise, what precisely is expected of states who are party to the ICESCR? Is derogation impermissible, for example? Impermissible across the board, or just for minimum core obligations? The former is not plausible: under general international principles, treaties can be suspended or otherwise avoided in certain circumstances. And regarding the latter, Amrei Müller has noted a tendency in

[99] CESCR, 'General Comment No 3: The Nature of States' Parties Obligations (art 2, para 1)' (14 December 1990) UN Doc E/1991/23; CESCR, 'General Comment No 14' (n 81) para 47, describing such obligations as 'non-derogable'.

[100] Including obligations of *jus cogens*, ie, obligations that are seen as having become especially important and thus especially protected.

[101] O De Schutter, *International Human Rights Law* (Cambridge University Press 2010) 552 notes: 'This significantly restricts the margin of manoeuvre for States acting under these derogation provisions. It also places [the HRC, the ECtHR or the IACtHR] in the awkward situation of having to decide whether a State has complied with other international obligations than those stated in the instrument which these bodies in principle are set up to monitor.'

[102] See, eg, International Committee of the Red Cross (ICRC), The Fourth Geneva Convention Relative to the Protection of Civilian Persons in Time of War (12 August 1949) 75 UNTS 487.

[103] HRC, 'General Comment No 6: The Right to Life (art 6)' (30 April 1982) para 5. See also HRC, 'General Comment No 24: Issues Relating to Reservations' (4 November 1994) UN Doc CCPR/C/21/Rev.1/Add.6, para 10, giving three reasons why certain rights are non-derogable.

the approach of both states and the CESCR 'to allow for derogations from the ICESCR's labour rights, but to exclude derogations from other ESC rights, in particular from minimum core obligations under these rights'.[104] Overall, however, we probably have a case of 'wait and see': with the entry into force of the Optional Protocol to the ICESCR, the CESCR's new power to receive and consider individual complaints of alleged violations of ESC rights should give it the opportunity to develop guidance on the matter of derogations.

In the meantime, analysis of the behaviour of states would be useful. Who has derogated for reasons of public health emergency, how often and for how long on average?[105] Have such derogations met the standard of proportionality, as well as the requirement set down in article 4 ICCPR of avoiding 'discrimination solely on the ground of race, colour, sex, language, religion or social origin'? More broadly, what precisely prompts a public health emergency derogation? Is it a desire to be seen internationally as a state that complies with treaty obligations? Or is it more about managing expectations 'at home' and, above all, heading off challenges from domestic courts and NGOs? Is the derogation process used, in other words, as a way of telling the home audience that what is happening is 'necessary, temporary, and lawful'?[106] The sort of work that can answer these questions is only just beginning.[107]

There are also gaps in knowledge on the use of limitations, which means empirical work would be useful on that front too. There are, moreover, at least four other ways in which such work would be useful. First, it would provide material against which claims concerning the standardisation of the 'state of exception' can be assessed; such claims are popular in critical scholarship and clearly merit enhanced empirical engagement.[108] Second, empirical work would bring actual pandemic-preparedness practices to the surface, demonstrating how states have been translating ideas such as 'contingency planning', 'protection' and 'resilience', as well as which of these

[104] Müller (n 86) 557.

[105] On the misuse of derogations to mask 'permanent emergencies', see O Gross and F Ní Aoláin, *Law in Times of Crisis: Emergency Powers in Theory and Practice* (Cambridge University Press 2006).

[106] See E Hafner-Burton, LR Helfer and CJ Fariss, 'Emergency and Escape: Explaining Derogations from Human Rights Treaties' (2011) 65 International Organization 673, 675.

[107] The OHCHR publishes on a biennial basis a list of states that have proclaimed or continued a state of emergency. Also, the treaty bodies' reporting guidelines now require states to explain derogations and limitations: see 'The Guidelines on Treaty Specific Documents' (24 March 2009) UN Doc E/C.12/2008/2, para 14, in conjunction with the 'Compilation of Guidelines on the Form and Content of Reports' (29 May 2008) UN Doc HRI/GEN/2/Rev.5, para 40(c).

[108] Drawing mostly on G Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford University Press 1998); G Agamben, *State of Exception* (University of Chicago Press 2005).

ideas has been finding favour where.[109] Third, empirical work would build understanding on how states see the requirement, unique to the ICESCR, that limitations must be 'compatible with the nature of [Covenant] rights'.[110] Finally, empirical work would help to draw out how states perceive the relationship between the general limitations clause in article 4 ICESCR and the obligation of progressive realisation, subject to maximum available resources, that is set down in article 2 of the same instrument. For instance, where a state adopts retrogressive measures, citing lack of resources as justification, does it see these measures as 'limitations' within the meaning of article 4? Should it? Put differently, given that each of these articles permits limitations on ESC rights, what is and what should be the relationship between them?[111]

Balancing and Proportionality

The second task I want to prescribe for human rights targets the terminology of balance. As terms go, 'balancing' sounds benign, beneficial even, but how precisely does it relate to the human rights term 'proportionality'? In particular, is one of these more human rights protective than the other? I appreciate that there may be a place for both. Yet it is worth looking more closely at where and by whom 'balancing' of rights (against other rights or against interests) is invoked, and whether proportionality produces a far stronger 'culture of justification'[112] than balancing.

Andrew Ashworth has developed a powerful argument on this point. For him, the imagery of balancing assumes a 'hydraulic relationship between human rights safeguards and the promotion of security': 'as one goes up the other must go down, and vice versa.'[113] Also, balancing (unlike proportionality) 'involves a broad brush, and sometimes opaque, analysis aimed at a resolution of the interests at stake and the rights involved'. Typically, it uses a 'utilitarian analysis of the rights and public interest goals in question, giving no significantly greater weight to rights than to security measures'.[114]

[109] See F Lentzos and N Rose, 'Governing Insecurity: Contingency Planning, Protection, Resilience' (2009) 38 Economy and Society 230, comparing three Council of Europe states.

[110] Limburg Principles (n 84) para 56 suggest this prohibits limitations that 'jeopardise the essence of' ICESCR rights, as reflected in minimum core obligations.

[111] For an argument on this question, see Müller (n 86) 584–91.

[112] This term, now in wide circulation, was coined by E Mureinik, 'A Bridge to Where? Introducing the Interim Bill of Rights' (1994) 10 South African Journal of Human Rights 31, who described it as 'a culture in which every exercise of power is expected to be justified; in which leadership given by government rests on the cogency of the case offered in defence of its decisions, not the fear inspired by the force at its command'.

[113] A Ashworth, 'Security, Terrorism and the Value of Human Rights' in Goold and Lazarus (eds) (n 62) 208.

[114] B Goold et al, 'Public Protection, Proportionality and the Search for Balance' (Ministry of Justice Research Series 10/07, 2007) 2.

Proportionality, by contrast, is potentially more protective of human rights. In particular, under the proportionality approach, there is a presumption that rights restrict public interest goals: they outweigh goals that are not legitimate, and where goals are legitimate, any measures giving effect to them have to be suitable, the least restrictive possible, and proportionate between the effects of the measures and the objectives to be achieved.[115]

The use of coercive measures such as quarantine requires particularly strong justification.[116] These measures infringe liberty and privacy rights, and if mistakes are made, healthy individuals are put at serious risk of infection. The threat of quarantine can lead individuals to delay seeking diagnosis and treatment. It can also provoke or compound discrimination and stigma against particular individuals and groups. And as Lucia Zedner has pointed out, the use of risk categories to target certain groups creates a further problem:

> At one level, it makes perfect sense to target security measures at those deemed most to threaten. Yet an inherent danger of selectivity is that precisely because it imposes restrictions only on targeted sections of the population, it is less likely to invoke the natural political resistance generated by burdens that affect us all.[117]

The history of targeted measures illustrates just how important Zedner's point is: quarantine, surveillance and the like have historically been targeted at the already disadvantaged—at the poor and at immigrants, for example.

More generally, there needs to be more straight-talking on quarantines. How often has a quarantine of a geographic area halted an epidemic, for instance? In answering this question, Mariner et al have been forthright: 'At best, [such quarantines] might delay the worst for short time. In the meantime, even voluntary quarantine can cause stress and imposes significant economic costs.'[118]

Precaution for the Sake of Rights

The third and final task I am proposing is the most controversial of the three. It asks human rights lawyers to consider whether there should be a more precautionary way of thinking within human rights, especially as

[115] See, eg, *Oakes* (n 79). See also WE Parmet, 'Public Health and Social Control: Implications for Human Rights' (International Council on Human Rights Policy 2009) para 165ff, analysing gaps in the 'least restrictive' framework and offering a series of recommendations; X Contiades and A Fotiadou, 'Social Rights in the Age of Proportionality: Global Economic Crisis and Constitutional Litigation' (2012) 10 International Journal of Constitutional Law 66.

[116] CESCR, 'General Comment No 14' (n 81) paras 28–29.

[117] L Zedner, 'Seeking Security by Eroding Rights: The Side-Stepping of Due Process' in Goold and Lazarus (eds) (n 62) 272.

[118] Mariner et al (n 55) 357.

regards creeping pandemics such as obesity. I appreciate that this sounds like a misstep, an invitation to states and others to trample over rights in the name of risk—and to go much further than appeals to the need to protect third parties from harm[119] or indeed the 'choice architecture' promoted by advocates of libertarian paternalism (known colloquially as 'nudging').[120] Yet as Roger Brownsword has put it, 'When we adopt a human rights perspective, it is precaution for the sake of human rights that becomes focal.' Moreover, there may well be a 'precautionary form of argument available, and waiting to be fully articulated, within human rights thinking'.[121] Brownsword has started work on this.[122] He believes that in a community of rights there will be support for the state being given a stewardship responsibility for the moral welfare of the community. Moreover, that responsibility will be owed not just to current members of the community but also to future members:

> [A]n environment that is conducive to … a way of life that hinges on agents trying to do the right thing, trying to respect the legitimate interests of fellow agents, and being held responsible for their actions … [is] the most precious thing that an aspirant moral community can hand on to the next generation.[123]

A more precautionary way of reasoning is, I accept, outside the comfort zone of human rights thinking. It could involve a lower threshold for state intervention, albeit one that comes branded with a friendly-sounding moniker such as 'state stewardship'. For human rights, that will look like quicksand—ordinary or plausible on the surface (we are, after all, familiar with the idea of thresholds for state intervention) but with the potential to be deadly in practice. Still, Brownsword's assessment of his own work on stewardship is modest. It is, he says, 'a significant item of unfinished

[119] But see the decision of the Court of Appeal of England & Wales in *R (N) v Secretary of State for Health*; *R (E) v Nottinghamshire Healthcare NHS Trusts* [2009] EWCA Civ 795, dismissing the judicial review challenge of a group of patients at Rampton Hospital, a secure psychiatric unit, to the termination of the exemption for mental health facilities from a general smoking ban, wherein the Court noted obiter that art 8(2) ECHR could potentially provide a justification for interfering with an individual's art 8(1) right to respect for private life, given that it refers to 'protection of health, not the health of others' (para 71).

[120] See, eg, R Thaler and C Sunstein, *Nudge: Improving Decisions about Health, Wealth and Happiness* (Penguin Books 2009).

[121] R Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies' in T Murphy (ed), *New Technologies and Human Rights* (Oxford University Press 2009) 39.

[122] See R Brownsword and M Goodwin, *Law and the Technologies of the Twenty-First Century* (Cambridge University Press 2012) chs 5–6. See relatedly H Somsen, 'Cloning Trojan Horses: Precautionary Regulation of Reproductive Technologies' in R Brownsword and K Yeung (eds), *Regulating Technologies: Legal Futures, Regulatory Frames and Technological Fixes* (Hart Publishing 2008), accepting the role of the precautionary principle in contexts of grave environmental risk but cautioning against its use in the regulation of assisted reproductive technologies.

[123] R Brownsword, 'So What Does the World Need Now?' in Brownsword and Yeung (eds), ibid, 45.

business'.[124] Human rights lawyers could do worse than take a lead from this, treating the question of a more precautionary way of thinking within human rights, as well as proposals for state stewardship and 'nudges', as items of under-explored—rather than unimportant—business. In fact, without such engagement, human rights advocates could find that in some circumstances, limits upon a state's power to intervene to protect public health—limits framed, for instance, in the rhetoric of avoiding the 'nanny state'—are an obstacle in the path of human rights protection.

B. Rights as Risk

I turn now to the equally complex terrain of rights as risk. This perhaps peculiar-sounding frame stems not from international, regional or domestic human rights law but from the 'rise and rise' of risk management, a form of management that has become standard for governments and organisations alike. Risk, it has been said, is the 'new lens through which to view the world'.[125] And to be honest, it does sometimes seem that—as Michael Power has put it—we are in the midst of 'the risk management of everything'.[126] However, because managing the risk of *rights* is surely part of managing risk, there might be opportunities here for what I have been calling 'human rights preparedness'. It is these opportunities that I suggest human rights should be exploring via 'rights as risk'.

Within risk management, organisational risk is a key term—a term designed to capture each and every risk that could affect an organisation, be it a government department, a UN agency or a pharmaceutical company. Organisational risks are reputational, financial, legal, political or operational, or some combination of these.[127] Human rights seem to produce a particularly complex organisational risk. Take, for instance, the fact that they encompass but are not limited to an organisation's legal risk (that is, claims and litigation for violations of human rights law): human rights consciousness, as manifested, for example, in an online or community group protest, can also put an organisation at risk. Furthermore, both engaging with and rejecting human rights carry risks for organisations. Discussing the imperative to manage human rights risks in the context of joint projects between governments and private companies, Michael Likosky has

[124] Ibid, 47.

[125] B Hutter, 'The Attractions of Risk-Based Regulation: Accounting for the Emergence of Risk Ideas in Regulation' CARR Discussion Paper 33, LSE (2005) 1.

[126] M Power, *Organized Uncertainty: Designing a World of Risk Management* (Oxford University Press 2007) 203.

[127] See generally C Hood, H Rothstein and R Baldwin (eds), *The Government of Risk: Understanding Risk Regulation Regimes* (Oxford University Press 2004).

emphasised that these parties will have to choose from an array of risk-mitigation strategies:

> Do they address the underlying human rights problem itself, making a project more respectful of human rights? Do they discredit the NGO or community group campaign? Do they negotiate with one NGO but not with another? Do they assuage the concerns of the NGOs and community groups by adopting guidelines? Do they adopt binding or nonbinding measures? Do they establish commissions to review human rights practices of specific projects?[128]

If we look at the public health emergency field, it seems clear that there is a wide range of influences, demands and obligations that could lead to rights being seen as an organisational risk. The cross-sector and cross-jurisdiction nature of public health emergencies (especially those of 'international concern') produces a particularly complex governance landscape: immediate responses will be expected and may in fact be essential in times of public health crisis, yet distinct histories, cultures and agendas could well be in collision. In what follows, I identify four reasons why rights can be a risk for state and non-state actors in the field of public health emergency preparedness. In so doing, I pay particular attention to what this might mean for human rights preparedness.

Expanding Sources

One obvious source of rights as risk is the mounting number of human rights instruments, both internationally and nationally. There is also the 'common law of human rights', that is, the expansion of human rights as national judges (in particular) draw upon international and foreign human rights law sources in deciding the human rights questions that have come before them. And as I noted in the Introduction, NGOs, expert groupings and academics seem increasingly attuned to this common law. A third potentially potent source of rights as risk stems from the campaign to develop corporate responsibility for human rights (including the principles of 'due diligence', 'do no harm' and 'sphere of influence' with respect to human rights risk[129]). Opposition to legally binding duties continues, of

[128] MB Likosky, *Law, Infrastructure and Human Rights* (Cambridge University Press 2006) 50.

[129] See, eg, UNHRC, 'Report of the Special Representative of the Secretary-General on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises, John Ruggie: Guiding Principles on Business and Human Rights: Implementing the United Nations "Protect, Respect and Remedy" Framework' (21 March 2011) UN Doc A/HRC/17/31, emphasising that human rights due-diligence is not akin to standard commercial due-diligence processes: 'it goes beyond simply identifying and managing material risks to the company itself, to include risks to rights-holders.' See further P Muchlinski, 'Implementing the New UN Corporate Human Rights Framework: Implications for Corporate Law, Governance, and Regulation' (2012) 22 Business Ethics Quarterly 145.

course, to run deep;[130] more broadly, as John Ruggie, the UN Secretary-General's Special Representative on Business and Human Rights made clear, 'there is no single silver bullet solution' to the multi-faceted challenges of business and human rights.[131] Still, calls for direct accountability do seem to have nudged corporations towards further self-regulation, and fresh attention is also being paid to the duties of both home and host states to protect rights by regulating the conduct of corporate actors.[132] There is also growing scholarly and NGO attention towards global health funds, impact certification systems, licensing campaigns and the like.[133] These take us beyond simple codes of conduct; more importantly, they involve taking action now, rather than waiting for a human rights utopia. More importantly still, they work to craft models that will appeal across the board, that take account of the spectrum of real world problems—not just injustice but also the claims of pharmaceutical companies vis-à-vis the need to recoup cost and make profit.

At least two other sources of rights as risk are readily apparent. The first of these is the human rights demands found within the conditional loan agreements between international organisations (such as the World Bank) and recipient governments, or within the contractual and public procurement rules relating to the providers of public goods and services. Secondly, in federal states, the legal relationship between federal and local government might render rights as a risk in the public health emergency field. A strong states' rights tradition could, on the one hand, hamper (or be used as an excuse by) federal government in developing particular national preparedness measures; on the other hand, however, where federal government seeks aggressively to assert its power and interfere with protected human rights, a tradition of states' rights could be a bulwark against such abuse.

Public Trust

The level of public trust within an individual state will also influence the extent to which rights are a risk. Lesley Jacobs, in a study of the divergent uses of quarantine in Hong Kong, Shanghai and Toronto during the SARS

[130] See, eg, the challenge to the applicability of the US' Alien Tort Statute (which allows US district courts to hear 'any civil action by an alien for a tort only, committed in violation of the law of nations'), details available at ccrjustice.org.

[131] UNHRC, 'Report of the Special Representative of the Secretary-General on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises, John Ruggie: "Protect, Respect and Remedy: A Framework for Business and Human Rights"' (7 April 2008) UN Doc A/HRC/8/5, para 7.

[132] See, eg, CESCR, 'Statement on the Obligations of States Parties regarding the Corporate Sector and Economic, Social and Cultural Rights' (20 May 2011) UN Doc E/C.12/2011/1.

[133] See, eg, A Hollis and T Pogge, *The Health Impact Fund: Making New Medicines Available for All* (Incentives for Global Health 2008); N Hassoun, *Globalization and Global Justice: Shrinking Distance, Expanding Obligations* (Cambridge University Press 2012).

crisis, has attributed Toronto's more extensive use of quarantine to the particular legal consciousness of its senior public health officials: 'health security was weighed much more heavily than rights concerns … whereas in Hong Kong and Shanghai there was much more of an even balance.'[134] Interestingly, even though there was dissent in Toronto, courts and human rights bodies were not used to raise concerns about rights violations. Why was that? One federal public health official speculated:

> The belief that the decisions about SARS by senior public officials, provided that they had a legal basis, would be made fairly was so deeply ingrained among the [Canadian] public that there was little need to question or scrutinize those decisions.[135]

Jacobs himself offers the view that legal avenues of redress may not be seen as a first port of call by citizens 'where the health security of the community is at stake'.[136] Organisations might of course see this as a reason to dismiss rights as a risk and indeed to downgrade the need for rights protection in both preparedness planning and implementation. If the odds of being held legally accountable are low, why worry about rights as risk? More than this, why not look for absolute protection from liability, and absolute discretion, using both public trust and the exceptionalism of emergencies by way of justification?

Such moves would be counter-productive. Protection from legal liability sends out a bad message: it suggests vast powers and minimal, or zero, accountability for their use, which in turn suggests that public trust in those with power would be foolish. I am not saying there should be no leeway for those called upon to respond to a public health emergency: standards of conduct and of care should be calibrated in a way that takes account of context—we should not expect the impossible in an emergency. But law should not facilitate the unacceptable either: the human rights principle of accountability needs to remain front and centre. Moreover, even those who prefer pragmatism to principle will recognise that 'public justification, deliberation, and other relationship-building activities may be more important for biopreparedness than state power because they maintain and nurture civic ideals, cooperation, and trust'.[137]

[134] LA Jacobs, 'Rights and Quarantine during the SARS Global Health Crisis: Differentiated Legal Consciousness in Hong Kong, Shanghai and Toronto' (2007) 41 Law and Society Review 511, 514.

[135] Ibid, 546.

[136] Ibid. On the moral and political consequences of remedies available in the wake of technological disasters affecting health, see A Petryna, *Life Exposed: Biological Citizenship after Chernobyl* (Princeton University Press 2002, reissued 2013 with new introduction).

[137] Childress and Gaare Bernheim (n 73) 1210. This of course demands that such measures are robust: see C Caduff, 'Public Prophylaxis: Pandemic Influenza, Pharmaceutical Prevention and Participatory Governance' (2010) 5 Biosocieties 199.

Public trust is complicated, however. Consider Matthew Weait's study of the Scandinavian and Nordic responses to HIV, in which he sets out to explain the following paradox. Denmark, Finland, Norway and Sweden have the lowest HIV prevalence in Europe, are respected for their work with developing states affected by endemic HIV and are widely seen as progressive and liberal on matters ranging from social policy to punitiveness; yet these same states have higher rates of conviction and imprisonment for HIV-related offences of transmission and exposure than almost all of their European counterparts.[138] How might this apparent paradox be explained? Weait has identified a cluster of factors—deeply entrenched social democracy, a strong public health tradition and considerable trust in law and legal institutions—which, he says, contribute to a culture 'in which people believe that it is the state which should, and will, protect them from harm and that they bear little or no personal responsibility for protecting themselves'.[139] One of the consequences of this culture is that criminalisation of non-deliberate HIV transmission and exposure (an approach that is *not* endorsed by either the Joint UN Programme on HIV/AIDS (UNAIDS) or the UN Special Rapporteur on the right to health) is seen as acceptable. There can be no complacency therefore about the relationship between public trust and human rights; this relationship requires careful crafting and regular review.

Organisational Cultures

It is of course not just national cultures that merit attention with regard to public trust, rights and rights as risk: organisational cultures, too, 'shape how human rights are framed, interpreted and institutionalised'.[140] Moreover, global health governance today is characterised by ever increasing and ever more influential roles for both non-state and hybrid organisations, including humanitarian NGOs (such as Médecins Sans Frontières[141] and Oxfam), public–private partnerships (such as the Global Alliance for Vaccines and Immunisation (GAVI)), pharmaceutical corporations and private philanthropists (such as the Bill and Melinda Gates Foundation).

[138] See, eg, M Weait, 'Punitive Economies: The Criminalization of HIV Transmission and Exposure in Europe' (November 2011), www.academia.edu/1087609/Punitive_Economies_the_Criminalization_of_HIV_Transmission_and_Exposure_in_Europe.

[139] Ibid.

[140] GA Sarfaty, 'Doing Good Business or Just Doing Good: Competing Human Rights Frameworks at the World Bank' in B Morgan (ed), *The Intersection of Rights and Regulation: New Directions in Sociolegal Scholarship* (Ashgate Publishing 2007) 93.

[141] See further RC Fox and E Goemaere, 'They Call It "Patient Selection" in Khayelitsha: The Experience of Médecins sans Frontières-South Africa in Enrolling Patients to Receive Antiretroviral Treatment for HIV/AIDS' (2006) 15 Cambridge Quarterly of Healthcare Ethics 302; P Redfield, 'Doctors without Borders and the Moral Economy of Pharmaceuticals' in A Bullard (ed), *Human Rights in Crisis* (Ashgate Publishing 2008).

Indeed, a few years back, in evidence to a UK Parliamentary committee, David Fidler stated:

> Increasingly, the Gates Foundation is the first place people will pick up the phone to call; not the WHO. In fact, someone told me—and I do not know if this is true—that Bill Gates is now going to fly to Indonesia to help intervene in that controversy over virus sharing. Something has changed here.[142]

Each of these organisational cultures merits ongoing attention; two, however, seem particularly important. The first is the culture of individual humanitarian NGOs. Why, for instance, do they make the choices they do about how to communicate, what to focus upon and when to change focus?[143] And how does their humanitarianism intersect with and affect human rights? The second key organisational culture is that of the WHO. The Organization hasn't been much studied within human rights,[144] but it doesn't require much study to notice that the WHO's history with human rights has been uneven—ranging from an initial keenness to deliberate disinterest and, later again, when the Organization entered the Alma-Ata years, fresh interest but also difficulty in finding any sort of foothold. Equally, without any further study, we might also speculate that staff at the WHO are likely to differ in their opinions on rights, and that these differences will both increase the Organization's exposure to risk and influence how it handles particular issues.

Galit Sarfaty's examination of human rights at the World Bank is a useful point of reference here. Looking at two Bank projects on HIV/AIDS prevention—one in Russia, the other in Saint Lucia—Sarfaty has speculated as to why different framings of the human rights dimension were adopted by Bank staff:

> One reason may be that the project team was dominated by staff who prefer a cost-benefit analysis to a legal approach, and who concluded that funds would be better spent on other preventative projects … The Russian Government [also] treats the human rights of [persons living with HIV/AIDS] as a sensitive, politically-charged issue that it would prefer to avoid. Even if the Saint Lucian Government took the same view, Russia holds much more influence than Saint Lucia over Bank project design because it is a major borrower and not a country that the Bank wants to upset.[145]

[142] House of Lords Select Committee (n 51) para 381.

[143] See relatedly below ch 3, text to nn 1–6.

[144] BM Meier, 'The World Health Organization, the Evolution of Human Rights and the Failure to Achieve Health for All' in J Harrington and M Stuttaford (eds), *Global Health and Human Rights: Legal and Philosophical Perspectives* (Routledge 2010).

[145] Sarfaty, 'Doing Good Business' (n 140) 104. See further GA Sarfaty, *Values in Translation: Human Rights and the Culture of the World Bank* (Stanford University Press 2012).

Sarfaty has identified two approaches to human rights among Bank staff, labelling the first 'instrumental' and the second 'intrinsic'. Those who use the latter framework draw upon moral or legal imperatives, and overall, they see human rights in normative terms as an end in themselves. The instrumentalists, by contrast, see rights as a means to an end. They use a functionalist, economics-driven rationale to determine whether and how human rights have value in any given case. This work raises many interesting questions for human rights in general and for human rights preparedness in particular. Should we, for instance, expect a similar divide amongst staff at the WHO or perhaps one that is more complex still, with both scientific evidence and public health commitments, such as equity, social justice and the like, added to the mix?

Human Rights Practices

If we are serious about exploring 'rights as risk' as a route to human rights preparedness, the risks attached to our own practices will need to be considered too. Take the emergence of human rights risk strategists. Michael Likosky, discussing public–private partnership infrastructure projects in different countries, has demonstrated that governments and organisations aiming to 'advance human rights interests for their own ethical or strategic reasons' may enter into negotiations and alliances with certain NGOs.[146] Human rights risk consultants, drawn from legal and other backgrounds, may also be employed by governments and organisations to offer expertise on particular projects and campaigns. Indeed, the WHO's new power under the IHR to use information about disease outbreaks provided by unofficial sources gives governments an incentive to work with human rights NGOs on questions concerning public health, which in turn gives NGOs increased influence—and, of course, increased responsibility. The end result is a complex mix of human rights agendas, including human rights advocates adopting instrumentalist strategies and language (for example, urging the avoidance of 'business risk') in order to promote human rights protection.

There is a lot to address here. One question that needs to be asked is: are there human rights risk strategists at work in public health preparedness projects and, if so, in what ways? Are they, for example, picking up on the argument made by Leslie Francis et al that it is not merely questions of justice within pandemic planning that demand attention but also the justice *of* pandemic planning:

> The triage choices in pandemic planning for the distribution of vaccines and antivirals are open, coordinated, and institutionally adopted. Perhaps this is one reason why they have drawn so much attention … No doubt there are other

[146] Likosky (n 128) 48.

> explanations, too, for the apparent assumption that devoting resources to pandemic planning is just … Nonetheless, there are serious questions of justice to be asked about the allocation of extensive resources to pandemic threats.[147]

And as Francis and her co-authors point out, the two sets of questions are related. If basic health care infrastructure is in a state of neglect or unavailable, if health professionals are in short supply or they are not trusted by the population, and if there is inequality in access to primary care, then global surveillance, hospital surge capacity and, more generally, preventing and coping with a pandemic will be all the more difficult. 'Pandemic myopia', in short, would be a seriously flawed approach to pandemic planning and indeed to public health.[148] Perhaps, then, we should start with the question 'What makes health public?'[149]

There are other questions too. Being at the health security table—as encouraged for example by the new IHR—is not going to be easy for human rights. How will human rights cope? Might it, for instance, meld into humanitarianism? If so, what sort of humanitarianism? Secondly, the pull of measurement will be extremely strong within human rights preparedness.[150] The value placed on early warning is one reason for this; another is that for as long as legal duties on corporations for violations of human rights are ill-defined and contested, indicators will appeal both to corporations seeking to display credentials of corporate social responsibility and to those who want responsibility to have more teeth. Each brings its own questions. Take the demand for social responsibility credentials: this has led to a proliferation of voluntary codes and reporting initiatives, and these in turn have led to rising demand for third-party assurances. But assurance providers, some of whom may be drawn from the human rights movement, face a conflict of interest: their role is to interpret, measure and verify corporate social responsibility, but that role only exists because corporations, the providers' clients, have requested third-party assurance. Thus as Sarfaty has pointed out, 'Given their conflict of interest, sensitive issues may be left out by assurance providers for fear of upsetting their clients'.[151] Combine this with the obvious difficulty of quantifying issues such as human rights and it is easy to see that measurement is a challenging matter. And if we add the human rights move into public health early warning

[147] LP Francis et al, 'Pandemic Planning and Distributive Justice in Health Care' in M Freeman (ed), *Law and Bioethics* (Oxford University Press 2008) 433.

[148] Ibid, 446.

[149] Asking this question and offering one answer to it, see J Coggon, *What Makes Health Public? A Critical Evaluation of Moral, Legal, and Political Claims in Public Health* (Cambridge University Press 2012).

[150] On human rights measurement, see also below ch 4.

[151] GA Sarfaty, 'Regulating through Numbers: A Case Study of Corporate Sustainability Reporting' (2013) 53 Virginia Journal of International Law.

and public health surveillance more broadly, further challenges arising from new roles, relationships and responsibilities come into view.

More generally, rights as risk is not home ground for human rights advocacy. Put bluntly, it smacks of bad faith, of working on 'their' terms, not on 'ours'. On an organisational risk approach, rights are viewed though a risk lens, not a human rights one, and compliance comes out of the process of managing the risks (for example, reputational or financial) to one's organisation. To advocate for an exploration of the human rights potential of such strategies is controversial—not least because it raises difficult questions about the role of instrumentalist approaches in human rights.

The counter-argument is that human rights advocacy has always been complex. Think, for example, of the diversity of human rights organisations and advocates (including those who use rights arguments to challenge new, or new interpretations of, human rights). Or of the fact that human rights victories have sometimes had unexpected, unintended and unwanted consequences: on occasion, for example, court victories or the passage of legislation have been used by governments as a way of claiming that appropriate action has been taken and no further governmental action is warranted—as a way, in other words, of disclaiming responsibility for any gaps between the law 'on the books' and the law 'in action'.

Moreover, if both state and non-state actors are now more engaged by human rights (even if for some this is happening primarily through the lens of risk management), then human rights advocates have little choice but to respond. There is also a chance, of course, that where a state or an organisation starts out with an instrumentalist mind-set towards human rights, it will internalise them over time. Overall, then, human rights advocates should not—and probably cannot—avoid engaging with rights as risk.

IV. CONCLUSION

One of the conclusions in the report of a recent UK Parliamentary Committee on infectious diseases and global health governance is that the WHO will need additional funding 'if it is to be able to respond effectively to threats on behalf of the international community'.[152] This statement is a reminder of the importance and, indeed, the fragility of public health emergency preparedness. It might also be read as a rebuke to those who would critique preparedness. Why critique something that is currently so precarious in practice?

Critiquing public health emergency preparedness is undeniably hard. Who in the end would choose to be 'against preparedness'—especially

[152] House of Lords Select Committee (n 51) para 114.

when one considers the extreme human costs of recent public health emergencies? I am not against it. However, my argument, stated simply, is that critique is an essential part of preparedness, and to date, critique *from a human rights perspective* has been in short supply.

This chapter has suggested an agenda—human rights preparedness—to address the gap. It has developed that agenda by focusing on 'risk within rights' and 'rights as risk'. And it has emphasised that neither focus is risk-free. For human rights, critiquing preparedness could well involve self-critique. Putting that another way, human rights preparedness is likely to be human rights without a safety net. With that in mind, I turn now to my next proposal, one that I imagine will sound less safe again: why the 'cost of human rights' can—and should—be part of human rights legal method.

3

The Cost of Human Rights

HUMAN RIGHTS STUDENTS, in my experience, like to talk about the future—both their own futures and the future in general. As part of this, they sometimes ask why I chose to be an academic, not an activist. I never know quite what to say in response. On the one hand, as a teacher, I welcome the question: it will often kick start a discussion on the world of human rights academics and how, if at all, that world differs from its activist counterpart, or what it means to be a 'scholar practitioner' or an 'activist academic'. On the other hand, however, the question niggles; to be honest, it niggles quite a bit.

I don't think the problem is vanity or regret concerning the choices I have made. Nor is that I am a critic of activism. I am aware of the arguments on NGO 'legitimacy', yet I feel mostly positive about the increasing size and influence of both civil society and international civil society. And as I said in the Introduction, I also welcome the swell of interest in seeing law 'from below'.[1] To my mind, numerous non-governmental organisations (NGOs) have affected health and human rights in profoundly positive ways.[2] They have helped to reshape conventional understandings of the relationship between trade and human rights; introduced sexual rights to the international human rights lexicon; pioneered new methods of measuring human rights compliance; and challenged the criminalisation of people living with HIV/AIDS. They have also faced down sceptics who insist that the right to health is not justiciable. Moreover, now that Amnesty International and Human Rights Watch, the two largest international human rights NGOs, have broadened their activities so as to encompass economic and social rights, human rights activism around health seems almost mainstream.[3]

[1] See, eg, B de Sousa Santos and CA Rodríguez-Garavito (eds), *Law and Globalization from Below* (Cambridge University Press 2005); U Baxi, *The Future of Human Rights* (3rd edn, Oxford University Press 2008).

[2] There is no accepted definition of NGO. See generally S Charnovitz, 'Nongovernmental Organizations and International Law' (2006) 100 American Journal of International Law 348.

[3] Of course, the mainstream also includes anti-rights NGOs, as well as NGOs that seem more attuned to profit than to rights. Increasingly it features single-issue campaigns too, and, relatedly, calls for vertical interventions rather than primary-care reform; these can limit our ability to engage with injustice.

So why does the students' question bother me? The problem is that the dichotomy 'academic or activist?' suggests that this choice—the choice of what to be in human rights—is the crucial one. It is, I agree, an important choice, one that will have consequences both for the individual making it and for the future of human rights. Yet choice does not end at this point: my job as an academic involves choice, and choice is also part and parcel of human rights activism. Choice, to be frank, is abundant, perhaps even oppressive, in the activists' world. Which projects should a human rights NGO select, and in what circumstances is it legitimate to amend project goals? On what basis are projects and thus the people they assist—and, indeed, the people to whom they have provided paid work—to be deselected? When and on what basis should NGOs collaborate with one another? In making such choices, should NGOs engage in triage, an approach to decision-making akin to that used by medical professionals in emergency situations? If so, what would count as *human rights* triage?

Money throws up another set of tough choices for human rights NGOs. When, if ever, should government money be accepted, and what is acceptable and unacceptable in fundraising more generally? How, for example, should NGOs respond to the power of 'creative capitalism', an approach promoted by the Bill and Melinda Gates Foundation, one of the pioneers in health super-philanthropy? Or to the rise of light-touch, consumer-driven activism, whereby buying chocolate, concert tickets or clothing in the global North helps to fund public health interventions in the South?[4] How, more generally, should NGOs manage the side effects of donors' priorities: the emphasis, for example, on particular diseases and, more than this, on pharmaceuticals as the solution to public health problems, or the way that time and place can be a major influence on donors?[5]

Also, how should NGOs respond to the humanitarianism now in play in the pharmaceutical industry—to gifts of free drugs, price reductions on particular drugs in low-income countries, and positive noises about patent pools and other such initiatives? What motivates this humanitarianism, and what are its consequences for health and human rights? For instance, if we ally it to super-philanthropy and to the efforts of individual consumers in the global North, is there a sense that we now have forms of 'giving back' that, intentionally or otherwise, cleave to the current intellectual property regime and thus limit fresh thinking on other ways of producing 'just

[4] See LA Richey, 'Representations of African Women and AIDS in Bono's Product RED' in V-K Nguyen and JF Klot (eds), *The Fourth Wave: Violence, Gender, Culture & HIV in the 21st Century* (SSRC/UNESCO 2011).

[5] B Klugman, 'Effective Social Justice Advocacy: A Theory-of-Change Framework for Assessing Progress' (2011) 19 Reproductive Health Matters 146, 152 noting that in South Africa, three out of the four reproductive rights NGOs that closed their doors between 2002 and 2008 did so in part because anti-apartheid donors had fallen away (or switched to funding government) and other donors were now choosing to fund HIV/AIDS activism.

health'? Still on the question of money, given that human rights activism is often viewed as a vocation and volunteerism is prized, who should be paid for their health and human rights work? For instance, should people from a local community be paid for helping their neighbours—especially if this sort of help facilitates adherence to complex drug regimens?

These choices, and others too, are beginning to be talked about openly. Activists are discussing them; scholars are too. They are also working together in order to address the undeniably difficult challenges involved.[6] I want to use this chapter to contribute to that work. In so doing, I focus on what I call the 'cost of human rights'. I shall argue that this can and should be part of human rights legal method.

I. AN UNLIKELY ARGUMENT?

The backdrop to my argument is rights-based activism around HIV/AIDS, specifically, one NGO—South Africa's Treatment Action Campaign (TAC), arguably the best known NGO in the field of access to treatment and amongst the best known NGOs worldwide. I am interested in the TAC because of the choices it made. It took on cost arguments—arguments made by the South African government, by pharmaceutical companies, by numerous public health experts and by fellow human rights advocates—and it won. The TAC's actions secured a nationwide programme to prevent mother-to-child transmission of HIV, encouraged the adoption of a national antiretroviral (ARV) treatment plan and helped to shatter both dissident science and the claims that drug prices could not—and should not—be brought down. The TAC's actions also demonstrated that health rights are justiciable and that justiciability need not bankrupt governments, destroy separation of powers or lead to individual human rights claims trumping all other interests. Similarly, the TAC demonstrated that justiciability does not mean that human rights advocacy will be routed through courts alone; justiciability, in other words, does not mean a hollowing-out of human rights work. The TAC's actions—from litigation, and both protest and networking at home and abroad, including with health professionals and pharmaceutical companies, to its grassroots Treatment Literacy Campaign—also demonstrated just how wrong it can be to assume that poor patients do

[6] See especially D Bell and J-A Coicaud (eds), *Ethics in Action: The Ethical Challenges of International Human Rights Nongovernmental Organizations* (Cambridge University Press 2007); LE White and J Perelman (eds), *Stones of Hope: How African Activists Reclaim Human Rights to Challenge Global Poverty* (Stanford University Press 2011); UN General Assembly (UNGA), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (13 August 2012) UN Doc A/67/302; KG Young, *Constituting Economic and Social Rights* (Oxford University Press 2012) 223–87.

not follow complex drug regimes, or that rights-respecting primary care is both out of reach and potentially an obstacle to effective health delivery, or indeed that rights talk mandates a choice between recognition and redistribution, and often promotes the former at the expense of the latter.

The TAC, in short, wielded law, but it also did more far than that. Moreover, whether wielding law or not, the TAC fought not just for freedoms and entitlements but also for institutions and processes.[7] Prompted by the TAC's success, this chapter asks: is the 'cost of human rights' as much ours as theirs? Is it, in other words, a way of thinking about rights that can and should be used by *human rights* activists and academics, not simply by anti-rights sceptics, cynics and pessimists?[8]

The cost of human rights is, I accept, an odd choice for an advocate of human rights. It sounds more like an argument *against* rights. It is easy to imagine it being used to say that rights are a luxury, something that cannot be afforded—that money-wise or security-wise, they cost too much. A variation on the claim insists that while rights do plenty to protect the rich, they tend to be a scarce resource for the poor. Another variation, heard sometimes in the development context, is that human rights—specifically, civil and political rights—are imposed by donors as a condition for development cooperation, with scant regard for either the sovereignty of developing states or the principle of national ownership of development programming. Yet another version of the argument, the mildest and most commonplace one, maintains that economic, social and cultural (ESC) rights are costly, whereas civil and political rights are no cost, low cost or, indeed, worth the cost.

These sorts of claims are made by those who are critical or sceptical of rights: what may be surprising is that they are popular in human rights circles too. The indivisibility, interdependence and interrelatedness of rights may now be widely acclaimed,[9] but in practice that way of thinking can still fall away. There is, to be sure, greater acknowledgement that all rights involve both positive and negative obligations; the tripartite typology 'respect, protect, fulfil' has been helpful in this regard. Yet neither the

[7] See relatedly B Simma, 'From Bilateralism to Community Interest in International Law' (1994) 250 Recueil des Cours de l'Académie de Droit International 217.

[8] See also S Holmes and CR Sunstein, *The Cost of Rights: Why Liberty Depends on Taxes* (WW Norton 1999); S Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford University Press 2008) esp 25–30. For discussion of the 'economics of social rights', see P Alston and M Robinson (eds), *Human Rights and Development* (Oxford University Press 2005) chs 4–5.

[9] UN, World Conference on Human Rights, 14–25 June 1993, 'Vienna Declaration and Programme of Action' (12 July 1993) UN Doc A/CONF.157/23, para 5. *Cf* JW Nickel, 'Rethinking Indivisibility: Towards A Theory of Supporting Relations Between Human Rights' (2008) 30 Human Rights Quarterly 984; A Cassese, 'A Plea for a Global Community Grounded in a Core of Human Rights' in A Cassese (ed), *Realising Utopia: The Future of International Law* (Oxford University Press 2012).

description 'positive rights' nor its counterpart, 'negative rights', has been dislodged. ESC rights also continue to be dogged by non-justiciability claims: indeed, for some, the emergence of justiciability (with cases from India, Colombia, Brazil and South Africa, amongst others) has led to bouts of fresh anxiety. Typically, the concerns run deep and wide. Will such litigation produce counter-majoritarian judgments, corrupting separation of powers and threatening democracy? Will it destroy any chance of social justice in health policy-making, with resources being channelled towards those who can afford to go to court to secure their right to a certain treatment or particular drug, which in turn will lessen the money available for health systems and indeed for the protection of other human rights? And, more broadly, will it draw not just courts but rights into disrepute—making them not the last, but rather a lost, utopia?[10]

To sum up: the 'cost of rights' is widely used as an argument against rights and against ESC rights in particular, and it is used in this way not just by those who are critical of rights but by human rights insiders too. In this chapter I challenge that by arguing that it can and should be cast in a *pro-human rights* way. I use two sources to support my argument. The first is NGO practice, where the questions to be examined are as follows: what does it mean and what does it take to be successful in health and human rights terms, and what are the effects of an individual success on human rights more broadly? What, in short, is the cost of success to NGOs themselves and to human rights? The second source is human rights law. Here the question to be addressed is: what resources does human rights law provide for addressing the cost—the actual, financial cost—of human rights? In discussing this, I focus on international human rights law, in large part because of the number of states parties to the two International Covenants[11] and also to specialist instruments such as the Convention on the Rights of the Child.[12]

II. AIDS EXCEPTIONALISM

To develop the argument, I look at the HIV/AIDS pandemic. This, too, may seem an odd choice, given that cost was rolled out to *counter* the claim that universal access to antiretrovirals had to be seen as a question

[10] Addressing these anxieties, see AE Yamin and S Gloppen (eds), *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Harvard University Press 2011). On rights as the last utopia, see S Moyn, *The Last Utopia: Human Rights in History* (Harvard University Press 2010). *Cf* R Blackburn, 'Reclaiming Human Rights' (2011) 69 New Left Review 126.

[11] International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR'); International Covenant on Civil and Political Rights (16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (hereafter 'ICCPR').

[12] Convention on the Rights of the Child (20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (hereafter 'CRC').

of human rights. The anti-rights camp argued that access would cost too much, typically giving two reasons to support their claim. First, treatment in resource-poor settings was economically unfeasible: poor people do not—cannot—follow ARV regimes, and hence prevention rather than access ought to be the priority. Secondly, because techniques to reduce the price of drugs would be needed to secure a human right of access to treatment, global patent protections would be undermined, and this in turn would limit incentives to engage in research and development (R&D) for new drugs. Surely, the anti-rights camp claimed, the global patent system should not change if, in so doing, its vital public health function might be damaged or, worse, destroyed. Wouldn't that be too high a cost to pay?

These arguments were challenged by human rights advocates: the first has now been countered pretty successfully,[13] and the second has been dented in a range of ways. Proponents of patent protection are adept when it comes to finding new ways to assert their claims,[14] but it is now accepted that the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property (TRIPS)[15] has flexibilities—notably, compulsory licensing and parallel importation[16]—that allow states 'facing national emergencies' to limit patents in order to protect the public health of their citizens. Additionally, the Committee on Economic, Social and Cultural Rights (CESCR) has advised states parties to the International Covenant on Economic, Social and Cultural Rights (ICESCR) that they must take action against intellectual property protections that make the cost of essential medicines 'unreasonably high'.[17]

States parties have other relevant duties too. For example, they must both 'ensure that their actions as members of international organizations take due account of the right to health' and comply with the obligation to seek and provide international assistance and cooperation; they must also 'prevent third parties from violating the right in other countries, if they are able to influence these third parties by way of legal or political means, in accordance

[13] Discussing the case of Haiti, see P Farmer, *Infection and Inequalities: The Modern Plagues* (University of California Press 1999).

[14] Notably, via bilateral and regional free trade agreements featuring so-called 'TRIPS-plus' provisions—provisions that go beyond obligations under the TRIPS Agreement.

[15] Agreement establishing the World Trade Organization (15 April 1994, entered into force 1 January 1995) 1869 UNTS 299, annex 1C (Agreement on Trade-Related Aspects of Intellectual Property Rights) (hereafter 'TRIPS').

[16] Compulsory licensing occurs when a state allows a third party to produce a generic (and thus low-cost) version of a patented medicine without the consent of the patent owner. Parallel importation occurs when a state (typically one that lacks manufacturing capacity), without the approval of the patent owner, imports a medicine under patent from another state where it is being sold at a lower price.

[17] CESCR, 'General Comment No 17: The Right of Everyone to Benefit from the Protection of the Moral and Material Interests Resulting from any Scientific, Literary or Artistic Production of which He or She is the Author (art 15(1)(c))' (12 January 2006) UN Doc E/C.12/GC/17, para 35.

with the Charter of the United Nations and applicable international law'.[18] In addition, spurred in part by the work of Paul Hunt, the first UN Special Rapporteur on the right to health,[19] there is now increased interest in human rights indicators and in human rights impact assessment mechanisms which can be used by states and others in order to determine the effects of free trade agreements on access to essential medicines.[20] Most important of all, the international community has pledged not just universal access to HIV prevention, treatment, care and support—'as close as possible … by 2010 for all those who need it'—but to halt and begin to reverse the pandemic by 2015.[21]

The Doha Round of trade talks was a turning point. The Declaration on TRIPS and Public Health, agreed at Doha, affirmed that the TRIPS Agreement 'can and should be interpreted and implemented in a manner supportive of WTO Members' right to protect public health and, in particular, to promote access to medicines for all'.[22] In so doing, it confirmed that TRIPS' flexibilities could be used by WTO member states. It also demonstrated the strength of emerging economies such as Brazil, India and South Africa, as well as the negotiating power that could be wielded by a network of these economies, less developed ones and NGOs. After two further years

[18] CESCR, 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/4, paras 38–42. But see F Coomans, 'The Extraterritorial Scope of the International Covenant on Economic, Social and Cultural Rights in the Work of the United Nations Committee on Economic, Social and Cultural Rights' (2011) 11 Human Rights Law Review 1, noting that the language in later comments is more recommendatory. See also the Maastricht Principles on Extraterritorial Obligations of States in the area of Economic, Social and Cultural Rights, adopted by a Group of Experts, Maastricht, 26–28 September 2011 (reprinted in (2011) 29 Netherlands Quarterly of Human Rights 578); O De Schutter et al, 'Commentary to the Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights' (2012) 34 Human Rights Quarterly 1084; M Langford et al (eds), *Global Justice, State Duties: The Extraterritorial Scope of Economic, Social, and Cultural Rights in International Law* (Cambridge University Press 2013).

[19] See, eg, UN Commission on Human Rights (UNCHR), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (13 February 2003) UN Doc E/CN.4/2003/58. See also, eg, UN Human Rights Council (UNHRC), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (31 March 2009) UN Doc A/HRC/11/12.

[20] See generally S Walker, *The Future of Human Rights Impact Assessments of Trade Agreements* (Intersentia 2009); J Harrison, 'Trade Agreements, Intellectual Property and Access to Essential Medicines: What Future Role for the Right to Health?' in O Aginam, J Harrington and P Yu (eds), *Global Governance of HIV/AIDS: Intellectual Property Rights and Access to Essential Medicines* (Edward Elgar 2012).

[21] The 2015 target is one of the Millennium Development Goals (MDGs); for the 2010 targets, see the 2001 Declaration of Commitment on HIV/AIDS (UNGA Res S-26/2) and the 2006 Political Declaration on HIV/AIDS (UNGA Res 60/262). See also the Political Declaration on HIV/AIDS, adopted 10 June 2011 (UNGA Res 65/277).

[22] Declaration on the TRIPS Agreement and Public Health (14 November 2001) WTO Doc WT/MIN(01)/DEC/2 (Doha Declaration) para 4.

of negotiation, agreement was reached on a mechanism giving further flexibility to WTO member states with either insufficient or no manufacturing capacity in the pharmaceutical sector, thereby allowing them to import generic versions of essential medicines from foreign producers.[23]

Complex problems remain, and ignoring them would be stupid. At the same time, however, it is hard to see how the world of intellectual property could revert to pre-Doha ways. For starters, the problems that rigid or 'one-size' TRIPS requirements pose to public health and to development have been widely advertised. Second, prompted by Argentina and Brazil, the World Intellectual Property Organization (WIPO) has adopted a development agenda.[24] Third, there has been a surge in R&D for neglected (that is to say, poverty-related) diseases: this is both belated and not enough, but it is also striking in that it is largely non-commercial R&D, funded not just by philanthropists but by the pharmaceutical companies themselves.[25] Fourth, companies' estimates of how much private investment it takes to develop a new drug have faced increased questioning. Activists have also used the so-called 10/90 gap to query industry arguments on incentives: namely, if patent rules work, why is it that 90 per cent of R&D has been focused on conditions affecting only 10 or so per cent of the world's population?[26] The answer is that 'where the market has very limited purchasing power, as is the case for diseases affecting millions of poor people in developing countries, patents are not a relevant factor or effective in stimulating R&D and bringing new products to market'.[27] Put shortly, arguments made by activists mean that the industry's own public health rhetoric has been biting back.

Robust TRIPS flexibilities have become a key interest for states such as Thailand, India and Brazil, for the World Health Organization (WHO) and the UN Special Rapporteur on the right to health, and for NGOs and scholars too.[28] More generally, seeing intellectual property as a trade issue seems less popular than it was, and both neglected rights (such as the right to enjoy the benefits of scientific progress and its applications) and new rights

[23] Implementation of Paragraph 6 of the Doha Declaration on the TRIPS Agreement and Public Health: Decision of 30 August 2003, WTO Doc WT/L/540; Amendment of the TRIPS Agreement: Decision of 6 December 2005, WTO Doc WT/L/641.

[24] Details available at www.wipo.int.

[25] M Moran et al, 'The New Landscape of Neglected Disease Drug Development' (Wellcome Trust 2005).

[26] For details, see the work of the Global Forum for Health Research, www.globalforumhealth.org.

[27] WHO Commission on Intellectual Property Rights, 'Innovation and Public Health, Public Health Innovation and Intellectual Property Rights' (WHO 2006) 34.

[28] See, eg, LR Helfer and GW Austin, *Human Rights and Intellectual Property: Mapping the Global Interface* (Cambridge University Press 2011); UNHRC, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (16 March 2011) UN Doc A/HRC/17/43; UNHRC, 'Report of the Special Rapporteur' (31 March 2009) (n 19).

(for example, access to knowledge or 'A2K' for short) have been attracting attention.[29] Other developments, too, point to new alignments. The WTO has been under increasing pressure to demonstrate the legitimacy of its decision-making[30] and to develop closer working relationships with other international organisations (including specialised agencies of the United Nations, such as the WHO and WIPO) wherein trade is not the priority value.[31] Additionally, because the UN Educational, Scientific and Cultural Organization (UNESCO), WIPO and others have been extending intellectual property (IP) rights to non-traditional arenas, such as traditional knowledge and community intangible cultural heritage, the possibility of a human rights-based approach to IP now seems a little more viable, a little less implausible.

There has been fresh thinking on the human rights side as well—though more is needed. There is now lively debate on new mechanisms, such as patent pools,[32] that might tackle the high cost of drugs. There is also debate on mechanisms, such as a Health Impact Fund,[33] that promise to tackle not just cost but also the need to incentivise R&D on new drugs. The Special Rapporteur on the right to health has taken up the challenge of health financing too; he continues to report as well on obstacles to access to medicines.[34] Additionally, amidst a growing body of case law on health rights, assumptions about the impossibility, impropriety or imprudence of making claims through the courts have started to give way. And in their place, as we saw in chapter one, there is debate on a range of important matters—from the standard of judicial review of socio-economic policies to the need for a minimum core concept (as recommended by the CESCR but rejected by South Africa's Constitutional Court), as well as the nature of the relief a court can and should order for litigants.[35] Relatedly, there is also greater

[29] See respectively UNHRC, 'Report of the Special Rapporteur on Cultural Rights, Farida Shaheed' (14 May 2012) UN Doc A/HRC/20/26; A Kapczynski, 'The Access to Knowledge Mobilization and the New Politics of Intellectual Property' (2008) 117 Yale Law Journal 804.

[30] See D Kinley, *Civilising Globalisation: Human Rights and the Global Economy* (Cambridge University Press 2009); S Joseph, *Blame it on the WTO: A Human Rights Critique* (Oxford University Press 2011); A Lang, *World Trade Law after Neoliberalism: Reimagining the Global Economic Order* (Oxford University Press 2011).

[31] See, eg, Standing Committee on the Law of Patents, 'Report on the International Patent System' (15 April 2008) SCP/12/3; WHO, 'Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property' (24 May 2008) Res WHA61.21.

[32] See, eg, the Medicines Patent Pool Foundation, www.medicinespatentpool.org, created by the International Drug Purchase Facility (UNITAID), www.unitaid.eu.

[33] A Hollis and T Pogge, *The Health Impact Fund: Making New Medicines Accessible for All* (Incentives for Global Health 2008). See also T Pogge et al (eds), *Incentives for Global Public Health: Patent Law and Access to Essential Medicines* (Cambridge University Press 2010).

[34] See, eg, UNGA, 'Report of the Special Rapporteur' (13 August 2012) (n 6).

[35] See, eg, Fredman (n 8); M Langford (ed), *Social Rights Jurisprudence: Emerging Trends in International and Comparative Law* (Cambridge University Press 2008); Yamin and Gloppen (eds) (n 10); Young, *Constituting Economic and Social Rights* (n 6).

acknowledgement of the ways in which civil and political rights protect and strengthen the right to health or health care.[36]

There is also growing awareness of the pioneering ways in which NGOs (like South Africa's TAC or Ghana's Legal Resource Centre) have been able to deploy constitutional rights litigation, as part of a mix with other legal and non-legal measures, in order to achieve a range of *negotiated*—not imposed or narrowly entitlement-based—human rights successes. The methods and the achievements of these NGOs offer a fresh way of thinking about human rights law—specifically, a way of thinking about ESC rights litigation as leverage, not simply as a vehicle for individualised relief for those who can afford to access the courts.[37] A way, we might say, of thinking about litigation that is 'litigation plus'.

III. AFTER THE RIGHT TO TREATMENT

So where does human rights stand today? The success of the access to treatment campaign has been nothing short of extraordinary: it has saved lives, and it has turned intellectual property law-making into a much busier, much more disputed field. And yet we are amidst AIDS, not after it. Millions may have gained access to ARVs, but there are less positive statistics too,[38] statistics that tell a story of devastation—devastation that is not the same the world over.[39] There is also no AIDS vaccine. And rights-based mobilisation for prevention is nowhere near good enough; the Executive Director of UNAIDS had to issue an appeal to his own organisation to deliver a 'prevention revolution' grounded in equality, human rights and science.[40] Also, although the fall in drug prices has been dramatic, cost is still an issue—an issue of life (with a chronic condition) or death, an issue that forces families who can afford ARVs, or can just about afford them, to take terrible, triage-like decisions. Stark choices have to be made:

> The economic question of who lives and who dies, and at what cost, becomes all too real as families ... are brought into the painful dynamic of triaging care among their own children and kin. The use and cost of these drugs are weighed

[36] See, eg, I Koch, *Human Rights as Indivisible Rights: The Protection of Socio-economic Demands under the European Convention on Human Rights* (Martinus Nijhoff 2009).

[37] See especially White and Perelman (eds) (n 6); Young, *Constituting Economic and Social Rights* (n 6). Civil society organisations (CSOs) working with legal frameworks *outside* of the court system also merit increased recognition: see, eg, the Learning Network for Health and Human Rights, Western Cape, South Africa, salearningnetwork.weebly.com.

[38] For statistics, see the global reports produced by the Joint UN Programme on HIV/AIDS (UNAIDS), eg, 'Global Report: UNAIDS Report on the Global AIDS Epidemic 2012' (UNAIDS 2012).

[39] See further CA Heimer, 'Old Inequalities, New Disease: HIV/AIDS in Sub-Saharan Africa' (2007) 33 Annual Review of Sociology 551.

[40] M Sidibé, 'Delivering Results in Transformative Times' (UNAIDS 2010) 3.

> against other socially valued priorities such as sending a sister or a daughter to school.[41]

Treatment starting later than it should is also an issue, and drug resistance (created in part by problems with supply) means that new, more expensive therapies are needed.[42] The commercialisation of health care, prompted in part by a period of enthusiasm for user fees on the part of the international financial institutions, is an increasing problem as well.[43]

For these and other reasons—indeed, 'for many reasons, now more than ever'[44]—the role of human rights in the response to HIV/AIDS needs reinforcement. Criminalisation remains a problem. The International Guidelines on HIV/AIDS and Human Rights[45] also remain controversial. And re-medicalisation—which neglects inequality, cleaves to quick fixes and sees human rights as an obstacle to mandatory testing—is an ever-present threat.[46] Perversely, the *success* of the access to treatment campaign creates human rights problems too. To explain: access to treatment may now be acknowledged as a human right, a global public good, even a smart global health investment,[47] yet none of this makes it secure or sustainable. What would happen if super-philanthropists like the Gates Foundation were to change their priorities? Or if treatment activists in other areas managed to emulate the success of AIDS activism; some of them want to 'put HIV in its place',[48] viewing its share as too large vis-à-vis other diseases. Equally, the campaign on access to treatment coincided with a growing global economy: today, amidst austerity, access may not have such priority for international donors (indeed, in late 2011, the board of the Global Fund to Fight AIDS,

[41] A Petryna and A Kleinman, 'The Pharmaceutical Nexus' in A Petryna et al (eds), *Global Pharmaceuticals: Ethics, Markets, Practices* (Duke University Press 2006) 29, describing the chapter 'Treating AIDS: Dilemmas of Unequal Access in Uganda' by Susan Whyte et al.

[42] Thailand has shown that TRIPS flexibilities—specifically, compulsory licences—can be used to access second-line, etc ARVs: see J Burton-Macleod, 'Tipping Point: Thai Compulsory Licences Redefine Essential Medicines Debate' in Pogge et al (eds) (n 33).

[43] See relatedly the Commission on Social Determinants of Health, Final Report, 'Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health' (WHO 2008), identifying reforms pushed by the WTO, World Bank and IMF as one source of the growing commercialisation of health care and, more generally, as harmful to systems for primary care and the reduction of social inequities.

[44] UNAIDS Reference Group on Human Rights, 'Recommendations Brief to Michel Sidibé, UNAIDS Executive Director' (January 2009) 1.

[45] UNAIDS/OHCHR, 'International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version' (UNAIDS 2006).

[46] See, eg, M Fox and M Thomson, 'The New Politics of Male Circumcision: HIV/AIDS, Health Law and Social Justice' (2012) 32 Legal Studies 255, examining increased promotion of male circumcision.

[47] EB Kapstein and JW Busby, 'Making Markets for Merit Goods: The Political Economy of Antiretrovirals' (2010) 1 Global Policy 75.

[48] R England, 'Are We Spending Too Much on HIV?' (2007) 334 (7589) British Medical Journal 344. *Cf* L Forman, 'Global AIDS Funding and the Re-Emergence of AIDS "Exceptionalism"' (2011) 6 Social Medicine 45.

Tuberculosis and Malaria was obliged to cancel its eleventh funding round, having received insufficient money to be able to finance new proposals).

Other challenges are pressing too. First, how precisely are states and the international community to manage demand for new drugs entering the market? How, for instance, is a line to be drawn between, on the one hand, new drugs that are needed and are in fact an advance on what is available at lower cost and, on the other hand, heavily marketed products that cost much more but are no improvement on their predecessors?[49] Brazil and India have legal provisions that both allow 'any person' to make a pre- or post-patent challenge (thereby opening up opportunities for NGOs to get involved) and block 'evergreening' (the practice whereby pharmaceutical companies look to stretch the life of a patented product by applying for a patent for a slightly modified version). Are these laws a model for other states?

Second, the success of the access to treatment campaign has focused attention on ARVs. That has been vital, but no one lives on ARVs alone. Moreover, free ARVs mean little if there is no clean water or if there is a shortage of transport to and from the health centre.[50] Free drugs also mean little if there are hidden user fees or under-the-table payments, or if individuals are treated so badly by health providers that they prefer to stay away from clinics and hospitals. More than this, people dying of AIDS need access to adequate pain medication, orphans need care and child-headed households need services and support.[51]

Infrastructure needs to be on the agenda too: degraded and crumbling health systems, or services that are overwhelmed, do not allow for scaling-up. Health workers also need reasons to stay in their home countries, working in the primary health system rather than in parallel programmes in '"NGOland" where salaries are better and the tools of [the] trade more plentiful'.[52] Finally, the political and social dimensions of the pandemic

[49] Pharmaceutical companies, too, have been seen as having responsibilities in this regard: see, eg, the WHO Criteria for Medicinal Drug Promotion; 'Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines' in UNGA, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (11 August 2008) UN Doc A/63/263.

[50] MDG Gap Task Force, 'Millennium Development Goal 8: Delivering on the Global Partnership' (UN 2008) 35, fn 2 defines access to mean 'having medicines continuously available and affordable at public or private health facilities or medicine outlets that are within one hour's walk from the homes of the population'.

[51] On the latter, see especially B Goldblatt and S Liebenberg, 'Giving Money to Children: The State's Constitutional Obligations to Provide Child Support Grants to Child Headed Households' (2004) 20 South African Journal of Human Rights 151.

[52] P Farmer, 'Challenging Orthodoxies: The Road Ahead for Health and Human Rights' (2008) 10(1) Health and Human Rights: An International Journal 5, 10. The adoption of 'International Recruitment of Health Personnel: Draft Global Code of Practice' (20 May 2010) WHO Doc A63/8 suggests states are conscious of this harm.

cannot be neglected—notably, poverty but also stigma, violence and discrimination against key populations at risk of HIV infection.[53]

Recall, too, that proponents of global IP protection remain steadfast in their ambition. TRIPS may well have 'wiggle room',[54] but these flexibilities have not proved easy to use in practice.[55] And were this to change, patent advocates would certainly look for other ways to protect their interests—they are already doing this via TRIPS-plus provisions, and doing it very effectively.[56] Moreover, no matter how much wiggle room there is in the patent regime, encouraging R&D for neglected diseases seems to require a different tack: weak markets have tended to be of little or no interest to pharmaceutical companies looking to reap profits through the intellectual property regime. To be fair, there is now considerable interest in incentives to encourage companies to enter the arena of neglected diseases, either directly or by supporting external R&D, or both. There are even proposals, notably the Health Impact Fund, promoted by the philosopher Thomas Pogge and others, which attempt to address both the lack of incentives and the high cost of drugs, without having to throw aside the current patent system.[57]

This focus on incentivisation is both promising and complicated. Neglected diseases, as their name suggests, call out for new incentives; at the same time, however, incentives could entrench the pharmaceuticalisation of public health. The centrality of treatment and testing and, more generally, the quest for a magic bullet make it all too easy to shrink the scope of rights-based approaches to the HIV/AIDS pandemic and, more broadly, to public health. Universal access to treatment is, as I have said, a vitally important goal, but it is not enough to cost and commit to programmes of treatment and voluntary testing. Rights-based approaches to health have to 'comprise more than packages of goods and services'.[58] And as Paul Farmer explains, if a way is not found to communicate this, 'the next orthodoxy

[53] On the problems caused by criminalisation, see UNHRC, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (27 April 2010) UN Doc A/HRC/14/20; UN Development Programme (UNDP) Global Commission on HIV and the Law, 'Risks, Rights and Health' (UNDP 2012).

[54] RC Dreyfuss, 'TRIPS and Essential Medicines: Must One Size Fit All? Making the WTO Responsive to the Global Health Crisis' in Pogge et al (eds) (n 33) 55.

[55] See, eg, M Rimmer, 'Race against Time: The Export of Essential Medicines to Rwanda' (2008) 1 Public Health Ethics 89. See more generally GB Dinwoodie and RC Dreyfuss, *A Neofederalist Vision of TRIPS: The Resilience of the International Intellectual Property Regime* (Oxford University Press 2012).

[56] See further A Mitchell and T Voon, 'Patents and Public Health in the WTO, FTAs and Beyond: Tension and Conflict in International Law' (2009) 43 Journal of World Trade 571.

[57] Hollis and Pogge (n 33).

[58] AE Yamin, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care' (2008) 10(1) Health and Human Rights: An International Journal 45, 48.

in public health' could be that 'it is acceptable to offer medicines but not acceptable to offer, say, access to microcredit, school fees, or food'.[59] More broadly, whether one supports health rights on the basis of dignity, freedom, survival or the growing consensus behind these rights, the separation of access to essential medicines from other aspects of health rights and from ESC rights more generally is a worrying development.

There is, in short, more than one funding problem and more than one human right at issue here. Funds are needed on the one hand to support both access to drugs and R&D for new and necessary drugs. On the other hand, these needs (and, in particular, success in articulating them in human rights terms) have produced other funding problems—most obviously, a shortfall in funding for health infrastructures, for reproductive rights and for basic survival needs. Recognising this, I turn now to the question at the core of this chapter: could the 'cost of human rights' be a resource for health and human rights advocacy—more specifically, for human rights legal method? In addressing this, I shall be looking to South Africa's TAC. In so doing, I am not saying that the TAC, and treatment activism more generally, cannot prompt other lines of enquiry. It is just that the question of cost is what interests me here.

IV. THE TREATMENT ACTION CAMPAIGN AND THE *TAC* CASE

The TAC was founded by a 'handful of people'[60] on International Human Rights Day in 1998. Its first campaign, still its best known in legal circles, was launched on the same day: centred on the right to access HIV/AIDS medicines, the campaign called on the South African government to implement a comprehensive national programme to prevent mother-to-child transmission (MTCT) of HIV.[61] Law, politics and the scale of MTCT made this a logical choice for the newly founded TAC.

As regards the law, there had been two promising developments. First, the post-apartheid South African Constitution, adopted in 1996, had a Bill of Rights with a cluster of health-related rights, including a right to have access to health care services, which the state has a duty to progressively realise by taking 'reasonable legislative and other measures, within its available resources'.[62] Elsewhere in the Bill of Rights, children were guaranteed

[59] Farmer, 'Challenging Orthodoxies' (n 52) 8.

[60] M Heywood, 'South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health' (2009) 1 Journal of Human Rights Practice 14, 15.

[61] Organisations, including the AIDS Law Project, began lobbying on the issue in 1997.

[62] Constitution of the Republic of South Africa 1996, s 27. The right to emergency medical treatment (s 27(3)) is not limited by the standard of progressive realisation.

the right to basic healthcare services.[63] There was also a guarantee that 'Everyone has the right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction',[64] as well as explicit reference to 'reproductive health care' in the provision on access to health care services. These rights were justiciable,[65] and the courts had been given substantial discretion to award 'just and equitable'[66] remedies. The provisions on legal standing were generous too, allowing actions in the public interest, for example.[67]

The TAC must also have been encouraged by the robust response of the new Constitutional Court to the concerns about economic and social rights that surfaced during the Constitution's certification process. The Court had accepted that having such rights in a constitution 'may result in courts making orders which have direct implications for budgetary matters'.[68] Crucially, however, it insisted:

> [I]t cannot be said that by including socio-economic rights within a bill of rights, a task is conferred upon the court so different from that ordinarily conferred upon them by a bill of rights that it results in a breach of the separation of powers.[69]

The Medicines and Related Substances Control Amendment Act 1997 was another encouraging sign. This statute made provision for both parallel imports and compulsory licences. In so doing, it promised not just affordable ARVs and other AIDS-related medicines but also a government that was ready to stand up for its citizens' health—more specifically, a government prepared to take on the multinational pharmaceutical companies that had gone to court in early 1998 determined to block implementation of the law. The TAC joined on the government side as an amicus (friend of the court), introducing evidence to show why the pharmaceutical companies' argument would have a devastating effect on access to ARVs. It also mobilised extremely effectively, drawing hundreds of protestors outside the courthouse and galvanising an international backlash against drug pricing practices. The pharmaceutical companies withdrew their case, leaving the government free to implement its medicines legislation.[70]

[63] Ibid, s 28(1)(c), noting that this right too is not limited by the standard of progressive realisation.

[64] Ibid, s 12(2)(a).

[65] As confirmed by the Constitutional Court during the certification process (*Ex parte Chairperson of the Constitutional Assembly: In re Certification of the Constitution of the Republic of South Africa 1996* 1996 (4) SA 744 (CC) para 78).

[66] s 173.

[67] s 38(d).

[68] *In re Certification of the Constitution* (n 65) para 77.

[69] Ibid. There were, however, indications that the Court saw limits to its own role: see para 78.

[70] See generally KG Young, 'Securing Health through Rights' in Pogge et al (eds) (n 33).

Finally, let's look at why the TAC chose prevention of mother-to-child transmission (PMTCT). At the time, up to 70,000 children with HIV were being born each year, most not living to be five years old. Life was extremely difficult for those who were caring for these children, particularly their mothers. A clinical trial in Thailand brought hope, however. It suggested that a short course of the antiretroviral drug AZT, starting at 36 weeks of pregnancy, could reduce mother-to-child transmission. A year later, in the summer of 1999, evidence came through from another study, HIVNET 012, showing that MTCT could be reduced by the antiretroviral Nevirapine. And crucially, a single dose given to a mother during labour and another to the infant following birth were enough to lower the chances of transmission. Concerns about cost, and about the need to start treatment early and to have a lengthy follow-up, immediately became less of an obstacle.

The TAC took action. There were meetings with government ministers, there were demonstrations and there was a 50,000-person petition that went to the President, Thabo Mbeki. There was also a close working relationship, at least initially, with reproductive rights organisations. The latter were strong in South Africa in the transition period (securing both liberalisation of abortion law and increased access to abortion and other reproductive health services), and at the start of the PMTCT campaign they worked in cooperation with the TAC to develop claims focused on women's rights.[71] There were also on-going appeals to major pharmaceutical companies to bring down the cost of ARVs. At first the government seemed sympathetic to the TAC's campaign, but relations deteriorated when President Mbeki made a speech in which he queried the safety of the antiretroviral AZT. That speech marked a new phase, one widely described as 'AIDS denialism', wherein a national programme to prevent MTCT was very clearly *not* on the government's agenda.

The government raised questions about the safety of Nevirapine. It also insisted that a nationwide programme was unaffordable. It maintained these arguments even after the WHO and South Africa's own Medical Review Board had approved Nevirapine, and the drug's manufacturers had offered it free of charge for a period of up to five years. What remained unaffordable, the government said, was the comprehensive package of services (including substitutes for breast milk) that had to be in place in order for Nevirapine to be maximally effective. Other cost arguments surfaced too: one of these was that public funding for a prevention programme would mean directing resources away from areas of equally important or more basic need. The Minister of Health for the KwaZulu-Natal Province made precisely this argument at the International AIDS 2000 Conference,

[71] See below section V-B.

asking 'What if we have money for ARVs but no money for clean water? How do we then treat diarrhoea?'[72]

A related argument alleged a different inequity. It suggested that implementing a national prevention programme would produce centralised vertical delivery systems, which would disrupt the development of local health management structures, thereby causing more health inequality.[73] The most the South African government was willing to agree to was a pilot programme that would make Nevirapine available at selected public sector sites. It claimed that by taking this approach it would be possible for the efficacy and safety of the drug to be tested. It refused to allow the drug to be administered at other public sector sites, even where those sites had the capacity for testing and counselling.

The TAC was not deterred. It continued to mobilise locally, transnationally and internationally, promoting both treatment literacy and access rights, and countering the financial cost claims that were being made by the pharmaceutical companies and the government. It also took its PMTCT campaign to the courts, securing a landmark judgment, *Minister of Health v Treatment Action Campaign*,[74] from the Constitutional Court in 2002. That judgment prompted a flurry of interest in the enforceability of economic and social rights and led eventually—thanks in part to the TAC's diligence in making the Court's decision count in practice—to increased access to PMTCT services in the public sector in South Africa.

The Constitutional Court saw the case as raising two questions concerning the government's obligations under sections 27 and 28 of the Constitution: first, whether it was reasonable to restrict the use of Nevirapine to the pilot sites, given that there were other public hospitals and clinics that had the requisite testing and counselling capacity; and second, whether the government was required to 'plan and implement an effective, comprehensive and progressive programme'[75] for PMTCT throughout the country.

In a unanimous decision, the Court answered those questions as follows: as regards the first, it said that 'a potentially lifesaving drug was on offer and where testing and counselling facilities were available it could have been administered within the available resources of the state without any known harm to mother and child'.[76] The Court dismissed the government's arguments about the need for a package of support services and for further

[72] Quoted by L London, 'Human Rights and Public Health: Dichotomies or Synergies in Developing Countries? Examining the Case of HIV in South Africa' in RJ Cook and CG Ngwena (eds), *Health and Human Rights* (Ashgate Publishing 2007) 133.

[73] Ibid.

[74] *Minister of Health and Others v Treatment Action Campaign and Others* 2002 (5) SA 721 (CC) (*TAC*). The High Court had decided in the TAC's favour: *Treatment Action Campaign and Others v Minister of Health and Others* 2002 (4) BCLR 356.

[75] *TAC*, ibid, para 5.

[76] Ibid, para 80.

research, emphasising that Nevirapine could still be effective in the absence of such support services, and given that lives could be saved, it was not reasonable to have a policy that confined the use of Nevirapine to the test sites.

In answer to the second question, the Court said that in the face of the 'incomprehensible calamity'[77] of the country's HIV epidemic, the government's policy of moving slowly from research and training programmes to increased availability could not be said to be reasonable. The Court directed the government to take immediate action. Restrictions on the availability of Nevirapine in public sector hospitals and clinics that had testing and counselling facilities were to be lifted 'without delay'.[78] The government was also to devise and implement a comprehensive national prevention programme. Specifically, counsellors were to be trained and reasonable steps were to be taken to extend testing and counselling capacity in the public sector.[79]

In answering the questions before it in this way, the Court rejected the three arguments made by the government. These were: first, separation of powers; secondly, cost; and thirdly, the safety and efficacy of Nevirapine. The first argument was, above all, about how the Court would choose to see its own role in South Africa's new constitutional order.[80] As we have seen, it chose—via its pursuit of reasonableness review—to install what has been called a 'culture of justification'.[81] The right to access health care services was not a trump; the new Constitution made that clear, both in its inclusion of the standard of 'progressive realisation' for economic and social rights and its inclusion of a general limitations clause.[82] But what was also clear, according to the Court, was the obligation on government to justify that any limitation upon this right was legitimate. The Court would not turn itself into the government of the state; informed deference was appropriate.[83] But equally the government would have to prove, not just assert, that its limitation upon a right was justified. And as we have seen, in the *TAC* case, the government failed to do this.

The government's second and third arguments—respectively, cost and safety—were of a different order, and here the TAC's evidence

[77] Ibid, para 93.
[78] Ibid, para 135.
[79] Ibid.
[80] On the latter, see further S Liebenberg, *Socio-Economic Rights: Adjudication under a Transformative Constitution* (Juta 2010); Young, *Constituting Economic and Social Rights* (n 6) 133–222.
[81] The term was coined by Etienne Mureinik, an eminent public lawyer, during the transition to democracy in South Africa: see E Mureinik, 'A Bridge to Where? Introducing the Interim Bill of Rights' (1994) 10 South African Journal of Human Rights 32. See further above ch 2, n 112.
[82] See respectively ss 27(2) and 36.
[83] See below, text to nn 85–94.

proved especially important. On the drug safety and efficacy point, the government submitted a thousand pages of technical medical evidence, to which the TAC had only ten days to reply. But the TAC was ready. Calling upon a network of support, nationally and internationally, it met the deadline: more than this, its evidence helped convince the Court that Nevirapine could and should be used.

The TAC had built up its network of support through prior action. The same strategy—prior action—helped it to destroy the government's argument on cost. The TAC's medical evidence showed that even in the absence of a support package, Nevirapine was beneficial. More generally, the organisation's consistent targeting of pharmaceutical companies—including joining as amicus *on the government's side* in the case taken by the Pharmaceutical Manufacturers Association (PMA) against South Africa's 1997 medicines legislation[84]—had helped to ensure that reputational risk became so great for these companies that the price of ARVs dropped dramatically. Indeed, by the time of the *TAC* case the government had been offered Nevirapine free for five years. This meant that it could not defend its preferred pilot programme on the grounds of drug cost. It was forced to rely on an argument about the cost of the ancillary support services (such as formula feed, testing and counselling) required for a comprehensive programme. But as the Constitutional Court pointed out, this was not convincing—not least because there was evidence before the Court to the effect that new funding allocations had been made for HIV treatment, including PMTCT.

Neither the TAC nor the two amici curiae got everything they argued for, however. The Court rejected the argument that section 27(1) of the Constitution gave rise to 'a self-standing and independent positive right enforceable irrespective of the considerations mentioned in section 27(2)'.[85] In so doing, the Court reiterated a position established in *Grootboom*,[86] a housing case it had decided two years earlier. The Constitution, it said, contemplated a 'restrained and focused role for the courts'[87] in the enforcement of socio-economic rights. This made a reasonableness-based approach the most appropriate way to proceed: the Court saw little place for the idea of minimum core obligations, as developed by the CESCR[88] and others.[89] As *Grootboom* had made clear, with reasonableness review, the

[84] See above, text to nn 69–70.

[85] *TAC* (n 74) para 39. It did not rule on whether s 28(1)(c) gave children born to mothers too poor to afford medical care an unqualified, direct claim to health care services.

[86] *Government of the Republic of South Africa v Grootboom and Others* 2001 (1) SA 46 (CC).

[87] *TAC* (n 74) para 38.

[88] See, eg, CESCR, 'General Comment No 3: The Nature of States Parties' Obligations (art 2, para 1)' (14 December 1990) UN Doc E/1991/23, para 10; CESCR, 'General Comment No 14' (n 18) paras 43 and 47.

[89] The Court expressed concern about the minimum core concept in *Grootboom* (n 86) paras 32–33; it did the same in *TAC* (n 74) paras 35–38, though it did also say that

question the Court asks is 'whether the measures that have been adopted are reasonable'.[90] In so doing, the Court does not ask 'whether other more desirable or favourable measures could have been adopted, or whether public money could have been better spent'.[91] That, not surprisingly, disappointed many.

On remedies, too, the Court's decision in the *TAC* case caused disappointment. The Court did reject the government's claim that separation of powers meant it had to avoid orders 'that have the effect of requiring the executive to pursue a particular policy'.[92] It also made both declaratory and mandatory orders against the government. Crucially, however, it declined to exercise supervisory jurisdiction. It took the view that there were no grounds to believe the government would fail to respect and give effect to its orders. It was wrong about that. After the decision, the Health Ministry 'continued as if it were business as usual: no apology was offered, no admission made that it had been wrong'.[93] In fact, in the absence of the TAC, it is not clear what would have come of the Court's ruling. Eventually the post-judgment pressure applied by the TAC—via meetings, correspondence, the filing of contempt proceedings and a complaint to the South African Human Rights Commission—did pay off. Presumably, however, this was not what the Constitutional Court had in mind when it ordered the government to take action 'without delay'.[94]

V. THE COST OF (HUMAN RIGHTS) SUCCESS

The *TAC* judgment continues to inspire comment, both supportive and critical, especially as regards the rights and wrongs, and the ups and downs, of justiciability.[95] There has been less comment, however, on what the TAC did (including what it did and did not do with law), what it achieved and what this cost the organisation and its members, other rights-focused

'the evidence in a particular case may show that there is a minimum core of a particular service that should be taken into account in determining whether the measures adopted by the State are reasonable' (para 34).

[90] *Grootboom* (n 86) para 41. It added: 'It is necessary to recognise that a wide range of possible measures could be adopted by the State to meet its obligations. Many of these would meet the requirement of reasonableness. Once it is shown that the measures do so, this requirement is met.'

[91] Ibid.

[92] *TAC* (n 74) para 97.

[93] M Heywood, 'Preventing Mother-to-Child HIV Transmission in South Africa' (2003) 19 South African Journal on Human Rights 278, 278.

[94] *TAC* (n 74) para 135.

[95] See, eg, M Pieterse, 'Health, Social Movements, and Rights-Based Litigation in South Africa' (2008) 35 Journal of Law and Society 364; Liebenberg (n 80); P O'Connell, 'The Death of Socio-Economic Rights' (2011) 74 Modern Law Review 532.

NGOs in post-apartheid South Africa and also health and human rights more generally. In this part of the chapter, I examine these matters, beginning with what the TAC has achieved.

As of 2010, South Africa had one million people living with HIV on treatment, the largest number worldwide.[96] The country's government had increased the HIV budget by 33 per cent and launched a campaign to test 15 million people by 2011—a move the Executive Director of UNAIDS described as 'the biggest national mobilization around any single issue since the end of apartheid and the largest HIV counselling, testing and treatment scale-up in the history of the HIV epidemic'.[97] All of these numbers would read very differently without the TAC. For starters, the TAC's work dealt a blow to AIDS denialism and the dissident science that supported it. It dealt a blow to anti-justiciability arguments too and, relatedly, to arguments about financial cost and about poverty leading to non-compliance with treatment regimes. In so doing, the TAC paved the way for a nationwide programme for the prevention of MTCT and, later, a national ARV treatment plan for all those with HIV/AIDS. In addition, it demonstrated that an NGO could work with the state, not just against it, and that a more activist state could emerge from a denialist one.

But success for the TAC was neither guaranteed nor immediate. Individual successes had to be followed up; new successes had to be thought-out and pursued.[98] This tells us something important about human rights success: about what it can take to be successful in human rights terms, in particular about the cost of success for NGOs and perhaps for their individual members too. Just as importantly, the TAC's success prompts enquiry into the ways in which one human rights success can affect other human rights claims (and the advocates associated with those claims) and also human rights claims-making more generally. Stated shortly, the TAC's success prompts enquiry into what I shall call the 'cost of success'—specifically, the cost to human rights of a human rights success.

A. Success TAC-Style

As we have seen, for the TAC, success had to be made and remade. There was nothing hard and fast about rights as achievements, and obstacles to positive, sustainable change were rarely technical, almost always political and cultural. Moreover, TAC's achievements were not without cost for the TAC and its members. The organisation was branded 'un-African',

[96] UNAIDS, '2009 Report on the Global AIDS Epidemic' (UNAIDS 2010) 29.

[97] Sidibé (n 40) 8.

[98] See, eg, C Cooper, 'Health Rights Litigation: Cautious Constitutionalism' in Yamin and Gloppen (eds) (n 10).

attacked both as the handmaiden of 'big pharma' and for being in cahoots with 'Western' advocates of sexual rights. It was also attacked for the narrowness of its focus: why campaign on PMTCT, the critics asked, when the entire health infrastructure was in need of change? Individual TAC activists put their own lives at risk; some lost their lives. The organisation also faced criticism both when it broke the law as part of a campaign for a national treatment plan and when it ceased this civil disobedience.[99] There was controversy, too, both when it opted to work with the state and when it took the state to court.

This, of course, was no ordinary state: it was the ANC post-apartheid state. What this meant for the TAC was explained by Zackie Achmat, a founding member and former chairperson of the organisation:

> The difficult decision … was not to take off my suit and go to the streets and fight for treatment … That was easy. The emotionally torturous thing for me to do was to recognize we had to take on the ANC. *Our* ANC.[100]

Taking on the ANC in the arena of *health* policy must have exacerbated the TAC's problems. By taking on health, the TAC was engaging directly with the legacy of apartheid—an era when health was used 'to justify, first, racial segregation measures and, later, exploitation of the labor force … [when] tuberculosis and syphilis provided a foundation on which to construct theories of black inferiority and African sexual promiscuity'.[101] The TAC's emphasis on treatment literacy brought problems too, most notably conflicts with both traditional healers and public health workers. Many ordinary South Africans were also sceptical. In the townships and villages, they 'found the new TAC-based, "HIV POSITIVE" community off-putting; like the evangelical churches, it seemed pious and preachy'.[102] Initially, many said no to testing, and others chose to move between the new TAC-approach and traditional medicine.

Throughout, the TAC had to be pragmatic about who was the 'enemy' and, relatedly, who could be an 'ally'. Thus, it worked with the humanitarian NGO Médecins Sans Frontières (MSF), and it also found ways to move

[99] See especially M Heywood, 'Shaping, Making and Breaking the Law in the Campaign for a National HIV/AIDS Treatment Plan' in P Jones and K Stokke (eds), *Democratising Development: The Politics of Socio-Economic Rights in South Africa* (Martinus Nijhoff 2005).

[100] Quoted in S Power, 'Letter from South Africa: The AIDS Rebel' *The New Yorker* (19 May 2003) 65.

[101] D Fassin, *When Bodies Remember: Experiences and Politics of AIDS in South Africa* (University of California Press 2007) xviii.

[102] W Forbath et al, 'Cultural Transformation, Deep Institutional Reform, and ESR Practice: South Africa's Treatment Action Campaign' in White and Perelman (eds) (n 6) 81. See also S Robins, 'Mobilizing and Mediating Global Medicine and Health Citizenship: The Politics of AIDS Knowledge Production in Rural South Africa', Working Paper 324 (Institute of Development Studies 2009).

forward with its Treatment Literacy Campaign when MSF moved on. It reached out to COSATU, the trade union federation, and to churches too. In the early stages of the PMTCT campaign, it worked in alliance with reproductive rights activists and lawyers with the aim of ensuring that any litigation would be framed around women's reproductive rights (though, as I explain below, arguments based on the right to health care and, particularly, to access to treatment later came to the fore).

The TAC, as we have seen, also worked with pharmaceutical companies in a range of ways, which helped to secure the offer of a free five-year supply of Nevirapine that proved influential upon the reasoning of the Constitutional Court. The organisation worked both locally and internationally with a range of others too, including scientists and health professionals. Again, this proved significant in the *TAC* case: when the Court enquired into the views of experts and professionals as part of its application of reasonableness review, the TAC's prior work with these groups meant it was well able to bring forward relevant evidence.[103]

Most interesting of all, amidst its global and local campaigning, the TAC never turned its back on the South African state. It sought instead to *inhabit* the state, believing that an AIDS activist state could be forged from the obdurate one it was clashing with again and again. Thus, as we have seen, it joined on the government side in the case against the medicines legislation brought by the Pharmaceutical Manufacturers Association. It also worked with the government on the national AIDS plan, and its own Treatment Literacy Campaign eventually became a model for primary-care clinics across South Africa. Put differently, the TAC did not see rights as trumps to be deployed via the courts against a duty-bearing state in order to obtain treatment for particular individuals and groups. What was crucial for the TAC was the place of such litigation within a far broader rights-based strategy—a strategy that sought to engage individuals, the state and beyond, a strategy that did not see litigation standing alone as a way to bring justice to health.[104]

At the same time, however, the TAC was prepared to take the South African government to court to secure a nationwide PMTCT programme. So rights litigation might not have been central for the TAC, but it was not wholly irrelevant either. Moreover, not long after the *TAC* case,

[103] See also Klugman (n 5) 154, noting that reproductive health researchers made a similar move as part of a successful effort to amend South Africa's abortion law: in the run up to the new law, the Choice on Termination of Pregnancy Act 1996, these researchers saw the need for data on the costs of unsafe abortion to the public health system, and had the data in place before the issue went to Parliament.

[104] See White and Perelman (eds) (n 6) examining conversion and constraint in changing institutions via economic and social rights activism; Young, *Constituting Economic and Social Rights* (n 6) 256–87, assessing whether governance, rather than constitutionalism, is the model that should be used to understand the TAC's role.

the organisation joined as amicus on the side of retail pharmacists in a challenge to government regulations that limited profit margins on prescribed medicines.[105] The government argued that the regulations were an attempt to make medicines more affordable and thus more accessible; the pharmacists disagreed, insisting that these regulations threatened their livelihoods. At first glance it may seem odd that the TAC would join on the pharmacists' side; the regulations after all were designed to control profits so as to make medicines more accessible. The TAC chose to intervene, however, not because it disagreed with the goal but rather because of the way in which the regulations set about achieving it. In the TAC's view, the regulations were too blunt: specifically, they could compromise the rural and courier pharmacies that were essential if people living outside the cities were to have access to medicines. The TAC's argument won the day: the Constitutional Court declared that the regulations needed to be amended so as to 'ensure that the right of access to health care is not prejudiced by driving such pharmacies out of the market'.[106]

B. After Success

To recap: using the 'cost of success' as a frame, we have seen what the TAC achieved, what that cost the TAC and its members and, more broadly, why it is that, amidst rising justiciability, human rights will have to think carefully about the place of litigation in achieving justice. I turn now to another way in which the 'cost of success' could be a useful frame for human rights. Staying with the TAC and its achievements, I explore how the organisation's success may have produced or added to costs elsewhere—notably, for local NGOs committed to sexual and reproductive health and rights, and also for health and human rights more generally. My point is not that the TAC intended to produce these costs—simply that unintended, unexpected and unwanted costs can follow a human rights success, and human rights must be alert to these.

We have seen that one clear strength of the TAC was its grassroots mobilisation. Yet could there be a problem lying in wait here as others look to copy the TAC's success, and states and other duty-bearers prepare to respond? Discussing access to HIV/AIDS prevention, care and treatment in Brazil, João Biehl has reflected on the increasing importance of belonging to an NGO or other similar group. 'To be "seen" by the state', Biehl

[105] *Minister of Health v New Clicks South Africa* 2006 (2) SA 311 (CC).
[106] Ibid, para 19.

has stated, 'people have to join these groups and engage in lobbying and lawmaking'.[107] More than this:

> Rather than actively seeking areas of need to address, [the new 'market-oriented' Brazilian state] … selectively recognizes the claims of organized interest groups that 'represent' civil society, leaving out broader public needs for life-sustaining assistance—in the domains of housing, economic security, and so forth.[108]

Related to this, if organised interest groups are set to become the norm in engagements around health, then the field of health and human rights will need to catch up. As Alicia Yamin has pointed out, as things stand, 'Beyond the HIV/AIDS groups, we know little about many of the social movements involved in health rights litigation.'[109] We also know little about how pharmaceutical companies have been positioning themselves amidst rising justiciability. Are they, for instance, encouraging organised interest groups to pursue litigation to increase markets, in particular markets for patented drugs?[110] Local conditions, including how easy it is to access the courts and how usual it is for judgments to be implemented, will need to be taken into account, as will the priorities and activities of super-philanthropists, international NGOs (such as Amnesty International) and international institutions (such as UNAIDS or the Global Fund to Fight AIDS, Tuberculosis and Malaria). How do these affect the emergence, the practices and the influence of organised interest groups?

In addition to investigating these broader possible costs, it is also worth asking, 'Has the TAC's success had local costs?' For instance, as the TAC has flourished, reproductive rights organisations in South Africa seem to have declined: are these related phenomena? As we saw earlier, reproductive rights organisations worked initially with the TAC on the PMTCT campaign, with the aim of preparing litigation that would centre upon reproductive rights. That framing fell away, however, replaced by a focus on the right to access health care, specifically ARVs. This new framing was highly successful. Yet did it also make it harder to see the relevance of reproductive and sexual rights, including how such rights are important in prevention and treatment? To focus on treatment to prevent mother-to-child transmission is typically to frame women as mothers and, more narrowly, as bearers of children. But this can mean we miss women as individuals—individuals who are particularly vulnerable to HIV because of breaches of

[107] J Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton University Press 2007) 10.

[108] Ibid, 11.

[109] AE Yamin, 'Power, Suffering, and Courts: Reflections on Promoting Health Rights through Judicialization' in Yamin and Gloppen (eds) (n 10) 367.

[110] See J Biehl and A Petryna (eds), *When People Come First: Critical Studies in Global Health* (Princeton University Press 2013).

sexual and reproductive rights, or because of a cultural imperative to have children. We can also miss women's rights as women, not just as mothers, to access treatment.

Reproductive rights organisations in South Africa seem, however, to have played a part in their own loss of standing. These organisations were strong, with a high public profile, in the immediate transition period from apartheid, as demonstrated by their role in securing South Africa's 1996 abortion law, the Choice on Termination of Pregnancy Act. They failed, however, to engage sufficiently with women living with HIV/AIDS, and this failure was exacerbated when the TAC, its clashes with government and its focus on access to treatment took centre stage in South Africa. Donors, for instance, shifted priorities: some moved to HIV/AIDS prevention, care and treatment (but did not see sexual and reproductive rights as integral to that focus), and others moved on from South Africa now that apartheid was at an end. Equally, 'many of those who had been employed in [NGOs] and research institutions focusing on reproductive rights were now working on HIV and AIDS, without taking sexual and reproductive rights concerns into those spaces'.[111]

The point, of course, is that success for one rights-based organisation does not automatically spell success for others or for health and human rights more broadly. The cost of success can help us to be more alert to this.

VI. THE COST OF HUMAN RIGHTS

I turn now to the final way in which human rights could deploy the 'cost of human rights'. Here my concern is cost in its ordinary sense—that is to say, the actual financial cost of human rights. Once again, the TAC acts as a prompt: from the outset, the TAC insisted that a rights-based approach had to address actual financial cost, and as we have seen, it set about reducing the cost of ARVs and other AIDS medicines in a range of ways. It went to court as amicus in the *PMA* case to support the South African government's right to legislate in ways that would bring down the cost of drugs.[112] It was also a pioneer in the use of competition policy, registering a string of complaints with the South African Competition Commission against the pricing practices of pharmaceutical companies, which led to out-of-court settlements that brought down drug prices. In the *TAC* case itself, it was TAC evidence which demonstrated how Nevirapine could still be effective in the absence of a support package. And it was the TAC's actions prior to the case, alongside those of its international allies, which meant that

[111] Klugman (n 5) 153.
[112] See above, text to nn 69–70.

the government came to court holding an offer of Nevirapine free for five years.

The NGO's stance on the actual financial cost of human rights is not without controversy in ESC-rights circles. The TAC has not been an advocate of the core obligations approach favoured by the CESCR. It also refuses to see rights litigation as a trump: for the TAC, litigation is a lever, not an endpoint. And it insists that going to court has to be just one part of an overall approach:[113] prior action, long-term follow-up and institution building have been the mainstays, with attention being given to research, advocacy, media blitzes, networking at home and abroad and, most of all, treatment literacy ('the base for both self-help and social mobilization'[114]). For the TAC, litigation is not divorced from politics, nor is it to be used as a way to bypass political decision-making on health budgets. Opening up the political is the TAC's goal—in particular, opening up what is seen as political, what can be achieved via political will and who has a say on these matters.[115]

A. Towards a Common Language

If, taking a lead from the TAC, we make actual financial cost part of human rights legal method, will that stop cost being used against human rights? It seems unlikely. It might, however, produce an alternative staging—one less focused on trade, IP or, more broadly, cost *versus* human rights. It might, for instance, provide a common language of disagreement—a way for human rights proponents *speaking through human rights* to engage more effectively on the terrain of trade and the like. It might also help human rights to develop a set of resources for enhancing and enforcing equity, both within health systems and between such systems and other legitimate demands on resources. And it should help to reinforce the point that all rights—civil, economic, political, social and cultural—involve actual financial

[113] Forbath et al (n 102) 52: 'Court victories are not the object of movement campaigns but one of several sources of political leverage and moral authority to promote pro-poor policy changes and institutional reforms.' See also S Epstein, *Impure Science* (University of California Press 1996), describing the early years of the epidemic in the US when activists focused primarily on the biomedical sciences, transforming conventions on drug testing and licensing, and accelerating the development of ARVs.

[114] Heywood, 'South Africa's Treatment Action Campaign' (n 60) 18.

[115] On the latter, see also *Port Elizabeth Municipality v Various Occupiers* 2005 (1) SA 217 (CC); *Occupiers of 51 Olivia Road v City of Johannesburg* 2008 (3) SA 208 (CC) for an introduction to the South African Constitutional Court's prescription of 'meaningful participation', or 'engagement', with rights-holders, as both a requirement for a reasonable government policy in ESC rights cases, and a remedy where inadequate engagement occurred prior to litigation. See further A Pillay, 'Towards Effective Social and Economic Rights Adjudication: The Role of Meaningful Engagement' (2012) 10 International Journal of Constitutional Law 732.

costs, which means in turn that the justiciability of ESC rights, albeit complex, is less likely to be seen as exceptionally threatening.

Staging actual financial cost as part of human rights might help in other ways too. It might, for instance, ease relations with health practitioners: some practitioners complain of the unreal character of human rights law; others treat it as 'synonymous with a programmatic requirement to service the poor and marginalized first—end of story'.[116] Relations with development professionals could benefit as well, especially as regards what is and what is not a human rights-based approach to development and to development aid.[117] Attending to the actual financial cost of human rights might also ease relations with those advocates of social justice who cast human rights as individualistic and court-centric and who seem pessimistic about the capacity of rights 'in principle' to translate into rights 'in practice'.

Staging the actual financial cost of rights as part of human rights might also help to keep states in the picture. States are not the only relevant actors, to be sure. NGOs, research institutes, pharmaceutical companies, international organisations, public–private partnerships and the like have to be in the picture too.[118] Yet if the actual financial cost of human rights is the concern, states cannot be side-lined. States decide how to engage with other states, and with the international financial institutions (IFIs); states also decide upon both the commercialisation of health care and, to an extent, the size and behaviour of pharmaceutical markets—partly through the obligation to protect.[119] States are responsible for ratifying or acceding to international instruments; states are also major players in the design and implementation of constitutions that provide for the right to health or to have access to health care. States create and enforce rules and programmes designed to 'domesticate' international human rights commitments, or to make use of TRIPS flexibilities. And states decide whether to tackle corruption and whether to persist with damaging forms of criminalisation, allegedly in the name of public health.[120]

[116] LP Freedman, 'Drilling Down: Strengthening Local Health Systems to Address Global Health Crises' in A Clapham et al (eds), *Realising the Right to Health* (Rüffer & Rub 2009) 413.

[117] So, eg, the states and multilateral organisations who agreed the 2005 Paris Declaration on Aid Effectiveness and the subsequent Accra Agenda for Action need to understand precisely how it is that the international human rights framework can bolster and benefit their development-aid commitments.

[118] See, eg, L Clarke, 'Responsibility of International Organizations under International Law for the Acts of Global Health Public-Private Partnerships' (2011) 12 Chicago Journal of International Law 55.

[119] See Petryna and Kleinman (n 41) 28, describing Brazil's universal access policy as a 'primary example of how markets can be innovated for human needs'.

[120] See respectively B Toebes, 'Human Rights and Health Sector Corruption' in J Harrington and M Stuttaford (eds), *Global Health and Human Rights: Legal and Philosophical Perspectives* (Routledge 2010); UNHRC, 'Report of the Special Rapporteur' (27 April 2010) (n 53).

The 'activist state'[121] is yet another reason to keep states in the picture. Describing the state—any state—as activist may not come easily: it has a topsy-turvy ring to it. Within human rights, states are not activists; they are the target for activists. Yet in the arena of HIV/AIDS, there *are* states that see themselves in this way. So where should human rights stand on this?

B. International Human Rights Law on the Question of Actual Financial Cost

For now, the important point is that if states are to be kept in the picture, it follows that law—in particular, international human rights law—ought to be part of any human rights approach to actual financial cost. This in turn means we have to ask: does international human rights law address the question of cost? The answer is that it does. What is more, it does so in a range of ways, and work is already underway in relation to most of these.

There is, for example, a good deal of work on proportionality review. This takes us towards the 'culture of justification' I mentioned in chapter two, and away from both anti-justiciability and any notion of rights as total trumps. In due course, it might also take us towards a better understanding of the relationship between the general limitations clause in article 4 ICESCR and the obligation of progressive realisation, subject to maximum available resources, in article 2 of that instrument.[122] Given that both make provision for justifiable limitations upon rights, do the same standards apply? Should they?

Work elsewhere has produced, first, the UN framework and guiding principles on business and human rights, developed by John Ruggie, the Special Representative of the UN Secretary-General;[123] second, the obligations of pharmaceutical companies developed by the first Special Rapporteur on the right to health;[124] and third, the Maastricht Principles on the Extraterritorial Obligations of States in the area of Economic, Social

[121] J Biehl, 'Pharmaceutical Governance' in Petryna et al (eds) (n 41) 224 has pointed out that 'In retrospect [former Brazilian president] Cardoso sees himself as the articulator of an "activist state"'. See also above Introduction, text to nn 66–71.

[122] See above ch 2, section III-A.

[123] See respectively UNHRC, 'Report of the Special Representative of the Secretary-General on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises, John Ruggie: "Protect, Respect and Remedy: A Framework for Business and Human Rights"' (7 April 2008) UN Doc A/HRC/8/5; UNHRC, 'Report of the Special Representative of the Secretary-General on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises, John Ruggie: Guiding Principles on Business and Human Rights: Implementing the UN "Protect, Respect and Remedy" Framework' (21 March 2011) UN Doc A/HRC/17/31. The Guiding Principles were endorsed by a resolution of the UNHRC in June 2011 (UN Doc A/HRC/17/L.17/Rev.1); that resolution also established a working group on human rights and transnational corporations and other business enterprises.

[124] UNGA, 'Report of the Special Rapporteur' (11 August 2008) (n 49).

and Cultural Rights.[125] In each instance, of course, as John Ruggie said of his own work, it is the 'end of the beginning'.[126] In line with this, the 'cost of human rights' looks to add value by clustering this work, as appropriate, and by drawing in other resources too.

One such resource is 'maximum available resources' (MAR), a concept used to limit state obligations in the field of ESC rights. Article 2(1) ICESCR, for example, obliges states parties to 'take steps, individually and through international assistance and co-operation', using 'the maximum of available resources', with a view to 'achieving progressively the full realization' of the Covenant's rights, advising also that 'all appropriate means' are to be applied to this end. Paul Hunt, the first UN Special Rapporteur on the right to health, flagged MAR in his final report, emphasising that it 'demands more attention'. He called for 'a meeting of experts, including economists': such a meeting, he said, would help to provide guidance on 'what this phrase means'.[127]

There has, to be fair, been some attention to MAR—notably with respect to budget expenditure, international assistance and cooperation, and the effects of economic sanctions.[128] So, for example, looking at the work of the treaty bodies, the Committee on the Rights of the Child has framed 'resources' in an expansive manner, encompassing 'human, technical, organizational, natural and information resources'.[129] The CESCR, for its part, has indicated that the phrase 'to the maximum of its available resources' refers not just to resources existing within a state but also to those available from the international community through international assistance and cooperation.[130] Drawing on the ICESCR, the UN Charter and 'well established principles of international law',[131] the CESCR sees international cooperation for development (and thus for the realisation of ESC rights)

[125] Maastricht Principles on Extraterritorial Obligations (n 18).

[126] UNHRC, 'Report of the Special Representative of the Secretary-General' (21 March 2011) (n 123) para 13.

[127] UNGA, 'Report of the Special Rapporteur' (11 August 2008) (n 49) para 54.

[128] CESCR, 'General Comment No 8: The Relationship between Economic Sanctions and Respect for Economic, Social and Cultural Rights' (12 December 1997) UN Doc E/C.12/1997/8, para 10 noting that the imposition of economic sanctions 'does not in any way nullify or diminish the relevant obligations of [the] State party'.

[129] Working Group Paper 3, 'States Parties Obligations: Realizing Economic, Social and Cultural Rights—Are Child Rights a Luxury during an Economic Crisis?', available at www2.ohchr.org/English/bodies/crc/docs/20th/BackDocWG3.doc.

[130] CESCR, 'General Comment No 3' (n 88) para 13. See also the Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights, adopted by a Group of Experts, Maastricht, 2–6 June 1986 (8 January 1987) UN Doc E/CN.4/1987/17, Annex (reprinted in (1987) 9 Human Rights Quarterly 121); CESCR, 'Statement: An Evaluation of the Obligation to Take Steps to the "Maximum of Available Resources" under an Optional Protocol to the Covenant' (10 May 2007) UN Doc E/C.12/2007/1.

[131] See in particular UN Charter, arts 1(3), 55 and 56; UDHR, arts 22 and 28; ICESCR, arts 2(1), 11(1), 11(2), 15(4), 22 and 23.

as 'an obligation of all States', but takes the view that this obligation 'is particularly incumbent on those States which are in a position to assist others in this regard', as well as 'other actors in a position to assist'.[132] Relatedly, the CESCR has emphasised that there is a collective responsibility to tackle the problem of diseases that readily transcend borders, and furthermore that developed states have a special responsibility in this regard.[133]

The obligation of international assistance and cooperation is potentially a remarkable resource; moreover, following the Maastricht Principles on the Extraterritorial Obligations of States in the area of Economic, Social and Cultural Rights, it should now draw more attention.[134] Two aspects of it are of particular note. First, because it frames international cooperation and assistance as a human rights obligation, it stands in strong contrast to charity and humanitarianism.[135] Second, because the CESCR focuses on 'all States' but with special reference to those that 'are in a position to assist', it offers a way to raise and confront *inequality*—a way to raise the question of distribution and to challenge framings that focus only on scarcity.[136]

Phrases such as 'states which are in a position to assist' beg lots of questions, of course. Similarly, if at times the CESCR uses the language of obligation but elsewhere refers to 'collective responsibility', what should be made of the difference? There are practical concerns too—not least the actual, on-the-ground effects of extant practices of assistance and cooperation, which tend to prioritise short-term interventions focusing on specific health issues and, in places, to produce over-dependence by states on such international funding. To counter these negative effects, the Special Rapporteur on the right to health has called upon states to develop treaty-based global pooling mechanisms grounded in the principle of global solidarity.[137]

[132] CESCR, 'General Comment No 14' (n 18) para 45.

[133] Ibid, para 40.

[134] Maastricht Principles on Extraterritorial Obligations (n 18). These principles examine two potentially overlapping extraterritorial obligations: first, those of a global character (such as that in art 2 ICESCR) and second, obligations relating to the acts and omissions of a state, within or beyond its territory, that have effects on the enjoyment of rights outside of that state's territory.

[135] AE Yamin, 'Our Place in the World: Conceptualizing Obligations beyond Borders' (2010) 12(1) Health and Human Rights: An International Journal 3.

[136] See M Craven, 'The Violence of Dispossession: Extraterritoriality and Economic, Social and Cultural Rights' in M Baderin and R McCorquodale (eds), *Economic, Social and Cultural Rights in Action* (Oxford University Press 2007); ME Salomon, 'Why Should It Matter That Others Have More? Poverty, Inequality, and the Potential of International Human Rights Law' (2011) 37 Review of International Studies 2137. See also S Skogly, *Beyond National Borders: States' Human Rights Obligations in International Cooperation* (Intersentia 2006); ME Salomon, *Global Responsibility for Human Rights: World Poverty and the Development of International Law* (Oxford University Press 2007).

[137] UNGA, 'Report of the Special Rapporteur' (13 August 2012) (n 6) paras 22–33.

Clearly, there is also what some will see as the primary question: namely, the *legal* nature of the obligation of international assistance and cooperation. The first Special Rapporteur on the right to health addressed this question in a report focusing on Sweden.[138] The latter's policies and programmes on international development, poverty reduction, and health and human rights received strong praise: they are 'among the best in the world … They deserve applause, support and study.'[139] But Sweden, as the report went on to note, does not accept that it has a legally binding obligation of international assistance and cooperation. Sweden's stance is commonplace amongst wealthy states, as became clear during the drafting of the Optional Protocol to the ICESCR (OP-ICESCR), when many such states emphasised that realisation of ESC rights was primarily the responsibility of the *domestic* state. Moreover, having examined the drafting history of the ICESCR, Philip Alston and Gerard Quinn have concluded that 'it is difficult if not impossible, to sustain the argument that the commitment to international cooperation contained in the Covenant can accurately be characterized as a legally binding obligation upon a particular State to provide any form of assistance'.[140]

Three points can be made. First, the obligation does seem to be firmer in times of natural disaster or other emergency.[141] Second, as pointed out by the Maastricht Principles on Extraterritorial Obligations, there are also other principles and priorities to guide states vis-à-vis international assistance and cooperation—for instance, the obligation to give priority to realising the rights of the disadvantaged, marginalised and vulnerable, and to avoid retrogressive measures.[142] In similar vein, the first Special Rapporteur on the right to health noted that the obligation has procedural dimensions. So, for example, a wealthy state should not withdraw critical aid without first giving the recipient state a reasonable opportunity to make alternative arrangements.[143] Equally, all states, irrespective of resource levels, should work towards the creation of a system of cooperation; the Maastricht Principles, for instance, refer to the obligation to create 'an international enabling environment'.[144] Furthermore, as affirmed by the Vienna

[138] UNHRC, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (28 February 2007) UN Doc A/HRC/4/28/Add.2. See relatedly UNHRC, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (5 March 2008) UN Doc A/HRC/7/11/Add.2.l.

[139] UNHRC, 'Report of the Special Rapporteur' (28 February 2007), ibid, para 134.

[140] P Alston and G Quinn, 'The Nature and Scope of States Parties' Obligations under the International Covenant on Economic, Social and Cultural Rights' (1987) 2 Human Rights Quarterly 156, 186–92.

[141] CESCR, 'General Comment No 14' (n 18) para 40.

[142] Maastricht Principles on Extraterritorial Obligations (n 18) principle 32.

[143] UNHRC, 'Report of the Special Rapporteur' (5 March 2008) (n 138) para 112.

[144] Maastricht Principles on Extraterritorial Obligations (n 18) principles 28–35, esp principle 29.

Declaration and Programme of Action, states are expected to engage in cooperation based on the principle of transparency.[145]

Third, dimensions of MAR other than international assistance and cooperation need work too. Thus the question is: what broader range of financial resources is available for rights realisation—resources which the state can and should mobilise? Responses have already been offered by a number of the UN Special Procedures. The Special Rapporteur on extreme poverty and human rights, for instance, pinpoints the failure to curb corruption as a failure to comply with the obligation to use MAR to realise ESC rights.[146] Elsewhere, a 'MAR star' has been proposed. It features 'five critical nodes for mobilizing resources'—not just aid and budget expenditure but also government revenue, debt and deficit financing, and monetary and financial sector policy.[147] In so doing, it changes the terms of the debate by offering a different way of looking at a state's 'available resources'. In similar vein, there have been calls for a greater attention to be paid to the qualitative use of already available resources.[148] Finally, it is worth noting the CESCR's view that 'even where available resources are demonstrably inadequate, the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances'.[149]

MAR is undeniably a tall order. But access to ARVs as a component of the right to health must have seemed difficult to deliver when it was first mooted in a serious way. The same could be said of TRIPS flexibilities. Neither is problem-free today, yet claims-making and modes of implementation are no longer blocked by neglect or by a presumption of impossibility. The headway being made on the obligation of 'progressive realisation', MAR's companion concept in article 2(1) ICESCR, is encouraging too. The enhanced focus on implementation and, more specifically, the rise of new forms of human rights measurement, which I outline in chapter 4, are playing a part here. So too is the rising interest in actually existing forms of review. Alluding to review in this way, I need to be clear that the

[145] UN, World Conference on Human Rights, Vienna, 14–25 June 1993, 'Vienna Declaration and Programme of Action' (25 June 1993) UN Doc A/CONF.157/23 art II, para 74.

[146] M Sepúlveda, *The Nature of Obligations under the International Covenant on Economic, Social and Cultural Rights* (Intersentia 2003). See also O De Schutter and M Sepúlveda, 'Underwriting the Poor: A Global Fund for Social Protection' (Briefing Note 07, October 2012).

[147] R Balakrishnan et al, 'Maximum Available Resources and Human Rights: Analytical Report' (Center for Women's Global Leadership 2011).

[148] UNGA, 'Report of the Special Rapporteur' (13 August 2012) (n 6) para 12: 'Investment in primary health care is … more cost effective in the long run because it prevents illness and promotes general health, which reduces the need for more costly secondary and tertiary care. The resulting savings may be reinvested in the health system, possibly in the form of additional health-care subsidies for the poor.' See generally S Skogly, 'The Requirement of Using the "Maximum of Available Resources" for Human Rights Realisation: A Question of Quality as well as Quantity' (2012) 12 Human Rights Law Review 393.

[149] CESCR, 'General Comment No 3' (n 88) para 11.

'cost of human rights' is avowedly 'litigation plus'. It is *not* a call to focus simply on what judges do. At the same time, however, moves by domestic courts to embrace or reject the CESCR's minimum core concept clearly merit scrutiny,[150] especially perhaps where a court promotes reasonableness review, given that the Optional Protocol to the ICESCR directs the CESCR to consider the 'reasonableness of the steps taken by the State Party'.[151] More broadly, the variety of review in ESC rights cases merits scrutiny: its existence exposes exaggerations within anti-justiciability, anti-court positions; reveals how courts actually navigate resource questions, especially when choosing remedies; and offers scope to study when and why judgments are distortive of equity, and when and why they can be precursors to better-quality deliberation on meeting health needs fairly.

VII. CONCLUSION

One point above all needs to be clear. The 'cost of human rights' is not a proposal designed to economise rights, to damage human rights activism or to encourage individuals or organised groups, backed perhaps by pharmaceutical companies, to skewer the chances of equity by using courts to access expensive medicines. It is a proposal rooted *in* human rights. It is, plainly and simply, a proposal for a particular human rights legal method, for a way of thinking and talking about cost from a human rights law perspective.

To achieve these goals, the 'cost of human rights' project mines both the tenets of human rights law and the practices of NGOs that work on health rights. In so doing, it does not topple the standing of rights as trumps. It simply calls for more honesty about what that means and what it requires. In line with this, it gives centre stage to two issues. The first is the cost of success; we must examine what it takes to be successful in human rights claims-making and the potential effects of success on other individual human rights and on human rights in general. The second issue is the actual financial cost of human rights—specifically, the need to engage directly with this issue via human rights law itself.

The 'cost of human rights' says, in short, that cost is both a question *of* human rights and a question *for* human rights. I turn now to a proposal of a different sort, one focused on what *not* to do—specifically, what not to do with numbers.

[150] See L Forman, 'What Future for the Minimum Core?' in Harrington and Stuttaford (eds) (n 120); Young, *Constituting Economic and Social Rights* (n 6) esp 66–129.

[151] Optional Protocol to the ICESCR (10 December 2008, entered into force 5 May 2013) UN Doc A/RES/63/117 (OP-ICESCR), art 8(4). See B Giffney, 'The "Reasonableness" Test: Assessing Violations of State Obligations under the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights' (2011) 11 Human Rights Law Review 275.

4

A Measured Response

WOULD YOU CONSIDER the relationship between numbers and words as an issue for human rights? Probably not. Yet today, amidst demand for more and better measurement in human rights work, that relationship seems more and more pertinent. Advocating for human rights does not of course make it mandatory to advocate for the use of numbers in human rights work; increasingly, however, it does call for an understanding of how numbers are being used, how they could be used and the likely effects, both positive and negative, of such uses. Being for human rights requires, we might say, a rights-based approach to numbers—an approach that asks: what are and what ought to be the roles of numbers and words (and perhaps images, too) in identifying human rights violations, assessing the enjoyment of rights and progress thereto, and improving human rights advocacy?

This chapter takes some first steps towards such an approach. It examines the enthusiasm for one particular form of measurement—the quantitative indicator—that has taken hold in the human rights community. It focuses on who has been backing this new human rights tool and for what reasons. It also explains why my own views on these indicators are mixed. To be clear: I am not against human rights indicators. Nor am I against having a wider range of non-judicial mechanisms for protecting human rights. For the most part, I am also not against attempts to determine and prioritise 'what works' in human rights terms. And I certainly find it hard to resist the idea of 'a science of human dignity'.[1] None of this, however, allows me to feel at ease about the institutionalisation of numbers at the heart of human rights.

My response, at its mildest, is quizzical. Summarised, my concerns run as follows: if words—and the politics and practices that go with words—were to be displaced by numbers (and by images too), what effect would this have on human rights? What effect would it have on the UN Special Procedures, on the treaty bodies, on courts, on NGOs and, more generally, on human rights legal method? What effect would it have on 'seeing from

[1] OHCHR, 'Human Rights Indicators: A Guide to Measurement and Implementation' (2012) 1, quoting former UN High Commissioner for Human Rights Mary Robinson.

below'—that is, on the ability to appreciate both the capacity and the limits of rights through the practices of those who turn to them to name and challenge injustice and who are in turn changed in the process? In this chapter I try to explain why I have these concerns and what they suggest vis-à-vis the project I have been calling human rights legal method. I begin by introducing the better-measurement boom. Thereafter, I take a closer look at who has been backing quantitative indicators in human rights work and why.

I. THE BETTER MEASUREMENT BOOM

As I read it, the measurement drive in human rights is mostly about how best to harness the power of quantitative data as a compliance tool: these data, it is said, have a capacity to pinpoint violations, to assess the enjoyment of rights and to measure realisation over time. There have also been moves to introduce performance indicators for human rights non-governmental organisations (NGOs)—the idea being that this allows individual organisations to assess their own work and also to be assessed, whether by donors or by others.

Supporters of the better-measurement drive are plentiful; they are also drawn from all parts of the human rights community and from elsewhere too. The Committee on Economic, Social and Cultural Rights (CESCR), the Inter-American Commission on Human Rights (IACHR) and the lead agency for human rights in the UN system, the Office of the United Nations High Commissioner on Human Rights (OHCHR), are on board. So too are the United Nations Development Programme (UNDP) and a host of national human rights institutions.[2] Both the donor community and numerous NGOs seem to be on side as well, and there is also a good level of scholarly interest.[3]

As things stand, for many, the quantitative indicator, allied with its narrative-based counterpart, the qualitative indicator, is the measurement tool of choice, and various projects exploring and sometimes trialling different indicators are now underway or already complete. These quantitative indicators are sometimes described as statistical or numerical indicators, or simply as indicators. But what exactly is a quantitative indicator? Specifically, what is a quantitative indicator for *human rights*? One early commentator proposed

[2] See, eg, IACHR, 'Guidelines for Preparation of Progress Indicators in the Area of Economic, Social and Cultural Rights' (19 July 2008), IACHR Doc OEA/Ser.L/V/II.132 Doc.14 rev.1.

[3] See, eg, E Felner, 'Closing the "Escape Hatch": A Toolkit to Monitor the Progressive Realization of Economic, Social, and Cultural Rights' (2009) 1 Journal of Human Rights Practice 402; the 'Indicators, Benchmarks, Scoping, Assessment' (IBSA) Project, www.fes-globalization.org/geneva/documents/HumanRights/6July10_BackgroundPaper_IBSA.pdf, led by Eibe Riedel, formerly a member of the CESCR.

the following definition: an indicator is at core a 'piece of information used in measuring the extent to which a legal right is being fulfilled or enjoyed in a given situation'.[4] More recently, the OHCHR, focusing on what it calls 'human rights indicators'—a term it uses to cover both quantitative and qualitative indicators—has offered the following definition:

> A human rights indicator is specific information on the state or condition of an object, event, activity or outcome that can be related to human rights norms and standards; that addresses and reflects human rights principles and concerns; and that can be used to assess and monitor the promotion and implementation of human rights.[5]

The OHCHR refines this via three distinctions: performance versus compliance indicators; fact-based versus judgement-based indicators; and indicators versus benchmarks. The first distinction captures the difference between, on the one hand, programme-specific indicator use in, say, development activities (where, at most, conformity with certain cross-cutting human rights principles will be checked) and, on the other hand, the full-bodied human rights orientation of indicator use designed to assess duty-bearers' compliance with human rights obligations. The message from the OHCHR is clear: conventional performance indicators from development programming are not a suitable template for human rights indicators.

The OHCHR's second distinction focuses on differences within human rights indicators—specifically, differences in information content. Thus, a fact-based or objective human rights indicator relies on information on objects, events or facts that are, in principle, verifiable and directly observable. By contrast, but accepting that it is not always possible to separate the two, its subjective or judgement-based counterpart relies on the perceptions, opinions or assessments of individuals.

The third and final distinction used by the OHCHR differentiates a benchmark from an indicator, before outlining how one complements the other. A benchmark, the OHCHR explains, is a predetermined value for an indicator that relies on normative considerations (for instance, international human rights standards) or empirical ones (related, for instance,

[4] M Green, 'What We Talk about when We Talk about Indicators: Current Approaches to Human Rights Measurement' (2001) 23 Human Rights Quarterly 1062, 1065. See also KE Davis and B Kingsbury, 'Indicators as Interventions: Pitfalls and Prospects' (Rockefeller Foundation 2011) ii: 'In technical terms, an indicator is *a collection of named, rank-ordered, simplified and processed data that purports to represent the past or projected performance of different units*. An indicator simplifies and processes data about a named social phenomenon in a way that makes it possible to compare and evaluate units such as countries, communities, organizations, or individuals'.

[5] OHCHR, 'Human Rights Indicators: A Guide' (n 1) 16. The guide, from which this is taken, offers conceptual, methodological and operational criteria designed to provide further clarification on the distinction between 'human rights indicators' and, what it calls, 'common indicators or statistics'.

to resources or to feasibility more generally).[6] To put that more simply, a benchmark is a goal or a target: to use an example given by the agency itself, 'Raising to 90 per cent the proportion of one-year-olds immunised against vaccine-preventable diseases'.[7] By setting a benchmark for an indicator, the duty-bearer is making a clear commitment: in effect, the duty-bearer is saying, 'Here is the standard I want to achieve; use it to hold me accountable.'

So far, so simple? Not quite. The new engagement with indicators, especially quantitative indicators, for human rights has not been entirely straightforward. A range of arguments has been raised against it, citing conceptual problems, technical ones or both. Calls for caution have been commonplace too—a result perhaps of earlier negative experiences with indices or, more likely, of a wider lack of trust in numbers and, relatedly, a concern about their institutionalisation across many different parts of life today.[8] Not surprisingly, proposals for universal or overarching indicators have generally provoked more concern than smaller, local initiatives. And as we shall see, performance indicators for human rights NGOs tend to provoke considerable concern. Will these indicators steer NGOs towards particular types of work, for example? Specifically, work that is more likely to produce the sort of 'champagne moments'[9] or clear-cut success that will look good in an indicators table in one of the NGO's activity reports?

Still, outright opposition to quantitative indicators has been rare, partly, I think, because of the swing towards implementation and monitoring as the essential next steps in human rights work, the steps beyond standard-setting. In part, too, the mainstreaming of human rights throughout the UN system[10] has created demand for tools that might help with that endeavour and, crucially, offer proof of results. More prosaically, the very multiplicity of human rights measurement schemes, targeting different users and diverse aims, can make it difficult to know what to be for and what to be against. Under these circumstances, outright opposition will clearly feel less attractive.

A more obvious reason, however, is that out-and-out rejection of quantitative indicators would be absurd. For starters and as explained in more detail below, rejection would fly in the face of the language of various

[6] Ibid, 20.

[7] Ibid.

[8] See generally I Hacking, *The Taming of Chance* (Cambridge University Press 1990); TM Porter, *Trust in Numbers: The Pursuit of Objectivity in Science and Public Life* (Princeton University Press 1995); M Poovey, *A History of the Modern Fact: Problems of Knowledge in the Sciences of Wealth and Society* (Chicago University Press 1998).

[9] I Gorvin, 'Producing the Evidence that Human Rights Advocacy Works: First Steps towards Systematized Evaluation at Human Rights Watch' (2009) 1 Journal of Human Rights Practice 477, 480.

[10] See, eg, UN World Summit GA Res 60/1 (24 October 2005) wherein states endorsed the integration of human rights throughout the UN system.

human rights treaties,[11] as well as the interpretations of that language offered in a range of general comments, recommendations and expert-generated principles.[12] Indeed, as early as 1990, the UN Special Rapporteur on economic, social and cultural rights was calling for 'indicators [to] … assist in the development of the "core contents" of some of the less developed rights in this domain, and [to] provide a basis from which a "minimum threshold approach" can be developed'.[13] Shortly thereafter, the CESCR published General Comment No 3, wherein it introduced the concept of minimum core obligations for states parties to the ICESCR.[14] The CESCR acknowledged that resource constraints would be pertinent to its assessment of the core obligations question; however, it also emphasised that a state party 'in which any significant number of individuals is deprived of … essential primary health care … is, prima facie, failing to discharge its [ICESCR] obligations'.[15] In so doing, it seemed to signal the importance of quantitative indicators to any assessment of core obligations concerning the right to health.

Outright rejection of quantitative indicators would also run counter to the collective view of the UN human rights treaty bodies. In 2005 the chairpersons of these bodies asked the OHCHR to examine how statistical information, including quantitative indicators, might be used in assessing state compliance with international human rights instruments. Three years later, the treaty bodies gave their backing to the basic framework that the OHCHR put before them,[16] and since then the agency has been working on the refinement, dissemination and operationalisation of its preferred approach.[17]

[11] See, eg, International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR') art 12; Convention on the Rights of Persons with Disabilities (13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (hereafter 'CRPD') art 31.

[12] See, eg, the Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights, adopted by a Group of Experts (8 January 1987) UN Doc E/CN.4/1987/17 Annex, para 79 (reprinted in (1987) 9 Human Rights Quarterly 122); CESCR, 'General Comment No 1: Reporting by States Parties' (24 February 1989) UN Doc E/1989/22, para 6.

[13] UN Sub-Commission on the Prevention of Discrimination and Protection of Minorities, 'Realization of Economic, Social and Cultural Rights', report prepared by Special Rapporteur Danilo Türk (6 July 1990) UN Doc E/CN.4/Sub.2/1990/19, para 7. On the minimum core concept and core obligations, see above ch 1, text to nn 90–99.

[14] CESCR, 'General Comment No 3: The Nature of States' Parties Obligations (art 2, para 1)' (14 December 1990) UN Doc E/1991/23, paras 10–11.

[15] Ibid, para 10.

[16] See OHCHR, 'Report on Indicators for Monitoring Compliance with International Human Rights Instruments' (11 May 2006) UN Doc HRI/MC/2006/7; OHCHR, 'Report on Indicators for Promoting and Monitoring the Implementation of Human Rights' (6 June 2008) UN Doc HRI/MC/2008/3.

[17] To follow the OHCHR's on-going work, see www.ohchr.org/EN/Issues/Indicators/Pages /HRIndicatorsIndex.aspx.

It is also worth noting that any outright rejection of indicators would pass over human rights scholarship on statistics and also on measurement more generally.[18] More importantly, it would pass over the ways that statistical information has been crucial in human rights litigation: think, for example, of how central such information can be in cases concerning indirect discrimination. Moreover, as the UN High Commissioner for Human Rights has pointed out, courts are now using indicators to monitor the implementation of their orders.[19] Thus, one has to ask: what human rights lawyer would want to reject a tool that might help to close the widespread gap between court orders and their implementation (albeit most will be wary of the disarray, discontent and disrepute that can flow from what has been called 'managerial judging')?[20]

Most important of all, outright rejection of quantitative indicators would ignore measuring traditions *within* human rights work. Human rights activists, in particular, are old hands when it comes to basic forms of quantitative indicators. Typically, it is treaty signatures and ratifications that have been tallied, but rights guarantees in national constitutions and rights-friendly laws have been tallied too, as have rights-based complaints before judicial and quasi-judicial bodies. By tallying such things, activists aim for a full record of formal rights commitments. They are, in other words, 'coding rights in principle'.[21]

But rights in principle are of course no guarantee of rights in practice. They may be nothing more than the illusion of progress—a form of 'magic legalism'[22] whereby states present the signature and ratification of international instruments as proof of their human rights accreditation. Various states have continued to commit serious human rights violations after ratifying human rights treaties, and it has even been suggested (though not without controversy) that ratification can lead to an increase in violations.[23]

[18] The earliest work includes RP Claude and TB Jabine (eds), 'Symposium: Statistical Issues in the Field of Human Rights' (1986) 8 Human Rights Quarterly 551ff. See also J Asher, D Banks and FJ Scheuren (eds), *Statistical Methods for Human Rights* (Springer 2008); M Langford and S Fukuda-Parr (eds), 'Special Issue: Quantifying Human Rights' (2012) 30 Nordic Journal of Human Rights 222 ff.

[19] UN Economic and Social Council (ECOSOC), 'Report of the UN High Commissioner for Human Rights' (26 April 2011) UN Doc E/2011/90, para 39. Judgment monitoring is increasingly a focus of both research and NGO work: see, eg, J Goldston, *From Judgment to Justice* (Open Society Justice Initiative 2011); ESCR-Net with Judgment Watch, details available at www.cesr.org/downloads/new.horizons.judgment.watch.

[20] See above ch 1, text to nn 56–59.

[21] T Landman, *Studying Human Rights* (Routledge 2006) 80.

[22] S Cohen, *States of Denial: Knowing About Atrocities and Suffering* (Polity Press 2001) 108.

[23] OA Hathaway, 'Do Human Rights Treaties Make a Difference?' (2002) 1111 Yale Law Journal 1935. *Cf* R Goodman and D Jinks, 'How to Influence States: Socialization and International Human Rights Law' (2004) 54 Duke Law Journal 621; BA Simmons, *Mobilizing for Human Rights: International Law in Domestic Politics* (Cambridge University Press 2009).

It should be no surprise, then, that human rights activists have generally done far more than count rights in principle: that basic form of counting has long had a vibrant *qualitative* supplement, whereby activists investigate, document, corroborate and call attention to human rights violations.

Thus, activists collect stories or testimony from victims and witnesses about what happened, when it happened and who was involved; they check and cross-check their facts and then produce reports (or films) and do their best to publicise them. In so doing, human rights activists are bearing witness. They are also laying the groundwork for holding offenders to account in judicial or quasi-judicial fora. More generally, by documenting violations in this way, they are engaged in what Human Rights Watch describes as 'an inherently preventive strategy'.[24] In sum, and as Stanley Cohen pointed out some years back, human rights reports are a means to an end. Of course, as Cohen went on to point out, where NGOs focus excessively on the production process, neglecting dissemination and impact, a report can also become an end in itself.

Those who 'trust in numbers' will probably have little time for these traditional practices of counting and reporting in human rights work. They might, however, be kinder about the methodological supplements of recent years, including human rights impact assessments[25] and budget analysis.[26] Socio-economic statistics are being used, too, in order to monitor the enjoyment of human rights,[27] and there is also a range of initiatives using expert judgements to produce rights-related indices.[28] For many, however, the most striking addition to human rights method is likely to be the conversion of qualitative data on rights into quantitative data, ready for statistical analysis[29]—and, in particular, the ways in which this work has been put to use by truth commissions and by international tribunals.

[24] S Cohen, 'Government Responses to Human Rights Reports: Claims, Denials, and Counterclaims' (1996) 18 Human Rights Quarterly 516, 517.

[25] See, eg, P Hunt and G MacNaughton, 'Impact Assessments, Poverty and Human Rights: A Case Study using the Highest Attainable Standard of Health' (WHO 2006); UN Human Rights Council (UNHRC), 'Report of the Special Rapporteur on the Right to Food, Olivier De Schutter, Addendum: Guiding Principles on Human Rights Impact Assessments of Trade and Investment Agreements' (19 December 2011) UN Doc A/HRC/19/59/Add.5; L Forman, 'From TRIPS-Plus to Rights-Plus? Exploring Right to Health Impact Assessment of Trade-Related Intellectual Property Rights Through the Thai Experience' (2012) 7 Asian Journal of WTO and International Health Law and Policy 347.

[26] See, eg, A Nolan, R O'Connell and Colin Harvey (eds), *Human Rights and Public Finance: Budgets and the Promotion of Economic and Social Rights* (Hart Publishing 2013).

[27] See, eg, the work of Social Watch, www.socialwatch.org; and the Center for Economic and Social Rights, www.cesr.org.

[28] See, eg, the corruption perceptions index compiled by Transparency International, www.transparency.org.

[29] See J Asher, 'Introduction' in Asher, Banks and Scheuren (eds) (n 18) 18–21, discussing the work of El Rescate, the HURIDOCS network and the Science and Human Rights Program of the American Association for the Advancement of Science (SHR-AAAS).

Take, for example, the testimony of sociologist Patrick Ball in the Kosovo phase of the four-and-a-half-year trial of Slobodan Milošević at the International Criminal Tribunal for the Former Yugoslavia (ICTY). As part of his defence, Milošević claimed that the deaths and flow of refugees from Kosovo had been caused not by ethnic cleansing operations by the Yugoslav forces but by NATO bombing and the activities of the Kosovo Liberation Army. Ball and his colleagues used a range of data, including records of exhumations by investigators for the ICTY and interviews collected by the Organisation for Security and Cooperation in Europe (OSCE), to demonstrate that this was not true. Milošević tried to cast doubt on the team's statistical methods, asking, 'How can that be a serious way of doing it? Tell me.'[30] Milošević claimed that 'statistics … can prove anything'[31] and went on to accuse Ball of simplifying war with statistics.[32] Ball responded as follows: he and his team had used well-established methods. In addition, procedures for dealing with missing data had been followed, and where significant doubts had arisen, these had been noted.[33] Milošević did not relent, but as a result of Ball's testimony, the attempt to shift blame away from the Yugoslav army was seriously weakened.[34]

For some, however, these measurement practices—new and old—within human rights are not enough. In recent years, demand has been growing, from within and outside the human rights community, for more and better measurement—in particular, for the installation of quantitative data at the heart of human rights work, including increased use of quantitative indicators as a monitoring tool for economic, social and cultural (ESC) rights. I document this rising demand below in section II, paying particular attention to the enthusiasm for indicators shown by the CESCR, by the first UN Special Rapporteur on the right to health, Paul Hunt, and by the OHCHR. In section III, I extend the account, drawing in other actors with experience of indicators, including the World Bank, the UNDP and NGOs. In sections IV and V, I change tack: I step back from the enthusiasm that pervades the earlier sections of the chapter in order to clarify my own position. In so doing, I also outline the concerns that others have raised about indicators and, more broadly, the need to be alert to what has been called 'numero-politics'.[35] The chapter is then capped by a short conclusion in section VI.

[30] Milošević transcripts at 2252, www.un.org/icty (14 March 2002).

[31] Ibid, 2216 (13 March 2002).

[32] Ibid, 2268 (14 March 2002).

[33] See especially P Ball et al, 'Killings and Refugee Flow in Kosovo March–June 1999: A Report to the International Criminal Tribunal for the former Yugoslavia' (American Association for the Advancement of Science 2002).

[34] On the Milošević prosecution, see generally J Hagan, *Justice in the Balkans: Prosecuting War Crimes in The Hague Tribunal* (University of Chicago Press 2003).

[35] A Martin and M Lynch, 'Counting Things and People: The Practices and Politics of Counting' (2009) 56 Social Problems 243.

That conclusion summarises my stance; it also bridges to chapter five, the final case study, where I build on my claim about the importance of words by calling for human rights legal method to engage ethnography in order to draw out what I call the 'dignity of choice'.

II. AT THE UNITED NATIONS

For the CESCR, the treaty monitoring body for the International Covenant on Economic, Social and Cultural Rights (ICESCR), quantitative indicators are a longstanding interest. One reason for this is that a range of the Covenant's provisions, including article 12 on the right to the highest attainable standard of health, make explicit mention of indicators. In addition, as confirmed at the Vienna World Conference on Human Rights,[36] the Covenant's emphasis on 'progressive realisation' seems to demand measurement tools that can be used by the CESCR, as well as by states parties and others, to monitor both the steps taken by individual states and the achievements, failures or gaps in the enjoyment of rights that follow. Measurement tools seem also to be a prerequisite for any assessment of whether a state party is fulfilling its obligation to deploy 'maximum available resources'.[37] They can facilitate violations-monitoring too—notably for obligations of immediate effect, such as non-discrimination. Moreover, in so doing, they break down unhelpful divisions between, on the one hand, civil and political rights (where a violations approach[38] has long held sway) and, on the other, their ESC counterparts—in particular, the division between positive and negative rights, with ESC rights being associated with the former and seen as resource-intensive and thus difficult to guarantee.

But as I mentioned earlier, even before Vienna, the CESCR was alert to the potential of indicators. In its very first General Comment, which dealt with reporting by states parties, the Committee called for the setting of benchmarks with respect to indicators; such benchmarks were, it said, useful as 'indication[s] of progress'.[39] Two years later, in a set of guidelines on reports by states parties, the Committee called on states to provide

[36] UN World Conference on Human Rights, 14–25 June 1993, 'Vienna Declaration and Programme of Action' (12 July 1993) UN Doc A/CONF.57/23, para 98.

[37] R Robertson, 'Measuring State Compliance with the Obligation to Devote the "Maximum Available Resources" to Realizing Economic, Social and Cultural Rights' (1994) 16 Human Rights Quarterly 693; Felner (n 3).

[38] OHCHR, 'Human Rights Indicators: A Guide' (n 1) 23 explains the violations approach as follows: 'It is based on the consideration that the normative content of these rights is explicit, the claims and duties are well known, and the rights can be enjoyed as soon as they are guaranteed by the State. Thus, any outcome that violates the treaty provisions related to a human right can be used as an indicator to monitor the implementation of that right … The focus is essentially on monitoring the absence of negative outcomes.'

[39] CESCR, 'General Comment No 1' (n 12) para 6.

article-by-article accounts of progress, featuring both specific outcome-level statistics (disaggregated by sex and other criteria) and structural and process-level detail.[40] Around the same time, in General Comment No 3 dealing with the nature of states parties' obligations, the Committee took a more plain-speaking stance:

> [T]he obligations to monitor the extent of the realization, or more especially of the non-realization, of economic, social and cultural rights, and to devise strategies and programmes for their promotion, are not in any way eliminated as a result of resource constraints.[41]

In recent years, the Committee's interest in quantitative indicators seems even more pronounced. In General Comment No 14 on the right to health, for example, it calls on states parties to 'include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored'[42] as part of their national strategies. It goes further too, emphasising that 'the failure to monitor the realization of the right to health at the national level, for example by identifying right to health indicators and benchmarks'[43] could constitute a violation of the obligation to fulfil the right to health.

The CESCR also seems enthusiastic about the idea of a four-step monitoring process. This process has been designed to allow the CESCR to monitor the monitoring being done by states parties themselves—to allow it, in other words, to act as an auditor of states' own efforts on the indicators front.[44] As currently conceived, the four-stage process opens with indicator-identification. Stage two involves the production of a set of benchmarks, ie, a set of 'self-identified targets or goals adopted by states committing to achieve them in a given period of time'.[45] Both of these stages are in the hands of individual state parties. Next, there is a scoping exercise, designed to allow the Committee to discuss the benchmarks with

[40] CESCR, 'Revised General Guidelines Regarding the Form and Content of Reports to be Submitted by States Parties under Articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights' (17 June 1991) UN Doc E/C.12/1991/1. See now CESCR, 'Guidelines on Treaty-Specific Documents to be Submitted by States Parties under Articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights' (24 March 2009) UN Doc E/C.12/2008/2, read in conjunction with the 'Compilation of Guidelines on the Form and Content of Reports to be Submitted by States Parties to the International Human Rights Treaties' (29 May 2008) UN Doc HRI/GEN/2/Rev.5.

[41] CESCR, 'General Comment No 3' (n 14) para 11.

[42] CESCR, 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/4, para 43(f).

[43] Ibid, para 52.

[44] On the downsides of this, see A Rosga and ML Satterwhaite, 'The Trust in Indicators: Measuring Human Rights' (2009) 27 Berkeley Journal of International Law 253.

[45] ECOSOC, 'Report of the UNHCHR' (n 19) para 4. The report goes on to point out, 'Such an exercise allows States to determine what would be a sufficiently ambitious, but at the same time realistic and reasonable, pace of progress in the light of the available resources.'

a state party, with the aim of reaching a consensus thereon.[46] Thereafter a final assessment takes place during the dialogue between the Committee and the state party that happens prior to the production of the Committee's concluding observations.

The entire process—commonly known as IBSA (identification, benchmarking, scoping and assessment)—is currently being developed and refined in the specific context of the right to food, by a research team at the University of Mannheim, in co-operation with the NGO FIAN International.[47] Its most obvious strength of course is its combination of indicators and benchmarks, allied to the scoping exercise. Together, these aim to create space for a contextualised approach while also curbing the risk that a state party will try to cheat—perhaps by setting benchmarks too low. How successful IBSA will be in practice remains, though, to be seen; it will certainly be no easy task for the CESCR to analyse states' claims about resource constraints.[48]

The ICESCR is, however, just one of the reasons for the CESCR's interest in indicators. Another reason, arguably more compelling, is the disarray of the state reporting system. Reports are often submitted late and in some cases not at all: even when states submit reports on time and in good faith, it can be difficult for the CESCR to assess progress over time or to compare progress across rights. There can be uncertainty too, with the Committee asking questions to which a state party says it has no answer. For some time now there have been calls from states and from others for the whole process to be streamlined. There have also been calls for the process to be more transparent and more objective.[49] The Committee, for its part, seems keen both to improve follow-up on the concluding observations it issues at the end of the process and to draw more extensively on the expertise of specialised agencies such as the World Health Organization.[50]

Perhaps the most obvious reason for the Committee's interest in indicators is that it is not easy to be the CESCR. This treaty body is charged with the task of holding states parties accountable vis-à-vis their duties to respect, protect and fulfil ESC rights. For many, however, these rights are still best seen as goals or aspirations rather than 'real' human rights. Some go even further, casting ESC rights as a distraction from 'real' or 'proper' rights. This dichotomy between civil and political rights and their ESC

[46] CESCR, 'General Comment No 14' (n 42) para 58.

[47] See the IBSA project (n 3).

[48] AR Chapman, 'The Status of Efforts to Monitor Economic, Social and Cultural Rights' in S Hertel and L Minkler (eds), *Economic Rights: Conceptual, Measurement, and Policy Issues* (Cambridge University Press 2007). On cost and human rights, see above ch 3.

[49] The effort to create a global or 'super' treaty body has to date led to little more than a 'common core document' which a state party can file with the treaty bodies to which it reports. See also UNGA, 'UN Reform' (26 June 2012) UN Doc A/66/860.

[50] Almost all of these goals were named in OHCHR (11 May 2006) (n 16) para 2.

counterparts developed in part because prior to the entry into force in 2013 of the Optional Protocol to the Covenant (OP-ICESCR),[51] the ICESCR lacked an individual complaints or communications mechanism. That gap made it harder for the CESCR and others (say, NGOs) to adopt a violations approach to ESC rights.[52] And that in turn undermined the claim that all human rights are indivisible, interdependent and interrelated, and that all carry positive and negative obligations alike. Thus, from the CESCR's perspective, one major attraction of indicators is that as a tool used across the different human rights treaty bodies, and also in the context of the universal periodic review (UPR) conducted by the UN Human Rights Council, they offer a shared method. That in itself challenges the longstanding bifurcation of rights, providing a boost to the legitimacy of the CESCR and to ESC rights too.

The CESCR is not, of course, the only advocate of quantitative indicators at the United Nations. As noted earlier, the chairpersons of the human rights treaty bodies and the OHCHR have both given their backing to the use of indicators in monitoring states parties' compliance with international human rights treaties. Support has also been forthcoming from parts of the Special Procedures system. For instance, it was Paul Hunt, the first UN Special Rapporteur on the right to health, who crafted the tripartite typology of structure, process and outcome indicators that has now been taken by up others.[53] Hunt realised that it would not be enough for the treaty monitoring bodies to focus on laws and institutions (structure), or on the resources and efforts a state party had expended (process), or indeed on de facto human rights (outcome); individual state party reports needed to include data on *all three* elements.

The OHCHR endorsed Hunt's typology as part of its on-going work on indicators. It takes the view that the structure–process–outcome approach both simplifies the process of giving shape to indicators and resonates with frameworks already in use in the development context. The OHCHR also believes the typology is a good way to capture the three key state

[51] Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (10 December 2008, entered into force 5 May 2013) UN Doc A/RES/63/117.

[52] Efforts have been made to promote a violations approach towards ESC rights, as for example in the CESCR's delineation of 'minimum core obligations' (see, eg, CESCR, 'General Comment No 14' (n 42) paras 12, 43 and 47), but these they have proved controversial. The term itself is usually traced to AR Chapman, 'A Violations Approach for Monitoring the ICESCR' (1996) 18 Human Rights Quarterly 23.

[53] UN General Assembly (UNGA), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (10 October 2003) UN Doc A/58/427; UNGA, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (8 October 2004) UN Doc A/59/422; UN Commission on Human Rights (UNCHR), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (3 March 2006) UN Doc E/CN.4/2006/48, Annex.

obligations: namely, to respect, protect and fulfil human rights. Its on-going work has clarified its position on several other points too, mostly as regards how it conceptualises what it calls 'human rights indicators' (which, as mentioned earlier, encompass both quantitative and qualitative indicators) and what would constitute an effective methodological approach to populating these indicators with the required data.[54]

On methodology—that is, on the question of where to find information for human rights indicators that could be useful in the state reporting process (that being the OHCHR's principal focus)—four different sources and data-generating mechanisms have been proposed by the OHCHR: first, socio-economic and other administrative statistics (censuses, administrative data and statistical surveys); second, events-based data on human rights violations;[55] third, data based on perception and opinion surveys which have asked a representative sample of individuals for their views on a particular matter; and finally, data based on the judgements of informed experts (eg, academic researchers and NGOs) on a particular matter.[56] Having canvassed the pros and cons of each, the agency is encouraging the use of a combination of sources and data-generating mechanisms so as to produce data that will be more comprehensive and credible. It is also keen to ensure that data are available on a consistent basis; thus its position on the use of socio-economic and other administrative statistics, which some argue are not appropriate for human rights work, is that parts of these can be reshaped into indicators that draw out the human rights aspect. In short, the OHCHR is willing to use both specially produced indicators (compiled for instance by NGOs) and reconfigured ones that can be compiled by national statistical agencies from surveys and administrative records. It also takes the view that 'in many cases, data are collected but not fully utilized due to the lack of communication between producers and users'.[57]

The OHCHR has a similarly pragmatic stance on data disaggregation. It is of course aware that disaggregated data (on grounds of sex, race and ethnicity, for example) are crucial in human rights work—the cross-cutting human rights principles of non-discrimination and equality seem to demand

[54] See OHCHR (11 May 2006) (n 16); OHCHR (6 June 2008) (n 16); OHCHR, 'Human Rights Indicators: A Guide' (n 1).

[55] OHCHR, 'Human Rights Indicators: A Guide' (n 1) 52 defines these as follows: 'qualitative or quantitative data that can be linked to events characterized by the occurrence of human rights violations. The collected information primarily describes acts of human rights violations and identifies victims and perpetrators. The information is recorded in standardized fashion, using common definitions and classifications based on the human rights normative framework … that permit the compilation and consolidation of the relevant data … The data sources in this case include testimonies of victims or witnesses; information provided by the media and reports of States; civil society organizations, national human rights institutions and international human rights monitoring mechanisms.'

[56] The final source is also known as 'standards-based data'.

[57] ECOSOC, 'Report of the UNHCHR' (n 19) para 17.

such disaggregation.[58] At the same time, however, it accepts that collecting such data may itself create human rights concerns: not just with respect to confidentiality, data protection, the right to privacy and participation[59] but also ensuring that data are not used to perpetrate rights abuses against, say, ethnic or religious groups.[60] These latter abuses, the OHCHR acknowledges, are 'the dark side of numbers'.[61]

Overall, then, as regards methodology, the OHCHR's position is that it is important to be inclusive in the search for sources and data-generating mechanisms that could be useful in building indicators for human rights purposes. At the same time, however, it accepts that there are both ethical and statistical considerations that have to be taken into account in the selection of human rights indicators. Data disaggregation is seen as a prime site of ethical sensitivity, in particular when the proposed disaggregation is on ethnic or religious grounds. There are also, the OHCHR accepts, cost implications attached to disaggregation. Hence, although disaggregation is generally seen as desirable, the OHCHR, at least as regards ethnicity and religion, takes the view that the decision to disaggregate 'rests with the national authorities and will depend on national circumstances'.[62]

Turning now to the conceptual side—in other words, what should be measured and how to develop indicators for that purpose—the OHCHR, as noted earlier, endorses the structure–process–outcome configuration suggested by Paul Hunt, the first Special Rapporteur on the right to health. It also focuses on what it calls the 'attributes' of particular rights; these, it says, should be used as a filter to concretise the normative content of individual rights in a way that makes it easier to craft a set of appropriate indicators. Three considerations influence the choice of attributes for any individual right: to the extent feasible, attributes should flow from an exhaustive reading of the relevant human rights standard; they should be few in number but, taken together, should both reflect the essence of the right and facilitate indicator-identification; and finally, they should not overlap.[63]

So for example, five attributes have been proposed by the OHCHR for its illustrative indicators on the right to health. The five, chosen by drawing on relevant provisions in the human rights treaties, as well as General

[58] See also CRPD (n 11) art 31.

[59] See, eg, Committee on the Elimination of Racial Discrimination (CERD), 'General Recommendation VIII concerning the Interpretation and Application of article 1, paragraphs 1 and 4 of the Convention' (22 August 1990) UN Doc A/45/18, which provides that identification with a particular racial or ethnic group 'shall, if no justification exists to the contrary, be based upon self-identification of the individual concerned'.

[60] W Seltzer and M Anderson, 'Using Population Data Systems to Target Vulnerable Population Subgroups and Individuals: Issues and Incidents' in Asher et al (eds) (n 18).

[61] OHCHR, 'Human Rights Indicators: A Guide' (n 1) 46.

[62] Ibid, 70.

[63] Ibid, 31.

Comments and Recommendations in the area,[64] are as follows: first, sexual and reproductive health; second, child mortality and health care; third, prevention, treatment and control of diseases; fourth, natural and occupational environment; and, finally, accessibility of health facilities and essential medicines. For each of these attributes, the next step is to identify, first, one or more structural indicators, then process indicators and finally, outcome indicators.[65]

Overall, the OHCHR hopes that by using both of these mechanisms—by converting the narrative of individual human rights into a set of key attributes and a companion-set of structural, process and outcome indicators—the sometimes inaccessible meaning of individual rights will be made clearer, and the steps taken by states to address their obligations will be placed front and centre in any compliance assessment. The OHCHR also emphasises the importance of having indicators not just for individual rights but, in addition, for the cross-cutting norms and principles of human rights, such as non-discrimination and equality, participation, accountability and access to a remedy.[66]

Three other important questions have been addressed by the OHCHR. The first is: should universal indicators be the ultimate goal? The OHCHR's view seems to be that they should not. It accepts that globally applicable indicators have a part to play in human rights assessment, especially as regards both the realisation of some civil and political rights and the core content of ESC rights, but it is more interested in *contextually meaningful* indicators, rooted in universal human rights standards. Stated simply, both universally relevant and contextually specific indicators are required. In line with this, the OHCHR has insisted that its conceptual framework 'neither seeks to prepare a common list of indicators to be applied across all countries irrespective of their social, political and economic development, nor to make a case for building a global measure for cross-country comparisons of the realization of human rights'.[67]

Secondly, although its work has focused primarily on the quantitative side, the OHCHR has made it clear that it backs the use of both quantitative and qualitative indicators.[68] Third and finally, it has emphasised that indicators are a tool, not a solution, and as a tool, they have their limits. They are no

[64] See, eg, ICESCR (n 11) art 12; CESCR, 'General Comment No 14' (n 42).

[65] See, eg, OHCHR, 'Human Rights Indicators: A Guide' (n 1) part IV, Annex 1.

[66] Ibid, 38–41.

[67] Ibid, 33.

[68] See, eg, ibid, 17. See also the OPERA framework, developed by the NGO, CESR, which aims to integrate qualitative and quantitative tools to monitor the obligation to fulfil ESC rights, www.cesr.org/section.php?id=179. This framework is discussed by A Corkery and S-A Way, 'Integrating Quantitative and Qualitative Tools to Monitor the Obligation to Fulfil Economic, Social and Cultural Rights: The OPERA Framework' in Langford and Fukuda-Parr (eds) (n 18) 324.

more than a component part of human rights method, and an imperfect one at that.[69] In similar vein, the High Commissioner for Human Rights has emphasised, 'The use of indicators does not replace the normative analysis of a human rights situation.'[70] For one thing, 'Data gathered for indicators need to be analysed in the context of the normative framework for human rights.' Furthermore, 'indicators alone will generally not provide a complete picture of the realization or violation of a certain right':

> For example, a failure to reach a benchmark for an indicator set for a certain right does not necessarily mean that the State is in breach of its international obligations deriving from the right. In order to determine whether such a trend is actually the result of a breach of human rights obligations, further investigation and analysis is required, including through judicial or quasi-judicial review.[71]

III. COUNT ME IN?

By now the picture should be clear: at the UN, the treaty bodies are interested in indicators, and with the help of the OHCHR and others, they are pursuing this interest. The hoped-for benefits are multiple. For instance, in the context of states parties' reporting, the hope is that indicators might help with transparency and efficiency, and also with follow-up on recommendations. In an ideal world, they would also make it easier for the CESCR to deal with challenges to its authority—for instance, if contextualised indicators, produced by states themselves, are the way forward, the Committee will simply monitor the monitoring done by individual states parties. More generally, as explained earlier, a common approach to identifying indicators for monitoring both ESC rights and their civil and political counterparts could go some way towards addressing the on-going divide between so-called 'real and proper' rights and their ESC counterparts.

Above all, though, indicators are seen as a way to help states to gauge their own progress and to pinpoint policies and programmes that facilitate the realisation of human rights. They are also seen as a tool for other stakeholders, including both NGOs and, as the OHCHR puts it, 'claim-holders at large'.[72] Moreover, if, like Navi Pillay, the UN High Commissioner for Human Rights, we accept that '[p]olicy management, human rights and statistical systems … need to be in tune with each other', then integrating

[69] OHCHR (6 June 2008) (n 16) para 43; OHCHR, 'Human Rights Indicators: A Guide' (n 1) 4.

[70] ECOSOC, 'Report of the UNHCHR' (n 19) paras 18–19.

[71] Ibid. See, similarly, the High Commissioner's foreword to OHCHR, 'Human Rights Indicators: A Guide' (n 1) iii, noting 'the limitations that are intrinsic to any indicator': 'In particular, it cannot and should not be seen as a substitute for more in-depth, qualitative and judicial assessments which will continue to be the cornerstones of human rights monitoring.'

[72] OHCHR (6 June 2008) (n 16) para 37.

human rights into policy and statistical indicator-production and use 'is not only a normative imperative, it also makes good practical sense'.[73] Failing to do so, as the High Commissioner has explained, 'can have real consequences'.

To summarise: at the UN, indicators are an important part of a broader move towards *implementing* human rights—a move designed to take human rights work to the next stage, the stage beyond standard-setting. That said, as this section of the chapter explains, enthusiasm about indicators is not in any way exclusive to the OHCHR, the treaty bodies and parts of the UN special procedures system: human rights NGOs and donors are clearly on board as well, and those who work in fields related to human rights—including governance and development—are perhaps keenest of all.

Measurement—quantitative measurement—took off in these latter fields some time back and now wields considerable influence. Its potential was not obvious to everyone from the start, however. Take the Human Development Index (HDI), a measurement tool designed by Mahbub ul Haq and pioneered by the UNDP in order to assess states' development progress using people-focused criteria (specifically, per capita income, life expectancy at birth, and literacy and school enrolment) rather than via GDP alone. Initially, Amartya Sen, Nobel Prize-winning economist, champion of the human capabilities approach and also one of the consultants on the 1990 Human Development Report which launched the HDI, had real doubts. Would such a crude indicator be any use?

The answer, it turned out, was that the HDI was of considerable use. And crucially, its bold and simple style of communication was what made it useful: as Sen later acknowledged, it was precisely because the HDI was a 'crude index' that it 'spoke loud and clear and received intelligent attention', which in turn helped to ensure that 'the complex reality contained in the rest of [the UNDP's Human Development Report] also found an interested audience'.[74]

A more sceptical assessment might be that complexity was sacrificed for impact, and that the success of the HDI made it harder to see the compromises on which it is based. This latter assessment seems to be borne out by the shift in media reporting on the Index. Initially, it was commonplace for reports to comment on the Index itself; today, however, it is widely used without comment, as 'convenient shorthand for describing a country'.[75] To be fair, the architects and backers of the HDI have generally been far more circumspect. They take the time, for instance, to point out that the Index needs to be supplemented by other, more detailed socio-economic indicators.

[73] OHCHR, 'Human Rights Indicators: A Guide' (n 1) iii.

[74] A Sen, 'Assessing Human Development' in UNDP, *Human Development Report 1999* (Oxford University Press 1999) 23.

[75] See KE Davis, B Kingsbury and SE Merry, 'Indicators as a Technology of Global Governance' (2012) 46 Law & Society Review 71, 97.

Interestingly, the UNDP's attempts to use an index of human freedom (HFI)[76] and later to build its own index of political freedom (PFI)[77] did not have the same success as the HDI. It was quite the opposite: the Programme's work in these areas provoked an outcry and was swiftly abandoned.[78] Nonetheless, the UNDP has continued to show interest in human rights indicators. Its *Human Development Report 2000* suggested seven roles for such indicators: first, making better policies and monitoring progress; second, identifying unintended impacts of laws, policies and practices; third, identifying which actors are having an impact on the realisation of rights; fourth, revealing whether the obligations of these actors are being met; fifth, giving early warning of potential violations prompting preventive action; sixth, enhancing social consensus on difficult trade-offs to be made in the face of resource constraints; and finally, exposing issues that have been neglected or silenced.[79] The UNDP has also done work on the relationship between human rights indicators and their human development counterparts.[80] The two, it says, should not be equated: human rights assessment calls for a wider range of data, and these data also need to be disaggregated on grounds such as race and gender.[81]

But what of donors other than the UNDP, and indeed, what of human rights NGOs? What explains their enthusiasm for quantitative measurement in human rights work? Donors are of course a diverse group, ranging across wealthy states, the UN, the international financial institutions (the World Bank, for example) and a cluster of philanthropists, yet what they share in common is a desire for fertile ground for their funding. Evidence on whom and what to fund has wide appeal. Evidence of impact is appealing too: donors like to see—and sometimes to advertise—the difference that their funding has made. Moreover, for at least one donor, the World Bank, making rights measurable might well be a way of making them matter for the economists who work at the Bank and who, in truth, dominate its culture. In this particular organisational culture, making rights measurable is, in Galit Sarfaty's phrase, a way of 'economizing' them.[82] Measurement is

[76] See UNDP, *Human Development Report 1991* (Oxford University Press 1991).

[77] See UNDP, *Human Development Report 1992* (Oxford University Press 1992).

[78] See similarly the furore that followed 'The World Health Report 2000—Health Systems: Improving Performance' (WHO 2000), wherein the WHO reported on its measurement of health systems in 191 member states. The Organization turned thereafter to proxy indicators rather than trying again with an explicit ranking of health systems.

[79] UNDP, *Human Development Report 2000: Human Rights and Human Development* (Oxford University Press 2000) 89.

[80] Ibid.

[81] See similarly OHCHR, 'Human Rights Indicators: A Guide' (n 1) 19–20. See also the warning against a 'culture of evaluation' in UNHRC, 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (12 April 2011) UN Doc A/HRC/17/25, paras 55–57.

[82] GA Sarfaty, *Values in Translation: Human Rights and the Culture of the World Bank* (Stanford University Press 2012) 20.

widely understood at the Bank; more than this, it is prized—in part because the organisation's Governance indicators and, more particularly, their Doing Business counterpart, which offer a ranking of developing countries based on the quality of their business laws and legal institutions, have been very influential.[83]

What then of human rights NGOs? Why might better quantitative data appeal to these organisations? The obvious answer is that data can help NGOs to establish why abuses happen and who is responsible for them, and they can also chart progress towards the realisation of rights. Today, as Philip Alston has pointed out, many NGOs see individual cases as 'time-consuming and backward-looking', perhaps even a barrier to 'the overall picture that is needed'.[84] Better data can also help NGOs to motivate their membership, and they can be useful when working with development and other policy-making actors for whom measurement is part of everyday practice. More than this, they can be a way in for NGOs. The WHO/UNICEF Code on Breastmilk Substitutes, for instance, gave NGOs 'the responsibility of drawing the attention of manufacturers or distributors to activities that are incompatible with [its] principles and aim'.[85] That power has been central to the success of the Code and to the vitality of NGOs such as the International Baby Food Network (IBFAN); it may also be one reason for the Code's reputation as a regulatory trailblazer.[86]

Data can also be valuable in setting NGO priorities, in designing and improving strategies, and in assessing impact. Indeed, as Ian Gorvin of Human Rights Watch (HRW) has explained, 'what impact have we had?' is now an important question for human rights NGOs.[87] Part of the reason for this is that donors will look for an evidence base before committing funds, as well as for proof of a return on any investment they do make. Human rights NGOs have little choice but to comply: donors, after all, are free to go elsewhere.[88] In part, too, the impact question is increasingly

[83] See respectively D Kaufmann, 'Human Rights and Governance: The Empirical Challenge' in P Alston and M Robinson (eds), *Human Rights and Development: Toward Mutual Reinforcement* (Oxford University Press 2005); Davis, Kingsbury and Merry (n 75) 90–95. Note, however, that the World Bank's Doing Business indicators have attracted criticism, including from the Bank's own Independent Evaluation Group: see Davis, Kingsbury and Merry (n 75) 93–96.

[84] P Alston, 'Promoting the Accountability of Members of the New UN Human Rights Council' (2005) 15 Journal of Transnational Law and Policy 49, 78.

[85] WHO/UNICEF, 'International Code of Marketing of Breast-milk Substitutes' (23 May 1981) WHO Doc A34/x, art 11.4.

[86] See K Sikkink, 'Codes of Conduct for Transnational Corporations: The Case of the WHO/UNICEF Code' (1986) 40 International Organization 823 describing it as: 'one of the most successful code efforts to date, in terms both of the detail of its provisions and the degree of its implementation.'

[87] Gorvin (n 9).

[88] International organisations, too, deploy indicators to reach out to and retain donors: see, eg, the account of the WHO/UNICEF immunisation indicators in A Fisher, 'From Diagnosing

important because self-assessment is now considered 'best practice', in the NGO world and also more broadly. This is a point I come back to later.[89]

IV. ALL KITTED-OUT?

I said at the outset that my own position on quantitative indicators is mixed; I want now to explain that. To be honest, it is easier for me to say what does not bother me about this rising form of human rights legal method than what does. For instance, at least for now, there seems no reason to fear universal indicators. The argument for them as a stand-alone seems to have been scuppered—they are certainly far less prominent in recent OHCHR work than they were when the agency first engaged with the issue of indicators in human rights reporting to the UN treaty bodies. Furthermore, it has to be said that, just like the OHCHR, most advocates of quantitative indicators offer careful, as opposed to cavalier, endorsements of this tool. Moreover, there are now signs of contestation over the production of indicators and the uses to which this new human rights tool is put, which should also help to keep excesses in check. Finally, it is clear that indicators do have the great benefit of simplicity, and as Sen said of the HDI, that simplicity facilitates 'high publicity', which in turn helps in 'getting the ear of the world'.[90]

Beyond these basics, my position feels less coherent. To start with, when teaching human rights classes I will often reach for numbers. Why is that? Perhaps I do it because, as the UN Committee on the Elimination of Discrimination against Women (CEDAW Committee) has said, 'Statistical information is absolutely necessary in order to understand the real situation of women in each of the States parties to the Convention.'[91] More broadly, it could be that I recognise the truth of the OHCHR's claim: indicators, it says, 'can help us make our communications more concrete and effective'.[92] The OHCHR emphasises other virtues too:

> Compiling indicators helps to record information efficiently and this, in turn, makes it easier to monitor and follow up issues and outcomes. Well-articulated indicators can improve public understanding of the constraints and policy trade-offs,

Under-Immunization to Evaluating Health Care Systems: Immunization Coverage as a Technology of Global Governance' in K Davis et al (eds), *Governance By Indicators: Global Power Through Quantification and Rankings* (Oxford University Press 2012).

[89] See below, text to nn 122–26.

[90] A Sen, 'Foreword' in S Fukuda-Parr and AKS Kumar (eds), *Readings in Human Development: Concepts, Measures and Policies for a Development Paradigm* (2nd edn, Human Development Report Office, UNDP 2005) x.

[91] CEDAW Committee, 'General Recommendation No 9: Statistical Data concerning the Situation of Women' (3 March 1989) UN Doc A/44/38.

[92] OHCHR, 'Human Rights Indicators: A Guide' (n 1) 1.

> and help in creating broader consensus on social priorities. More importantly, when used properly, information and statistics can be powerful tools for creating a culture of accountability and transparency in the pursuit of socially valued progress.[93]

To argue against that line-up would be undeniably hard; frankly, it would also be an unappealing task.

The other reason my mixed reaction to indicators feels odd is that, as must be clear by now, I believe in thinking more deeply and critically about human rights legal method. The medical doctor and anthropologist Paul Farmer is right to insist that, for anyone who is serious about health and human rights, 'studies, conferences and exhortations' fall a long way short.[94] Other methods, too, can fall short. Monitoring violations, for instance, whilst ignoring root causes;[95] or legalising rights and assuming that this alone will realise them in practice. Practitioner-advocates like Farmer often point to the importance of 'kit'. Standard rights-based approaches have, they say, 'left us weak in this arena':

> While many who care about rights are prepared to discuss gender inequality, too few of us are ready to buy generators, c-section kits, sutures, or OR lamps. Not even contraceptives are considered in pragmatic enough terms.[96]

So, is the problem that I am not thinking of quantitative indicators in 'pragmatic enough terms'? Are these indicators best seen as part of a new human rights kit? Are they, as their advocates insist, a tool for achieving human rights *in practice*, not just in principle?

I am also mindful that, as Philip Alston has said, 'The least well developed dimension of human rights practice and scholarship is evaluation.'[97] Within human rights we claim success, but what precisely is a human rights success, and when is it legitimate to say that human rights work—by a field office, by one or more NGOs, by scholars, by foreign states and so on—has produced, or at least contributed to, that success? Alston raises these questions in his introduction to a study written by Christian Salazar, director of the OHCHR's field presence in Colombia from 2009–11, on that Office's attempts to limit and, ideally, to stop extrajudicial executions by Colombian armed forces. True, Salazar's account is self-evaluation; it is not the assessment of an expert, impartial outsider. Still, as Alston says, neither external

[93] Ibid.

[94] P Farmer, 'Challenging Orthodoxies: The Road Ahead for Health and Human Rights' (2008) 10(1) Health and Human Rights: An International Journal 5, 10.

[95] *Cf* S Marks, 'Human Rights and Root Causes' (2011) 74 Modern Law Review 57 for the argument that 'planned misery' would be a better orienting concept than root causes.

[96] Farmer (n 94) 9.

[97] Philip Alston introducing C Salazar Volkmann, 'Evaluating the Impact of Human Rights Work: The Office of the High Commissioner for Human Rights and the Reduction of Extrajudicial Executions in Colombia' (2012) 3 Journal of Human Rights Practice 396, 396.

nor internal assessment comes with guarantees: a combination of the two is perhaps the optimum, allowing audiences to reach their own conclusions based on the evidence. More important still, Alston says, is the quality of any evaluation of human rights work: 'the real test lies in the strength of the methodology used, of the research undertaken, and of the degree of persuasiveness of the conclusions reached when measured against all available evidence.'[98]

If we combine Alston's plain speaking on the need for a stronger evaluative instinct within human rights with the calls by Farmer and others for new, more practically-focused human rights engagements around health, as well as the OHCHR's account of the various virtues of measurement, it seems hard to be less than keen on quantitative indicators. Yet a range of commentators has been exactly that. So why might that be? For some, the problem with these indicators is their impracticability. Measurability looms large here: for instance, will there be enough information to produce indicators that are reliable and sufficiently comprehensive to be used in the work of the treaty bodies? A culture of statistics may well evolve, but in the meantime, how should the CESCR, for instance, deal with a state party offering incomplete information? And what if that state party has also focused on what is easy to measure rather than on what matters most in human rights terms—say, for instance, compliance with core obligations? Furthermore, what if declaring the imprecision of one's indicators was to become the norm amongst states parties? This would bring an apparent gain in transparency, and it would also act as a reminder of the need for interpretive caution; at the same time, however, when a warning becomes ubiquitous, it generally slides all too easily into the background.

For others, the problem with quantitative indicators as part of human rights method lies elsewhere. Their concern is that, by taking up these indicators, human rights advocates will produce a slew of controversies and, ultimately, bad human rights outcomes. For instance, if the treaty bodies make ever increasing use of indicators to measure state compliance with human rights obligations, will that turn 'an exercise of judgment into one of technical measurement'?[99] In so doing, is the standing of *judgment* likely to be diminished? Will it be cast aside as subjective—improperly so—by contrast with the apparent objectivity of numbers?[100] Bluntly, will it come to seem like a case of politics versus truth?

The risk seems very real, not least because of a general tendency towards 'autonomisation of statistics': 'If a statistic is produced, it will be used in many cases without contextual analysis and without any appreciation of

[98] Ibid.
[99] Rosga and Satterwhaite, 'The Trust in Indicators' (n 44) 258.
[100] Ibid.

the methodological constraints under which it was generated.'[101] With statistics, it is, in short, all too easy to miss the human judgement that went into producing them. This in turn means we fail to ask important questions, such as: who is deciding how to use numbers to measure normative concepts like human rights, and who is collecting the data? What do we really know about these new experts? Also, in what ways are these numbers being reported, and with what effects?[102]

New and unproductive forms of naming and shaming are a further risk. The treaty bodies are not likely to construct composite indices—indeed, the OHCHR has made it clear that there is no intention whatsoever to put indicators to that sort of use[103]—but others may be unable or unwilling to resist the pull of comparison. Indices might also be one unintended result of preparing for the reasonableness assessment that will be used by the CESCR in hearing complaints under the OP-ICESCR. For NGOs assisting with any such complaints, comparative data will be a big draw: being able to demonstrate that another state party with similar resources has achieved human rights compliance would greatly enhance the chances of success. But as I have said, this could also lead to the unintended and unwanted production of an index of state performance.

States, for their part, may look to 'game' indicators, opting to measure what will make them look good rather than the actual across-the-board achievement (or otherwise) of human rights. Equally, states may treat indicators as targets, aiming above all to evidence their own success in achieving particular targets rather than working towards actual fulfilment or enjoyment of human rights on the ground. By way of illustration, consider the high level of attention that has been paid to how many individuals are being placed on antiretroviral therapy (ART). This is an important number, to be sure. But as Sofia Gruskin has explained, its grip on our attention creates problems too. It is, she has emphasised, 'vitally important that numerical targets exist'; however, 'taken on their own they are insufficient'.[104] What we need to know is not simply how many now have access but also 'who is gaining access to ART (and who is not), how they are gaining access, and over what time period'. Furthermore,

> We must ask, for example, whether access to treatment is accompanied by appropriate care and support? How are issues of adherence addressed? Are human rights

[101] N Thede, 'Human Rights and Statistics: Some Reflections on the No-Man's-Land between Concept and Indicator' (2001) 18 Statistical Journal of the UN Economic Commission for Europe 259, 270. See also A Rosga and M Satterwhaite, 'Measuring Human Rights: UN Indicators in Critical Perspective' in Davis et al (eds) (n 88).

[102] See generally Davis et al (eds) (n 88).

[103] OHCHR, 'Human Rights Indicators: A Guide' (n 1).

[104] S Gruskin et al, 'Beyond the Numbers: Using Rights-Based Perspectives to Enhance Antiretroviral Treatment Scale-Up' (2007) 21 AIDS (suppl 5) S13, S16.

> considerations raised in relation to food, education and non-discrimination taken into account or is the focus simply on medical issues around adherence?[105]

Berit Austveg has made a similar point in her account of maternal health indicators. She emphasises that a reduction in the number of maternal deaths at a specific institution 'is not always a sign of improvement'.[106] That of course sounds counter-intuitive: when would it not be a sign of improvement? The answer, as Austveg has explained, is when there is such pressure on managers and staff to make their own institution look good in the statistics that, rather than treat a dying woman in labour or at least do what is possible for a dignified death, staff work towards transferring the woman elsewhere as soon as possible.[107]

ARTs and maternal health are, moreover, not the only sites where improving numbers are not always a sign of an improving situation for individuals and groups. Examining social welfare in the United States, specifically the Personal Responsibility and Work Opportunity Act (PRWORA), passed by Congress in 1996, Tara Melish has shown how performance indicators are to the fore amidst the legislation's focus on new governance (whereby decentralisation, flexibility, local discretion and the like are favoured in regulatory law-making, as opposed to the fixed rules and centralised enforcement that prevail under a command-and-control approach).[108] Whilst performance indicators are not bad per se, what Melish has drawn out is how PRWORA's indicators are not 'a metric for human well-being'; these result-oriented indicators do not measure 'client-centered fairness, personal needs, or overall human welfare'—their focus is welfare-roll reduction.[109] These reduction measures are 'being continually met, even exceeded'; at the same time, however, 'levels of economic hardship, deprivation, and exclusion of the poor from both social life and the political process have been on a noted rise'.[110] Moreover,

> *[H]ow* programs get roll numbers to decline is largely inconsequential to this competitive system: *means* are left to the discretion of the local welfare agency and *process* indicators are generally not measured. What matters is that numbers

[105] Ibid.

[106] B Austveg, 'Perpetuating Power: Some Reasons Why Reproductive Health Has Stalled' (2011) 19 Reproductive Health Matters 26, 32.

[107] Ibid. See also AE Yamin and KL Falb, 'Counting What We Know; Knowing What to Count: Sexual and Reproductive Rights, Maternal Health, and the Millennium Development Goals' in Langford and Fukuda-Parr (eds) (n 18) 350.

[108] TJ Melish, 'Maximum Feasible Participation of the Poor: New Governance, New Accountability, and a 21st Century War on the Sources of Poverty' (2010) 13 Yale Human Rights and Development Law Journal 1.

[109] Ibid, 24. As she indicates, similar concerns arise in the criminal justice context if 'doing justice' loses sight of any higher aim or principle and becomes focused upon numbers of persons prosecuted. See further M De Ming Fan, 'Disciplining Criminal Justice: The Peril Amid the Promise of Numbers' (2007) 26 Yale Law & Policy Review 1.

[110] Melish (n 108) 8.

> *in fact* go down. The system thus, wittingly or unwittingly, creates incentives to reduce caseloads by any means possible.[111]

Melish has also emphasised that the backstory of improving numbers—which may well involve arbitrary decision-making being rolled out as 'best practice' as states compete with one another to come out on top—is not the only complication here. There is also the unwillingness, or at least reluctance, to track certain kinds of data over time. Why, for instance, is there no tracking of those taken off or turned away from welfare programmes? How are these people faring, and why is it that data on this are not pertinent for programmes geared towards 'success'? In similar vein, in a study of indicator use by humanitarian NGOs operating in Haiti in the aftermath of the devastating earthquake that hit Port-au-Prince in 2010,[112] Margaret Satterwhaite has reported that, amidst significant levels of measurement, there is at least one striking gap: gender-based violence within IDP camps is generally not measured, and more than this, there appears to be a reluctance to measure it.

In short, then, when it comes to indicators, there are mounting questions about what should be counted, what can be counted and what effects it has to count one thing but not another. There are also questions as to when, how and by whom counting should be done. There is, it might be said, a veritable 'numero-politics'[113] of counting. To drive home this latter point, we need only turn to a cluster of more basic examples. Recall, for instance, the on-going and often aggressive disputes as regards estimates of endangered species or global temperature changes. Alternatively, recall the US case of *Bush v Gore* where, in order to resolve a disagreement about who had won the 2000 presidential election, the Supreme Court had to decide what exactly counted as a vote.[114] A further compelling illustration of numero-politics is provided by humanitarian emergencies: these emergencies give rise, more and more it seems, to competing estimates—one notable recent example was whether the deaths in Darfur constitute genocide.[115] True, US-based lawyers, along with the American Bar Association and related NGOs, have been working towards new ways to document the scale and scope of such humanitarian emergencies; but this brings its own complications. Traditionally, questions of scale and scope were handled by

[111] Ibid, 33.

[112] M Satterwhaite, 'Indicators in Crisis: Rights-Based Humanitarian Indicators in Post-Earthquake Haiti' (2011) 43 New York University Journal of International Law and Politics 865, 957–58.

[113] Martin and Lynch (n 35).

[114] *Bush v Gore* 531 US 98 (2000).

[115] See further M Madmani, *Saviors and Survivors: Darfur, Politics and the War on Terror* (Verso 2009); R Levi and J Hagan, 'Lawyers, Humanitarian Emergencies and the Politics of Large Numbers' in Y Dezalay and BG Garth (eds), *Lawyers and the Construction of Transnational Justice* (Routledge 2011).

public health professionals, not by lawyers: the entry of lawyers into this field not only changes law ways of doing human rights but also raises the prospect of duelling professions, duelling numbers and thus an array of choices for political leaders, media outlets and so on.[116]

To be clear, it is not just large numbers that have a numero-politics. Writing about the US phenomenon of stillborn birth certificates, Carol Sanger has pointed out that two documents—a death certificate and a stillborn birth certificate—now testify to a single event. Two documents for one event produces questions concerning demographic integrity: 'What are their implications for population figures, for mortality statistics, and for other key demographic indicia?'[117] At a deeper level, as Sanger goes on to point out, the presence of two documents produces questions about how categories—here, birth and death—are established and defined in the first place, and how they acquire legal and social meaning. We face, in other words, not just a numero-politics but one that can have very considerable consequences.

V. WORDS, WOUNDS AND NUMBERS

Some will say these examples and the concerns that preceded them are over the top. They will argue that indicators are just another alternative, simply one part of an expanding menu of methods in human rights work. They will argue that even if indicators do regulate the world in particular ways, regulation of indicators is possible too. They may also argue that how we respond to the turn towards indicators in human rights should depend on who is producing them, who is promoting them and who is using them, and for what reason. Producers, promulgators and users, in other words, need to be differentiated (even if some organisations or individuals occupy all three roles). Moreover, within each class there may be relevant differences that also need to be drawn out. AnnJanette Rosga and Margaret Satterwhaite have made precisely this sort of argument when they emphasised that the UN treaty bodies using numbers to hold states parties to account—and more particularly, human rights NGOs making a similar case—are surely very different to a situation in which a state uses numbers to drive down welfare claimants or insists that the number of persons in prison is evidence of 'justice achieved'.[118]

[116] Levi and Hagan, ibid.

[117] C Sanger, '"The Birth of Death": Stillborn Birth Certificates and the Problem for Law' (2012) 100 California Law Review 269, 274. See relatedly M Lock, *Twice Dead: Organ Transplants and the Reinvention of Death* (University of California Press 2002), documenting different cultural practices in counting a patient as 'a death'.

[118] Rosga and Satterwhaite, 'The Trust in Indicators' (n 44) 55–56. See relatedly Melish (n 108), arguing that PRWORA's 'new governance' approach to social welfare in the US needs

I accept these arguments for differentiation rather than dismissal of indicators within human rights work, with two caveats. First, producers, promoters and users of indicators are not always as careful about the question of difference as Rosga and Satterwhaite have been. Indeed, as these authors have noted, in some OHCHR work on potential uses of indicators, there has a been a definite lack of explanation of the risks and opportunities that may arise depending on whether indicators are being used by the UN treaty bodies, by states themselves or by NGOs.[119]

Second, any and all claims concerning 'best practice' in measurement call for rigorous, on-going study. We need a far better sense than we have at present of the risks and opportunities carried by particular types and uses of indicators. Consider, for instance, the case of human rights NGOs turning to qualitative and quantitative data as part of their response to the entry into force of the OP-ICESCR and, more broadly, to the full range of developments that have been reshaping ESC rights as claimable rights. There is, of course, an opportunity moment here—one that should not be squandered. But how should NGOs proceed? Specifically, what should guide them as they consider optimum combinations of qualitative and quantitative evidence? I have already said that comparative data—on maximum available resources, for instance—could be important for the reasonableness analysis that is likely to dominate judicial and quasi-judicial assessments in the arena of ESC rights. But what is also important is that individuals see themselves in the evidence: successfully demonstrating a violation of ESC rights would be a peculiar sort of victory if it were to shut out the voices or, more broadly, the participation of rights claimants. Victory via numbers would also be hollow if that evidence somehow were to shut out structural conditions and consequences,[120] or if it has adverse effects on the standing of the judiciary, perhaps because it tempts judges towards the overly interventionist remedies that can be characteristic of what is known as 'managerial judging'.

NGOS clearly have to think about indicator use in non-ESC rights cases too, as well as uses that go beyond cases. Is there, for instance, a difference between court-centric forms and uses of human rights quantitative indicators and other forms and uses? And to what extent has the rising interest in what has been called 'naming and arresting'[121] (as opposed to the more

to be complemented by the 'new accountability' approach that has been pioneered by grassroots organisations for the poor: both approaches engage metrics, but the latter does so in a manner more focused on human well-being.

[119] Rosga and Satterwhaite, 'The Trust in Indicators' (n 44).

[120] See relatedly A Kleinman and J Kleinman, 'The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times' in A Kleinman and V Das (eds), *Social Suffering* (University of California Press 1997).

[121] L Waldorf, 'White Noise: Hearing the Disaster' (2012) 3 Journal of Human Rights Practice 469, 471.

conventional human rights practice of 'naming and shaming') been fuelled not just by the growth of international criminal law but also by the growth in number use in human rights work?

A further challenge for NGOs is that they are now expected to use indicators as a way of assessing their own impact.[122] Here, in the realm of performance indicators, one obvious risk is that NGOs may be tempted by projects that promise better and more immediate prospects of what Ian Gorvin of Human Rights Watch (HRW) calls 'champagne moments'.[123] As a leading international NGO, HRW has undoubtedly had many such moments. Hence it may not face the same pressures as others; even so, as Gorvin has explained, working in a world of self-evaluation remains complex:

> [F]or any issue where we get clear forward motion if not out-and-out success, there are dozens where we are confronting the entrenched and apparently intractable … With little expectation of a successful outcome anytime soon, how do we determine that we are having any impact at all? And what of those situations where we confront apparently relentless backsliding, and the best we might hope for is to try to hold the line and stop things getting worse.[124]

Gorvin goes on to make three other important points. First, successful human rights work often demands shared or collective advocacy, so how is an NGO to evidence its own *individual* contribution? Demands for this sort of evidence must not undermine ways of working collectively.[125] Second, evaluating and evidencing impact takes time. But from where or what is that time to be taken? Third, inside individual NGOs it is not just projects that will be evaluated; people, too, are subject to evaluation or 'performance assessment'. As such, as Gorvin has pointed out, 'evaluation of impact must be seen as distinct from personal performance evaluation if it is to be an honest and unbiased exercise about which staff can feel enthusiastic'.[126]

I want finally to say something about words, wounds and numbers—the trilogy I used to label this part of the chapter. I gestured towards this earlier, asking, 'What will happen when words find themselves in the company of numbers and, in light of our visual culture, of images too—notably images of wounds or other injuries?' In particular, are the numbers and images

[122] For a study of indicator use by humanitarian NGOs, see Satterwhaite (n 112).

[123] Gorvin (n 9) 480.

[124] Ibid.

[125] Especially where such collaboration is already under par: see P Alston and C Gillespie, 'Global Human Rights Monitoring, New Technologies and the Politics of Information' (2012) 23 European Journal of International Law 1089, 1119 arguing that the existing system, 'at least in some respects, could be characterized as fragmented, hierarchical, largely non-collaborative, and excessively shaped by organizational self-interest rather than a shared vision of the common good'.

[126] Gorvin (n 9) 480.

likely to speak louder than words? Human rights has long concentrated on words—as text, in, say, international instruments or national constitutions, and also by ‘giving voice’. But numbers and images could well seem easier to convey to diverse audiences. Are they not more objective, more reliable and, crucially, less political than words? Isn’t it the case that even familiar sayings stack up against words? How can words hope to compete when, for instance, ‘seeing is believing’ and ‘what gets measured gets done’?

It is more complicated, of course. Complementary co-existence between words, images and numbers may be possible, desirable even; each has its own particular strengths and weaknesses as a vehicle for justice. Equally, words in human rights work cannot be painted as always and everywhere positive. As we learn more about how audiences ‘do denial’[127] and also about why and how they take action when called upon to engage with violations of rights, we may well find that human rights appeals require more than words (or at least more than our conventional ways of communicating with words). Others have already been blunt on this point; amongst their number is the filmmaker behind Invisible Children’s ‘Kony 2012’ online video—the video that called for the arrest of Joseph Kony, alleged Commander-in-Chief of the Lord’s Resistance Army (LRA) in Uganda, so as to bring him before the International Criminal Court (ICC). ‘Kony 2012’ is, I have read, the most shared human rights video ever, watched by over 100 million people within six days of its release. Its filmmaker seems clear on what made it effective in this way: ‘No one wants a boring documentary on Africa. Maybe we have to make it pop, and we have to make it cool. We view ourself as the Pixar of human rights stories.’[128] Others, of course, insist that the video’s effectiveness came at the expense of ethics—specifically, the ethics of representation. Where, for instance, were the voices of Ugandans in the video?[129] Others again dispute the video’s effectiveness. ‘Kony 2012’ was widely shared, to be sure, but what was its effectiveness beyond that? Was it more about ‘clicktivism’, an utterly light touch, technologically-enabled form of human rights activism, than an actual engagement with child soldiering or the root causes of human rights violations?[130]

The missing voices of Ugandans in ‘Kony 2012’ raises another question relevant to the relationship between words, numbers and images in human

[127] See, eg, Cohen, *States of Denial* (n 22); IB Seu, ‘“Doing Denial”: Audience Reaction to Human Rights Appeals’ (2010) 21 Discourse & Society 438; IB Seu, ‘“Shoot the Messenger”: Dynamics of Positioning and Denial in Response to Human Rights Appeals’ (2011) 3 Journal of Human Rights Practice 139; L Chouliaraki, *The Ironic Spectator: Solidarity in the Age of Post-Humanitarianism* (Polity Press 2012).

[128] Quoted in Waldorf (n 121) 470.

[129] These voices were present in the follow-up video; it, however, was not so widely shared.

[130] For discussion, see ‘Review Essays: “Kony 2012 in review”’ (2012) 4 Journal of Human Rights Practice 461ff.

rights legal method: namely, human rights' own track record on 'giving voice'. For instance, how conscious has human rights reporting been of what one commentator calls the 'responsibility to the story'[131]—the responsibilities that lie beyond fact-checking, report-proofing and securing publicity? Human rights lawyers, some complain, play with people by playing with words. There can be considerable tension, it is true, between what is important in telling one's own story and what is seen as crucial if testimony for prosecution purposes or, more broadly, 'global reach' is the goal of the human rights advocate. Equally, for individual rights-claimants there can be impossible pressure to tell the story that seems likely to be heard by the relevant audience.[132] Moreover, once we move inside the courtroom, as a general rule, 'law's ways of knowing seem strange, out of touch, disconnected from the usual ways in which people acquire information or make decisions'.[133] The problem runs deep and wide: apparently some of the expert witnesses at the international criminal tribunals—experts drawn from history and the social sciences—want eventually to counter-claim, 'It is more complex than that.'[134]

There is work to be done here. For now, however, what I want to emphasise is that working within the legal idiom gives us no monopoly on the vocabularies of justice; others, too, use words, images and numbers to speak of violations, vulnerability and injustice. How, then, do these uses affect ours? And where is the engagement with this within human rights legal scholarship and practice? E-testimonies, for instance, seem to be ever-proliferating. Journalism, too, embraces more and more citizen voices. Even humanitarian organisations—organisations long associated with the principles of neutrality and impartiality[135]—are apparently now 'telling lives'. They have moved, Didier Fassin argues, from 'biology to biography': today, these organisations speak of suffering 'in the language of subjectivity',

[131] See 'Special Issue: "Responsibility to the Story"' (2010) 2 Journal of Human Rights Practice 177ff.

[132] See KB Sandvik, 'The Physicality of Legal Consciousness: Suffering and the Production of Credibility in Refugee Resettlement' in RA Wilson and RD Brown (eds), *Humanitarianism and Suffering: The Mobilization of Empathy* (Cambridge University Press 2009).

[133] A Sarat et al (eds), *How Law Knows* (Stanford University Press 2007) 2. See also LE White, 'Subordination, Rhetorical Survival Skills, and Sunday Shoes: Notes on the Hearing of Mrs. G' (1990) 38 Buffalo Law Review 1; C Sanger, 'Decisional Dignity: Teenage Abortions, Bypass Hearings, and the Misuse of Law' (2009) 18 Columbia Journal of Women and the Law 409.

[134] RA Wilson, *Writing History in International Criminal Trials* (Cambridge University Press 2011) 218.

[135] On the tensions between 'speaking out' and the principles of neutrality and impartiality that underpin humanitarianism, see P Redfield, 'The Impossible Problem of Neutrality' in E Bornstein and P Redfield (eds), *Forces of Compassion: Humanitarianism between Ethics and Politics* (SAR Press 2011).

not that of medicine or other expert discipline.[136] These developments complicate the use of words in human rights lawyering. Occupying a more crowded field, with competing speakers and competing vocabularies and vehicles of justice, raises the question: for what purpose are words used in human rights legal method?

Today some might answer this by reference to the apparent melding of human rights, international humanitarian law and international criminal justice—a phenomenon now described as the 'justice cascade'[137] or 'humanity's law'.[138] In these answers it is *human rights violations*—in particular successful prosecution of the perpetrators of mass atrocities—that move to the centre ground. What higher purpose could there be, these respondents will ask, for words, images and numbers, whatever their source? And what better way to galvanise and sustain a twenty-first-century global constituency of human rights activists? Cause, they will say, is what is crucial now. The integrity of individual branches of law, and their reach and purpose, have to take second place.

This justice cascade coincides moreover with rising concern about conventional fact-finding and reporting practices within human rights. For some, the NGO human rights report continues to stand out as a 'unique type of description', one that establishes its 'authority to speak' by '[l]etting credible facts speak for themselves; a non-emotional tone; and exclusion of all interpretive frameworks apart from international human rights law'.[139] Others, however, are less well-disposed towards extant practices of both NGO and UN fact-finding, emphasising that the 'nature, purpose and objectives' of these exercises call out for enquiry.[140] The stakes are undeniably high. On the one hand, more and more information is available, from increasingly diverse sources, amidst broadening opportunities for sharing and dissemination, and growing expectations concerning widening participation, prevention and rapid response. On the other hand, traditional human rights reporters (be that an NGO or a Special Procedure

[136] D Fassin, 'Inequality of Lives, Hierarchies of Humanity' in I Feldman and M Ticktin (eds), *In the Name of Humanity: The Government of Threat and Care* (Duke University Press 2010) 255. See also D Fassin, *Humanitarian Reason: A Moral History of the Present* (Rachel Gomme (trans), University of California Press 2011).

[137] K Sikkink, *The Justice Cascade: How Human Rights Prosecutions are Changing World Politics* (WW Norton & Co 2011).

[138] RG Teitel, *Humanity's Law* (Oxford University Press 2011).

[139] R Dudai, '"Can You Describe This?" Human Rights Reports and What They Tell Us about the Human Rights Movement' in Wilson and Brown (eds) (n 132) 250–51.

[140] UNGA, 'Report of the Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions, Philip Alston' (29 July 2009) UN Doc A/64/187, para 14. See further P Alston, 'The Challenges of Responding to Extra-Judicial Executions: Interview with Philip Alston' (2010) 2 Journal of Human Rights Practice 355; A Cassese, 'Gathering Up the Main Threads' in A Cassese (ed), *Realizing Utopia: The Future of International Law* (Oxford University Press 2012); C Moon, 'What One Sees and How One Files Seeing: Human Rights Reporting, Representation and Action' (2012) 46 British Journal of Sociology 876.

of the UN) who have experienced the hyper-scrutiny of reported facts cannot easily embrace new methods that might jeopardise the credibility of their work.[141]

Other aspects of human rights legal method have sustained criticism too. Indeed, for one commentator, the human rights movement 'degrades the legal profession'.[142] Its faults are, first, 'sloppy humanitarian argument' and, second, 'overly formal reliance on textual articulations that are anything but clear or binding'.[143] These criticisms have a particular sting amidst the proliferation of human rights texts at all levels, rising numbers of ESC rights cases and a growing sense that dialogue between courts, and between human rights actors more broadly, is not just possible but inevitable. These different developments raise a number of important questions, one of which is: what counts as a legitimate interpretive practice in human rights?

Human rights NGOs and expert groupings, in both reports and the statements of principle that have proliferated in recent years, generally cleave to international human rights law, but without saying so, they also push not just particular interpretations of existing law (sometimes particularly strong interpretations) but also new law.[144] Is that a legitimate human rights legal practice? It has also been said that in human rights reports, 'The law is applied in ways that helps the case; counter arguments are not necessarily engaged with full candor.'[145] Others, such as the UN agencies, the treaty bodies and the Special Procedures, engage in these practices too—albeit unevenly so and with the risk of backlash from states claiming to be irritated by misstatements of the law, by international actors who cannot stay within their mandates and by blatant disrespect for state sovereignty.[146] Again, the question is: can these practices be said to be legitimate?

The sanguine will say that each of these practices is sound, that ways have to be found to model, to induce, to nudge: this is part and parcel of persuasion and, ultimately, of norm development and cascade in human rights law. Furthermore, because treaties, constitutions and the like are living documents, they are open to being interpreted in an evolutive

[141] See further Alston and Gillespie (n 125).

[142] D Kennedy, 'The International Human Rights Movement: Part of the Problem?' (2002) 15 Harvard Human Rights Journal 101, 120.

[143] Ibid.

[144] Using the example of sexual rights, MJ Roseman and AM Miller, 'Normalizing Sex and Its Discontents: Establishing Sexual Rights in International Law' (2011) 34 Harvard Journal of Law & Gender 313, 338 describe such statements as 'both models and inducements' for governments and others.

[145] R Dudai, 'Advocacy with Footnotes: The Human Rights Report as a Literary Genre' (2006) 28 Human Rights Quarterly 783, 789.

[146] Both the current and former Special Rapporteur on the right to health have encountered this problem: see, eg, the reaction to Anand Grover's 2010 report examining how criminalisation of sex work, HIV/AIDS transmission and same-sex sexual conduct and orientation has impaired realisation of the right to health (27 April 2010) UN Doc A/HRC/14/20.

manner (indeed, some argue that human rights treaties, because they are non-reciprocal, merit their own particular modes of interpretation and that regional courts, notably the European Court of Human Rights (ECtHR), have demonstrated an interest in developing such practices[147]). Relatedly, on the legal institutional side, the International Criminal Court surely illustrates how a court can start out with relatively little authority to enforce its judgments yet can over time come to command far greater coercive authority.[148] The less sanguine will, of course, point out that with such practices, an expectations deficit, a backlash by states, or both, are on the cards as well. I cannot adjudicate between these stances here; but I will say that assessing interpretive practices and, more broadly, the place of words, images and numbers in human rights legal method requires us to focus on far more than what domestic courts are saying in health rights cases. Those judgments do of course merit close scrutiny, not least because judges may reach for indicators in an effort to give teeth to the remedies they prescribe. They are, however, far from being the whole of what should concern and occupy human rights legal method.

VI. CONCLUSION

I know that this chapter will have irritated some readers. Where, for instance, is the definite stance on quantitative indicators? Am I for or against this new human rights tool? Others will be irritated by the fact that throughout this book, I call for a stronger culture of evaluation within human rights legal method, yet here in this chapter I stop short of endorsing evaluation that might be facilitated by quantitative indicators.

In reply I would say the following: first, I have not dismissed or discarded indicators. I have simply tried to slow down the measurement juggernaut. Second, I have recognised that human rights work requires more than advocacy and that it can and should be done in a range of ways. These points are of course made throughout this book. Third, I have suggested that we should not be tallying the pros and cons of measurement by looking only at measurement practices. A better question is: what precisely is human rights *legal* method? And as I have explained, to answer that we need in turn to ask: what precisely is the place of words, wounds (or more broadly, images) and numbers, respectively, in this particular form of human rights method? Neither of these questions can be answered here. But I am going to use the next chapter, my final case study, to look more closely at the standing of words within human rights legal method.

[147] See, eg, *Tyrer v United Kingdom* (1978) Series A no 26.

[148] See J Hagan, R Levi and G Ferrales, 'Swaying the Hand of Justice' (2006) 31 Law & Social Inquiry 585.

5

The Dignity of Choice

I HAVE TWO aims in this chapter. I want first to show why reproductive choice can seem like a bad argument in debates about assisted reproductive technologies (ARTs). Second, I want to make the case for what I call the 'dignity of choice'. These aims mean that some, of course, have already cast what follows as pro-choice and prejudged it as entirely predictable. In a way, though, I have written the chapter for that very reason. I see choice as hemmed in—trapped by for-or-against framings that stem in part from human rights' slow progress in defining the rights to reproductive choice and reproductive health, and determining how such rights are best made real, and in part too from the grip of the legal on how we see and think about the right to choose. In this chapter, I explore this hemming-in and make a proposal to bring it to an end.

The chapter develops as follows. Section I assesses the standing of reproductive rights and offers a set of lessons learned. Section II builds on this, prescribing two routes ahead. It also explains why just one of the routes becomes the focus in the remainder of the chapter. Next, in section III I offer a further, more directed diagnosis, exploring what makes reproductive choice seem like a flawed argument today. That diagnosis leads in turn to the prescription in sections IV and V: human rights legal method must draw out and defend the dignity of choice. One way of doing this, I suggest, is to engage with choice 'in action' in ARTs, and this in turn means that human rights needs to engage with ethnographic work and perhaps ethnographic method too.

I. SLOW PROGRESS

Let's start though with reproductive rights here and now, beginning with the imprint of criminalisation on the area. We know, for instance, that lifting restrictive abortion laws does not necessarily lift restrictive attitudes on the part of families, of health professionals or of local decision-makers more generally—at least not straight away and certainly not without due care both to the terms of the new law and, relatedly, to access in practice. In the case of ARTs, too, the question of limits—of what should be out of bounds, cordoned off ideally by the criminal law—can seem both ever

present and ever dominant. The need for 'red lights' is frankly the abiding preoccupation in the field (though, as we shall see, this does not mean that limits are always imposed in practice, or that they should be).[1]

What is also clear is that in certain parts of the world, in law on reproduction—and especially in legal adjudication—it can be hard to get past duelling rights claims. Moreover, getting past such claims can be more damaging still. Take the recent US twist on women's rights which says that in order to prevent harm to health professionals and to women themselves, the opportunity to choose abortion needs to be excluded in certain contexts.[2] Equally, take South Africa's Choice on Termination of Pregnancy Act 1996: a much lauded statute but one that opted to say nothing about health providers' rights to conscientious objection. That silence means the standard for refusal is unclear, and that in turn has led to both court challenges and under-regulation of the discretion exercised by local health providers.[3]

The rising and very welcome focus on maternal mortality reduction following its selection as a Millennium Development Goal (MDG)[4] is another case in point. Maternal mortality is a field where the technical now prevails—a field dominated by indicators and management approaches that have proved problematic in practice. Historically, maternal mortality reduction was a good indicator of 'all the elements of reproductive health'. However, following its selection as MDG 5, there was a 'zooming in on maternal health care, often with the justification of ensuring that mothers should remain alive for their children'[5] and in turn a zooming in on delivery care by skilled attendants as the way to achieve and also to evidence this. But what this loses sight of is that 'maternal health is in fact about pregnancy and the outcome of the pregnancy—be it the delivery of a living child, stillbirth, induced abortion, or miscarriage'.[6] Put differently, what has been lost is the importance of reproductive and sexual health, of maternal

[1] See below, text to nn 88–89.

[2] See *Gonzales v Carhart* 550 US 124 (2007).

[3] See further R Rebouché, 'The Limits of Reproductive Rights in Improving Women's Health' (2011) 63 Alabama Law Review 1.

[4] See also International Covenant on Economic, Social and Cultural Rights (16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (hereafter 'ICESCR') art 12(2)(a); Convention on the Rights of the Child (20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (hereafter 'CRC') art 24(2)(d); Convention on the Elimination of All Forms of Discrimination against Women (18 December 1979, entered into force 3 September 1981) 1249 UNTS 13 (hereafter 'CEDAW') art 12(2). On CEDAW art 12(2), see *Alyne da Silva Pimental Teixeira v Brazil* (10 August 2011) UN Doc CEDAW/C/49/D/17/2008.

[5] B Austveg, 'Perpetuating Power: Some Reasons Why Reproductive Health Has Stalled' (2011) 19 Reproductive Health Matters 26, 28. See also AE Yamin and KL Falb, 'Counting What We Know; Knowing What to Count: Sexual and Reproductive Rights, Maternal Health, and the Millennium Development Goals' in M Langford and S Fukuda-Parr (eds), 'Special Issue: Quantifying Human Rights' (2012) 30 Nordic Journal of Human Rights 222 ff.

[6] Ibid. In 2005 the UN General Assembly added a new target to MDG 5—target 5b, which calls for universal access to reproductive health by 2015. But as Austveg has pointed out, this came late, and many states had already chosen to focus on delivery care by skilled attendants.

health that isn't reduced to keeping mothers healthy for the sake of their children and of mothers' health that isn't evidenced simply by skilled attendance at birth.

The desire to achieve maternal mortality reductions generates other exclusions too. Morbidity can be neglected, for instance. And where health maximisation is the focus, women living in remote or rural areas with a high maternal mortality ratio can be neglected in favour of the better statistics that will flow from targeting areas with the largest aggregate number of deaths. Moreover, even with its status as an MDG, maternal mortality reduction has not been proceeding at the hoped-for pace. Pace has, of course, been a problem elsewhere too: the UN General Assembly recently accepted that the Programme of Action from the International Conference on Population and Development—the key output from the 1994 Cairo conference, which was acclaimed as transformative for population and development policy[7]—will not be met by the 2014 deadline. By way of response, the General Assembly has called for governments to recommit to the ICPD Programme's goals and objectives; however, it has also granted an indefinite extension to the deadline for meeting them.[8]

What should we take from all of this? One lesson is that understanding how claims concerning the right to reproductive choice and the right to reproductive health are best structured is crucial. Another related lesson is that reproductive rights must encompass both; they must include both liberty, or decisional autonomy, and reproductive health. And human rights also needs to understand and explain why the rights to equality and non-discrimination[9]—more than this, a constellation of rights[10]—are relevant

Moreover, the indicators chosen to meet the new target, though laudable, may not be sufficient to prompt sector-wide change in health services.

[7] International Conference on Population and Development, Cairo, Egypt, 5–13 September 1994, 'Report of the International Conference on Population and Development' (18 October 1994) UN Doc A/CONF.171/13 (hereafter 'ICPD').

[8] UNGA Res 65/234 (21 December 2010) UN Doc A/65/L.39/Rev.2.

[9] See, eg, C Ngwena, 'Inscribing Abortion as a Human Right: The Significance of the Protocol on the Rights of Women in Africa' (2010) 32 Human Rights Quarterly 783, criticising the UN Human Rights Committee's (HRC) failure to engage with the equality claim in *KL v Peru* (22 November 2005) UN Doc CCPR/C/85/D/1153/2003. See relatedly S Cusack and RJ Cook, 'Stereotyping Women in the Health Sector: Lessons from CEDAW' (2010) 16 Journal of Civil Rights and Social Justice 47.

[10] The ICESCR does not make explicit reference to sexual and reproductive freedom; however, the Committee on Economic, Social and Cultural Rights (CESCR) has said that the right to control one's health and body must extend to sexual and reproductive freedom: see CESCR, 'General Comment No 14: The Right to the Highest Attainable Standard of Health (art 12)' (11 August 2000) UN Doc E/C.12/2000/49, para 8. See also Committee on the Rights of the Child (CRC Comm), 'General Comment No 15: The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art 24)' (17 April 2013) UN Doc CRC/C/GC/15 para 24. Other treaties do have explicit references: see the Convention on the Rights of Persons with Disabilities (13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (hereafter 'CRPD') art 25(a); Protocol

to reproduction. The rights in this constellation might not always have an explicit coupling in constitutions or international instruments, but choice will not be protected by focusing only on the right to privacy—neither will health or life or the right to live free from violence. To put all of this differently, the language of rights-claiming matters—especially when rights in practice, not just in principle, are the end goal.

Life—the right to life—is also relevant to abortion in ways that are rarely if ever raised by anti-abortion campaigners. Human rights law places positive duties on states to prevent danger to life: this means that restrictive abortion laws which force millions of women into unsafe abortions that lead to their deaths are far more than a tragedy. Unsafe abortion has of course been a major focus of human rights campaigning in recent years; this has been crucial—unsafe abortion kills and injures women. But this focus may need to be reworked now that medical abortion pills (often known as 'early medical abortion') offer what has been described as 'safer "unsafe abortion"'.[11] The ensuing human rights challenges are substantial. For instance, will decriminalisation be side-lined as states determine that the public health reasons for changing strict abortion laws—namely, to reduce rates of mortality and morbidity associated with unsafe abortion—can now be met by leaving women to procure early medical abortion? Other challenges include the thriving market in fake pills, the accessibility of genuine pills and how to get safer-use information to women who intend to self-administer these pills.

Let's take a moment to look at the question of safer-user information. It is clear that the right to health includes the right to seek, receive and impart information; information must also be accessible to all.[12] Equally, in *Open Door Counselling and Dublin Well Woman v Ireland*, the European Court of Human Rights (ECtHR) found that an injunction that prohibited counsellors from giving to women in Ireland information on lawful abortion services in the United Kingdom violated the freedom to receive and impart information.[13] But there are still questions: notably, what are the human rights obligations of states and health providers when it comes to imparting information to women who are not eligible for *lawful* abortion—women whose self-administration of abortion pills will constitute unlawful abortion but, crucially, an abortion that is far less likely to kill or seriously injure them than other clandestine forms? Moreover, given both the risks involved

to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (13 September 2000, entered into force 25 November 2005) OAU Doc CAB/LEG/66.6 (hereafter 'Maputo Protocol') art 14.

[11] See JN Erdman, 'Access to Information on Safer Abortion: A Harm Reduction and Human Rights Approach' (2011) 34 Harvard Journal of Law and Gender 413.

[12] CESCR, 'General Comment No 14' (n 10) para 12(b).

[13] *Open Door Counselling and Dublin Well Woman v Ireland* (1992) 15 EHRR 244.

and the importance of self-determination, should more attention be paid to ways of imparting safer-use information other than through the patient–health professional relationship—eg, through safe abortion hotlines as promoted by the non-governmental organisation (NGO) Women on Waves or through email advice as provided by the NGO Women on Web?[14]

What other lessons might be learned from the recent history of reproductive rights? I hinted at one earlier: sexual, reproductive and maternal health is more than mothers' health for the sake of their children. Secondly, reproductive health and rights and sexual health and rights are not the same thing. Thirdly, neither states nor human rights itself seem sufficiently alert to the contradictions that can exist between ART law and abortion law (including on questions concerning disability[15]) or to the burden of 'responsible reproduction' that faces individuals and couples amidst rising access to prenatal and pre-implantation technologies.[16] Fourthly, the potential of public health, or population, approaches to sexual and reproductive rights seems to have been neglected within human rights. This means, for instance, that we have a poor appreciation of the relationship between harm reduction approaches and their human rights counterpart. In places, it has also meant that ground has been ceded to opponents of rights—consider the success that US anti-abortion advocates have had with the claim that abortions are harmful to women, convincing the US Supreme Court in *Gonzales v Carhart* that a ban on partial birth abortion is justified because it is 'women-protective'.[17] Fifthly, reproductive, sexual and maternal health are not matters that can be dealt with through management alone: indicators and other evidence-based approaches have a role, but if human rights turns to these in order to turn away from the politics of these forms of health, we are simply ducking what has to be faced.[18]

[14] Women on Waves (www.womenonwaves.org) is best known for providing medication abortions in a clinic on board a ship in international waters. See *Women on Waves and others v Portugal*, App no 31276/05 (Judgment of 3 February 2009, ECtHR). Women on Web describes itself as a 'digital community of women who have had abortions and individuals and organizations that support abortion rights': see www.womenonweb.org/en/page/521/about-women-on-web. Note also CRC Comm, 'General Comment No 15' (n 10) para 70: 'The Committee recommends that States ensure access to safe abortion and post-abortion care services, irrespective of whether abortion itself is legal.'

[15] *Cf Costa and Pavan v Italy*, App no 54270/10 (Judgment of 28 August 2012, ECtHR).

[16] See generally I Karpin and K Savell, *Perfecting Pregnancy: Law, Disability and the Future of Reproduction* (Cambridge University Press 2012).

[17] *Gonzales* (n 2). See further WE Parmet, 'Beyond Privacy: A Population Approach to Reproductive Rights' in JG Culhane (ed), *Reconsidering Law and Policy Debates: A Public Health Perspective* (Cambridge University Press 2011); BM Meier, KN Burgh and Y Halim, 'Conceptualizing a Human Right to Prevention in Global HIV/AIDS Policy' (2012) 5 Public Health Ethics 263.

[18] *Cf* United Nations Development Programme (UNDP), 'Who's Got the Power? Transforming Health Systems for Women and Children', Millennium Project, Child Health and Maternal Health (UNDP 2005), which does not displace political problems and solutions but rather places them centre stage.

The problem of 'stratified reproduction'[19] also looms large. This chapter may be about ARTs, a mode of reproduction used principally by the growing number of individuals and couples who are affected by infertility, but high *fertility* is a serious problem too—so serious that some 215 million women continue to have an unmet need for contraception; and in 2010, almost 300,000 women died during pregnancy and childbirth.[20] Moreover, even in states where restrictive abortion laws have been lifted and access to contraception and ARTs is facilitated, choice can be far from a reality. Paradoxically, law's own processes for protecting choice—its modes for informed consent, for instance—can undermine dignity and reinforce inequality.[21] At times, choice itself has these effects. Consider the high rate of sex-selective abortions in certain states:[22] these abortions take place because foetuses are female; thus they represent a choice that compounds negative stereotypes about the value of female life and discriminates against it. There is also a tendency for particular legal models to dominate, which can lead to neglect of the cultural considerations that affect choice—for instance, the stigma of childlessness. Designing new law by focusing above all on the problems experienced elsewhere (notably in the United States) has been damaging too.

There have, it is true, been success stories. Consider Nepal, for instance, where a strict anti-abortion law was liberalised in 2004, following collaboration between the government and a range of stakeholders. Equally, there is the striking obligation in the Maputo Protocol, which calls on states to 'ensure that the right to health of women, including sexual and reproductive health is respected and promoted'.[23] On the other hand, the case law of both regional and international human rights bodies makes it very clear that serious human rights violations—such as non-consensual sterilisation of particular groups of women—continue to occur.[24] More generally,

[19] For this term, see FD Ginsburg and R Rapp (eds), *Conceiving the New World Order: The Global Politics of Reproduction* (University of California Press 1995). See also CH Browner and CF Sargent (eds), *Reproduction, Globalization, and the State* (Duke University Press 2011).

[20] See respectively WHO factsheet on 'Maternal Mortality' (May 2012), http://www.who.int/mediacentre/factsheets/fs348/en/index.html; S Singh et al, 'Adding It Up' (Guttmacher Institute/UN Population Fund 2009).

[21] See C Sanger, 'Decisional Dignity: Teenage Abortions, Bypass Hearings, and the Misuse of Law' (2009) 18 Columbia Journal of Women and the Law 409. On problems more generally with informed consent, see J Montgomery, 'Law and the Demoralisation of Medicine' (2006) 26 Legal Studies 185; D Beyleveld and R Brownsword, *Consent in the Law* (Hart Publishing 2007); NC Manson and O O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge University Press 2007). For an ethnographer's perspective, see A Mol, *The Logic of Care: Health and the Problem of Choice* (Routledge 2008).

[22] See J Drèze and A Sen, *India: Development and Participation* (2nd edn, Oxford University Press 2002) 257–62. Distinguishing sex-selective abortion from IVF, see RM Dworkin, *Sovereign Virtue* (Harvard University Press 2000) 433.

[23] Maputo Protocol (n 10).

[24] See *María Mamérita Mestanza Chávez v Peru*, Case 12.191, Report no 71/103, Inter-Am CHR (22 October 2003) OEA/Ser.L/V/II.118 Doc.5, rev.2 (friendly settlement); *AS v Hungary*

reproductive health seems neglected, at least by comparison with some other aspects of health rights, and choice is often more a right in principle than in practice—unless one has information[25] and the means to pay.[26] Travelling to exercise reproductive rights raises difficult questions too. When this travel involves crossing state borders, it is sometimes cast as 'circumvention tourism': it can of course have that aspect, but it can also be an escape hatch for home states—a way of exiling particular problems and, thus, particular people too.[27] The position of host states also calls for examination: are they, for instance, dressing up largely unregulated markets as evidence of a commitment to reproductive rights?

There is one final lesson related to stratified reproduction that I want to mention: the HIV/AIDS pandemic has produced stratifications to which reproductive rights advocates have not always been attuned. HIV/AIDS prevention, care and treatment hardly registered at the 1990s ICPD in Cairo. Even today the reproductive rights of people living with HIV tend to be neglected by many reproductive health advocates. Consider, for instance, the irony that in South Africa, where there is now a liberal abortion law, 'nurses often put pressure on women living with HIV to have abortions or to be sterilized after giving birth, not out of support for women's right to make reproductive choices, but as a result of the stigma of HIV and AIDS'.[28] Equally, it is only recently that an integrated approach has been proposed for HIV/AIDS and maternal mortality and morbidity.[29]

(14 August 2006) UN Doc CEDAW/C/36/D/4/2004; *VC v Slovakia*, App no 18968/07 (Judgment of 8 November 2011, ECtHR).

[25] On information, see CEDAW Committee, 'General Recommendation No 24: Women and Health (art 12)' (5 February 1999) UN Doc A/54/38/Rev.1.

[26] Minors seeking to make decisions about reproductive health and rights can face additional obstacles, including rules requiring parental notification or consent, which may invoke the right of parents 'to ensure the religious and moral education of their children in conformity with their own convictions': see International Covenant on Civil and Political Rights (16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (hereafter 'ICCPR') art 18(4). *Cf* CRC (n 4) arts 5, 16 and 24; Committee on the Rights of the Child, 'General Comment No 4: Adolescent Health' (1 July 2003) UN Doc CRC/GC/2003/4, paras 26, 28 and 30–33; *P and S v Poland*, App no 57375/08 (Judgment of 30 October 2012, ECtHR); CRC Comm, 'General Comment No 15' (n 10) esp paras 56 and 69. See generally JN Erdman, 'Moral Authority in English and American Abortion Law' in S Williams (ed), *Constituting Equality: Gender Equality in Comparative Constitutional Rights* (Cambridge University Press 2009).

[27] See, eg, S McGuinness, 'A, B, and C leads to D (for Delegation!)' (2011) 19 Medical Law Review 476, criticising the response of the ECtHR in *A, B and C v Ireland* [GC], App no 25579/05 (Judgment of 16 December 2010) to Ireland's treatment of women seeking abortions. See generally IG Cohen, 'Circumvention Tourism' (2012) 97 Cornell Law Review 1309.

[28] B Klugman, 'Effective Social Justice Advocacy: A Theory-of-Change Framework for Assessing Progress' (2011) 19 Reproductive Health Matters 146, 158.

[29] S Fried et al, 'Integrating Interventions on Maternal Mortality and Morbidity and HIV: A Human Rights-Based Framework and Approach' (2012) 14(2) Health and Human Rights: An International Journal 1, 2.

II. WHERE TO FROM HERE?

The question is: where do we go from here? I see two interconnected routes. The first would develop the rights to reproductive choice and reproductive health. Developing these rights means attending to law.[30] It means attending to lessons learned from prior and extant laws, and to the lessons that still need to be learned. It also means attending closely to the elaboration of the General Comment on reproductive and sexual health and rights that has been promised by the CESCR, and to any similar work by, say, the Committee on the Rights of the Child or the Committee on the Elimination of Discrimination against Women (the CEDAW Committee).[31] In similar vein, close attention has to be paid to the work that is being done by human rights courts and quasi-courts, such as the ECtHR and the CEDAW Committee, to make access to contraception and abortion more than paper rights, to stop non-consensual sterilisation and to guide states in rights-based regulation of ARTs.[32] More thought also needs to be given to the relationship between reproductive health and rights, on the one hand, and family planning and population, on the other: the Cairo ICPD model should not be abandoned, but it does need to engage far more openly with the continuing appeal of claims focused on family planning and population.

This first route means attending to practicalities too. It is all too easy to think of human rights lawyers as crucial to the drafting of legal rules but, by and large, beside the point when it comes to implementation. In so doing, rights 'in principle' can become all-important, and the very same rights 'in practice' tend to be neglected. This needs to be addressed: practicalities are crucial. Certification requirements (needing two or three doctors to

[30] Examples of pioneering work include RJ Cook, BM Dickens and MF Fathalla, *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law* (Oxford University Press 2003); UN Commission on Human Rights (UNCHR), 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Paul Hunt' (16 February 2004) UN Doc E/CN.4.2004/49; UN General Assembly (UNGA), 'Report of the Special Rapporteur on the Right of Everyone to Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Anand Grover' (3 August 2011) UN Doc A/66/254. See also S Corrêa, R Petchesky and R Parker, *Sexuality, Health and Human Rights* (Routledge 2008): though not focused on law per se, it offers penetrating analysis of the effects of rights.

[31] See, eg, the latter's inquiry into the Philippines regarding a Manila City Executive Order that prohibited the distribution of hormonal contraceptives in public health services (report pending).

[32] Both the ECtHR and the HRC have held states liable when access to legal abortion services was not possible in practice: see *Tysiąc v Poland* (2007) 45 EHRR 42; *RR v Poland* (2011) 53 EHRR 31; *P and S* (n 26); *KL* (n 9). In the Inter-American system, *Paulina del Carmen Ramírez Jacinto v Mexico*, Case 161-02, Report no 21/07, Inter-Am CHR (9 March 2007) OEA/Ser.L/V/II.130 Doc.22, rev.1, a friendly settlement before the Inter-American Commission on Human Rights led to a state ministry issuing a circular calling on public institutions to secure lawful abortion.

support the need for an abortion), for instance, will make lawful abortion inaccessible if doctors are in short supply.[33] Similarly, where there is little or no regulation of conscientious objection by providers, that will tend to compromise law's efforts towards 'conscientious commitment' to women's health.[34]

The second route I have in mind should be seen as an essential complement to the first. It calls for another point of reference—one that might be described as the 'story'. It proposes, in other words, that ethnographic work (and perhaps ethnographic method too) should be part of human rights legal method. It insists that we need to draw out and defend the responsibility of reproductive decision-making. One way of doing that is to draw out and defend the dignity of choice, doing so by reference to the stories of actual decision-makers—not the judges, advocates, campaigners or philosophers with whom we are familiar but instead the individuals and couples who are making, or want the opportunity to make, reproductive choices.

In what follows I focus on this proposal, using ethnographic studies of ART users (mostly from the United Kingdom and the United States). I have chosen to look at ARTs rather than abortion or contraception for a number of reasons. One such reason is the high profile of the latter in human rights law work: I have no desire to detract from that,[35] but ARTs too have to be seen as relevant to reproductive rights. Moreover, as I explain below in section III, how we think about and regulate abortion affects ARTs and vice versa. And as I explain towards the end of the chapter, ethnographies of users and would-be users of ARTs seem an ideal starting point for human rights legal method as it takes its first steps with a new mode of enquiry.

I want to be clear about a number of further points. Drawing out the dignity of choice will not eliminate conflict. It will not temper the unarguable quality of certain positions on choice. And it will not lead to universal celebration of choice. That is no bad thing. Health services such as abortion and ARTs raise questions about which people care deeply and about which they disagree. For these and other reasons, access to abortion or to ARTs is never going to be law-free. Moreover, from a human rights perspective,

[33] See HRC, 'Concluding Observations: Zambia' (20 July 2007) UN Doc CCPR/C/ZMB/CO/3, para 18.

[34] B Dickens and R Cook, 'Conscientious Commitment to Women's Health' (2011) 113 International Journal of Gynecology and Obstetrics 163.

[35] The Vatican, a range of states and 'pro-family' NGOs, active at the UN and elsewhere, denounce reproductive rights as a covert reference to abortion and, more generally, an attack on motherhood and the 'natural' family: see D Buss and D Herman, *Globalizing Family Values: The Christian Right in International Politics* (University of Minnesota Press 2003); F Girard, 'Advocacy for Sexuality and Women's Rights: Continuities, Discontinuities, and Strategies Since ICPD' in L Reichenbach and MJ Roseman (eds), *Reproductive Health and Human Rights: The Way Forward* (University of Pennsylvania Press 2009); JW Muthumbi, *Participation, Representation, and Global Civil Society: Christian and Islamic Fundamentalist Anti-Abortion Networks and United Nations Conferences* (Lexington Books 2010).

going law-free would not be a good thing: it would, for instance, leave the dignity of choice under-defended.

III. WHY DOES REPRODUCTIVE CHOICE FEEL LIKE A BAD ARGUMENT?

To reach the next stage in my argument I need to revert to preliminaries. I began by saying that reproductive choice can feel like a bad argument; I need now to explain and justify that claim. So what, then, is a bad argument? One contender might be an argument that gets choked by controversy; another would be an argument that does not seem to fit the facts. In what follows, I test reproductive choice against these standards. The argument develops over two sections: the first looks at intersections or overlaps between abortion and ARTs, between different forms of ART and, relatedly, between treatment and research, noting how these can envelop ARTs in controversy; the second explores aspects of ARTs in practice that seem far from any commonsense notion of 'choice'.

A. Choked by Controversy

To suggest that reproductive choice is the 'abortion argument' is to risk immediate counter-argument; moreover, it is easy to see why. Claims grounded in reproductive choice have not been limited to the abortion setting: they have also been central and indeed widely accepted in debates about access to contraception. In addition, a range of scholars, including Ronald Dworkin, Emily Jackson and John Robertson, appeals to reproductive autonomy in arguing for a right to self-expression in reproductive matters.[36] On the other hand, there is also an almost relentless association of choice with abortion, and this does tend to cause problems for choice in other reproductive contexts, including ARTs.

Furthermore, when *in vitro* fertilisation (IVF) is allowed to lead to a high multiple pregnancy rate, 'selective reduction' has to be considered. Reduction can be essential to protect a woman's health and also her life; it also increases the chance of a full-term pregnancy and a live birth, and reduces the risk of spontaneous abortion. Hence the challenge is: how to enable multi-foetal pregnancy reduction to be seen 'not as abortion per se,

[36] See, eg, R Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins 1993); J Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton University Press 1994); E Jackson, *Regulating Reproduction* (Hart Publishing 2001).

which ends pregnancy, but as a means of preserving pregnancy against the danger of spontaneous abortion of all embryos or foetuses in utero'?[37]

Interestingly, the intersection between ARTs and abortion has already surfaced in international human rights law.[38] In 2004, the Inter-American Commission on Human Rights admitted a case that involved a challenge to a decision of the Costa Rican Constitutional Chamber prohibiting the use of IVF. The Chamber's ruling said that fertilised eggs (embryos) have a right to life, and given the high risk of embryos being discarded in IVF, the technology needed to be banned to give effect to that right; it also claimed that the American Convention on Human Rights (ACHR)[39] supported its stance. A continuum was thus produced between protection of the life of a foetus and that of the fertilised ovum. IVF, in short, became linked to abortion law and to abortion politics. In 2010, the Inter-American Commission on Human Rights ruled that this complete ban on IVF was incompatible with the ACHR: it violated the rights of private and family life and the right to form a family under articles 11 and 17 of the Convention. It also constituted discrimination against infertile individuals. The Commission called upon Costa Rica to lift the ban within a specified period of time. Costa Rica did not comply, however, so the Commission brought the case before the Inter-American Court of Human Rights. The latter handed down its ruling in late 2012, and like the Commission, it found the ban incompatible with the ACHR. It found violations of the rights to privacy, liberty and personal integrity, as well as of the right to form a family. It also found that obstructing access to reproductive health services violated the right to be free from discrimination.[40]

Overlap with abortion is, however, not the only problem facing reproductive choice arguments in the field of ARTs: there are also problems generated by the overlap between reproductive technologies and genetic technologies, and between treatment and research. Take, for example, the coupling of pre-implantation genetic diagnosis (PGD) with IVF or the use of 'spare' IVF embryos in research. These practices introduce debate about a whole new set of limits, taking us from IVF as 'assisting nature' towards a host of concerns about science racing ahead, playing God and the consequences of 'sheer choice'. Such concerns tend to close down low-key depictions of ARTs as a helping hand to nature: in their place, we have

[37] Cook, Dickens and Fathalla (n 30) 307.

[38] See also *Costa and Pavan* (n 15).

[39] American Convention on Human Rights (22 November 1969, entered into force 18 July 1978) 1144 UNTS 123 (hereafter 'ACHR').

[40] *Gretel Artavia Murillo and others v Costa Rica*, Case 12.361 (Judgment of 21 December 2012, Inter-Am CtHR). The Court's judgments are legally binding for states parties to the ACHR.

increasing anxiety about 'rogues and red lights' and the imminence of a 'genetic supermarket'.[41]

This may sound like a case of 'back to the future', and in some ways, it is. In others, though, it is not. There are new elements, including the fact that since the birth of Louise Brown, the world's first 'miracle baby', more than 5 million children have been born as a result of IVF. This number certainly helps to naturalise ARTs, but it also helps to explain why the human embryo has been provoking fresh concern: higher numbers using ARTs means higher numbers of embryos that are surplus to treatment—embryos that are stored, shared, used to progress research or allowed to perish. Another new element is increased migration of people and bodily material (notably, ova), as well as increasing concern about not just the appropriateness of extant state engagements with these phenomena but also the potential impossibility of effective regulation.[42]

There is also a broader concern about the continuing rise of patient autonomy. For some, as we saw in chapter one, patient autonomy is out of control; it has become a burden on health systems, on health professionals and professionalism, and also on patients themselves. That concern has its own local manifestations in the field of IVF, ranging from worries about exploitation of reproductive needs and reproductive material such as ova, to worries about demanding parents insisting upon 'bespoke' babies or, rather differently, worries about social context being forgotten amidst a roll-out of informed consent as an ethical universal with the power to protect and promote would-be parents' rights anywhere and everywhere.

B. Reproductive Choice Does Not Seem to Fit the Facts of Assisted Reproductive Technologies

In what follows I build on these latter points, asking: does reproductive choice fit the facts of ARTs? I start with the question 'Reproductive choice for whom?', examining aspects of contemporary discourses on choice for women and for men; thereafter, I move to a cluster of other reasons— from cost to success rates—which seem to make ARTs an odd sort of choice.

[41] See respectively R Brownsword, 'Red Lights and Rogues: Regulating Human Genetics' in H Somsen (ed), *The Regulatory Challenge of Biotechnology: Human Genetics, Food, and Patents* (Edward Elgar 2007); R Nozick, *Anarchy, State and Utopia* (Basic Books 1974) 315.

[42] See, eg, C Waldby and M Cooper, 'From Reproductive Work to Regenerative Labour: The Female Body and the Stem Cell Industries' (2010) 11 Feminist Theory 3; Cohen (n 27); I Turkmendag, 'Home and Away: The Turkish Ban on Donor Conception' (2012) 2 Law, Innovation and Technology 144.

Reproductive Choice for Whom?

To give a full answer to the question 'Reproductive choice for whom?' would be a complex task, one that would take us in different directions. Here, however, I am going to limit my focus to gender equality, asking the further question 'Are *equal* rights to reproductive choice as between women and men possible or desirable in the context of ARTs?' It seems fair to say that reproduction is widely considered to be a matter of concern more for women than for men. A similar assumption seems, moreover, to have attached itself to assisted reproduction—in part because ARTs claim women 'as their primary patients, even when there is male-factor infertility'; generally speaking, 'men just aren't around as much because they aren't required for most of the procedures'.[43] By and large, then, men have been seen as fathers-to-be, with choices and responsibilities that kick in around birth (eg, the decision whether to be present during labour and delivery).[44] So does it follow that we think of men as having choice but not *reproductive* choice? Put differently, do we—and the law—reflect and reinforce the view that reproductive choice is gender-specific, not gender-neutral—that it is a 'woman thing' (albeit that for women this choice has been 'respected more in the breach than in the observance')?[45]

If so, there is evidence that the picture is changing. In some parts of the world, fathering is now a personal and a political imperative. Men 'find themselves called upon to make "responsible" reproductive choices, not just in avoiding unwanted pregnancy, but also in taking appropriate measures to safeguard their own reproductive health and to avoid conception of a child likely to suffer from illness or disability'.[46] Technology seems to be part of the reason for this, not least because future technologies—ectogenesis, for example—raise the possibility of a *de-gendering* of reproduction.[47] In part too, in today's ARTs, men's bodies are more visible following the development of techniques such as intracytoplasmic sperm injection (ICSI), which tackles severe male-factor infertility.[48] Also, the evidence suggests

[43] C Thompson, *Making Parents: The Ontological Choreography of Reproductive Technologies* (MIT Press 2005) 120.

[44] See further S Sheldon, 'Reproductive Choice: Men's Freedom and Women's Responsibility?' in JR Spencer and A Du Bois-Pedain (eds), *Freedom and Responsibility in Reproductive Choice* (Hart Publishing 2006).

[45] J Harris, 'Rights and Reproductive Choice' in J Harris and S Holm (eds), *The Future of Human Reproduction: Ethics, Choice and Regulation* (Oxford University Press 1998) 5. See generally RJ Cook and S Cusack, *Gender Stereotyping: Transnational Legal Perspectives* (University of Pennsylvania Press 2010).

[46] Sheldon, 'Men's Freedom and Women's Responsibility?' (n 44) 195. See further R Collier and S Sheldon, *Fragmenting Fatherhood: A Socio-Legal Study* (Hart Publishing 2008).

[47] For a sceptical response, see E Jackson, 'Degendering Reproduction?' (2008) 16 Medical Law Review 346.

[48] Such techniques have opened up ARTs in states where donor conception—especially donor sperm—had been considered unacceptable: see further MC Inhorn, *The New Arab*

that within clinics, women—whether as partners or employees—work hard at finding ways to 'include' men, partly because of a perception that 'manliness' needs to be restored or secured.[49]

A range of legal rules adds to this sense of a changing picture. In some jurisdictions there are rules obliging genetic fathers to pay child support, as well as rules designed to capture the identity rights, or 'right to genetic truth', of children born via assisted reproduction.[50] There is also relevant case law from a range of domestic courts and from the ECtHR. One early example, *R v Human Fertilisation and Embryology Authority, ex parte Blood*,[51] decided in the United Kingdom in 1997, did not augur well for men's reproductive choice. The case arose when Diane Blood applied for judicial review of the decision of the UK regulatory body for ARTs, the Human Fertilisation and Embryology Authority, refusing permission for her to use the sperm of her deceased husband, Stephen, to try to conceive via assisted reproduction either in the United Kingdom or elsewhere in the European Union.

Mrs Blood's application was successful. The Court of Appeal, emphasising that the case was a one-off, directed the Authority to reconsider the issue, this time taking proper account of Mrs Blood's EU free movement rights. The Authority followed the Court's direction and determined that Mrs Blood should be permitted to export the sperm to another EU Member State. Mrs Blood subsequently travelled to Belgium, where the law permitted treatment in the absence of Stephen Blood's written consent, and there she received assistance to conceive two children.

The case can be read in different ways. The Court of Appeal, as I have said, was at pains to emphasise that it was one-off and that its judgment was not to be treated as a precedent. The dominant popular account applauded the ruling, contrasting the Court's decency and common sense in helping Mrs Blood to give effect to her and her dead husband's desires, with what was seen as a lack of humanity on the part of the Human Fertilisation and Embryology Authority. There was also a third cluster of responses. These queried the export decision, noting that the Court of Appeal and, in turn, the Authority had given insufficient attention to the grounds on which EU

Man: Emergent Masculinities, Technologies, and Islam in the Middle East (Princeton University Press 2012); MC Inhorn and S Tremayne (eds), *Islam and ARTs: Sunni and Shia Perspectives* (Berghahn Books 2012).

[49] See, eg, Thompson (n 43).

[50] Human rights, in part because it champions truth, openness and transparency, needs to look more closely at this trend: eg, what should a human rights stance on family secrets look like? See generally C Smart, 'Law and the Regulation of Family Secrets' (2010) 24 International Journal of Law, Policy and the Family 397; I Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom' (2012) 39 Journal of Law and Society 58.

[51] *R v HFEA, ex p Blood* [1997] 2 All ER 687 (CA).

free movement rights can be limited. It was also suggested that the doctors who extracted sperm from Mr Blood whilst he was in a coma might have acted unlawfully: English law provides that incompetent patients are to be treated in their best interests, and it is not easy to see how having children after one's death can be said to be in a person's best interests. So had there been due respect for Stephen Blood's reproductive choices and, more generally, for him as an incompetent patient?

At the time of the case, feminist legal scholars asked, 'Why did Diane Blood succeed?' Was it because law supported autonomous reproduction (a prospect that terrified many when ARTs were first mooted and still strikes fear today), or was it because Mrs Blood's request was perfectly in line with what has been termed the 'sexual family'? Put differently, did Mrs Blood succeed in her legal quest because her actions were explicitly cast as undertaken in her husband's name?[52] If a grieving widower sought to retrieve eggs from his dying wife, would he attract the same degree of judicial sympathy as Mrs Blood? Should he?[53]

Let's develop this line of thought. What if a woman and a man create and then store embryos but at a later point disagree about their use for treatment purposes? Should a human rights court proceed on the basis that there is a right of veto, and if so, should the woman and the man be given equal rights of veto? The ECtHR had to consider these issues in *Evans v United Kingdom*,[54] a case concerning six embryos stored in the United Kingdom in accordance with the provisions of the relevant legislation, the Human Fertilisation and Embryology Act 1990. For the applicant, Natallie Evans, these embryos were the only chance to try for a child who would be genetically related to her: the embryos had been created using Evans' eggs and the sperm of her then-fiancé, Howard Johnston, before she underwent cancer treatment that destroyed her fertility.

Johnston triggered the dispute when, following the end of his relationship with Evans, he refused consent to the continued storage or use of the embryos: under the 1990 Act, this meant that the embryos had to be destroyed.[55] Evans responded by challenging that law on a range of grounds: here I focus exclusively on her human rights claims—her claims, in other words, that the 1990 Act was not compliant with the ECHR. At

[52] D Morgan and RG Lee, 'In the Name of the Father? *Ex parte Blood*: Dealing with Novelty and Anomaly' (1997) 60 Modern Law Review 840. *Cf Jocelyn Edwards; Re the Estate of the Late Mark Edwards* [2011] NSWSC 478.

[53] M Brazier, 'Hard Cases Make Bad Law?' (1994) 23 Journal of Medical Ethics 341.

[54] *Evans v United Kingdom* (2006) 43 EHRR 21 (Chamber); *Evans v United Kingdom* [GC] (2008) 46 EHRR 34.

[55] The Human Fertilisation and Embryology Act 2008 introduced a range of changes to the 1990 Act. One of these, a 'cooling off' period, bears the mark of *Evans*: its introduction means there can be no immediate destruction of stored embryos following a disagreement as to their future disposition.

the outset there were four such claims: first, that the six frozen embryos were entitled to protection under articles 2 and 8 of the ECHR; second, that the consent provisions of the 1990 Act violated her rights to respect for private and family life under article 8 because they did not permit her to proceed to treatment with the embryos without the agreement of Johnston; third, and relatedly, that these provisions violated her article 12 right to marry and found a family; and, finally, that these provisions were discriminatory and thus contrary to article 14 of the ECHR read in conjunction with article 8.

Four courts considered the case—the High Court and Court of Appeal in England and then both the Chamber and Grand Chamber of the Strasbourg Court—and all four decided against Evans (though there were dissenting opinions in both the Chamber and Grand Chamber).[56] The arguments centred on articles 8 and 14: the other claims, concerning articles 2 and 12 respectively, were either disposed of swiftly or, latterly, abandoned by the applicant.

Evans' core argument was that the consent provisions of the 1990 Act violated her right to respect for private life under article 8. However, Johnston also had a right to respect for private life: if Evans proceeded to treatment, Johnston could find himself being made a genetic father against his wishes. Evans' position was that 'She was the primary figure in reality, and should be so in law.'[57] She insisted that the aims of the 1990 Act could be as well or better served by allowing the man's withdrawal of consent to be overridden in exceptional cases, or by allowing gamete providers to give an irrevocable consent at the point of fertilisation.[58] Thus her argument was that the law as it stood was not 'necessary in a democratic society'; specifically, its insistence on a bright line—permitting no exception in hard cases and thus no balancing of the interests concerned—rendered it unfair and disproportionate. Evans also invoked article 14 in conjunction with article 8 to argue that because of the 1990 Act, she and other infertile women seeking to implant frozen embryos against the wishes of the genetic father were treated differently to fertile women. Specifically, women who conceived through intercourse rather than IVF could determine the future of an embryo from the moment of fertilisation. This different treatment

[56] At the domestic level, judgment was delivered by the High Court of England and Wales (*Natallie Evans v Amicus Healthcare Ltd and Others* [2003] EWHC 2161 (Fam)) and, on appeal, by the Court of Appeal (*Natallie Evans v Amicus Healthcare Ltd and Others* [2004] EWCA (Civ) 727). The (then) UK House of Lords declined leave to appeal, at which point Ms Evans (having exhausted domestic remedies) lodged an application against the UK at the ECtHR.

[57] C Morris, '*Evans v United Kingdom*: Paradigms of Parenting' (2007) 70 Modern Law Review 992, 995.

[58] *Evans* (Chamber) (n 54) para 51.

meant, Evans said, that there was discrimination in the enjoyment of article 8 rights.

So how did the Grand Chamber of the ECtHR, the final court of appeal, respond to these claims? On the article 14 point it decided against Evans simply by referring back to its reasons for deciding against her under article 8: those reasons, it said, would afford a reasonable and objective justification for any difference in treatment. As regards article 8, the Court accepted, first, that the right to respect for the decision to become a parent 'in the genetic sense'[59] fell within the scope of that article's right to respect for private life. This meant that article 8 was engaged. But Johnston, of course, had an article 8 right too—a right 'not to have a genetically related child with [Evans]'.[60] Thus there was a conflict of article 8 rights, and in the Court's words, each person's interest was 'entirely irreconcilable with the other's'.[61] There were also wider, public interests to be taken into account. Two such interests were identified by the Court: first, the impugned provisions upheld the principle of the primacy of consent, and second, their 'bright line', or no-exceptions, approach promoted legal clarity and certainty.[62] Ultimately, the question that had to be resolved was: did the provisions as applied strike 'a fair balance between the competing public and private interests involved'?[63]

Before answering this, the Court addressed the margin of appreciation to be afforded to the state in assessing whether there had been an unjustified interference with article 8. It concluded that the margin had to be a wide one, giving two reasons for this: first, there was no European consensus on how to regulate the matter at issue; secondly, 'the use of IVF treatment gives rise to sensitive moral and ethical issues against a background of fast-moving medical and scientific developments'.[64]

The next move made by the Court, its penultimate one, was to say that the impugned provisions were clear and had been brought to the attention of Evans. Moreover, Evans (like Johnston) had signed the consent forms required by the law. All that remained was the fair balance question, and as we already know, this went against Evans. The Court said that the no-exceptions approach of the impugned provisions served public interests that were both legitimate and consistent with article 8, and as regards the competing private interests, it could see no reason for ranking Evans' interest above that of Johnston.

[59] *Evans* [GC] (n 54) para 72. See also *Dickson v UK* [GC] (2008) 46 EHRR 41.
[60] *Evans* [GC] (n 54) para 90.
[61] Ibid, para 73.
[62] Ibid, para 74.
[63] Ibid, para 76.
[64] Ibid, para 81.

This is a hard case in all sorts of ways. How then did human rights stand up to the challenges involved? To me, the Court's insistence on symmetry between Evans and Johnston, and its reliance on consent having been given by Evans, missed crucial contextual factors.[65] True, Evans did give consent, but let's review her other options. She could not freeze eggs because at the time that technology was not sufficiently advanced; by contrast, a man who had just received a diagnosis of cancer and been advised of the need for treatment that would destroy his ability to produce sperm would have been able to freeze sperm. The 1990 Act did not recognise this difference. Equally, Evans might have asked to create one or more embryos using donor sperm. There was, however, no guarantee of access to that option. At the time, the 1990 Act required providers to make access decisions with reference to the 'need for a father':[66] thus by asking for donor sperm, Evans would have raised questions about her relationship with Johnston and, more broadly, her suitability as a treatment recipient. She would have had to explain her reasoning to Johnston as well: how exactly might she have broached this topic with the man who was her fiancé?

So did Evans have options? The answer has to be 'Not really'. Yet for the Court, the 1990 Act was to be applauded for its emphasis on consent and on 'bright lines' that brought certainty and clarity. What the Court does not explain is that the Act did not take account of what seems to be a relevant difference (that between egg and sperm freezing technologies). Or that it produced a further difference in its requirement that providers take account of the need for a father.[67] The Court's decision, to be fair, does see that parents come in different kinds:[68] it speaks of right to be and not to be a parent, and it emphasises that this includes the right to be a *genetic* parent. Mostly, though, what I take from this is that further human rights challenges lie ahead. In life, motherhood and fatherhood are crafted in all sorts of ways: in law, however, as the ECtHR points out, clear and certain rules are preferred. But it will be no easy matter to configure rights-based 'bright lines' around genetic, gestational, social and legal parenthood. Relatedly,

[65] See also S Sheldon, '*Evans v Amicus Health Care*: Revealing Cracks in the "Twin Pillars"' (2004) 16 Child and Family Law Quarterly 43. For another ART case that raises questions about quality of consent, see *U v Centre for Reproductive Medicine* [2002] EWCA Civ 565.

[66] See further S Sheldon, 'Gender Equality and Reproductive Decision-Making' (2004) 12 Feminist Legal Studies 303. The Human Fertilisation and Embryology Act 2008, an amending statute, replaced this with a requirement that providers take account of the 'need for supportive parenting'. For an examination of the operation of the new provision, see E Lee et al, 'Assessing Child Welfare under the Human Fertilisation and Embryology Act: The New Law' (September 2012), http://blogs.kent.ac.uk/parentingculturestudies/files/2012/06/Summary_Assessing-Child-Welfare-final.pdf.

[67] The ECtHR of course may have avoided this out of concern that the welfare of yet-to-be-realised children would force it into the territory of embryos, foetuses and art 2 ECHR.

[68] This seems implicit too in *SH and Others v Austria* [GC], App no 57813/00 (Judgment of 3 November 2011).

pregnancy has been central to thinking and disputes around reproductive choice; but I am not sure that means human rights is well prepared for the challenges of choice in ARTs. Has pregnancy left us thinking of female parenthood as more gestational than genetic? Equally, how might the challenge of building rights-based approaches to ARTs affect how human rights apply to pregnancy?[69] There are questions to be answered here.[70]

An Odd Sort of Choice

The idea of reproductive choice could also be said to jar with other aspects of ARTs—from cost through clinic practices to the low success rate of many ARTs. In the United Kingdom in 2010, for instance, for women under 35 having IVF using fresh embryos created with their own fresh eggs, the percentage of cycles started that resulted in a live birth was 32.2. And as this was the average rate, there would have been variation between providers.[71] Put differently, 70 per cent of cycles started ended in failure.

PGD is a more complex procedure than basic IVF, which means the chance of success drops again. Field notes written in 2001 by the British sociologist Sarah Franklin on her first visit to a PGD clinic testify to this. Staff at the clinic felt obliged to give patients '"the really bleak picture" of PGD, thereby "putting the fear of God into them"'. Franklin, who had extensive experience as an ethnographer of IVF, admits she had not been expecting this:

> I am amazed how much failure is emphasised, how much they go on about how many things can go wrong, how it is all very early days for the technique and for the clinic, and how complicated all of the procedures are.[72]

So does publication of clinic-specific success rates help would-be parents, faced with the prospect of the failure, to make choices? It seems not: such data may do little to enable more informed choices, and for certain patients, their publication produces reduced choice. The nub of the problem is that data can result in league tables, which in turn 'present clinicians with a

[69] M Ford, '*Evans v UK*: What Implications for the Jurisprudence of Pregnancy' (2008) 8 Human Rights Law Review 171.

[70] Such questions might be answered in different modes, including via the new scholarly practice of rewriting judgments: see, eg, S Harris-Short, 'A Feminist Judgment in *Evans v Amicus Healthcare Ltd and Others*' in R Hunter, C McGlynn and E Rackley (eds), *Feminist Judgments: From Theory to Practice* (Hart Publishing 2010); P Londono, 'Redrafting Abortion Rights under the Convention: *A, B and C v Ireland*' in E Brems (ed), *Diversity and European Human Rights: Rewriting Judgments of the ECHR* (Cambridge University Press 2012).

[71] See the Human Fertilisation and Embryology Authority website, www.hfea.gov.uk/ivf-success-rate.html.

[72] A Kerr and S Franklin, 'Genetic Ambivalence: Expertise, Uncertainty and Communication in the Context of New Genetic Technologies' in A Webster (ed), *New Technologies in Health Care: Challenge, Change and Innovation* (Palgrave Macmillan 2006) 50.

series of incentives towards clinical practices which may not be in patients' best interests'[73]—practices such as patient exclusion policies, multiple embryo transfer and the misreporting of abandoned cycles.

But neither the high level of failure nor the adverse effects of publishing data that generate league tables is the only reason for describing ARTs as an odd sort of choice. Cost is an obstacle too: treatment is expensive, and access is often contingent upon the ability to be self-funding. Where access involves travel to another jurisdiction (to avoid waiting lists or perhaps to avoid the legal rules governing ARTs that operate in one's home state), it may be more expensive again; it may also come with the risk of criminalisation or at least social censure. Thus the answer to the question 'Reproductive choice for whom?' may be that there is choice but only for an elite clientele, or perhaps an elite, exiled one.

Differential access also comes through in practices such as egg-sharing, whereby a woman who wants IVF agrees to provide a percentage (perhaps 50 per cent) of the eggs retrieved during one cycle so that her own treatment will be provided at a reduced cost. The question is: does the desire for a child—specifically, the chance to try for a child through a procedure that is out of reach financially—place a would-be mother in a no-choice situation about sharing? The name that has been given to the practice is interesting too: for what purposes and with what effects is it called 'sharing'?[74]

'What choice do we have?' could also be said to capture the position of parents who want to use PGD and tissue typing because they have a sick child who might be cured by a saviour sibling, or those who want to use PGD to start a pregnancy in the knowledge that they have done all that they can to avoid passing on a serious genetic disorder and that they will not have to resort to prenatal diagnosis and abortion. Would-be parents in these circumstances may not readily think of themselves as having reproductive choice.[75] Moreover, were they to walk away from choice, how would we judge them? How far are parents required to go? Would we say that parents, if they refused to attempt to create a saviour sibling, were being unreasonable? Would we censure them?[76]

[73] E Jackson and H Abdalla, 'IVF Birth Data Presentation: Its Impact on Clinical Practice and Patient Choice' in F Ebtehaj et al (eds), *Birth Rites and Rights* (Hart Publishing 2011) 271, 272.

[74] For views from those who have shared eggs in the UK, see C Roberts and K Throsby, 'Paid to Share: IVF Patients, Eggs and Stem Cell Research' (2008) 66 Social Science and Medicine 159; E Haimes et al, 'Eggs, Ethics and Exploitation? Investigating Women's Experiences of an "Egg Sharing" Scheme' (2012) 34 Sociology of Health and Illness 1199.

[75] And the law may not offer it to them either, even if abortion is permitted for the same condition: see *Costa and Pavan* (n 15), wherein the ECtHR found a violation of art 8 in such circumstances.

[76] M Freeman, 'Saviour Siblings' in SAM McLean (ed), *First Do No Harm* (Ashgate Publishing 2006) 405–6.

There are other dissonances too. For instance, is choice really what comes to mind when one needs assistance, the 'artificial', to do what is widely considered entirely natural? For women, using ARTs challenges assumptions about universal motherhood, and ARTs are hard also for men, not least because of the association between fathering a child and virility or potency. Some cultures attach deep stigma to childlessness and draw strong links between paternity and social standing. Furthermore, for women and for men, but more so for women because they are the primary patients in ARTs, bodily integrity can feel battered by the actual techniques of assisted reproduction.

One final point: today in some parts of the world trying to get pregnant via technology may well be mandatory in order actually to be infertile. In other words, to be infertile one needs to have 'tried'; one needs to be incapable of both reproduction *and* technologically-assisted reproduction. A diagnosis of untreatable infertility might be devastating, but it is also a socially acceptable reason to stop trying. This diagnosis can be rare, however. Hope and perseverance tend to prevail in ARTs: patients may be given advice on other options (say, adoption), but 'the structuring of treatment is open-ended in the sense that another combination of hormones, another cycle of artificial insemination, another go at IVF can always be embarked on, age and finances permitting'.[77]

To summarise: assisted reproduction is not a context in which one can 'Just say no' or, for that matter, 'Yes', or indeed, 'Just do it'. Assisted reproduction is therefore an odd sort of choice. But this, I want to argue, is one of the reasons why the dignity of choice needs to be drawn out and defended.

IV. ADDING TEXTURE

To recap: I have suggested that the right to reproductive choice can seem like a bad argument today when used in relation to ARTs. In part, the problem can be traced to overlaps; in part, too, choice does not quite fit the facts of ARTs. In what follows, however, I use ethnographic studies—primarily, one from the United Kingdom by Sarah Franklin and Celia Roberts and another from the United States by Charis Thompson[78]—to explain why the tendency to think of reproductive choice as dangerous, off point or otherwise out of place in the field of ARTs needs to be

[77] Thompson (n 43) 95. S Franklin, *Embodied Progress: A Cultural Account of Assisted Conception* (Routledge 1997) describes ARTs as 'hope technologies'.

[78] See respectively S Franklin and C Roberts, *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis* (Princeton University Press 2006); Thompson (n 43).

countered. Put differently, the aim is to show why the dignity of choice needs to be made secure.[79]

My stepping-off point is the many would-be parents in Franklin and Roberts' study who described opting for PGD as their 'only choice' whilst giving full, thoughtful accounts of their other choices. These messy, mixed-up descriptions are nothing like the for-or-against framings that tend to dominate public discourse on reproduction; they are also a deep challenge to standard notions of consent. Remember too that for these would-be parents, the 'only choice' of PGD came with no guaranteed outcomes. All that was certain, at least in the short term, was the need for further, follow-on reproductive choices in conditions of hope and anxiety.

To my mind, these messy, mixed-up descriptions demonstrate why the dignity of choice ought to be drawn out and defended. As I have said, their richness is strikingly different from the for-or-against model of choice that has been dominating popular, legal and scholarly discourses. The descriptions are also far away from perennial fears about 'parental eugenics' (known colloquially as 'designer babies'). They speak instead to a form of decision-making that is shot through with obligation or responsibility—to a potential future child or children, to family, clinic staff and other patients (past, present and future) and also to community more generally. They also point to choice as a process—to recurrences of the need to judge and decide.

Anne, one of the participants in Franklin and Roberts' study, captures what I am driving at here. In the following extract, she explained why PGD was her 'only choice':

> I can understand it is a very grey area. Because obviously … we've used PGD because we didn't want to have another child that was going to die within 12 months. But I mean … at what point do you draw the line? At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where? … What conditions are we going to allow PGD to be used for? … I don't know where the line should be drawn.[80]

These reflections speak to potentially extensive chains of responsibility. There are questions here for Anne herself, for Anne and her partner, and for all of us—not just for the 'experts'. To describe Anne or the other would-be parents in the Franklin and Roberts study as choosy—or as

[79] For illustrations of how to use existing law to defend the dignity of choice see, eg, Sanger (n 21); RB Siegel, 'Dignity and the Politics of Protection: Abortion Restrictions under *Casey/Carhart*' (2008) 117 Yale Law Journal 1694. On the need for a fuller theoretic account see, eg, L Morgan, 'Fetal Relationality in Feminist Philosophy: An Anthropological Critique' (1996) 11 Hypatia 47; J Downie and J Llewellyn (eds), *Being Relational: Reflections on Relational Theory and Health Law* (UBC Press 2012); J Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press 2011).

[80] Franklin and Roberts (n 78) 1.

'would-be parents "for choice"' in the fashion of the lapel pins and placards that are familiar from abortion politics in some states—seems not just inaccurate but insulting. Moreover, Franklin and Roberts' findings do not stand alone: they chime with those of Charis Thompson, which I discuss below, and also with Rayna Rapp's work on parents faced with decisions about amniocentesis.[81] Rapp positions the parents in her study as 'moral pioneers', a point I picked up on in chapter one whilst looking at human rights' non-engagement with the various forms of biological citizenship that are being closely studied within other fields.[82] As I said there, I am at a loss to explain why such biologically-based claims and practices have not fascinated human rights scholars. Why have we not been enquiring into the relationship between such biological citizenship and moral pioneering and rights-based forms of citizenship and activism? Equally, why have we not started to historicise these relationships?

Thompson's study of US IVF clinics resonates with Rapp's emphasis on moral pioneering in decision-making with regard to amniocentesis. Patient activism around ARTs was, Thompson says, active not passive: would-be parents were finding forms of agency amidst the rigours of treatment. There are traces of moral pioneering and the obstacles law can place in its path in other studies too, including Australian and UK projects looking at would-be parents' decision-making around 'spare' or surplus embryos. Frustration at mandatory storage limits for these embryos tends to be strong, for instance. Equally, willingness to donate embryos to research tends to be high and to be framed in terms of trying to 'give something back'. Donation is seen as a way of reflecting the value or preciousness of embryos—it certainly does not represent a lack of concern for them.[83]

Each of these accounts offers an important corrective to stories of 'demanding parents' procuring 'designer babies'—the sort of stories that have been making choice almost 'unspeakable'. Interestingly, they also address the popular fear of 'anything goes'-doctors who believe in nothing bar 'patient knows best', as well as of 'rogue' scientists who are hell-bent on practices that will strip away human dignity. In Franklin and Roberts' study, as in Thompson's work on IVF in the United States, clinic staff

[81] R Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (Routledge 2000).

[82] See above ch 1, text to nn 148–50.

[83] See, eg, S Parry, '(Re)Constructing Embryos in Stem Cell Research: Exploring the Meaning of Embryos for People Involved in Fertility Treatments' (2006) 62 Social Science and Medicine 2349; I Karpin, 'The Legal and Relational Identity of the "Not-Yet" Generation' (2012) 2 Law, Innovation and Technology 122; R Scott et al, 'Donation of "Spare" Fresh or Frozen Embryos to Research: Who Decides that an Embryo is "Spare" and How Can we Enhance the Quality and Protect the Validity of Consent?' (2012) 20 Medical Law Review 255. See also MN Svendson and L Koch, 'Unpacking the "Spare Embryo": Facilitating Stem Cell Research in a Moral Landscape' (2008) 38 Social Studies of Science 93.

facilitated and reinforced what I have been calling the dignity of choice.[84] Thompson, for example, interviewed lab technicians who described access to ARTs as a moral issue, linking it to their responsibility as possessors of knowledge to surrender that knowledge in a non-discriminatory way.

I don't wish to promote naïveté. I appreciate that reproduction is a booming business, and ARTs are not simply 'value-free, inherently beneficial medical technologies' that can be transferred, along with models for regulating them, from one state to another. As Marcia Inhorn, who works on ARTs in the Middle East, has pointed out, any assumption that these technologies are '"immune" to culture' has to fall away 'once local formulations, perceptions, and actual consumption of these technologies are taken into consideration'.[85] The same point might well be made about the assumption that ART markets are everywhere the same. Thompson, for instance, insists that in the United States, ARTs have 'become in some ways a model medical speciality'. This, she says, was not how they started out; initially, 'there were few clinics, which had astonishingly low success rates, imposed gruelling treatment regimens, and excluded most would-be patients because they were unable to pay or were judged to be [not suitable] as parents'.[86] Today, however, ARTs have become 'unusually accountable to various stakeholders' and genuine sites for activism within medicine (including, 'patient activism, scientific activism, legal activism, and professional self-regulation').[87] Thompson attributes this rise in accountability to the fact that the ART market is a crucible that holds reproductive privacy, scientific interests and commercial priorities, each of which acts as a check and balance on the others.[88]

Thompson's claim is fascinating. It throws down a challenge to conventional accounts of the need for particular forms of state regulation through law—notably the fixation on the need for limits, for ever more 'red lights'. On the other hand, red lights continue to merit human rights interrogation too. As mentioned earlier, they can function to exile particular problems and particular people. Equally, red lights are not the same everywhere. In Europe, for instance, giving to the reproductive and stem cell industries is

[84] See also R Scott et al, 'The Appropriate Extent of Pre-Implantation Genetic Diagnosis: Health Professionals' and Scientists' Views on the Requirement for a "Significant Risk of a Serious Genetic Condition"' (2007) 15 Medical Law Review 320.

[85] MC Inhorn, 'Gender, Health, and Globalization in the Middle East: Male Infertility, ICSI, and Men's Resistance' in I Kickbusch et al (eds), *Globalization, Women, and Health in the 21st Century* (Palgrave Macmillan 2005) 114. See also D Birenbaum-Carmeli and MC Inhorn (eds), *Assisting Reproduction, Testing Genes: Global Encounters with New Biotechnologies* (Bergahn Books 2009); Inhorn, *The New Arab Man* (n 48); Inhorn and Tremayne (eds) (n 48).

[86] Thompson (n 43) 25–26.

[87] Ibid.

[88] Ibid, 241.

widely framed through altruism (albeit that transactional practices such as 'egg-sharing' operate within this frame), but elsewhere in the global North, as well as in the global South, there are largely or wholly unregulated markets. There are also global providers who make substantial profits by crossing these borders.[89] I am not, to be clear, arguing that human rights should now dedicate itself to the universalisation of particular red lights; I am instead calling for us to attend to the context of ARTs, focusing above all on what does and does not defend the dignity of choice.

V. THE CHALLENGE OF SPEAKABILITY

Some years back I wrote an essay on the hoopla over patient 'voice'. In it I noted that 'although the cultural conversation about abortion may appear increasingly cacophonous, it is, at least from certain speaking positions, less and less inclusive'. I gave the example of a woman who has terminated one or more pregnancies and pointed out:

> Her voice is infrequently heard. It is also prey to vulgar mishearings. It is suspiciously uniform: it is tentative and, in my view, unnecessarily tortured, and the substance of its speech seems to have been censored. Today, in giving voice to the decision to abort a pregnancy, one *must* declare oneself saddened by the choice.[90]

In retrospect, I think I missed something important. I don't take back what I said, but I should have thought through the idea of being 'saddened by the choice'. Concern about levels of anti-abortion rhetoric may have stopped me from doing so; I suspect I was entirely caught up in the conventional for-or-against framing of reproductive choice, and I could not see how being 'saddened by the choice' was not necessarily anti-choice.

Today, I see it in a different light. It remains counter-intuitive in that it resonates most strongly with a standard anti-abortion narrative wherein a woman always regrets terminating any pregnancy. But I can also see how it resonates with what I have been calling the dignity of choice. It doesn't flatten out choice into 'for' or 'against', into 'right' choices and 'wrong' ones; and for these reasons it manages to hint at the complexity that can attach to reproductive decision-making. In short, it seems to me now that 'saddened by the choice' has the great advantage of leaving space for complexity—for the complexity of making choices. We speak of the right choice, yet choosing rightly is not necessarily easy or indeed either carefree or careless. How then should a rights-respecting society respond to this? Should it strip away

[89] Waldby and Cooper (n 42).

[90] T Murphy, 'Health Confidentiality in the Age of Talk' in S Sheldon and M Thomson (eds), *Feminist Perspectives on Health Care Law* (Cavendish Publishing 1999) 164.

opportunities to choose, citing perhaps the need to prevent harm? Should it hyper-regulate choice, introducing ever more consent forms, ever more 'bureaucracies of virtue'?[91] I don't think either path is desirable. Instead, as I have said, the obligation is to draw out, defend and respect the dignity of choice.[92]

After I had finished writing the first draft of this chapter, I read a fascinating article by the Australian health care lawyer Roger Magnusson, which bolstered my own thinking on the dignity of choice. Magnusson's focus is the end of life, not ARTs or reproductive choice more generally, but what resonated with me was his argument that although it is often assumed 'explicitly or implicitly, that the role of medical ethics and law is to guide us towards the "right choice", some of medicine's most painful decisions are, in fact, the devil's choices'. The devil's choice is, he says, a better model 'than the traditional account found in law and medical ethics' when it comes to explaining practices such as the provision of pain relief in end-of-life care:

> The benefit of applying the devil's choice to palliative care is that it permits empathy with the dilemmas physicians face, while still acknowledging the extraordinary power that physicians have over the lives of patients at what is perhaps the most vulnerable time of their lives.[93]

Magnusson's topic was end-of-life care; mine was abortion. Neither of us addressed ARTs. Moreover, his focus was physicians, whereas mine was patients. Yet these accounts are relevant here because lying behind each of them is a sense that something is missing in dominant accounts of choice.

I accept that there isn't a prescription in any of this as to how ARTs ought to be regulated, and some will see that as a gap in my argument. Others will be frustrated by the fact that I am not offering a conventional pro-choice argument. Others again may wonder whether my argument would have a better chance if it avoided the loaded idea of choice—if, for instance, I pursued the right to reproductive health as a distinct human right rather than focusing on reproductive rights in general and the dignity of choice in particular.[94] In so doing, might I also see that *care* has 'a logic of its

[91] See M-A Jacob and A Riles, 'The New Bureaucracies of Virtue: Introduction' (2007) 30 Political and Legal Anthropology Review 181.

[92] See relatedly R Brownsword, *Rights, Regulation, and the Technological Revolution* (Oxford University Press 2008) 258–82 explaining 'how, and why, the availability of choice matters for an aspirant moral community'; R Dixon and MC Nussbaum, 'Abortion, Dignity, and a Capabilities Approach' in B Baines, D Barak-Erez and T Kahana (eds), *Feminist Constitutionalism: Global Perspectives* (Cambridge University Press 2012); Nedelsky (n 79).

[93] R Magnusson, 'The Devil's Choice: Re-thinking Law, Ethics, and Symptom Relief in Palliative Care' (2006) 34 Journal of Law, Medicine and Ethics 559, 559.

[94] See, eg, L Gable, 'Reproductive Health as a Human Right' (2010) 60 Case Western Law Review 957, arguing for a focus on having the right to reproductive health recognised as a distinct human right.

own'[95] in health contexts, one that contrasts with choice and is potentially more appealing than it? These are valid points. My response to them is as follows: reconnecting dignity and choice and, more particularly, securing the speakability of the right to reproductive choice—stopping it from being rendered unspeakable in the field of ARTs, and perhaps elsewhere too—has to be the priority. And given that, the very first priority has to be techniques that draw out the dignity of choice.

As I see it, ethnographies could help to change what human rights notices and, in turn, how it frames reproductive rights and how it conducts arguments using these rights. In advocating for them, I am not suggesting that they are an entry point to fundamental or ultimate truth. Equally, I am not proposing either Richard Rorty's 'sad and sentimental stories'[96] or clinical vignettes produced by medical professionals, psychologists and scientists, as the way ahead for human rights. My focus on ethnographies of ART users is deliberate: would-be parents face difficult choices and gruelling treatments with low chances of success, but the public discourse on ARTs is generally far less furious than that which surrounds abortion, and would-be parents seem less likely than other sorts of patients to be viewed exclusively as victims. I am, in short, deliberately calling for human rights legal method to avoid sites where the question of suffering could prove overwhelming as we take the first steps in drawing out and defending the dignity of choice. 'Are you in pain?' should not be the only route to rights-based concern and recognition.[97]

What I *am* suggesting is that ethnographies could deepen and develop the human rights understanding of what is involved in autonomous decision-making, why that form of decision-making needs to be protected and how law can best support it. Thus, the key argument for ethnographies is that they might assist a 'sluggish imagination'.[98] Ethnographies might also help human rights to fight back against claims that it is willing to play fast and loose with human life and, more generally, with human dignity.

[95] Mol (n 21) xii.

[96] R Rorty, 'Human Rights, Rationality and Sentimentality' in S Shute and S Hurley (eds), *On Human Rights: The Oxford Amnesty Lectures* (Oxford University Press 1993). See further R Rorty, *Contingency, Irony, and Solidarity* (Cambridge University Press 1989).

[97] As to reasons why see, eg, D Fassin, 'Inequality of Lives, Hierarchies of Humanity' in I Feldman and M Ticktin (eds), *In the Name of Humanity: The Government of Threat and Care* (Duke University Press 2010); M Ticktin, *Casualties of Care: Immigration and the Politics of Humanitarianism in France* (University of California Press 2011).

[98] H Garfinkel, *Studies in Ethnomethodology* (Prentice Hall 1967) 11. For reflections on the past, present and future of medical anthropology, see MC Inhorn and EA Wentzell (eds), *Medical Anthropology at the Intersections: Histories, Activisms, and Futures* (Duke University Press 2012).

VI. CONCLUSION

I am not suggesting that human rights legal method should leave law behind. In places, reproductive rights have made forward progress via litigation and legislation. These rights have also attracted fresh thinking, both theoretic and applied, and they have striking new manifestations in places such as the Maputo Protocol and the Convention on the Rights of Persons with Disabilities. The idea instead is to add a point of reference, one that should help human rights law to promote and protect the dignity of choice.

That leaves the question of who should be the ethnographer. Should human rights use the ethnographies of anthropologists or work towards using ethnography itself? Anthropologists are longstanding experts in ethnography, including ethnographies of both legal and medical decision-making, and today they lead the way in ethnographies of human rights practices. But for human rights to use such 'outsider' ethnographies, they need to be more than just human rights research; they must also be the product of rights-based approaches to research.[99] There is also the matter of how human rights lawyers should use such ethnographies. What are our obligations to the stories, to the people behind these stories and indeed to those who listened to them, the anthropologists?[100]

Human rights could of course develop its own ethnographies. The foundations are there: 'voice' is a core value;[101] listening and witnessing are at the heart of human rights reporting, and civil and political rights promote the right of citizens to participate in public affairs.[102] What we need to ask is: what challenges will ethnography throw up for those who come at it steeped in human rights law and human rights legal method? And how might the arrival of law and lawyers affect ethnography? How, for instance, does human rights law 'choreograph suffering and empathy'?[103] Traditions of listening, assessing credibility and handling stories may be strong within human rights law, but is this an asset, an obstacle or both in broaching ethnographic method? There is also a strong human rights tradition of

[99] P Gready, 'Introduction: "Responsibility to the Story"' (2010) 2 Journal of Human Rights Practice 177, 188.

[100] Ibid, 184, emphasising that '"responsibility to the story is not a one-off event, but a process'. See also A Riles, 'Anthropology, Human Rights, and Legal Knowledge: Culture in the Iron Cage' (2006) 108 American Anthropologist 53.

[101] See LE White and J Perelman (eds), *Stones of Hope: How African Activists Reclaim Human Rights to Challenge Global Poverty* (Stanford University Press 2011) 176, listing voice alongside inclusion, equality and security.

[102] ICCPR (n 26) art 25.

[103] KB Sandvik, "The Physicality of Legal Consciousness: Suffering and the Production of Credibility in Refugee Resettlement' in RA Wilson and RD Brown (eds), *Humanitarianism and Suffering: The Mobilization of Empathy* (Cambridge University Press 2009) 244.

'war stories'. We like to regale one another, and others too, with famous victories, terrible losses and accounts of the dogged persistence of the advocate, whether in court, in print or in the field. Does this mean that listening and allowing others to speak outside these particular visions of human rights law and practice is going to prove difficult?[104] We need to try it and see.

[104] On the problems the human rights mode of 'listening and witnessing' produces for anthropologists, see I Jean-Klein and A Riles, 'Introducing Discipline: Anthropology and Human Rights Administrations' (2005) 28 Political and Legal Anthropology Review 173.

Conclusion

I STARTED WITH a puzzle. It has taken, though, no time at all to see there is no puzzle—no conundrum, no mystery, no brainteaser. There is only human rights, and the tensions that are the price of living, and regulating, with rights. These tensions, moreover, feel especially pointed in the context of health. Grappling with them, I have turned to human rights legal method. Others would have chosen differently. Others again will ask: where is the human rights legal method in what I propose? Isn't this book just a set of questions—the 'cost of human rights' question, the 'human rights preparedness' question and so on? My response is twofold. First, ask a question on a regular basis and it becomes a method. Second, this is a book about 'doing' health and human rights through human rights law. That makes it a book about human rights legal method. Yet others may say that even within human rights legal method, there is much more that could be said. Fair comment: I would be thrilled, frankly, to see new work entitled, 'What Should Human Rights Legal Method Become?'[1] If that work takes health and human rights as its focus, I shall be more enthusiastic again.

Still, I hope the following is clear. Last-word versions of human rights law are no use at all. They are not viable, they are not helpful and they are not accurate. Human rights law is a way of protecting what we do and should care about; it allows and obliges us to reason in particular ways about what matters. Human rights legal method is at its best when it captures and sustains that; it is at its worst when it is sodden with talk of rights as total trumps—when it believes, for instance, that authority is clear and final, implementation is inevitable and inevitably positive, and engagement with limits to human rights is damaging or simply surplus to requirements.

Neither the diagnosis nor the prescriptions offered here—ranging from the cost of human rights, through human rights preparedness and the dignity of choice, to a measured response to numbers—are meant to be the last word. I have tried to be clear and accurate in each diagnosis, and persuasive with my prescriptions as to how human rights legal method might further

[1] Borrowed, of course, from RM Unger, *What Should Legal Analysis Become?* (Verso 1996).

health and human rights. Vibrant debate is, however, what is required; debate that works from health and human rights, and from human rights legal method, as they are today. If there is a blueprint here, that is at its centre.

Second, human rights legal method would benefit from a stronger sense of what it is today and what it could and should be. It needs, too, a clearer sense of what it should not try to be. Human rights law has never been the whole story of human rights. Equally, human rights legal method (to the extent anyone has considered what it is) has not been the only mode of engagement within health and human rights. Nonetheless, in today's more openly plural environment of human rights—amidst biocitizens, activist states, rights-based approaches to development, humanitarianism and the like, deeply pragmatic engagements with litigation by non-governmental organisations, and an array of non-legal fields committing to empirical and theoretic investigations of rights, human rights law and even human rights legal method—it seems vital that we know 'our place'.

Third, 'our place' will be particular, but it need not be cramped by convention. Constitutional rights and international human rights might not be identical, but health and human rights will not benefit from forms of human rights legal method that focus on one to the exclusion of the other. Private law also has to be part of the picture. Equally, freedoms and entitlements may be the lingua franca of rights, but again, health and human rights would be ill-served by a legal method that does not see limitations on rights as part of human rights law too. In similar vein, the rights to health and to have access to health care can be at the centre, but other rights need to be present too: I have called this approach 'right to health plus'. Clichés, moreover, need to be routed. The justiciability of economic, social and cultural rights is genuinely complex, especially perhaps for health rights, but it not exclusive to the Supreme Court of India or the South African Constitutional Court; nor is it unavoidably anti-democratic. The enforceability of economic, social and cultural rights is not synonymous with justiciability; it is broader than it. Non-discrimination and equality are not the same thing either. Public health is a ground for limiting rights, but it is more than that too. And giving rights a 'minimum core content' has attractions, but given what we know about the effects of unequal societies—lower life expectancies, higher levels of discrimination and worse health outcomes—the drive for minimum thresholds must not occlude overall equality. The list goes on and on. Compiling and tackling this list, however, make for 'rights without illusion',[2] and that is the optimum perspective for human rights

[2] 'Rights without illusion' was used by Alan Hunt some years back to respond to arguments asserting the 'myth of rights': see A Hunt, 'Rights and Social Movements: Counter-hegemonic Strategies' (1990) 17 Journal of Law and Society 309. Hunt's focus was social movements; I of course am using his phrase more broadly.

legal method today. It is, frankly, the only perspective that can pinpoint the place and, thus, the promise of human rights legal method. And because that promise is in turn part and parcel of the promise of health and human rights, human rights lawyers should settle for nothing less.

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