



A Right to Health Equality: What Does This Mean, Exactly?

If equality is understood as a fundamental human right and a basic principle of social justice (this is how it is described in the ERT mission statement), what does it mean in respect to health? How is health equality thinkable? In this issue of *The Equal Rights Review*, ERT searches for answers to this question.

In a double interview published inside this issue, two remarkable experts in health rights (Paul Hunt) and health policy (Norman Daniels) give us a taste of the legal, moral and political complexities surrounding this question. To the extent that the issue of health equality does not fall within any “discipline”, it has become a professional field in its own right that has attracted researchers and practitioners coming from many different angles: health policy experts, medics, philosophers, lawyers, economists, political scientists, etc. Reframed in the terms of human rights law, the question is what kind of an enforceable right to equality related to health is conferred to persons by the laws – as they are, or as they should be.

At minimum, a right to health equality includes a right to non-discrimination in relation to health. This can be understood in two senses: that health status is a protected **ground** of discrimination, or that discrimination on a protected ground (which can also be, incidentally, health status) is prohibited in the **area** of health. In the first sense, one’s

health condition should not be – as a general rule – a ground of discrimination in areas such as employment. For example, in *Hoffman v S. A. Airways* (2000) the South African Constitutional Court found that an airline, by maintaining a policy not to employ HIV-positive persons, was guilty of unfair discrimination on grounds of HIV/AIDS status. In the second sense, a person should not be discriminated against on a protected ground such as race, gender, or religion, in the area of health. For example, a hospital which ignores a call to send an ambulance to an ethnic minority neighbourhood, while it normally sends ambulances to other areas of the city for the same emergencies, would be guilty of race discrimination in the area of health. A service providing treatment for HIV/AIDS which is not as accessible to homosexuals as it is to heterosexuals *prima facie* discriminates on grounds of sexual orientation in the area of health.

But some difficult questions arise in relation to both types of discrimination. Regarding health status (as well as the related category of disability) as a protected ground, surely employers, service providers and others can’t be required to treat persons with different health conditions identically in all cases. A job may require an employee to have a health status that rules out certain conditions, be they of a sensory, physical or mental health nature. Still, there are rules to be

followed to ensure that different treatment which is unavoidable is not discriminatory. In recent years disability equality law, as shown in Jarlath Clifford's article in this issue, has developed progressive approaches to answering this type of questions, and has introduced the critical concept of reasonable accommodation as part of the right to equality.

Many moral and political puzzles exist also in respect of the right to non-discrimination in the area of health, including in the narrower area of healthcare – the services offering diagnostic, preventive, therapeutic or rehabilitative interventions. It may seem easy and unproblematic to ensure that such services do not discriminate on grounds of race, gender or religion, but problematic it is, as a closer look would reveal. For example, should the accommodating of religious needs in hospitals (special diet, religious or spiritual counsel, or expensive drugs, e.g. the genetically engineered version of Factor VII which is effective in causing rapid blood clotting and is required by a Jehovah's Witness awaiting serious surgery) be paid for out of public funds or should it be the responsibility of those concerned? It is even more challenging to determine what would amount to discrimination in healthcare on the grounds of disability or age, or indeed on the ground of health status! As early as 1984, Aaron and Schwartz showed that in the National Health Service (NHS) in Britain, there was no formal rationing rule about dialysis but an informal "understanding" that patients over 65 would not be given dialysis, and patients over 55 whose kidney failure was related to heart disease and diabetes would be ineligible. Was the NHS in this case discriminating on the ground of age? To take a more extreme case, is a person in a permanent vegetative state, or a person in stage 4 of Alzheimer, who is at risk of a fatal arrhythmia, equally entitled to

an ICD (implantable cardiac defibrillator) at a cost of \$40,000 as any other patient with the same risk? Or would the denial of ICD be discrimination on ground of disability?

From the unitary human rights perspective on equality, as expressed, *inter alia*, in the 2008 Declaration of Principles on Equality, the right to health equality is "bigger" than the right to non-discrimination on the ground or in the area of health. It includes an entitlement to such healthcare which enables the person to participate on an equal basis with others in economic, social, cultural, civil and political life, as required by Principle 1 of the Declaration of Principles on Equality. It also implies a duty of the authorities to develop a healthcare system aimed at realising this right. If health is not (just) a tradable commodity but a matter of rights and a public sector duty, it appears that equality in health is best promoted through a publicly funded health care system, as recommended by the WHO Commission on Social Determinants of Health. And while it may be futile to try to translate general principles on equality into more specific health policies and practices, the latter should be consistent with general principles on equality.

Among the central issues of healthcare equality, in particular related to equal access to healthcare, is the process of setting priorities in the distribution of healthcare resources, also known as healthcare "rationing". The term is controversial partly as a result of the continuing denial by many stakeholders that rationing exists. It is easy to deny the existence of rationing as in the most part it is invisible: there is no public scrutiny and those who make rationing decisions are rarely, if ever, accountable for the health consequences for individuals as well as segments of the population. As in a democratic society publicity is a precondition of justice, invisible

rationing is presumptively unjust. Rationing, while invisible, can be explicit (formulated in medical protocol) or implicit, as the shared “understanding” in the NHS mentioned above. But if we want to make rationing visible in the public eye, the critical question of course is who should be the decision-maker creating rationing protocols: the market, the politicians, administrative bodies, physicians’ committees, courts, the public? An example of rationing by court is the case *Soobramoney v Minister of Health (Kwazulu-Natal)*¹, in which a diabetic who suffered from ischemic heart disease and cerebro-vascular disease and had an irreversible kidney failure was denied admission to the dialysis program of a state hospital because, due to scarce resources, the hospital had adopted a rationing policy that made him ineligible for dialysis. The Constitutional Court upheld the policy, but at the same time noted that the responsibility for making the difficult decisions of fixing the health budget and deciding upon the priorities that needed to be met lay with political bodies and the medical authorities and that the Court would be slow to interfere with such decisions if they were rational and taken in good faith. From the point of view of general principles on equality, the most attractive approach seems to be to entrust the rationing process to the public, through forms of democratic deliberation, as advocated by Daniels in a number of his books and in this issue – although this approach in turn carries serious risks, both in practical terms and through inherent limitations.

A further question of healthcare equality is what are the legitimate criteria on which rationing decisions should be based? Should the principle be to prioritise those who are the worst off – the most seriously ill? Or should the principle be to maximise the total benefits of healthcare expenditures, where cost-effectiveness would be measured in in-

dicators such as QALYs (quality-adjusted life years)? This last criterion may seem reasonable but would lead to many blatantly unjust or absurd results. It has been shown, for example, what kind of problems could occur if kidneys were distributed for transplantation most “efficiently”: as Veatch points out, the best way to get as much aggregate good as possible from the available kidneys is to distribute them only to Caucasian males as they do better (in terms of survival of the organ graft) due to some complicated tissue compatibility factors.² Most people would agree that this outcome of the cost-efficiency principle would be unfair. It is then interesting to ask whether it would be similarly unfair if a certain beneficial drug were offered only to categories of persons whose genetic predisposition is such that they have a three times higher chance to benefit from it. Would this not be discrimination on the ground of genetic predisposition? This is not a hypothetical example: in modern medicine, e.g. in cancer research, genetic predisposition to positively react to certain treatments is increasingly important.

There are many other questions regarding rationing: Should age matter? Should irresponsible behaviours and lifestyles that have resulted in illness be penalised? What to do with the so called “bottomless pits” – patients who have interrelated conditions likely to require a disproportionately higher number of costly interventions over long periods of time? How does the current (implicit or explicit) rationing work in our society at present? Is it just? And given the tremendous importance and inescapability of healthcare rationing for equality, the most striking question is why there is so little public discussion about it.

Another area of health equality that is of concern in this issue of *ERR* is related to the

social determinants of health, in recognition of the causal links between socio-economic status and health status. Studying the social determinants of health is an exercise in the indivisibility and inter-connectedness of human rights. As health depends on the enjoyment of many human rights, a person does not have an equal opportunity to be or remain healthy if he was born in an impoverished community, became a victim of violence, suffered harassment in school, or was treated unfairly when looking for a job. The lifetime risk of maternal death is one in eight in Afghanistan; it is one in 17,400 in Sweden. In the USA, 886,202 deaths would have been averted between 1991 and 2000 if mortality rates between whites and African Americans were equalised. This contrasts to 176,633 lives saved by medical advances in the same period. The prevalence of long-term disabilities among European men aged 80+ years is 58.8% among the lower educated versus 40.2% among the higher educated.³ Furthermore, the relation between socioeconomic status and health is graded. In an example of what has been termed the “social gradient in health”, people in the second highest quintile

have higher mortality in their offspring than those in the highest quintile.⁴ It has sometimes been asserted that life is a value of the highest order, an end in itself, and that it is therefore “priceless”. But in practice, as noted by Leonard Fleck, “the lives that are priceless are the lives of paytients [sic] – individuals who are very well insured, permitting them access to many very expensive, marginally beneficial medical interventions”.⁵ How health insurance works in a given society is one of the best ways of revealing its structure of inequalities.

This issue of *ERR* is inspired by all of the above and similar questions. While there is a wealth of literature in political theory, health care policy, economics, social medicine and medical law addressing the central issues of relevance to health equality, an equality and human rights law approach is underdeveloped. But a rights-based holistic perspective should be integrated in the theoretical and practical search for health equality. Equal before the law, people should in some important sense of the word be equal before the doctor.

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¹ Case CCT 32/97, decided on 27 November 1997.

² Veatch, R. M., *Patient, Heal Thyself: How the New Medicine Puts the Patient in Charge*, OUP, 2009, p. 55.

³ Commission on Social Determinants of Health Final Report, *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health*, World Health Organisation 2008, p. 30.

⁴ *Ibid.*, p. 31.

⁵ Fleck, L. M., *Just Caring: Health Care Rationing and Democratic Deliberation*, OUP, 2009, p. viii.