

Rights To Health—Or Medicine: The Health Promotion Perspective

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The right to perfect health—something that in its fullest sense is unattainable—and the right to pursue it can distract us from achievable goals that take into account the inevitability of disability and death and the necessity of providing people with the capacities and rights that will enable each person to cope with their own imperfections.

RIGHTS IN AUSTRALIA

The Declaration of Independence, the foundation of the American conception of rights, says:

We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness.

We have a right to *pursue* happiness, not a right to have it. Do we have a right to health, or a right to pursue it? And what would 'health' be if we were successful in our pursuit and caught it?

Australia has come late to the notion of human rights. We come from the British tradition, where the rights of the free-born Englishman extend to the right to walk slowly down the pavement by yourself, breathing through your nose, and very little further. The Australian Constitution has no Bill of Rights. We have now, however, been influenced immensely by American culture, which does have a Bill of Rights, and we are, collectively, signatories to a range of United Nations Declarations—the Universal Declaration of Human Rights, for example, and the Declaration of Rights of Disabled People. For many reasons, Australians are somewhat confused in our notions of what it means to have a right and we are unsure how we would go about dealing with a right if we had one. This may explain, although it cannot excuse, our past and present flagrant disregard of the rights of Aborigines, disabled people, and women. Australia is, on the other hand, very keen on health. We go to the doctor more often than almost everybody else in the world, we go on a variety of diets, we expect to be healthy; and we are beginning to formulate our expectation as a claim or right.

Yet the rights that generally reach the arena of public discussion are in fact rights to medicine. The media will

seize upon a case where a person has been told that a drug is not available, or that a low weight baby must be flown interstate to get a particular high-technology intervention. Each of these cases individually may give cause for legitimate concern, but for them to be the main focus of public attention reflects a distortion of priorities, indicating an expectation of any intervention at any cost at any time to delay death. For one thing, economic considerations do have a place; we would not be well served by a medical system that consumed twenty percent rather than ten percent of GNP. For another, the greater salience of individual medical issues (as opposed to public health issues) means that political pressures dictate where money is spent, and a high proportion of health funding is in fact spent on activities of marginal significance to broader health indices. In developed countries, for example, about a quarter of the health budget is spent on people over the age of 65, in their last years of life.

More generally, however, we must ask ourselves what lies beneath this demand for unlimited attention to our medical needs? If we look behind the debate we find a primitive demand *that the health system should never let us die*. If we are going to die, it is a mistake. Somebody can prevent it, and we have a right to make them prevent it. The denial of the reality, of the inevitability, of death is a pronounced characteristic of our society (and it is possible that the popularity of zombie horror movies represents the return of the repressed unconscious desire to live forever, even if the form it takes is less than desirable).

Medieval tombstones used to bear the legend, 'I have been like you, and you will be like me'. In this sense, all medicine is doomed to failure; the all-causes death rate is eventually 100%. Each of us faces successive medical challenges as our bodies and minds age, but however often these are successfully mastered, the option of retiring undefeated is not offered to any of us. It can certainly not realistically become a right, even though the presumption of just such a right to live for ever imbues the construction of our health system.

Does this matter? I am not suggesting, after all, that the function of a health system should simply be to say

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‘Well, people have got to die sometime, I suppose it might as well be today’. The extension of life, or in public health terms, the extension of life *expectancy*, is generally a worthy goal, even if its benefits may need to be weighed against other possible expenditures. In certain sections of the population—in the Aboriginal community, for example, where the average life expectancy is fifteen years less than in the general population—the extension of life is a primary imperative, something we owe. In general, however, Australians are a long-lived people, with life expectancies within a year or two of the best in the world, within a few years of what we can ever expect to get.

If we did have a culture that recognised the impermanence of life, what would be different? One answer might be that our denial of death shapes our view of what is acceptable in life.

As Irving Zola said,

People in the Western world have great difficulty accepting realities. We continually deny that we may get old, sick, disabled, and die. We think of all those things as happening to someone else. And in all those denials we deplete ourselves of the very resources to deal with our own inevitable fallibility. And as long as we deny such vulnerability in ourselves, we will never be able to accept the disease and disability in others (1982).

This in turn affects our decisions about resource allocation and our fascinated obsession with the wonders of genetic engineering. Rather than accepting disability and disability rights, rather than directing our resources to services that will enable people with disabilities and chronic illness to live fully supported lives in our society, we are now instead investing vast sums in the possibility of engineering many people out of the gene pool through modern genetic technology. Is this a new eugenic movement that says we have a right to filter out the imperfect and the damaged, and the morally dubious, and reduce the variability of the population? Is this really what we want?

The Right to Bodily Perfection and Eternal Youth: A Right to Healthism

If we do not accept death, we cannot accept imperfection. Health, in the Australian media and in the lifestyle campaigns of middle-class healthism, is about living for ever in an indefinitely young and perfect body—this is what I would describe as healthism. Imperfection is seen as a spectrum ranging from chronic illness and disability at the far end to overweight at the near end.

The right to healthism is symbolised by our growing obsession with virulent campaigns to reduce people’s weight. Our society is particularly vicious in defining being overweight as sinful, and being thin as good and beautiful. Fatness is regarded as bad, greedy and uncontrolled. From babyhood, women in particular are socialised into a consciousness that there is a correlation between external cultural views of beauty and personal worth. This valuation is also becoming significant to young men, and is reflected in a rising incidence of male anorexia, bulimia and obesity. This body valuation is of

course continually and powerfully reinforced by advertising, marketing, fashion, popular culture and lifestyle campaigns, all of them mobilising a demand for the right to healthism.

As most people cannot meet the totalitarian requirements of body image, this quest for the impossible has profoundly unhealthy effects. When asked to select the female figure that looks best, 14% of boys and 54% of girls selected figures illustrating less than 90% of ideal body weight. This means that there is a completely misconceived perception of the desirable male and female body weight in these young people. The ‘ideal’ body at the core of healthism is unachievable, while our efforts to achieve it can have profound harmful iatrogenic effects in the form of eating disorders, diets and miserable obsessive lives, which also contribute to, and generate, enormous industries. Research undertaken by the Adolescent Health Research Centre shows a robust association between strict dieting, clinical depression, and distressing bingeing on food, smoking, alcohol use and unsafe sex. At Year 7 level 16% of males and 30% of females exhibit these health-compromising behaviours.

At the other end of the continuum are chronic illness and disability, conditions that are even less acceptable than overweight. It is as well to remember at this point that illness and disease make up a large part of all our actual lives. Illness is normal, almost universal—the question is, is it healthy? A disease free status is almost rare enough to be a pathological condition. In the 1989–1990 National Health Survey, 64% of males and 68% of females reported having one or more long-term health conditions (eyesight disorders, 32%; arthritis, 10.6%; hay fever, 9.8%; back troubles, 8.1%; asthma, 8.0%; hypertension, 7.1%; deafness, 4.0%; eczema, 3.7%). In people over 75 this figure rose to 96%. Do all these people have a right not to have these problems?

In fact, most people have a chronic illness. Seventy-five percent of Australians reported having taken health-related actions (ranging from medication to hospitalisation) in the previous fortnight, 70% reported having experienced one or more illnesses or injuries, and 66% reported that they suffered from long-term conditions. Twenty per cent (20%) had consulted a doctor, and 9.4% had consulted another health practitioner, 8% had taken a day off work or school, and a further 10% had had a day of reduced activity. Over fifteen per cent (15.6%) regarded themselves as having a disability and 11.5% regarded themselves as having a handicap. Nonetheless, 79% of those surveyed perceived their health to be good and only 4.5% thought they had poor health (ABS, 1991).

If health (meaning freedom from disease, illness or disability of any kind) is impossible, what does it mean to have a right to something that does not exist? Is it like the resolution by the guerilla cell in Python’s *Life of Brian*, where Stan says ‘It’s every man’s right to have babies if he wants them’. Someone else says ‘But you can’t have babies’. This starts Stan crying, so the group agree that while that he can’t actually have babies, not having a womb, he can have the *right* to have babies. Another guerilla complains, though, ‘What’s the point of fighting for his right to have

babies when he can't have babies?' The leader tells him 'It is symbolic of our struggle against oppression', but there is a mutinous murmur: 'Symbolic of his struggle against reality, more likely.'

Health and healthism

In the public health field, of course, we regard ourselves as pursuing a right to *true* health rather than a right to healthism. We have a wider view of health. As the Ottawa Charter tells us, health is something more than simply not being sick. Health, as defined by the World Health Organisation, is a state of physical, mental and social well-being. This means that health is not confined within the body of the person, but incorporates both the concept of an autonomous and resilient personality confident in his or her own capacity to cope with the trials of life and the notion of a citizen within a supportive and equitable community.

We have all heard the WHO definition so often that it tends to slip by, but I want now to point out that it is an extraordinarily all-encompassing formulation. It comes very close to treating health as a synonym for 'life'. Is there any human endeavour, in any sphere, that could not be seen as adding to or subtracting from physical, mental and social well-being? How can one reduce something of that scope to an outcome-based measure? How can one catch something of that scope under a 'right'?

The reality, though, is that 'health' is not inconsistent with quite a lot of illness, disease, and imperfection, and the figures that I quoted earlier show that most people recognise this. Most people use the word 'health' that way. In other words, if health encompasses disability and chronic illness—if you can be disabled, chronically ill, dying, and healthy—why are we talking about a state of physical well-being? There are no absolute standards. When we're talking about ourselves, we define health as what we're used to. And we're all used to different things.

What, then, if anything, do we have a right to? We have, perhaps, a right not to be handicapped by society, where people with physical and emotional impairments are handicapped by people's attitudes, and the consequences of discrimination are reflected in the strident demand for rights to healthism. What then do rights to health mean, and what can we do towards establishing them?

'RIGHTS TO HEALTH' MEANS 'HUMAN RIGHTS'

Right to health requires a right to the skills that will help us generate health. This requires the development of systems that will enhance people's capacity to bear change and to hope. In our schools, our workplaces, and our communities it is important to foster the ability to fight for the right to the power over our own lives: the power that we know, incidentally, accounts for many of the observed differences between the mortality and morbidity of different groups in our society.

The Marmot studies of British public servants have shown that health indices are tightly linked to rank

(1997). Those at the very bottom of the civil service hierarchy have heart disease rates four times higher than those at the top. After adjusting for such heart disease risk factors as blood pressure, serum cholesterol, smoking, social support, and so on, the difference between these groups is still three-fold. Those one step down from the top of the hierarchy—civil servants who are professionals and executives, such as doctors and lawyers—have heart disease rates that are twice as high as those at the very top. It is not surprising that those at the bottom have higher rates of disease than those at the top, but it is surprising that doctors and lawyers one step from the top also have higher rates. Doctors and lawyers are not poor, they do not have bad houses or bad medical care, they do not have poor education or poor nutrition. It is not just that those at the bottom have the highest rates of heart disease: there is a gradient of disease from the top of the British civil service hierarchy to the bottom (Syme, 1997).

The less powerful you are, the less control you have over your own life, the worse your health is, in every respect. This rank gradient accounts for more of the differences in health—more than diet (64%), exercise, or even smoking status (46%). So if the problem is that people lack a sense of control, what is the remedy? What is it that we need to offer them? It is difficult to think of an answer that doesn't include the p-word. What these people lack is power. What they need, therefore, is power. If we want to improve their health, that is what we have to give them.

Here, mainstream medicine could be seen to reinforce directly perceptions of powerlessness. The medical model has historically been centred around the acceptance by the client of the 'sick' role. A sick person received certain social privileges; he or she was exempted from normal social activities and responsibilities, and from responsibility for his or her illness, and was until recently not thought of as morally culpable for the condition. In return the sick person was expected to accept the sick state as aberrant and undesirable and to work towards 'recovery', and towards this end was expected to co-operate with the doctor and comply with his or her instructions. The 'right' to medicine is in this context *a right to be disempowered*.

The AIDS/HIV experience of the last fifteen years has seen a combination of moral obloquy combined with a deep-seated strengthening of the fledgling self-help movement, where people with illness or disability of any kind are claiming:

- a right to control over decisions about their treatment
- a right to a mutual contract where mutual benefits are acknowledged
- a right to access and add comments to their file

The right to health is also the right to power over our body images, valuing bodies of any age, shape, colour or disability, accepting variation as a positive force. When the decision about what constitutes an acceptable body image is, as now, completely taken by forces external to the individual, and shaped by fantasies of eternal life and perfection, then very many people in the community, not just people with disabilities, lead sad, cruel and frustrating lives, distorting their bodies with dieting and

surgery in unsuccessful attempts to achieve unrealistic images (Galbally, 1992). A healthier alternative would be to reconstruct our notions of physical acceptability so that the intrinsic worth of every human being is internalised.

As public health workers, we must ourselves relinquish the right to dictate what in people's lives is healthy. Leonard Syme's work with the Wellness Guides Project with disadvantaged communities in California has shown that the only really effective health promotion campaigns are those that are guided by the priorities of those previously disempowered groups (Syme, 1997). All the large expert-driven healthism intervention trials, in contrast (the Framlingham study, the Minnesota study, the Stanford Five Cities Program) have produced deeply disappointing results (Feinleib, 1996).

Healthy food and comfortable exercise, for example, need to be promoted for the natural pleasure and sense of well-being they bring, rather than as agents which expel the 'badness' of obesity. Self-help groups which focus on helping individuals regain their self esteem without using their bodies as a reference point should supplement, or in some cases even replace, a rehabilitation process and lifestyle programs which have as their goal the makeover of an individual's body or behaviour. We ourselves must accept our vulnerability, our ageing bodies, and our flaws from birth to death, if we are to think seriously about our lives. The right to health is best exemplified by the human right to respect, dignity and a purposeful life for all people:

- an acceptance of ageing, disability, or illness, rather than denial, abhorrence and revulsion

- a valuing of different bodies, minds and behaviours, rather than discrimination, concealment, and contempt
- the inclusion of all citizens within families, workplaces, schools and communities, rather than isolation, segregation, and abandonment

As a public health movement we must accept that knowing our vulnerabilities and accepting our limitations is vital if we are to be able to form, seize, and defend our rights to 'health'—a state which is made up of both the faculties we need to pursue that struggle and the qualities that emerge from the process of that struggle. A right to pursue happiness as a substitute for well-being may end up not only wasting our time and resources but also reinforcing our fantasies of what living is all about.

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Editors and their Sheds: Marriage and Parenting

Daniel T. L. Shek in 'Parental Marital Quality and Well-Being, Parent-child Relational Quality, and Chinese Adolescent Adjustment', in *The American Journal of Family Therapy*, 28: 147–162, 2000, concludes that his 'findings suggest that fathers, not the mothers, are more influential as far as adolescent well-being is concerned' (159). You may like to turn to:

- Adler, Robert G., 1983. 'Daddy Come home Soon!' Intermittent Father Absence and the Family, *AJFT*, 4, 2: 87–90.
- Condon, John J., 1985. Therapy of the Expectant Family: The Foetus as a Force to be Reckoned with, *ANZJFT*, 6, 2: 77–81.
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