

## Afterword: An Allegory

By

Hiram Caton and John I. Fleming

The title of this symposium, *Limits on Care?*, refers to the resources available for health care and other support services.

People with disability are among those whose needs exceed present commitments. But budget shares reflect human commitments. Over the past several decades public commitments to the disabled have expanded enormously, due in no small measure to organised voices of the disabled and their advocates. But are there limits to how much the abled, the parents and loved ones of the disabled, and governments, care about the disabled? Do we in our shared community life reach a point when we will say No to more services?

The attitudes that denied adequate services for so long remain very much with us. As Joan Hume stated: our century has been the best of times and the worst of times for people with disability. The tendency to ostracise "abnormal" persons seems deeply laid in us. To see it in action, visit a playground. The child with an impairment is likely to be teased and harassed. Cultural and racial differences also attract attempts to stamp out offending differences.

Adults do not always outgrow this mischief. "Why don't you just commit suicide?" an abled person asked a quadraplegic. Quads challenge our sense of the normal, and disturb our sense of life's goods, simply by choosing to endure in what for the abled seems purgatory. "But how do you put up with all the pain, the confinement, the boredom?" we ask, forgetting the many millions who endured internment camps where inflicted pain and humiliation were the daily routine. From David Charles-Edwards we learn that the condition of disability (in this case, head injury) is a Sisyphian task. None of the abled, not even kith and kin, know what it's like to wake each morning having to climb Mt Everest again. One slip on the icy slopes and you plunge into the abyss; in this case, into psychiatric detention.

Not all lethal attitudes stem from visceral reactions. They may flow from a generalized benevolence and enlightened views. Penny Robertson recalls that her scientific training and progressive outlook disposed her to terminate the Down syndrome child with "no qualms"

had she been advised by prenatal diagnosis. “I looked at it purely in terms of the gene pool and the good of society . . .” When the infant was born, physicians warned her gravely of what the infant’s limitations were, but “I was never told what her opportunities were. Now eleven years on, there is no way I would make that decision [to terminate the pregnancy].”

It would be interesting to insert this testimony in the midst of a bioethics conference for philosophers. Many argue that the Down syndrome fetus and Down syndrome infant, should, for their own sake and ours, be painlessly deleted from the gene pool and patient lists. Joseph Fletcher, considered in the United States to be the father of bioethics, declared flatly that “a Down is not a person.” It cannot imagine a future in which it is the agent of its own well being; and in general, the Down syndrome infant’s incapacity for moral choice upsets Fletcher’s view of a just and happy world. So, he wants to be rid of misfits.

Had Fletcher done his homework, and consulted the experience of families on the personhood of the Down syndrome child, he might have recognized that his list of defining human traits was biased toward the abled adult. The strong attachment between the Down syndrome child and family, and carers, did not figure in his list of human attributes.

Does society dare tell these parents and friends: Your child is not a person?

The ILSMH knows well that this attitude is not unusual in prenatal diagnosis counselling, in genetic counselling, and in infant intensive care units. It has come to light very overtly in newspaper reportage and letters columns here in Australia. Medical staff entrusted with the care of persons with disability have been prominent among the euthanasia advocates.

Aggressive feelings toward misfits become dangerous when they are translated into legislation or policy. We are aware of the German catastrophe. We have recently become aware that in its Dred Scott decision upholding a law requiring the return of fugitive slaves, the U. S. Supreme Court ruled that Negroes were not persons in terms of the law of the United States.

It was not an uncommon opinion. The *Canada Indian Act 1880* states that “the term person means an individual other than an Indian.” In the *Canada Franchise Act 1885*, we learn that “[a person] is a male person, including an Indian and excluding a person of Mongolian or Chinese Race.” Here is progress; in only five years Indians were upgraded to personhood and Asians are called persons in the very clause denying them personhood. By 1925, Canadian legislation had determined that all races—and women—are persons. Change in

Canada continued. By 1980, the government had recognized the Inuit, or Eskimos, as Indigenous Peoples with entitlement to lands. And the nation had developed a cadre of advocates dedicated to the empowerment of the disadvantaged.

If some bioethicists are lethal to the disabled, it may be because they have learned their lessons from the evolutionary ethics that underwrites the impulse to clean up the gene pool. The core of evolutionary theory is the notion that species evolve by a struggle for existence in which the more fit, or better adapted, successfully compete to leave a larger number of offspring; by this process the less fit are culled. Charles Darwin likened the process to “ten thousand sharp wedges packed close together and driven inwards by incessant blows, sometimes one wedge being struck and then another with greater force . . . The preservation of favourable individual differences and variations, and the destruction of those which are injurious, I have called Natural Selection, or the Survival of the Fittest.” To leave no doubt about the brutality of the process, he said: “. . . we may feel sure that any variation in the least degree injurious would be rigidly destroyed. This preservation of favourable variations and the rejection of injurious variations, I call Natural Selection.” Darwin viewed human history as lethal intra-group competition that serves gradually to improve the human race. Thus he declared: “The inhabitants of each successive period in the world’s history have beaten their predecessors in the race for life, and are, in so far, higher in the scale of nature; and this may account for that vague yet ill-defined sentiment, felt by many paleontologists, that organisation on the whole has progress.” The moral is that morals advance to the extent that human groups develop their capacity to cooperate in the domination or extinction of other groups.

This naturalism was taken up by progressive thinkers throughout Europe as an applied ethics for human improvement. One vocal advocate was the father of ecology, the Austrian biologist Ernst Haeckel. Haeckel enjoyed an enormous following. Like his successors today, he was a guru whose books sold by the hundreds of thousands, for he prophesied a “new period of higher mental development.”<sup>1</sup> But to reach this plateau of pure benevolence and reason, the race must undergo the anguish of purging its dross. (His successors today invoke the frightening vision of a “people plague,” “population bomb” and the like). Haeckel strongly supported euthanasia and was fond of praising the Spartan example of exposure of malformed infants. He denied the equal worth of all human beings, and advocated lethal injections for “utterly useless” people, among whom he numbered

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<sup>1</sup> George J. Stein, *The Biological Basis of Ethnocentrism, Racism and Nationalism in National Socialism*. In V. Reynolds, *et al.*, *The Sociobiology of Ethnocentrism*, Beckenham: Croom Helm, 1987, p. 262.

incorrigible criminals, the disabled, the mentally ill. He ridiculed the false humanity of his opponents, insisting that there are “hundreds of thousands of incurables—lunatics, lepers, people with cancer, etc.—who are artificially kept alive . . . without the slightest profit to themselves or the general body.”<sup>1</sup>

Recent scholarship has shown how these concepts entered into public health policy and prepared the ground for a sort of health fascism in Germany a decade before Hitler made it a national reality. It was the citizen’s duty to be vigilant of personal hygiene, to avoid foods and habits harmful to health, and to support government efforts to revitalize the nation. This included sterilisation of those suffering congenital illnesses and euthanasia for “hopeless cases.”

We recite the facts because bioethics, cohabiting as it does with hi-tech medicine, shares its voracious appetite for the present and heedlessness of the past. History is irrelevant because the world changes every day. However, human beings don’t change that rapidly; neither do medical philosophies.

Exemplary of this forgetfulness is the silence, among philosophers, about the most prolific, systematic, uncompromising, and admired utilitarian ethical philosopher of the last century, Herbert Spencer. This is a great loss, for he has much to teach. Like most utilitarians of his age, Spencer parlayed the popular belief in progress into a certification of his abundant certainties. One was the conviction that the good life was a life of agreeable feelings. This was a certainty because his study of the biological sciences taught him that nature has wired the animal machine so that the good is the pleasant and evil is pain. He easily demolished an opposing view, the ascetic ideal, by tracing it to the ignorance, brutality and supersition of “blood-thirsty ancestors.” Equipped with this insight, Spencer was able to decide whether “life is worth living.” His answer was that life is worth living when agreeable feelings predominate over disagreeable feelings. When this is not so, suicide is a rational choice. And if it could be proved that even the best life is one in which pains equal pleasures, then suicide would be warranted as the philosopher’s choice. Obviously, euthanasia would be warranted as the clinician’s choice.

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<sup>1</sup> He proposed medical commissions to study these questions in order to come up with euthanasia measures that would provide “redemption from evil.” It needs hardly to be added that Haeckel was firmly convinced to the superiority of the Caucasian race. The Negroid race he thought “incapable of true inner culture or of a higher mental development . . . no woolly-haired nation has ever had an important history.” Stein, *op. cit.*

Spencer lived to see the clouds of war gather over Europe. Progressive Englishmen were cheering on what he called the “social cannibalism” of the imperial era. The philosopher of progress grew pessimistic and brooded about the “rebarbarisation” of Europe. This was most serious for him, since the “necessity” of progress was his core evolutionary teaching. Despondent in the evening of life, he wrote that “did I think that men were likely to remain in the far future anything like what they are now, I should contemplate with equanimity the sweeping away of the whole race.”

In this statement the dynamics of utilitarian optimism and benevolence come to light. Spencer’s enthusiasm for moral progress is driven by moral contempt of the past: the more wretched it seems, the more the present needs redemption by faith in the future. The misanthropy latent in this view comes to light when Spencer admits that he would “contemplate with equanimity,” that is, would derive moral satisfaction from the destruction of the “whole race” should it revert to barbarism. The odium he heaps on blood-thirsty ancestors is transferred to every human head that does not conform to his idea of the good.

Our allegory becomes a little clearer when we recognize who exactly those blood-thirsty ancestors are. Did he mean the Visigoths, the Golden Horde, the Huns? Yes, but not only them. He also had in mind the ethical exemplars and heroes of every culture prior the enlightened “industrial era.” Here is monoculturalism with a vengeance; is it not the same Cyclopean vision of human beings expressed in the *Canada Indian Act*? What Spencer could not endure in unenlightened ethics is its “asceticism,” its affirmation that pain is ingredient to the good life.

This attitude is widely diffused in contemporary health services, which interprets pain as a minus sign against the “quality of life.” The physician’s task is to “manage” pain using a pharmacopia of “painkillers.”

The task is daunting. To form an idea of it, consider first its cost. Job absence and disability from pain is estimated, in the U.S., to account for over 700 million lost work days, while the bill for lower back pain alone, in 1980, is estimated at \$23.2 billion.

A number of types of pain pose major challenges to the pain management commitment. Among them are untreatable chronic pain, and chronic pain that can be treated only at the risk of developing analgesic dependency. Then there is emotional pain incident to psychiatric disorders and medically-related distress, such as the anguish of involuntary childlessness and the grief syndromes discussed by Jenny Kearney.

The commitment to deal with this enormous mass of pain sometimes stretches the human capacity for sympathy beyond its limits. It is recognized that, confronted with cases that do not respond to treatment, the doctor “grows less sympathetic toward chronic pain patients and less willing to seek or acknowledge complaints of pain . . .”<sup>1</sup> In some situations medical staff may become systematically aggressive toward patients and institute a “culture of violence” against them, as happens all too often in psychiatric care.<sup>2</sup>

We must recognize, then, that healers themselves may be subject to a vocational hazard—chronic stress deriving from the superhuman attempt to “manage” the vast mass of patient pain. The common term for analgesics, “painkillers,” is indicative of the aggression attending pain management. When the patient’s pain isn’t “killed,” the doctor may propose case management alternatives whose unconscious intention is to cope with their own professional stress-related anxiety.

In considering the ethical dimensions of pain management, then, we should recognize that health providers are not the neutral experts that they are assumed to be in the various instruments calculating quality of life. Health provider distress is an unacknowledged quantum in the equations for reckoning the balance of pain over well-being, so that we must always ask: whose pain does this treatment regime address, the patient’s or the doctor’s?

In their avidity for general happiness, utilitarians do not tolerate obstruction by mere rights. But human rights are the cornerstone of disability ethics. In his report on the Third Workshop (Vancouver) on Bio-Ethical Issues of the International League of Societies for Persons with Mental Handicap (ILSMH), Helmut Spudich draws attention to the principles agreed on by the participants. Among other things, the participants affirmed:

that persons with mental handicap are as valued and have the same rights as all other persons. These rights are outlined in the UN Declaration of Human Rights and the UN Declaration on the Rights of the Child. The fulfilment of these interests must be measured by outcome and not merely be equal access to opportunities.

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<sup>1</sup> V. C. Lee and J.C. Rowlingson, Chronic Pain Management, in *Quality of Life Assessments in Clinical Trials*, edited by B. Spiker, 269-93, at p. 27, New York: Raven Press, 1990.

<sup>2</sup> *Commission of Inquiry into the Care and Treatment of Patients in the Psychiatric Unit of Townsville General Hospital. Report* Brisbane: Government Printing Office, 1991.

The human rights claims made by ILSMH at Vancouver, are of great significance, perhaps greater than ILSMH realised at the time. ILSMH is appealing to a universal human agreement that every human individual has rights over and against the policies, goals, wishes and desires of the community in which he or she lives, and that every nation is obliged to protect the human rights of each of its citizens.

The emphasis on human rights in the wake of crimes against humanity, and the determination of the nations of the world to see that human rights are observed is a major ethical development. By the end of 1988, 97 per cent of the world's population belonged to a nation that was a member of the United Nations and therefore bound by the Charter of the United Nations. When the ILSMH appeals to the UN Declaration of Human Rights it is in tune with the aspirations and moral commitments of the world at large.

This does not mean that nations always behave in a way that is consistent with their moral and ethical obligations. It does mean that the world has agreed to a minimum set of human values, expressed as human rights, and that that set of human rights remains as a constant reference point for the adjustment of practice to principle. Accordingly the disability movement does well when it points out to governments and peoples that there is a mismatch between their human rights obligations and their practice.

When nations join the United Nations, they commit themselves to a Charter. The Charter of the United Nations has, among its purposes, the achievement of "international co-operation in solving international problems of an economic, social, cultural or humanitarian character, and in promoting and encouraging respect for human rights and for fundamental freedom for all without distinction as to race, sex, language, or religion." The Charter further commits the United Nations to promote "universal respect for, and observance of, human rights and fundamental freedoms for all without distinction as to race, sex, language, or religion" by way of a pledge.

All members pledge themselves to take joint and separate action in cooperation with the Organisation for the achievement of the purposes set forth in Article 55.

This is the idea of a *consensus gentium*, an agreement among the nations, a consent to be bound by certain values expressed as human rights. This doctrine of consent involves the idea that the "basis of obligation of all international law, and not merely of treaties, is the consent of States."

What is the standing of human rights in international law? Authoritative opinion of international legal scholars has it that the “protection of human rights is now within the domain of international law.” Bruno Simma and Philip Alston have explained how we can see human rights in terms of international law by “treating the Universal Declaration and the body of soft law built upon it as an *authoritative interpretation* of the obligation contained in Articles 55 and 56 of the UN Charter.” Moreover, those bound in international law to observe human rights are individuals as well as groups of persons, corporations, and states. While the United Nations does not have a mechanism to enforce human rights obligations, the pressure that can be applied to governments, corporations, and individuals that have broken a universal agreement is considerable. D.J. Harris has underlined this fact with his observation that “the idea that the treatment of a state’s own nationals is a matter within its own jurisdiction has been abandoned.”

The Universal Declaration on Human Rights, in its *Preamble*, states that “the foundation of freedom, justice and peace in the world” is the “recognition of the inherent dignity and the equal and inalienable rights of all members of the human family.” Article 1 specifies that human beings “are born free and equal in dignity and rights.” Article 2 asserts that, in the entitlement to the rights and freedoms in the Declaration there is to be no distinction of any kind, “such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”

In contemporary moral discourse distinctions between persons and non-persons are common. Persons have rights. Non-persons have no rights. Yet this distinction, attractive as it appears to be for those who wish to justify abortion, eugenic infanticide, and killings of other persons with major physical or mental disabilities, is fraught with difficulties. There is no philosophical agreement on what constitutes personhood and, accordingly, no agreement as to when personhood begins or ends. This distinction does not appear in the Universal Declaration; indeed all such distinctions which affect the entitlement to human rights is rejected. What the Universal Declaration says is that human rights are recognised for “all members of the human family.” What matters, for the purposes of human rights, is membership of the human species. The Universal Declaration deals with the problem by treating all human beings as members of the human family.

The ambivalence on the abortion issue in the disability movement could be resolved, then, in the terms that the Universal Declaration affords as part of the law of nations. The wrongfulness of using termination of handicapped fetuses as a population policy would be



located where it belongs—in the killing of a member of the human family simply because that individual had disabilities.

The disability movement is, on this analysis, in a strong position to insist that the nation states of which they are members, protect in law the fundamental human rights of persons with disabilities. Since the subjects of international law where human rights is concerned are individuals as well as corporations and states, the movement would be entitled to point out that bioethicists who promote the medical killings of persons with disabilities enjoy no special status that exempts them from their human rights obligations.