

The resource allocation dilemma

The new wave of brilliant technologies witnessed in the past 20 years (such as organ transplantation and in vitro fertilisation) has presented health care providers and lawmakers with issues which go to the very heart of the value and purpose of life. The era of finite/reduced funding has added another layer to this set of challenges: the questions Who lives? Who dies? Who pays? and Who decides? In this paper, bioethicist Hiram Caton sounds a warning over the community's growing permissiveness toward "medical killing" and the danger of euthanasia being accepted and broadened to contribute to population and resource control. He predicts the greatest competition for resources will be between the young and the aging, and asks whether the "health care crisis" might be due, at least in part, to medically-induced mass anxiety about pain and sickness.

Hiram Caton[§]

The most formidable challenge to health care in the 1990s is the equitable allocation of resources. Human resource and facility utilisation are under continuous review. Efforts are made to substitute, where possible, less costly satellite installations - such as day care centres, hospices and visiting home care - for hospital care. These measures go some way toward reducing the numbers of patients on waiting lists, estimated to be about 75,000 nationwide.

At the public health level, renewed emphasis is placed on prevention and client awareness of their responsibility for their own health and safety. Alcohol consumption and alcoholism are implicated in 20% of road trauma and in 85% of domestic violence that results in treated injuries. Costs also accrue from treatment for alcohol detoxification, cirrhosis and psychiatric care. Health promotion campaigns are slow to show results but they need not be all that slow when they are accompanied by tangible sanctions, such as heavy penalties for drink-driving.

[§]Director of the Bonhoeffer Institute (Queensland) and Professor of Politics and History at Griffith University.

This paper is based on a paper "Strengths and weaknesses of QALYs as an allocation instrument" which Caton presented to the Australian Catholic Health Care Association's conference on the Challenge of Change (Canberra, June 1-3).

The Bonhoeffer Institute (named after and inspired by the theologian Dietrich Bonhoeffer) was established in 1988 to conduct research and to promote education in the field of health policy and bioethics. Its sponsor is the All Saints Anglican Church, Brisbane.

The institute's mission is to furnish sound assessments of the difficult questions confronting health providers and patients alike. It works closely with the Southern Cross Centre for Bioethics (Adelaide) and the John Plunckett Centre for Bioethics (Sydney) and in association with government bodies, hospitals, professional, religious and civic groups. Initially the institute directed its attention to birth technologies and their regulation. It now includes equity in resource allocation, disability, and euthanasia

Linking efficiency with resource allocation ethics is another trend in cost containment. The increased use of available beds and reduction of the number of emergency outpatients by shifting some to local medical facilities are two efficiency measures.

The unpleasant fact is, however, that gains won through such measures are swamped by increasing demands for service and escalating costs. They do not put us ahead but are a stop-gap against falling too far behind.

Since the early 1970s, health officials have warned of the impending crisis in health care funding. That talk has continued until, in the past three or four years, OECD Health Ministers have voiced grave concern.

In May, the *Journal of the American Medical Association* published another warning. Editor Dr George Lundberg stated that the US health care system faces "meltdown" in a few years if the cost rise continues at the present rate.

He illustrated the point by projecting a national health bill of \$1.4 trillion or 17% of the GDP for 1996 on present expenditure rates.

The dilemma is acute for 35 million Americans without medical insurance. The public finance of their health care draws on monies intended for other services to the poor, thus whittling away at the total services provided to this group. A similar phenomenon is observed in private group insurance, where firms maintain current health benefits by diminishing other employee benefits. These measures are stop-gap because they provide no relief from the relentless expansion of ever more costly medical services.

The picture in Europe and Australia is similar if not so grim. The combined annual Commonwealth and state health services bill in Australia is \$19 billion. The National Health Strategy review found last year that health care costs could rise by 44% in a decade unless economies are found. Yet membership in private insurance has fallen by 20% and the Medicare levy raises only about 6% of the total Commonwealth health bill.

A strategy presently favoured to meet these costs is to shift them into the "user pays" modality. Attempts in this direction have not been conspicuously successful, as the experience with the attempted reconstruction of the Pharmaceutical Benefits Scheme showed.

The PBS had blown out to a cost which is doubling every three years. The government sought to impose a small charge on prescriptions to encourage discriminating client use but the charge fell disproportionately on those least able to pay - the pensioners. The outcry forced a government retreat, thus returning the problem to the unsolved basket.

Contemplating such indices of national and international disequilibria between demand and supply, one wonders whether the era of the welfare state largesse has crested. Is the crisis in health care funding - and the apparent inability to resolve it - one more signal that we have quietly entered a long period of retrenchment from the comprehensive ethical commitments of the welfare state? If so, the economic presuppositions of the best health care for all will give way to an ethics of care appropriate to an increasingly stringent rationing regime.

The novelty in this scenario is not rationing as such. There is now, as there always has been, a rationing regime whose configuration is traced by identifying those categories of patients for whom demand substantially exceeds supply.

What will change is the horizon of expectation. For about 15 generations, the peoples of OECD nations have experienced a phase of economic, technological, cultural and population growth without historical parallel. This long period of prosperity created a horizon of the future which promised that tomorrow will be better than yesterday.

In the post-war period, economic growth was taken so much for granted that governments constructed the comprehensive care of the welfare state on the assumption that it will always be thus. As political parties vied with one another to provide ever better and more expanded services, the public came

to regard the best medical care as a right. Best care, as we know, has never been extended to all Australians but the expectation was that it ought to be and would be - and sooner rather than later.

This horizon, I suggest, is being retrenched to less buoyant futures consistent with the shortfall between the economic performance of the welfare states and their promise.

The high visibility given to clawbacks, microreform, efficiency, industry shakeouts and other euphemisms for stringency is the language signalling the transition. Alarming futures, such as the "banana republic", have from time to time been dangled before us. Yet pressures from constituencies make it difficult for politicians to maintain a consistent position.

Thus the message of permanent retrenchment is diluted to a message of temporary austerity pending the success of economic reform. Home truths such as "the depression Australia had to have" are retracted with apologies. And the public, weary or angry at what they interpret as duplicity or corruption, defect from parties that long enjoyed their loyalty.

The simple truth seems to be that the most affluent economy never has, cannot now, and never will fund the full benefits of the welfare state. One response to this impasse has been the development of a sophisticated cost-benefit tool called the Quality Adjusted Life Year (QALY), to bring economic efficiency to health services.

The development began some decades ago as an attempt to identify probable therapeutic outcomes of costly procedures¹. The strategy was to construct a database of patient populations who had received a specific treatment and whose life course after the treatment was known.

The intention was to provide concrete information to inform the selection of the most effective treatment from among the range of options available. The database would identify where the high probabilities of treatment to desired outcome were occurring and where the opposite occurred. Moreover, the database yielded estimates of the relative costs of therapy options, thereby adding a cost-benefit dimension to the choice of treatment.

In its initial phases, the QALY instrument did not reflect the important fact that outcomes vary with the health status of the patient. But over the years, information on health status was gradually added. The database developed into a distinctive information processing system expanding from individual hospitals to municipalities, to regions and today, on the near horizon, national and even international health systems.

Eventually, longevity as the sole outcome indicator was refined into a more discriminating instrument assessing the quality of the years of life added by treatment.

Thus, to a refined probability of out-

come and cost-benefit ratio was added the third dimension that gives the instrument its name. One year of current life in good health is counted as one QALY and one year of current life with a lower level of health q ($q < 1$) is counted as q QALY. This system allows a health profile over expected life to be calculated as the probability of a numerical gradient for quality of the life that a given treatment would extend.

The original inspiration of QALY was the need for informed judgment about the selection of costly treatment. However, the proliferation of surgical, pharmacological and diagnostic interventions has advanced at such a pace that it emerged as a tool for identifying the range of treatments available.

Furthermore, as the cost of hospitalisation and drugs increased and as ever more costly treatment of common chronic care conditions bulked ever larger, the original distinction between expensive and commonplace treatment proved to be less significant than the statistical distribution of health costs across the spectrum of services.

The strength of QALY is its power to describe the distribution of treatment costs relative to outcomes in a given system and its capacity to identify the likely treatment outcomes for a given patient. This information assists the doctor to decide when to abstain from procedures unlikely to yield any healing or palliative effect or to abstain from treatments whose likely benefits are not proportional to the costs.

Of the numerous objections to the implied ethics of the QALY, I shall discuss two.

It has been noted that QALY trades off the lesser benefits to one patient against the greater benefit to another. This is inherent in any cost-benefit approach to resource allocation. But it is contrary to declared international and Australian norms, which direct care toward the patient irrespective of other patients.

Thus the Australian Medical Association *Declaration of Co-operation* with the Commonwealth National Health Strategy states that:

"All Australians must have optimal access to health care... the well-being of the patient must be central to all policies. This must over-ride any considerations of bureaucratic convenience... the highest standard of patient care, commensurate with resources available, requires regular and genuine consultation with professional clinicians."

However, the AMA and the Commonwealth government are aware that only a portion of Australians have optimal access to health care; that chronic care, rehabilitation and other categories of care are markedly under-resourced while some services are generously resourced; and finally that there is no prospect that all Australians will have equal access to optimal care. To continue to proclaim this ideal risks entrenching an hypocrisy that provokes the anger of client

groups.

It is more truthful and probably better politics to acknowledge that care is scarce relative to demand and that consequently patient claims to care are in competition with one another. In this matter I differ from Nick Tonti-Filippini who states² that *"rationing... cannot help but produce grave injustice at the clinical level. Illness is not measurable in economic terms"*.

Yet Tonti-Filippini states in the same essay³ that:

"Expressions of anger and frustration toward government and bureaucracy are the norm in our hospitals, and the public is losing confidence in a health system which cannot deliver the reassurance that care is available to all the sick... the so-called 'health system' is no system at all but a conglomeration of interests [competing for budget shares]."

Here it is admitted that illness after all has a dollar measure; that inequities exist; and that the public - tutored by government and health providers to expect optimal service - are angry about the shortfall.

These are structural features with which any allocation ethics must deal. The welfare state in its heyday did not eliminate them, and in its decline there is no probability that equality will be achieved.

The second objection to QALY is one that I share. It is that the quality of life index q is a specious number. It purports to be objective in the sense that it calculates the values that a sample of patients, care-givers and immediate family assign to health statuses in rank order from the most to the least acceptable. The judgments are averaged to obtain the value of living with different degrees of comfort, pain and disability.

But the value assigned to q will depend on how the sample is determined. If it is composed of the parents and immediate family of a seriously disabled child, q will be high. If the sample is expanded to include spouses who elected to terminate a handicapped fetus, the q value will diminish.

Inclusion of medical staff will diminish q still further, while the inclusion of irritated taxpayers and chronic care patients will lower q yet again. Clearly, the sample can be manipulated to obtain any q value one pleases. If q were an objective value, QALY would assuredly merit a Nobel peace prize.

A noteworthy feature of QALY is that it weights pain negatively, as if a life of pain were not worth living. One is surprised that a profession that deals every day with chronic pain should not have challenged this bias.

Pain clinics, not to mention biographies and memoirs, are stocked with histories of tormented lives that were nonetheless creative and abundant in giving.

Other histories - histories of inhumanity - tell of millions subjected to unspeakable insults to the soul and torture of the body. Reading the narratives, we wonder why they wished to endure for a day. Those who returned home from these contrived hells say

that the will to live was steadfast and that mere survival was a badge of victory over brutality.

Further lessons lie in the extraordinary idea that pain is a stigma. Medical training indirectly endorses this curiosity in teaching that the appropriate response to complaints of pain is to relieve the symptoms and to remove the cause if possible.

In the neighbourhood doctor's surgery, this usually translates into prescriptions for analgesics. One side effect is 8,000 prescription drug-dependent Australians, most of them women and teenagers.

Another side effect is that the lore on how to live with pain based on millennia of human experience is brushed aside even though pain clinics validate at least part of the lore - for example, the fact that placebos give some pain relief for about 30% of complaints.

Contemporary medicine strips pain of its moral qualities to interpret it as a dysfunction from which the patient has a right to relief. Meanwhile, the basic zoological fact that pain is ingredient to life is forgotten in the course of promoting the fantasy of a painless existence. This in turn drives escalating demands for medical care.

Ponder the irony. Although there is probably no greater source of inflicted suffering than therapeutics and diagnostics, medicine - to the applause of utilitarians - denies the personal and ethical value of pain and pain tolerance. In that way medicine contributes to the anxiety about suffering which is manifest in the clamour for ever more health care and to the consumer movement for a pleasant death.

Might the health care crisis be due in part to medically-induced mass anxiety about pain and sickness? Have we medicalised sickness, pain and death to the point of neurosis?

That we may have become sick of sickness is suggested by the increasing acceptability of a solution to the glut of sick people: let them be selectively killed - painlessly, of course. However, killing is homicide and this creates a difficulty.

There is a way around it. As the abortion experience shows, judges in applying the law of homicide to clinics follow considered medical opinion. Change medical opinion and you have changed the law.

Thus it is proposed that the physicians' last duty to patients is to prevent unnecessary suffering by terminating life deemed to be irreversibly beneath what healthy persons regard as unacceptably low quality.

It is claimed that there is a right to a painless death and consequently that law must permit it. But this is still small beer. The threshold to something really big is the conviction that there is "life unworthy of life".

On the yonder side of the threshold roams the bioethical culling team pondering which categories of patient, in addition to PVS, are to be deemed "no better than a lettuce" and which categories will be denied

the enabling label, "person".

This is no longer euthanasia. It is mock triage of large patient populations to prepare clinical staff mentally to administer death according to schedules of eligibility. The cultivation of this conceptual killing field for several decades has made it so familiar that one is no longer startled by the titles *Who lives?, Who dies?, Causing death and saving lives and Should the baby live?*

The results of this ethical training are now coming in. Everywhere on the current scene of the experiment in dying are signs of the impending killing frenzy.

Derek Humphrey's best-seller *Final Exit* contains detailed advice on the acquisition, storage and use of 16 lethal doses. He explains the use of other devices, such as a plastic bag, to assure that the suicide attempt will succeed.

While he warns away all readers who do not "rationally" consider "self-deliverance", this is unlikely to deter vulnerable groups, such as youth, whose suicide rate has soared in recent years.

He does not consider at all that suicide recipes can be used equally well for homicide. He praises the German euthanasists' preferred method of suicide, the cyanide tablet, even while acknowledging its previous "misuse" to destroy millions. Neither he nor apparently his readers are deterred by the memory of horrific slaughter.

And then there is Dr Jack Kevorkian, dubbed "Dr Death" by the American press. Dr Kevorkian was recently indicted for the murder of Susan Williams.

At his trial for the death of Janet Adkins, the prosecution established that he did not medically examine her or another woman who, rescued from his attention, was found to be suffering from treatable migraines.

In an assessment of Kevorkian written two years ago, bioethicist Colleen Clements noted that he made contact with Adkins through advertisements for persons willing to be experimental subjects for the use of his killing machine (having failed in his attempt to recruit prisoners on death row).

She believed that he had an eroticised obsession with death. This was an obnoxious opinion among her colleagues at the University of Rochester Medical School, who had only praise for Kevorkian's "courage".

It disturbed Clements that qualified psychiatrists could not recognise his sickness. It meant that they were even less able to recognise the aggression in their own enthusiasm for medical killing. In a sardonic mood she wrote⁴ that ethics had been so transformed that "it becomes hard to tell a physician from a mortician".

That anxiety, depression and other syndromes drive the euthanasia movement is apparent in its morbid ideation. Consider this passage by Daniel Meynen, writing for the German Society for Humane Death⁵:

"The duty to suicide occurs when through my continued living lack of

autonomy, misery, isolation, uniformity, unfruitfulness, incurability, lameness, pain, insensitivity, disgrace, madness, and sin threaten to become the norm for humanity and my suicide is the only means available to me to prevent this."

Here is sickness writ large. The guilt and worthlessness expressed in this passage are readily recognised as the ideation of sickness depression. Many patients who said "Doctor, let me die" have been returned to health by caregivers who ignored the request.

The euthanasia movement death wish is distinctive for the linkage made between the individual sickness depression and the dignity of humanity. The link is provided by the belief that humankind is the ethical peak of all existence because there is no God and no Redeemer.

However, "sickness unto death" is a profound blemish on the humanist world. The alternative to eliminating death is to tame it, to humanise it, by making it an act of will. For the humanist, life as such is of no value; alternately, there is, as they say, "life unworthy of life". Human will alone is sacred.

The sanctity of the enlightened will is the fulcrum of bioethical exercises in mock killing. In a manifesto that seems to be the Bible of official Australian bioethics, John Stuart Mill angrily denounced the "despotism of custom" as "the standing hindrance to human development". He went on to declare⁶ that "all restraint, qua restraint, is evil". The natural inhibition on killing, strongly confirmed by custom and traditional medical ethics, is a restraint and therefore evil.

In the sanctity of life debate, humanists seek to vindicate the sanctity of the will against the despotic inhibition on killing and other manipulations of life, for these restraints hinder human development.

The argument strategy is stereotyped. The bioethicist begins with a consumer desire or an expert opinion in favour of some uncustomary practice, such as surrogacy or euthanasia, and asks whether there is a good reason to restrain this will.

Will as will is thereby structured as the ethical. Reasons for restraining it are construed as merely instrumental to preventing harm to others: Me is First.

However, as the philosopher usually regarded as the father of bioethics has said⁷, there are no absolutes (except the will) so that one should do no harm "unless the end justifies the means".

Since the end is good willing, the means is always in principle justified. Ethical reasoning is thus an exercise in finding in the welter of contingencies ways to apply good willing. This is why the bioethics of killing starts with the assumption that willing good death is permitted and canvasses reasons why we should not kill.

The current trial with euthanasia in the Netherlands tests the confidence that the

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removal of restraint on the will to medical killing will not lead to abuse. Since modern humanism arose three centuries ago in the midst of Dutch theological controversies, it is fitting that the second nation to experiment with euthanasia (after the stern warning of the German experiment) should be the Dutch.

The official *Dutch Euthanasia Survey Report*⁸ published last year indicates that the good will to killing has set to its benevolent work with gusto. The overall figure is 25,306 physician-assisted deaths in 1989-1991. That is a staggering 20% of the total deaths. The breakdown is:

- 2,300 deaths on request
- 400 assisted suicides
- 1,000 lethal injections without explicit request
- 4,756 deaths after request for non-treatment
- 8,750 deaths in which treatment was withdrawn or withheld without the request of the patient with the intention of killing

In his evaluation of the report, John Keown, Director of the Leicester University Centre for Health Care Law, stated⁹ that "the vast majority of deaths from euthanasia are illegally and incorrectly reported as natural deaths, [which] itself casts doubt on the lawfulness of much of the euthanasia which is being carried out".

This should come as no surprise. The prediction that tolerance of euthanasia would be abused is based on considerable evidence - some of it surveys carried out by euthanasia advocates - showing that 20%-30% of responding doctors (or 10%-15% of the sample) acknowledge killing some patients even though this act is homicide. As happened with abortion, doctors disregard the law and say privately that "the law is an idiot".

As John Fleming writes¹⁰ in his digest of the Dutch report: "*The right to life cannot be given up without threatening the right to life of other members of the community. When medical killing is allowed in some circumstances, the number of circumstances in which such killings occur quickly increase.*"

To assess the extent of the likely killing if euthanasia is condoned, we need a clear view of collateral influences. One of these is the anxiety about overpopulation. This spectre has been with us since Malthus raised it in 1798.

Two decades ago it went to international agendas under the slogan "zero population growth". Today it is integral to the charismatic environmentalist movement, whose compassion for man-damaged nature often translates into malice toward human beings.

Traces of this attitude are found among sober and responsible authorities. The Challis Professor of Anatomy at the University of Sydney is exemplary. For him, population growth is a "people plague".

After a careful review of population growth and its relation to environmental carrying capacity, Professor Jonathan Stone stated¹¹: "*We are threatened by the realisation that these many problems are but symptoms of an underlying cause, and the cause is a plague and the plague is us.*"

He notes that the simultaneous decline of fertility to well below replacement value in Europe and elsewhere signifies a "subliminal recognition" that there are too many people; that the Boat is Full.

One result is 30 million aborted births annually worldwide as estimated by the World Health Organisation, which vigorously supports population control as fundamental to a sustainable future. Here medical killing has been promoted from a woman's right to control her reproduction to a collective moral duty to *prevent* reproduction, as is starkly explicit in the Peoples' Republic of China¹².

When these and other collateral influences are borne in mind, the question is not whether this or that set of guidelines for assisted death provide adequate safeguards, but whether the inviolability of life asserted in welfare state guarantees of human rights and human dignity can withstand the strong impulses driving acceptance of medical killing as a means of reducing the "people plague" and of obtaining relief for stressed health budgets.

Let us recall the pressure points:

- Medical killing is now a consumer item strongly promoted by the media and by many in the health field.
- The clientele for this item is potentially large, because the mass administration of analgesics has eroded the religious discipline for living with bleakness, pain and death.
- Competition for scarce resources among patient groups and within health services already exerts pressure to reduce patient populations. The pressure will increase as the public become aware that a large proportion of the health budget is expended on the last 18 months of life.
- The acceptance of abortion has established for many the legitimacy of medical killing to control populations.
- Permissiveness toward medical killing holds some promise of solving "social problems" that are intractable for the welfare state as currently constituted.

Abortion is limited by the circumstance that it presupposes pregnancy. But there is no such limit to euthanasia. Nearness to death is not a limit because patients in stable conditions may be deemed to have an insufficient quality of life.

Indeed, there is considerable support for treating the designation "person" as a status assignment that issues from philosophical inquiry. Since philosophers apparently have no stable method of inquiry, there is no predictability of outcome. Thus the "rational"

determination of personhood places every life at the hazard of the next syllogism.

What lessons for allocation equity can be drawn from these reflections? In a long period of retrenchment, the horizon of expectations will scale down. This does not mean that competition for scarce resources will relax; the short term effect is more likely to be the reverse.

However, the various avenues for public consultation on allocation equity may help the public to appreciate what harassed governments already know: that any conceivable equity formula will be perceived to be unfair by significant sections of the public.

Certain loci of contestation have been identified as probably structural features of future allocation equity. Among these the competition between generations - the young v. the aging - will be the most severe.

Since aging is a natural process irreversible by health policy, the most draconian social change can provide no remedy. When the limit of solutions is reached, so is the limit of the will. The "problem" then becomes a signature of the human predicament.

Our culture of emancipated desire chafes at predicaments even though no generation has ever escaped them. Now the predicament of everyone is mortality.

Medical experience has long since learned how to deal with it - to heal where possible, to comfort always and to provide those small but humanly significant mercies of restoring confidence, courage and hope. This is obvious at the bedside.

Yet as the poet has said, the mark of wisdom is to see the miraculous in the common. The beast of desire will wheeze and hiss but these small mercies are in the end the best that caregivers can provide.

References

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2. Nick Tonti-Filippini. *Ethics and the allocation of scarce health resources*. In *Ethics and Resource Allocation in Health Care* (eds Bernard Clarke and Mary Stainsby), p 129. St Vincent's Bioethics Centre, Melbourne, 1991.
3. *Op Cit*, p 127.
4. Personal communication, June 25, 1990.
5. *Zur ethischen Beurteilung der Selbsttötung*, Deutsche Gesellschaft für humanes Sterben, 1982.
6. Mill SJ. *On Liberty*, p 116. Bobbs-Merrill, Indianapolis, 1956.
7. George J. Annas, quoting with approval Joseph Fletcher, JAMA (1989) 261:454. Annas notes that this outcome follows from Fletcher's utilitarian estimate of the net amount of human happiness produced by an act. Since such estimates are mostly subjective, this ethic empowers the will to do as it will.
8. Known as the Rummelick Report, The Hague, 1991. See Paul J. van der Mass et al. *Euthanasia and other medical decisions concerning the end of life*. Lancet (1991) 333:669.
9. Keown John and Keown JJ. *The law and practice of*

euthanasia in the Netherlands. *The Law Quarterly Review* (1992) 108:7-8

10. John I Fleming. Euthanasia, the Netherlands and slippery slopes. Occasional Paper. The Southern Cross Bioethics Institute, Adelaide, 1992.

11. Jonathan Stone. Environment, plague and the problem of charity. Australian Foundation for Science lecture, ANZAAS, October 1, 1991. Mimeo.

12. A cameo of this predicament is the dispute about whether China's population control program is in fact coercive. If it is, then the Australian government is obliged, by its human rights commitments, to protest it. The government sought advice from an AIDAB demographer, who advised that although coercion sometimes occurred, it was contrary to the Chinese policy. This report, Recent population policy in China,

was rebutted by another report tabled in the Senate. See John S. Aird, Foreign assistance to coercive family planning in China, Australian Senate.