

# UNIVERSITY OF SYDNEY

## CENTRE FOR HEALTH GOVERNANCE, LAW & ETHICS

### ORATION 2009

## SHARING CARING IN A TIME OF BUDGET INSUFFICIENCY: IS THERE AN ETHICAL REFORM PARADIGM?

### Introduction & Acknowledgement

1. I wish to commence tonight by acknowledging with gratitude the kind invitation of Professor Roger Magnusson to deliver this oration.
2. May I say to the Dean of the Law Faculty, Professor Triggs, how much of a pleasure and delight it is to be speaking in this magnificent new Law School. Having experienced the brutality of the 1960s concrete architecture of the Sydney University Law School in Phillip Street, it is a complete revelation to me that law can be both taught and learnt in such positively luxurious surroundings.
3. Last year, after nearly 30 years in practice as a barrister, I had the opportunity to preside over a Special Commission of Inquiry into Acute Care Services in New South Wales Public Hospitals. It was a fascinating experience. Besides being taken into the confidence of many many people who have spent their professional lives working for the good of their patients and the public of NSW, I was also treated to being told some of the very best things about the practice of medicine in public hospitals and some of the worst.
4. In the course of the Inquiry, I had the pleasure of meeting some extraordinarily dedicated, wise and articulate people who gave me great support and guidance. Two of those people are here tonight. I particularly valued their contributions and I am glad to be able to pay public tribute to them. The first is Professor Mary Chiarella

who is in the Chair this evening. This University, and the Faculty of Nursing & Midwifery are very fortunate indeed to have her on staff and be able to benefit from her immense knowledge and thoughtfulness. The second is Professor Kerry Goulston who is a senior member of the Faculty of Medicine. Kerry has been tireless in his pursuit of a better public hospital system and he continues to provide wisdom and inspiration through the Faculty of Medicine here at this University.

### **Learning about the Issue**

5. In the course of the Inquiry, it became quickly apparent to me that there is a significant discrepancy between, on the one hand, the expectation of the delivery of acute care services by the public at large, and by the many participants in the health sector, and on the other, the amount of money which can be made available nationally, and by any particular state for health care.
6. This raised for me two very important questions. The first was how it is that at a higher level, health care resources are allocated, and secondly, how it is on an individual patient basis that one patient rather than another receives the benefit of limited health resources.
7. These are questions which I decided largely fell outside my Terms of Reference in the Inquiry. In the Report, I touched on some of them tangentially. But I readily came to the view that what was required was a public, inclusive and rational discussion to decide what as a society can be done about reaching a consensus on these two issues. The Centre for Health Governance, Law and Ethics here at this University is ideally placed to take a lead role in stimulating that discussion.

### **This Evening**

8. This evening, I propose to outline what I see to be the issues for you by examining what influences will affect the availability of health resources at least into the foreseeable future, to identify as a commencement point some essential levers for and impediments to reform, and to make some suggestions for how the reform can be started.

9. May I commence with an outline of the influences which affect the extent of the available resources for health care, in particular public hospital care, in NSW. However, there is no reason to think that any other state is in any significantly different position.

### Universal Health Care Principles

10. I was told in the course of my Inquiry:

*“It does not matter who you are, how rich or how poor, or where you live, you have the right to enter our public health care system free of charge. That is the thing we obviously hold most dear in the system”.*

11. This evidence articulated the principles of universal health care in Australia. Section 68 of the *Health Services Act 1997* (NSW) sets out, in legislative form, the three principles to which the Commonwealth and all States are committed and which form part of the Australian Health Care Agreements.

12. They are:

- *Principle 1:* Eligible persons must be given the choice to receive public hospital services free of charge as public patients;
- *Principle 2:* Access to public hospital services is to be on the basis of clinical need;
- *Principle 3:* To the maximum practicable extent, a State will ensure the provision of public hospital services equitably to all eligible persons, regardless of their geographical location.

13. The mechanism by which these principles are enforced is through the Australian Health Care Agreement. Currently, NSW, as does every other State, undertakes to be responsible for the provision of public hospital services to eligible persons and it promises that it will “... **ensure** that eligible persons are able to access public hospital facilities free of charge as public patients”.

14. The principal source of funding for healthcare throughout Australia, at least in the public perception, is the Medicare levy. The effect of this is that through the taxation system, 1.5% of one’s taxable income is levied to fund health care throughout Australia. The consequence of this levy is that every taxpaying Australian believes

that they are making a contribution towards, and therefore have an entitlement to, and will receive, treatment in a public hospital for whatever condition they suffer from, when they demand it and at a level which they regard as appropriate..

15. So far so good. The impression one has is that through the taxation system the people of Australia fund a public health system to which they all have access, as of right, free of charge. But what is the reality of expenditure on health care and the demands on the health care system.
16. Again I will use NSW as an example but there is no reason to think that any other state will present a different picture.

### **NSW Health Budget**

17. The recurrent (not capital) NSW health budget is \$13.2bn which amounts to almost 28% of the entire State budget for NSW. This includes the funding provided by the Commonwealth (a little over \$3bn) under the Australian Health Care Agreement. When one says the number quickly, it doesn't sound very much. But what that means is \$36M a day or \$1.5m each hour of each day for a state with a population of about 6M people.
18. In 2001-2002, the health budget in NSW occupied a little less than 25% of the entire budget. It has occupied more of the budget each year since then. It is the single largest spending department in NSW. The nearest to it is the Department of Education which spends about 23% of the State budget. No other department spends more than 8% of the State budget.
19. The rate of increase in health spending is the highest of any government sector. Health economists will tell you that the rate of inflation in the health sector exceeds that of general inflation by about 1% per annum.
20. Health expenditure is increasing as a result of other factors including population growth and the aging profile, new health technologies such as new clinical treatments and medications, and rising community expectations which increase the usage of health services. The combined increase in health costs which includes both health inflation and the increases to which I have just referred, appears to be a little under

5% in the last financial year, whereas the combined average of increases in other sectors is just on 3.3%. Whilst a precise comparison may be inaccurate, it is nevertheless clear that the annual cost of continuing to provide health care in NSW is growing at a rate which significantly exceeds the costs of the provision of services in other sectors and the ordinary rate of inflation.

21. One estimate given to me in the course of my Inquiry was that without radical change in this economic picture, by 2040, health expenditure would consume the entire budget of NSW. In other words, in 30 years, unless something radical is done in the health sector, the State will not be able to provide education, roads, police and criminal justice systems or any other services which we all regard as being an integral part of a civilised society.
22. The onus rests on the health sector and those interested in it to devise a reform process which will address this.

#### **Some Additional Features**

23. These increases and rates of increase are the more concerning when one pauses to reflect upon the fact that wages and other staffing costs represent about 61.5% of the health budget. Under the NSW Government wages policy, which has existed for some years, the increase in taxpayer funding for wages in all NSW public sector employees is limited to 2.5%. Where health sector inflation is higher than this, it can be observed immediately that pressure is being placed on the existing health budget and will have consequences on the workforce.
24. This comment is not to suggest that such a policy is inappropriate. That is a matter for others not me. It is merely a comment which identifies the consequence of such a policy.
25. In addition, in NSW, as part of an attempt to reduce excessive spending, the NSW Government (and now the Commonwealth Government in its departments) has imposed efficiency targets, usually called efficiency dividends, on all government departments including NSW Health. The theory behind this program is that all government departments can become more efficient in the way in which they deliver their current services. Greater efficiency ought to lead to a lower cost of service

delivery. Accordingly, by requiring monetary savings to be made which are returned to central funds for redistribution, as appropriate, services will be delivered more efficiently. It is said that these savings are to be made by ongoing efficiencies which do not result in a reduction of front line clinical services. The efficiency target, which commenced in the first year at 1% of the recurrent budget is cumulative, with the effect that in each year a department is expected to again make all of the saving from the previous year and then to add the target for that year. For NSW Health, in the current year, it is expected to make efficiency savings of \$417.5million. In short, what that means is that in a time of growth of expenditure, increase in demand and underfunding of real wage increases, the standing health budget, unless otherwise augmented, is being reduced in general budget terms.

26. I would expect that the current financial strictures caused by the global financial crisis will exacerbate this position.
27. It can be seen that the attractiveness of the universality of health care comes into conflict with the limited nature of the health resources. In my opinion, that conflict is reconcilable and the time has come to start talking about how one can go about it.
28. This is, at the very least for this reason, namely that the claims on the State budget by all government departments are many and meritorious. Health in good conscience cannot expect much more than it presently receives.

### **NSW Patient Profile**

29. But these financial strictures are only one side of the picture. In considering the future one has to understand the patient population. It is well known that we live in a society where we are living longer than we used to. The life expectancy of NSW men is 79.2 years. The life expectancy of NSW women is 84.2 years. This exceeds every country in the developed world except Japan, Switzerland and Iceland.
30. Rational population projections suggest that over time the older age groups, that is those presently over 45, are expected to increase as a proportion of the whole of the population.

31. But what does that mean for hospitals? In 2007, although only 13.5% of the population of NSW is over the age of 65, 33% of hospital admissions in NSW were from this age group.
32. Some other features of the aging population are important. They are:
- On any one day, a half of all hospital beds in NSW are occupied by patients aged over 65;
  - People aged 65 and over consume 42.9% of total acute bed days in public and private hospitals;
  - By 2011, persons aged over 65 will account for 38% of NSW public hospital admissions and 52% of bed days;
  - By 2026, over 20% of the NSW population will be aged 65 and over representing an 87.3% increase in this population segment between 2001 and 2026;
  - Hospital presentations by the over 75 age group are growing at the rate of 20% per annum;
  - The average length of stay in a public hospital is 4 days. This increases to 9 days for people over 75;
  - By about 2021, there will be 1.3million Australians over the age of 85. The incidents of neurodegenerative diseases rises most rapidly after 80 years of age which means that demand for domestic care, personal care, assistance with patients with cognitive impairment and assistance with patients who are mobility impaired will rise dramatically.
33. As well as the changing patient demographic, NSW Health is faced with a changing workforce demographic. The skilled workforce, particularly doctors, are not evenly distributed amongst the population. The sandstone curtain of the Great Dividing Range provides a barrier which the skilled workforce finds hard to cross.
34. The nursing workforce faces a very real challenge with 22% of the entire profession in NSW qualifying for retirement in 2011 which is just a few short years away.
35. It was the combination of these features which led me to conclude in my Report that:
- “... we have entered into a period of crisis for a public hospital system which has always been free and accessible to all. If public hospitals are to survive as providers of free care for all, there will have to be some radical changes in the way they do business. We are on the brink of seeing whether the public system can survive and flourish or whether it will become a relic of better times”.*

## Public Expectations

36. NSW is fortunate to have a high standard of care in its public hospitals. The service is provided by trained professionals and support staff:

*“We have created a government charitable hospital service that claims to offer unlimited health care on demand, as a right to every citizen regardless of circumstances”.*

37. Part of the problem with the public expectation and the clash with the reality of limited resources is that the public is not generally aware of the nature of the problem and, particularly, the cost of the provision of health services, nor is it aware who pays for their treatment, except perhaps a general notion that the system is funded by the taxpayers of Australia. I was told that public patients have little or no interest in the cost of the service or of its overall efficiency, but rather have a much narrower focus, namely how their particular episode of care affected them. However, I think that, as taxpayers who are supporting the health system, we all have an interest in how the money is being spent and an expectation that it will be done so properly and fairly.
38. This occasion is not the time to discuss the complexities of the funding system as between Commonwealth and State. It is sufficient to say that in my view the current system is at least inefficient and may be seen to have reached, or be nearing, the stage of being dysfunctional. On these complexities, it was submitted to me in the course of my Inquiry, and I think correctly, that:

*“Our present allocation of health resources is haphazard, secretive, costly and unjust.”*

## Individual Patient Perspective

39. In the course of the Inquiry, as you might expect, I took evidence both in public and confidentially from individual patients. What struck me was the prism of self interest through which they viewed the public hospital system.
40. One person gave evidence about the admission into the emergency department and hospital of her 93 year old mother. She was clearly devoted to her mother who was in the terminal stages of her life. This patient at some length explained to me how

she and her mother had been let down by the public health system because although her condition may have been remedied by lengthy, complex and difficult heart surgery which had a small chance of success, it was not offered to her in any way which was encouraging. Her view was that had the surgery been undertaken, her mother would have survived for another few months or perhaps a year of life which she was unjustifiably denied. Her evidence was heartfelt, sincere and troubling. On the other hand, I received evidence from another family about the indignity with which their 88 year old father had been treated because he had been taken to the intensive care unit and had his life supported by equipment and machinery, no doubt involving insertion of appropriate tubes, monitoring and the like, when really, so I was told, he ought to have been given palliative care until he died in peace.

41. Another patient gave evidence to me at a large regional Hospital drawing my attention to the fact that it was not possible for her young son, who was severely disabled from birth, to obtain adequate services for his needs from properly trained staff at her local regional hospital. She could however obtain those services from a specialist paediatric hospital in a large city but that would have required moving her family of 6 to live nearby to one or other of those hospitals. She was not prepared to do this, and complained that it was not right that the specialised care she required was not available to her son in their locality.
42. One's perspective of the reasonableness (or perhaps lack of it), which this evidence reveals will depend upon the prism through which the evidence is viewed. Each family member will regard their views as entirely reasonable and no more than is their entitlement. Over worked clinicians, or bureaucrats, charged with attempting to ensure an adequate distribution of limited resources, will regard these complaints as unreasonable. Both are right. But that conclusion merely restates the problem with which I started, namely, how one adequately deals with limited resources.

### **Three Simple Solutions**

43. There are of course three simple solutions. The first is to increase the Medicare levy, that is, our taxes so that a proper, fully funded safe and effective health care system can be an integral part of Australian society. After all, the world comparative statistics show that Australia spends less per head on health than many other developed countries.

44. The second alternative is to modify the principles of free universal health care by raising a charge for each patient which relates to some or all of the health service which they have received. Some people in Australia, presently choose this option because they take out private hospital or medical insurance.
45. The third option is to recognise the reality, preserve the principle of universal health care but to recognise that it occurs within appropriate budgetary constraints. The solution then is to devise a system both for the allocation of resources generally and for the allocation of particular care for individual patients which reflects a fair and just distribution of those limited resources.
46. In practical terms, whilst one may talk about the first two options, the reality is that it is the third option upon which there needs to be concentration and about which there needs to be greater thought.
47. The first question is who should be doing this? Logically, it is a matter for political leadership but experience shows that in difficult areas involving fairness, ethical and moral constructs, politicians are slow to initiate discussion and change. This reluctance is perfectly understandable. Pressure for considered change in this area needs to come from the leaders of the health system, informed by thoughtful academics and garnered by public support.

#### **A Limiting Legal Context**

48. Although from the perspective of the health professionals, this desired pathway to reform can be seen against a blank canvas, one needs to remember that there are laws which affect the way in which one might go about this process.
49. First, there is a suite of Commonwealth discrimination legislation which will impact upon what choices are made.
  - The *Sex Discrimination Act* 1984 (C'wth) prohibits discrimination against a person on a ground relating to their sex. The *Disability Discrimination Act* 1992 (C'wth) prohibits discrimination against a person on the ground of a disability of that person.

- The *Racial Discrimination Act 1975* (C'wth) prohibits discrimination on the ground of race. Section 9 of that Act is quite broad. It reads:

*“(1) It is unlawful for a person to do any act involving a distinction, exclusion, restriction or preference based on race, colour, dissent or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of any human right or fundamental freedom in the political, economic, social, cultural or any other field of public life”.*

The Act calls up the definitions which are included in Article 5 of the *International Convention on the Elimination of all Forms of Racial Discrimination*. That article notes that the parties to the Convention guarantee the right of everyone, without distinction as to race, colour, national or ethnic origin to equality in the enjoyment of particular rights including the right to public health, medical care and social services.

- Another piece of legislation which is relevant is the *Age Discrimination Act 2004* (C'wth). This Act prohibits discrimination on the ground of age, whether that discrimination be direct or indirect. However, section 42 of that Act provides a variety of exemptions from the provisions of it with respect to health. For example, it exempts from its provisions health programs which apply to people of a particular age providing that the program is reasonably based on evidence of effectiveness and on cost. Subsection (3) of section 42 includes this provision:

*“(3) This Part does not make it unlawful for a person to discriminate against another person, on the ground of the other person’s age, by taking the other person’s age into account in making a decision relating to health goods or services or medical goods or services, if ... taking the other person’s age into account in making the decision is reasonably based on evidence, and professional knowledge, about the ability of persons of the other person’s age to benefit from the goods or services ...”*

50. There is a variety of NSW legislation as well. The *Anti-Discrimination Act 1977* has provisions which are similar to those to which I have just referred. Another piece of legislation in NSW, is the *Human Tissue Act 1983*, which only permits the removal of

tissue from the body of deceased person where there has been consent in writing given during the person's lifetime and the consent has not been revoked. Imagine, for example, what difference in health services would occur if the shortage of donor organs, such as kidneys, could be addressed by simply removing that section. In other words, consent for organ donation was assumed unless you opted out.. But at the moment, the Parliament does not permit that. Perhaps it should. That is for others to decide.

51. The point to be made is that the context in which this discussion must take place is limited by legislation which may be ripe for reform. However, it is my experience that one major force for legislative change is encouragement of the politicians by the electorate. In short, it is a matter for the whole community, for each one of us, to start this conversation and to allow it to gain a momentum which makes inevitable that proper consideration will be given to all facets of it at State and Commonwealth government level.

## Enablers for Reform

52. A reform process requires enablers. That is those steps which must precede rational reform and which enable it to happen.
53. The starting point for any sensible discussion about limited resource allocation is knowledge. This is the single most important enabler of reform. At the moment, the knowledge differential between bureaucrats, administrators, clinicians and the public generally is enormous. One only has to observe the constant debate about the length of waiting lists for surgery in NSW to understand that knowledge is essential. But not just any knowledge. Knowledge of statistics which are accurate, timely and verifiable.
54. And that knowledge must be current. There are presently significant publications about health influences and trends in Australian society but to my observation these are often some years behind the present when they are distributed.
55. To me, accessible health information which is timely and accurate is vital and will enable an understanding of, and therefore form a basis for, a rational discussion to take place about these features. One of the recommendations I made in my Report was that it ought establish a Bureau of Health Information which would:

*“ ...develop and publish patient care performance criteria which are adequate to enable measurement on a continuous basis of the performance in the provision of care to patients of each unit or ward, hospital, area (or functional) health service and NSW Health as a whole ...”*

55. The sort of information which in my view ought to be collected falls into these areas:
- (a) Access to and availability of hospital services including timeliness of the provision of the services and the proximity of those services to a patient's home or locality;
  - (b) Clinical performance including patient outcome, appropriateness of clinical treatment method and identified benefits or detriments to the health and well being of the patient;
  - (c) Safety and quality of clinical care the whole of the hospital attendance or admission;

- (d) The costs of and associated with the provision of the episode of care;
  - (e) Patient experience and satisfaction;
  - (f) Staff experience and satisfaction.
56. In combination, these will enable an understanding about the sustainability of the health system. But importantly it will enable a sensible discussion to take place about where health resources are, where the need for the health resources is, how that need is being most efficiently met and whether there is in truth a shortage or one form of service or another.
57. This in my view is the first and most critical enabler of reform.
58. The second enabler of reform is to accept that there must be an articulated process by which rules are created and decisions are made about the sharing of limited resources. There must be some essential features of such a process. May I suggest these:
- The development of the process is an inclusive one. The process must be developed after a comprehensive discussion in which all those who wish to participate can do so and are listened to;
  - The process once developed must be one of universal application. In my opinion there is nothing more confusing and counter productive to reform than a process which consists principally of exceptions to the rule, rather than of the rules themselves;
  - The process must have in-built dispute resolution mechanisms;
  - The process must be a transparent one. That is to say how something is going to happen, when it happens and what is the result of it happening, must all be visible; and
  - Confidence in the process must be engendered by periodic independent auditing with public reporting of that audit.
59. The third enabler of reform is more difficult and may require a cultural change for the health sector, and clinicians, in particular. There must in my view be an embracing of the fundamental proposition that a process of limited resource allocation is not an occasion for the advancement of idiosyncratic or partisan interests of an individual or of one particular group or another, but rather the underlying and guiding principle must be that the good of all the people of NSW and the provision of health care in an

orderly and systemic way must prevail over individual, sectional or geographical interests whose motivation is largely, if not entirely, self-interest.

60. In my view, Cicero was right when he said:

*“Salus populi suprema lex esto”<sup>1</sup>.*

61. Those who studied Roman Law here at the law school will immediately know that the usual translation of this phrase is “Let the good of the people be the supreme law” or putting it slightly differently that “The welfare of the people shall be the supreme law”. To me it exemplifies the central principled basis and hence the essential enabler for reform in this area. Without adherence to this principle, I fear that decisions dealing with limited resource allocation will make the historical internecine struggles of the Balkan peninsula look like pathetic attempts at warfare.

### **Impediments to an effective Allocation Process**

62. Determining the content of the allocation process is where this whole issue gets hard and controversial. Primarily I suspect that this is so because there is no right answer. One is entering the field where economic rationalism comes face to face with individual standards of morality, individual values and a multitude of different perspectives.
63. Ethicists, commentators and academics have been searching for at least 25 years, and probably much, much longer, for answers to the really big companion questions: “Should the Baby Live?” and “Should the Grandparents Die?”<sup>2</sup> There is no single and obvious answer to these questions.
64. Whilst one day, we may all come to a common understanding of the right answer, I think that attacking the issue of limited resource allocation by starting with these large and difficult questions is actually a real impediment to progress. May I suggest that what is needed is a different approach rather than continuing to try and find the right answer before we start.

---

<sup>1</sup> This phrase is found in Cicero's *De Legibus* (Book III, Part III, Sub VIII). It was also used by John Locke as epigraph in his second treatise on government.

<sup>2</sup> See: H. Kuhse, P. Singer, *Should the Baby Live* (Oxford University Press, 1985), and “*Should the Grandparents Die? Allocation of Medical Resources with an Aging Population*”, Margaret A. Somerville, 1986, Vol. 14, 3-4, *Law, Medicine & Healthcare*, p.158.

65. In 1990, the National Health & Medical Research Council of Australia issued a discussion paper on “Ethics & Resource Allocation”. It said:

*“In the allocation of any public resource our concern should be primarily with justice. This involves giving to each person his or her due. In allocating health care resources our concern is largely with the distributive justice – to distribute among members of the community those benefits and burdens due to them. The basis of distributive justice is the notion of fairness. The most appropriate criterion for a fair distribution of resources would appear to be those of equity and need. More specifically, a just allocation should offer equal treatment to those whose needs are similar. In other words, each person is entitled to enjoy an appropriate share of the sum total of resources available according to their need. However, the need which justifies one person’s entitlement must be a need which can be fulfilled in a way compatible with fulfilling the similar needs of others”.*<sup>3</sup>

66. Thus, the search for the perfect model of distributive justice, in advance of commencing reform, is the second impediment which I identify. No one has yet designed such a system which can be copied for NSW. Such a system rather seems to me to be what would be known in economic rationalist terms as a “stretch target”.
67. The third impediment to reform is the existing system itself, and the long standing culture which it represents. By that I mean that most decisions involving the allocation of limited resources are being made by front line clinicians who may be working in isolated pockets and who bring to bear their own training, perceptions and values in that decision making. These are hard working genuine, dedicated and well intentioned and well meaning individuals who are regularly confronted with difficult choices. They are trained to be advocates for their patients, to try and get the best possible treatment for these individuals. But the result of these idiosyncratic isolated and non-centralised decisions is that the decision making process is hidden, it is masked, it is secretive, it engenders the perception (if not the reality) of inequity, and it engenders the perception that allocation of limited health resources is made on the basis of who you know rather than what you need and how your need compares with others who are also in need.
68. The Honourable Michael Kirby AC CMG QC, the now retired Justice of the High Court of Australia, in delivering the inaugural, but eponymous, *Kirby Lecture on*

---

<sup>3</sup> National Health & Medical Research Council of Australia, *Discussion Paper “Ethics & Resource Allocation”*, Australian Government Publishing Service, Canberra, 1990.

*Health Law & Ethics* for the Australian Institute of Health Law & Ethics, said this in 1996, with respect to the decision making process involved in limited resource allocation:

*“Such decisions will be better made, and more likely to be just, if they are made after the accurate exposure of the most relevant preconditions for their making. Not only will that course submit those preconditions to individual and social criticism and possible change. It will also impose on the decision maker a discipline and self-scrutiny which the vital importance of health care decisions demands from a civilised society.”*

69. With respect, I agree.
70. I have outlined, perhaps at too great a length, in this challenging area of allocation of limited health resources, the context which necessitates reform, the impediments to reform and the enablers of reform. So, I hear you say, tell us what your paradigm of reform should be.

#### **An ethical Paradigm for Reform**

71. As you will by now have appreciated, I see the key to successful reform as starting with achievable small steps, and then developing to embrace the larger and more difficult decisions rather than the reverse. But at all times the central principle of Cicero must be the touchstone.
72. First, I would ensure that standard evidence based protocols or models of care according to identified guidelines are designed and implemented for every typical surgical intervention, and common disease or syndrome encountered in NSW public hospitals. There is no reason why over time the more esoteric conditions can't be addressed in this way.
73. These must be developed and agreed upon by networks of a broad base of clinicians through a process of consensus. The networks should include community representatives and managerial input to ensure their workability. The standard protocols and models of care ought be made public, so that patients and their families understand what care will be provided and by whom.

74. This will mean that clinician's choice is limited, and individual decision making truncated, but if the protocol is clinically appropriate, then in the public health system, the removal of idiosyncratic, non evidence based treatment and decision making is for the better.
75. It is important to emphasise that standardised medicine is not sub-standard medicine. It is in fact more likely to ensure, on an ongoing state-wide basis, better, safer, more efficient and more cost-effective patient care thereby resulting in a better and fairer distribution of limited resources.
76. The second reform which I advocate really is a consequence of the first. It is a reform which requires the input of the clinical networks configured as I have described as a starting point to develop a comprehensive State-wide plan for the distribution of fixed resources in a way which maximises clinical benefit, maximises efficiency and acknowledges budgetary constraints.
77. I would advocate the development of a 25 year (or perhaps longer) plan which for that time period describes the capital works and fixed resources necessary to support the effective implementation of protocols and models of care.
78. I immediately need to say that I do not suggest that there is handed over to clinicians the decision-making process about the deployment, redeployment or upgrade of hospitals. That is, and must always remain, the responsibility of the Minister for Health and the Government of the day.
79. But what is necessary to prevent the dominance of overtly sectional interests and idiosyncratic, and perhaps short term, decisions is a long term plan, that is clear and specific in its aims.
80. Of course, those in commerce will immediately recall at the horror of a plan for such a lengthy period. They are used to three year plans or perhaps one year plans. But that is because business is far more volatile and reactionary to short term changes. A sustainable balanced and ordered system of the provision of health care to a population at large does not have those particular features. As well, capital planning at the moment in NSW for the health sector has a generally ten year turn around.

But it is essential to see, for each expenditure of capital resources, where that fits in the overall plan.

81. Of course, any such plan needs to be reviewed. I would doubt that a review at less than five year intervals would be conducive to fair, ordered and rational decision making. Another feature of such a plan is that once made it must be made known to the public. Indeed, as I have earlier pointed out, involvement of the public in the process of development of such a plan is an essential step in order that trust in the plan and confidence in its success will develop.
82. The third area for reform, which I advocate, perhaps somewhat counter-intuitively, is to increase the involvement of the public in their own health care. Let me see if I can explain what I envisage.
83. The traditional culture of health care is that the health care professional knows what is right and what is appropriate for each patient. That of course is self-evidently correct. Whether a patient needs one procedure or another, or one medication or another, is not a matter in which they have any particular expertise. That rightly remains the domain of the clinician. But, whether the patient chooses to undergo the treatment at all, and if so, for how long and with what goal in mind, is a matter in which the patient has the greatest interest rather than the clinician.
84. It is critical in this area of resource allocation to involve the patient at an early a time as possible in determining the path of their health care. When the patient is unconscious and brought into hospital it is too late to discuss with distraught relatives what treatment the patient wants or does not want.
85. Whether a patient chooses to undergo a lengthy course of treatment such as dialysis in preference to one or other treatment is a decision that can only be properly be made before the dialysis commences. There are many other examples.
86. The legal system permits living wills. The legal system permits an adult of rational mind to refuse treatment. Such decisions are recognised by the legal system as entirely valid and predominant effect in governing someone's life decision. Of course, euthanasia and other conduct which the law regards as criminal must remain so. This part of the reform which I advocate is not to be understood as in any way

articulating a process whereby the practise of medicine permits a breach of the criminal law. Rather, it is a process which exists within the constraints of the criminal law and allows patients to make rational decisions about their treatment.

87. The key to this reform is education of the patients and early decision making. The supporting and necessary component of this reform is the adequate documentation, recording and ready availability of the terms of that decision when required. I suggest that patients involved in this early and considered decision making, will in fact make entirely rational decisions which reflect their own values rather than those imposed by others. It would be surprising if those values, except in a small number of instances, vary greatly or at all from the values of the whole community.
88. The final reform which I would propose is that a Charter of Patient Rights and Entitlements be instituted which makes it plain what it is that a patient and their family can expect to receive from public health care system. And this must be promulgated widely.
89. It is only when a clear understanding can be created of what the hospital or public health system will provide that the more extreme expectations of patients or their relatives can be addressed. Such a patient charter, which will, of course, be well known to the staff in the public hospital system, and which will I suggest have the effect of providing the staff with clear guidelines as to what can be demanded of them and as to how they should respond.

## Conclusion

90. I accept that these suggestions for reform may be seen to be somewhat low key. They may seem overly simplistic to some. But in the course of the preparation for tonight, and all of the research I have done, one thing is obvious, and that is to date no-one has yet answered the difficult questions. No-one has yet found the perfect system, and from my perspective we cannot afford in NSW to wait until that perfect system is identified.
91. If we wait and continue to search for the perfect system, or the system which is perfectly just to everybody, nothing will change.
92. In this year we celebrate the 200<sup>th</sup> anniversary of Charles Darwin. No doubt you all know that he visited Sydney, strolled through the Royal Botanic Gardens, made his way out to Bathurst where he saw bushfires and wondered about the cruelty of the great land we live in. But I digress. What he said about 150 years ago I think is something we should keep well in mind. He said:

*“It is not the strongest of species which survive, nor the most intelligent, but the ones most responsive to change.”*

**Peter Garling SC**

26 March 2009