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**A CODE OF HEALTH AND DISABILITY SERVICES
CONSUMERS' RIGHTS : A DISCUSSION PAPER**

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ABSTRACT

The purpose of this paper is to provide a broad working document for future discussion and consultation in relation to the preparation and drafting of a Code of Health and Disability Services Consumers' Rights pursuant to the Health Commissioner Bill.

The paper argues that medical ethics and its principle of beneficence is not only outdated but is being increasingly eroded by the State. As a result, the law in relation to consumer rights is both piecemeal and difficult to access. It therefore outlines what is meant by a "right" and examines the source and current legal status of health and disability services consumers' rights in New Zealand. In light of that discussion, a draft Code of Health and Disability Services Consumers' Rights, as prescribed in the Health Commissioner Bill and amended by clause 18 of the Supplementary Order Paper (dated 3 August 1993), is submitted.

The paper concludes that health and disabilities services consumers' rights can only be enforced through legislation. Moreover, if such consumers are to have true autonomy, both liberty and entitlement rights must be given statutory protection.

WORD LENGTH

The text of this paper (excluding contents page, footnotes and bibliography) comprises approximately 12,300 words.

I. INTRODUCTION

There is little doubt that a Code of Health Consumers' Rights ("the Code") is needed in New Zealand¹ particularly now the Government's new health reforms are in force which provide for the separation of health service funding and provision and fusion between public and private services.

Legal recognition of fundamental health consumer rights is both timely and essential. The Code will ensure accountability within the new health structure and promote health and disability services consumers' autonomy and protection where legislation has not already done so. Such a Code will also regulate, in a co-ordinated way, what has up to the present date been a piecemeal approach to health consumer rights. This has largely been as a result of the no-fault accident compensation scheme and a reliance on professional self-regulation and its principle of beneficence.

The writer believes that the primary reasons for having such a Code are these, namely:

- (a) the medical ethics principle of beneficence is both paternalistic and outdated and undermines the principle of health consumer autonomy;
- (b) the new health reforms' emphasis on corporate ethos may erode medical ethics so that the doctor/patient

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Margaret M A Vennell *Review of the Health Commissioner Bill and the Proposed Medical Practitioners Bill, A Report to the Minister of Health and the Social Services Select Committee* August, 1992, see Ch 2 "Rights, Standards and Ethics" 20; *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and Into Other Related Matters* (Government Printing Office, Auckland, 1988) 176.

relationship is no longer safeguarded voluntarily, as has happened in the United States;

(c) existing hospital codes of Patients' Rights appear not to have gone far enough in protecting health consumer interests and rights; and

(d) clarifying the present legal status of health consumer rights is currently both difficult to access and analyse.

A. Principle of Beneficence

Brody believes the principle of beneficence of the "old" medical ethics was based on a view of the doctor/patient relationship which was paternalistic. He quotes Childress' definition of paternalism as:²

"... refusing to acquiesce in the wishes or desires of another person for that person's own benefit."

He goes on to say:³

"When we acquiesce in somebody else's wishes or desires, we recognize the moral principle of autonomy - seeing that person as entitled to make his own free choices. When we act paternalistically, we place the moral principle of benefitting that person (according to our view of benefit) on a higher plane than the moral principle of autonomy (Beauchamp and McCullough 1984)."

However, he believes the "new" medical ethics indicates that the moral principle of beneficence may now be only one principle

² Robert M. Veatch *Medical Ethics* (Jones and Bartlett Publishers, Boston, 1989) 65, see Howard Brody "The Physician/Patient Relationship", p68.

³ Above n2, 69.

amongst many and the principle of autonomy, one of special importance.

B. *Corporate Ethos*

It is argued by Shenkin⁴ that despite defined codes of ethics, the historical code of "duties to patients" enshrined in the Hippocratic Oath has been increasingly eroded. This is no more clearly exemplified than in the United States where the corporate takeover of the delivery of doctors' services (with its emphasis on corporate ethos) has diminished medical ethics to the point that the doctor/patient relationship has become a static, even adversarial affair. Patient rights within that relationship are no longer safeguarded voluntarily and the doctor/patient relationship has become one described in purely business terms. He concludes that in effect the objective of reducing the cost of medical care has introduced more competition among doctors and other providers. As a result, patient autonomy now takes precedence over doctor beneficence.

Clearly, it is important that health and disability services consumers' rights are recognised and given legal status in New Zealand if there is any likelihood that "duties to patients" will be eroded here in a similar way.

C. *Existing Rights*

Certainly the Patients' Rights movement in the United States was behind the perceived need by the American Hospital Association to formulate A Patients' Bill of Rights in 1973. That Bill of Rights encapsulated what many believed were moral and legal

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Henry A Shenkin *Medical Ethics : Evolution, Rights and the Physician* (Kluwer Academic Publishers, Netherlands, 1991).

rights that Americans had long possessed. However, it has no legal standing and has been criticised for not going far enough to protect health consumer rights.

In particular, it is argued that:⁵

"It is not for the hospital community to outline the rights it will offer, but rather for the patient consumer to delineate and then demand those rights to which he feels entitled by utilizing all the instruments of society designed for that purpose - including the legislature and the courts."

Furthermore, the rights provided in the Bill are largely those defined as "liberty rights" or the right to non-interference, not entitlement rights claims which involve calls for actual delivery of certain health services or "the right to health care".⁶

D. *Legal Status of Rights*

The aim of clarifying the law on health consumer rights is not a new one. In Australia, for example, the legal status of the rights of health consumers and the responsibilities of health service providers has been both ambiguous and unclear, as in New Zealand.

A report commissioned by the Australian Consumers' Health Forum entitled "Legal Recognition and Protection of the Rights of

⁵ Robert M Veatch (ed) *Cross Cultural Perspectives in Medical Ethics : Readings* (Jones and Bartlett Publishers, Boston, 1989) 92, see Willard Gaylin "The Patient's Bill of Rights", p94.

⁶ Robert M Veatch on the Patients' Rights Movement in *A Theory of Medical Ethics* (Basic Books in Publishing, New York, 1981).

Health Consumers"⁷ concluded that the law had not kept pace with consumer expectations. Moreover, the law was not only out of date but, was "flawed and out of balance because the interests of health providers and health administrators [were] invariably well represented compared to the interests of consumers."⁸ It also concluded that few health laws focused on the well-being of health consumers nor did such laws make consumer rights explicit or allow consumers to participate in decision making.

Key recommendations arising out of that report included the need for a responsive legal framework of legally enforceable rights which encouraged principles, aims and protective mechanisms⁹ thereby ensuring appropriate recognition and protection of all health consumers' rights. This would give Australia a co-ordinated regulation of the health system driven by both consumer needs and by consumer interests and rights.

Accordingly, the purpose of this paper is to provide a broad working document, particularly a draft Code of Health and Disability Services Consumers' Rights, that can be utilised as a preliminary discussion paper for future consultation and representations from a wide range of persons, bodies, organisations and agencies pursuant to clause 19A of the Health Commissioner Bill.¹⁰

It is submitted that any draft Code must: the following parts.

⁷ News Journal of the Health Issues Centre *Health Issues* 27 (Health Issues Centre, Melbourne, 1991) see Michael Hogan "Health Consumers and the Law in Australia", p11.

⁸ Above n7, 11.

⁹ Above n7, 12.

¹⁰ Health Commissioner Bill No. 44-1, (New Zealand Government, Wellington, 1990) as amended by Supplementary Order Paper dated 3 August 1993, see Below n92.

- endorse current statutory and common law rights pertaining to health consumer rights; confidentiality and privacy. In addition, other rights such as the right to access
- endorse principles already ratified by New Zealand in international instruments; opinion, the right to the assistance of an interpreter, the right of access to adequately
- be sufficiently broad to encompass both acceptable and proposed codes of practice, administrative and/or departmental guidelines;
- nationalise a standard of care applicable to both public and private providers thereby ensuring consistency; sons with disabilities and the rights of elders.
- address perceived difficulties and/or failures in current Part VI legislation in respect of health and disability services Code in consumers' rights;
- provide adequate procedures and redress when rights are breached; and
- contain specific provisions as set out in clause 18 of the Health Commissioner Bill, in particular, rights relating to privacy, confidentiality and health consumers' consent. In a variety of different senses, both popular and jurisprudential. It may be used as reporting a positive duty in some other individual for the non-performance of which the law will provide an appropriate

This paper will therefore be divided into the following parts.

Part II will canvas the concept of a "right".

Part III will outline the classification of rights and look particularly at statements on world health rights, the British patient charter, and then analyse both common and statutory law in New Zealand currently providing consumer health rights.

Part IV will focus on individual health consumer rights such as those relating to treatment, patient consent, confidentiality and privacy. In addition, other rights such as the right to access medical records, the right to lodge a complaint, the right to an advocate, the right to a second opinion, the right to the assistance of an interpreter, the right of access to adequately qualified health personnel and the right to be free from physical and mental abuse will also be discussed.

Part V will then look at specific rights as they relate to particular health consumer groups such as the mentally disordered, the rights of older persons, the rights of persons with disabilities and the rights of minors.

Part VI will set out a Health and Disability Services Consumers' Code in draft format.

II CONCEPT OF "RIGHT"

The word "right" has recently been defined by Lord Oliver in *In re KD (A Minor)* as follows¹¹:

"The word right is used in a variety of different senses, both popular and jurisprudential. It may be used as importing a positive duty in some other individual for the non-performance of which the law will provide an appropriate remedy, as in the case of a right to the performance of a contract. It may signify merely a privilege conferring no corresponding duty on any one save that of non-interference, such as the right to walk on the public highway. It may signify no more than the hope of or aspiration to a social order which will permit the exercise of that which is perceived as an essential liberty, such as for instance, the so-called 'right to work' or a 'right' of personal privacy."

¹¹ (1988) 2 WLR 398, 412.

It would seem that in analysing what we mean by rights, "rights" can be described in terms of claims. A "claim" it is said is being able to justify a demand with legitimate or legitimising grounds.¹²

Childress endorses this view:¹³

"A right is a justified claim, and a moral right is a morally justified claim, that is, a claim justified by moral principles and rules. For the most part, rights and duties correlate so that one implies the other."

Stoljar expands on the idea of there generally being a correlative duty stating:¹⁴

"Normative relationships, whether moral or legal or both, thus break up into dual components in that two-party relations have to include a right on the one hand with a duty on the other."

However, he admits there exist certain non-correlative rights and duties but argues that these are specific exceptions "of marginal rather than central significance".¹⁵

He believes that while rights refer to the interests of individuals, duties are indicative of the requisite commissions or omissions protecting those interests:¹⁶

¹² Samuel Stoljar *An Analysis of Rights* (Macmillan Press Ltd, Great Britain, 1984) 1-2.

¹³ James E Childress *Who Should Decide : Paternalism in Health Care* (Oxford University Press, Oxford, 1982) 70.

¹⁴ Above n12, 36.

¹⁵ Above n12, 38.

¹⁶ Above n12, 46.

"A right defines an area of freedom, the duty specifies conduct for which one is answerable or responsible."

As a result, he argues that the right can be dispensed with as it is the notion of duty which describes the two party relationship, particularly in law. This he says is why lawyers focus on duties and moral philosophers on rights "but a total inquiry has to deal with both rights and duties, both as correlatives and complementaries".¹⁷

Rights can be either positive or negative rights. According to Childress a positive right is a right to other persons' positive actions whereas a negative right is a right to other persons' omissions or forbearances. "For every positive right ... someone else has a duty to do something; for every negative right someone else has a duty to refrain from doing something."¹⁸

Positive and negative rights are also sometimes described as "entitlement" or "liberty" rights respectively. "Entitlement" rights require some action by others in order for a person to be free to act, e.g. the right of access to medical treatment and therefore "normally imply a duty on the part of another ... to act in a particular way."¹⁹

"Liberty" rights on the other hand identify, define and protect a person's status as an independent and equal person. As such they involve claims in the sense that an individual can choose to act without interference from others, e.g. the right to refuse medical treatment.

17 Above n12, 48.

18 Above n13, 71.

19 Above n5, 90 see "A Patient's Bill of Rights" American Hospital Association; Above n6, 194-195.

It is argued that "both kinds of rights ... are related to the fundamental principle of autonomy but clearly they are different conceptually."²⁰ However, many rights which derive from the principle of respect for persons are negative or liberty rights. Such rights are generally provided in constitutional documents or under the common law. Unfortunately, most of these rights are not self-executing. Nor is there necessarily a guarantee that those rights will be either implemented or enforced. Accordingly, the issue then arises as to which consumer rights should get legal protection if a Code for health and disability services consumers is to be formulated.

It has been stated that it is commonplace today to call upon the law to vindicate rights:²¹

"the case for legal protection [derives] ... from what individuals may do, by self-help, to protect and enforce their own rights. ... it can be important to vindicate one's right not because its content is so important, but because one's status is."

It is submitted that this is particularly so where there is a special relationship such as a professional relationship in that the professional is frequently in a position of dominance and thus the other party dependent.

It is argued that this is accentuated even more so in today's economic climate and resulting "government largess" which bring forceful pressures to bear on professionals and the like. It is suggested that this "growth of largess has made it possible for

²⁰ Above n6, 195.

²¹ Theodore M Benditt *Rights* (Rowmann and Little Field, New Jersey, 1982) 130-131.

the government to 'purchase' the abandonment of constitutional rights."²²

For these reasons it is said that with "more and more of our wealth [taking] the form of rights or status rather than of tangible goods (Reich 1964)",²³ there needs to be some redress and balance accorded to consumers.

In essence any redress and balance can only occur if that same government provides legislative recognition of consumer rights and appropriate mechanisms to enforce those rights. However, any rights given protection must go further than has been done to date. Both liberty and entitlement rights must be enforceable if individual consumers are to have true autonomy.

III. CLASSIFICATION OF RIGHTS

A. *Statements on Health Rights*

Rights can generally be classified into four categories, namely: constitutional rights such as those found in constitutions; common law or fundamental rights as provided in international instruments; rights accorded by professional bodies such as those contained in medical Codes of Ethics; and lastly, entitlement rights found in statute or regulation.

Nelson and Rochricht²⁴ make an implicit assumption that adequate health care is a human right and not simply a privilege for those who can afford it. They argue that rights and duties

²² Above n21, 137.

²³ Above n21, 137.

²⁴ J G Nelson and J A Smith Rochricht *Human Medicine: Ethical Perspectives on Today's Medical Issues* (Augsburg Publishing House, Minneapolis, 1984)

relating to health care have long been expressed in founding documents such as the Charter of the World Health Organisation which "claims that health care should be regarded as a human and civic right".²⁵

United Nations International Instruments on Human Rights also endorse desired health standards in various areas of human rights. In particular, Article 25 of the *Universal Declaration of Human Rights*, adopted by the United Nations General Assembly in 1948, states:

"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including ... medical care ..."

Article 12, *International Covenant on Economic, Social and Cultural Rights*, ratified by New Zealand in 1978, states:

"The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standards of physical and mental health."

Article 7 *International Covenant on Civil and Political Rights*, ratified by New Zealand in 1978 states:

"... no one shall be subjected without his free consent to medical or scientific experimentation."

Article 5, *International Convention on the Elimination of All Forms of Racial Discrimination* states:

²⁵

Above n24, 211.

"... States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone ... (e) Economic, social and cultural rights, in particular: ... (iv) The right to public health, medical care ..."

In September 1981, the 34th Assembly of the World Medical Association met in Lisbon and endorsed a statement on patient rights known as the Declaration of Lisbon.²⁶

In 1992, the British Patient Charter defined ten rights to care under the National Health Service ("NHS").²⁷ The basic

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"Recognizing that there may be practical, ethical or legal difficulties, a physician should always act according to his/her conscience and always in the best interest of the patient. The following Declaration represents some of the principal rights which the medical profession seeks to provide to patients. Whenever legislation or government action denies these rights of the patient, physicians should seek by appropriate means to assure or to restore them.

- (a) *The patient has the right to choose his physician freely.*
- (b) *The patient has the right to be cared for by a physician who is free to make clinical and ethical judgments without any outside interference.*
- (c) *The patient has the right to accept or to refuse treatment after receiving adequate information.*
- (d) *The patient has the right to expect that his physician will respect the confidential nature of his medical and personal details.*
- (e) *The patient has the right to die in dignity.*
- (f) *The patient has the right to receive or to decline spiritual and moral comfort, including the help of a minister of an appropriate religion."*

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"Every citizen has the following established National Health Service rights:

- *to receive health care on the basis of clinical need, regardless of ability to pay;*
- *to be registered with a G.P.;*
- *to receive emergency medical care at any time, through your G.P. or the emergency ambulance service and hospital accident and emergency departments;*
- *to be referred to a consultant, acceptable to you, when your G.P. thinks it necessary, and to be referred for a second opinion if you and your G.P. agree this is desirable;*
- *to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment;*
- *to have access to your health records and to know that those working for the NHS are under a legal duty to keep their contents confidential; and*

principles of that Charter being that the health service put the patient first, that it provide services that produce clear measurable benefits to people's health, that it be highly efficient and that it respect and value the immense resource skills and dedication of those that work within the service.²⁸

In addition, the Charter also sets out National Charter Standards²⁹ and although not legal rights, these are specific standards which the government expects the NHS to achieve as circumstances and resources allow. From 1 April 1992 health authorities were required to develop and publish their own local charter standards which more accurately reflect differing local circumstances.

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- *to choose whether or not you wish to take part in medical research or medical student training."*

From 1 April 1992, three further new rights were introduced by the Government as follows:

- to be given detailed information on local health services, including quality standards and maximum waiting times;
- to be guaranteed admission for treatment by a specific date no later than two years from the day when your consultant places you on a waiting list; and
- to have any complaint about NHS services - whoever provides them - investigated and to receive a full and prompt written reply from the chief executive or general manager.

²⁸ Coalition for Public Health "Coalition Calls for Patients" Charter" Media release, 15 April 1992.

²⁹ The nine standards relate to the following:

- respect for privacy, dignity and religious and cultural beliefs;
- arrangements to ensure everyone, including people with special needs, can use services;
- information to relatives and friends;
- waiting time for an ambulance service;
- waiting time for initial assessment in accident and emergency departments;
- waiting time in outpatient clinics;
- cancellation of operations;
- a trained qualified nurse, midwife or health visitor responsible for each patient; and
- discharge of patients from hospital.

B. Professional Standards

There have also long been established medical codes of ethics. The New Zealand Medical Association's ("NZMA") Code of Ethics³⁰ specifically includes a section on Patients' Rights.

Plueckhahn (1983)³¹ states there can be little argument that the duty of a doctor to their patient is the most important aspect of medical ethics but suggests many of the issues today pose "controversial moral, ethical and legal problems".

³⁰ New Zealand Medical Association *Code of Ethics* (Wellington, 1989) paras 6-13

6. Recognise a responsibility to render medical service to any person regardless of colour, religion political belief, and regardless of the nature of the illness so long as it lies within the limits of expertise as a practitioner.
7. Accept the right of all patients to know the nature of any illness from which they are known to suffer, its probable cause, and the available treatments together with their likely benefits and risks.
8. Allow all patients the right to choose their doctors freely.
9. Recognise one's professional limitations and, when indicated, recommend to the patient that additional opinions and services be obtained.
10. Keep in confidence information derived from a patient, or from a colleague regarding a patient, and divulge it only with the permission of the patient except when the law requires otherwise.
11. Recommend only those diagnostic procedures which seem necessary to assist in the care of the patient and only that therapy which seems necessary for the well-being of the patient. Exchange such information with patients as is necessary for them to make informed choices where alternatives exist.
12. When requested, assist any patient by supplying the information required to enable the patient to receive any benefits to which he or she may be entitled.
13. Render all assistance possible to any patient where an urgent need for medical care exists.

³¹ Vernon D Plueckhahn and Stephen M Cordner *Ethics, Legal Medicine and Forensic Pathology* (2ed, Melbourne University Press, Australia, 1991) 4.

C. *Common Law Rights*

Whilst overseas jurisdictions have in some cases (US)³² developed a substantial body of law in relation to health consumer rights, until recently New Zealand has not, as a result of its Accident Compensation legislation, given legal status to ensuring health consumer rights are protected. There has been little case law pertaining to the same and professional disciplinary proceedings have largely been the avenue utilised by aggrieved health consumers. The Report of the Cervical Cancer Inquiry (1988)³³ highlighted the failure of the existing system to be accountable and responsive to the rights of health consumers in relation to appropriate treatment and research.

However, common law rights that do exist in New Zealand include the right to be treated with reasonable care and skill. A failure to care for a patient at the requisite standard may give rise to a tort action in negligence (for example, exemplary damages) but such cases are likely to be confined to cases of gross negligence. It is uncertain in New Zealand whether exemplary damages are restricted to intentional torts but it is submitted as such damages are punitive they are dependent primarily on the gravity of the conduct. Unfortunately, the basic principles of negligence are pitted against the protection of a health consumer's right to self-determination. In particular, negligence actions demand standards rooted in the norms of current social behaviour by looking to accepted practice

³² Collins David & Medical Law in New Zealand, Brooker & Friend Limited, Wellington, 1992, p. 1.3 see *Hidalgo Pty Ltd v Ashwell* [1989] VR 401 where the court declined to decide whether exemplary damages could be awarded for personal injury by accident caused by negligence. 4.1.4-4.1.7 as to causation.

³² Celia Valerie Lampe *Patients' Rights Policies Within the Restructured Health System in New Zealand* A Research Paper for the Degree of Master of Public Policy, Faculty of Commerce & Administration, Graduate School of Business & Government Management (Victoria University of Wellington, 1993) 6.

³³ Above n1.

in determining what is reasonable. Furthermore, causation is often difficult to prove.³⁴

Health consumers also have a common law right to consent to or refuse medical treatment. A failure to act according to a patient's direction can result in a tort action, particularly where the patient has been misled or consent obtained fraudulently, in battery or assault.³⁵ Battery has a number of advantages for the health consumer over negligence actions in that once it is proven that s/he was touched, the burden of proof is on the defendant to show that there was consent and it was adequate, voluntary and informed to the extent the consumer understood the nature and quality of the act.

However, where there is failure to inform health consumers adequately of the risks of treatment when asked, the cause of action rests in negligence not trespass.³⁶ According to Collins,³⁷ the New Zealand courts are unlikely to have to determine the extent to which a New Zealand doctor's common law duty extends beyond this.

Health Consumers also have a common law right to confidentiality in their relationships with health professionals. A breach by the latter may give rise to a tort action for breach of fiduciary duty.³⁸

³⁴ Collins David B *Medical Law in New Zealand*, (Brooker & Friend Limited, Wellington, 1992) 6.7.5 see *Midalco Pty Ltd v Rabenalt* [1989] VR 461 where the court declined to decide whether exemplary damages could be awarded for personal injury by accident caused by negligence; 6.3.6-6.3.9 as to causation.

³⁵ Above n34, 3.1.2.

³⁶ Above n34, 2.3 see *Smith v Auckland Hospital Board* [1965] NZLR 191, CA.

³⁷ Above n34, 2.8.

³⁸ Above n34, 6.5.

D. *Statutory Rights*

Until recently statutory recognition of health consumer rights in New Zealand was negligible. In 1990, The New Zealand Bill of Rights Act provided two important health consumer rights, namely the right not to be subjected to medical or scientific experimentation without consent³⁹ and the right to refuse to undergo any medical treatment⁴⁰.

Since then there has been further legislative recognition of health consumer rights in the recently enacted Mental Health (Compulsory Assessment and Treatment) Act 1992. In particular, the provisions relating to rights of patients are to be found in Sections 64 to 75.⁴¹

In addition, the new Health and Disability Services Act 1993 makes provision to secure for all New Zealanders the best health, care and support, and independence for those with disabilities, as funding can reasonably achieve.⁴²

³⁹ The New Zealand Bill of Rights Act 1990, s10 "Every person has the right not to be subjected to medical or scientific experimentation without that person's consent."

⁴⁰ Above n39, s11 "Everyone has the right to refuse to undergo any medical treatment."

⁴¹ Mental Health (Compulsory Assessment and Treatment) Act 1992, ss64-75. The rights, however, are only applicable upon persons becoming a patient and so do not cover the preliminary stages of assessment.

⁴² Health and Disability Services Act 1993, No. 22 (New Zealand Government, Wellington, 1993).

IV CONSUMER RIGHTS

A. *Rights Relating to Treatment*

Health consumers have a "right to be treated with reasonable professional skill and care". This right has legal recognition under both the common law and statute. Common law rights, in relation to breach of duty of care, have been mentioned earlier in the paper.

Failure to administer surgical or medical treatment with reasonable knowledge, skill and care can render a health professional liable under the Crimes Act 1961⁴³. A breach, except in the case of necessity, can result in a charge of manslaughter if death occurs or in prosecution if injury results⁴⁴. Furthermore, such a breach may also result in a claim of professional misconduct and initiation of disciplinary proceedings against the health care professional. It should be noted that in cases of emergency, health professionals can avail themselves of the common law doctrine of necessity to escape liability for their actions⁴⁵.

The "right not to be abandoned" may be covered by Section 151 of the Crimes Act 1961, which places a legal duty on persons in charge of another to supply the necessities of life including the provision of medical care and hospital treatment⁴⁶. Collins suggests that the section could be invoked if a health professional omitted to supply a person with essential medications or life support system unless having lawful

⁴³ Crimes Act 1961, s155.

⁴⁴ Above n34, 7.6.2.

⁴⁵ Above n34, 3.4.5.

⁴⁶ Above n34, 7.5.3.

excuse⁴⁷. He says such lawful excuse might be mere inadvertence as opposed to gross negligence⁴⁸.

In addition, the New Zealand Medical Association ("NZMA") Code of Ethics⁴⁹ prescribes that doctors "[r]ecognise a responsibility to render medical service to any person ... so long as it lies within the limits of expertise as a practitioner."

The "right to receive prompt attention in an emergency" is similarly endorsed by the NZMA. Paragraph 13 of the Code of Ethics states that doctors "[r]ender all assistance possible to any patient where an urgent need for medical care exists".

The "right to refuse to undergo any medical treatment" now has statutory recognition under the New Zealand Bill of Rights of Act 1990, as mentioned earlier.

It may be that a health and disability services consumer ought to have a "right to know of the costs of any proposed treatment" and should only be obliged to pay for the costs of treatment contracted for and not for treatment either not anticipated and/or inappropriate. This right would pertain to the assessment of the costs before that treatment was undertaken. Certainly the NZMA Code of Ethics⁵⁰ prescribes that doctors be prepared to discuss any fees with their patients. In the case of high technology the actual cost involved and the consumer's perception of the cost may be substantially different⁵¹.

47 Above n34, 7.5.5.

48 Above n34, 7.5.6.

49 Above n30, para 6. and 11.

50 Above n30, para 26.

51 *Australian Health and Medical Law Reporter* (CCH, Australia Limited, 1992) 28-380.

The "right to know of services relating to treatment" becomes particularly important under the new health regime because the previous distinction between private and public providers may be visibly blurred for many consumers. The consumer again ought to know and have a right to choose the services s/he wishes to exercise. To exercise this right the consumer must know the details of what services are available. The right appears to be recognised, in part, by the NZMA Code of Ethics in that doctors are ethically obliged to "recognise their professional limitations and, when indicated, recommend to the patient that additional opinion and services be obtained" and that they "exchange such information with patients as is necessary for them to make informed choices where alternatives exist". However, it appears that this only applies in relation to diagnostic procedures and therapy⁵².

The "right to seek legal advice in relation to treatment" is also fundamental. In the past, consumers have not realised that accepted treatment protocols that should have been followed and/or discussed with them were not in fact followed. The case of the Inquiry into the Treatment of Cervical Cancer at National Women's Hospital⁵³ is one such illustration.

B. *Right to Confidentiality*

The right to confidentiality in respect of a consumer's health is well recognised in common law,⁵⁴ departmental guidelines, codes of professional ethics and legislation albeit that such a

52 Above n30, paras 9 and 11.

53 Above n1.

54 Michael A Jones "Medical Confidentiality and the Public Interest" (1990) Professional Negligence, March, 16.

right's corollary is seen as a positive duty on the part of the health professional.

The concept of the right of confidentiality is based on a proprietary right⁵⁵ in that information divulged by the consumer to the health provider remains the property of the consumer.

The doctor/patient relationship in particular is considered one of total trust and mutual respect and requires absolute secrecy even after the patient's death. An undertaking to this effect can be found in the Hippocratic Oath⁵⁶. It has since been repeated in the Declaration of Geneva, the International Code of Medical Ethics, in the Declaration of Lisbon (1981)⁵⁷ and also in the NZMA Code of Ethics⁵⁸.

Under the common law, a breach of confidentiality can result in civil actions in contract or tort (negligence, fiduciary duty) and/or disciplinary proceedings. Accordingly, disclosure should not be made to third parties without the consumer's consent unless the law states otherwise. In rare circumstances it may be necessary to disclose personal information, such as when the public interest is paramount. The leading case in New Zealand

55 Above n34, 1.2.2.

56 Above n34, 1.2.3.

"... whatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge as reckoning that all such be kept secret."

57 "The patient has the right to expect that his physician will respect the confidential nature of his medical and personal details."

58 Above n30, para 10 provides:

"Keep in confidence information derived from a patient, or from a colleague regarding a patient, and divulge it only with the permission of the patient except when the law requires otherwise."

on this point is *Duncan v Medical Practitioners Disciplinary Committee*⁵⁹.

There are in addition express legislative provisions that prevent disclosure of confidential information to third parties in certain circumstances. Employees of health institutions were not permitted previously to disclose information about patients, without consent, pursuant to the Area Health Boards Act 1983, and Hospitals Act 1957. In prescribed situations those Acts provided a discretion to do so without the patient's consent. Collins (1992)⁶⁰ outlines what factors might be taken into account when exercising such discretion.

Those provisions have now been repealed but have been carried over into the new regime under the Health and Disability Services Act 1993. However, they now not only apply in respect of health service purchasers, but also apply to health providers who contract with those purchasers⁶¹. Moreover, exceptions impose duties on providers to release patient information, in addition to the discretion to do so, irrespective of the patient's consent.

Other statutes impose similar duties of disclosure on health professionals. These include the notification of venereal diseases; the reporting of notifiable diseases and tuberculosis; sterilisations; abortions; maternal deaths; deaths; and various provisions under the Transport Act 1986, Medical

⁵⁹ [1986] 1 NZLR 513; Above n34, 1.8 see also *Tarasoff v Regents of University of California* (1976) 551 P 2d 334; Confidentiality has been held not to extend to situations in which another's life is immediately endangered and urgent action is required or the wider interests of society and greater interests of the potential victim justify disclosure, respectively.

⁶⁰ Above n34, 1.3.6.

⁶¹ Rodney Harrison "Patient Confidentiality: The Competing Demands of Personal Privacy and Public Interest" (Medico-Legal Summit, AIC Conference Paper, Auckland, 1993) 13.

Practitioners Act 1968 and Psychologists Act 1981⁶². Similarly, information may be required mandatorily on request, such as under the Coroner's Act 1988, Accident Rehabilitation and Compensation Insurance Act 1992 and others⁶³. In effect, the right of patient confidentiality has been somewhat eroded by the State.

The Privacy Act 1993, also provides that Codes of Practice⁶⁴ There are however, situations where, pursuant to the Evidence Amendment Act (No. 2) 1980, the right to patient confidentiality may be upheld in a Court on the ground that such information is subject to professional privilege as "protected communications" between a patient and doctor, even after the patient's death⁶⁴.

to be a breach of that principle. Failure to comply with a Code will be deemed a breach whatever the privacy principles state.

C. Right to Privacy

A temporary Code of Practice has been released under the Privacy Act 1993, which came into force on 1 July 1993, prescribes specific statutory protection to the right to privacy. The Act sets out twelve privacy principles relating to the collection, use, disclosure and access to information about individuals⁶⁵.

The Health Amendment (No. 2) Act 1993, amends the Health Act 1956 accordingly. It allows any health or disability service provider or purchaser to disclose health information if that health information is required by specific persons for certain purposes and if permitted either by the privacy principles or a Code of Practice. Disclosure by persons holding health information can be to either the individual or the individual's health/disability service provider. Any person may supply such information if the

⁶² Above n34, 1.6.

⁶³ Above n34, 1.7.

⁶⁴ Above n34, 1.3.28.

⁶⁵ Privacy Act 1993, s6.

individual is not identified. Purchasers may be required to provide health information to the Minister for statistical or research purposes. Furthermore, a person must make records available for inspection to a Regional Health Authority or Public Health Commission if they have claimed a benefit from the same.

The Privacy Act 1993, also provides that Codes of Practice⁶⁶ may be issued which prescribe standards different from the privacy principles, may exempt specified actions from those principles and detail how those principles might be applied. Where a Code of Practice is in force, any action which would, but for the Code, be a breach of a privacy principle, is deemed not to be a breach of that principle. Failure to comply with a Code will be deemed a breach whatever the privacy principles state.

A temporary Code of Practice has been released under the Privacy Act 1993⁶⁷, covering health information held by health agencies. The Health Information Privacy Code provides specific guidance to those in the health sector as to how to comply with the objectives of the Privacy Act, recognising the particularly sensitive nature of health information. It applies to both purchasers and providers, including agencies, private hospitals, health professionals and health insurers.

⁶⁶ Above n65, ss46-58.

⁶⁷ Privacy Act 1993 *Health Information Privacy Code 1993* (Temporary) with commentary. (Issued by the Privacy Commissioner, New Zealand, 1993) which came into force on 10 August 1993.

"Health information" is defined as including information on an individual's health, disabilities, health or disability services rendered or in connection with donation of any body part or substance.

Right to Access Medical Records

A health consumer's access to his/her medical records in public health establishments was already permitted pursuant to the Official Information Act 1982. The guiding principle was that information be made available unless good reason existed under that Act for withholding it. The Act states that a refusal is permitted in certain specific circumstances, such as if the disclosure "would be likely to prejudice the physical or mental health" of the person making the request, the onus however being on the establishment to justify the refusal⁶⁸. It should be noted that refusal to disclose does not preclude the entire information being withheld but only the specific information thought to be likely to prejudice the health of the person seeking it. In other words the right of access is principally for the consumer's benefit.

The Act also stipulates that a person can nominate the way in which they wish to receive that information, such as inspection, photocopy of all or part of the records, a summary of the contents or oral information about the same. Some establishments require access to be supervised to prevent damage or removal of items.

The recent Health Information Privacy Code expressly permits health consumers access to their health information⁶⁹. If information is inaccurate, incomplete or misleading, the consumer can request that it be corrected pursuant to Rule 7 of the Health Information Code. Unlike the Official Information Act 1982, the Code applies to both purchasers and providers of health services which includes medical practitioners, private hospitals, private medical insurance providers and the Health Research Council.

⁶⁸ Official Information Act 1982, ss24 and 27.

⁶⁹ Above n67, R6.

Decisions about requests must be made no later than 20 working days after receipt and as soon as practicable but this may be extended in certain circumstances. Reasons must be given why access to health information has been denied. Accordingly, practitioners will no longer be able to claim that private health records are the property of the private practitioner or private institutions and are obliged to provide access to consumers to their private treatment records.

As a matter of common practice, this had already been happening on request. The NZMA policy in particular has been that a patient should be allowed access to records at any time. It supports the right of patients (or ex patients) to obtain a copy of their medical records or a summary of the essential points.⁷⁰ Although patient notes have previously been accepted as the property of the doctor, doctors have been encouraged to provide correspondence, reports, test results, x-rays and operation results on request.

It is interesting to note that in a recent Canadian case, *McInerney v MacDonald*⁷¹ the Court held that whilst the doctor, institution or clinic compiling the medical records own the physical records, the patient has a general right of access to the information therein and is entitled to reasonable access. Although access is limited to information the doctor obtained in providing treatment, the Court stated that the discretion to withhold information should not be exercised readily and only when "there [was] a significant likelihood of a substantial adverse effect on the physical, mental or emotional health of the patient or harm to a third party."⁷² This finding, it was

70 NZMA.

71 (1992) 93 Dominion Law Reports 415 see Rossiter G P "A patient's access to medical records: recent guidance from the Canadian courts (1993)108 NZMJ, No. 958, 257.

72 Above n71, 258.

submitted, "[reflected] the contemporary ethical emphasis on the right of the patient to autonomy and self determination."⁷³

E. Right to Assistance of Interpreter

It would appear that until recently there were no specific statutory provisions requiring an interpreter to be available to assist non-English speaking patients nor provisions requiring them to be made available. However, some health establishments may have administrative directives to this effect although it is suspected that in the majority of cases the use of them is discretionary. The provision of this right seems particularly important in the context of informed consent⁷⁴.

It has been stated that it is difficult enough for patients to assert their rights in health care, but those who do not speak English are in a particularly vulnerable position:⁷⁵

"A failure to use an interpreter when assessing, treating and caring for people who do not speak English can result in misdiagnoses, inappropriate, expensive and harmful care and treatment and even death. Interpreting services are not just an "ethnic" issue. It is a fundamental question of human rights."

The Mental Health (Compulsory Assessment and Treatment) Act 1992⁷⁶ now provides that any person, court or tribunal in exercising any power under the Act in relation to a patient, whose first or preferred language is Maori or other than English, or because of physical disability is unable to understand

⁷³ Above n71, 258.

⁷⁴ Above n1.

⁷⁵ Above n7, 10.

⁷⁶ Above n41, s6.

English, must ensure that the services of an interpreter are provided wherever practicable.

F. *Rights Relating to Patient Consent*

Health consumers are entitled, as consumers of other products and services are, to legal protection in respect of health services provided. Common law rights exist in some situations where a health care provider provides treatment without consent. This has been discussed broadly earlier in the paper. Mere agreement by a consumer does not satisfy the requirement of consent in that the consumer has a legal right to be informed to some extent about a proposed treatment.

The common law recognises that the principle of consent is an inherent right to self determination which permits autonomy and dignity of every human being⁷⁷:

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body" per Cardozo J (1914).

In 1990, the Medical Council of New Zealand published a statement on Information and Consent, which emanated from a working party on the subject⁷⁸. In preparing the statement the Council

⁷⁷ *Schloendorff v Society of New York Hospital* (1914) 105NE 92, 93; Above n34, 3.2.1.

⁷⁸ Medical Council of New Zealand *A Statement for the Medical Profession on Information and Consent* (1990). In particular: "Information must be conveyed to the patient in such detail and in such a manner, using appropriate language, as to ensure that an informed decision can be made by that particular patient... The particular patient's autonomy is the overriding consideration but other issues may justifiably modify the doctor's approach to providing information..."

recognised that there was a need for a system which accommodated both the patient's rights of self determination and information and the requirement that there be professional discretion as to what information should be disclosed in individual cases. In addition the NZMA Code of Ethics also outlined the principle of ethical behaviour expected of doctors⁷⁹.

In 1989, the Court of Appeal⁸⁰ decided that failure to inform a patient amounted to medical misadventure and accordingly a civil action was barred under the Accident Compensation Act 1982. As a result, there has been no New Zealand case law on point and any redress has been restricted to bringing disciplinary proceedings against the health professional concerned or claims

In conveying that information the Council states the doctor must consider:

- The nature, status and purpose of the procedure including its expected benefits and an indication as to whether it is orthodox, unorthodox or experimental.
- The likelihood of the available doctors achieving the specific outcome that the patient seeks.
- The appropriate and relevant management options or alternatives with their possible effects and outcomes.
- The associated physical, emotional, mental, social and sexual outcomes that may accompany the proposed management.
- Significant known risks, including general risks associated with procedures such as anaesthesia, the degree of risk and the likelihood of it occurring for that particular patient.
- Any likely or common side effects, particularly in drug therapy.
- The consequences of not accepting the proposed treatment.
- The name and status of the person who will carry out the management and of others, from time to time, who may continue the management.

⁷⁹ Above n30, para 7, states that a doctor:

"Accepts the right of all patients to know the nature of any illness from which they are known to suffer, its probable cause, and the available treatments together with their likely benefits and risks."

⁸⁰ Green v Matheson [1989] 3 NZLR 564.

for medical misadventure under the Accident Compensation legislation⁸¹.

Collins distinguishes between the giving of information and obtaining a patient's consent for a proposed treatment or procedure⁸². So far as consent is concerned, he states that consent is not always a pre-requisite before any medical procedure or treatment is carried out and that "inadequate information does not necessarily invalidate consent".⁸³

Consent may be dispensed with pursuant to common law principles, in cases of necessity. Such situations would include emergencies where the patient was unconscious or where there is no known objection to that treatment.

There are also numerous exceptions to the requirements for consent. These are discussed fully by Collins⁸⁴ in his text and include: the Health Act 1956, Armed Forces Discipline Act 1971, the Transport Act 1962, Criminal Justice Act 1985, Mental Health (Compulsory Assessment and Treatment) Act 1992, Contraception, Sterilisation and Abortion Act 1977 and Children, Young Persons and Their Families Act 1989.

The writer submits that the issue as to what general standard the information should be judged on or the extent of details required to be divulged to the patient is beyond the scope of this paper. However, Collins acknowledges that there has never been an attempt to rationalise the law of consent in New Zealand and

81 D Hollings *Informed Consent - An Achievable Ideal?* (Contracting Quality Health Care, Institute for International Research, Conference Paper, Auckland, 1993) 10.

82 Above n34, 2.1

83 Above n34, 3.1.2.

84 Above n34, 3.5.

believes that Parliament is the only effective forum to do so.⁸⁵ It is interesting to note that a report produced jointly by the Victorian and New South Wales Law Reform Commissions, Australia, in relation to informed consent, concluded that there should not be any statutory standard prescribed⁸⁶.

G. *Right not to be subject to medical or scientific experimentation*

Rights relating to consent encompass the "right not to be subjected to medical or scientific experimentation without that person's consent" enacted in Section 10 of the New Zealand Bill of Rights Act 1990.⁸⁷ It has been submitted by Trevelyan⁸⁸ that this provision is wider than that contained in Article 7 of the *International Covenant on Civil and Political Rights* because the words in the latter are qualified by the words preceding it, in that Article 7 states:

"No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation."

Furthermore, although Section 10 is not applicable to experimentation carried out or funded privately, she suggests the

⁸⁵ Above n34, 3.7.

⁸⁶ Above n81, 23.

⁸⁷ Above n39.

⁸⁸ Lucy M Trevelyan *Medical Experimentation on Humans: The Impact of Recent Legislation* LLB (Hons) Research Paper, Law and Medicine (Laws 546) (Law Faculty, Victoria University of Wellington, 1992) 12.

existence of section 10 is a "reminder of the vulnerability of such people."⁸⁹

She concludes that section 10 should be modified to better reflect Article 7 as the rights provided presently therein are unnecessarily strict and are therefore likely to hinder medical progress⁹⁰. She suggests:⁹¹

"The protection of patient/subject rights, can be better achieved through the more flexible and responsive mechanisms recommended in the Cartwright Report. These were the introduction [of] Patient Advocates and a Health Commissioner ..."

It is interesting to note that the proposed Health Commissioner Bill and subsequent Supplementary Order Paper simply refer to the Health and Disability Services Consumers' Code prescribing provisions relating to "health teaching" and "health research".⁹² On the basis of Trevelyan's argument medical research or "observational research" differs from medical experimentation in that it is a passive activity which does not require intervention by the observer to alter the conditions of the study.⁹³ Accordingly, she submits that the Bill of Rights Act provision "will not unduly compromise protection afforded subjects of medical research" and therefore, the minimisation of those research subjects being exposed to physical risks

89 Above n88, 13, 19.

90 Above n88, 2, 60.

91 Above n88, 60.

92 Supplementary Order Paper, Health Commissioner Bill Proposed Amendments No. 247 (House of Representatives, New Zealand Parliament, 3 August 1993) 7, see cl 18(c)(ii).

93 Above n88, 28-29.

"justifies medical research [as] having less regulatory protection."⁹⁴

However, as neither "health research" nor "health teaching" is defined specifically in the Health Commissioner Bill, it could be argued that it was not intended to include "medical experimentation" particularly as the former words are incorporated into the definition of "health care procedure" in clause 2 of that Bill.⁹⁵ Either way guidance concerning health and disability consumers' rights and obligations of providers in respect of health research can be gleaned from the NZMA Code of Ethics which summarises the *Declaration of Helsinki* principles particularly in relation to clinical research.⁹⁶ Certainly the

⁹⁴ Above n88, 32.

⁹⁵ Above n 10, cl 2 defines "health care procedure" as "... any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any health consumer by any health care provide; and includes any provision of health services to any health consumer by any health care provider:"

⁹⁶ Above n 30, paras 16-19 in particular:

16. Recognise that medical progress is based on research which ultimately must rest on experimentation and systematic observations involving human subjects. Accept a responsibility to medicine to participate in such studies where possible.
17. Before initiating any clinical research involving human beings ascertain that previous research and the purpose of the experiment justify this additional investigation. Determine that the studies proposed may reasonably be expected to provide the answer to the questions raised. Ensure that a responsible committee that is independent of the investigators appraises any such clinical research both scientifically and ethically. Ascertain that the study is sufficiently planned and supervised so that the subjects are unlikely to suffer any harm. Before proceeding obtain the consent of all subjects or their agents, but only after explaining the purpose of the clinical research and any possible health hazard which can be reasonably foreseen.

Do not allow a refusal to participate in a study to interfere with the doctor-patient relationship.
18. Never allow the interests of science or society to take precedence over considerations related to the well-being of the subject. In any medical study ensure that every

Code of Ethics endorses the right of those involved, in the giving of consent to such clinical research, to be fully informed of any possible health hazard reasonably foreseen and to be given information about the drug or treatment to be used including the fact that the treatment is new or unorthodox.

Similarly, the NZMA Code of Ethics provides that patients must be fully informed as to what is involved in clinical teaching if they are to have the right to freely consent to what is proposed.⁹⁷

Despite Cartwright DJ, as she was then, highlighting the importance of ensuring all patients and subjects who were involved in medical education and research being fully informed and freely able to consent to being involved, both advocacy services and women's groups continue to receive complaints of situations involving teaching and the training of students without consent having first been obtained.⁹⁸

patient is assured of the best proven diagnostic and therapeutic methods.

19. Protect the right of any doctor to prescribe and any patient to receive any new drug or treatment which in the doctor's mature and considered judgment offers hope of saving life, re-establishing health or alleviating suffering. In all such cases the doctor must fully inform the patient about the drug or treatment including the fact that the treatment is new or unorthodox where such is the case.

⁹⁷ Above n 30, para 21.

Clinical Teaching

21. Recognise that clinical teaching is the basis on which sound clinical practice in the future is based. Before embarking on any clinical teaching involving patients ensure that they fully understand what is involved and have freely consented to what is proposed. Do not allow a refusal to participate in a study or in teaching to interfere with the doctor-patient relationship. In any teaching exercise ensure that every patient is assured of the best proven diagnostic and therapeutic methods.

⁹⁸ Federation of Women's Health Councils *Is Cartwright Still an Issue?* Discussion Document (Federation of Women's Councils, 5 August, 1993).

Moreover, it is said that:⁹⁹

"Medical practitioners in particular continue to distance themselves from the Cartwright Report dismissing it as a 'thing of the past'. For women, the Report continues to be a cornerstone for their rights as health consumers."

It is submitted that all health and disability services consumers should have the right to consent, if they have the capacity to do so, regardless of the nature of the research whether it be experimental or observational, therapeutic or non-therapeutic.

However, this begs the question as to what happens in situations where such consumers do not have the capacity to consent. The vulnerability of particular consumer groups in this regard is discussed in Part VD of this paper.

H. *Right of Access to Qualified Health Personnel*

It is essential that health consumers should be able to expect that they have access to appropriately qualified health professionals based on available health resources and health planning.

The Health Commissioner Bill defines health professionals as being persons registered under their respective registration Acts.¹⁰⁰ An offence is committed under some Acts where persons

⁹⁹ Above n98, 22.

¹⁰⁰ Above n10, clause 4; compare definition of "Registered health professional" in s2, Accident Rehabilitation and Compensation Insurance Act 1992 which excludes psychologists, opticians and dietitians.

not being qualified hold themselves out to be so.¹⁰¹ In addition, the NZMA Code of Ethics endorses this principle.¹⁰²

I. *Right to Obtain a Second Opinion*

It has long been accepted in practice that health consumers are not prevented from obtaining second opinions,¹⁰³ and indeed, from time to time this is done when a health professional is faced with a moral dilemma because his/her opinion is contrary to a health consumer's personal wishes.

However, practical difficulties can arise in relation to obtaining a second opinion because of the non-availability of other appropriately qualified health professionals, as in the case of medical practitioners qualified as specialists. For example, one of the perceived difficulties arising under the new Mental Health (Compulsory Assessment and Treatment) Act 1992, which specifically provides for patients to have the right to choose an independent psychiatrist of their own choice¹⁰⁴, is how can the consumer exert this right if the only available psychiatrists are all contracted through the Regional Health Authority and working for that particular Crown Health Enterprise.

Furthermore, the Act does not stipulate that the provider must ensure that there are appropriately qualified staff to give

¹⁰¹ Medical Practitioners Act 1968, s69.

¹⁰² Above n30, para 38 states: "Ensure that those persons assisting in the care of the patient are properly qualified to do so. Ensure that any doctor to whom the care of the patient is delegated is fully competent to carry out that care."

¹⁰³ Above n30, para 9 states: "... when indicated, recommend to the patient that additional opinions and services be obtained."

¹⁰⁴ Above n41, s69.

second opinions. In reality certain geographical areas may only have one person serving the population. In the case of a public provider, the question also arises as to who is expected to pay for that second opinion, the health consumer or the health provider?

J. Right to be free from physical and mental abuse

The *International Covenant on Civil and Political Rights* recognises the right of individuals to freedom from cruel, inhumane or degrading treatment, amongst other things.¹⁰⁵ This has now been domesticated into New Zealand law with the enactment of the New Zealand Bill of Rights Act 1990, which provides:¹⁰⁶

"Everyone has the right not to be subjected to torture or to cruel, degrading, or disproportionately severe treatment or punishment."

It would appear that such rights would also include those in relation to medical treatment and/or care. Such rights have been codified in the Mental Health (Compulsory Assessment and Treatment) Act 1992¹⁰⁷ which provides that every person in charge of or employed in an institution or residence or in care/control of mentally disordered persons commits an offence and is liable to a maximum of two years' imprisonment where a mentally disordered person is "intentionally" ill-treated or neglected.

According to Collins¹⁰⁸ the provision, now enacted, endorses a New Zealand Court of Appeal decision which held that an offence

¹⁰⁵ United Nations International Instruments on Human Rights (Human Rights Commission, 1989) 16, Article 7.

¹⁰⁶ Above n39, s9.

¹⁰⁷ Above n41, s114.

¹⁰⁸ Above n34, 7.15.3.

is only committed if the necessary element of intention on the part of the accused is proved.

It would seem conceivable that "abuse" need not be limited to violence and/or assault but could also include situations where patients are subject to procedures and/or experiments which might be dangerous, outmoded or contrary to acceptable practice or situations relating to sexual abuse of health consumers by health providers.¹⁰⁹

K. *Right to Lodge Complaints*

There is little doubt that to be effective "rights" must be enforceable. The right to be able to make a complaint about health care is a fundamental one but the present avenues for redress, at least in New Zealand, are confusing and often difficult to access.

Resolution of complaints frequently denies any tangible remedy to the complainant. Moreover, aggrieved persons may be unable to get satisfaction from the health facility administration with whom they initially lodged their complaint. Accordingly, it is necessary that where there are no complaint procedures in place or where these are ineffective, the health consumer has a right to access an alternative procedure endorsed by the legislature.

The right to lodge a complaint against a registered health professional for breach of the Health and Disability Services Consumers' Code ensures that this right is legally enforceable. However, it is submitted that a complaint procedure cannot function effectively unless there is a written baseline defining the minimum rights health consumers can expect even if those

rights have been implicit rights previously. It is interesting to note that in Australia health consumers' rights appear to be best protected in Victoria where there is a greater degree of legislative support for consumers' complaint procedures.¹¹⁰

L. *Right to an Advocate*

This is probably one of the most contentious rights. It been said that "advocacy generally involves the implementation and enforcement of rights" and that the concept can be defined broadly as:¹¹¹

"... a device for increasing pressures against the social structure to achieve social equity and justice."

It is not proposed to examine this right in any detail in this paper as the Supplementary Order Paper provides that the Advocacy Services be purchased by the Director of Health and Disability Services Consumer Advocacy, appointed under the State Sector Act, as an officer of the Ministry of Health. Accordingly, the monitoring of those services and training of advocates is now removed from the auspices of the Health Commissioner.

¹¹⁰ Jaleen Caples "Health Consumers and Complaints - How the States in Australia Compare" in *New Journal of the Health Issues Centre Health Issues* No. 20, September 1989, 19, 23.

¹¹¹ Bernard L Bloom & Shirley J Asher (eds) *Psychiatric Patient Rights and Patient Advocacy Issues and Evidence* (Human Sciences Press Inc, 1982) 19, see Ch 1 "Patient Rights and Patient Advocacy : A Historical and Conceptual Appreciation", p25.

V RIGHTS OF SPECIFIC CONSUMER GROUPS

A. *Rights of the Mentally Disordered*

It has now been accepted in New Zealand that persons mentally disordered should have the same rights as everyone else, except in specified circumstances. As a result, the aim of the recent Mental Health (Compulsory Assessment and Treatment) Act 1992 is to treat these persons in the least restrictive environment possible. Legislative provisions now accord explicit rights to patients detained involuntarily in psychiatric hospitals.¹¹²

However, it has been noted in America that whilst there has been "inexorable progress ... made toward the full protection of the civil rights of psychiatric patients"¹¹³ it would seem that:¹¹⁴

... these rights now seem ... better protected in the case of inpatients than outpatients While it may seem that patient rights issues arise only when there is an involuntary civil commitment, significant concerns in the case of voluntary patients exist and have yet to be resolved."

It should be pointed out that this matter has already been perceived as a failure of the new Mental Health legislation. It would appear that the patient rights provided expressly by that Act do not cover those persons in the preliminary assessment period because at that time they are not considered "patients" for the purpose of the Act. In particular a "patient" is defined in Section 2 as being a person required to undergo assessment pursuant to section 11 or 13 of the Act. Section 11 is the first

¹¹² Above n41, see long title.

¹¹³ Above 111, 46.

¹¹⁴ Above n111,46.

period of Assessment and Treatment at 5 days. But what if the patient is detained in hospital following the assessment examination pursuant to Section 9, because s/he is considered to pose a serious danger to him/herself or others or is unable to take care of him/herself?

Bloom and Asher acknowledge that the relationship between patient and health care provider has undergone "profound change" and see the challenge ahead as organising "mental health services in a manner that protects both civil and clinical rights".¹¹⁵ They believe that legislation and judicial decisions will not be enough to protect patients' civil rights fully.¹¹⁶ Rather, it will involve health professionals and lawyers learning to work together. They quote Ennis and Siegel:¹¹⁷

"There is an enormous difference between the rights mental patients have in theory and the rights they have in practice. Doctors, hospital officials, and even judges frequently pay no attention to patients' 'rights', preferring, instead, to do what they believe to be in the patients' 'best interest'."

As a consequence they believe that general attitudes towards patients' rights have to be changed as studies to date tend to reflect generally negative, although improving, attitudes to the mentally ill, particularly as support for patients' rights threatens the very power structure that keeps the institutions functioning. Accordingly:¹¹⁸

"... changing the laws regarding patients' rights will not necessarily affect daily life on the wards. Vigorous

115 Above n111, 47.

116 Above n111, 48.

117 Above n111, 227.

118 Above n111, 253.

monitoring by groups with real power may be necessary to ensure that legislative ... changes are implemented. This need for monitoring may be even more critical in those private facilities that have few outside groups reviewing their activities."

B. *Rights of Older Persons*

The Federation of Women's Health Council's paper "In Recognition of Older Women"¹¹⁹ arose out of a frustration experienced in participating with groups and individuals who perpetually classified older people as an homogeneous, expendable group called "the elderly".

The Federation believe that ageing should be considered a normal process and not a disease. Accordingly, the older woman (or person) should be treated as an adult who is capable of participating and making decisions concerning his/her own health and well-being.¹²⁰

The paper notes¹²¹ that of admissions to the geriatric service in the former Auckland Area Health Board region, 7-10% were for iatrogenic (doctor induced) illness. A report, produced as a discussion paper by the former Auckland Area Health Board, found this was a condition unique to older people. Moreover, TRANX confirmed that overprescribing of sleeping pills occurred "too frequently in those residing in rest homes" and workers had particular concerns "that women [were] more likely to be given medication where men [would] be offered other options such as

119 Audrey Fenton *In Recognition of Older Women* (Federation of Women's Health Councils, January 1993) 2.

120 Above n119, 3.

121 Above n119, 17.

medical tests."¹²² In reality, they state, seven out of ten of all residents/patients in long term care rest homes or public/private hospitals are women and "[o]verall, the rate of institutionalisation is 36% higher for women than for men, ..."¹²³

That paper also outlines several specific rights perceived as basic requirements in enhancing older persons' health, and in particular women's health, namely:¹²⁴

"2. The older woman has a right to informed participation in all health and medical decisions for herself. If she is unable to participate in decision making she has the right to designate another person to make informed decisions on her behalf.

3. The older woman has the right, prior to receiving any drug or medical treatment, to be given full and accurate information. This includes any potential, direct or indirect effects, risks or hazards to herself which may result from the use of a drug or procedure administered to her at any time. All information should be given in a language she can understand with access to an interpreter if needed.

4. The older woman has a right to information about alternatives to proposed care, treatment or drugs, **including non treatment**, and their benefits and risks.

5. Older women have the right to refuse treatment and to be supported in this decision with no fear of recrimination, refusal, or withholding of care."

¹²² Above n119, 17 where TRANX is defined as meaning Tranquillizer Recovery and New Existence Inc.

¹²³ Above n119, 6 see Bonita (1989).

¹²⁴ Above n119, 3.

In Australia, legislation has been passed in some states protecting the rights of older persons in nursing homes and hostels following a report entitled "Residents' Rights in Nursing Homes and Hostels" published in August 1989.¹²⁵ Such legislation now requires nursing home proprietors to enter into an agreement with residents consistent with a statement known as the Charter of Residents' Rights and Responsibilities, formulated by the Community Services and Health Minister. Those rights include the right to be treated as an individual, the right to personal independence, the right to privacy and the right to assess records relating to the resident.

It is well recognised that standards of care vary between private and public institutions for older persons. It is said the conflict between autonomy and paternalism is far more complex in the context of geriatric medicine.¹²⁶ As a result, the law needs to make special provision to ensure the interests and rights of older persons particularly those who are incompetent are protected. As Mason and McCall Smith note "the borderline between competence and incompetence is often indistinct in old age."¹²⁷

C. *Rights of Persons With Disabilities*

It is submitted that the *Declaration on the Rights of Disabled Persons*¹²⁸ should provide a frame of reference for the

¹²⁵ Above n51, 28-855.

¹²⁶ J K Mason and R A McCall Smith *Law and Medical Ethics* (2ed, Butterworths, London, 1987) 197 see Ch 12 "Treatment of the Aged".

¹²⁷ Above n126, 205.

¹²⁸ Robert P Marinelli and Arthur E Dell (eds) *The Psychological and Social Impact of Physical Disability* (2ed, Springer Publishing Co, New York, 1984) proclaimed by the General Assembly 9 December 1975.

protection of disability services consumers in drafting and interpreting domestic legislation. In particular, clause 6 of that Declaration states:¹²⁹

"Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational education, training and rehabilitation, aid, counseling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration."

In proclaiming the *Declaration on the Rights of Disabled Persons* in 1975, the United Nations sought to assure the welfare, rehabilitation and protection of the rights of persons with physical or mental disabilities.

In addition to the rights contained in that Declaration, New Zealand's Health and Disability Services Act 1993 has endorsed the broad right that the best health, care and support, and greatest independence for people with disabilities, be secured for all New Zealanders as funding can reasonably achieve. In particular, Section 4 of that Act states:

"The purpose of this Act is to reform the public funding and provision of health services and disability services in order to -

- (a) Secure for the people of New Zealand -
 - (i) The best health; and
 - (ii) The best care or support for those in need of those services; and
 - (iii) The greatest independence for people with disabilities -
- that is reasonably achievable within the amount of funding provided; and

- (b) Facilitate access to personal health services and to disability services; and
- (c) Achieve appropriate standards of health services and disability services."

It is submitted that this extremely broad general right, which is qualified by what resource allocation may be reasonably achievable, is not dissimilar to the qualifications placed on the National Charter Standards implemented under the British Patient Charter.

Accordingly, it seems particularly appropriate that the Supplementary Order Paper, introduced into Parliament by the Right Honourable Mr W.F. Birch on 3 August 1993, proposes to amend the Health Commissioner Bill to ensure disability services consumers are included as an integral group of those entitled to statutory protection of their rights.

D. *Rights of Minors*

There is widespread recognition that the issue of minors' rights is complex generally because of both the differing age range of children and the varied needs, abilities and capacity to understand between infancy and "full age". As a consequence, many of the rights accorded minors, such as those accorded in the United Nations *Declaration on the Rights of the Child*,¹³⁰ are essentially what are understood by many as welfare rights.

In particular Principle 4 of the Declaration states:

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Above n105, 85 Adopted by the General Assembly of the United Nations in 1959 and recognised in the Universal Declaration of Human Rights.

"The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate ... medical services."

Principle 5 states:

"The child who is physically, mentally or socially handicapped shall be given the special treatment, ... and care required by his particular condition."

In 1993, New Zealand ratified the *Convention on the Rights of the Child*.¹³¹ Article 24 of the Convention provides for the right of the child to have the highest level of health possible and access to health and medical services, with special importance being placed on primary and preventive health care, public health education and the diminution of infant mortality. In addition, it sets out the state's obligation to work towards the abolition of harmful traditional practices and the need for international co-operation to ensure this right is complied with.¹³²

¹³¹ *The United Nations Convention of the Rights of the Child* (The Office of the Commissioner for the Child, Wellington, NZ, 1992) Adopted by the General Assembly of the United Nations on 20 November 1989.

¹³² Article 24 provides:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
 - (a) To diminish infant and child mortality;
 - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

Two areas of particular difficulty that arise concerning the rights of minors are first, the right of minors to consent to medical treatment and secondly, the right of minors to participate in medical research.

A person in New Zealand is not considered to be of "full age" until s/he is 20 years,¹³³ is under 20 years and is or was married¹³⁴ or is over 16 years for the purposes of donating blood or giving consent to any medical, surgical or dental procedure.¹³⁵ As such s/he is then vested with legal capacity to give or withhold consent.

However, difficulties arise when minors do not have legal capacity to consent. The problem then becomes one of at what

(c) To combat disease and malnutrition, including within the framework of primary health care, through, *inter alia*, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breast-feeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents, and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

¹³³ Above n34, 3.6.2; see Age of Majority Act 1970, s4(1) and (2).

¹³⁴ Above n34, 3.6.2; see Guardianship Act 1968, s25(2).

¹³⁵ Above n34, 3.6.2; see Guardianship Act 1968 s25(1).

stage should the child's rights take precedence over parental rights.

This void has been filled to some extent in the common law by the House of Lord's decision in *Gillick v West Norfolk and Wisbech Area Health Authority*.¹³⁶ In that case it was held that once a minor achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed in relation to medical treatment then the parental rights terminate. In all other situations the parental rights continue unless exceptional circumstances exist such as an emergency, parental neglect, abandonment or the parents cannot be found. Furthermore, a doctor will only be justified in proceeding with treatment in the latter circumstances, without parental knowledge and consent, if this is in the minor's best interests.

However, it would appear that a New Zealand court might not allow a minor to exercise his or her right to consent if it was considered that the consent was not in that minor's best interests. In such a situation the court could either use its inherent jurisdiction of "parens patriae"¹³⁷ or could use its wardship jurisdiction¹³⁸ to override the minor's consent, despite the latter having capacity to consent in terms of *Gillick*. Indeed, the Courts may also do so despite parental consent in some circumstances.¹³⁹

But what of the situation where the minor achieves sufficient understanding and intelligence but wishes to refuse to consent to treatment? The New Zealand court has already been called upon

¹³⁶ [1987] 3 All ER 402.

¹³⁷ Above n34, 3.6.12 where Collins states that this jurisdiction is not confined to minors under S17 Judicature Act 1908.

¹³⁸ Above n34, 3.6.16; see below n141, 589.

¹³⁹ Above n34, 3.6.12 - 3.6.19.

to interpret what is meant by "everyone" in Section 11 of the New Zealand Bill of Rights Act 1990. The court held it to mean a person who is competent to consent but in that case excluded "everyone" to mean a committed psychiatric patient.¹⁴⁰

It is noted by Austin¹⁴¹ that existing restrictions on minors' ability to decide about medical treatment for themselves would be a reasonable limit prescribed by law which could be demonstrably justified pursuant to Section 5 of the Bill of Rights Act 1990. Although other enactments are not affected by the Bill of Rights Act 1990 it seems unlikely the Court would displace the statutory principle of giving paramountcy to the child's welfare (for example in the Guardianship Act 1968) and interpret a preferred meaning consistent with the meaning in the Bill of Rights Act 1990.¹⁴² He goes on to state:¹⁴³

"The value of *Gillick* for assessing whether restricting the right of children to refuse medical treatment is a justified limitation is in the majority speeches' emphases, not only on children's developmental capacity to understand the decision, but, as significantly, on the importance of such decisions to children's relationships with and within their families. For many children, there will be 'moral and family questions' impacting on many decisions. It is only appropriate that the law should acknowledge them."

This then leads on to the second issue, namely that of research on minors. It has been argued that there seems to be no compelling reason why the *Gillick* principle should not be applied to cases of research, particularly non-therapeutic research on

¹⁴⁰ Re S [1992] NZLR 363.

¹⁴¹ Graeme Austin "Righting a Child's Right to Refuse Medical Treatment Section 11 of the New Zealand Bill of Rights Act and the *Gillick* Competent Child" (1992) 7 Otago LR 578, 589.

¹⁴² Above n141, 590.

¹⁴³ Above n141, 595.

minors.¹⁴⁴ However, where the minor lacks sufficient understanding and intelligence then the parental right of proxy by consent can be justified by allowing greater autonomy to the family, rather than the child, thereby lessening the role of the state in its exercise of parental decision-making.¹⁴⁵

Certainly there has been much debate in medical ethics on the subject of minors as to whether research, particularly non-therapeutic research is not in the child's best interests. In Britain the Institute of Medical Ethics has endorsed the principle that proxy consent might be given on behalf of minors for non-therapeutic research provided it poses no more than minimal risk to the child's health or life.¹⁴⁶ The justification for this is that to allow it is necessary for the child to develop into an adult autonomous being or alternatively, that it fulfils the generic interests of autonomous human agents.¹⁴⁷

It would appear that usual practice accords with the *Declaration of Helsinki* drawn up by the World Medical Association in 1964, amended in 1975, 1983 and 1989, which enunciates the principle that informed consent should be obtained from a legal guardian or responsible relative to replace that of the minor subject, in accordance with domestic legislation. In the case of biomedical research the standards are intended as a guide only. In particular, principle 11 of the Declaration's basic principles states:¹⁴⁸

144 Above n126, 268 see Ch 17 "Research on Children and Fetal Experimentation", p272.

145 Above n126, 270.

146 Peter Byrne (ed) *Medicine in Contemporary Society : Kings College Studies 1986-7* (Oxford University Press, England, 1987) 13.

147 Above n146, 14.

148 Above n31, 12; Above n34, 4.1-4.8 and Schedule 5.

"In cases of legal incompetence, informed consent should be obtained from the legal guardian in accordance with national legislation. Where physical or mental incapacity makes it impossible to obtain informed consent, or when the subject is a minor, permission from the responsible relative replaces that of the subject in accordance with national legislation. Whenever the minor is in fact able to give a consent, the minor's consent must be obtained in addition to the consent of the minor's legal guardian."

In New Zealand, medical research involving humans is subject to the Health Research Act 1990, which in effect generally makes sure medical research complies with our international obligations such as that under the *Declaration of Helinski*. However, there is no statutory obligation imposed on the Health Research Council to ensure that the requirements of informed consent are met and this is left to the individual researcher as his or her own responsibility.¹⁴⁹

Accordingly, it is submitted that the proposed Health and Disabilities Services Consumers' Code should make provision for the right of minors to consent to medical treatment and health research provided that they have sufficient capacity to understand what is proposed, in accordance with the principle enunciated in *Gillick*. In other situations parental consent must be obtained.

VI A DRAFT CODE OF HEALTH & DISABILITY SERVICES CONSUMERS' RIGHTS

Having discussed particular health and disability services rights in relation to both individuals and particular consumer groups, the writer is mindful that this has been done with little input or consultation with interested parties.

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Above n34, 4.7.9.

It is acknowledged that the following draft is simply a proposal as to one form such a Code might take. In addition, it is essential that further detailed and informed debate take place not only about the substantive content of the Code but also as to the format of any subsequent drafts.

In view of this, and for present purposes, this draft Code is in legislative format. However, it is accepted that the draft Code finally prepared by the Health Commissioner when appointed, may be substantially different to that proposed here. On that basis a draft Code of Health and Disability Services Consumers' Code is set out below. Part A contains the substantive provisions. The meanings of the various terms used throughout the draft Code are defined in the Appendix at the end of this paper.

(b) Every health and disability services consumer shall have the right to exercise any health rights as recognized in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and in other relevant United Nations instruments on Human Rights.

(c) Every health and disability services consumer shall be treated with humanity and respect for the inherent dignity and worth of the human person.

(d) Every health and disability services consumer shall be entitled to protection from all forms of exploitation, including economic, sexual, physical or other abusive or degrading treatment.

(e) Every health and disability services consumer shall have the right to exercise any rights recognized in accordance

A. *Health and Disability Services Consumers' Rights Code*

1. *General Limitation Clause*

The exercise of the rights set forth in this Code may be subject only to such limitations as are prescribed by law.

2. *Fundamental Rights*

(a) Every health and disability services consumer shall be entitled to the best available health care provided by the health care system.

(b) Every health and disability services consumer shall have the right to exercise any health rights as recognised in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and in other relevant United Nations instruments on Human Rights.

(c) Every health and disability services consumer shall be treated with humanity and respect for the inherent dignity and worth of the human person.

(d) Every health and disability services consumer shall be entitled to protection from all forms of exploitation, including economic, sexual, physical or other abusive or degrading treatment.

(e) Every health and disability services consumer shall have the right to exercise any rights recognised in accordance

with this Code without discrimination of any kind as set out in the Human Rights Act 1993.

3. *Notice of Rights*

- (a) Every health and disability services consumer shall be informed by a health care or disability services provider, as soon as reasonably practicable in writing, and in a manner the consumer understands, of his or her rights in accordance with this Code which information shall include an explanation of those rights and how to exercise them, provided -

5. *Standard of Care*

- (i) if and for as so long a consumer is unable to understand such information, the rights shall be communicated to the personal representative, if any and if appropriate, and to the person or persons best able to represent the consumer's interests and willing to do so; or
- (ii) a consumer who has the necessary capacity shall have the right to nominate a person who should be informed on his or her behalf.

4. *Provision of Health Services*

- (a) Every health and disability services consumer is entitled to receive and every health care and disability services provider shall provide to a health or disability services consumer health care services as are appropriate to his or her condition and, as indicated by the urgency of the condition -

- (i) in accordance with this Code; and
- (ii) not less than the standard necessary to comply with the provisions of this Code; and
- (iii) which takes into account the needs, values and beliefs of different ethnic, cultural, religious, and social groups; and
- (iv) in a manner that respects the dignity and worth of the individual.

5. *Standard of Care*

(a) Every health and disability services consumer is entitled to be treated with reasonable skill and care subject to subclause (b) of this clause.

(b) Every health care and disability services provider shall treat a health or disability services consumer with reasonable skill and care in accordance with law or principles of health professionals Codes of Ethics or United Nations standards.

6. *Right to Care*

(a) Every health and disability services consumer is entitled to the following rights to care -

(i) the right of access to health services or medical treatment of his or her choice;

(ii) that is accurate, relevant and culturally appropriate; and

(ii) the right of access to appropriately qualified health professionals;

(iii) the right to receive prompt response in an emergency;

(iv) the right to seek information as to the costs of any proposed health care procedure;

(v) the right to request a second opinion concerning any health care procedure;

(vi) the right not to be abandoned, neglected or subjected to any physical, mental or emotional abuse.

7. *Right to be Informed About Procedure*

(a) Every health and disability services consumer is entitled to receive an explanation of the expected effects of any health care procedure offered to the health or disability services consumer, including the expected benefits and the likely side-effects, before the health care procedure is commenced.

(b) Every health care or disability services provider shall provide an explanation to a particular health or disability services consumer -

(i) in a manner that can be reasonably understood; and

(ii) that is accurate, relevant and culturally appropriate; and

- (iii) which gives the name, experience and relevant status of the person who will carry out the health care procedure.

8. *Right to Consent to Procedures*

- (a) Every health or disability services consumer is entitled to receive information necessary to enable him or her to give informed consent before the health care procedure is commenced.
- (b) Every health care or disability services provider shall provide information to a particular health or disability services consumer which includes, but is not necessarily limited to -

9. *Right to Refuse Treatment*

- (i) an assessment of the condition that the health care procedure is proposed for;
- (ii) an assessment of the nature, likely effects, significant risks and benefits of the specific health care procedure;
- (iii) an assessment of the expected outcome; and
- (iv) the relevant options including available alternatives with their possible effects and outcomes.

- (c) Every health or disability services consumer is entitled to give or withdraw informed consent before any health care procedure commences unless -

- (i) in an emergency; or

- (ii) where the law provides otherwise; or
- (iii) where the health or disability services provider, having in its possession all relevant information is satisfied that, at the relevant time, the health consumer lacks the capacity to give or withhold informed consent to the health care procedure.

- (d) Clinical research both therapeutic and non-therapeutic and experimental treatment shall not be carried out by any health care or disability services provider on any health or disability services consumer without informed consent.

9. *Right to Refuse Treatment*

- (a) Every health or disability services consumer is entitled to refuse any treatment or participation in any health research or health teaching.

- (b) Every health care or disability services provider shall in such circumstances inform the health or disability services consumer of the medical consequences of failure to undergo treatment.

10. *Right to Interpreter*

- (a) Every health or disability services consumer is entitled to receive the assistance of the services of an interpreter.

- (b) Where -

12. (i) the first or preferred language of the consumer is Maori or any language other than English or the consumer is unable, because of disability, to understand; and
- (ii) the consumer wishes to exercise the right prior to the granting of consent for a health care procedure; or
- (iii) the consumer wishes to make a complaint that a right conferred on the consumer by this Code has been denied or breached in some way -

it shall be the duty of the health care or disability services provider to ensure that the services of an interpreter are provided wherever practicable or to take such measures reasonably necessary to enable a consumer to communicate effectively with the health care or disability services provider.

11. *Right to Privacy*

- (a) Every health and disability services consumer is entitled to the right to privacy and to confidentiality of information by health care and disability services providers to whom this Code applies.
- (b) Every health care and disability services provider shall not unlawfully impose upon the privacy of any health or disability services consumer either in respect of personal health information or personal health communications subject to the Health Information Privacy Code 1993 (Temporary) under the Privacy Act 1993.

12. *Right to Access Records*

(a) Every health and disability services consumer is entitled to have access to all information concerning his or her health and personal records held by health care or disability services providers, subject to restrictions imposed by law, provided that -

(i) where domestic law may provide, any such information not given to the patient be given to the consumer's personal representative upon the consumer's request; or

(ii) where information is withheld from a consumer the consumer or consumer's personal representative, if any, shall receive notice of the withholding and the reasons for it; or

(iii) any written comments by the consumer or consumer's representative shall be inserted in the consumer's record upon request.

14. *Right to an Advocate*

13. *Right to Complain*

(a) Every health and disability services consumer is entitled to take action, personally or through an advocate or personal representative, to enforce his or her rights in respect of a breach of any of the rights as set out in this Code provided that -

(i) where there is a complaint procedure provided by the health care or disabilities services provider or by law the health or disability services

15. *Right to an Advocate* Every health and disability services consumer is entitled to the services of a health consumer advocate or personal representative concerning any health matters between a health or disability services consumer and a health care or disability services provider and if the advocate or personal representative agrees, he or she shall be permitted access to the consumer upon request.

(ii) if unable to resolve the complaint then the health and disability services consumer may refer the matter to the complaint procedure as set out in the Health Commissioner Act; and

(iii) the health and disability services consumer shall not be disadvantaged by the health care or disability services provider for having complained or taken action to enforce his or her rights as set out in this Code.

16. *Saving* Every health care and disability services provider shall establish and maintain complaint procedures for dealing with complaints against them by health consumers or disability services consumers, or both, and shall provide access to health and disability services consumers to such procedures upon request.

14. *Right to an Advocate*

Every health and disability services consumer is entitled to the services of a health consumer advocate or personal representative concerning any health matters between a health or disability services consumer and a health care or disability services provider and if the advocate or personal representative agrees, he or she shall be permitted access to the consumer upon request.

Disability services, protection of both liberty and well-being rights.

Whilst it is accepted that many physicians may have legitimate concerns about compromising their legal and social position even

15. *Right to Legal Advice*

Every health or disability services consumer is entitled to request a lawyer to advise the health or disability services consumer on any legal matter and, if the lawyer agrees to act, he or she shall be permitted access to the health or disability services consumer upon request.

16. *Saving of Existing Rights*

There shall be no restriction upon or derogation from any existing rights of health or disability services consumers, including rights recognised in applicable international or domestic law, on the pretext that this Code does not recognise such rights or that it recognises them to a lesser extent.

VII CONCLUSION

Legislative intervention, until recently, has failed to adequately preserve the rights and status of health and disability services consumers. Moreover, health laws have largely been shaped by the politics of health care. As a result, health care has operated relatively freely with little account being taken of either the well-being or rights and interests of those consumers.

A Health and Disability Services Consumers' Code must address the current imbalance by prescribing for consumers of health and disability services, protection of both liberty and entitlement rights.

Whilst it is accepted that "many physicians may have legitimate concerns about compromising their legal and social position even

more than is currently the norm",¹⁵⁰ codifying what have often in practice been implicit rights is unlikely to interfere with those who already acknowledge consumer autonomy as improving consumer outcome. According to Robin¹⁵¹:

"Modern medicine, with its new technology and science, increasingly deals with patients in an impersonal and dehumanized manner. ... Supporting changes in the malpractice system that are good for patients would, ... play an important role in improving the general image of the doctor in society. There is little question that the image needs some improvement. Supporting what is good for patients may turn out to be good for doctors."

It is submitted that this is equally applicable to health and disability services consumers and providers in the New Zealand health system.

¹⁵⁰ James R Vevaina, Roger C Bone, Edwin Kassoff (eds) *Legal Aspects of Medicine* (Springer-Verlag, New York 1989) see E D Robin "Improving and Refocussing the Medical Legal System", p72.

¹⁵¹ Above n150, 73.

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(a) Reduces that person's ability to function independently; and

(b) Means that the person is likely to need support for an indefinite period;

3. "Disability services provider" means any person who provides, or holds himself or herself or herself out as providing, disability services;

4. "Health consumer" includes any person on or in respect of whom any health care procedure is carried out;

5. "Health care provider" means -

(a) Any of the following bodies:

(i) Area health boards;

(ii) The Department of Health;

(iii) The Children's Health Camps Group;

(iv) Camp Committees under the Children's Health Camps Act 1972;

(b) A licensee of a private hospital licensed under Part V of the Hospital Act 1967;

(c) A licensee of an aged persons' home licensed under regulations for the time being in force pursuant to section 120A of the Health Act 1966;

(d) A controlling authority of a home registered under the Disabled Persons (Employment) Act 1970.

APPENDIX

A. *Meanings of Terms*¹⁵²

1. "Disability services" includes goods, services and facilities -
 - (a) Provided to people with disabilities for their care or support or to promote their independence; or
 - (b) Provided for purposes related or incidental to the care or support of people with disabilities or to the promotion of the independence of such people:
2. "Disability services consumer" means any person with a disability that -
 - (a) Reduces that person's ability to function independently; and
 - (b) Means that the person is likely to need support for an indefinite period:
3. "Disability services provider" means any person who provides, or holds himself or herself or itself out as providing, disability services:
4. "Health consumer" includes any person on or in respect of whom any health care procedure is carried out:
5. "Health care provider" means -
 - (a) Any of the following bodies:
 - (i) Area health boards:
 - (ii) The Department of Health:
 - (iii) The Children's Health Camps Board:
 - (iv) Camp Committees under the Children's Health Camps Act 1972:
 - (b) A licensee of a private hospital licensed under Part V of the Hospital Act 1957:
 - (c) A licensee of an aged persons' home licensed under regulations for the time being in force pursuant to section 120A of the Health Act 1956:
 - (d) A controlling authority of a home registered under the Disabled Persons Community Welfare Act 1975:

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These definitions other than "personal representative", are those prescribed in the Health Commissioner Bill and as amended by the Supplementary Order Paper.

- (e) A householder, occupier, or other person in charge of any house or place to which an authority under section 110 of the Mental Health Act 1969, and for the time being in force, relates:
 - (f) A manager of a certified institution within the meaning of the Alcoholism and Drug Addiction Act 1966:
 - (g) Any registered health professional:
 - (h) Any person who provides ambulance services to the public:
 - (i) Any person employed by the School dental Service to carry on the practice of dentistry:
 - (j) Any other person who provides, or holds himself or herself or itself out as providing, health services to the public or to any section of the public.
6. "Health services: -
- (a) Means -
 - (i) Services to promote health:
 - (ii) Services to protect health:
 - (iii) Services to prevent disease or ill-health.
 - (iv) Treatment services:
 - (v) Nursing services:
 - (vi) Rehabilitative services:
 - (vii) Diagnostic services; and
 - (b) Includes -
 - (i) Psychotherapy and counselling services:
 - (ii) Contraception services and advice:
 - (iii) Sterilisation services:
7. "Health care procedure" means any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any health consumer by any health care provider; and includes any provision of health services to any health consumer by any health care provider:
8. "Informed consent", in relation to a health consumer on or in respect of whom there is carried out any health care procedure, means consent to that procedure where that consent -
- (a) Is freely given, by the health consumer or, where applicable, by any person who is entitled to consent on that health consumer's behalf; and
 - (b) Is obtained in accordance with such requirements as are prescribed by the Code of Health Consumers' Rights:
9. "Personal representative" means a person charged by law with the duty of representing a health or disability services

consumer's interests in any specified respect or of exercising specified rights on the health or disability services consumer's behalf, and includes the parent or legal guardian of a minor unless otherwise provided by law.

10. "Registered health professional" means -
- (a) A medical practitioner which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a medical practitioner under the Medical Practitioners Act 1968, including a person conditionally registered, and a holder of a certificate or probationary registration, and a holder of a certificate of temporary registration, and a holder of a provisional certificate of registration, under that Act:
 - (b) A dentist, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a dentist under the Dental Act 1988, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:
 - (c) A clinical dental technician, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a clinical dental technician under the Dental Act 1988, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:
 - (d) A dental technician, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a dental technician under the Dental Act 1988, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:
 - (e) A pharmacist, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a pharmacist under the Pharmacy Act 1970, including a person conditionally registered under that Act:
 - (f) A nurse, which [in accordance with the Health Commissioner Bill] means any person for the time being registered or enrolled as a nurse (whether as a

- comprehensive nurse, or a general nurse, or otherwise), or as a midwife, under the Nurses Act 1977, including a holder of a provisional certificate of registration or enrolment, and a holder of a certificate of temporary registration or a certificate of temporary enrolment, under that Act:
- (g) A psychologist, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a psychologist under the Psychologists Act 1981, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration under that Act:
- (h) A chiropractor, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a chiropractor under the Chiropractors Act 1982, including a holder of a certificate of temporary registration under that Act:
- (i) An optician, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a dispensing optician or an optometrist under the Optometrists and Dispensing Opticians Act 1976, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:
- (j) A dietitian, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a dietitian under the Dietitians Act 1950, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:
- (k) An occupational therapist, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as an occupational therapist under the Occupational Therapy Act 1949, including a holder of a provisional certificate of registration under that Act:
- (l) A physiotherapist, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a physiotherapist under the Physiotherapy Act 1949, including a holder of a provisional certificate of registration, and a holder of a certificate of temporary registration, under that Act:

- (m) A medical auxiliary, which [in accordance with the Health Commissioner Bill] means any person for the time being registered as a medical laboratory technologist or a medical radiation technologist or a podiatrist under the Medical Auxiliaries Act 1966, including a holder of a provisional certificate or registration, and a holder of temporary registration, under that Act.
- (2) For the purposes of this Code [in accordance with the Health Commissioner Bill] any person who is receiving training or gaining experience under the supervision of a registered health professional shall be deemed to be a registered health professional.

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