

ago. The answer is 'very few'. Alastair's involvement has frequently been seminal, and his influence has always been felt. His time here has truly been revolutionary.

The Bioethics Centre has grown in size and stature, as postgraduate students have realised what it has to offer them, and as visitors from numerous countries have discovered it and learnt of its subtle attractions. The Bioethics Summer Schools have become established, and most of the board members of the International Association of Bioethics were enticed here for a conference and board meeting (a significant achievement for such an isolated location). It is no exaggeration to say that the Centre has become one of the University's notable successes.

While all these frenetic events have been going on, Alastair has continued to publish - books, papers, and reports, as well as giving numerous talks and lectures. The books over the past six years have included *Health as Liberation* (an outcome of his study leave and occupancy of the Tuohy Chair of Interreligious Studies at John Carroll University in Cleveland), and *Practical Medical Ethics* of which he is a co-author (incidentally, this is one of the Centre's most visible contributions to medical ethics, and will shortly appear in its second edition). He is also author of significant chapters in books such as *Bioethics Yearbook*, *Medicine and Moral Reasoning*, *Principles of Health Care Ethics*, and *Dictionary of Christian Ethics*.

Alastair's ever-present smile belies the excitement and pace with which he lives, attributes that have proved crucial in bringing bioethics to its current state of maturity in both this University and this country. It is the hope of those of us associated with the Centre that the foundation which Alastair has so ably helped to lay over the past six years will continue to be built on and that bioethics debate will continue to flourish within the University and beyond. It is also our fervent hope that Alastair Campbell will be able to make just as major a contribution to ethical discourse in Bristol, and that the founding editor of the *Journal of Medical Ethics* will be as entrepreneurial in the late 1990s as he was in the far off days of the late 1970s when the journal commenced and when medical ethics as a serious scholarly discipline was unknown to most of us.

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Article

The Code of Rights: Ten New Commandments for Providers

Ron Paterson*



Health and Disability Commissioner Robyn Stent presents Ron Paterson with a 'Rights t-shirt' to celebrate the making of the Code Regulations.

It's been a long time coming, but New Zealand finally has a code of rights for consumers of health and disability services. Judge Sylvia Cartwright, in her 1988 *Report of the Cervical Cancer Inquiry*, recommended a legislative statement of patients' rights, to protect patients involved in research and treatment in a public hospital. The Code of Health and Disability Services Consumers' Rights 1996, which comes into force on 1 July, goes much further in covering the whole gamut of health and disability services (see accompanying article by Peter Skegg). It spells out 10 rights enjoyed by all health or disability services consumers. Since each right imposes a corresponding duty, the Code is effectively a set of ten 'new commandments' for providers.

The Health and Disability Commissioner, Robyn Stent, has encouraged providers to view the Code as "an opportunity for improvement in quality and effectiveness rather than another burden". NZMA Chair Dr Brian Linehan responded in this vein, welcoming the Code as "an important step in consumer protection and professional accountability". Minister of Health Jenny Shipley, in announcing the making of the Code regulations, described the Code as "easily

understood and able to be implemented effectively". Yet health activist Phillida Bunkle says the Code is "legalistic", and RNZCGP chair Gregor Coster has claimed that "GPs will need to be more defensive in consultation" once the Code takes effect. Are these assessments of the Code justified?

Something old

New Zealand's lack of a code of rights to date does not mean that consumers have previously had no rights. Indeed, the

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very notion of a code suggests the drawing together or 'codification' of existing principles. There is already a significant body of professional guidelines, ethical precepts, and legal rules which govern interactions between providers and consumers. Much of the Code is entirely consistent with established codes of ethics and current law.

Rights 1(1) and 3 state that consumers are entitled "to be treated with respect", and "to have services provided in a manner that respects the dignity and independence of the individual" - words

which echo the NZMA 'Code of Ethics' requirement to practise "with compassion and respect for human dignity". The right to have one's physical privacy respected (right 1(2)) is recognised, in the context of collecting health information, by rule 4 of the Health Information Privacy Code 1994. The common law (and Consumer Guarantees Act 1993, s 28) requirement to practise with "reasonable skill and care" is affirmed in right 4(1).

A package of rights deal with the vexed issue of informed consent. Right 6 provides for a 'right to be fully informed', a potentially daunting standard, but no more than the Medical Council required in its 1990 'Statement on Information and Consent'. The fine print of the Code makes it clear that providers are not expected to recite chapter and verse, nor to be mind-readers; rather, to answer questions honestly and accurately, and to volunteer the information that a 'reasonable consumer', in the particular consumer's circumstances, would expect to be told about her condition and available options (with an assessment of risks, costs, and estimated time for each option). This follows the patient-centred standard set by Australian and North American courts. As illustrated by sharply divergent views on the necessity to disclose risks of contamination to blood product recipients, reasonable consumer expectations may be a matter of debate.

Right 7 builds on existing legal requirements for consent to any health care procedure, and preserves existing statutory and common law exceptions (eg, non-consensual emergency treatment in the best interests of an unconscious patient). The right to "use an advance directive in accordance with the common law" is affirmed in right 7(5), with "advance directive" defined to mean a written or oral directive by which consumers make a choice, about a possible future health care procedure, intended to be effective only when they become incompetent (clause 4). The right to refuse to undergo any medical treatment (New Zealand Bill of Rights Act 1990, s 11) is broadened into a right to refuse or withdraw consent to any health or disability services, via right 7(7).

Something new

The Code does, however, make some significant advances on current law. Sensitivity to "different cultural, religious, social, and ethnic groups" is

dictated by right 1(3), with Maori singled out for mention. A provider is not required to offer a different level of service to a Pacific Island, Jewish, gay or Greek consumer, but the manner of provision should take into account the that individual's differing "needs, values, and beliefs". It would not be acceptable to make off-hand remarks about healing practices traditional in a consumer's culture. In a relationship based on trust and intimacy, providers are expected to show discretion in dealing with consumers from backgrounds other than their own.

Right 4(2) requires providers to comply with "legal, professional, ethical, and other relevant standards". This means that standards set by Colleges and ethical bodies will now have the force of law, via the Code. Since all manner of documents in the health and disability sectors are called 'standards', drafters of such protocols may wish to review their status. Providers are not expected to guarantee a successful outcome, but the way services are performed must minimise potential harm and "optimise the quality of life" of the consumer (right 4(4)). This means "to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances" (clause 4). What was once seen as 'new age' medicine is now a legal duty. Providers must also cooperate "to ensure quality and continuity of services" (right 4(5)). This gives legal backing to the increasing emphasis that government, RHAs, and consumers have placed on 'coordinated care'.

The Code sensibly highlights, in Right 5, 'the right to effective communication' as the starting point for consumer decision making. Consumers will be legally entitled to receive information in a comprehensible form, language, and manner, and in an environment that enables both doctor and patient "to communicate openly, honestly, and effectively". Providers should be on the look-out for signs that a consumer has special communication needs, and should ensure that both the venue for the consultation, and the manner of discussion, are appropriate. This may involve talking separately to children or patients with intellectual disability, and their guardians. Interpreters are not mandatory, but must be provided "where necessary and reasonably

practicable" (eg, if needed because a patient cannot speak or understand the doctor's language, reasonable steps must be taken to obtain interpretive assistance).

The Code's right to be fully informed contains some novel features. Consumers may insist that their provider answer the questions 'who are you and what are your qualifications?', and 'what do you recommend that I do?' (right 6(3)). Doctors accused of paternalism and accustomed to the mantra of patient autonomy may find it strange that they can be legally required to recommend which option a patient should take. Consumers will also be entitled to receive the results of tests and procedures, without asking, (right 6(1)(f) & (g)), and of research¹, on request (right 6(3)(d)). Another new feature is a consumer's right to request a written summary of information (right 6(4)); standard practice when seeking quotes for work on one's house or car, but curiously atypical for work on one's body.

The duty to obtain informed consent is extended, by rights 6(2) and 7(1), beyond health care procedures to the provision of any health or disability services. This is a natural progression, but some distance from the original role of consent in the common law, which protected bodily integrity by treating an unauthorised touching of the body as a battery. Consent need not be in writing

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(although it may be useful in case of a later dispute), except for health care procedures which are experimental or involve research participation, general anaesthetic, or "a significant risk of adverse effects" (right 7(6)).

Right 8 permits a consumer to be accompanied by one or more support persons of his or her choice, except "where safety may be compromised or another consumer's rights may be unreasonably infringed". The presence of a support person may serve to put a consumer at ease, help convey complex information, and provide useful corroboration in the event of a complaint.

The 'right to complain' (a supremely '90s concept) requires every provider, unless an employee of a provider, to

have a complaints procedure which facilitates the "fair, simple, speedy, and efficient resolution of complaints" (rights 10(3) & (6)). All complaints must be acknowledged in writing within 5 working days of receipt and, as a general rule, responded to 10 working days later, with reasons for accepting or declining to accept that the complaint is justified, a plan of action, and notice of any appeal procedure (rights 10(6)-(8)). Consumers must also be told of their right to complain to the Commissioner or to a consumer advocate (see the Health and Disability Commissioner Act 1994, s 31, and forthcoming article by Peter Skegg on consequences of breach of the Code).

Something borrowed

Right 2 borrows from the Human Rights Act 1993 in affirming a consumer's right to freedom from discrimination on the prohibited grounds under that legislation (the s 21 grounds include sex, marital status, race, disability, age, and sexual orientation). "Coercion, harassment, and sexual, financial, or other exploitation" are also banned by right 2, in line with professional ethics (eg, the Medical Council's 'zero tolerance' policy) and the legal duties imposed on a fiduciary.

The Code introduces a legal presumption of competence to give consent, "unless there are reasonable grounds for believing that the consumer is not competent" (right 7(2)). This is similar to the presumption that applies in proceedings under the Protection of Personal and Property Rights Act 1988 (PPPPRA, s 5). The Code recognises that competence is not an all-or-nothing concept. A consumer who is not competent to make a major decision retains the right to make choices and give consent "to the extent appropriate to his or her level of competence" (right 7(3)). Where no legal guardian is available, and a consumer is not competent to consent to a specific procedure, a provider may proceed if it is in the consumer's best interests, but only after taking reasonable steps to find out, and conform with, any previously expressed views about treatment or, in the absence of such views, after taking into account the views of "suitable persons who are interested in the welfare of the consumer" (right 7(4); cf PPPRA, s 18(4)(c)(ii)).

Something to rue?

Consumer advocates and NZMA have lamented the omission from the Code of a right to access services in the first place. As the 1995 furore over access to dialysis showed, some sections of the community believe that providers in the publicly funded health system have a duty to treat whenever there would be some clinical benefit. Yet when positive rights against government are so studiously avoided in the Bill of Rights, for the good reason that courts are not well equipped to resolve resource issues, it would be bizarre to create a system which funnels such complaints to the Complaints Review Tribunal, and where individual providers would be in the dock, rather than the Minister or RHA responsible for the macro allocation of resources.

Legally, the Commissioner's hands were tied, since the statutory parameters for the Code confined it to quality of service issues (s 20(1)(f)).

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Parts of the Code in fact come quite close to giving a right of access. Right 4(3) - "to have services provided in a manner consistent with" the consumer's needs - might well be invoked by a patient, currently receiving CAPD treatment for end stage renal failure, whose failing peritoneal membrane makes costly incentre dialysis the only viable option. Equally, this right could support a complaint by an incentre patient whose hours on dialysis have been reduced because of competing demands. And the CAPD patient might alternatively point to right 7(8) - "the right to express a preference as to who will provide services and to have that preference met, where practicable" - in support of a claim to switch from the services of the hospital's visiting dialysis nurse to those of the incentre unit. The line between quality and quantity of service may not be as clear as has generally been assumed.

Sandra Coney has claimed that the Code is "not worth the paper it's written on", due to the 'escape clause' that says a provider is not in breach of

the Code if it has taken "reasonable actions in the circumstances" to give effect to a consumer's rights, "reasonable actions" being defined to include "the consumer's clinical circumstances and the provider's resource constraints" (clause 3). Her assessment seems unduly pessimistic. The onus remains on a provider to prove it took reasonable actions, and a lack of money is no more than one of the circumstances against which the provider's effort to comply will be measured. For many of the rights, such as the right to be treated with respect or to be free from discrimination, it is difficult to see how clause 3 would ever excuse less than full compliance.

Conclusion

There are two overarching duties on providers: they must take action to (a) inform consumers of their rights and (b) enable consumers to exercise their rights (clause 1(3)). At the least, providers should ensure that there is a copy of the Code of Rights prominently displayed in the premises. It would also be a good idea to obtain promotional material about the Code from the Commissioner's Office, and to have copies readily available. Providers must assist consumers to exercise their rights; the cautious individual who wants everything explained is to be helped, not hindered.

The Code sets a benchmark for good practice. Approached with common sense and pragmatism, it should pose no problems for competent providers. The Commissioner has stressed that there will not be a heavy-handed attitude to compliance, and that there will be a learning phase from 1 July. Robyn Stent had a tough job in drafting a Code which promoted and protected consumers' rights, kept within its statutory parameters, yet avoided being a wish list. After extensive consultation, the resulting document is clear and workable: broad enough to state the underlying principles for the ethical delivery of health and disability services, yet sufficiently specific to ensure achievable outcomes for consumers.

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¹ The application of the Code in a research context raises a number of complex issues beyond the scope of this article.