

anyone who is not a doctor. Coney noted with her usual cynicism that these were usually people who were part of the social network of those doing the choosing. The scenario may not be quite as bleak in Australia but it was noted for example in the research conducted by McNeill et al. (1988) that the vast majority of lay representatives on institutional ethics committees in Australia are appointed by recommendations from within the institution. Furthermore, research by Hiram Caton (1990) indicated that a substantial proportion of institutional ethics committees in Australia regard the membership of their committees to be confidential. This therefore avoids any requirement for such bodies to demonstrate that their lay members (or any other members for that matter) are representative of or accountable to a public constituency.

The appointment of general lay representatives is, arguably, an inadequate means of obtaining community input. It is naive at best, and at worst becomes an exercise in self-serving control by the medical profession. Coney (1990) suggests that lay representatives with no involvement in community groups and thus no real background, experience, or knowledge of the issues under discussion risk being overwhelmed by the medical personnel on their committee.

Sandra Coney argues (1990, p. 231) that truly effective consumer representatives are experts in community health issues. They belong to consumer health groups from which they receive support and information, and to whom they are accountable. The representative will have been chosen by the group as the best person for that position and she will have a mandate from her community to represent it. These are clear, sensible, and helpful criteria which represent a vast improvement on the traditional requirement of a lay representative. This view is supported by the Consumer Health Forum of Australia which regards reporting procedures as a safety valve against ineffectual performance by various committees and working parties. It was on

this basis that it published the *Guidelines for Consumer Representatives* (1990). Feminists and consumer advocates are working to democratise structures that currently only represent the interests of a powerful minority elite. We must fight hard to ensure that such guidelines have more currency and credibility in our communities, particularly with the all-powerful medicos.

Anna Yeatman (1990, p. 37) has observed on this point that the development of a modern interventionist state that reaches into virtually every aspect of our lives has created difficulties for principles and institutions of democracy that were created in a context in which the administrative state was barely developed.

Yeatman goes on to note that bureaucracies respond to this dilemma in different ways. In New Zealand, where the political climate has been dominated by the conservative forces of the New Right under the guise of a Labor government, their response was to try to reduce the size of the state itself. In Australia, Anna Yeatman argues, the Australian federal Government response was initially to reassert central controls over the workings of the bureaucracy in order to control the activities of the state. In the latter months of 1990, however, the Australian Government made moves to sell off a number of state-owned enterprises to the private sector. Therefore the Australian federal Government's response now more closely resembles the New Zealand government's approach to the dilemma of the modern bureaucracy; both are attempting to increase their control by reducing the size of the bureaucracy itself.

Yeatman argues, however, that in order to reconcile our need for democracy with the workings of the modern bureaucracy, ultimately, we must accept the basic problem and develop a new concept of what it means to live in a democratic and complex society by moving to democratise the administrative state itself. Public administrators must understand and express their duties as citizens within their work in public administration. In other

words, methods must be found to make the modern bureaucracy more accountable to the citizens it was created to serve.

Ensuring consumer advocates and representatives have genuine input into planning and decision-making in bureaucracies is an important example of the tasks involved in this process of democratisation. Judge Cartwright's proposal for a patient advocate accountable to a structure independent of the health care system is another specific example of an attempt to democratise the health care bureaucracy.

### COMPLAINTS MECHANISMS

At present in New Zealand, there is a proposal before the parliament for the appointment of a number of patient advocates based in the various local government-area health board hospitals. These patient advocates would be accountable to a health commissioner, who is attached to the New Zealand Human Rights Commission. This element of external accountability is critical to the maintenance of independent avenues of investigation and arbitration in complaints involving health care practitioners.

To date there has only been one patient advocate appointed in the manner proposed by Judge Cartwright. This advocate, Lynda Williams, is currently servicing Greenlane and National Women's Hospitals in Auckland and is currently accountable to the director-general of health in New Zealand. She has said that she feels isolated and unsupported without a network of other patient advocates or other necessary administrative infrastructure. Any increase in the number of advocates, however, is dependent on the successful passage of proposed legislation. This legislation will establish the framework, structure, and powers of the office of the health commissioner and delineate the jurisdiction and process of handling complaints.

In New Zealand, the timing of the introduction of this important innovation

was unfortunately at the mercy of a Labor government which faced almost certain defeat in the October 1990 election. The Labor government repeatedly expressed support for the establishment of an office of the Health Commissioner. However they did not see fit to present the legislation to the house until the last sittings before the election. Therefore the bill did not complete its passage through the parliament before the house rose. At this stage therefore, the only tangible evidence of government support for necessary reforms is the sole patient advocate at National Women's Hospital.

Phillida Bunkle, one of the authors of the article that led to the Cartwright Inquiry, suggested that this was a cynical strategy on the part of an ailing Labor government to attempt to retain the women's vote. In theory, the bill was assured bipartisan support but in practice it is naive to expect that it would not be substantially watered down in the amendment process by the incoming National Party Government. The National Party has, after all, traditionally enjoyed the support of the medical profession in New Zealand. One could predict therefore, that in return for their loyalty, medicos will expect support from the new National Government.

The experience at National Women's Hospital in New Zealand demonstrated very clearly that self-regulation by the medical profession has been unsatisfactory for the protection of consumer rights. Jaleen Caples noted in her recent review of patient complaints structures in Australia:

Making a complaint about a health service should not amount to a battle of David and Goliath proportions. Unfortunately, in some circumstances this is not far from the truth. (1990, p. 30)

Complaints and quality control issues are invariably more vigorously pursued when an independent voice for the consumer is present. To be effective, consumer advocates must be able to

challenge the power of the dominant elite without fear of reprisal or discrimination from the individuals or organisation under scrutiny. Ideally there should be enforcement provisions attached or associated with such functions to ensure service providers comply with any standards that exist.

Caples' (1990) recent review of the patient complaints structures in each of the Australian states and territories explores many of these issues. Alarming, she discovered no consistency across Australia with respect to the protection of patient rights and the complaints avenues available to consumers. Furthermore, there has been little in the way of coordinated community debate on what should happen. In response, Caples argued that the federal government is in a strong position to push for greater levels of protection for health care consumers Australia-wide. It is therefore with some disappointment that Caples states:

Even though complaints units form a vital part of our consumer protection system, the economic woes of government have a great impact upon the implementation of social justice policies. . . . What is forgotten in the general malaise, is the vital nature of such structures in maintaining community confidence in government regulation which seeks to promote both access and equity. (1990, p. 30)

In New South Wales, a complaints unit has been established which is directly accountable to the Minister of Health in relation to complaints matters. This unit has the primary function of investigating complaints relating to health care services provided by any health service professionals in both the public or private sectors. Bodies such as the New South Wales Medical Registration Board have powers to suspend, deregister, fine, order an individual to undertake further training, education or clinical practice, or to undertake counselling. Because the complaints unit derives its powers from the various professional registration acts

they have a mandate to investigate health professionals in both the public and private sectors. The complaints unit does not, however, currently have the capacity for privileged conciliation.

In 1988 in Victoria, the Office of the Health Services Commissioner was established with a legislative base and is directly accountable to the Parliament of Victoria. The Health Commissioner does have some limited powers to undertake formal investigations with the sanction of fines for non-compliance with any recommendation. There is an obligation, however, under the act to use the conciliatory or educative processes in the first instance. The conciliatory process also allows for financial settlement by mutual agreement as an alternative to a common-law remedy in many complaints.

Unlike New South Wales, the Victorian Health Commissioner does not have powers to prosecute. Instead, the Commissioner is bound to refer complaints to the various registration boards. This weakness is compounded by the fact that the various Professional Registration Boards have limited resources to handle the complaints and a limited range of sanctions attached to them compared to New South Wales.

The Northern Territory patient complaints system is a good example of a "Mickey Mouse" system that offers no real independence or redress to consumers. Work has only recently commenced on this issue in the Northern Territory. Currently there is a proposal under consideration for the creation of a client services network to be established within the Department of Health and Community Services. It is not envisaged that this network would provide patient advocacy or investigative functions. At present the only avenue for handling complaints that is accountable outside the health care system or its service providers in the Northern Territory is the office of the ombudsman.

Complaints relating to private health care practitioners must be referred directly to the various professional registration boards. The medical, nurses, and dentists

registration boards in the Northern Territory are composed entirely of representatives of the respective professions. The nursing and medical registration boards are undoubtedly the largest and the most important in ensuring the maintenance of minimum standards within the Northern Territory health care system. It therefore concerns me that there is currently no specific provision for representation of the public interest on these bodies. All professional boards, (except the medical board) have the power to investigate complaints about members and apply sanctions where necessary.

The medical registration board refers disciplinary matters to a medical tribunal. This tribunal consists of a supreme court judge who chairs it and the chair appoints a further two doctors. There is no provision for representation of the consumers' interest on this body. There have been only two occasions in the past decade when the medical tribunal has convened in the Northern Territory. An optimist would suggest this was because there had been no other incidents meriting investigation. By contrast, a cynic would observe that the present system is totally inaccessible to consumers.

### **PATIENT RIGHTS AND CLINICAL TEACHING**

The final aspect of patient rights examined in this paper is the need for the establishment of minimum standards for the involvement of patients in clinical teaching situations. The establishment of these standards is critical for the protection of patients in teaching hospitals all around the world.

In the Cartwright Inquiry's discussion concerning the standards of practical teaching, Judge Cartwright suggests that patients need to be involved in treatment or management decisions (1988, p. 216). The Inquiry found that clinical teaching practices requiring medical students to have access to live teaching models were frequently given priority over patient rights. Furthermore, the Cartwright Inquiry found that access to patients for

teaching purposes was often taken for granted by senior clinicians.

Sandra Coney (1990) commented in relation to medical teaching that:

University doctors are of course the elite of the medical world. In a hierarchical profession they occupy the pinnacle of the pyramid, (p. 225)

Senior clinical instructors and specialists are powerful role models to young and impressionable students and recent graduates who aspire to their example. It is therefore all the more serious when senior doctors and professional leaders demonstrated by their behavior in the evidence given to the Inquiry that both their technical and interactive skills left a lot to be desired. These very same people induct young, inexperienced doctors to a clinical style that they are supposed to emulate.

The necessity of developing ethical guidelines for the involvement of patients in clinical teaching became apparent in New Zealand following the revelations of the Cartwright Inquiry. Undoubtedly a similar need exists in other countries. When they are developed, the guidelines must specify how patients are to be informed of their rights, when, and by whom. Patients should also know what kind of teaching they might be asked to participate in, and under what guidelines doctors and students are operating. Patients must be able to easily identify who is and who isn't a student. It is also important that the consent of patients is sought for students to observe clinical treatment and that the number of students who would like to observe a procedure is made very clear at the time consent is sought.

I was concerned and interested to note that in the Australian *Report of the Committee of Inquiry into Medical Education and the Medical Workforce* (1988) there is scant consideration of these issues. This weakness could easily be attributable to the composition of the committee. Although the committee received a "very substantial number of

submissions” (p. 38) from consumers of medical care there was no provision for consumer representation on the committee itself. Yet again consumers had very limited control over the agenda of such a review. In almost 700 pages of discussion there are only superficial references to the education of doctors about patient rights. By contrast the report examines at length and in a variety of contexts issues of remunerative parity and the current crisis of the declining availability of patients as teaching material for medical students. There was no apparent connection made in this report between the willingness of patients to participate in clinical teaching situations and the protection of their human rights.

### THE MEDIA

Predictably, the Cartwright Inquiry in New Zealand raised many more questions than it answered. What happened in general terms in New Zealand was that issues previously presented as being of marginal significance to the community generally, and women in particular, are now firmly on the centre stage of public interest.

The commitment of cohesive feminist and consumer health rights movements in New Zealand ensures that these issues are pursued in the best investigative tradition by the mainstream New Zealand media. Ironically, the one major exception to this is *Metro*. In July 1990, *Metro*, the magazine that published the original article which led to the Inquiry, published a follow-up feature article by Jan Corbett which was tantamount to a total retraction on the original.

Corbett (1990a) questioned whether the Inquiry was a radical feminist witch hunt and presented Sandra Coney and Phillida Bunkle as women who were already heavily loaded down by psychological baggage because of their experiences and feelings about doctors. The feminist opinions expressed by Coney in her writings were discredited as polemic and biased. However Pat Rosier was astute when she said in defence of feminist writers such as Sandra Coney:

The difference between feminist writers and almost all others is that feminists are overt about having a point of view. Everyone writes from a point of view, it's just not common in mainstream media for that to be acknowledged. (1990, p. 7)

Corbett repeated her disparaging treatment of Coney and Bunkle in the October 1990 edition of *Metro*. She alleged that she was so fearful for her safety when the July article was published that a security guard was posted at the door of the *Metro* office. Corbett then went on to state that:

But in truth one man at the door isn't going to turn back the tide of feminist wrath. It hadn't occurred to me when I was writing "Second Thoughts" that I really wasn't dealing with arguments [sic] between doctors over cervical cancer. Instead I was tampering with the front line of radical feminist activism which over the last few years has shifted from the fringes of the university campus to women's health where they have introduced an extremely effective state of siege. The doctors are terrified. (1990b, p. 156) Elsewhere in the article Corbett admitted that:

It turned out that we didn't need the security guard. We had been unnecessarily paranoid, (p. 158)

Perhaps the most disturbing effect of such visible mainstream media misogyny is that it creates the fanciful impression that feminists have enormous power. Oh, if only she was right!

Corbett went on in the same article to lampoon Phillida Bunkle's receipt of the Hodge Fellowship in 1989 to study DES (diethylstilbesterol). Depo Provera and Noristerat, the Dalkon Shield, the copper seven IUD, and ultrasound. Corbett attacked Phillida Bunkle's research ethics, her academic credentials, and the validity of her choice of referees in her application for the award.

Corbett concluded her vitriolic vendetta by stating:

Do we need Fertility Action and the Auckland Women's Health Council? Yes, I think so. If only to force us all to assess our attitudes and positions, to shift the centre ground to a fairer position. Watchdog groups are part of the democratic tradition; they fulfil a valuable role. But should they be given free rein, go unquestioned and have all their demands automatically acquiesced to? No, never. (1990b, p. 165)

The backlash against women's health activists, and feminists generally, is clearly well under way in New Zealand. The articles in *Metro* during 1990 demonstrate that there is a naive perception in the community that feminists in New Zealand have already got their own way. The tone of the writing suggests that there has been a subversive revolution in New Zealand led by the feminist "Thought Police" and that the recommendations of the Cartwright Report are all but implemented. In reality, as research undertaken during my Anzac fellowship in New Zealand in 1990 clearly demonstrated, nothing could be further from the truth.

## CONCLUSION

The findings of the Inquiry are now herstory but, significantly, as the vicious attacks in *Metro* illustrate, the saga is far from over. In April of 1990, a statement of claim was made to the High Court in New Zealand. The applicant was Mrs. Valerie Smith, a retired school teacher who had previously presented a statement to the Inquiry. The applicant challenged the veracity of the findings and the impartiality of the Cartwright Inquiry and sought an order that the findings be set aside. This application was subsequently withdrawn in July of 1990, but not before it subtly eroded some of the gains made to enlist widespread public sympathies.

Few other countries have ever had an Inquiry as bold or potentially as far

reaching as the Cartwright Inquiry in New Zealand, nor was it usual for the public to focus with such intensity on the issues it explored. As one women's health issue resolved itself in New Zealand another of equal importance arose for serious consideration. In many respects the popularising of health rights and women's health issues took the lid off a proverbial Pandora's Box.

The women's health movement in Australia and New Zealand has never had such a receptive political climate to create truly accountable mechanisms and structures in the health care system. If we are to eliminate the condition Jo Anne Ashley (1980) referred to as structural misogyny, which continues to afflict our patriarchal, medically controlled health system, then we must, as always, expect resistance from those with a vested interest in maintaining the status quo.

As activists in the women's health movement, we must monitor the struggles of the New Zealand women's health movement to participate in decision-making processes about their own health care. In doing so, we can continue to consolidate the successes and experiences of women everywhere. There are certainly many important lessons to be learned from the New Zealand experience. Consumer health and women's rights activists in New Zealand succeeded in articulating and publicly highlighting a number of problems within the health care system and forced concessions from the powerful elite of medicos who dominate it. The Cartwright Inquiry provided a focus but, more importantly, through the media, it also provided a vehicle to harness the all important political support from a population that was outraged by the abuses of power revealed during the inquiry. In short it was the catalyst for change.

If women are not to be marginalised during the reform process and if consumer health rights are to continue to progress, then it is important that we critically review the lessons already learned by feminist and consumer health activists in New Zealand. They have openly battled the obstructions of medicos and

bureaucrats and made considerable visible gains but not without great personal and political costs. They have been vilified, mocked, and ascribed with an amazing amount of power that they do not in fact have.

So for each of us struggling in so many ways to speak out in defence of the rights of women and patients we should call to mind the words of Pat Rosier, editor of *Broadsheet* who, in support of Sandra Coney's courageous work and in response to the backlash wrote:

I suspect Sandra's greatest 'crime' . . . is that she has refused to be intimidated and simply won't shut up. She will not be silenced because her advocacy arises directly from the women who tell her their stories. Sandra does not create distrust of the medical profession among women, she expresses it. (1990, p. 6)

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## NEW REPRODUCTIVE TECHNOLOGIES: A REPORT FROM ARGENTINA

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**Synopsis** — In this article the author reports on two centers in Buenos Aires (Argentina's capital) involved in the new reproductive technologies. The centers offer IVF, GIFT, and PROST procedures and also use egg donors. Data is presented on the success rate of the technologies. The many ethical and legal questions that arise from these procedures have not yet been widely discussed. The Argentinian Senate has recently started public hearings on the subject of the new reproductive technologies.

There are currently (August 1990) nine centers in Argentina working in the area of reproductive engineering. Recently, the Argentinian Senate started a series of public hearings on the subject of the new reproductive technologies. At the first meeting, members of the medical profession reported that 187 babies were born from 1985 to 1989 using new reproductive technologies. A total of 1,323 eggs have been obtained from women's bodies, so that the estimated overall success rate would be 14.1%.

I have interviewed members of two centers in Buenos Aires (capital of Argentina) involved in the new reproductive technologies: CER (Centro de Salud Reproductiva) and Fecunditas.

CER's director is Dr. Ester Polak de Fried and her center has a working relationship with Ricardo Asch, who developed gamete intrafallopian transfer (GIFT) technology. Fecunditas has a three-man board of directors and I interviewed Dr. Roberto Coco. Fecunditas defines itself as the only "integral" institution. Both are privately owned.

Before the advent of these centers affluent people traveled abroad (mostly the United States) to obtain IVF (in vitro fertilization) and GIFT procedures. Now they can get them at home. All of these centers get some press coverage, but it is not easy to get a clear picture of what is going on from this cover age.

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I wish to thank Rita Arditti for her help and encouragement, which started when I first met her, as well as the helpful suggestions in the preparation of this article.

The usual lines about "advances of human knowledge" and the "altruistic value of science" are stressed in their public presentation.

### CER

During my interview with Dr. Ester Polak de Fried, I learned that CER was founded in 1987 and that the doctor has specialized in endocrinology and reproductive medicine. Her staff includes surgeons, gynecologists, biologists, and a psychologist. In this center, the first baby was born in February 1989 from pro-embryos transfer (PROST) in the fallopian tubes. I was told that this was the first pregnancy in South America using this method. According to Dr. Fried, whenever fallopian tubes are functioning, the rate of success of the technologies is higher than when they are absent. This is the case using either eggs and sperm or embryos. At this center they claim to have success rates of 40% with PROST, 30% with GIFT, and 20% with IVF, although I could not get a clear explanation of how these success rates are computed. The transfer of embryos or eggs and sperm is done transvaginally with eco-graphic control.

CER has a programme on Premature Menopause and Ovodonation. The first baby born at the center originated from the father's sperm and an egg from a donor. Donors that agree to allow their eggs to be used are not informed if the eggs were used for research purposes or to create embryos.

When I asked more questions about egg



donors, I was told that the eggs are given by anonymous and “altruistic” donors, who do not receive any monetary compensation. Women patients sign agreements regarding the fate of their supernumerary eggs, and they may decide not to donate them to anybody. The records on eggs and sperm used for each embryo remain secret and women donors do not know the fate of their eggs. There is no legislation on this subject at the time in Argentina, and the legal and ethical aspects of these procedures have not yet been discussed. If a baby born now wants, at some future time, to know about her or his origins, there would be, most likely, no way to obtain the relevant information.

CER also maintains a sperm bank, some of the donors to which are “altruistic” and others are paid. As mentioned above, women donors are never paid (possibly because it is so much easier to donate eggs than sperm!). Some of the fertilized eggs are implanted immediately while others are stored as frozen embryos for later use by the patient.

At CER, embryos are frozen, but not eggs. Egg donors have to be younger than 35 years of age and are checked for genetic and viral diseases. There does not seem to be a set limit regarding the age of women undergoing these technologies, their acceptance in the program depends on their physiological state and overall health condition.

Dr. Fried believes that CER’s high success rates with women with premature menopause is due to the fact that the patients are not hyperstimulated. They are treated with hormones to simulate a normal cycle. According to Dr. Fried the failure of implantation with frozen embryos is due to embryonic deficiencies. The number of frozen embryos kept in storage depends on space availability, but usually they are not kept longer than a year.

In Dr. Fried’s view, legal and ethical controls are necessary. She believes that a

pluralistic committee made up of men and women who represent the major religions and professions in Argentina, as well as representatives of research groups involved in these procedures should be created to develop these controls.

Because Argentina is a country in which Catholicism is the official religion, one may wonder about the decision to use procreative technologies. Dr. Fried explained that many Catholic patients want to use GIFT technology, while others just do whatever their doctors tell them to do. Patients of Jewish origin are less rigid, but many times if the husband is azoospermic (which is considered an indication for treatment of the woman!), they want sperm from non-Jewish donors because Judaism forbids them to spill sperm and the Jewish identity is inherited through the mother.

Regarding the need for information by the general public, Dr. Fried believes that the public is well informed. She also said that while there is a large number of women gynecologists in Argentina, the Argentine Society on Fertility and Sterility does not have a single woman on its board of directors.

## FECUNDITAS

Fecunditas is headed by three men: a gynecologist, an ecographer, and a biochemist/cytogeneticist. I interviewed Dr. Roberto Coco, the biochemist/cytogeneticist. They consider their centre quite unique and claim that they can take care of every step of the process, although they do not have a maternity ward. They perform IVF, GIFT, and PROST procedures on patients that come directly to them or are referred by other physicians. They do not perform laparoscopies, the egg pickup is performed transvaginally through ultrasound. They claim to treat all sorts of fertility disorders and they have sexologists in their team.

When asked about their success rates, they said that in 4 years (1984–1988) 35 babies were born out of 345 proceedings. Some of these babies were born while the doctors were working with another team.

Since they founded Fecunditas, 170 more proceedings have been undertaken and 45 babies have been born. Of these births, 85% were single births and 15% were multiple births, mostly twins, although there were two pairs of triplets. The fee for induction of superovulation, its control and pregnancy testing is \$3,000US, which for Argentina is quite a bit of money.

Fecunditas does not freeze embryos, because they view them as potential orphans. When I asked about sperm banks, I was told that although Fecunditas does not maintain one, heterologous insemination is carried on and donors are chosen who have similar phenotypes to the prospective father. They do perform chromosomal studies of the donors. Sperm donors are paid approximately \$80US for their trouble (no one expects men to be altruistic). This points, once again, to the low value that is attributed to women and to their eggs. Although no surrogates (see Arditti, 1990) are used, egg donation from other women on treatment is also practiced in this clinic. They claim that 85% of all eggs obtained from a woman will be

fertilized and they use 3 to 5 eggs at a time for implantation.

According to this center there is not a higher incidence of malformations in newborns. However, as no population studies have been made on the babies already born and no one has done chromosomal studies of the spontaneous abortions produced during the use of these technologies, it is not really known if there is chromosomal damage due to the manipulation of eggs, sperm, and embryos.

Once again one sees that here, as in other countries, women are paying to be submitted to experimental techniques the rate of success of which are questionable and the long-term health effects of which are unknown.

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