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Autonomy in the Debate Concerning the Care of Mentally Ill People

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Historical background

Over time, the place of the concept of autonomy in the explanation of psychiatric illness, and in the ethical consideration of care of psychiatrically-ill people, has swung between two extremes.

Until the advent of the nineteenth century the causes of mental illness were thought to be outside the control of the individual. Since mental illness was thought to be the result of possession by evil spirits or by God (depending on the content of delusions), the concept of autonomy did not feature in the explanation. Sufferers were burned at the stake or revered as saints: the good of the community, not the fate of the patients, was paramount.¹

In the early nineteenth century the concept of autonomy began to enter into the causal explanation of mental illness. Mental illness came to be thought of as the result of immoral lifestyle choices, that is to say, the result of the abuse of alcohol or of sexual promiscuity.² Patients were treated as criminals who were thought to have some control over their immoderate lifestyle choices. Treatment involved incarceration, physical restraint and intimidation.

In the late nineteenth century this emphasis on moral factors gave way to the idea that mental illness was due to brain disease, and that heredity played a part. This owed something to Darwin's Theory of Evolution. Autonomy played no part in this explanation nor in treatment. But this new emphasis meant that medicine gradually took over the care of the mentally-ill. The issue of rights was prominent, but the main concern was that those who were sane should not be misdiagnosed as insane. The legal system continued to play a part in deprivation of the liberty of the mentally-ill.

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After World War 1, the phenomenon of returning servicemen suffering shell shock or war neurosis introduced the idea that organic causes were not the only reasons for mental illness. Legislative changes allowed voluntary admissions to mental hospitals and outpatients clinics were set up as part of the general hospital system.

The Great Depression followed by World War II saw little government expenditure on psychiatric services. Conditions in psychiatric hospitals were overcrowded and the care sub-standard.

In the 1950s, new treatments such as electroconvulsive therapy and the use of phenothiazine drugs did enable some patients to recover and be discharged. But conditions in psychiatric hospitals did not substantially improve in New South Wales, or elsewhere in Australia, until after the Royal Commission into Callan Park Hospital in 1961.

In the 1960s and 1970s the 'self help group' became a prominent feature in western industrial countries. This movement relied on the idea that the individual can, with support, overcome difficulties and participate in his or her own rehabilitation. From this idea it came to be thought that the mental condition of patients in long-stay psychiatric hospitals was more a product of their institutionalisation than of their illnesses.³ Respect for individual autonomy was the paramount feature of the 'self help' movement. This idea of 'self help' was particularly attractive in Australia where the 'self made man' had been an icon since colonial days.

In the 1970s, and arising from these ideas the Whitlam Government made funds available for community mental health centres to offer support to those patients who were beginning to be discharged in increasing numbers from psychiatric hospitals. The plan was that these people would be housed in hostels as a transition phase in their treatment, and that then they would progress to mainstream accommodation once they had been rehabilitated through the community services.

In the 1980s the practice began of discharging long-stay patients from psychiatric hospitals. Mr David Richmond was commissioned by the New South Wales Department of Health to formulate a plan to expedite this. Mr Richmond envisaged that the funds saved from closing beds in institutions would be transferred to the community to provide the accommodation, medical care and social support that people needed successfully to integrate into the community.⁴ The word 'autonomy' was used many times in departmental documents of this era. Unfortunately this occurred at a time when economic rationalism, with its emphasis on outcome measures, was being embraced by economists and politicians in Australia as well as in other English speaking countries.⁵ As the outcome or 'cure' rate for chronic mental illness is generally poor, the best that can be hoped for is management. The prospects for these people, with the wisdom of hindsight, did not look good.

The Burdekin Report of 1991/2 revealed that funds saved from closing beds in institutions were never transferred to the community.⁶ Beds were closed, appropriate accommodation was provided for very few, and services were inadequate or poorly distributed. Burdekin uncovered wide-scale abuse, neglect and intimidation of those people who had been discharged to the community and given the 'freedom' to direct the course of their own lives. It seems that the N.S.W. Government saw an opportunity to save money by closing beds in psychiatric hospitals. There was little chance that this policy would be unpopular, for it seemed consistent with the belief which had gained currency in the previous decades that the mentally ill should have their autonomy respected.

By the 1990s, the discussion has moved on again. Perhaps it is the Burdekin Report which represents the "baseline" of current debates. Burdekin was certainly unhappy about the plight of the psychiatrically-ill. He described the living conditions of many mentally-ill people as "third world", and thought that their situation was a disgrace to any society that pays even lip service to concern for its disadvantaged members.

Readers of Burdekin might be tempted to conclude that the idea of personal autonomy for the chronically mentally ill has become a euphemism for neglect. In the wake of the Burdekin Report, there has been something of a push for increased funding for institutional care of psychiatrically-ill people. Equally, there has been something of a countervailing push against this precisely because of the risks it could represent to positive results of the "de-institutionalisation movement". Where should we go from here? What place does the idea of the ill person's autonomy have in arguments about these matters?

Autonomy ethics: the impasse

In many liberal ethical outlooks, the thought that individuals are centres of value - not to be treated as mere means but as end in themselves - is often spelt out in terms of autonomy. The thought is, roughly, that the capacity for autonomous decision-making is the ground of a person's dignity and of our obligation not to treat him or her as a "mere means".

Now, let us consider the psychiatrically-ill. Let us consider them insofar as we find the conditions of their institutional care abusive, neglectful and in various other ways inconsistent with their dignity as human beings, especially where we think we can do better for them outside institutional care. Respect for the patient's autonomy seems to require de-institutionalization, and paternalistic intervention seems unjustified. However it has also been argued that the capacity of many of the psychiatrically-ill who have been de-institutionalized for autonomy has been seriously compromised by one thing or another (in particular, by their psychiatric condition). The conclusion can seem inevitable that we must institutionalise many of these psychiatrically-ill people. Is this thought inevitable?

It is not. We can, and usually do, value personal autonomy without reducing human dignity and worth to the capacity for autonomy. Human dignity is not only expressed in the obligation to respect the autonomy of those who exercise it or are able to. It is expressed in a number of ways. For instance, it is expressed

not only in the obligation to nurture autonomy in those - such as children - able to become autonomous, but also in the obligation to see to the well-being of those who depend on us, as well as we can. In addition to concern for the autonomy of the psychiatrically ill, this latter expression of human dignity and worth is also relevant in thinking about how we care for different categories of patient. Despite the good intentions of liberal thinkers who wish to give the mentally-ill equal opportunity to make life choices, it seems clear that our choices in the care of the mentally ill are not exhausted by the false dilemma between (a) strengthening institutional care and placing more patients in such facilities and abandoning what is right about the de-institutionalisation movement and (b) insisting on de-institutionalisation (understood as defending human dignity-as-autonomy) and placing so many psychiatrically-ill persons under conditions that are harmful, dangerous or otherwise negligent, without paternalistic intervention or support.

A virtuous third way: some general considerations

Where does this leave us in post-Burdekin days? What ethically-defensible response is there to our predicament in caring for the psychiatrically-ill? There is a *via media* between (a) and (b). Understanding it is aided by a brief observation of some suggestions from Virtue Ethics.

The problems of human life are often deep and complicated and require decision-makers who are mature in 'practical wisdom' to make the right decisions. According to Virtue Ethics there is no 'blue-print' for making right decisions. The current issue is no exception to this. It requires those in decision-making positions to be people whose characters are guided by the virtues of courage, temperance, prudence and justice as they respond to the ethically-salient features of the situations they must decide about. We have already mustered some of these features: the aspiration to autonomy of those who can become autonomous, or whose illness episodically disrupts their autonomy, or whose autonomy is typically fragile or compromised by their condition; the well being and safety of those unable to care for themselves reliably; the

resources of the society which must bear the burdens of providing the necessary services. There will be other things that matter too.

But, according to Virtue Ethics, good decision-making also requires us to look at ourselves as a community. It requires us to take a critical posture towards our community values and our traditions of decency. It requires of us the kind of critical self-knowledge with which Socrates challenged his community. In particular, it is at our peril that we forget that, even though the chronically mentally-ill are a sizeable minority of the population, they are rarely on electoral rolls. Nor should we forget that we frequently shun them because of their unattractive appearance and often bizarre behaviour. It is often more comfortable to ridicule them or ignore them. This can go in two directions in the current setting.

It can often seem wasteful to contribute financial support and to encourage de-institutionalised individuals trying to make it in the community: after all, we are supporting their "autonomy". And there are few votes for politicians in advocacy for the psychiatrically-ill. Alternatively, we can jump on a re-institutionalisation bandwagon in the name of patient welfare as the panacea for getting "them" off the streets. Both concern for autonomy and concern for welfare can be corrupt smokescreens for indifference and neglect.

We must seriously confront ourselves, both at a personal and political level, with the question: do we consider the psychiatrically-ill worth the trouble to give them the support they will need whether they live in the community or in institutional care? We should – on both counts. But the public debate requires a more nuanced consideration of the different needs of different kinds of patient than is currently emerging.

The rush to de-institutionalise in the name of patient autonomy has led to the neglect of many individuals whose capacity for autonomy is terribly fragile or almost non-existent. For these vulnerable people, the old adage could not be more true that the free market is only as ethical

as its least ethical player. These folks are often the worst cases to which Burdekin draws our attention. Their continued neglect is unconscionable. Either they will not be able to look after themselves safely without risk to self or abuse by others. Or their potential to do so will require such extreme remedial or intensive work as to be prohibitively expensive. Recognising that there are people on the street who fall into this unfortunate category and suffer from its tragedies – often chronically mentally-ill persons – does not require abandoning the positive results of de-institutionalisation for those more fortunately situated and less well served by institutional care. (Of course, the real question is which patient is which. The important role of families in this connection deserves stress).

This brings us to a final point: the need for institutional reform. If we are going to recognise that there are certain chronically mentally-ill people to whose neglect or abuse de-institutionalisation has led, we must consider whether our current institutions adequately meet the needs of these people. Many advocates of the autonomy of mentally-ill persons seem to argue, in effect, that the risks to patients of de-institutionalisation are worth running to avoid the problems of institutionalised care. Now, these risks are quite significant. If advocates of the mentally ill think this, we must wonder why. We must face honestly and with adequate resources the question of how we can improve institutions in ways that make this kind of thought unnecessary or, at least, less plausible. Relatedly, we need to ask ourselves why psychiatrists generally cannot get out of the public mental health system quickly enough. What is going wrong here? We can and must do better.

Some suggestions for concrete changes that need to occur

- The ideals of justice for the mentally ill should be supported financially in the way that Mr Richmond envisaged.
- Housing has been identified as the greatest single issue for concern in the Burdekin Report.

- If the Government is unable to fund appropriate housing for these people, then the small number of non-government organizations, identified by Burdekin as doing this well, should be expanded. These are not run for profit and their staff are not motivated to maximize employers' financial interests by compromising on standards of comfort and nutrition as allegedly occurs in too many privately-run boarding houses.
- Anomalies in the Pharmaceutical Benefits Scheme need to be addressed, so that those most in need of service receive it.⁷
- Staffing levels in Community Health Centres need to be commensurate with the needs of each community.
- These changes should be accompanied by a community education programme so that all members of society are aware of their responsibilities to provide a decent standard of care to those of their society who are less fortunate.
- Appropriate levels of training should be required for those who would work with de-institutionalised people in the community setting, and realistic and regular supervision of accommodation, living arrangements, etc., should be in place and expanded.

We believe that those responsible for the current plight of the mentally-ill have been motivated by a theory devoid of charity as a value, and that they have embraced the concept of de-institutionalisation merely as a means to save money. They correctly predicted that there would not be initial public or professional outrage, because the concept appeared supportive of current misguided thinking about autonomy. It took some ten years before the Burdekin Report illuminated what workers in the field had long been suspecting: that the reforms Mr Richmond recommended had occurred, at best, in a very piecemeal way. This

has resulted in the chronically mentally-ill living in sub-standard conditions with few resources for the dignity enjoyed by most citizens.

We now need decision-makers committed to social justice, who have the courage to address the issues that Burdekin has uncovered. Mostly, this is a matter of political courage and the good will of the general community.

References

- 1 J. Krupinski "Social Psychiatry & Sociology of Mental Health: A View on their Past & Future Relevance", *Australian and New Zealand Journal of Psychiatry* 1992: 26 p.94.
- 2 M. Lewis *Managing Madness - Psychiatry in Australia 1788-1980*, Australian Publishing Service, Canberra 1988 p.2.
- 3 R. Peele "The Ethics of Deinstitutionalization" in Sidney Bloch and Paul Chodoff (eds) *Psychiatric Ethics* Oxford University Press, New York, 1994.
- 4 D. Richmond *Mental Health Services. Statewide Forward Plan* p.6.
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- 7 *Ibid.* p.326.

Note

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The McKay Report on Optimum Utilisation of the Psychiatric Workforce

John Quilter

The McKay Report is the result of a project of the National Mental Health Strategy.¹ It concerns a problem which, when seen from an ethical point of view, is an aspect of the resource allocation debates. It concerns the institutional, financial and professional arrangements that should be put in place to ensure that the resources expended by our community (whether from the public or private purse) on the care of psychiatric illness are expended in the most ethically-defensible way consistent with realistic constraints. The report's language does little to invite the reader to see the issues with which it deals, the propositions it defends and the proposals it urges, as ethical issues. If we let the report's language guide us, the matter of the report would look like an issue merely in social or health policy, as if we can understand these as ethically-neutral areas of decision-making: as matters of technical understanding only. But we should not let it guide us in this way. The issues it engages are ethical ones. Specifically, they concern the proper allocation of resources for the care of the mentally-unwell, and the specific arrangements of the funding system, the patterns of professional practice and ideas of "worthwhile medicine" that subserve the proper way of allocating resources. I will, therefore, read the report in this light.

Resource allocation

Obviously, resource allocation is a huge topic. In the large, the problem is one of seeing to it that the community's needs are as well met as resources permit. Generally, there are five strategies available to come to terms with problems with resources for meeting these needs. One can:

- (i) increase the resources available;
- (ii) meet needs with the available resources in more efficient ways, so that needs can be

better and more fully met per unit of resource expended;

- (iii) prioritise the methods of meeting needs to ensure that the resources we expend are expended on those methods of meeting needs that are most justified (why do more expensive surgery when cheaper pharmacological methods are no worse and their outcomes are good enough?);
- (iv) ration the methods of meeting needs which are resourced, among those who have the needs, so that we ensure that those whose needs are met are those whom we are most justified in resourcing;
- (v) decrease the need in the community.

In general, most approaches to our problems in Australia have employed the second strategy. Diagnostic Related Groups (DRGs) and Casemix funding represent this kind of move. But we have also made attempts in the other ways. In these terms, some aspects of benchmarking represent an approach in the way of (iii). Medical triage is the most obvious example of (iv). The recent Federal budget's increase of the Medicare levy for certain income tax brackets represents an approach in the way of (i) (abstracting from other hoped-for effects which offset this). The proposals for co-payments and the push for health promotion and illness prevention represent the way of (v). I do not think that any specific strategy or combination of strategies is written into the structure of the universe as the uniquely best. But this point applies as much to the would-be revolutionaries towards our health care system as to the conservatives who deplore the changes. What matters is the values that the system we eventually evolve incorporates and how these values interact with other social, ethical and political values we cherish as parts of our tradition and into the future.

I think that equality is a central value here, as are solidarity with the ill and compromised, as well as service to the patient. But so are professional standards of excellence, the freedom of professionals to practice sensitively to the social responsibilities they have as bearers of the grand tradition of the healing arts. Again, for myself, despite its sillinesses and frustrating features, our system of health care and health care funding is an achievement not to be sniffed at, and something of which we can, as a people, be very proud. I am not in favour of wholesale change. And I am convinced that movement in the direction of the United States towards a more and more free market style of medical system would be a profound mistake. I think that there is general consensus about this despite the "America boosters". However, like any important institution, we should not be complacent about it. Still, against this background, the place of psychiatric services in a publically-funded health care system is bound to be controversial. Not whether it should be funded, but how much, what sort of psychiatry, what mix of public and private delivery, etc.

The report's findings

The McKay Report paints a picture of our situation which emphasises or argues the following:

1. Resources are limited but the total cost of Medicare is uncapped. These costs must be reined in. The component of Medicare expenditure on psychiatric services needs to be better targeted.
2. There is a great deal of unmet need of psychiatric services. Rural needs are poorly supplied and many chronically, or seriously, mentally-ill people lack access to specialist care from which they could benefit. The public system is overstressed and there is too little working relationship between the public system and private specialists. Particular groups – especially children and adolescents – are inadequately provided for by specialists in their early diagnosis and prevention of onset.
3. There is a great deal of "met un-need". That is, a considerable number of currently funded psychiatric services represent high-user consumption in private practices which have small

throughput rates in comparison with other specialties.

4. The primary source of the undesirable skewing of services provided is the Medical Benefits Schedule's incentivisation of private, labour intensive, direct-contact service. The Schedule little distinguishes between early consultations in which the diagnosis and treatment may require patience and be labour intensive on the one hand, and follow up consultations. (This has changed with recent revisions to the Medical Benefits Schedule.) And the Schedule does not reimburse private practitioners for work involving liaison with community and in public care fora, thus entrenching a kind of divide between public and private sectors.
5. The marginal benefit to patients of direct, face to face therapy declines rapidly after a certain number of sessions, and much of it can be achieved by less expensive modalities, for example by work with psychologists, social workers and counsellors. Yet, the report argues, private practitioners take only about 2-4 new patients in a week, a strikingly lower rate of patient throughput than obtains in the case of other kinds of specialist providers.

The main features of the report's positive program are these²:

- A. Redesign the Medical Benefits Schedule to disincentivise the current predominance of direct, face-to-face, long-term care in private practitioners' practice.
- B. Redesign the Schedule to reimburse work done in liaison with public facilities, community care teams and general practitioners, especially to encourage a move towards having specialist psychiatrists act more regularly in consultant specialist roles with brief consultations and as members of holistic care teams. In effect, on this picture, specialist psychiatrists would work more on the model of consultant physicians, and much of the more long-term care of those patients currently occupying most of the psychiatrists' time would be turned

over to general practitioners, mental health nurses and other allied health professionals.

- C. Incorporate more psychiatric training into the preparation of general practitioners and develop the ranks of the other professions involved in care of the mentally ill. These professions will then use the specialist psychiatrist as a consulting resource as need arises for many of the patients currently under the care of specialists (at the cost this implies).
- D. Move the burden of the care of the chronically and seriously mentally-ill (who cannot gain access to public facilities because of their resource constraints) to private practice. The report urges the establishment of associations of private practices to enable them to achieve the economies of scale that would permit employment of the mental health nurses and allied health professionals needed give care to the chronically-ill. The report explores some models for such associations and the mix of funding sources under which they might operate. This will be particularly useful for bringing specialist services into under-supplied rural areas and for making such services available for the constituencies (such as children and adolescents) who are currently under-supplied.
- E. Improve the provision of services for paediatric and adolescent psychiatric patients to prevent the emergence of serious illness, or put management regimes in place at an early enough age to prevent the onset of worse problems.

Hesitation on the report's ideas

An unfair depiction of the report's assumptions would be the following: Currently, the psychiatric workforce is devoted mostly to the service of the "worried-well" for its own financial gain. Their patients never die and never get better. But while some improvements are achievable, the work is gratifying and lucrative! Meanwhile, Rome burns and the gates of public facilities are shut on chronically-ill people whose symptoms are quite florid, though perhaps not acute, and the institutions are overworking already-overworked professionals trying to deal with episodically or

repeatedly acutely-ill people. I suspect that many in the health care system are possessed by some such stereotype. They are proportionately unsympathetic with private psychiatry to the extent that it resists the kinds of proposal the McKay Report makes. They may, then, be expected to welcome something like the report's recommendations for change.

I would like to counsel a word of warning, however. A major source of consternation in the report (and elsewhere) is that a disproportionately high percentage of Medicare expenses on psychiatric patients is spent on patients whom their psychiatrist has been seeing for a long time. The 1.8% of patients receiving 49 or more services in 1993/94 accounted for some 19% of the total benefits paid for psychiatry services.³

Without further argument (and the report gives none), why should it be puzzling that patients who are neediest will cost most? If it is not puzzling, why should we take consternation at it? There is an answer in the report. Considering that answer brings us to a major problem facing our consideration of resource allocation in psychiatric medicine.

The report's answer to the question is that these neediest (if they are needy and not just malingerers or bad people) do not enjoy marginal benefits from this treatment by specialists sufficient to justify its expense when (a) the benefit in full could be got more cheaply from general practitioners and other non-specialists, and (b) the left-over money could be expended with greater benefit overall by targeting specialist services to mentally-ill persons who currently lack access to services from which they can gain greater marginal benefit. Now this sounds fine. However, there are reasons to be hesitant about becoming enthusiastic over it. For, there has been no research to evaluate the social costs and long-term economic costs of withdrawing specialists from the care of the kinds of patient they currently care for long-term in private practice. So, there are no grounds for straightforward comparative efficiency arguments here. Hence, it is hard not to suspect that there is a certain ideological or philosophical axe-grinding

behind the dissatisfaction with current private practice. (Both internally and externally psychiatric medicine is the paradigm of ideological and philosophical axe-grinding among the health professions!)

We can all agree that chronically mentally-ill people deserve better care than we are giving them. Many are de-institutionalised since the public hospitals take only the worst chronic patients and the acute ones. Most chronically-ill people cannot afford private insurance and, to the extent that they do not have access to specialist care, this needs to be repaired. However, *prima facie*, it is hard to see how disincentivising long-term care in private practice will help these people obtain access to the specialist care they need. That is, if they need long-term specialist care, they need long term specialist care. If we spend 19% of our psychiatric Medicare payments on these folks, then we spend it on some of those who need it. Behind the resistance in the report to this kind of thought, one suspects that the central thought may be the idea that these people do not need specialist care.

Of course, this may be true. It is well known, for instance, that the degree of specialisation in the United States leads to the bizarre effect of "service padding" that is, where specialists perform non-specialist functions for patients, charging the insurance companies specialist rates, because, if they did not, they would not have enough work to do. In effect, the report suggests that this is what specialist psychiatrists in private practice are doing under Medicare. How plausible is this? My guess is that this is true for some psychiatrist for some of their patients but untrue for others. Also, it is plausible that there are some patients who need long-term specialist care who are not getting it. But to suppose that all or many of the patients receiving long-term specialist care do not need it must require very strong argument indeed.

Moving to a conception of psychiatric specialist consultancy that more closely resembles the physician consultant's practice may have its technical and ethical problems too. The mind is not only a terrible thing to waste, it is excruciatingly difficult to understand. Much

more so when we are talking about an individual mind or, if multiple personality disorder exists, several minds in one body. An organic conception of mental medicine fits best with the "physician consultant model" of the practice of specialist psychiatry. Quick examination, quick consultation, maybe a few pills or getting the registrar to do some rational emotive therapy, and perhaps a further referral, are its order of the day. But one should pause to consider whether the mind can be treated like that. Arguably, the mind is not merely a natural object in nature, understood as bereft of values. If so, the ethical tone of the medical relationship in psychiatry is of particular importance in psychiatric medicine in ways that are not true of somatic medicine. One can easily see the point of subjecting oneself to a surgeon who is the best in her field, though she is bereft of much to impress one ethically, besides cold curtesy. But in the care of one's mental health, surely the trustworthiness of the practitioner, her moral goodness, is critical. Patience, courage, honesty, trustworthiness and self-possession, and a working sense of what life is about, are critical to an effective therapeutic relationship in psychiatry, and for many conditions we think of as mental disease. This will take time and, so, cost money, to bring to fruit.

Perhaps, then, we should give some more thought to the one strategy that McKay explicitly excludes. That is, perhaps we should try to increase the number of psychiatrists to ensure that need is met. In particular, we need more paediatric and adolescent specialists, just as we need specialists in geriatric psychiatry. In this, the report surely is right: prevention is better than cure.

References

1. McKay & Associates, (1996), *Proposals for Change: Final Report: Optimum Supply and Effective Use of Psychiatrists*.
2. With apologies to McKay & Associates, my summary is necessarily brief and unnuanced. I wish to convey a view of the thumbnail sketch of the vision of the provision of psychiatric health care that they favour. I think this summary is reasonably accurate.
3. McKay, p.9.

AHEC issues new guidelines on reproductive technologies

Bernadette Tobin

The Australian Health Ethics Committee (AHEC)¹ has recently presented its new guidelines on assisted reproductive technology to the National Health and Medical Research Council (NHMRC) and to both Houses of the Commonwealth Parliament. The new guidelines are the product of the work of a Committee whose members held diverse views about some key ethical issues at stake in both clinical practice and in research in reproductive medicine. It is not surprising, therefore, that the final form of the Guidelines represents something of a compromise between a variety of views of what constitutes ethically-sound clinical practice and research in this area of medicine.

A short **Background** section outlines the history of the preparation of the new guidelines. Mention is made of the fact that the old guidelines, known as Supplementary Note 4, were the only guidelines not saved when the NHMRC Act was passed in 1992. In the **Glossary** a key distinction is made between therapeutic experimentation on an embryo (that is to say, an intervention which directed towards the well-being of the individual embryo involved) and non-therapeutic experimentation (that is to say, an intervention which is not intended to benefit the individual embryo but rather to improve scientific knowledge or technical application). A further distinction is then made between non-therapeutic experimentation which involves the destruction of the embryo and non-therapeutic experimentation which does not involve the destruction of the embryo. In the **Introduction**, four ethical and social values which are engaged by contemporary reproductive technologies are set out. They are:

- a serious regard for the long-term welfare of any fetuses brought into existence, and any children who may be born, as a result of the application of these technologies;

- a corresponding regard for the long-term welfare of the individuals, both women and men, who have recourse to these technologies;
- the recognition that any experimentation and research involved in these technologies should be limited in ways which reflect the human nature of the embryo, acknowledging that there is a diversity of views on what constitutes the moral status of a human embryo, particularly in its early stages of development, and
- a concern that the whole of the society be well-served by the development and application of the technologies.

The eleven main sections of the guidelines then follow. They cover the following topics: (i) the relationship of the guidelines to legislation; (ii) accreditation and approval processes; (iii) informed decision-making; (iv) counselling; (v) research, dissemination of results and the role of Institutional Ethics Committees; (vi) research on embryos; (vii) storage of gametes and embryos; (viii) record keeping; (ix) complaints and appeals; (x) conscientious objection and (xi) prohibited/unacceptable practices.

How satisfactory are the new guidelines?

The satisfactoriness of the guidelines will, no doubt, be the subject of some debate. Certainly they are a genuine improvement on the old Supplementary Note 4. One notable weakness in the new guidelines is that, although 6.2 says that embryo experimentation should normally be limited to therapeutic procedures, 6.4 allows non-therapeutic destructive experimentation on embryos "in exceptional circumstances". Another weakness is that the guidelines do not require that the couples who have recourse to these technologies be offered counselling which is independent of the clinics who provide the reproductive services.

1. Bernadette Tobin has been a member of AHEC in the triennium 1994-1996.

Amongst the strengths of the new guidelines are:

- 1 the recognition of the fact that reproductive technologies do not treat infertility but merely circumvent it;
- 2 the distinctions between therapeutic and non-therapeutic experimentation and between destructive and non-destructive forms of non-therapeutic experimentation;
- 3 the requirement that, if an embryo is to be created outside the body and used for treatment or research, the donors of the gametes (the sperm and eggs) must consent to the specific purpose for which it is to be used. If it is to be used for experimentation or research, they must consent to the specific form of experimentation (therapeutic or non-therapeutic, destructive or non-destructive experimentation) which is proposed;
- 4 the recognition of the ethical entitlement of any child born as a result of the use of these technologies to knowledge of his or her biological parents, and thus the necessity for identifying information to be recorded, and the necessity for potential donors to be informed of this fact;
- 5 the inclusion of a provision which encourages clinicians and researchers not to produce spare embryos;
- 6 the requirement that Reproductive Medicine Units keep records in a standardised way and in particular that their records employ the definition of treatment cycle which is set out in the Medicare Schedule. (In the past, there was nothing in the NHMRC guidelines to prevent a clinic using one definition of a treatment cycle when it was reporting its success rates and another when claims were made for reimbursement from Medicare.);
- 7 the requirement that Reproductive Technology Units record all the outcomes of the application of these technologies, including both singleton and multiple pregnancies, both pre-term births and multiple births. In addition these records should facilitate both short- and long-term follow-up of the couples who use these technologies and the children who are born as a result of the application of the technologies;
- 9 the additions to the list of prohibited practices: the production of embryonic stem cell

lines and the use of fetal gametes for fertilisation; and finally

- 10 the requirement that couples should be told in advance about all the component costs which will be involved in each treatment cycle.

Who is required to abide by the guidelines?

Three states, Victoria, South Australia and Western Australia, have enacted legislation (which prevails over these guidelines) to regulate the use of reproductive technologies. Though the guidelines are intended to apply to all clinical as well as research activities, the only people who must abide by their provisions are those researchers who are funded by the NHMRC. They must obtain the approval of an Institutional Ethics Committee (IEC) for any proposed research, and these guidelines set out the issues which the IEC must take into account in assessing the ethics of research proposals in this area. Other funding bodies are admittedly beginning to require that similar research proposals be assessed by an IEC, and that the IEC base its assessment on the relevant NRMRC guidelines. However practitioners of reproductive medicine, together with researchers whose experiments are funded by bodies other than the NRMRC, are generally not required to abide by these guidelines in their ordinary clinical practice.

Notwithstanding the fact that some clinicians claim that they voluntarily follow any guidelines issued by the National Health and Medical Research Council, AHEC itself, in an associated move, has written to the Commonwealth Minister for Health strongly and unanimously recommending the introduction of legislation in the area of assisted reproductive technology to complement existing legislation in the other States and Territories. AHEC has thus recognised the need for the establishment of an independent body (with appropriate powers and finances) which can maintain a national data collection and monitor the conduct of all research in this area. In recognising the need for independent oversight of the use of these technologies AHEC has made it quite clear that such independent oversight requires the enacting of uniform legislation in all States and Territories.

NOTEBOOK

Studies in Health Care Ethics

Ethics in Health Care or Bioethics is increasingly important in society, in health care institutions and in professional practice. Australian Catholic University offers two programmes in Health Care Ethics. Both courses are scheduled by negotiation with students. The aim is for maximal flexibility to fit in with students' busy lives. Each course will be of value to professionals and other citizens interested in the moral and social significance of ethical issues in health care. Each course can be of special value to particular people, such as members of institutional ethics committees:

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Master of Arts: professional qualification with experience; or suitable undergraduate degree in Philosophy or Theology.

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- advanced studies by coursework, with the opportunity for research
- one year full-time study or two years part-time study

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Erratum

The follow footnotes were omitted from Keith Joseph's article, "The Re-emergence of Eugenics", *Bioethics Outlook*, September 1996:

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1. The introductory quote is from Robert L. Sinsheimer, "The Prospect of Designed Genetic Change", in Ruth F. Chadwick (ed), *Ethics, Reproduction and Genetic Control*, revised edition, Routledge, 1992, pp. 136-146, at pp. 145-146.

The section entitled *Eugenics - a brief history*

2. Second paragraph, 'the trait for "feeble-mindedness" was thought to be a single gene defect ... as late as 1930': H.S. Jennings, *The Biological Basis of Human Nature*, W.W. Norton & Company Inc, New York, 1930, pp. 240-241.

3. Third paragraph, 'a bill to allow for the voluntary sterilisation of the feeble-minded failed to pass through Parliament in 1912': G.R. Searle,

Eugenics and Politics in Britain, 1900-1914, Noordhoff International Publishing, Leyden, The Netherlands, pp. 109-111.

4. Third paragraph, 'in 1927 the constitutional validity of statutes allowing for the compulsory sterilisation of the feeble-minded was upheld': D.J. Kelves, *In the Name of Eugenics*, Alfred A. Knopf, New York, 1985, p. 111.

5. Third paragraph, 'This legislation became the model for the legislation which Germany adopted early in the Nazi period': R. Proctor, *Racial Hygiene: Medicine Under the Nazis*, Harvard University Press, Cambridge Massachusetts, 1988, p. 103.

6. Third paragraph, '360,000 "feeble-minded" were sterilised between 1933 and 1945': P. Weindling, *Health Race and German Politics Between National Unification and Nazism: 1870-1945*, Cambridge University Press, 1989, p. 533.

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