

AUSTRALIAN INSTITUTE OF HEALTH, LAW AND ETHICS

Paper presented to the

6th Annual Conference

July 2001

“SCIENCE TECHNOLOGY AND CULTURE”

VOLUNTEER BRAIN DONATION AFTER DEATH FOR SCHIZOPHRENIA

RESEARCH:

CONSUMER AND RESEARCHER VIEWPOINTS.

COLLABORATIVE PAPER

by

Paper #1 Margaret Boyes (researcher)

and

Paper #2 Marilyn Mitchell (Consumer Perspective)

NISAD

**(NEUROSCIENCE INSTITUTE OF SCHIZOPHRENIA AND ALLIED
DISORDERS)**

NISAD is supported by infrastructure funding from NSW Health

VOLUNTEER BRAIN DONATION AFTER DEATH FOR SCHIZOPHRENIA

RESEARCH:

CONSUMER AND RESEARCHER VIEWPOINTS.

ABSTRACT

The nineties was the Decade of the Brain and this decade is predicted to be "The Decade of the Ethics of Brain Research". Tissue collections are developing around the world for neuroscience research into some of the most distressing of all illnesses, including schizophrenia. Not surprisingly, they raise questions about meaning, embodiment and sovereignty over one's body, ownership of biological materials, informed consent in people with mental disorders which could affect their decision making capacity, confidentiality and others. In Sydney, NISAD is developing a voluntary program for people who want to donate their brain after death for research into schizophrenia.

A sibling of psychiatry's progress in the last century is its occasional sorry history as an instrument of social control. Consumer involvement is one mechanism for monitoring whose agenda is being driven by the research. In what ways do researchers' and consumers' viewpoints overlap or diverge? Consumers tell researchers that they must be certain they are working to get rid of the disease, not the people who have it. Many consumers are concerned about the eugenic implications of the removal of choice for persons who have a defective gene or condition. How does this sit with the principle that tissue should be used only for the purpose for which it was collected and consented? Consumers tell researchers that becoming a donor gives them a sense of contributing. However the requirement for consumers (but not people without mental illness) to be assessed for their capacity to give informed consent can increase the sense of intrusion or not being trusted.

The ethics which guide the conduct of the research are a product of a particular (Western) cultural tradition. What meanings do people place on the gift? On the theme of hope? On bodily integrity and the body after death?

...oooOOOooo...

Paper #1
Margaret Boyes
“Gift Of Hope” Tissue Donor Program Co-ordinator

Introduction

NISAD’s “Gift of Hope” Tissue Donor Program was established in 1998 for people who wish to donate their brain when they die for schizophrenia research.

Schizophrenia is a uniquely human disease. Whilst most neuroscience research is performed on animals, the study of human brain tissue can play a vital role in schizophrenia research. Therefore, NISAD has given a high priority to collecting human brain tissue for distribution to neuroscientists studying the neurobiology of schizophrenia. NISAD’s “GIFT OF HOPE” Tissue Donor Program is creating a database of research volunteers. Donors will undergo a research program during life, including comprehensive psychiatric assessment and magnetic resonance imaging, longitudinal medical and psychiatric treatment histories with annual follow-up. Arrangements are made so that when a prospective donor dies, rapid notification procedures are in place to ensure timely retrieval of the donor's brain tissue. Over a number of years, the “GIFT OF HOPE” Tissue Donor Program will enable NISAD to provide brain tissue to researchers with an unprecedented depth of accompanying clinical and neuroradiological data.

A number of ethical issues were considered in the course of establishing the TDP. These included

1. Informed consent for people who have mental disorders which may affect their decision making capacity
2. Issues relating to archived tissue specimens, such as future developments in genetic information which may be of value to relatives.
3. eugenics

4. Ownership of tissue, including sovereignty over one's body and the extent to which the donor can determine the uses of their donated tissue.
5. Patenting
6. Who's driving the research agenda
7. Cultural issues around death and the body, including the sensitive nature of the concept of organ and tissue donation which may not be easily articulated by people with mental illness.

Gindro and Mordini have said that, following the Decade of the Brain in the 1990s, that this decade may be "the Decade of the Ethics of Brain Research"¹. Brain research is challenging many current accounts on personal identity,² and at the same time advances in schizophrenia research are indicating that many of the answers to this distressing illness can be found in the brain itself (without discounting the importance of environmental confounders). Of the ethical issues listed above, we want to talk about who's driving the research agenda, and how this applies to the vexed questions of ownership of tissue and eugenics.

The nature of the Tissue Donor Program is donor focused. Some donors have a vested interest in schizophrenia research and some donors are members of the general public who've heard about it on the radio or by word of mouth and have thought that it would be a good thing to do. This has made it a project open to considering the extent to which researchers and consumers can form a partnership or whether a hierarchy exists similar to the one Paul McNeill³ describes in his analysis of research ethics committees, in which he concludes that scientists' opinions are afforded greater value than the opinions of lay members, clergy and nurses.

One aspect of the Tissue Donor Program which illustrates this is the extent to which donors can determine the use of their donated tissue. How does this sit with the principle that tissue should only be used for the purpose for which it was collected and consented?

¹ Gindro, Sandro and Mordini, Emilio (1998) "Ethical, Legal and Social Issues in Brain Research" *Current Opinion in Psychiatry* 11:575-580 @p578.

² Gindro and Mordini op cit p575.

³ McNeill, Paul M (1993) *The Ethics and Politics of Human Experimentation* Cambridge, Melbourne.

While it is fairly easy for research to agree to the proviso that, for example, "your brain tissue will only be used for research into Motor Neurone Disease, Alzheimers Disease, or schizophrenia", the subject of eugenics is not so easy. Consumers and carers tell researchers and health workers that they must be certain that they are working to get rid of the disease, not the people who have it.⁴

Consumers of mental health services and carers are, like many other groups of people with disabilities and chronic and genetic illnesses in this age of lobbyists and pressure groups, well-informed in the research and conscious of movements in other ethical corridors. They are concerned about the developments in IVF, genetic research and ante-natal diagnosis which provide options such as embryo selection or termination of pregnancy for a fetus with an identified gene. Some people characterise this not as an option, but rather as a social pressure which is grounded in stigma about disability. This is the new eugenics and it, too has the potential to diminish human diversity by encouraging a narrow view of what is acceptable.

But there seems to be a gap in the discussion. However much a research project such as a tissue bank might support a donor's autonomous right to determine the use of their tissue, it may be that these ethical corridors don't intersect. The desire to have a child who is free from the suffering or the social stigma of schizophrenia is, bioethically speaking, a distant relative of the research which searches for the causes and cures to the illness. The brain tissue is a tool in the search for the cure. Thus the brain donor's autonomous wishes (which remain after their death) may become blurred.

Eugenics originally referred to the science of improving the human race, and was championed in Australia by Sir McFarlane Burnett and some public health discussion around family planning. More recently it has included an idea which claims to promote the wellbeing of individuals without reference to the population. Described as "negative eugenics", this idea refers to the prevention of births of people with genetic disease and

⁴ Peterson, Dymphna Rees (2000) "The Ethics of Research into Schizophrenia Prevention: A Carer's Perspective" *Australian and New Zealand Journal of Psychiatry* ppS101-103 @ p103.

eschews racist connotations of "positive eugenics"⁵. People with disability, however, argue that this amounts to claiming that life with disability is worse than no life at all, and that such judgements are made by able bodied people from a position of both ignorance and power⁶. It has also been called "home-made eugenics", an insightful term given to "individual families deciding what kind of kids they want to have"⁷. And it is a more easily digestible way of presenting eugenics.

It is perhaps worth mentioning here Sidney Bloch's work in psychiatry on socially determined "normality", which began when he treated a man in the 1960s for the "psychiatric disorder" of homosexuality. He then reflected on what he had done and what he called psychiatry's mirroring of "the prevailing ethos by construing psychological functioning in ways shaped by the dominant Zeitgeist"⁸. He then traced the human rights abuses in the Soviet Union and Nazi Germany that were perpetrated in the name of psychiatry and eugenics. It's not such a great leap from Bloch's extensive work in the area of the socially constructed norm to the home-made eugenics of today and tomorrow.

This eugenics is a manifestation of structural discrimination, which exists in a framework for what Margaret Thornton describes as the "insidious need of the state for a manageable, homogeneous citizenry"⁹. Structural discrimination is one way in which inequality is legitimized. And this returns us to hierarchies. The two hierarchies referred to above (ie the researcher/consumer and scientist/lay person) are sustained by structural discrimination and take account of the socio-economic and educational context in which people find themselves. Consumers especially experience the stigma of being outside the socially constructed norm.

The ownership of body tissue in this context becomes an instrument for the maintenance of social order. Legal decisions about ownership of tissue sometimes don't reflect public

⁵ Bradby, Hannah (1996) *Genetics and Racism*. In: Marteau, Theresa and Richards, Martin (eds) *The Troubled Helix* Cambridge University Press, Cambridge UK p300.

⁶ Ralph, Sue "Existence Without Life: Disability And Genetics" *Australian Disability Review* 1-95.

⁷ Kevles, D *Eugenics and the Human Genome Project: Is the Past Prologue?* in Murphy, Timothy F and Lappe, Marc A (eds) (1994) *Justice and the Human Genome Project* University of California Press, Berkeley pp14-29.

⁸ Bloch, Sidney (1997) "Psychiatry: An Impossible Profession?" *Australian and New Zealand Journal of Psychiatry* 31: 172-183 @173

⁹ Thornton, Margaret (1990) *The Liberal Promise* Oxford Uni Press, Melbourne, p44.

opinion. The case of John Moore is arguably an example. John Moore's doctor patented his cell line without Moore's knowledge from a tissue specimen taken after his spleen had been removed. Moore filed suit against the doctor and UCLA in 1983. The celebrated case ("spleenless in Seattle" according to the *Canadian Medical Association Journal*¹⁰) illustrates the somewhat fluid divide between popular feeling and legal discourse. The former is often not in the realm of the rational, and finds itself dominated by legal and medical expertise.

Donors sometimes say to me with a sense of certainty that they want to be able to decide what happens to their body after death. Where conflicting interests arise, such as changed circumstances or unanticipated distress in those left behind, there is the potential for that much overused term, the ethical dilemma. Equally, the tension between individual and public good can give rise to conflict. We have seen this in recent revelations in Australia and elsewhere about stored body parts and tissue specimens, many examples of which are not breaches of the law but have distressed relatives nevertheless. The recent enquiry into the events in Sydney found that some actions of staff of the Institute of Forensic Medicine were illegal, but that they were unaware that this was the case, had believed that their actions were legal and they were acting correctly¹¹. The enquiry found that changes were called for, but it did not find any unethical conduct. In a discussion of the events, the *Sydney Morning Herald*¹² observed that far more gruesome events (albeit necessary and orthodox work by pathologists) are described in Patricia Cornwell's bestselling novel "The Body Farm" and make good bedside reading, yet the events at the IOFM evoked a visceral response from the public. Whether the events at the IOFM were right or wrong is not my point, rather that matters outside the realm of the rational are often agents of change.

So, too are the administrative practices of the state. The Australian Law Reform Commission and the Australian Health Ethics Committee are currently also conducting a joint enquiry into the uses of genetic samples and genetic information, in all areas including their uses in medical research. This enquiry also aims to address questions of

¹⁰ Cairney, Richard (1998) "Venting His Spleen" *Canadian Medical Association Journal* V159 (12) Dec 15 p1451-2.

¹¹ Walker, Bret (2001) *Inquiry Into Matters Arising From the Post-Mortem and Anatomical Examination Practices of the Institute of Forensic Medicine: Report* Ausinfo; NSW Dept of Health, August Pp87-91.

¹² Whelan, Judith and Brown, Malcolm (2001) "Body of Evidence" *Sydney Morning Herald* March 24, p27.

control, ownership of and intellectual property rights in relation to human genetic samples and information. Public interest and pressure groups for (especially) people with disabilities have already expressed an interest in the dangers of “genetic essentialism”.¹³

The distinction between ownership and property is one familiar to legal discourse. Lantos¹⁴ makes a helpful distinction which is relevant to donors and consumers at the point where decisions affect them. He notes that "Brain banks act as stewards in the sense that they have responsibilities and obligations associated with ownership but without the rights associated with property". By retaining a notion of stewardship, research may be better able to sustain its responsibility to donors.

To Conclude

The vexed question of ownership of tissue and the information it contains oblige us to remind donors that we cannot be sure what the future holds, especially with regard to DNA archiving. A generation ago individuals and society may have regarded surgically removed body tissue as discarded material, but more recently it has become common to hear that people feel that "their body and its materials should not be owned by another"¹⁵. Human experience has a social and cultural context.

On the broader question of how tissue is used, yes, we can say that if you become a donor with the Tissue Donor Program that your brain tissue will be used for schizophrenia research. I don't know whether we can say that the research (and your freely given gift) won't contribute to the genetic advances which may in turn be linked to the home-made eugenics that's already emerging faster than we can understand it. And nor do I think that we as researchers are off the hook. At the very minimum we have an obligation to simultaneously work towards de-stigmatising mental illness.

...oooOOOooo...

¹³ Australian Law Reform Commission and Australian Health Ethics Committee (2000) Protection of Human Genetic Information: Issues Paper Info Access, Canberra p92.

¹⁴ FF Cruz Sanchez (1997) "Emerging Ethical Issues in Brain Banking" Retrieved www April 28, 2001 www.iprs.it.brainelsa p16.

¹⁵ Stott Despoja, Senator Natasha (1998) Genetic Privacy and Non-discrimination Bill, Second reading speech, Hansard 11 March, Australian Senate, p592.

Paper #2
Marilyn Mitchell
Consumer Educator
Patron, “Gift of Hope” Tissue Donor Program

Introduction:

Firstly, a quick thumb-nail sketch of where I am coming from.

I have had schizophrenia for 21 years.

I am also a qualified teacher and a non-scientist.

I have a major in Linguistics from Macquarie University and a major in Women’s Studies (which later became Gender Studies) with Honours from University of Sydney.

For most of my 21 years of illness I have worked casually or part-time, mostly as an educator at all levels, including university.

For 10 years I have also worked as a consumer representative in mental health, on hospital committees, etc. I’ve made about a dozen media appearances such as on 60 minutes, on ABC Radio National, in the Women’s Weekly, etc in an attempt to improve community attitudes to and understanding of mental illness, especially schizophrenia.

I’ve only mentioned all this preamble because many people still think you can’t or shouldn’t hold responsible positions if you have a severe psychiatric disability. And, when you’ve been “put down” so often, you can be left with a burning desire to succeed.

I'd just like to start off with a few definitions:

SCIENCE – Is what we know

TECHNOLOGY – Is what we do with it

ETHICS – Is the moral guide-wire; the guiding principles that determine which technology is developed and used.

CULTURE – Is the HUMAN context (and hopefully HUMANE) in which all of this takes place.

And now I am going to try to highlight some possible ethical dilemmas or considerations from a consumer perspective.

But first, some background. I recently signed on for the NISAD “Gift of Hope” brain tissue donor programme. My “hope” was that my “gift” of brain tissue, when I am deceased, will benefit future generations of persons with schizophrenia. In particular, because of an apparent family history of the illness, my “hope” was that my own children and their progeny will be spared the extreme suffering and upheaval in the lives of the sufferer and those associated with them; should any of them be unfortunate enough to be the bearers of the genetic predisposition.

In doing this, I was required to obtain the signatures of my next of kin. I nominated my 3 children, a triumvirate, as I did not wish to unduly burden any one individual loved-one. Imagine my surprise, however, when my eldest daughter “jacked up” and said she would not sign. When I asked her why, she replied that she “did not want them cutting up my brain”. It had never occurred to me that she would feel this way and so it became

necessary for me to sit down and really think through the issue very carefully indeed, after which, I approached her again with my explanation and plea.

In trying to win her over the second time around, I outlined the reasons for my decision and wishes. I explained that (perhaps to some, selfishly) I was interested in being of assistance in the search for better treatments for sufferers of schizophrenia, this devastating and debilitating conditions. Further, given that there would appear to be a genetic predisposition for this, then obviously, other (future) members of our family could be at risk, and so it would be desirable if “screening” procedures, say, could be devised. Therefore, if the study of my and others’ brain tissue could yield useful information for both of these avenues of research, then my “donation” could be a “gift” indeed of multiple benefit.

Further still, information derived from the study of my and others’ brain tissue could also obviously help alleviate or reduce the suffering and burden on a whole future population. Having explained and discussed all this to my daughter, she eventually agreed to add her signature in order to “approve” my wishes.

This is all well and good, you might say but unfortunately the matter doesn’t end there. The next hurdle relates to exactly which area of research my brain tissue will eventually go and I suppose the harsh reality is that currently I (and no one else) will not be able to control or dictate the future, uses or misuses made of research findings, it may have to be culturally determined.

By this I mean I would not be pleased about my brain tissue being used for research aimed at:

- 1) Aborting so-called “defective” fetuses; whereby schizophrenics are “not wanted in the world”. There would need to be culturally – acceptable limits with regard to such practices, I believe.

- 2) Changing, deleting or destroying so-called “defective” schizophrenic genetic material in individuals, in particular, in unborn embryos, obviously without their permission.

Now in view of the notorious side effects that most of us experience on psychotropic medications (even though medical persons are often in denial about this and people in the community are often ignorant of) I am a fervent believer in the development of better treatments and early intervention for schizophrenia. Indeed, I would not be here now speaking with you (but would need to be permanently confined to a mental institution in a constant state of psychosis) were it not for the so-called “miracle drugs”. But even here, there is still great need for improvement.

However, on the question of the possible development of genetic testing or screening for the illness, there are ethical concerns. Firstly, there is the fear of the unknown about (neuro) science and technology and a need for the element of choice to remain in the hands of the consumer. I am referring here to the possible “zapping” of so-called “defective” or “schizophrenic” gene material in the embryo – or worse still, the possible termination of the life of a foetus found to be carrying “defective” genotype.

To illustrate my concern, imagine that a so-called “gay” gene were to be discovered. We all know that homosexuality was once (not that long ago!) considered to be a “mental disorder”. Now if homophobic or well-meaning parents were to have that gene “removed” or altered so that their child did not turn out “gay” then I think that most of us would consider that “criminal” (even more so, to some, should that child be denied the right to be born). Rather, I think that most of us would regard the gay person merely as “different” but not “defective”.

You see we just don’t know enough, even about schizophrenia itself; about how to tap into the beneficial aspects whilst doing away with the disadvantages.

So to me there is a comparable situation with schizophrenia. Should “schizo-phobic” parents or communities be allowed to genetically alter embryos thereby removing what I regard as a significant component of our character or identity, or again, denying us the right to BE.

I recently saw an episode of “INSIGHT” on SBS – TV. There a deaf woman had been given a sort of bionic ear to enable her to hear. However, she soon gave it back because she said that she could not cope with hearing, because to her, being deaf was “NORMAL” I feel the same way about my schizophrenia. It is as much a BENEFIT or BLESSING as it is a BURDEN. To explain what I mean by this.

Most of us would be aware that many artistic people use drug – induced creative psychotic states to do their work, to enhance their performance. I know that some of my best ideas, poems, etc have been produced when I’ve been at my most “manic” so I can have naturally what these artists use to produce a more “creative” state! This “hypersensitivity” can help the schizophrenic “see” or understand things that others can’t. It is in fact, a kind of added dimension that I and many other consumers would not want to lose or be without. It would probably sort of feel like losing a limb.

Further there is the consideration that we would not be quite the “same person” that we are; nor would we know what we know without the schizophrenia. Personally I think I would feel like a mental “eunuch” minus the condition and merely (that awful word!) “NORMAL”.

Some of my psychotic experiences, for instance, and confinement to psychiatric hospitals or experience as a recipient of what I call “schizo – phobia” have, in fact, enabled personal growth and helped me to empathize with other stigmatised and marginalized groups such as black people, indigenous groups, gays and lesbians. There is a verse in Hebrews:

“And he learnt obedience in the school of suffering”

which I strongly relate to. That is, adversity can be empowering. Now while I would not wish the suffering of schizophrenia on anyone (especially my children) nevertheless I feel that the experience has made me a more thoughtful, compassionate and considerate person. At the very least, much stronger (although part of the deal is the very real having to survive the suicidal lows, manic highs and dangerous delusions, which a significant number unfortunately don't).

So you see, I would not be desirous of my brain tissue going down the path of the destruction or removal of so-called "schizophrenic" gene material or of screening that aims to eliminate persons such as myself through "routine" abortion. Indeed, I think that we may become "disabled" (in another sense) through removal or "lack" of the so-called "defective" component. Consider the scandal of lobotomies, which were initially considered the "perfect cure" for psychotic illnesses.

But how to police all this? Well, perhaps, as with the use of scientific information that led to the making of atomic bombs, it will have to be culturally – determined because once such knowledge is out in the public arena, scientists and those who develop the technologies will do what they will with it. For me, tampering with genes should not be imposed on an embryo, however, as an adult that individual would have every right to choose intervention at a genetic level. I was watching a programme on ABC – TV last Sunday (COMPASS) after I'd written this paper and an important point was made that we as a society should not become too "perfectionist" about its members or otherwise we could in the long run become less tolerant of less able people whether "disabled" or just "different", we are still equally human beings with dreams. We can participate, contribute and be deserving of rights and respect as much as any other member of the community. So there is a real ethical dilemma (as far as aborting "carrier" fetuses or altering them is concerned) if a culture conspires to deny us the right to BE or even to be BORN.

On a more practical level, if genetic testing becomes a technological reality then ethically this ought not lead to discrimination in education, employment, insurance or in any other way for the unfortunate person with the so-called “defect” through no fault of their own.

So you see that a seemingly simple matter turns out to be not so “simple” after all. Ethically, I think that there needs to be a lot of fine-tuning and sensitivity with regard to brain donation after death for schizophrenia research, and most importantly, that at the end of the day the element of CHOICE should preferably remain with the affected individual or consumer

Getting Paid

Now I would like to talk a little about “getting paid and getting laid”; further ethical considerations from a consumer perspective.

Firstly, I will talk about the contentious subject of consumers being paid for their donation, although I realize that this is a very radical opinion.

My view is that we, the persons with schizophrenia, should receive a one-off payment of say \$1,000, for signing over our brain tissue. The reason that I strongly believe this is that it would go a small way towards alleviating the stress, distress and/or trauma associated with going through the process; as well as also compensating us in a small way for our lifetime suffering the condition. It is no simple matter to have to discuss this subject with or perhaps reassure or convince our nearest and dearest that it is acceptable to become a donor. Then there are the logistics associated with signing on, such as being “assessed”, going for the MRI scan and having our medical history/records poured over by researchers.

My view is that the consumers only should receive the remuneration because non-sufferers signing on are presumably not as susceptible to stress and distress as are

consumers. In addition, consumers are generally not on high income compared with non-sufferers. Indeed, 70% of the homeless population are found to have a mental illness, usually schizophrenia. Yet it never ceases to amaze me that the community at large thinks almost nothing about this but rather, just seem to think that it is “ok” or “normal”, consumers being in this situation through no fault of their own. Finally nowadays we have to pay for virtually everything and anything. We can’t even sneeze without it costing us money!

My question, then is why shouldn’t we be paid for something that will almost certainly benefit the community and in a substantially financial way in the long-term? In particular, pharmaceutical corporations, researchers and the like could end up being “rich and famous” through accessing our brain tissue, without having paid for it. Why should it be considered “acceptable” or the “norm” that the work and body parts of schizophrenia patients are given no value whatsoever? Rather, the converse is true; our contribution could prove to be invaluable, so that the ethical thing to do would be to pay the consumer for their contribution.

Now although I understand that such a concern may be considered “outrageous” to some and simply “NOT the way things are done”, nevertheless I believe that perhaps the time may have arrived when remuneration for effort or contribution by consumers SHOULD be considered. These are, after all, in reality of considerable value to individuals, families, organizations and the community as a whole. So perhaps we need to have another look at this issue in the future.

Getting Laid

I feel that ethically it should also be the responsibility of the organisation receiving my brain tissue to ensure that if my children wish to view the body before burial then this should be offered or suggested by them for this to take place BEFORE the brain tissue is removed (it could be messy) and I would not want my loved ones to have a

lifetime of trauma at seeing my face. “not as it was”. This is a small ask and surely easily done and could be of great importance to the bereaved relatives.

My understanding is, however, that disturbance to the face would NOT be at all likely to occur. Lay persons such as myself , though, may not be confident of this and may therefore require the written reassurance of the organization plus the offer to view beforehand if this is practical. It could be standard procedure not a hit or miss component to extend this offer to relatives whilst NOT intruding on but mindful of the important time factor involved in obtaining brain tissue

Assessment

I find it offensive and insulting that consumers have to be psychiatrically assessed before our brain donation is accepted. I can understand that it might be intended to “protect” us, however I feel it would be more ethical to make such assessment optional. After all, non-consumers are not required to have any “checks” made on them, and assessment by an unknown practitioner can be a stressful and traumatizing experience. Even if I were to be “psychotic” when I signed on I could easily sign off again when I became post-psychotic, if I wished. Otherwise, this policy perpetuates a life-sentence of suspicion and mistrust and impinges on the consumer’s autonomy, the apparent need to determine the “right-mindedness or otherwise” of the consumer.

Subsequent to the time of writing the above regarding this concern, steps were taken to eliminate the (to some) demeaning procedure of being “assessed” or determined to be “of sound mind” in order to make such a momentous decision as donating one’s brain following death. This has been a VERY gratifying and exciting achievement as far as respect for the rights of consumers is concerned.

...oooOOOooo...