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May 5th 1999

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Dear Professor Richardson,

**Review Of The Mental Health Act Draft Proposals 1983:**

It is noted straight off that the Scoping Study Committee (hereafter referred to as 'the Committee' or 'Team') is not asking for comments on its skimpy and ill-considered recommendations re. ECT. For what it is worth, the comments of ECT Anonymous are nevertheless appended and we wish to make absolutely clear our rejection of the ECT and related recommendations in their totality, our disgust at this travesty of "a consultation exercise" and the disregard for concerns generated not out of thin air but because of psychiatric research findings. Our intention is to publicise the objections to follow. It is also our intent to withdraw from this process failing a specific reply to our concerns, (rather than the rather ignorant sending of a 'round robin' style generalised letter without the courtesy of even being addressed correctly), and considerable revision of the proposals.

We would demand that you quantify the number of "users" who have supposedly claimed that ECT can be "lifesaving". We suspect that this is nothing but a transparent attempt to disguise what is essentially, with respect to compulsion, a clinician v. user issue. We can provide hundreds of user testimonials to the damaging effects of this process. We very much doubt you can do likewise with respect to the opposite view. Crucially, you would have to do this immediately, with evidence of post-dated correspondence, to substantiate that your present claim is not misleading.

Please don't attempt to evade the issue by citing "confidentiality" as an excuse for non-disclosure. Many of our members are quite happy to go

ECT Anon working in partnership with Alex Doherty's 'Need for Change Campaign (Scotland).

Affiliated to UKAN (United Kingdom Advocates Network).

Member of the UK Federation of Smaller Mental Health Agencies.

public about this, and are increasingly doing so. If your pro-forced ECT users, (assuming they exist in substantial numbers-which we doubt), feel so strongly about the issue, perhaps they too would not object to the facts being examined in the open? Equally, we would demand that you provide qualitative and quantitative evidence from the clinicians consulted that ECT is lifesaving.

Failure to do this will result in, at best, claims being made in the public domain that you have been amateurish in conducting this exercise in that you have not fully examined the facts, and, at worst, questions will be raised about the integrity of this whole exercise. In any event, the fact that this review may be considered as inexpertly handled is evidenced by the complete contradictions that are apparent in paragraph 107, for example, and by recording that the overview must be that of an evidence-based one whilst, at the same time, citing unqualified observation like that of ECT being "***possibly even life saving.***"

If you counter these requests with the observation that you said ECT is "possibly even life saving", rather than it is lifesaving, then by your own admission you negate any justifiable argument for it's continued use without consent. The RCP's own Benbow report records that ECT can kill. The term "possibly" is starkly missing in this context. We would advise you to run this past the legal profession representatives on your team, lest you and the Government are embarrassed when this insistence on forced shock is ultimately challenged in Europe. As you know, they are not too happy about forced ECT in Europe.

Of course, there are other reasons for the appeal of ECT:

One Robert Kendell, President of the RCP, a passionate supporter of forced ECT, regardless of his own findings that ECT affects the blood-brain barrier. Yet despite even this, he is on record as saying; "*no one in their right mind would have ECT unless they were ill*", when challenged to have it himself, coldly telling those damaged by it to take their complaint to court. More chillingly still, he is on record as saying in a memo to the Select Committee On Health in December 1997; "*The number of beds in NHS hospitals has been drastically reduced over the years.....Those who are in hospital are, **almost by definition, already safe and adequately cared for.** As a result "bedblocking" is a constant problem, particularly on medical, geriatric and psychiatric admission wards, and a permanent source of **irritation** to NHS staff."*

It is no secret that ECT is used primarily on elderly women and is considered as rapid in its effect. It's use, as a powerful political tool to empty beds cannot be underestimated. Yet if in hospital they are "***already safe and adequately cared for***". So says the President of the RCP to a Government that **knows** just how useful ECT is, regardless of the cost to the individual, and regardless that the patient is already safe.

It seems to us a sub-text of the draft document is that the official position as disseminated by the RCP and others is pretty much a sacred cow, such that psychiatric practices have had to be raised beyond controversy and sources discrediting such practices deflected.

of dressing up many, in effect, "forced" treatments as consent based. Imagine our horror to read that you in effect condone "persuasion" on a persistent basis. This is totally dishonest and unethical. We believe that if ECT were made a consent only-based process, such that coercion could not be used, a significant drop in its usage would be evident. This would, of course, frustrate Government interests in keeping "headline grabbing" beds empty. In a similar way to the situation that exists for psychosurgery, (nsmd), you would hardly get people lined up for it in significant numbers, certainly not by comparison to its present use.

The only way to combat this systematic abuse would be for the level of capacity to be established on admission to hospital and if capacity was confirmed, the patient informed of all possible treatment options, THE INTERVIEW TAPED, AS IS NORMALLY THE RIGHT OF SUSPECTS IN POLICE CUSTODY, AND THE PATIENT GIVEN ACCESS TO A LAWYER, and, finally, the patient given the right to issue advanced directives concerning those treatments he finds objectionable. If found not capable, the tribunal would be transparently involved from the outset. This would greatly reduce abuse in this respect and introduce more honesty concerning compulsion. We cannot see how the team could object to this especially bearing in mind the pledge to avoid discrimination. NB. It is unjust and discriminatory to limit access to a lawyer to cover only the oral stages in a Tribunal.

Incidentally, we note reference paid to "Who decides". If the team were to advocate any move of nsmd from section 58 or allow its use without consent then this would guarantee co-ordinated outrage and the most bitter of court fights from which neither politicians or members of your team would emerge unscathed. The same applies to any consideration given re: experimental procedures on non-consenting adults or children.

Your definition of "lacking" capacity is so broad-based as to be meaningless. To force a person to undergo a possibly dangerous process on the off-chance they may have reached a different decision when they were well is outrageous. Then only way this could be applied would be to deny patients the right of redress if in fact the doctor was wrong on the patient's recovery. This would be even more outrageous and probably even illegal if examined by the European Court. If this policy was implemented it could only be done so with an automatic right to compensation if the doctor was wrong. It is thus unworkable.

The question, "What is mental health legislation for?" is indeed fundamental and the decision to adopt a limited model seems remarkably tongue-in-cheek. Looking at service quality and provision might at least have allowed the Committee to appreciate more of the contradictions inherent in what is being proposed - even, perhaps, something of the rottenness at the system's heart.

We state categorically that the Mental Health System is built on sand and to address the mechanics of compulsion without exploring its unsafe foundations begs many questions, some of which are touched upon below. From our point of view, the blinkered approach envisaged makes clear to us no meaningful consultation has happened. Information highlighting the falseness of claims by medical professionals, which

should have fostered a radically different, far less smug approach, is treated as irrelevant.

Please be clear that we are unable to countenance any references giving the false impression that we were consulted and our views taken into account. The heading of Appendix 1 currently implies that actual consultation has taken place. We also refuse permission for the names of the individuals involved to appear in Appendix 1, as these are marginalised by the failure actually to look at and take seriously complaints of consequences, including iatrogenesis, from a treatment where usage is fostered by a tissue of lies. The unseemly haste with which this exercise has been conducted bodes ill. Rapidly drawn up legislation is invariably bad legislation, and from what we have seen so far, there is every indication that this is going to be the case.

### **General Principles**

#### **Other Principles / Paragraphs 19 and 21**

ECT Anonymous proposes that the Committee has been seriously misled by psychiatrists about the nature of ECT and, despite receiving information expressing grave reservations, has largely taken the official (RCP) position at its face value. It is our urgent contention that except the nature of ECT becomes properly recognised, special safeguards, even though becoming defined in legislation (Para. 19 'Treatment'), could not be appropriate, nor effective.

The Committee declares themselves attracted to the principle of 'evidence-based medicine,' but articulating such a principle would necessarily involve recommending that evidence be forthcoming concerning the treatments currently in use in psychiatry. For starters, the phrase "safe and effective" used of ECT is improperly applied as ECT, unlike a vaccine, carries no requirement that safety and efficacy is proven. Until such time as a requirement comes into force for the safety and efficacy of ECT to be proven, the ideal of "least restrictive alternative (Para. 19 iv), of treatment in the least invasive manner is unattainable.

Let's be realistic; although psychiatry regularly issues the same old statements, these are belied. For example, it is commonly claimed that ECT is used as a treatment of last resort, yet the 'Making Sense' MIND publication on ECT points out that in the U.K. "around 20,000 people have ECT every year." In fact, there is little regulation of ECT governing when and on whom it can be used and why. The bottom line is ECT is given because psychiatrists control the psychiatric situation - and all such claims as that it is a treatment of last resort are so much hot air. Paternalistic dictum, not rational scientific basis, establishes ECT as the medical treatment is has not been independently validated as being. All areas are controversial - knowledge lacunae psychiatry actively encourages, the idea being that ECT will remain forever empirical with much supposedly still to be learnt.

After 61 years, isn't it peculiar that so few hard facts are being acknowledged? Clinical indications - to say nothing of a considerable non-clinical component - contra-indications, therapeutic aim and agent, the necessity (or otherwise) for a convulsion, method of application, mode of action, stimulus dose, side-effects, efficacy, consent... and so on, are each disputed by the clinicians. With ECT the most controversial treatment in medicine, are demands for detached verification unreasonable? If the Committee is serious about advocating evidence based medicine, then the whole question of ECT ought not to be settled already, as seems to have taken place, but should be declared the difficult issue it is with discernment a prime necessity.

Further, to articulate the principle of evidence based medicine in practice would be to open a can of worms not merely in connection with ECT but also about the nature of illnesses that are 'mental.' Certainly, for evidence actually to matter, the pretence that psychiatry knows far more than is actually known about disturbed or disturbing people would have to go. (Or are we dealing here primarily with what is politic and political?)

Psychiatrists have too often been unable or unwilling to impose upon themselves the limitation of saying no more than they know, or the humility to admit uncertainties. Nevertheless, exaggeration and immodesty fail to provide them with the external validating criteria for illnesses that are not subject to measurement, even if psychiatrists are in denial about the impossibility of deriving data from impartial physical mechanisms.

Although the history of psychiatry is riddled with claims that the body fluids of psychiatric patients show abnormalities or that specific anatomic lesions have been discovered, replication of findings proves elusive. Where there are genuine attempts to disprove hypotheses - rather than uncritical presentation of data - acknowledgement is eventually made that blue urine or enlarged ventricles do not operate as antecedents for schizophrenia or any other major mental illness. In truth, the breakthroughs consistently prove illusory. It is appreciated, naturally, that the Committee might after all prefer to keep the lid on this particular can, but choosing that option means buying into a theoretical hoax.

It isn't just that classifications of mental diseases glaringly do not adequately represent the person with a problem. There is also the matter of public misinformation, where biochemical imbalances are claimed to be responsible for mental conditions, and where the impression is given that theories are proven and treatments therefore soundly based. Besides, the realignment-of-neurotransmitters hypothesis currently favoured by biopsychiatrists who condone the use of ECT and toxic chemicals to 'bring back to normal' an allegedly malfunctioning physiology is the product of distorted reasoning when we are talking about 'illness' that is 'mental.'

As for brain disease, there is no evidence confirming the brain disease attribution. Really, it is imperative that these facts are openly declared relevant and acted upon. At present we are guilty of allowing psychiatrists arbitrarily to decide that a condition they say is a mental

brain and other diseases are acknowledged as the province of branches of medicine other than psychiatry.

### **Framework for Compulsion**

#### **The Diagnostic Criterion / Paragraphs 35 - 37**

It is especially noteworthy that "mental illness," the diagnosis identified in 97% of NHS formal admissions (Dept. of Health Statistical Bulletin 1994/'5, para. 2.4.1), is not defined and is not to be defined (which is understandable, given the impossibility of a viable operational definition). As mental illness is what is almost invariably meant by "mental disorder," that the favoured definition proposed by the Law Commission is one not restricted to psychiatric disorder would seem to be an attempt to insert other considerations by the back door. As the Introduction to DSM IV makes clear, what the professionals are actually keen on is that the term mental disorder should not imply a distinction between mental disorders and physical disorders.

There are strong objections to this business of an unethical introduction of the inaccurate and unreliable biomedical model of mental illness, which will have the effect of strengthening the marriage of psychiatry to somatic medicine. Needless to say, the idea that specific biological defects underlie mental illnesses is known to be the one which provides the rationale for ECT and physical treatments generally - so we suggest there is recognition of compelling objections or the move would be being effected openly and explicitly. Regarding underhanded dealings, it's strange indeed that these 'treatments' and their biological justifications are, in effect, a means to an end - which isn't to make sick people well, physically or mentally, but to oblige them to behave themselves and do as they are told. If ill health were the criteria, logically there would have to be compulsion to treatment for all serious health problems.

One obvious form objections take is that there is continuing and predictable absence of consistent biochemical or neurological data in support of the involvement of biophysical causes for the mental illness component of which the category 'mental disorder' is overwhelmingly comprised. Seemingly the intention is to proceed as if reliable, properly interpreted, associations are demonstrated, and that this somehow strengthens the notion of a "diagnostic trigger for compulsion," which will be to claim, implicitly, that the value of the construct 'mental disorder' has been established. Yet the apologia in the Introduction to DSM IV, xxi, makes clear "it must be admitted that no definition adequately specifies precise boundaries for the concept of "mental disorder." In fact, all definitions of the term are arbitrary, as, ultimately, is that all-important diagnosis 'triggered' by the definition.

### **Assessment**

#### **The Right to Assessment**

Of note is that the right to assessment is in relation to mental health. This in spite of the fact that a wide range of neurological, endocrine,

treated. Moreover, the treatments offered in psychiatry may induce physical illness, including diabetes, hypothyroidism, systemic lupus erythematosus, liver disease, tardive dyskinesia / tardive akathisia and sexual dysfunction - and these, the acknowledged iatrogenic conditions, are the tip of the iceberg. For some reason, there exists reluctance or inability to detect physical illness in psychiatric patients.

This may come about partly as a result of the discrimination such patients note - but this does not exonerate the physicians from failure to differentiate or to see the whole clinical picture and treat accordingly. Quite honestly, what is being perpetrated is rank disregard for the realities of so called mental illness. Para. 38 ('Exclusions') mentions the likelihood of changes in connection with dependence on alcohol or drugs. Blurring of the clinical picture is even more likely to occur with the substance dependent individual, where few doctors spot symptoms unrelated to the substance abuse or see beyond the rare likelihood that the chronic alcoholic, etc., will respond to treatment.

### **Section G. 3. ECT**

#### **Paragraph 140**

While ECT Anonymous agrees with the Committee's finding that some clinicians feel ECT can be effective, we wish to see specifically addressed the issue of whether or not shared idiosyncratic belief in this matter is sufficient. Firm indications of absence of a rational scientific basis, alongside the existence of a preposterous knowledge gap - which must, of necessity, lead to lacunae in professional practice - should give the Committee pause for thought regarding even a cautious endorsement of ECT.

The Committee is already in possession of a list we have produced of quotations from the literature, not merely confirming the claimed knowledge hiatus but also making absolutely clear - via the pens of psychiatrists - that statements made nowadays, if not downright untruthful, are certainly both misleading and partial. In short, the professional opinion on ECT is not capable of withstanding logical analysis, nor could it bear close scrutiny for veracity.

The disappearance from mode-of-action explanations of references to known and understood adverse effects upon the limbic system relating both to amnesia's and homeostatic dysregulation effects is singularly revealing. It would hardly be prudent for the clinicians who feel ECT can be effective to admit that the price of a random and short term euphoric reaction, in itself indicative of damage, is an increased risk of everything from nonconvulsive status epilepticus and hypothermia to susceptibility to rape, now would it?

Unfortunately, such outcomes are not minor - and nor can they be dismissed as "subjective," given a big danger with hypothermia is that the apparently fit sufferer doesn't usually realise what's happening and that by its nature nonconvulsive epilepsy usually requires an EEG to confirm the diagnosis. Logically, no patient, even if 100% retentive of capacity, can ever give informed consent, where the hidden risks have become unacknowledgeable so, clearly, will not be disclosed.

We are cognisant of the centrality to what is decided of the law relating to consent and the Committee must be only too conscious that adequately informed consent is what prevents the charge of battery. Our understanding is that a failure to warn of a known risk falls within the Bolam test for negligence. The body of medical opinion that fails to warn of a known risk must be able to provide justification on a logical basis, establishing reasonableness for the failure to warn.

ECT Anonymous very much doubts that those clinicians who feel ECT has its uses will have established reasonableness for the non-disclosure of risks which psychiatry dares no longer mention - but which haven't gone away simply because nowadays unstated.

However, this isn't simply a matter of a cavalier approach by psychiatrists. There is the possibility that a treatment which was once openly known to have an actively sought permanent and adverse effect on a person's overall health is arguably unlawful, especially in that current legislation does give people the right to an informed choice and to forego treatment that entails what for the person are intolerable consequences.

The defence in the past was that it was considered acceptable to compromise physical health in order to get at unacceptable behaviour or thinking - an argument that isn't sustainable in the current climate where emphasis is increasingly on human rights, which is doubtless why acknowledgement of somatic harm has ceased. This does not alter the fact that consent may be vitiated if obtained by deliberate failure to mention risks, particularly grave risks. Clearly, therefore, for those users who claim ECT is beneficial, the right knowingly to choose compromised health is one thing but, as matters stand, just because ECT has its supporters that does not fundamentally legitimise it - even if the Committee appears to think differently.

Likewise, it is reprehensible of the Committee to make the assertion that ECT is possibly life saving, without also stating the existence of research indicating that ECT decreases life expectancy and clinical findings that it increases the risk of suicide.

Please be absolutely clear it isn't merely that the treatment can be imposed in the absence of consent which is objected to, but also the level of flagrant dishonesty surrounding the subject of ECT - which dishonesty the Committee, seemingly happy to remain sublimely ignorant, is guilty of perpetuating.

### **Paragraph 141**

From the point of view of what the Committee acknowledges is an essential right to autonomy, the statements in this sub-section lack the necessary precision and are therefore totally inadequate because they skim over the possibility of abuse by paternalistic clinicians firmly of the

wishes regarding treatment and primary reliance on their clinical judgement.

What that is meaningful in terms of outcomes is being done about the continuing likelihood that patients will be labelled as without capacity purely because of a decision to refuse ECT? The issue of clinicians moving from their disagreement with the decision to refuse treatment to a label that characterises someone as sufficiently incompetent at whatever level of capacity they're talking about has not been addressed.

Indeed the myth continues to be promulgated that such beings, i.e. patients without (!) capacity, actually exist. However, let's be clear about it, if the standard for finding a patient not competent to refuse treatment were no less than generalised incompetence, including clear evidence that the patient is uninformed on emotionally neutral issues and cognitively incapable of making ordinary decisions on matters unrelated to the crisis at hand, few persons if any could legitimately be deemed "incapable." So where the viable measures to safeguard the much vaunted patient autonomy, and where the requirement for a truly patient-friendly measure of capacity?

Replacing the present system with a tribunal is all very well, but the necessity for a second opinion from a doctor appointed by the Mental Health Act Commission has been widely condemned as little more than a rubber stamping exercise, with the SOAD in more than 90% of cases upholding the original decision. As well, current procedures were liable to circumvention by invocation of common law, with treatment claimed to be in the best interests of the patient effectively depriving someone of the right to refuse.

Persons in authority decided something should be done to the 'patient,' and it was done, with little or no comeback until very recently. It didn't appear to matter that the legality of such action was decidedly shaky, given the MHA trumped the common law. Likewise, the revised MHA shall supposedly take precedence, yet the principle of necessity is to mean that a flawed state of affairs can continue.

Why does the Committee imagine concern is expressed about the potential for over reliance on emergency treatments? No matter how disturbed the person, if they offer objections, they have the right to a weighing up of those objections rather than it becoming possible, in an 'emergency' for everything they say to be ignored.

Take 'emergency' ECT; if nobody cares that evidence supporting the 'necessity' for compulsory ECT is missing, what about the person who insists it caused them, or a loved one, brain damage - and for a reason of the sort they don't want it? Where ECT is concerned, what is there about the tribunal system as anticipated - that would have to expressly approve ECT through its medical member - which is strategically different from the prevailing situation? What about the major stumbling

consent to ECT, given the issues herein highlighted, is in doubt. Tribunals ignorant or dismissive of these issues would be worse than useless.

It seems clear that the Committee is proposing to reject survivors' views on ECT which are unsupportive of professional interests, emphasising the likely irrationality of patients but not the inherent unreasonableness of ECT due to irremediable lacunae in knowledge and therefore in usage, nor the fallacious reasoning on which psychiatrists base the negating of patient autonomy. As ECT Anonymous has made clear, we do not accept that consequential consultation has taken place. Moreover, aside from mention of receipt of "many powerful submissions," the absence of even token attempts to incorporate the essence of the opposition to ECT indicates that "consultation" existed to facilitate the drawing up of Appendix 1.

## **Section H. Incapacity**

### **Paragraphs 154 and 155**

In respect of lack of capacity, Paragraph 154 is both Machiavellian and nonsensical. Despite the impossible nature of the quest for the elusive definition of mental competency, the making of irrational decisions should not be equated with lack of capacity. It is perfectly possible to have competently made irrational decisions - and the real problem here is that psychiatry is distinguished by its eagerness to override the wishes of patients whose decisions they have the power to view as irrational.

Isn't the Committee aware it's already the case that the clinical situation reflects the judgement that such patients not infrequently make irrational decisions that seem part of the disease and that they can be expected to reverse their wishes after treatment? Who says this is what happens? On the whole, not the persons whose decisions have been undermined by a piece of reasoning peculiar to psychiatry.

The Committee should have the sense to appreciate that enshrining fallacy in law, without any comprehensive or long-term research to back the claim that mental illness is a special case, would be done for the wrong reasons and is not a good idea. The already too broad, Law Commission, definition being argued for, that in Mental Health would permit capacity to be negated by the back door, so to speak - strengthens coercive paternalistic intervention.

If this is what is being advocated - which can be said to be primarily a product of the belief in a certain sort of disorder - the Committee should say so clearly. The Law Commission definition wasn't set up with mental illness in mind and reflecting such a definition strengthens the justification for treatment of mental illness through the expressly physical, as already mentioned.

In short, a Committee declaring themselves anxious to recommend a definition with which the professionals can feel at ease, closely resembling clinical judgement, is a Committee that will invariably end

categorically fails to take into account the demand by patients for a greater say in their own healthcare.

In the light of the foregoing with regard to ECT, this is irresponsible of the Committee. As those same professionals, armed with a definition of competency that suits them, are the ones who will play God and decide that a decision judged irrational is the product of the disorder and that it does not reflect the person's true preferences, the Committee offers little but window dressing.

There has to be a burden of proof on those who allege a patient is not capable. Will a tribunal be truly vigilant and "alive to the dangers," as is hoped (Para. 115, 'The Specification of Conditions'), or would there be a high rate of acceptance of what the doctors say? Wouldn't it be embarrassing for tribunals generally to question too deeply, as that might undermine the whole ethos of the new-and-improved Act in which the public can have confidence?

Let's face it the philosophy of the 1983 Act was to "strengthen the rights and safeguard the liberties of the mentally disordered" (Bluglass, 1984); the same principles were being expressed then as are being expressed now. By and large, the mentally ill is a vulnerable group, so what absolutes would change for the better for them? Besides, like it or not, it is necessary that some pretty rigorous questioning be done, because mental health human rights issues (around capacity, informed consent / personal decisions concerning what treatment risks are acceptable and - above all - the nature of disorders those in charge insist be seen in a certain light) are becoming increasingly compelling. Those learned gentlemen whose role is that of senior legal chair to the panel are likely to find their work cut out as, apart from anything else, the revised Act will soon be seriously out of date.

Where the patient is a psychiatric patient proof as opposed to say so must be a stringent requirement if the person's full right to exercise autonomy is genuinely to be respected. As well, and given the tremendous difficulties surrounding agreement about what defines mental competency, a compelling reason, clearly articulated and legibly presented in the casenotes, to over-rule the wishes of any patient should be required of the psychiatrist.

Because casenotes can be mislaid or tampered with, some system that guarantees proper recording procedures is essential. (see above re: "tapes".) However, this sort of thing having been said, in order to come up with an appropriate definition of incapacity, what's really necessary is to start with the whole basis for the alleged inability by many psychiatric patients to consent. There's more to this than a simple presumption for or against lack of capacity. Is examining the notion of illness that allows psychiatrists to get away with claiming there is such a thing as incapacity or unsoundness of mind (among other things) too radical a move for the Committee to countenance?

In respect of ECT itself, if this is, as the evidence from professional journals indicates, a procedure carrying inherently unacceptable risks which are kept secret, then that in itself places ECT beyond the range of rational choice - and nobody is ever in a position to make a rational decision to have or not to have it. Indeed, we put it to the Committee that the ostensibly irrational choice, to refuse ECT against a physician's clinical judgement, is arguably the reaction of a person of remarkably sound mind and clear judgement!

On the test of whether or not we would allow a reasonable and autonomous person the right to opt for a possible chance of relief from depression for up to four weeks in order to spend the rest of their life dogged by ill health, changed personality, etc., the answer must be "No" because the evidence just isn't such that the choice can be shown to be reasonable.

The body of professional opinion that declares ECT safe, effective and no more risky than having a tooth extracted is neither reasonable nor responsible. We are led to believe it was past recipients of ECT who agreed that the ECT experience is no worse than a visit to the dentist - and in the absence of accurate information and the presence of anaesthesia this is certainly a superficially correct interpretation. After all, ECT patients see little and comprehend less. However, the difficulty is, ECT recipients are never told that their symptoms post-ECT - sometimes many years later and including depression, recognised to be common following brain damage - are not 'continuing mental illness' but only exist because their psychiatrist inflicted ECT. So fostering the 'no-worse-than-having-a-tooth-out' myth is deplorably irresponsible.

It must be emphasised that the issue of the rationality of consenting to ECT does not depend on obtaining any more factual information, but on independent evaluation of the already compelling and precise existing information, so as to permit total accuracy in communicating the magnitude of the risks involved.

Psychiatrists know that their scientific evidence is extraordinarily weak, i.e. that there's a huge gap between psychiatry's knowledge claims and the evidence available to support those claims. Psychiatry has been faced with the arguments that their failure to draw on scientific discourse invalidates psychiatry's concepts and thus the so called medical practices based upon them - but to no avail. Literally, a reversal of what goes on in science, where evidence is what effects changes and makes a difference, pertains here. It is even the case that negative evidence is either ignored or the findings distorted as necessary.

Psychiatrists are perpetrating a scam and crippling lives in the process. They are selling a package they know is irrelevant to healthcare as such. What about the Committee? The question is, on the basis of solidly viable evidence to invalidate the package - should it be allowed to carry on? Must we keep on pretending that psychiatrists are

compulsion, shouldn't apprising the public of where psychiatry and Mental Health care are coming from be compulsory? Needless to say, ECT Anonymous recognises that actual clinician basis for choice of diagnoses and treatments, not being the traditional evidence-based method, is 'clinical judgement.' In our informed judgement, it makes a difference that disposing of people on the basis of illness and disorder is backed only by weak opinion and ideas.

We should not be the ones obliged to point out that ECT falls outside the scope of rational choice, but apart from this there are no circumstances under which it is so necessary to use ECT that doctors should be permitted to countermand patient wishes by calling those wishes "irrational" or negating capacity.

It is never true that ECT is the only alternative to an otherwise unacceptable future. Careful nursing by dedicated staff willing to speak and listen to patients would substitute even better for whatever benefits ECT is alleged to convey.

The Committee ought to have asked why psychiatrists are so insistent on their right to use a treatment they themselves have documented to be iatrogenically damaging. In the Fifties when a mood of authority prevailed, all that seems to have been necessary was for psychiatrists to give themselves permission to tinker with basic somatic mechanisms. As long as unacceptable behaviour and thinking were ostensibly reduced as a result (and knowledge was added to!), no one seems to have questioned what went on.

Not surprisingly, psychiatry has since had to ditch the reasoning behind such tampering - but ECT does continue to inflict conditions linked to homeostatic dysregulation. Pathological brain wave patterns following ECT have been noted, but the fact that nobody appears to have scrutinised what was being claimed in years gone by and drawn some pretty damning conclusions about ECT should not lull the Committee into imagining that it could not conceivably induce disequilibrium, through creating a breakdown of the controlling mechanisms of homeostasis normally so carefully preserved by the autonomic nervous system.

Interestingly, the reputed mental illness that ECT reputedly treats is NOT accompanied by pathological changes in the EEG. Shouldn't it forcefully strike the Committee that ECT isn't just irrational in terms of consent - where risks not only aren't but can't be stated? It is irrational as well because it alleviates (sic) mental distress through destroying bodily health. Do any survivors for whom compromised health is an issue regard the outcome as worthwhile?

In fact, if ECT really worked as a treatment in mental illness, one would expect to note pathological EEG rhythms prior to ECT, and afterwards an improvement - instead of which one gets rhythms within normal parameters only until ECT is given - after which the abnormalities

contrivance of paternalistic dictum where there is insistence on retaining use of ECT and through it control and privilege. The real reason ECT is given is because doctors think it should be.

Challenge to the validity of all consent to ECT in the present circumstances extends to many of the precepts upholding it, as these too are questionable. To the extent that the alleged outcome of saving life is raised above alternative values such as autonomy, the patient who makes decisions that appear contrary to his or her best interests is likely to be declared unable to decide in a rational manner. As is pointed out in Para. 171 ('Suicide'), where there is mental disorder "most clinicians would regard the patient as lacking capacity." The more cynical among the survivors of ECT would say that the way clinicians regard patients is more to do with self-interest than with the presence of mental disorder and / or incapacity. Leaving those who wish to die to the tender mercies of psychiatric regard, where clinical judgement and invasive treatment is the norm, is to deny a very basic human dignity - as anybody who has let a loved one go in the firm conviction that death is what the person prefers will testify. All the regulations and enforcement's against self-harm in the world won't make the person in whom the desire for death is sufficiently powerful prefer life, whether or not mentally disordered.

Therefore, let us at least be open about whose interests are served by any insistence that the mentally disordered without capacity are going to have to accept being 'protected' from themselves. It isn't themselves from which vulnerable people most need protecting. There are survivors of ECT who make absolutely plain that they may as well have been allowed to succeed in their suicide attempt because the damage from the treatment which is claimed prevents suicide certainly doesn't leave them whole and able to live a quality life afterwards.

So what is going to be done to ensure that arrogant physicians as well as incapable or protesting patients are held accountable and that serious institutional failings are addressed? Of the Bristol heart babies' case, Sarah Bosely in 'The Guardian' (25.6.'98) noted the senior doctors involved had "told the parents what they thought fit to tell them, and did not always tell them the truth." This state of affairs is even more prevalent in psychiatry than in any other branch of medicine, and although Professor Robert Kendell has remarked the lack of major scandals in psychiatry, scandals in connection with ECT are beginning to surface and are not going to go away. Public demand for the truth in matters medical is a factor to be reckoned with in our litigious society and psychiatry isn't secure against the process.

### **The New Tribunal**

#### **The case for the tribunal**

Para. 84 i) by no stretch of the imagination is going to be what enhances the psychiatrist / patient relationship. If those who are or have been vulnerable to psychiatric abuses don't find this first statement credible, why should there be a great deal of faith in the rest

inarticulate patients!), enabling consistency of decisions, etc. It remains to be seen if the introduction of judicial imposition would work significantly to improve the situation for patients, seeing as decisions regarding treatment are to be made by the medical member.

Where appropriateness of a treatment plan involving ECT is concerned, the contents of our urgent response here presented make unambiguous the impossibility of the tribunal obtaining accurate necessary advice, evidence and expertise. (As for guardians appointed for persons deemed incapable of making treatment decisions, they are liable to be just as misinformed about ECT as is a tribunal.) A lot of ECT can potentially be given to detained patients who have to comply with an approved treatment plan for up to 6 months. A set limitation on the number of treatments that may be administered is imperative, as extensive ECT is never in a patient's best interests. In the 1980s, Dr. Graham Shephard was insisting,

"The results of the studies which gave the longest courses of ECT, twelve or more ECTs, did not indicate that their patients showed a greater responsiveness to real ECT than the patients in the remaining nine studies which gave less than twelve treatments" ('A Critical Review of the Controlled Real versus Sham ECT Studies in Depressive Illness')

All such findings as Dr. Shephard's within psychiatry, that would restrict practice, are ignored - which should surely imply the necessity for proper regulation and stringent controls. If psychiatry had to show proof around safety and efficacy, ECT would be quietly phased out, it's as simple as that.

Therefore, although the Committee pays lip service to the importance it attributes to the principles of non-discrimination and autonomy, they are paper principles where ECT is concerned, given the Committee is largely content to make those principles subservient to the views of clinicians (abetted by a minority of users) who declare the autocratic belief that ECT can be life-saving. Thorough consideration needs to be given to some hard facts. Claims that ECT is life-saving are unverified -, as what the literature reveals is that ECT has no effect on suicide. They are literally unverifiable, seeing as they're fallacious. Apart from anything else, these unverifiable assertions, the claims of persons too long accountable to nobody, depend on the existence of a proven correlation between suicide and depression (with ECT said to prevent suicide by 'working' in depression). In the absence of such a proven correlation, a finding (quoted in 'Human Freedom and Mental Illness,' Canadian Psychiatric Assoc. Journal. Vol. 14, 1969) is telling. The author cites Wijsenbeck, who

"found an exaggerated sense of freedom in patients suffering from manic and schizophrenic reactions, suicidal reactions, personality disorders and acute brain syndromes. A decreased sense of freedom was found in patients presenting depressive, catatonic, chronic schizophrenic reactions, character neurosis and chronic brain syndromes." (Italics added.)

If correct, suicidal reaction and depression do not 'fall together' on a continuum - but instead are being facilely placed together in order to justify ECT. It therefore need not surprise that a positive effect of ECT upon the suicide rate isn't demonstrated. Another criticism being levelled at psychiatry is that practitioners are prone to selecting those effects which fit their hypotheses and neglecting those that invalidate them. We won't mince words here; the claim that ECT is effective in preventing suicide is a falsehood it suits psychiatry to foster.

The professional function that such a falsehood serves - permitting psychiatrists carte blanche to administer ECT virtually as they see fit - is unlikely to be duplicated by an alternative interpretation of the causes of suicide. ECT Anonymous rejects the notion of acceptable psychiatric practice, whose acceptability, as this submission repeatedly states, is based not on empirical evidence but on what psychiatrists claim - which, in turn, is tailored to policy.

#### Section 1. Medical treatment of the patient with capacity

Make no mistake, the personality disordered who retain capacity are likely to have temporal lobe damage. Some of this could even have been caused by ECT, which inflicts epileptiform brain wave patterns - found with personality disorders. To say such people are the most likely to present a significant risk to themselves or to others is convenient, but it puts the cart before the horse - and does not exonerate the Committee from a responsibility to recognise the existence of a dilemma.

It is imperative that the Committee exercise due care when proposing that these putative 'patients' be compulsorily treated under a revised MHA - when this means compulsory psychiatric treatment. We are informed in Para. 9 ('The Diagnostic Criteria') that "the Committee favours a broad definition of mental disorder which is defined as any disability or disorder of mind or brain whether permanent or temporary which results in an impairment or disturbance of mental functioning." This catch-all definition perpetrates misconceptions and will lead to human rights abuses - but it actually is also far too loose. It really is risky to suppose simply implying that everything to do with disability or disorder of mind or brain, which results in a disturbance of mental functioning, is illness that couldn't possibly fall outside the designation 'presence of mental disorder.'

Given people who suffer from a physical disorder are free to refuse treatment, what precisely will be the criteria entitling whoever makes the medical assessment to decide that a person unequivocally is mentally (rather than physically) ill? Might not misinterpretation, in the environment of concealment that prevails, render the doctor concerned liable for damages? Isn't there a risk of false imprisonment charges, where the experts deliver a sentence without trial? Do all the categories subsumed under the definition provided really render a person liable to compulsory treatment, given brain disability is NOT primarily psychiatric?

decision that would not have been reached had the person been well. It is clear that we are into a unique ball-game here. If, for instance the disability or disorder is permanent, then, logically, the person is never going to be 'well.'

Are we to understand that intermittent treatment over decades is a possibility? But the big 'if' is, what if the condition is not psychiatric? We trust it is evident that extending, as does the Law Commission's definition, the meaning of 'mental disorder' beyond the psychiatric is potentially fraught with legal and ethical pitfalls. To start with, anything that has a specific brain pathology becomes the province of neurology. Epilepsy is described by the National Society for Epilepsy as "the most common serious neurological disorder," in which "A sudden temporary interruption in some or all of these functions may be termed a 'seizure.'" Yet a condition known as nonconvulsive status epilepticus (SE) is recognised, which

"...is often more difficult to detect clinically and is either absence (petit mal) or partial complex (temporal lobe) in nature. Symptoms include acute changes in mental status.... A recent study found a high incidence of patients with psychiatric disorders...among those who have nonconvulsive SE. This type of SE often requires an EEG to confirm the diagnosis."

(Daniel J. Lacey, MD, PhD, 'Status Epileptics in Children and Adults,' J. Clin. Psychiat., 49:12 (Suppl), 1988)

How likely, one wonders, is it that psychiatric patients who have unrecognised nonconvulsive SE are exhibiting behaviours indicative of changes in mental status that have been designated part of a psychiatric disorder but which are, at least according to the National Society for Epilepsy, part of a "neurological disorder?" Just supposing, for the sake of argument, that instead of 'treatment' based on assumptions of psychiatric illness and therefore the possibility of wrongful diagnosis, which is what is being advocated, the assumption was to be of neurological disease, with the personality disordered individual given neurological assessments as an obligatory part of the assessment in relation to mental health needs. What happens when a neurological condition is found to underlie somebody's disordered state? Would this still legitimately fall within the province of the MHA? Bournemouth suggests not.

Despite the Committee regarding the principle of non-discrimination as central, the qualifier is non-discrimination "wherever possible" and there isn't to be a recommendation that non-discrimination be expressly included within the revised Act.

Given the Mental Health Act's primary concern is with providing a framework for compulsory detention and treatment of particular sorts of person suffering from a mental disorder, and given the acknowledged impossibility of incorporating a principle of non-discrimination into an Act which seeks to empower authorities to compel treatment, at the end of the day we are still left with mental illness as a special and inherently

person is designated "ill." (It is of course doubtful that neurologists would be keen to be involved.)

Dubious treatments enhance discrimination; ECT being a treatment reserved expressly for psychiatric patients. Aren't the extensively zapped at peculiar risk of being declared incapable of retaining information relevant to the treatment decision, due to ECT-induced cognitive dysfunction - or prevented by that same incapacity from using information provided to arrive at a sensible choice? And what if it emerges, perhaps as a result of ECT litigation, that many individuals have disorders caused by previous psychiatric treatments - will they be obliged to undergo more of the same? It would be short-sighted of the Committee to imagine that professional denial of damage effects can carry the day for much longer.

So are these difficult issues to be swept under the carpet, in the hope that the facts (i.e. that incurable personality disorders are more likely than not to be neurological and that a proportion of such disorders may have been iatrogenically induced) will remain largely unremarked? The problem here is that the Committee has been apprised of these matters. To whom is a Scoping Committee which fails to grasp the nettle answerable?

The option envisaged in Para. 161, where the patient, being "exposed to prolonged negotiation and encouragement on the part of the clinical team would eventually 'consent' to the offered treatment," invites coercion. In fact this constitutes coercion. Prolonged negotiation about ECT would be nothing of the sort, because patients are never told the truth about ECT. The alternative proffered in Para. 162 b) is a thin-end-of-the-wedge type of option, which, given a gross want of insight into the realities of mental illness, presents a risk to patients of being fitted into "carefully defined circumstances" or threatened with it. As for c), again we encounter the note of invitation, in this instance to find that the patient has lost capacity, "as might typically be the case with regard to mental illness." The Committee here betrays the material focus of their attentions.

Intellectual and scientific dishonesty pervades this whole business. As an example of the dishonesty complained of, which the Committee doubtless prefers to ignore, the first thing to be born in mind about the so-called "signs of relapse" mentioned in Para. 163 (2. 'The person with a deteriorating condition') or "history of relapse" (Para. 165) is that this sort of sign could be due to overuse of toxic chemical restraints, which involves some severe withdrawal symptoms. Where the admissions tardive dyskinesia and dementia are part of the "display" of so-called "signs of relapse?" Just how "appropriate" can treatments in psychiatry be shown to be? Crucially, would the public benefit from an increase in forced drugging of patients (and possible forced testing / forced incarceration in prisons hypocritically termed "hospitals"), or is it drug companies that are most likely to benefit?

Are treatments, however "appropriate the standard," not in themselves part of the overall risk picture; furthermore, do they 'work?' If, as is implied in Para. 138, it has regularly been the done thing to "obtain a second opinion certification" after 3 months of medication, the conclusion to be drawn is that drugging frequently doesn't improve the patient's condition in the sense of 'making better' - though it doubtless creates docility. "A framework for the authorisation of medication" is all very well, but a framework for inspection of the role of medication throughout would be far more revealing - that is, if someone wished to examine the imposition of what are little more than chemical straitjackets.

Then there's the matter of what exactly is meant by "deteriorating conditions," i.e. is this whole business largely about limiting inappropriate behaviour? If so, it is highly unscientific for actions to be taken as if behaviours are reliably associated with deterioration in social functioning. It is unmedical to allow 'health' to stand in for moral standards, where it is no longer fashionable to examine the evil that men do so there has to be a complex yet decidedly unsound 'mental disorder' framework in place for constraining the mad and bad. The notion that psychiatry is a branch of medicine, with what psychiatrists do and are permitted to do purportedly stemming from their allegiance to science, has worn decidedly thin.

In respect of personality disorders, the crux of the matter is that damage to the temporal lobes and limbic system results in untreatable pathological states - as psychiatrists have realised. Andrew Wilski, consultant psychiatrist, writing in 'The Times' (4.3/'99) makes absolutely clear it is generally recognised that the psychopathically personality disordered,

"...cannot be successfully 'treated' in the context of psychiatric systems - i.e. that on the whole they do not significantly or lastingly change as a result of psychiatric procedures, while causing turmoil in psychiatric wards."

Clearly, psychiatry isn't keen to be held accountable for such individuals. Moreover, all the options proffered by the Committee, built around the central tenet of 'treatment' with or without consent, singularly fail to take into account the nature of personality disorder, a condition notably unresponsive to treatment. A sensible way forward would be to make acknowledgement of neurological impairment as opposed to mental illness.

By the way, erroneous insistence on some definite category labelled 'mentally disordered' would make any likely definition of capacity / incapacity less than valid. The reasons for an insistence on treatment for mental disorder are also questionable in this context. Is it more a matter that a locking away for supposed medical treatment legitimises detention than that the interests of public safety justifies not only detention but the imposition of treatment?

If there is to be insistence on treatment in such circumstances, let it be clear that the treatment is being used to appease the public, as well as clinicians, carers and the families of patients. Other than this, the pre-emptive approach favoured by the Committee is likely to lead to violations of human rights, especially as psychiatric treatment of personality disorder is known not to be a viable option. It would require changes to the law to implement, especially after the Court of Appeal finding of 15.6.'98 (Para. 37, Bournemouth) that patients with neurological conditions, such as Alzheimer's Disease and learning disabilities, are being detained illegally.

In making recommendations in connection with filling the legislative gap revealed in the Bournemouth case, might not the Committee risk diminishing the rights of the majority of the long-term incapacitated in order to control a tiny minority? Revisions that make the Mental Health Act essentially backward-looking will perpetrate injustice. The few who really should be compelled may well prove incredibly wily, resulting in tightening of controls, scape-goating and intimidation for the many. In any case, supposing it were possible to "significantly or lastingly change" the patient, isn't that to rob him of the right to his own personality - or at least a familiar one where his natural personality has been altered by psychosurgery or closed head injury, including that inflicted by ECT - a serious and destructive course of action, and of very doubtful morality?

### **Best Interests**

#### **Paragraph 174 a)**

It is noteworthy that most if not all of the ECT medical negligence cases currently in the pipeline have arisen because doctors presumed to know better than the patient what was in that patient's best interests.

### **Children**

#### **Paragraphs 237 and 239**

Never mind that professionals are unsure of their authority, children are as needy of protection from said professionals as they are of protection from all adults in a position to take advantage of their lack of experience and obedience to adult demands. Empowering professionals to override parental consent may be to exchange one set of abusive authority figures for another. In respect of treatment with ECT, there exists a singularly pressing concern that consequences be scrutinised to bring in the damage aspect. It is high time serious consideration was given to the impact of ECT on an immature and developing brain.

Review of the Mental Health Act 1983: Contribution from ECT Anonymous.

Yours Faithfully,

Pat Butterfield, Co-Founder.