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Electroconvulsive therapy (ECT) - The imposition of 'truth'?

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Abstract

Within the contemporary psychiatric setting where the controversial operative procedure Electroconvulsive therapy (ECT) is applied, the identity of the person to be 'treated' is positioned at a convergence point of competing disciplines. ECT's contradictory existence is additionally quantifiable through analysis of official statistical data, where omissions and inconsistencies obscure the contexts and activity of ECT's administration. Whilst a number of other states have either banned its usage, or applied increasing restrictions, it is proposed bio-medical frameworks in this arena of UK healthcare inhibit rights based policy initiatives. Such frameworks further limit the admission of alternate socio-legal method which is are coupled with evidence bases from service user/survivor experience. The article recognises the need for genuinely collaborative research – rather than research done by consumers for consumers and by clinicians for clinicians. It is positioned to produce a transitional domain between differing perspectives of ECT from evidence based research. The contemporary socio-legal debates about safeguards for excessive treatments, consents, legal status, and the questioning of a person's capacity also find convergence in ECT's administration processes, as care becomes interchangeable

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with authority through its outreach, and intrusion. The article intends to inform further research, and, in the context of the Mental Health Bill [HL]2006, offers recommendations toward the implementation of equality in NHS service delivery. These include proposing structural changes in the clinic accreditation regimes, and the promotion of rights-based measures for inclusion in changes to the Mental Health Bill [HL]2006 from the comparative perspective of the Mental Capacity Act 2005.

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1. Contemporary socio-legal contexts

The area of primary legal scope for this paper is the mental health service domain of England and Wales and the administration of the operative procedure Electroconvulsive therapy (ECT) in psychiatric settings. On 23 March 2006, the UK government withdrew the draft Mental Health Bill 2004 following a previous draft Bill in 2002 and nearly a decade of debate and controversy over mental health legislative reform. The government stated its intention to amend existing legislation, primarily the Mental Health Act 1983, and the Mental Capacity Act 2005. The latter amended provides also for a regime of "Bournewood" safeguards – safeguards for people "who lack capacity and are deprived of their liberty but who are not detained under the Mental Health Act...typically residents of a care home or people receiving treatment in hospital...in their own best interests". ¹ The previous draft Bill's provisions for further safeguards and prescription of ECT practise have been significantly adjusted in the recently published Mental Health Bill 2006.²

The socio-legal comparatives for this article remain extant, and the emphasis on legal frame-works contributes to the debate for the possible inclusion, in amendment form, of rights and autonomy in healthcare assessment and delivery in this healthcare domain.

Ethical considerations include the civil rights for people who are in a marginalised domain, due to the perceived difference of their "mental health", which are intrinsic to the re-introduction of human value in socio-cultural and identity terms. Moving the locus of the mental health domain from the Law, to that of socio-cultural relationships, provides this article's comparative ethic. An awareness of the requirement for sensitivity and, where necessary, confidentiality, has been applied, with the awareness that recommendations made may potentially affect directly people's life choices in this area of healthcare.

The Socio-Legal Studies Association Ethical Code has been noted, particularly Principle Five, Principle Six, and their relevant sub-sections. ³ ESRC Guidance on Research ethics and confidentiality has been noted, with particular reference to the independence of researchers to the subject of the research. ⁴

¹Department of Health The Mental Health Bill: Plans to amend the Mental Health Act 1983 - Briefing sheets on key policy areas where changes are proposed 2 May 2006 Gateway reference 6420. The draft Mental Health Bill (Sept 2004) was withdrawn on 16 Mar 2006. See also: Mental Health Act 1983 (Royal Assent 9 May 1983); Mental Capacity Act 2005 (c.9) (Royal Assent on 7 Apr 2005) and replaces Part 7 of the Mental Health Act 1983 amongst other provisions; and Mental Health Bill 2006: Regulatory impact assessment (Nov 2006) 2,24, hereafter cited as Mental Health Bill 2006: Reg impact...(2006).

² Mental Health Bill 2006 [HL] ordered to be printed 16 Nov 2006

³ ESRC Postgraduate Training Guidelines 3rd edn (2001), in M Everson and A Gearey (eds), Masters in Research in Law, Starter Pack (2004) 90-95

⁴ in ibid A Boon, L Mulcahy and A Mumford (eds), *Socio-Legal Studies Association Ethical Code* (1993) (re-stated, date unknown) 96-104

1.1. Toward definitions of ECT

In the context of inter-professional rivalry over the domain of the mind, the 1920's saw psychiatric experimentation and research into a number of different "shock" treatments which induced either a coma or convulsion in the patient. In the following decade electroconvulsive therapy (ECT) was introduced.⁵

Electroconvulsive therapy remains the only "somatic" - or directly bodily intrusive treatment - leftover from the experimental period of the 1930's, although it has much earlier antecedents. The American Psychiatric Association guidelines for ECT administration allow for its use as first-line treatment in a significantly greater number of clinically defined instances than the UK. Its usage in the UK, though declining, is still significant, administered supposedly within UK National Institute for Health and Clinical Excellence (NICE) *Technology Appraisal No. 59 (TA59)* guidelines for "the treatment of severe depressive illness, a prolonged or severe episode of mania, or catatonia". Further, within these guidelines, ECT should be used to "gain fast and short-term improvement of severe symptoms after all other treatment options have failed, or when the situation is thought to be life-threatening". NICE does not recommend ECT for maintenance treatment. Acting within the NHS, NICE is an independent agency, receiving commissions for technological appraisals from the Department of Health.

The position paper of the Canadian Psychiatric Association (CPA), current in May 2006, defines Electroconvulsive Therapy as:

...a medical procedure in which a brief electrical stimulus is used to induce a cerebral seizure under controlled conditions. Its purpose is to treat specific types of major mental disorders......although the mechanism of action of ECT is not completely understood, over fifty years of clinical experience and a substantial volume of research have lead to the CPA's current recommendation that ECT should remain readily available as a treatment option. Like other significant medical interventions, ECT has clearly defined indications, demonstrated efficacy and safety, well known side-effects and established standards for optimal practise.

⁵ C Samson, in B S Turner (ed) *Medical Power and Social Knowledge* (1995) ch 4 63-66 hereafter cited as, C Samson, in B S Turner (ed) *Medical Power...*(1995)

⁶ M Philpot, et al, "Barriers to the use of electroconvulsive therapy in the elderly: a European survey European Association of Geriatric Psychiatry" (2002) abridged version for EAG web-site (Eur)*European Psychiatry* 17:41-45

⁷ E Yuzda, et al, "Electroconvulsive Therapy Training in Canada: A Call for Greater Regulation" (Dec 2002) *Can J Psychiatry* (2002) 47:938-944 hereafter cited as, E Yuzda, et al, (Dec 2002)

⁸ National Institute for Health and Clinical Excellence - *NICE Technology Appraisal No.59 TA59 Guidance on the use of electroconvulsive therapy* (Apr 2003) 1.1,1.8 5-6, 3.1-3.8 8-10 hereafter cited as, NICE TA59

⁹ M Enns and J P Reiss "Position Papers Electroconvulsive Therapy" (current at 03/05/06) Canadian Psychiatric Association-Association des psychiatres du Canada

There is no mention in the CPA opening statements that ECT remains viewed as one of the most controversial and contradictory medical treatments, in theory and practise, that continues in widespread usage. This operative procedure is imposed on hundreds of people each year in the UK without the psychiatric team having obtained their informed consent, or administered to people perceived to be without the initial capacity to give, or refuse, consent.¹⁰

The NICE *TA59* has a more explicit definition of the procedure (ECT will be used throughout this article to describe processes of the following)

During ECT, an electric current is passed briefly through the brain, via electrodes applied to the scalp, to induce generalised seizure activity. The individual receiving treatment is placed under general anaesthetic and muscle relaxants are given to prevent body spasms. The ECT electrodes can be placed on both sides of the head (bilateral placement) or on one side of the head (unilateral placement). Unilateral placement is usually to the non-dominant side of the brain, with the aim of reducing cognitive side-effects. The amount of current required to induce a seizure (the seizure threshold) can vary up to forty fold between individuals. ¹¹

To summarise from this section of NICE *TA59*, the "most prevalent hypothesis (that explains its mechanism of action)* is that it causes an alteration in the post-synaptic response to central nervous system neurotransmitters". Whilst recognising "moves to improve standard...however, there is still variation in the use and practise of ECT within England and Wales". This causes:

...changes in cardiovascular dynamics, (...and other...)* immediate potential complications, such as status epilepticus, laryngospasm and peripheral nerve palsy, which overall have an estimated incidence of one per 1300 to 1400 treatments. The mortality associated with ECT is reported not to be in excess of that associated with the administration of a general anaesthetic for minor surgery. (brackets by the author).

The Salford Report produced by people with current or past direct experience of receiving treatment from the ECT service, in conjunction with the Salford Community Health Council, summarises much of the research literature pre-NICE concerning ECT. They recognise that few longer-term studies of people who have received ECT are available. Even fewer reports were available concerning the direct views of those in receipt of an ECT service, hence the importance of this comprehensive report at that time. ¹³

¹⁰ Department of Health, *Statistical bulletin Electro Convulsive Therapy: Survey covering the period January 2002 to March 2002, England* (2003/08) 3.18 6 hereafter cited as, 2002 ECT Survey Statistical bulletin (08/2003)

¹¹ NICE TA59 3.1 9

¹² ibid 3.1-3.8 9-11

¹³ Salford Community Health Council, *The Salford Report, Electro-convulsive Therapy, its Use and Effects* (Apr 1998)

The ethical, identifying, and rights-based imperatives to be explored include information presentation and communication, diverse cultural requisites, and pre- and post- ECT-associated intra-disciplinary medical and psychiatric service intervention. These imperatives become directed toward the person, being brought to the foreground as aspects of subject autonomy and inclusion are investigated through the constructions of consent, and consensual decision-making.

1.2 Questions of safety and effectiveness

The assertions concerning how or why ECT may or may not be a viable option to relieve serious or life-threatening "conditions" as an emergency and "last-resort" treatment option detracts from an ECT "action" that does not necessarily prevent a person's later suicide. ¹⁴ Despite the earlier admission by the Royal College of Psychiatrists (RCPsych) that "the anti-depressive action of ECT is obscure", ¹⁵ the extensive RCPsych ECT Handbook (2005) promoting effective administration and the procedure's efficacy includes the statement

the place of ECT in contemporary psychiatry is founded instead upon empirical demonstration of safety and effectiveness....it is precisely because the pathophysiology of mood disorder is incompletely understood that explanations of how the treatment works must remain provisional. ¹⁶

Fewer available published papers have successfully competed for entry to academia and associated medical journals to surveying ECT from the position of the user/survivor movement. Two systematic reviews were commissioned by the UK Department of Health (DH) in 2001, providing additional evidence for the NICE technology appraisal. Editorial comment in the British Medical Journal noted both "reveal the limitations of the primary studies and the need for genuinely collaborative high quality research – rather than research done by consumers for consumers and by clinicians for clinicians resulting in research with limited credibility". The proposed further restriction of usage by provisions in the Mental Health Bill 2006, to those set by the Mental Health Act 1983, continue the paradox of empirical and methodological contest in the socio-legal rights arenas.

¹⁴ J Breeding "Electroshock and informed consent" (2000) *Journal of Humanistic Psychology* 40:1 65-79 see also M Dolan, "appendix electroshock annotated bibliography" www.wildestcolts.com, see also

H A Youseff, "Electroconvulsive therapy and benzodiazepine use in patients who committed suicide" (1990) abstract Adv Ther (1990) May-Jun 7(3) 153-158

¹⁵ Royal College of Psychiatrists *The Practical Administration of Electroconvulsive Therapy* (1989) in C Samson, in B S Turner (ed) *Medical power...*(1995) 4 64

¹⁶ A Scott (ed) The ECT Handbook: The third report of the Royal College of Psychiatrists' special committee on ECT 2nd edn (2005) 201

¹⁷ D Rose, et al, "Patients Perspectives on Electroconvulsive Therapy: Systematic Review" (June 2003) *BMJ* 326(7403) 1363ff hereafter cited as, D Rose, et al, "Patients Perspectives ...(2003)

¹⁸ ibid 1343-1344. See also: P Tharyan and C E Adams, "Electroconvulsive therapy for schizophrenia. Cochrane schizophrenia group" (2003) *Cochrane database systematic review* CD000076, also The UK ECT review group, "Electroconvulsive therapy: systematic review and meta-analysis of effectiveness and safety in depressive disorders" (2003) *Lancet* 799-808.

Frequent citing of memory loss and other disabling features are made by people who have received the treatment, backed by other medical analysts who claim effects are achieved via iatronic brain damage in the areas responsible for memory. ¹⁹ ECT is not expected to achieve improvement in all patients. Rarely do studies show improvement rates with ECT alone above eighty percent of people treated, the treatment outcomes for those people where ECT was not viewed as beneficial may arguably be unclear. ²⁰

Mead in Rights, Research, Liberation writes

At a time, in mental health, when we are talking about "paradigm shifts" we forget that our methods and practises of research must also shift. Instead of focussing on individual illness constructs, we must focus on relationships, meaning, and social change.²¹

The further exclusion from the result process in terms of information, acknowledgment, and social change is arguably disintegration into the closing systems of the biological psychiatric model.

Social science has a role in collating and enabling the presentation of individual's recognition of discrimination and non-access to services. The Experts by Experience (EBE) group of the adult mental health service review in Northern Ireland emphasise that people themselves in receipt of healthcare "are the evidence in a very real sense" that is taken from them for evidence-based research, and that "autobiographical evidence must be given more importance than clinical data". Such narratives hold "a wealth of information about the roots of our distress and the process of recovery". The data collated in surveying ECT administration demands the human context is returned.²²

2. Omissions, data collection, and mandates

Research of the literature for this article found an initial assumption unwarranted that the number of people receiving ECT on a year on year basis in England since 1989 had stayed at near-constant levels. There was a steady decline in usage since 1991, shown in the *Electro Convulsive Therapy: Survey covering the period January* 2002

¹⁹ Dr L Rami-Gonzalez, et al, "Pattern of cognitive dysfunction in depressive patients during maintenance electroconvulsive therapy" (2003) *Psychological Medicine* 33 345-350

²⁰ Experts by Experience (EBE) group of The Review of Mental Health and Learning Disability (Northern Ireland), A Strategic Framework for Adult Mental Health Services (Jun 2005) 203-266, also, "Statement from Experts by Experience" part 9 ECT Appendix 7 225-232. See also: P R Breggin, "Electroshock: Scientific, ethical, and political issues" (1998) International Journal of Risk and Safety in Medicine 5-40 hereafter cited as, P R Breggin, "Modified ECT" (1998); D Rose, et al, "Patients Perspectives" (2003); Salford Report (1998) 2.84 13-16; S Bazire, Psychotropic Drug Directory (1994) 49 hereafter cited as, S Bazire, Psychotropic...(1994); Mind - The National Association for Mental Health, Mind nationwide ECTSurvey (March www.mind.org.uk/news+policy+and+campaigns/Presss+archive hereafter cited as, Mind nationwide ECT Survey (2001).

S Mead, *Rights, Research, Liberation* (Jul 2001) on-line at Shery Mead Consulting www.mentalhealthpeers.com 1-3 hereafeter cited as, S Mead, *Rights, Research, Liberation* (Jul 2001)

²² Experts by Experience (EBE) group (2005) 2.4 2.6 9.13 9.14 207,227

to March 2002, England. ²³ In the three months surveyed, 12 800 administrations were given to 2 272 people. These figures showed a 22% overall fall in administrations compared with a similar period surveyed and reported in 1999. ²⁴ This situation is contrasted with the approximately 140 000 recorded ECT administrations in 1985. ²⁵

The 2002 Survey was only the second attempt at ECT data collation and analysis from all English NHS trusts providing mental health services, and English private hospitals registered to detain people under the Mental Health Act 1983.²⁶ The NHS aggregate data return method was discontinued in 1991, and replaced by Hospital Episode Statistics (HES) where much finer detailed data was proposed to be collated for analysis.²⁷ However, ECT Survey data in comparison to HES data from the last quarter of 2001-2002 shows "clear evidence of the inadequate recording of ECT data on the HES system.....HES still appears to significantly under-estimate activity".²⁸

The category of "not stated" from ethnicity census group data accounted for nearly 18% of people within the 2002 Survey derived from HES. A statutory duty to collate such ethnicity data existed from 1996, and improved collection was supposed to have alleviated omissions from 1998/1999.²⁹ From a comparative contextual perspective, concerns about NHS Black and Minority Ethnicity census group recording were further raised in the context of the independent inquiry report and recommendations following the death of David Bennett during prolonged restraint. ³⁰ In highlighting the need to pursue the question of care construct origins, the report's recommendations were intended to inform processes leading to further health and social care progressive policy-making "to ensure that the findings and recommendations inform all relevant parties including the black and minority ethnic mental health strategy".³¹ The explicit statements from UK government social policy directions emphasise the ethical, legislative, and regulative mandates in respect to the rights and diversity of people and their experience, such statements finding their inscription, for example, within the Equality Act 2006.³² Following the report, discrimination and a poorer

²³ 2002 ECT Survey Statistical bulletin (08/2003) 3.18 6

²⁴ ibid

²⁵ ibid Figure 1, 3 The number of ECT administrations totals from 1985 at approximately 140 000, with an approximation given in 2002 of between 50 000 and 60000. The survey returns for January-March 2002 are available - is therefore the annual total an estimate by the Department of Health?

²⁶ 2002 ECT Survey Statistical bulletin (08/2003) 1.2 2

²⁷ ibid The NHS KH17 Korner central return 1990-1991 was replaced by Hospital Episode Statistics (HES)

²⁸ ibid 3.1, 3.2, 3.27, 3.18, 2, 6, 5; (e.g. Table 10 in Annex B compares survey data with HES data in the Q4 of 2001/02) 6.

²⁹ ibid 3.20, 3.21, 3.22 5-6

³⁰ "Report of The Independent inquiry into the death of David Bennett", report presented to the Secretary of State for Health and the Norfolk, Suffolk and Cambridgeshire Strategic Health Authority (17 Dec 2003) (set up under SHG (94)27) having limited powers. Hereafter cited as, "Report of The Independent inquiry into the death of David Bennett" (17 Dec 2003)

³¹ ibid terms of reference item 12 3, recommendation 4 67.

³² Equality Act 2006 (Commencement No. 1) Order 2006, see also, White Paper 'Our Health, our care, our say: A new direction for community Services', published (Jan 2005), hereafter cited as, White Paper 'Our Health, our care, our say...' (Jan 2005)

quality mental health service is still inherent in the contacts with black and minority ethnicity communities, where black men continue to be sectioned under the Mental Health Act 1983 at proportionally higher rates than people from other ethnic groups, and receive proportionally harsher treatment regimes, including ECT. The mental health and ethnicity census *Count me in* was carried out on 31 March 2005 by the statutory-endorsed bodies the Healthcare Commission, National Institute Mental Health England (NIMHE) devolved regional development centres, and the Mental Health Act Commission. Of 99% of people eligible for the census, previous research was confirmed that proportionately higher rates of admission to psychiatric care and detention are occurring among black people.³³

The 1999 ECT Survey highlighted HES where "many" NHS Health Trusts did not realise ECT should be recorded as an "operative procedure". Also, "Mental Health Trusts who do not usually carry out operations do not appreciate that there may be codes relevant to them". ³⁴ This misconception continued, exemplified by the 2002 Survey. ³⁵

Outpatient or day-case clinics were not yet covered by HES data collection.³⁶ Mental health was excluded from NHS National tariff cost codes 2006/2007, and NICE can only estimate costs associated with ECT administration.³⁷

The lack of official data from ECT administration sessions, people's ethnicity census group origin, and tariff cost to the NHS in delivering ECT has significant implications for considering current administration policy. Additionally, the 2002 Survey identified the majority group of ECT recipients were women aged over sixty-five years, being 47% of all women surveyed, with 45% of men surveyed being over sixty-five years of age. The 2002 Survey's associated statistical bulletin states that "the move in public policy from providing institutionalised care to community care is unlikely to account for these trends". 38

Additional research requires to be undertaken concerning these trends and the contexts of decisions that produce the disproportionate administration of ECT to people over the age of sixty-five, which may include examining the consent processes

also the accompanying 'Partial Regulatory Impact Assessment' (Mar 2006) hereafter cited as, 'Partial Regulatory Impact Assessment' (Mar 2006)

[&]quot;Count Me In mental health and ethnicity census of 31 Mar 2005", report in www.healthcarecommission.org.uk/nationalfindings/nationalthemedreports/mentalhealth/. See also: Mind nationwide ECT Survey (2001); and M MacAttram, (29 Apr 2004) in *Blink - Black Information Network* www.blink.org.uk.

³⁴ Department of Health, Statistical bulletin 22/1999 Electro Convulsive Therapy: Survey covering the period January 1999 to March 1999, England, (Sept 1999) 2.3 2.36

³⁵ 2002 ECT Survey Statistical bulletin (08/2003) 2.2. 2

³⁶ ibid 2.2, also iii 3.3 3. Approx. 19% of people were estimated to receive treatment in NHS outpatient settings in 2002 quartile, a rise from 14% in 1999.

³⁷ The Department of Health national Payment by Results tariff 2006/07 Gateway ref 6139 Appendix A: Specialised Service Exclusions, (31 Jan 2006)(revised 17 Mar 2006). The NICE TA59 estimates ECT cost by referring to six ECT sessions (£2475 not including estimated in-patient costs £171 per day 2003) 3 3.8 10. HC/HWA 18 Apr 2006 (pt 56): Column 214W - continued, Electroconvulsive Therapy [57595].

^{38 2002} ECT Survey Statistical bulletin 08/2003 Key facts 1

in these instances to ascertain whether they were exchanged actively or passively, and if current safeguards are adequate.³⁹

2.1. Human rights and the moral mandate to care

Understanding the basis of the moral mandate to care and how concepts of care are constructed may additionally reveal origins of intrusive ideological aspirations in the socio-economic and socio-legal domains. The explicit statements from UK government social policy directions emphasise the ethical, legislative, and regulative mandates in respect to the rights and diversity of people and their experience,

The communicative process for both subject as "patient" and healthcare professionals is also an internal process for each individual placed in the contested arena of best interest and necessity. As O'Hagan shows, assumptions embedded in medical practise from the extrapolation of belief, or ideological systems, contain within themselves the contradictions that must be overlooked for the delivery of, for example, ECT, to continue. 40 An ethic that may adversely affect longer-term quality of life could be viewed as an ethic of care that intends to overcome emergency situations to promote contingent being/life. Outreach and in-reach of care by ECT in mental health treatment enforcement commodifies the person - who has become a "patient". In the wider mental health domain, the subject is viewed as autonomous, yet is paradoxically being exposed to a generic system of care. The extrapolation of a person occurs into a group of people sharing common attributes, or a "class" of people, defined also in the Equality Act 2006, and the associated response is from a mental health service delivery "system". 41 The original subject may become the subject of intense medical de-humanisation. Roots of disparities in perspective are revealed where medicalised social normative constructs collide with personal rights, a personal culture, and group allegiance that find psychiatry's "belief in science, progress and rationality...informs the view that it is possible to objectify and systematically and clinically to study dysfunction in isolation from social and cultural factors..."42

An ethic that overrides refusals of consent, expressly interfering with the person in physical and psychological terms and legitimised by legal frameworks, seems paradoxical beyond the emergency. If the subject refuses consent for ECT in these instances - the legal, socio-cultural and ethics of subject and identity are continually fore-grounded.

2.2. Emergency treatments and the care relationship

The philosophy of care for "treatment" - and particularly for the interests of this article "emergency treatment" - is stated in the imperatives of Part IV of the Mental Health Act 1983. ECT currently comes under the auspices of s. 58 of this Part of the

⁴⁰ M O'Hagan *Force in Mental Health Services: International User/Survivor Perspectives*, Keynote Address Australian and New Zealand College of Mental health Nurses 29th International Conference, Rotorua (Sept 2003) hereafter cited as, M O'Hagan *Force* (Sept 2003)

³⁹ NICE TA59 1 1.4 5

⁴¹ Equality Act 2006 pt 1: The Commission for Equality and Human Rights: Duties Groups 10 2

⁴² D Pilgrim and A Rogers, *A sociology of mental health and illness* 2nd edn (1999) cited in B Fawcett and K Karban *Contemporary mental health, Theory, Policy and practice* (2005) 13-15 19

Act. Here, the Secretary of State also has powers to include or exclude treatments where treatment requires consent or a second opinion. In the accompanying Code of Practice, consent, necessity, and best interest are considered. This area of the Code of Practise also concerns adult patients who "may be mentally incapable of consenting to treatment or refusing treatment (...) due to temporary factors (...)" or which "may be more long-lasting". This controversial aspect of capacity and consent carries into legal argument surrounding so-termed "incapacitated compliant patients" and whether the Mental Health Act 1983 is an appropriate tool for the provision of treatment, or provides any appropriateness or protection for people liable to be detained in such circumstances. Section 58 treatments may be prescribed in the person's best interests under the common law doctrine of necessity. Explicitly, treatment is required to be:

necessary to save life or prevent a deterioration or ensure an improvement in the patient's physical or mental health; and in accordance with a practice accepted at the time by a reasonable body of medical opinion skilled in the particular form of treatment in question. 44

A person capable of giving consent or refusing consent, detained under the auspices of the Mental Health Act 1983, can only be given treatment by the operative procedure ECT in accordance with provisions of Part 1V, s. 58 of the Act. Application to the Mental Health Act Commission (MHAC) is required for assessment by the second opinion appointed doctor (SOAD) of the decision to treat in this manner. For instances of emergency treatment, the application of s. 62 provisions means the safeguards in s. 58 do not apply. The current legal and ethical safeguard in such s. 62 situations includes immediate referral when treatment commences to the Mental Health Act Commission SOAD, and a request for approval of the emergency treatment to continue, if this is deemed clinically necessary.

A differing enactment of the care relationship occurs when intervention, medically viewed to promote contingent being/life in such emergency situations, has demanded referral to the emergency clauses of s. 62.⁴⁶ Refusal of consent and any subsequent treatment administration implies in itself the imposition of a bodily intrusive operative procedure arising from the communicative and care relationships.⁴⁷ For those 1 656 people being treated as NHS voluntary patients receiving ECT in the three-month period of the 2002 ECT Survey, there were almost no instances of consent being refused. ⁴⁸ Conversely, a majority of the people administered ECT and detained under

⁴³ Code of Practice (revised 1999) 15.14 ff

⁴⁴ ibid 15.21 [the test that was originally laid down in Bolum v Friern Hospital Management Committee [1957] 1 WLR 582]

⁴⁵ Mental Health Act 1983 Part IV 60-64

⁴⁶ Mental Health Act 1983 Code of Practice (revised 1999) 16.40-16.44 hereafter cited as, Code of Practice (revised 1999)

⁴⁷ Mental Health Act 1983 Part IV 60-64, see s. 58, s.62 16.40-16.41 Part IV: 'is largely concerned with consent to treatment for mental disorder by detained patients in NHS hospitals and mental nursing homes, but certain safeguards in this part of the Act also apply to informal patients'. The process of consultation with the MHAC SOAD continues s.62 emergency treatments, for example, can be given without the patient's consent. It is stated in Part IV that treatments "for mental disorder will, of course, rarely come into this category".

⁴⁸ 2002 ECT Survey Statistical bulletin (08/2003) 3.18 5

the Mental Health Act 1983 provisions refused to consent to the procedure, at 60%, or 370 people. 49

2.3. Technology and protocols of performance

In the contemporary psychiatric domain where this particular operative procedure is used, the subject potentially is antagonistically related, being placed in a "clinical" yet non-"clinical" position where a convergence of disciplines competes.

The RCPsych Research Unit is responsible for leading the ECT Accreditation Service, launched May 2003. The purpose of this Service "is to assure and improve the quality of the administration of ECT in the United Kingdom and Ireland. Currently, this is a voluntary Accreditation process." ⁵⁰ Self and peer review is the core basis of this support network. If breaches of "service users" rights, dignity and safety are found, these are intended to be rectified by referral to the appropriate authority. ⁵¹

Comprehensive standards and accreditation process documents are available to aid the technical applications of the operative procedure, in conjunction with protocols for multi-disciplinary team working "these standards relate to the process of administering ECT and in this regard are consistent with NICE guidance. They do not relate to clinical decisions about which patients should be given ECT". ⁵²

Three levels of accreditation standards are available - rising from Type One to Three, where the explicit statements of minimum standards include "Type One: failure to meet these standards would result in a significant threat to patient safety or dignity and/or would breach the law..." 53

The standards require clinic protocols to be available for scrutiny, and emphasise "patient" safety and monitoring in both the short and longer term. ECT is therefore a collective process, not just the instance of the current of electricity being passed.

ECTAS is supported by the Royal College of Nursing and the Royal College of Anaesthetists, the Healthcare Commission recognising the accreditation as informing its mental health service inspection processes. Whilst the service users forum was involved in the design of the standards, the ECTAS December 2005 newsletter displays apprehension as to the inclusion and potential "bias" of service user/layperson representation in the clinic review processes "there was concern that those chosen should be subject to selection criteria to ensure their input is as balanced and objective as possible". ⁵⁴ Patently, there is an entrenched anxiety inherent in attempts at crossing the perceptual gulf from practitioner to "layperson".

The NICE administration criteria are different to ECT practise in countries, where, for example, those people with a medical diagnosis of schizophrenia may be more

⁴⁹ 2002 Survey Statistical Bulletin Key Facts Reference tables (08/2003) fig 4 3.17 3.18 5-6

⁵⁰ ECT Accreditation Service (ECTAS) *The Standards for the administration of ECT* 3rd edn (Dec 2005) CRU033 4 hereafter known as, ECTAS standards CRU033

⁵¹ ECTAS Accreditation Process booklet 4

⁵² ECTAS standards CRU033 4

⁵³ ibid

⁵⁴ ECTAS newsletter (Dec 2005) Issue 3 3

routinely treated. Such international practises have been initially surveyed by the Scottish ECT Accreditation Network (SEAN). This network being the only other such accreditation body before the formation of ECTAS, taking on a role post-2000 national audit, to "reassure the public" of ECT's "safe and effective" application, by providing "hard data" from "routine clinical practice" evidence to refute criticisms and lack of confidence expressed of the psychiatric profession in Scotland. 55 SEAN's website has not been updated since May 2005, and carries limited debate. A significant amount of ECT administration is applied worldwide in "un-modified" form i.e. without anaesthesia, oxygenation, and muscle paralysing drugs to prevent, e.g. bone fracture and respiratory difficulties. ⁵⁶ In this context, thirty-three countries of the wider Europe in 1999-2000 returned completed survey questionnaires for frequency of use, clinical indications, and associated clinical and legal guidelines for the European Association of Geriatric Psychiatry research study. Slovenia has introduced a ban on ECT usage, as have administrative areas of Italy. Other European states have stringent restrictions and use ECT in a limited fashion, such as Belgium and Germany. Few European states "have national or even regional guidelines on the administration of ECT". Certain Cantons of Switzerland had banned the practice, whilst "respondents from Latvia and Spain commented that obsolete equipment and lack of staff training also limit use to some extent". Of respondents, 39% cited treating schizophrenia as a main requirement, opposed by NICE for such routine administration, and only two respondent countries cited emergency criteria as a specific indication, again contrary to NICE. Protocols for obtaining consent are markedly varied, and further varied when consent is refused or cannot be given. In four countries, the option then cannot be ECT, and alternatives may be offered.⁵⁷ This research highlights the contradictory application of ECT across national boundaries, and brings the socio-legal frameworks if not into disrepute, then requiring further debate toward a human rights based consensual position, that is inclusive of "laypeople" and people from the mental health service user/survivor movement.

The variances of ECT technique, both in the UK and within worldwide healthcare systems are coupled with contradictions in diagnostic conditions. There are operative administration differences in the size of voltage applied, length of seizure requirements, in ranges from the placement of electrodes, associated pharmaceutical prescriptions for pre-medication and additional drugs to make the seizure to occur. However, the consensual effect required is to overcome the person's natural state of resistance to seizure, as detailed in the *Psychotropic Drug Directory* where the stated drug choices, and cross-references, give a complex scenario of chemical performance and potential risk, in association with the technology itself.

Previous indications were NICE would re-appraise ECT in November 2005.⁶⁰ The parliamentary written answers in April 2006 on behalf of the Secretary of State for

⁵⁵ SEAN Scottish ECT Accreditation Network (Project CA/96/10) National Audit of Electroconvulsive Therapy (ECT) in Scotland Final Report (Jan 2000) introduction

⁵⁶ SEAN Professional References 5 www.sean.org.uk/References/Guidelines

⁵⁷ M Philpot, et al, (2002) 41-45

⁵⁸ P R Breggin, "Modified ECT" (1998) pt 5

⁵⁹ S Bazire, *Psychotropic*...(1994) 49

⁶⁰ NICE TA59 9.1 22

Health state, "NICE is currently considering whether a review of the guidance is necessary at this time". 61

NICE emphasises the role of advocacy and prohibits coercion of the subject in their decisions concerning the choice or otherwise of ECT. NICE particularly requires interdisciplinary teams ensure that clarity of consent to treatment is achieved, with clear and accessible information and communication systems in place to achieve this position. ⁶²

Further research is required to analyse the impact of ECTAS as a voluntary network in the operative and socio-legal domains, and the extent of "best practise" dissemination. With the comparison to global usage, grounds exist for disseminating "best-practice" initiatives during the period of debate surrounding the underlying efficacy and ethics of ECT. This safeguards both the subject in receipt of ECT, and those administering this procedure.⁶³

In seeking a means to bring ECTAS and its protocols into the domain of NICE guidance, removing its voluntary emphasis in the UK might be a transitional compromise to the contradictory existence of ECT. There may be sufficient transference of protocol to devise a new transitional rights and autonomy-based document that could have influence beyond the UK and Ireland. Alternately, establishing an independent agency constituted with statutory authority to scrutinise, enforce, and disseminate "best practise" could be viewed as a progressive route forward. This, I argue, would also remove ECT monitoring responsibility from the associated voluntary accreditation networks, guidance bodies, and Royal Colleges, bringing such an agency into a more public domain. This proposal could enable people with direct experience of ECT to provide direction on policy and practise, and inform wider public debate.⁶⁴

Further debate is required as to whether this move would legitimise an already controversial practise that was subject to increased restriction of use in the now withdrawn draft Mental Health Bill 2004, a significant proportion of such restrictions being brought forward also to the Mental Health Bill 2006. The ECTAS First national report notes if rates of ECT usage continue to fall, following the trend from the collated 2003 DH Survey figures, "projected forward the rate will reach zero in 2012". Legislative restrictions, coupled with effective accreditation and scrutiny including any consideration of statutory interventions, could, I suggest, hasten this

⁶¹ HC/HWA 18 April 2006 (pt 56): Col 214W - continued, Electroconvulsive Therapy [57598]

⁶² NICE TA59 "Consideration of the evidence" 4.3.3 15

⁶³ Cf for a non-UK practice perspective SEAN Professional References (May 2006) 5,

also ECTAS First National Report (Oct 2003-Oct 2005) Appendix 1 ECT Clinic Staff Questionnaire, Referring Psychiatrists Questionnaire, Service User Questionnaire 29-33

⁶⁴ E L Simpson and A O House "User and carer involvement in mental health services: from rhetoric to science" (2003) *The British Journal of Psychiatry* 183 89-91. Also: Experts by Experience (EBE) group (2005) 225-232.

⁶⁵ J Cresswell, Z Fortune and P Lelliott (eds) foreword C Freeman ECTAS First national report Oct 2003 – Oct 2005 (2005) 1

process. Similarly, clinic viability in the meantime may become questionable as usage falls.

3. Standards and techniques of performance

In the news media, the operative procedure ECT can be described as though it is a limited series of linked actions - the general anaesthetic, the emphasis on the passing of the voltage - the machinery of ECT in conjunction with the doctor. The RCPsych ECT Handbook, and ECTAS Standards, for example, exemplifies the multifaceted and multi-professional dimensions of the procedure, yet the paradox of separation of the person from the technology is apparent in such media reports. Communicating the technological and chemical aspects of the procedure may become, in the clinical setting, separated from the bodies of medical research and academic articles where much of the debate occurs by practitioners.

In the clinical setting, informed consent is of paramount importance. Questions of trust arise in terms of checks and balances with regard to the integrity of the subject in relation to the competence of the chemical and technological administrators, and the ECT equipment itself. This is highlighted by reports of inadequate training and facilities. The December 2005 ECTAS newsletter explains the difficulties in providing accreditation for a number of clinics. This newsletter notes the target membership for the year was reached - eighty-one member clinics. Of these, thirtyeight had completed accreditation, three with excellence. The service is to undertake a "comprehensive recruitment drive" from April 2006 once research was completed to ascertain the exact number of ECT clinics within its remit in the UK and Republic of Ireland. Increasingly, the presentation of its improved technical administration is a feature promoted by advocates for its current and expanded application. Conversely, researchers state that the use of recent techniques of "modified" ECT actually increase risk of complications. The use of general anaesthesia, oxygenation, and additional medications for this method of delivery are thought to require higher voltages to induce the seizure, potentially increasing risk to the person. 68 69 Poor documentation, the absence of an anaesthetic assistant, lack of a capnograph (of use to measure CO2 to assess the adequacy of ventilation) and the lead consultant psychiatrist not having dedicated sessional time were "common reasons" for "mandatory Type 1 standards that clinics persistently fail to meet, resulting in those clinics accreditation being deferred".70

⁶⁶ www.news.bbc.co.uk/2/hi/health/619450.stm, also 460864.stm, also 295597.stm

⁶⁷ BMJ 326 (June 2003) 1343-1344

cf from a perspective of Scottish Executive Health Department, additionally enabling the psychiatric profession to respond to public criticism, CRAG (Clinical Resources and Audit Group) chaired by the Chief Medical Officer, the Final report (Project CA/96/10) National Audit of Electroconvulsive Therapy (ECT) (Jan 2000) introduction www.sean.org.uk/AuditReport/

⁶⁸ NICE TA59 5 5.2

⁶⁹ P R Breggin, "Modified ECT" (1998) *International journal of risk and safety in medicine* 11 (1998) 5 5-40

⁷⁰ Dr. J G McFadyen, "Respiratory Gas Analysis in Theatre" (2000) *Update in Anaesthesia* 11:34-37. Also: ECTAS newsletter Dec 2005 Issue 3: 2-3 nb The first edition of the ECTAS National Report was due to be published at the end of December 2005, although it is in the public domain, copies were not available via their website and links until an unspecified date after 04/05/06.

The Canadian Journal of Psychiatry carries the original research by Yuzda, et al, which nationally surveyed psychiatric residents in their final year of Canadian medical schools. Only 18% of respondents reported that "they feel completely competent administering ECT. Despite this, 59.3% anticipate working in an inpatient setting". The article highlights training deficits across national boundaries. This places responsibility on the discipline of psychiatry to decide whether it wishes to promote, for example, more consistent training, "...if not, ECT may be legislated into obscurity - an outcome that will certainly compromise the care of a sub-set of patients who are severally ill and whose lives have been improved by this treatment". ⁷¹ The training deficit in Canada is echoed by the first national ECTAS report, which identified training as a particular need reported by "more than one half of referring psychiatrists..."

3.1. Legislating against intrusion

In light of the government bringing forward an amendment Bill to the 1983 Mental Health Act, provisions in the Mental Capacity Act 2005 - concerning, for example, consent, advance directives, and legal safeguards for incapacitated people regarding intrusive healthcare, may be models for a direction for mental health legislation that promotes autonomy and choice in this operative area of psychiatric practise.⁷³

Within the now-withdrawn draft Mental Health Bill 2004, it was proposed electroconvulsive therapy would not have been available to those under eighteen years of age, unless certain safeguards were fulfilled, including restrictions that held sixteen-seventeen year old people to be viewed as autonomous subjects who could over-ride previous parental or guardian consents given on their behalf. Ensuring such socio-legal protections are maintained in proposed legislation could be viewed as promoting the quality of consensual relationships. Otherwise, "a general prohibition" of ECT would come into being, to quote the parliamentary Joint Committee.⁷⁴ Legislative proposals in effect left ECT as a legal option only for voluntary patients having giving informed consent, and emergency treatment. These potential legislative revisions were mostly welcomed by the Mental Health Alliance membership and wider opinion. 75 The alliance consisted then of seventy-seven mental health charities, professional bodies, and human rights organisations. It continues uniquely to span all reaches of society and interest groups, coming together as a political lobbying grouping. Current proposed legislation is separate to the Scottish Mental Health Act 2003, whereas a public consultation and review of the Northern Ireland mental health services has produced the directional document A Strategic Framework for Adult

⁷¹ E Yuzda, et al, (Dec 2002) 938, 942. Also: ECTAS standards CRU033 'Staff and training' 2 5-8

⁷² As above, ECTAS First national report (2005) 2 Theme 5 19

⁷³ Mental Capacity Act 2005 ch 9 s. 2-6, 24-26, 35-41

⁷⁴ Report from the Joint Committee on the Draft Mental Health Bill (HL Paper 79-I HC 95-I), Session 2004-05, (23 Mar 2005) (346, clause 178 response) The draft Mental Health Bill 2004, published Sept 2004, was proposed to replace the Mental Health Act 1983. Also: Law Society evidence to draft Mental Health Bill 2004 consultation 367 (411 evidence).

⁷⁵ Mental Health Alliance on-line coalition web page <u>www.mentalhealthalliance.org.uk</u> hereafter cited as, coalition <u>www.mentalhealthalliance.org.uk</u>

Mental Health Services. ⁷⁶ Under the Government of Wales Act 2006, the 2006 Bill's implementation, development of a Code of practice and much of the statutory instrument making are Welsh Ministers' responsibility. A differential system in the policy and practise of ECT administration potentially emerges across the UK.

3.2. Emergency administration and consent

The recently published Mental Health Bill 2006, as with the previous draft Bill, still permits ECT if judged an "immediate necessity". In such situations, it could be applied to a person without their consent. In comparison with the Mental Health Act 1983, the safeguard conditions required to be complied with in this Bill are more comprehensive for previous s. 58 treatments, as are the three conditions for "immediate necessity" of treatment for people believed to lack capacity or competence. 77 However, for a person to arrive at a fair and informed choice, alternate choices require presentation in order for informed consent or refusal of consent to be "positively" rather than "passively" given, as currently required by the current Act's Code of Practice.⁷⁸ A call for clear limits of two emergency ECT administrations for inclusion in the draft Bill 2004 was tempered by the intended Government response of permitting two per week for two weeks.⁷⁹ It should be noted that the average course of usual administrations per patient given in the 1999 and 2002 ECT Surveys was between five and six.⁸⁰ NICE holds a pivotal role in recommending treatment protocols for these ECT emergency administrations. But, as the RCPsych ECT Handbook asserts, "NICE guidance on ECT does not have any legal jurisdiction over clinical practice, and its legal significance could be established only if it were cited in a court case". 81 It should be recalled at this point that a number of other countries have developed alternate healthcare options in situations where ECT is at present chosen in the UK, as shown by Philpot, et al.⁸²

3.3. Anomalies in official statements concerning emergency treatments

An anomaly exists in the Government's response to the 2005 Joint Committee's consultative report concerning the administration of "emergency treatment", with regard to the now-withdrawn draft Mental Health Bill 2004. The Government estimated that 10% of patients are given "emergency treatments" with ECT. This differs from the 2002 ECT Survey, where emergency treatments are recorded. 83

⁷⁶ Mental Health (Care and treatment) (Scotland) Act 2003 ASP 13. Also: The Review of Mental Health and Learning Disability (Northern Ireland) A Strategic Framework for Adult Mental Health Services (Jun 2005).

⁷⁷ Mental Health Bill 2006 [HL] ch 1 6, 7 ch 2 11 ch 4 27,28

⁷⁸ Code of Practice (revised 1999) 16.9 16.40-16.41

⁷⁹ Government Response to the Joint Committee's Report (Cm 6624) (13 Jul 2005) Department of Health recommendation 77

^{80 2002} ECT survey Statistical bulletin (08/2003) 3.5 3

⁸¹ RCPsych ECT Handbook 'Place of ECT in contemporary Practice' (2005) 7

⁸² M Philpot, et al, (2002) 41-42

⁸³ Joint Committee on the Draft Mental Health Bill - First Report (09 Mar 2005) 367 [411] evidence of the Law Society 2004, see Schedule of Comments, Government Response, Emergency ECT:

In the 2002 Survey, "emergency treatment" was administered to 1.6% of voluntary patients. These "emergency treatments" total 102 of the 2 272 total of people surveyed, with seventy-six of those 102 surveyed representing people being detained under the Mental Health Act 1983. ⁸⁴ Therefore, the Department of Health could be seen to have over-estimated ECT emergency treatments in citing over 220 people in this quarter of 2002, rather than 102 people.

There also appears to be an anomaly in the data recording or otherwise of the use of the Mental Health Act 1983, and the definitions of "emergency treatment" as perceived by the government. The legal status of the "patient" is unclear if both voluntary and involuntary "patients" are included in the government "emergency treatment" assumptions.

Clear and comprehensive data collection is required to enable informed debate in areas of potential ECT policy-making and legislative formulation.

It is assumed in the 2002 Survey that s. 62 provisions of this Act are being used for ECT emergency administration. The 2002 Survey alludes to the contextual situation for the refusal or giving of consent, but is not required to draw further inferences. The stated assumption is that emergency treatment data "...will include those people unable to consent because of the serious nature of their illness". 85 The survey does not record whether people were detained previously to ECT, or whether contexts surrounding consents or refusals for ECT precipitated the detention. Such detail, if known and continually monitored beyond the surveying by the Mental Health Act Commission, may provide assistance toward determining coercion or otherwise in terms of the imposition or withholding of the Mental Health Act 1983. 86 This is prohibited for use as a persuasive tool to gain voluntary consents, or ultimately to enforce treatment options.⁸⁷ The MHAC eleventh biennial report *In place of fear?* discussed the question of capacity, including the "indeterminacy of the concept of capacity" and use of emergency powers in light of the proposed changes in legal frameworks for treatment interventions and detention in conjunction with amending the Mental Capacity Act 2005. It notes an increase in the average percentage of ECT SOAD visits where emergency treatment has already begun, from an average of 12% in 2002/2003, to 19% 2003/2004, to 25% in 2004/2005. MHAC states the increase cannot be explained, "although it may be related to the effect of NICE guidelines promulgating ECT as a treatment only of last resort". 88 Viewing the figure given, it would seem in 2003/2004 to 2004/2005, approximately 206 people - refusing, or incapable of giving consent, were administered ECT in such situations. This is a significant departure from 2002 ECT Survey analysis and definitions of "emergency treatment", highlighting further the requirement for increased clarity and additional

conditions 128(b) annex 4, responding to National Voices Forum [DMH 240] Matrix Advocacy Service [DMH 169] see press release DH 2006/0147

⁸⁶ The Mental Health Act Commission, *In place of Fear?* (Jan 2005) Eleventh Biennial Report 2003-2005 238-242 hereafter cited as MHAC (Jan 2005)

^{84 2002} ECT Survey Statistical bulletin (08/2003) 3.17 5

⁸⁵ ibid 3.18

⁸⁷ Mental Health Act 1983 Code of Practice (revised 1999) 15.13

⁸⁸ MHAC (Jan 2005) fig 64 footnotes 99-101 240-241

detail of information, with increased monitoring of actual practise to enable full comprehension of ECT activity.

The use of the operative procedure as one of "last resort" limits choice for both clinical team and the potential recipient, arguably inducing further compliance. Additionally, The Law Society, referring to the government estimates of the extent of emergency interventions, was concerned that the emergency treatment power would come to be used extensively. The Law Society, in their evidence, "... found it difficult to envisage an emergency where the patient would retain capacity". However, the MHAC report recalls legal argument surrounding so-termed "incapacitated compliant patients" and whether the Mental Health legislation is an appropriate protection, whilst O'Hagan questions the assumption that capacity is absent in situations. 91

3.3.1. Debating requirements for safeguards

This places the debate about safeguards for excessive treatments, consents, legal status, and the questioning of a person's capacity into sharp focus in relation to rights and autonomy. Bringing forward legislative proposals to restrict the use of ECT for adults giving informed consent, and/or restriction to adult "emergency treatment" are policy options. The maintenance and extension of legal safeguards concerning consent, with people under the age of eighteen years referred to the Mental Health Tribunal for decision overview, would re-establish ground in the Mental Health Bill 2006 from the previous generally consensual positioning. ⁹²

4. Contexts and capacity

4.1. Force and personal imperatives

An imperative exists for the personal narratives to break through the figures forming the constituent identity of those administered ECT with, or without consent, as the potential for coercive practice is present.

O'Hagan recognises that "the long and labyrinthine process of legislative reform" is the ultimate way to reduce or eliminate force and compulsion in mental health services. The conclusion can be drawn that other routes or methodologies exist to "discourage" models that imply coercion in their structure. 93

"Force" is defined by O'Hagan as "a user/survivor movement term for compulsory interventions by mental health services that are allowed by the law". 94 She recognises the origins of the:

see also Mind nationwide ECT Survey (2001), also Experts by Experience (EBE) group (2005) 9.9 9.10 226

⁸⁹ M O'Hagan Force (2003) 8

⁹⁰ Joint Committee on the Draft Mental Health Bill - First Report (09 March 2005) 367 [411] evidence of the Law Society 2004

⁹¹ MHAC (Jan 2005) 240-241. Also: M O'Hagan, Force (2003) 4-5

⁹² coalition www.mentalhealthalliance.org.uk/alliancepolicies/children.htm

⁹³ M O'Hagan Force (2003) 8

⁹⁴ Ibid 4

...user/survivor movement's stand on force....as a liberation movement on the same historical wave that carried other movements of that era - women's liberation, gay liberation and civil rights - in which the oppressed claimed their right to self-determination. 95

O'Hagan continues to foreground human rights agreements, "including the legally binding 'International Bill on Human Rights' ... users/survivors recognise the violation of these articles by the use of force in psychiatry". The debate from within the movement is presented, as "compulsory treatment sets out to control who you are, whereas compulsory detention merely controls where you are". Also, "due process needs to include the upholding of rights protections and advocacy processes in mental health legislation". Two prevailing views persist

...that people with serious mental distress lose competence to take responsibility for their lives. The second is the assumption that mental health services are helpful to these people. Both these assumptions operate in a context where the bio-medical model is used to explain and treat mental health problems. ⁹⁸

Alleged breaches of rights and damage to the subject in the mental health domain may be enforceable legally against statutory authorities. In practise, it is very difficult to seek recourse, as more often such breaches highlighted by user/survivor are interpreted by "disciplines" as evidence of an un-cooperative identity. ⁹⁹

Stefan's article *Competence Issues in Self-directed Care* addresses individual choice within a self-directed care framework, challenging legal or clinical assumptions that "competence inquiries" should be an element in any care planning models. Historically, such "inquiries" have been used to limit choice and maintain discrimination, "with proper planning, competence should rarely, if ever, be a concern in self-directed care for people with psychiatric disabilities". Self-directed care models, deriving from self knowledge and self-sustaining networks of relationships, and continuing through acute crisis, or "increased symptoms" as one project described, enables these "crisis" to become "managed" in a community setting "with reassurance and assistance". The self-directed care program in Florida has not noted "a single involuntary (hospital) commitment since the inception of the program". ¹⁰⁰

ECT, unless restricted in administration to the emergency setting, exemplifies the user/survivor movement challenge to the healthcare assumptions detailed by O'Hagan. Its restriction to the emergency setting meets only the minimum requirement argued toward reducing the use of force in psychiatric practise - a

⁹⁶ International Bill on Human Rights, inclusive of the universal declaration of human rights, adopted by resolution 217 A (iii) (10 Dec 1948) Articles 4,5,6

⁹⁵ Ibid

⁹⁷ M O'Hagan Force (2003) 4-5

⁹⁸ Ibid 5

⁹⁹ ibid 3 8

¹⁰⁰ S Stefan, Competence Issues in Self-directed Care (March 2004) Centre for Public Representation, Massachusetts 2 10

guiding principle of the movement. The maintenance of bio-medical models with interrogation of mental capacity within mental health service intervention principles continues the legislative process of imposing truth via coercion.

A gulf is seemingly apparent from positions of peoples' experiences of the affects and efficacy of ECT, situations of consent or refusal, and those involved in the administering and administration of the process. Yet little literature is available viewing the affects of involvement in ECT administration and surrounding processes for individual staff, staff teams, carers, families, friends - the social milieu of relationships and personal and professional interfaces, whether they be in the clinic settings or beyond. This is an area requiring further research.¹⁰¹

4.2.1. Reform and holistic experience

Here, the Mental Capacity Act 2005 is pertinent "as a new legal presumption is entered: that everyone has the capacity to make decisions unless it is shown otherwise". 102

This Act lays the foundation for substitute decision-making, with a premise of supporting people to come to their own decisions where possible. The delivery of "care and treatment" must be in the person's "best interests" and the option of "least restriction" must be taken with regard to the person's rights and freedoms. The Court of Protection's role is now changed to cover applications for challenge of care and treatment decisions. ¹⁰³

Written Advance Directives, already legally recognised and embedded in the Mental Capacity Act 2005 - that may contain refusals of certain medical treatments and aspects of substitute decision-making - do not apply to those people detained under a section of the Mental Health Act 1983. Advance statements for choices of care and treatment when capacity may be in question, were not proposed for legal recognition in situations coming under the auspices of Part IV Mental Health Act 1983, or 4A proposals - treatment of a person subject to Supervised Community Treatment (SCT) - of the subsequent 2006 Bill, including "immediate necessity" treatment. They are acknowledged to be taken into account in the communicative processes exploring different forms of treatment that may achieve the same effect. When people are deemed as lacking capacity, those in contact with mental health services will be receiving medical treatment and advocacy by different principles in the situations of

Department of Constitutional Affairs Consultation Paper (Mar 2006) 9.28

¹⁰¹ for a discussion of ethics and empathy in mental health situation see,

S E Estroff, Subject/Subjectivities in Dispute: The Poetics, Politics, and performance of First-Person Narratives of People with Schizophrenia, (2004) ch 11 282-302 see also,

S Clay, "The Wounded Prophet" (1994:2) paper presented at the First National Forum on Recovery from Mental Illness sponsored by the National Institute of Mental Health cited in J H Jenkins and R J Barrett, (eds), Schizophrenia, Culture, and Subjectivity (2004) 287-288

¹⁰² Mind briefing notes on-line Mental Capacity Act 2005 www.mind.org.uk

¹⁰³ Mental Capacity Act draft Codes of Practice ch 7 89-95, see also

¹⁰⁴ Mental Health Bill 2006 draft illustrative code of practice (Nov 2006) 16A.12 97

"serious medical treatment" decision-making processes and safeguards. ECT is named as one of such treatments attracting advocacy rights for people without capacity as outlined in the "summary of responses document" toward the establishment of the Independent Mental Capacity Advocacy (IMCA) service in 2007. The government "realises that secondary legislation will be needed to set out the types of serious medical treatment decisions where an IMCA should be involved". 106

The government recognised that definitive lists of "serious medical treatments" were not advisable, and included within the Consultation on the IMHA service responses document a commitment to "set out the characteristics of the decision to be reached", potentially providing for greater autonomy and choice for each individual. ¹⁰⁷ ECT is explicitly referenced alongside, for example, such "major" operative procedures as open-heart surgery, non-therapeutic sterilisations, and the withholding/withdrawing of artificial nutrition and hydration (ANH). ¹⁰⁸ There is acknowledgement that a court application will need to be made in certain cases of such treatments. ¹⁰⁹ Therefore, whilst ECT has been the subject of small-scale research producing an outcome of a "routine" procedure, its status places it legally and operatively in the perceptual boundaries of "serious medical treatments". ¹¹⁰

The Mental Health Bill 2006 did not redress the existing Act's absence of advocacy services in terms of rights and autonomy for supporting informed choice, for example in ECT administration decision-making. In one setting, individual independent advocacy provision is viewed as a right; in another – detention by the Mental Health Act 1983, including Part IV provisions, no recognition of similar rights or advocacy provisions are provided for, removing aspects of autonomy. Treatment impositions derive from concepts of best interest and necessity, interpreted from differing assumptions of "reason" in the Mental Capacity Act and Mental Health Bill, leaving an apparent hierarchy of rights.

The consensus view beyond this government decision was that including binding recognition for such advance decisions would be a positive contribution to rights and autonomy. ¹¹¹ On requesting the governments intended direction for ECT safeguards in any future amendment Bill, and following the parliamentary written answers of April 2006, ¹¹² a reply was received from the Minister of State, Department of Health. The government position, in stating it had "no plans to change the provisions" for ECT "in any amendments to the Mental Health Act 1983", differs from previous increased restrictions welcomed by the Mental Health Alliance and placed in the

¹⁰⁵ Mental Capacity Act 2005 ch 11 90-92

Department of Health "Consultation on the Independent Mental Capacity Advocate (IMCA) service 2005: summary of responses" (5 Jul 2005) ch 11 90 24

¹⁰⁷ ibid ch 11 90-92 24-25

¹⁰⁸ ibid ch 11 92 25

¹⁰⁹ ibid 92 25

¹¹⁰ S M Benbow and J Crentsil "Subjective experience of electroconvulsive therapy" (2004) Psychiatric Bulletin 28 289-291

¹¹¹ coalition www.mentalhealthalliance.org.uk/alliancepolicies/advancedirectives.html

¹¹² HC/HWA 18 Apr 2006 Col 213W [57586]

withdrawn draft Bill 2004.¹¹³ Yet, this change occurred, the evidence base for the legislative drafting remaining unclear following the changes to lesser restriction than the 2006 draft Bill's predecessor, and the absence of services and recognitions, as detailed above, required by the Mental Capacity Act 2005.

4.3. Alternate research methods and evidence bases

Methodological attempts to find governing loci of prevailing "reason" to law and regulation include scrutiny of how controversial practises in the mental health domain become legitimised, albeit though progressive legislative and regulatory frameworks. The selection and extrapolation of peer-reviewed research that provides alternate perspectives is an ethical goal for achieving equality in evidence promotion. The trauma-informed research methodologies of Mead, Hilton and Curtis, and social discourse-theory methods, re-position the subject, whom medical research often treats as an experimental repository of data rather than an individual person. Stefan, likewise this current article concerning ECT, may be seen to be positioned in a transitional domain between these differing perspectives.

In the context of the recent UK government White Paper Our Health, our care, our say: A new direction for community Services, and its accompanying Partial Regulatory Impact Assessment, an opportunity exists to develop alternate model service community support, coupled with individual autonomous recovery and health promotion facilitation. ¹¹⁶

In the White Paper, communication, dignity, and autonomy are emphasised, alongside individualised care delivery and the development of prevention strategies particularly in Primary Care Trust driven primary care commissioning. This may provide opportunities for people to access appropriate support earlier, and negate emergency hospital admissions. Service models will need to be developed with the full support, engagement, and trust of people with direct experience of mental distress and contact with mental health services. This could further reduce the use of ECT in the UK. However, concern has been expressed that the extension of compulsory powers (SCT) into community settings may increase the contacts with mental health services, causing increased medical interventions to the person. 118

¹¹³ Personal correspondence, Letter from the Minister of State, Department of Health (31 Aug 2006) ref C/246/06JL

¹¹⁴ S Mead, D Hilton, and L Curtis "Peer Support: A Theoretical Perspective" (2001) *Psychiatric Rehabilitation Journal* 3-6 also,

S Mead "Rights, Research, Liberation" (July 2001) 1-3

¹¹⁵ S Stefan (Mar 2004). Also: S Mead, D Hilton, and L Curtis (2002) 5-6

¹¹⁶ White Paper 'Our Health, our care, our say: A new direction for community Services', published 30th January 2005, and its accompanying 'Partial Regulatory Impact Assessment' (10 March 2006) 2.80-2.83

¹¹⁷ DH/Patient and Public Involvement Team A stronger local voice... (2006)

¹¹⁸ Mental Health Bill 2006: Reg impact...(2006) Annex B 8 59

5. Toward a conclusion

A moratorium of ECT administration is an option to pursue, enabling full consideration of alternate research and surveying of actual clinic practice that is inclusive of service user/survivor expert by experience evidence. ¹¹⁹ In light of previous and current draft legislation further restricting the use of ECT in England and Wales, permitting its use solely for situations of an adult person giving fully informed consent would be a transitional compromise. The draft Mental Health Bill 2004, now withdrawn, and its 2006 successor, do begin to address a number major concerns expressed from the public arena.

I am reminded of Dworkin's statement on the role of social scientists in the processes of social change, offered in her book *Life and Death*. Extrapolating from her statements concerning battered women:

Social scientists find a pattern of injury and experts describe it...They are listened to respectfully, are often paid to give evidence in legal cases. Meanwhile, the voice of the victim still has no social standing or legal significance. She still has no credibility such that each of us-and the law-is compelled to help her.¹²⁰

With the voices of individuals and political movements continuing to enter the debate on the administration and efficacy of ECT, coupled with further possibilities of involvement from legal frameworks in compelling socio-cultural change "those of us who are not jurors have a moral obligation to listen..."

To face both the silences and bodies of accumulated evidence, such an obligation is inclusive of the equal right of admission to alternate methodologies and promotion of "expert by experience" evidence-based data collection, analysis and presentation. The methodologies from trauma-based perspectives coupled with the fact that the people subjected to ECT and the mental health system are both the expert witness and, for an alleged ECT medical research "industry", the personal evidence that is appropriated to drive this "industry". Alternate evidence-bases assertively challenge the widespread adherences of state-endorsed medicalised practise to prescribed hierarchies of method. Retaining prevailing structures of evidence recognition that predispose the extrapolation of certain medical/scientific models for ECT's functional efficacy and placement in a diagnostic and operative setting mean limiting possibilities for fully informed debate, and collaborative research. This paper has sought to find a position in a transitional domain between the differing perspectives.

Declaration of Interest

Whilst a voluntary patient in 1987, I refused consent to have ECT administered, and was given alternative treatments. National and local positions with third sector organisations were vacated to mitigate any potential conflict of interest in policy decisions, should they have arisen.

¹¹⁹ Experts by Experience (EBE) group (2005) 9.2 230

¹²⁰ A Dworkin, Life and Death, (1997) 45-46

¹²¹ ibid 47

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