# REPRESENTING THE MENTALLY ILL\*

## The critical role of advocacy under the Mental Health Act 1986 (Vic)

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We call upon all people committed to human rights to work together to build a mental health system that is based upon the principle of self-determination, on a belief in our ability to recover, and on our right to define what recovery is and how best to achieve it.<sup>1</sup>

This statement forms part of the National Association for Rights Protection and Advocacy (NARPA) call for action in the United States. However, it is a call that should be recognised and acted on by advocates in Victoria (and the rest of Australia). Currently, the Mental Health Act 1986 (Vic) (MHA)—although a hard fought for improvement on the earlier laws — affords no real self-determination in the treatment of mental patients. Further, a severe lack of advocates means that even least-restrictive treatment (parliament's key objective in enacting the MHA) is a shamefully unrealistic expectation for mental patients unable to represent themselves where psychiatrists and other mental health workers base their Mental Health Review Board (MHRB) testimonies on often erroneous and biased evidence.

#### Regulating the mental health system

The objectives of the MHA are, in essence, to provide for the care, treatment and protection of mentally ill people (MHA s 4). These objectives are advanced through the provisions of the MHA that, among other things, allow for the involuntary detention and treatment of those who appear mentally ill, require immediate treatment through admission to hospital, cannot or will not consent to treatment, and are seen as a danger to themselves or the community (MHA s 8(1)).

The state of a person's mental health determines whether they have the capacity to consent to or refuse treatment and thereafter the treatment options. Via their privileged position of clinical judgment, psychiatrists are employed as the gatekeepers of patient care, treatment, protection and rights.<sup>2</sup> The majority of patients have no representation outside psychiatry, and in order to regulate an otherwise plenary discretion, the MHA set up the MHRB. However, without independent representation or advocacy on behalf of the patients who cannot speak for themselves, the MHRB will make a determination based on the evidence of the treating psychiatrist, which may not be the least-restrictive treatment option.

#### The Mental Health Review Board

The MHRB periodically reviews and hears appeals against involuntary detention (and therefore treatment) (MHA s 22). The MHRB consists of a legal, a psychiatric

and a community member. Unlike most administrative boards, the MHRB is deciding on patient liberty. As such, a system of unbiased decision-making open to accountability should be in place.

However, there are a number of potential problems with these elements of the MHRB. For example, the Board 'must have regard primarily to the patient's current mental condition and consider the patient's medical and psychiatric history and social circumstances' (MHA s 22(2)). In doing so, 'the Board will always give great weight to the opinion of treating doctors ... it would only be in a rare case that a board would reject a clinical judgment reached by a treating doctor'.<sup>3</sup> And, 'it is almost impossible in most places to find any psychiatrist at all who would even consider providing a counter-expertise in favour of a user contesting a civil commitment order'.<sup>4</sup>

This means that without advocacy, a mental patient's review or appeal depends almost wholly on clinical judgment. On the one hand, this is positive, because the treating doctor presumably knows the patient better from their frequent contact and care, although anecdotal evidence suggests 'frequent' may be an overstatement. On the other hand, however, if a psychiatrist relies on a patient's history in recommending treatment, this recommendation may be coloured by or based on this history, not on their current mental state, resulting in a more restrictive treatment than necessary. Also, the treating psychiatrist's judgment may be flawed, and since this judgment is the basis for the MHRB's decision, incorrect decisions may be made. This is where the role of an advocate — be it a lawyer or other person — is critical. An advocate will act to critically examine the evidence of the psychiatrist and other persons acting to maintain a patient's current treatment, and submit less restrictive treatment options for the Board to consider. It is pertinent, therefore, to examine exactly how a typical decision is made, the basis for clinical judgment, and therefore the likelihood of incorrect decisions being made in the absence of appropriate representation.

#### In the matter of JM

In the matter of JM (1996) 2 MHRBD (Vic) 282 was an appeal of a 36-year-old woman diagnosed with schizophrenia in the early 1980s. The appeal concerned an involuntary admission. Among other things, JM contested the treatment on the grounds that the costs of side effects were so severe — both in the long and short term — that they far outweighed any possible benefits. Her reasoned analysis of the side effects

#### REFERENCES

- \* Use of terms such as 'mentally ill' represents an adherence to the wording of the MHA. not the author's views.
- 1. 'The Highlander Statement of Concern and Call to Action' (25 March 2000) <a href="http://www.narpa.org/highlander.htm">http://www.narpa.org/highlander.htm</a> at 2 August 2004.
- 2. Victoria, Second Reading Speech, Legislative Assembly, 30 May 1985, 925-37 (Mr Roper, Minister for Transport) 72: 'the state of a person's mental health is a matter for clinical judgment'.
- 3. In the Appeal of TJS, Mental Health Review Board, and Decision No. 220989: 701:525372. NV.
- 4. Michael McCubbin and David Cohen, 'The Rights of Users of the Mental Health System: The Tight Knot of Power, Law and Ethics' (Paper presented at the XXIVth International Congress on Law and Mental Health, Toronto, June 1999).

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'impressed' the Board and was (along with JM herself) referred to as 'intelligent' numerous times. However, the Board decided that treatment was in her best interests. Instrumental to this decision was the extended testimony of Dr LW (and to some extent Dr SP), which included the following:

- the doctor was unable to identify any factors rendering JM unable to make decisions but, as a generalisation, her illness may erode her powers of judgment (at 294);
- because JM did not acknowledge that any improvements were a result of the medication, her insight was still somewhat limited (at 290);
- the side effects she indicated were not 'recognised side effects of the medication' (at 291); and
- specifically, the delusions experienced as a side effect of the medication were 'not plausible' (at 291).

Although these arguments can be shown to be erroneous and may be quashed with little effort, the third and fourth should be refuted because they require no subjective debate. Breggin and Cohen demonstrate that 'all of them [neuroleptics] can cause toxic psychoses with delirium, confusion, disorientation, hallucinations, and delusions' (emphasis added).5 Although this book was not published until three years after JM's case was heard, the studies were available as early as the late 1970s — which is presumably where JM found the material for her analysis. In fact, every one of IM's fears is supported by solid evidence. That IM was keen to control her symptoms with alternative medicines held little weight with the Board who did not think 'it would be as beneficial to her in practice as the existing course' (at 294).

Although the Board commendably commented on the delicate balance that must be struck in such a case, this does not help JM. She (if still alive) will be 44, and one wonders what sort of future remains for her now. Has she developed Tardive Dyskinesia (25-35% risk after five years<sup>6</sup>)? Has she died from Neuroleptic Malignant Syndrome (2.4% risk<sup>7</sup>)? More importantly, why did the treating psychiatrists fail to take account of the findings that consistently undermine their basis for detaining JM?

These are the questions that JM did not — perhaps could not — raise, and questions a *well-versed* advocate would. Had this not been the case, it is likely that a different result would have ensued. This is also a reason for advocates to raise JM's request for self-determination in public policy forums.

#### Reliability and validity problems

Further, in critically examining a psychiatrist's testimony, an advocate would be in a better position than the patient before the Board to question the basis of the psychiatrist's clinical judgment.

For example, there is substantial evidence questioning the reliability and validity of psychiatric diagnosis.<sup>8</sup> Diagnosis often determines the treatment of the particular mental illness which of itself may lead to a less restrictive alternative. If this evidence were produced by an advocate it may be damaging to the psychiatrists giving evidence, but would certainly assist in encouraging actual evidence to be produced, rather than mere subjective judgment.

#### Bias

A lack of zealous advocacy creates the possibility that lax clinical studies may influence the treatment options of patients. In a recent Swedish study, for example, a thorough analysis of data — both publicly available and not publicly available — showed the prevalence of multiple publishing of clinical trial results, and selective reporting and publishing of these results. The authors concluded that '[w]ithout access to all studies ... and without access to alternative analyses ... any attempt to recommend a specific drug is likely to be based on biased evidence'.9 They also noted the conflicts of interest because the sponsor (normally pharmaceutical companies) has all the available data and — along with editors and investigators — affect whether and how scientific data reach the public domain. Obviously, this public domain includes psychiatrists, the MHRB as well as drug consumers, and this report is not publicised in leading psychiatric textbooks. This is not an isolated study.10

These studies are supported by independent findings from various psychiatrists, in particular International Centre for the Study of Psychiatry and Psychology (ICSPP) members: most notably, Breggin in *Toxic Psychiatry*l systematically undermines many of the leading studies (usually funded by drug companies, either directly or indirectly).

But biased decision-making cannot be blamed on the MHRB or the judiciary (or in some cases, even psychiatrists) if no valid dissent appears in their reference material.<sup>11</sup> This is where the voice of the advocate is particularly important.

For example, in New Zealand there have been judgments that have gone against the opinion of clinical judgment. 'In In the Matter of an Inquiry under the

- 5. Peter Breggin and David Cohen, Your Drug May Be Your Problem: How And Why To Stop Taking Psychiatric Medications (1999) 80.
- 6. Ibid 78. Tardive Dyskinesia involves irreversible abnormal movements of any of the voluntary muscles of the body.
- 7. Ibid 79. Neuroleptic Malignant Syndrome is characterised by abnormal movements, fever, sweating, unstable blood pressure and pulse, and impaired mental functioning. Delirium and coma can also develop. NMS can be fatal
- 8. See for example the Rosenhan study that showed that psychiatric diagnoses are in the minds of the observers (Richard Gosden, Punishing the Patient) (2001) 190) and the Temerlin study that showed that psychiatrist's clinical judgment is influenced by outside suggestions of a patient's illness (Gosden, 191-3) it can be inferred that a patient's history could influence this judgment also. See generally: Stuart A Kirk and Herb Kutchins, The Selling of the DSM (1992) ch 2.
- 9. Hans Melander et al, 'Evidence b(i)ased Medicine — Selective Reporting from Studies Sponsored by Pharmaceutical Industry: Review of Studies in New Drug Applications' (2003) 326 BMJ 1173.
- 10. Joel Lexchin et al, 'Pharmaceutical Industry Sponsorship and Research Outcome and Quality: Systematic Review' (2003) 326 BMJ 1167; Ben Thornley and Clive Adams, 'Content and Quality of 2000 Controlled Drug Trials in Schizophrenia over 50 years' (1998) 317 BMJ 1181; Seymour Fisher and Roger Greenberg, From Placebo to Panacea: Putting Psychiatric Drugs to the Testl (1997).
- 11. Kaplan & Sadock (Benjamin and Virginia Sadock, Kaplan & Sadock's Synopsis of Psychiatry: Behavioral Sciences/Clinical Psychiatryl (2003)), for example, seems to be a well respected textbook, although numerous studies and papers have shown many of their assertions to be erroneous. See, for example, Peter Breggin, Toxic Psychiatryl (1991).

12. Carmel Rogers, 'Proceedings under the Mental Health Act 1992: the legislation of psychiatry' (1994) New Zealand Law Journal 411.

13. Ibid.

14. JR v The Medical Superintendent of Manly District Hospital Psychiatric Unit (Unreported, Supreme Court of NSW, Powell J, 15 May 1987).

15. Sadock and Sadock, above n 11, 1144.

16. For example: John M Friedberg, 'Shock Treatment, Brain Damage, and Memory Loss: A Neurological Perspective' (1977) 134 American Journal of Psychiatry 1010; Breggin, above n 11.

17. Mental Health Legal Centre Inc. 'A Position Paper on the Law and Electro Convulsive Therapy in Victoria', March

18. Phillip A Swain, 'Admitted and Detained: Community Members and Mental Health Review Boards' (2000) 7 Psychiatry, Psychology and Lawl 79.

19. Ibid 86. 20. Ibid 87. Mental Health Act 1969 [1984] 2 DCR 303, at 305, Judge Finnigan held that while the patient was clearly experiencing delusions, she should not be forced to take the medication that four psychiatrists who gave evidence insisted that she needed.'12 Similarly, 'in the Re: GHQ decision ... Keane DCJ expressly rejected the argument put by Counsel for Porirua hospital that the psychiatrist's written certification that he considered the patient to be mentally disordered was, of itself, sufficient for "mental disorder" to be established'.<sup>13</sup>

These two decisions — highlighted in an article written by Rogers, herself a zealous advocate who is particularly critical of the mystique surrounding psychiatry and the discouragement of dissent as a result — show that it is possible for clinical judgment to be overruled in favour of self-determination in a jurisdiction similar to our own.

Unfortunately though, in Australia, no such 'judicial robustness' can be demonstrated in any of the leading cases. In fact, it is rare for an appeal to be upheld or a review to go in favour of discharge or voluntary treatment — according to the 2001/02 MHRB Annual Report, between 4% and 6.7% of appeals/reviews are resolved in favour of discharge each year. Even the judge in  $JR^{14}$  relied solely on Kaplan & Sadock, advocates of the (unproven) biopsychiatric theories for information regarding electroconvulsive therapy (ECT). This text states that ECT is 'an important, effective and safe treatment for a variety of neuropsychiatric disorders', and that 'there is no evidence of brain damage caused by ECT', 15 although there has been conclusive evidence since the 1970s and earlier that ECT causes brain damage and is neither safe nor effective. 16 Unfortunately, without this information, Powell J decided that ECT was justified against the patient's express wishes (at 14). This decision is the norm.

However, where advocates do step in, there should be room to change this. The Mental Health Legal Centre, for example, has released a position paper on ECT<sup>17</sup> which quoted Breggin's *Toxic Psychiatry*l and other dissenting works and raised patient concerns about this particular treatment. More position papers that raise this kind of dissent and unravel the mystique are needed to ensure least-restrictive treatment is adhered to.

#### Promoting the existing safeguards

There are mechanisms in the MHA that an advocate can use to improve outcomes for their client. These include the patient's rights to:

- receive information about their legal rights (MHA ss 18 and 19);
- appeal (MHA s 29);
- review (MHA s 30);
- receive a statement of reasons (MHA s 27).

Without advocacy, it is unclear whether these checks and balances hold any weight in practice. There are a number of difficulties in drawing conclusions with respect to the practical effect of these rights. These include the fact that hearings are closed (*MHA* s 33), the proceedings are confidential (*MHA* s 34) and therefore unreported (except for a selected small percentage — usually around 2-3% according to the MHRB annual reports), and as a result any studies are likely to be prejudiced due to the lack of publicly available information. Nevertheless, a relatively recent study<sup>18</sup> that observed 25 MHRB hearings found that:

- there was no matter in which the Board made any variation to the order appealed against
- in only two of the 25 observed MHRB matters was an advocate or legal representative of the patient present
- 36% of hearings were completed in less than 10 minutes, 60% in fewer than 15 minutes, and only 4% in more than 30 minutes (the longest being 38 minutes).

These figures are consistent with the 1998 MHRB Annual Report figures. The study questioned what is achieved by such hearings, and concluded that 'the laudable aims of participation, fairness and the achievement of justice do not necessarily sit well with the reality of mental illnesses'. 19 It suggested that a review ought not be completed in the absence of legal representation, particularly where the review concerns continued involuntary detention and treatment 'against the express wishes of the applicant involved' (emphasis added). Without an advocate, a patient is at the mercy of psychiatry-based clinical judgment. Only 9.6% of cases in 2002 involved legal representation, which means that 90.4% of patients are at risk of more restrictive than necessary treatment options.

#### Advocacy and accountability

If the least-restrictive treatment is routinely not used, prima facie, there are gaping holes in accountability and it may fall to advocates to remedy this by strongly defending their client's right to accountable decision-making. Although accountability must be weighed against a patient's right to confidentiality, which is of paramount importance in the MHA and in MHRB decisions (ss 34 and 35) — and in this context generally attracts the stigma associated with mental illness — it

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is problematic if confidentiality is used as a cover to disguise the inadequacies of clinical judgment.

For example, a mental patient may not appear at their own hearing if the MHRB finds it would be detrimental to their health (MHA s 26(6)). Similarly, a patient may not personally inspect the documents to be given to the Board in connection with their hearing if the Board or the authorised psychiatrist is satisfied that access would cause serious harm to the patient's health, among other things (MHA s 26(8)). These decisions are reliant on clinical judgment, which a patient is not in a position to refute.

Added to this, lawyers are liable to be denied presence in interviews/evaluations and are unable to tape-record if it is not in their client's best interests. <sup>21</sup> This is where a special knowledge of the MHA and a patient's rights is crucial. If an advocate is unable to validly criticise the clinical judgment on which such decisions are undoubtedly reliant, there is a danger that the subjectivity inherent in clinical judgment will be used to exclude consequential advocacy.

As such, the advocate also has a role in ensuring accountability in decision-making. For example, like the moving target posed by the Diagnostic and Statistical Manual of Mental Disorders (DSM), objective researchers are likely to have a difficult time piecing together meaningful criticisms based on the current methods of reporting — an annual report and a few cases selected to go in a volume of case law not updated since 1997. As such, accountability is currently inadequate. Advocates are in a unique position because they have access to hearings and can use this opportunity to further not only their own client's interests, but indirectly to enlighten the Board on matters of new lessrestrictive treatment options to the benefit of patients with similar attributes who do not have an advocate present. This directly affects the level of accountability because those in MHRB hearings are immediately aware that they need to produce good reasons why a patient should be subject to a particular treatment — especially when it is against a patient's will.

#### The advocate's role in treatment

#### The right to refuse treatment

A further problem with inadequate advocacy is the patient's capacity to consent to and to refuse treatment. The patient may know that the treatment is not the least-restrictive available but, as with JM above, doctors are quick to point out that the patient's condition leads

them to lack insight into the illness preventing them from recognising which treatment is needed.<sup>22</sup> In these circumstances, an advocate is clearly in a better position than the patient to challenge the basis for these claims.

#### **Alternatives**

Also, advocates are in a position to suggest alternative treatment options that are less restrictive than those currently offered. In a climate dominated by pharmaceutical companies and biopsychiatry, nondrug alternatives are either relegated to last place or overlooked entirely.

As such, alternatives are not well documented, and although the Burdekin Report, for example, stressed that 'more effort ... needs to be devoted to identifying factors that contribute to successful outcomes for people with mental illness who are utilising non-clinical care and support services', 23 the reality is that there is little or no money to be made in non-clinical care. Yet, perhaps non-clinical care — that encourages self-determination — is indeed the only alternative consistent with a least-restrictive treatment model, and if so, advocates need to make the alternatives known.

#### The Soteria model

One study that documents a highly successful and cost-effective alternative is the Soteria House Project. The Soteria Project was designed to compare the Soteria treatment methods<sup>24</sup> with usual general hospital and psychiatric ward interventions for persons newly diagnosed as having schizophrenia and deemed in need of hospitalisation.

The results of the study, confirmed in replicated studies and critical evaluations, showed that around 85-90% of acute and long-term patients deemed in need of acute hospitalisation can be returned to the community without conventional hospital treatment and without anti-psychotic drug treatment. In fact the study found that the Soteria drug-free environment was as successful as drug treatment in reducing psychotic symptoms in six weeks. Further, the clients were treated at a *considerably lower cost*.

Soteria Bern has replicated the original Soteria findings and now Soteria 'lives and thrives' in Europe. More recently, the San Joaquin Psychotherapy Centre is a similar model based in the US that successfully treats any mental patients, not just those with schizophrenia, using drug-free methods and in a non-coercive environment that encourages self-determination.

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- 21. See for example, Murray and Another v Director General, Health and Community Services Victoria; Superintendent, Larundel Psychiatric Hospital; and Another (Unreported, Supreme Court of Victoria, Eames J. 23 June 1995).
- 22. See also Harry v Mental Health Tribunal 33 NSWLR 315 at 311.
- 23. Human Rights and Equal Opportunity Commission, 'Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness', ('The Burdekin Report') (1993) 837.
- 24. '[] he 24 hour a day application of interpersonal phenomenological interventions by a non-professional staff, usually without neuroleptic drug treatment, in the context of a small, homelike, quiet, supportive, protective, and tolerant social environment': Loren R Mosher, 'Soteria and Other Alternatives to Acute Psychiatric Hospitalization: A Personal and Professional Review' (1999) 187 The Journal of Nervous and Mental Disease 142.

6. ICCPR Article 18(4).

7. ICCPR Article 19(3).

8. ICCPR Art 47 & ICESCR 1(2).

9. ICCPR Art 1(1) & ICESCR Art 1(1).

10. ACT Bill of Rights Consultative Committee, n 3, [5.62].

11. Human Rights Act 2004 (ACT) Preamble [7].

12. Human Rights Act 2004 (ACT) s 8.

13. Human Rights Act 2004 (ACT) s 31 (international human rights jurisprudence may be considered when interpreting a human right).

14. Human Rights Act 2004 (ACT) s 43(2)(b)

\* For more information you can visit the Bills of Rights resource page on the website of the Gilbert + Tobin Centre of Public Law <www.gtcentre.unsw.edu.au>.

25. Rae Unzicker, 'To be a mental patient' <a href="http://www.narpa.org/to\_be\_a\_Mental\_">http://www.narpa.org/to\_be\_a\_Mental\_</a> Patient.htm> at 2 August 2004.

one's own country and other rights relating to marriage, immigration, deportation and nationality.

Some *ICCPR* rights recommended for inclusion by the Consultative Committee failed to make it into the *HRA*. These include the guarantee to respect the decisions of parents in the religious and moral education of their children according to their own convictions, <sup>6</sup> the restriction on freedom of expression to respect the rights and reputations of others, <sup>7</sup> and the right of all peoples to enjoy and utilise fully and freely their natural wealth and resources. <sup>8</sup>

One glaring omission is the right of all peoples to self-determination.<sup>9</sup> The Consultative Committee noted that this right and the *ICESCR* rights 'are of particular significance to Indigenous Australians'.<sup>10</sup> Though the Preamble to the *HRA* expressly acknowledges 'the first owners of this land',<sup>11</sup> there is no other express mention of indigenous Territorians in the Act.

#### Other rights

During the consultation process and subsequent public debate, many advocates argued for the recognition of rights which are not expressly acknowledged in the *ICCPR* and *ICESCR*.

These include an express recognition of indigenous and gay, lesbian, bisexual and transgender minority rights. Arguably these rights are protected by the right to recognition and equality 'without distinction or

discrimination of any kind $^{\prime 12}$  and in international human rights jurisprudence. $^{13}$ 

Rights relating specifically to the environment were not included in the *HRA*, but the review of the Act's first year of operation will examine whether 'environment-related human rights would be better protected ... by someone with expertise in environmental protection'.<sup>14</sup>

Other controversial exclusions include: the right to own property and not to be arbitrarily deprived of it; the right to life for the unborn; and victims' rights.

#### All eyes on the ACT ...

The challenges for Australia's first Bill of Rights have only just begun. How the *Human Rights Act* is received and used over the next 12 months could very well determine such important questions as whether internationally recognised economic, social and cultural rights and environmental rights will be added to it.

And beyond the borders of the ACT, many will be hoping the *HRA* will prove to be a successful working model for other Australian jurisdictions.\*

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This poses the question: why is a Soteria-like or San Joaquin-like environment not offered as an alternative in Australia? Both are *the* least-restrictive treatment models available, and both work just as well, if not better, than more restrictive treatment models. Since schizophrenia affects 1% of the population, and is the most common mental illness to result in involuntary detention and treatment, aside from the vested interests of the drug companies in retaining a biochemical bias, there seems to be no logical answer.

Given that they are not funded by the pharmaceutical companies, advocates are once again in a uniquely disinterested position to comment in this context.

#### Advocating change

To be a mental patient is not to die, even if you want to
— and not cry, and not hurt, and not be scared, and not
be angry, and not be vulnerable, and not to laugh too loud
— because, if you do, you only prove that you are a mental
patient even if you are not.<sup>25</sup>

Parliament has relied heavily on psychiatry for guidance in enacting and amending the MHA. As such, the powers under the MHA are largely discretionary. In an environment where legitimate dissent from current and former mental patients, psychiatrists and organisations such as the ICSPP is either ridiculed or dismissed by mainstream psychiatry, and mainstream psychiatry is the gatekeeper of clinical judgment, there is an even greater need for patient advocacy both in MHRB hearings, and generally.

#### Conclusion

Without zealous advocacy, there can be no legitimate attempt to care for, treat and protect mental patients, since the decision-making behind their involuntary detention and treatment can be at best biased, at worst damagingly erroneous. If the MHRB, under the existing MHA, is to act as a fair and impartial judge of the mannerisms and differences among individuals throughout the community, in a manner that is overreliant on clinical judgment and dismissive of self-determination, a strong voice of defence and dissent must be offered by the legal profession. Otherwise, the MHA is merely a legislative justification for coercing individuals in the interests — not the protection — of the community, contrary to parliament's original intention of least-restrictive treatment.

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