The model law of Szmukler, Dawson and Daw – the next stage of a long campaign?

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Abstract

Except for the criminal justice system, the Mental Health Act 1983 (as amended by the MHA 2007) is the most significant Statute in England and Wales that can be used to challenge a central principle of democratic society, that of the right of an adult to self-determination. Such legislation is considered necessary as there are circumstances when it is right and appropriate to admit individuals to hospital and to treat them for their mental disorders in the absence of their consent. The need for an option of nonconsensual treatment for a physical illness is also apparent, such as in the case of unconsciousness where, for example, treatments without consent for diabetic coma or cerebral haemorrhage are likely to be lifesaving. Whether the treatment is for a mental or physical disorder, the question is the same – when is it appropriate for someone else to take a decision on behalf of another? The paper of Szmukler et al and their proposal for what they refer to as 'fusion' legislation goes to the heart of the issues. What are mental health and mental capacity legislation there to do? What are the principles that should underpin such legislation? What safeguards should there be? In this paper the Szmukler proposals as set out are considered from a clinical perspective in the light of studies that have examined model capacity-based mental health legislation, internationally-based principles that should guide mental health law, and other proposals such as those of the Bamford report in Northern Ireland. Whilst the approach that is proposed is non-discriminatory and ethically defensible and desirable, the difficult issue is the balancing of the need for such legislation to be both versatile and non-bureaucratic and the need for an appropriate hierarchy of safeguards that protect the vulnerable from unnecessary or inappropriate interventions. The proposed Bill put forward moves away from the thinking behind the Mental Capacity Act 2005 and is closer in its thinking to an expanded and capacity-based Mental Health Act. This requires further consideration.

Introduction

Szmukler et al have in this issue proposed what they refer to as a 'fusion' law that brings 'non-consensual' treatment, whether for treatment of a mental or physical disorder, within the framework of one Statute. What they are proposing should, in my view, be a development based on the general framework of the *Mental Capacity Act 2005* (MCA). As is now generally acknowledged such capacity-based legislation respects and promotes autonomy where a person has the ability and provides the lawful means for action

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when such capacity is impaired. As such, it is clearly in keeping with Government policy on promoting choice and inclusion, for example, for people with learning disabilities (see Valuing People, 2001², and Valuing People Now, 2008)³, and it would be respectful of the principle of non-discrimination – i.e. the same principles apply for treatment of a physical and/or mental disorder.

At present, very different principles underpin mental capacity legislation compared to mental health legislation. In the MCA, with respect to 'Acts in connection with care and treatment', accepted common law principles have been brought into Statute and the MCA has set the criteria and standards which apply when a decision has to be made on behalf of an adult who lacks the capacity to make that specific decision at that time. The MCA has also established that any substitute decision must be in that person's best interests. The MCA does not give the authority to act rather it gives the justification for acting and with it protection from liability in the event of a subsequent challenge. In contrast, the amended *Mental Health Act 1983* (MHA) (like the pre-amended Act) does not generally⁴ consider that decision-making capacity is relevant nor expressly⁵ requires the person making the decision in question to act on the basis of best interests. This MHA vests authority in particular person(s) to take action on behalf of another under specific conditions. The different principles underpinning the two Acts are illustrated by the well-known case of *Re:* C⁶. When decisions were made about his physical illness (gangrene of the leg), it was his capacity to make that decision that was pivotal as to whether his refusal to consent had to be accepted. The same would not have been true for the treatment of his mental disorder, schizophrenia, under the *Mental Health Act 1983*.

The question arises as to why the Government insisted, against advice⁷, that such contrasting approaches to mental capacity and mental health legislation should remain? The central point of disagreement can be seen, in my opinion, in the answer to the fundamental question 'What are the MCA and the MHA there to do?' I suggest that both Acts are about substitute decision-making - when and under what conditions is it appropriate and lawful to make a decision on behalf of an adult when that decision would normally have been for him/her to take? Whilst the Government would accept that this was the fundamental role of the MCA 2005, the MHA 1983 was seen by them as focusing on public protection. Whilst this might rightfully be the priority if someone is suspected of or found guilty of an offence, the need for assessment and treatment in that person's best interest should be the guiding principle for the use of civil orders under the Act. People without a mental disorder are not detained in order to protect the public unless he/she has been suspected of, or convicted of, an offence, with all the accompanying safeguards that come with Court proceedings. Why then should it be different for a person with a mental disorder? What is proposed by Szmukler et al acknowledges that in fact both the Mental Capacity Act 2005 and the Mental Health Act 1983 (as amended by the MHA 2007) are in essence about substitute decision-making. Once that is accepted, then it is clear that the two should be combined into one Act. The question then arises whether essentially to modify the MCA 2005 by strengthening the protections and powers or, alternatively, widen the scope of the MHA 1983, or to start completely afresh.

- 2 Department of Health (2001) Valuing People: a new strategy for learning disability for the 21st century. Department of Health, London.
- 3 Department of Health (2007) Valuing People Now: from progress to transformation. Department of Health, London.
- 4 One exception is the central role given to 'capacity' in the application of the treatment provisions of community patients not recalled to hospital, as set out in Part 4A MHA
- 5 Although it should be noted that the Court of Appeal have insisted on a best interests test being satisfied when compulsory treatment is certified under section 58 MHA 1983 (R (on the application of B) v Dr. SS (RMO), SOAD and the Secretary of State for Health [2006] EWCA Civ 28.)
- 6 Re C (Refusal of Medical Treatment [1994] 1 AII ER 819.
- 7 Department of Health (1999) Report of the Expert Committee: Review of the Mental Health Act 1983. London: Department of Health

Context for the Proposal

Legislation similar to that put forward by Szmukler et al was suggested by Zigmond and Holland in 2000 in their paper entitled 'Unethical Mental Health Law: History Repeats Itself'⁸. Prior to the implementation of the MCA 2005 in 2007, and prior to changes in mental health legislation, Zigmond in particular, had argued that two new Statutes were needed but not in the form of the two proposed Statutes. Rather, the first required was mental incapacity legislation (as was being considered at the time) that would go beyond the proposed legislation and would also encompass what was covered in the civil orders of the Mental Health Act 1983. The second Statute proposed was Home Office legislation that would focus on mentally disordered offenders. For this second piece of legislation, if a person has been charged and/or convicted of an offence, then an additional consideration should rightfully be that relating to public safety. Szmukler et al consider possible options including keeping the treatment of mentally disordered offenders within the proposed fusion legislation and the option proposed by the Bamford Review⁹ in Northern Ireland (see below). As they argue, capacity-based interventions could still be the proposed ethical framework for treatment without consent.

Bellhouse et al (2003, 2004)¹⁰ 11 developed their own capacity-based mental health legislation, using it to assess a consecutive series of patients admitted to psychiatric hospital to determine the extent to which those admitted informally or formally under the then MHA 1983 had capacity to consent to admission and/or treatment. One central aim of this study was to address Government fears that capacity-based mental health legislation would not have allowed for the detention of those they felt needed to be detained – i.e. in the Government's view, those that may be a danger to the public. In addition, there was also the opposite concern that there may be those admitted to hospital informally who lacked capacity and who therefore had not formally consented to admission. This had just been highlighted at that time in the case of R v Bournewood Community and Mental Health NHS Trust. 12 This case subsequently went to the European Court of Human Rights and the UK was found at fault¹³, thereby leading to the development of the recent Deprivation of Liberty Safeguards. Using methodologies based on previous work and the then Law Commission definition of incapacity, Bellhouse was able to interview 49 out of 67 people approached, the majority with a psychotic illness. Thirty-one of the 39 informal patients and two of the ten detained patients were judged to have the capacity to consent or refuse consent to admission. With respect to the capacity to consent to treatment, it was found that the vast majority of those admitted under Section lacked capacity at the time the decision had to be made, and therefore any capacity-based mental health legislation would have enabled their compulsory admission and treatment in the same way as the existing 1983 MHA had done. Of particular interest was the fact that there were eight informal patients who were judged to lack capacity to consent to admission - i.e. similar to Mr HL in the Bournewood case. Some years later Owen et al (2008; 2009)14 15 undertook a much larger study,

⁸ Zigmond and Holland 'Unethical Mental Health Law; History Repeats Itself'. (2000) Journal of Mental Health Law, February, 49–56.

Bamford Review of Mental Health and Learning Disability (Northern Ireland) A Comprehensive Legislative Framework August 2007.

¹⁰ Bellhouse J, Holland AJ, Clare ICH, Gunn M, Watson P. (2003) 'Capacity-based mental health legislation and its impact on clinical practice: 1) admission to hospital'. Journal of Mental Health Law (July):9–23

¹¹ Bellhouse J, Holland A, Clare ICH, Gunn M, Watson P. (2004) 'Capacity-based mental health legislation and its impact on clinical practice: 2) treatment in hospital'. Journal of Mental Health Law, (July):24–37

¹² R v Bournewood Community and Mental Health Trust ex p L, [1999] 1 A.C. 458

¹³ HL v United Kingdom (2005) 40 E.H.R.R. 32

¹⁴ Owen GS, Richardson G, David AS, Szmukler G, Hayward P and Hotopf M. (2008) 'Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study'. BMJ 337: 448

investigating the extent to which people admitted to psychiatric hospital had capacity or not. As in the Bellhouse et al study, they found that the majority of those detained and a significant minority who were informal patients lacked capacity to make treatment decisions. The same group have also reported that a significant proportion of people admitted to general hospital wards lacked capacity to make the relevant decisions (Raymont et al 2004)¹⁶. In a different setting – that of Accident and Emergency – Jacobs et al (2005)¹⁷ reported that nearly two-thirds of people seen due to self harm appeared to initially lack capacity to consent to what would be seen as treatment for a physical disorder. However, when information was presented to them in a different and more structured way, the proportion was reduced significantly. As in the study of Owen et al (2009) it was also found that those who lacked capacity were more likely to resist the intervention.

Prior to the MCA 2005 coming into force in 2007, when action was required to intervene on behalf of an adult who lacked capacity, that action was justified on the grounds of best interests under the common law grounds of necessity as articulated initially in the case of *Re*: *F*¹⁸. This was the case of a woman with learning disabilities who, it was suggested, should have a sterilisation operation. This is hardly a case that should be generalised and set standards for how people should be responded to in less problematic circumstances! It was perhaps the *Bournewood* case that challenged the system in a rather different way. This case demonstrated just how potentially vulnerable people lacking capacity are, and how, in the absence of statute such as the MCA, there had been no ready means of challenge available to HL or his carers. The MCA and the subsequent Deprivation of Liberty Amendments¹⁹ now provide for such an eventuality.

The above studies and cases that have come before the High Court all indicate that in health settings, for many reasons and in different circumstances, people may lack the capacity to consent to interventions. Similarly, outside of health settings this concept of 'decision-making capacity' is pivotal and those who lack that ability for a given decision may be at risk of neglect or of exploitation (see Suto et al 2006^{20} , re: financial decision-making by people with learning disabilities). The arguments in support for 'fusion' legislation, as Szmukler et al have proposed, are strong on ethical and legal grounds and also on clinical and practical grounds as described above.

Within the UK it is in Northern Ireland that the idea of 'fusion legislation' has been accepted in principle by the politicians if the requisite powers are devolved. The recommendation put forward in the Bamford review is that there should be '..a single, comprehensive legislative framework for the reform of Mental Health legislation and for the introduction of Capacity legislation in Northern Ireland. This should be through the introduction of provisions for all persons who require substitute decision-making. A framework is proposed for interventions in all aspects of the needs of persons who require substitute decision-making, including mental health, physical health, welfare or financial matters'. The review goes on to set out the importance of the principles of respect for autonomy; the participation of people who may lack capacity; the principle of justice in that

- 15 Owen GS, Szmukler G, Richardson G, David AS, Hayward P, Rucker J, Harding D and Hotopf M. (2009) 'Mental capacity and psychiatric in-patients: implications for the new mental health law in England and Wales'. British Journal of Psychiatry 195, 257–263
- 16 Raymont V, Bingley W, Buchanan A,. David AS, Hayward P, Wessely S, Hotopf M. 'The Prevalence and Associations of Mental Incapacity in Medical Inpatients', 364 Lancet 1421 (2004).
- 17 Jacobs R, Clare ICH, Holland AJ, Watson PC, Maimaris
- C and Gunn M (2005). 'Self-harm, capacity, and refusal of treatment: implications for emergency medical practice. A prospective observational study'. Emergency Medicine Journal. 22 (11), 799–802
- 18 F v West Berkshire Health Authority [1990] 2 AC 1.
- 19 See Schedules 1A and A1 Mental Capacity Act 2005
- 20 Suto WMI, Clare ICH, and Holland AJ (2006). 'Understanding of basic financial concepts among adults with mild learning disabilities'. British Journal of Clinical Psychology. 45 (2), 261–266,

the law is applied fairly regardless of whether it is for treatment of a physical or mental disorder; that any action should benefit the person concerned and is undertaken in a manner that minimises harm. Much of what is then proposed for Northern Ireland is taken from the MCA 2005. Interestingly, it may well be those countries/provinces who have experienced discrimination and civil strife (such as South Africa and Northern Ireland) who take most seriously the need for just and non-discriminatory mental health legislation (Fistein et al 2009)²¹.

The main proposal

What would be required of genuinely comprehensive legislation that would be both practicable and ethically and legally defensible? First, it would have to provide the means for making decisions on behalf of people who at the time lack the capacity to make such decisions for themselves, such decisions going beyond simply those relating to health, needing to include areas such as welfare and financial matters. Secondly, whatever the principles guiding such legislation, they must be compatible with international standards and with national and European law – this includes respect for human rights and a robust and efficient means of challenge. Thirdly, the legislation should not discriminate on the basis of whether the decision in question is related to a physical or a psychiatric disorder. Fourthly, it must be flexible enough to enable substitute decision-making under very different circumstances – the person in A & E who is drunk and lacks capacity; the unconscious, anaesthetised, or sedated person; the person with advanced dementia or with an acute psychotic illness; or the person with profound intellectual disabilities in need of day-to-day support and lacking the capacity to consent to this. It must also enable action to be taken (such as restraint or the transportation of a person), with the necessary safeguards, when such action is necessary and in the individual's best interests. Finally, it must have robust safeguards and a ready means of challenge.

Fistein et al (2009)²² compared the Mental Health Acts of 32 Commonwealth countries with a common legal heritage and compared these against the standards for such legislation set by the World Health Organisation and by the Council of Europe. They identified the following as central:

- 1. The presence of a mental disorder based on functional impairments and symptoms informed by ICD-10;
- 2. Exclusion criteria to prevent the misuse of psychiatry as a means of political or social control;
- 3. A treatability test requiring that treatment that is likely to alleviate the effects of the disorder or prevent it worsening is available;
- 4. A risk test based on welfare interests a relatively low threshold is proposed, providing it is combined with a capacity criteria (i.e. those with capacity may not be liable to detention if not wishing for the treatment);
- 5. A capacity test based on decision-making ability assessed in terms of the person's ability to make the decision in question, such as is the case in the MCA 2005. Under such circumstances a capacitous person refusing treatment could not be forced to come into hospital or to have treatment (for possible exception see 6 below).

²¹ Fistein EC, Holland AJ and Gunn MJ (2009) 'A comparison of mental health legislation from diverse Commonwealth jurisdictions'. International Journal of Law and Psychiatry 32, 147–155

²² Ibid.

6. Special provisions for the treatment of people posing a serious risk to others – under specific circumstances and with special safeguards it is recognised that there may be occasions when the detention of a person with capacity refusing admission would be justified. Such an eventuality is likely to be best managed through the criminal justice system, but another example, one relating to physical illness, might include the detention of a person with a serious infectious disease.

Szmukler et al have proposed tiered legislation, but in its proposed form it is still written in a manner that mental health practitioners will be familiar with, but not other medical practitioners and others from disciplines outside of mental health. The balance to be achieved, particularly with respect to health decisions, is to ensure that action can be taken when needed and that it is in the individual's best interests, on the one hand, and on the other, that there are safeguards and the means of challenge that are practicable, affordable, and accessible. For legislation that addresses substitute decision-making in diverse settings and circumstances, there clearly needs to be a staged approach with safeguards becoming more prominent as the consequences of any decision become either more serious or more contentious. In the Szmukler et al proposal they refer to 'compulsory care and treatment and compulsory detention' and suggest 'a staggered set of phases'. What they do not examine is how this would work in very different settings, such as intensive care. The MCA 2005 now provides some protection to the unconscious or heavily sedated person in intensive care and relatives have a right to expect to be consulted and would have leave to apply to the Court of Protection if they disagreed with the action of the decision-maker. At what point should a Tribunal be required whether in the case of a person lacking capacity being admitted to psychiatric hospital or to general hospital? In my view this has to be more nuanced than is proposed.

The following framework, based fundamentally on the MCA with added safeguards taken from the MHA, is a start.

First, the process outlined in the present MCA, as it stands, provides the legal basis for intervention in matters relating to day-to-day 'Acts in connection with care and treatment' (Szmukler et al use the term first used in earlier drafts of the Mental Capacity Bill – 'General authority' – which was changed on the advice of the Parliamentary Scrutiny Ctte), provided to people who lack the capacity to consent to such intervention. Under such circumstances issues relating to capacity and best interests should be part of regular care planning discussions.

Secondly, the framework similar to that of the MCA continues to provide the basis for routine and uncontentious healthcare decisions or urgent and emergency healthcare decisions, such as might be required in primary care or in A & E Departments, or occasionally in Intensive Care.

Thirdly, under specific circumstances additional safeguards would become available, much in the way that certain decisions, when someone lacks family or friends, require the involvement of an Independent Mental Capacity Advocate (IMCA), or most MHA-detained patients are entitled (since 1/4/09) to the allocation of an Independent Mental Health Advocate (IMHA). This might include situations where someone is actively resisting intervention, where serious medical treatment is required (as defined in the MCA and Code of Practice); longer term changes in accommodation (e.g. moving residence or remaining in or potentially being admitted to hospital for longer than a defined period, whether for psychiatric or medical treatment); and finally, further additional safeguards (such as compulsory application to the Court of Protection) for specifically named treatments where the person lacks the capacity to make the decision for him/herself e.g. sterilization; termination of pregnancy; experimental treatments, such as those for new variant CJD; and for those in a persistent vegetative state requiring decisions about continuation of treatment.

The safeguards would progressively include the protections provided by the best interests procedures, such as consultation and arbitration; the requirement to have a second opinion; the statutory duty to provide an independent advocate; the availability of a tribunal system (under the Court of Protection); and the right of appeal to, and/or a requirement for, referral to the Court of Protection for a ruling on capacity and/or best interests. In addition, surgeons and intensive care clinicians, for example, would be encouraged to discuss with and document the wishes of people who, whilst having capacity, are likely to have a period of incapacity or have a significant risk of incapacity arising through complications of the procedure – e.g. those having major cardiac surgery and who would be sedated and semi-conscious in Intensive Care for some days. This would ensure that the wishes of the person were clearly document and could guide subsequent intervention when the person later lacked capacity. The same approach would be encouraged for those caring for people with cyclical illnesses that result in potential periodic incapacity including bipolar disorder, confusional states that might arise in people with chronic physical illnesses, or those with metabolic or endocrine disorders such as diabetes mellitus.

The MCA 2005, except in particular circumstances (e.g. a Court appointed Deputy or a donee of a Lasting Power of Attorney), does not vest all decision-making power in one person, rather it is the person requiring the decision to be made that has the duty to assess capacity and to determine best interests, when the person concerned lacks capacity. Szmukler et al are proposing the appointment of a 'Substitute Decision Maker' (SDM) which in essence is similar to the above. However, elsewhere in the draft Act there is an indication that SDMs may be more widely used under these proposals. Whilst the appointment of an LPA donee is to be encouraged and the use of Deputies to take single decisions can be important safeguards, to what extent SDMs are able to achieve outcomes that are better for the individual in other circumstances is a matter of debate. What the MCA 2005 does is ensure protection (under certain circumstances) through the use of statutory advocacy. The advocate is not there to be a SDM, rather he/she is there to ensure that the 'voice' of the person lacking capacity is heard. This approach has had some qualified acceptance in medical settings (Luke et al, 2008)²³.

Conclusions

The basic idea that any mental health legislation should be capacity-based and therefore respectful of the principle of autonomy has had very wide support. ²⁴ Such an approach essentially recognises that the MHA is fundamentally about substitute decision-making under specific circumstances. Once this step has been taken it is then logical to consider 'fusion' legislation as is proposed by Szmukler et al bringing together mental capacity and mental health law. This has the advantage of being non-discriminatory and may help reduce stigma experienced by people with mental disorders. Whilst the style of the draft Bill is close to that of the MCA 2005, its thinking is closer to the MHA 1983 (as amended by the MHA 2007). It moves away from the idea that decision-makers have to be able to justify their actions to instead vesting responsibility in others, such as Tribunals or substitute decision-makers. The test is whether such an approach is appropriate in those situations that are now governed by the present MCA 2005 and would be governed in the future by 'fusion' legislation, the best example being that of intensive care. As argued in this paper there is compelling evidence that 'decision-making' capacity is a pivotal issue in determining how, what may be complex and difficult clinical and social situations involving vulnerable people, are best

²³ Luke, L. Redley, M. Holland, A.J. & Clare, I.C.H. (2008). 'Hospital clinicians' attitudes towards a statutory advocacy service for patients lacking mental capacity: implications for implementation'. Journal of Health Services Research and Policy. 13 (2), 73–78.

²⁴ Evidence submitted by the Mental Health Alliance to the Scrutiny Ctte examining the Draft Mental Health Bill 2004

resolved. The options available in these situations may be finely balanced. No Act of Parliament can provide answers to all possible scenarios; what it can do is set the framework within which it is lawful to act and there is a duty to act in the best interests of the person lacking the capacity to make the decision in question. The tension is one between empowerment and protection. This is very familiar to those of us working in services for people with learning disabilities but goes well beyond this group of people. Vulnerability and the need for protection is both about inherent and situational risks and requires a very nuanced approach (Dunn et al 2008)²⁵. The proposal of Szmukler et al is the next stage in what is likely to be a long campaign.

²⁵ Dunn MC, Clare ICH, Holland AJ (2008) 'To empower or to protect? Constructing the 'vulnerable adult' in English law and public policy'. Legal Studies 28: 234–253