Mental Health Alliance

Advance decisions

House of Commons Committee stage amendment briefing

To move the following Clause:-

‘(1) The 1983 Act is amended as follows.

(2) After section 76 (visiting and examination of patients) insert—

76A Advance decisions and advance statements

(1) In this Act—

(a) reference to an advance decision is to an advance decision (within the meaning of the Mental Capacity Act 2005) made by the patient, and

(b) “valid and applicable” in relation to such a decision means valid and applicable to the treatment in question in accordance with section 25 of that Act.

(2) If an advance decision is found to be valid and applicable to the treatment regulated by Part 4 of the 1983 Act, at the material time, the person making the decision shall have regard to the advance decision.

(3) Where a decision is made which is inconsistent with a valid and applicable advance decision then the requirements set out in subsection (4) below must be complied with.

(4) Those requirements are—

(a) recording in writing the circumstances in which treatment and the reasons why;

(b) supplying—

(i) the patient concerned, and

(ii) the patient’s nearest relative with a copy of that record and placing a copy of that record in that patient’s medical notes.

(5) A person performing a function under this Act shall consider, so far as reasonably ascertainable the patient’s past and present wishes and feelings (and in particular any relevant written statement made by him when he had capacity.”.

(3) In section 63 (treatment not requiring consent), at the end, insert—

> “(2) When deciding what treatment to give, the approved clinician in charge of the treatment shall consider so far as reasonably ascertainable the patient’s past and present wishes and feelings (and in particular any relevant written statement made by him when he had capacity), and shall record any treatments requested by the patient in the patient’s medical record, and if that treatment is not given shall record the reasons for this.”.’.

Purpose of the amendment

1. To define the nature and function of advance decisions and advance statements.
2. To outline the procedure which shall be followed if decisions are taken that are inconsistent with a person’s wishes expressed in an advance directive.
3. To define how a person’s wishes and feelings with regard to their care and treatment should be taken into account in decision making.

Reason for the amendment

1. Overview

Choice and self-determination are a cornerstone of health policy. Ideally, the Mental Health Bill should aim to enhance choice available to people within an appropriate therapeutic framework, provide support to them in expressing wishes, and ensure their wishes, where they have expressed them, are considered when decisions are made about their care. However, the Bill as proposed limits choice further than the existing Act, but does not place in statute a right to express wishes or to have those wishes formally recognised and recorded. This is inconsistent with other legislation.

By enabling and supporting the expression of wishes in the Mental Capacity Act through advance decision making, but not placing parallel provision in the Mental Health Bill, this will discriminate unfairly against those detained under mental health legislation and will miss an opportunity to involve people in their care and treatment, thus improving engagement and outcomes.

> “People know from experience what works and what doesn’t when they are or are becoming ill…. These may be of real concern to a patient where compulsion is being considered and their satisfactory resolution may help reduce the crisis, As individuals we are usually happier when we feel in control of any situation. Advance directives offer patients some of this control.”[1]

2. Advance decisions, expressed through advance directives

Advance directives are documents drawn up by individuals when they are well in order to express their wishes as to their future care and medical treatment, and their personal affairs, in the event that at some point they may be unable to express those wishes

[1] Joint Scrutiny Committee on the Draft Mental Health Bill: Volume III.Memorandum from Malcolm Turber, Chair of Peterborough and Fenland Mind. (DMH 226)

themselves. It is most commonly used to refer to the anticipatory refusal of medical treatment.

Advance directives are important mechanisms for safeguarding and promoting a patient's interests and health. They should have a significant place in the care and treatment of people who fall under the Mental Health Act. For example, if a person lacks capacity and is in need of care and treatment, an advance directive would indicate whether the patient had stated that a treatment was to be refused. Advance refusals of treatment should be legally binding unless there are extra reasons why this should be overridden. This provision already exists under the Mental Capacity Act, and this amendment would bring these two pieces of legislation into line.

> "When individuals are well, they want to stay well, and at that time have good insight into the treatments they know work well for them and those that do not. The medical/social professionals must embrace the concept of Advance Directives and, if requested, help and advise individuals in drafting them. They must see them as an opportunity, not a threat."[2]

In general, an advance directive is already binding under common law. However, an advance directive can be over-ridden if the person is subject to compulsory treatment under the Mental Health Act 1983. We believe that this discriminates against people with mental health problems.

An important opportunity has been missed to include, as part of primary legislation, a legal basis for the use of advance directives under a future Mental Health Act. The importance of advance directives for patients should not be underestimated: they can promote individual autonomy and empowerment; they can enhance communication between patients and those involved in their care; and they can protect individuals from receiving unwanted or possibly harmful treatment.

> " It is one thing living in the knowledge that one could be sectioned against their will but quite another to live in the knowledge that even under section informed decision made pre-emptively can be ignored… The Bill needs to keep the right to advance directives and consider ways they can be used to empower patients and at the same time limited to ensure they receive the care their condition requires when a crisis occurs."[3]

The Mental Health Alliance therefore strongly believes that advance directives should be given formal status by making provision for these on the face of the Mental Health Bill.

Advance statements

Advance statement give people the opportunity to positively state their wishes for the care and treatment should they lose the ability to make decisions for themselves at some time in the future. This may not relate solely to medical care but could, for example, include wishes relating to care of dependent children, place of residence, religious preferences etc. Enabling people to express their wishes and have these taken into account in the process of providing care and treatment is important in protecting the dignity and

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[2] Joint Scrutiny Committee on the Draft Mental Health Bill: Volume III. Memorandum from Simon Charrington (DMH 127)

[3] Joint Scrutiny Committee on the Draft Mental Health Bill Volume III: Memorandum from Keith Kinsella (DMH 14)

autonomy of people who experience mental health problems and fall under the scope of the Mental Health Act.

The Joint Committee on Human Rights, in its report on the 2002 draft Mental Health Bill, recommended that:

> "the rights of patients to give directions about their future treatment, during periods when they are capable of doing so, should be respected where doing so would not present a threat of death or serious harm to the patient or anyone else."

It may not be appropriate or feasible to provide all forms of care and treatment proactively requested by a patient in every case. However, advance statements are valuable for clinicians in gaining an insight into the care which a person wishes so that they can act in accordance with these wishes where possible, and provide reassurance to service users that their views will be heard and acknowledged. This amendment would bring the Mental Health Bill into line with provisions already existing in the Mental Capacity Act (2005).

The Mental Health Alliance therefore believes that provision for taking account of the previously expressed wishes and feelings of the person, including through an advance statement, should be included in the Mental Health Bill.

3. Comparison with the Mental Capacity Act (2005) and the Mental Health (Care and Treatment) Act (Scotland) 2003.

The Mental Capacity Act (2005) has extended the right to advance decision making explicitly to those who lack capacity to make decisions for themselves, stating that an individual's wishes, expressed through an advance directive, must be respected. However, the current Mental Health Bill allows no way for individuals to express a wish for their care and treatment for mental disorder and have this respected. Including this in the Code of Practice does not place sufficient emphasis on the importance of this issue, will not ensure that it is followed, and is inconsistent with the Mental Capacity Act (2005). We therefore argue that provision for advance decision making through advance directives and advance statements should be included on the face of the Bill.

The Mental Health (Care and Treatment) (Scotland) Act (2003), enables people who are detained to make an advance statement, not only in terms of an advance refusal of treatment, but also in terms of wishes for treatment. This is extremely helpful for a clinician when faced with a patient who is unable to express their wishes, as it give them a clear indication of the patient's views and the types of treatment which they have found helpful and most acceptable in the past, and this can significantly assist them in decision making. It also means patients themselves can play as full a part in decision about their care and treatment, thus meaning their engagement at a later date is likely to be more positive.

Research evidence

A number of studies of advance directives have been carried out nationally and internationally. American research indicated that potential benefits of advance decision making include increased empowerment of mental health service users, improved communication between service users, their families, and mental health professionals, and

increased understanding of the importance of service users' autonomy in decision making as well as potentially beneficial clinical outcomes (Srebnik & La Fond 1999[4]).

A more recent review of research in the UK (Papageorgiou et al 2004[5]) found that people with severe and enduring mental health problems who were subject to compulsory treatment were able to draw up realistic and logical advance directives, and did not use them as a means of refusing all possible future treatment (as some mental health professionals had feared). However, there was no evidence of improved outcomes as a result of advance decision making. A main explanation provided was that mental health professionals failed to place sufficient value on advance directives. This had an impact upon service users' faith in advance decision making, as their experience was that their wishes were disregarded in clinical decision making.

This was also documented by the Mental Health Foundation in a recent development project on the use of advance directives. Specific concerns expressed by service users which acted as barriers to the use of advance directives were:

- The lack of legal status and the resulting lack of impact they would have in practice
- Concern about upsetting staff involved in their care as a result of expressing their views about treatment
- Feeling of lack of control over care and treatment, resulting in a feeling of disempowerment about their care.

Papageorgiou et al's research concluded that it is necessary for advance directives to be legally binding so that service users are reassured that their preferences will be acknowledged. The Mental Health Alliance endorses this view.

4. Patients' wishes regarding treatments not requiring consent or a second opinion

Section 63 of the Mental Health Act permits any treatment for mental disorder not governed by sections 57 and 58 to be given without consent. This means that drug treatment up to three months does not require consent. There is therefore a need for a mechanism to ensure that patient's wishes are heard and taken into account.

Psychiatric medication can have very serious adverse effects. For example drug side effects can include painful muscle spasms, involuntary movements, neuroleptic malignant syndrome – an uncommon but potentially fatal reaction, loss of energy, loss of capacity for pleasure, intense restlessness, weight gain, diabetes, heart problems, loss of sex drive. When deciding on treatment, the likely benefits need to be weighed very carefully against the potential harms. The patient's own views and wishes should be central to this equation.

People are frequently not involved well in decisions about their treatment, even where they are not detained under the Mental Health Act. As the Act authorises treatment to be given against the will of the patient it is even more important that it make clear that this should

[4] Srebnik, D., & La Fond, J., (1999) Advance directives for mental health treatment, *Psychiatric Services*, 50, 919-925

[5] Papageorgiou, A., Mohamed, A., King, M., Davidson, O., Dawson, J., (2004) Advance Directives for patients compulsorily admitted to hospital with serious mental disorders: Directive content and feedback from patients and professionals, *Journal of Mental Health*, 13, 379-388

not in any way stop clinicians seeking the best fit possible between the patient's wishes and what is therapeutically beneficial and feasible.

> "Being mentally unwell does not mean you abdicate your right to choose what goes into your body."[6]

This amendment will promote patient safety, participation, and the possibility of consensual treatment. It would require the approved clinician to consider the reasonably ascertainable past and present wishes of the patient, particularly those expressed in an advance statement or directive. It is especially important in the absence of an impaired decision-making criterion that people are able to have their present wishes taken seriously. The amendment requires the recording of treatment requested by the patient, and reasons if it is not provided, in their medical record. This means that it becomes part of the overall picture of their care needs and that there can be scrutiny of, and accountability for, the treatment decision. There is no extra form-filling, but rather the appropriate recording of information in the patient's notes.

5. Conclusion

The Mental Health Alliance believes that the above amendment will ensure that, in this respect, the Mental Health Bill is compatible with parallel legislation. Incorporating provisions for advance decisions and advance statements will also ensure the rights of individuals to be involved in decision making about their care and treatment are protected, and will address the inequity which will otherwise arise. This will not only assist clinicians and other mental health professionals in fulfilling their roles but is also likely to promote more positive engagement with mental health services in the future.

[6] From Patrick Olszowski's memorandum to the Joint Scrutiny Committee on the Draft Mental Health Bill (DMH 13)