

The future of Advance Decision Making in the Mental Health Act

About this note

‘Advance decision making’ refers to people planning for a future when they may become unwell. At present, people living with mental illness in England and Wales have little reassurance that advance decisions they make about their own future mental health treatment will be respected, even those decisions made during times when they are well, which are supported by professionals and family. This is in sharp contrast to those making advance decisions about treatment for physical health problems. In this case the Mental Capacity Act 2005 ensures all valid and applicable advance decisions to refuse medical treatments are respected and preferences are acknowledged. This inequality was highlighted and addressed by the Independent Review of the Mental Health Act, which formulated a recommendation for statutory provision for mental health advance decision-making in the form of ‘**Advance Choice Documents**’. This recommendation has been accepted by government. Plans for Advance Choice Documents were drawn from a report submitted by the Mental Health and Justice Project.¹ This report argued that legal reform should enable a culture shift towards mental health advance decision-making which is collaborative, encourages treatment requests, as well as appropriate treatment refusal, and respects service user expertise borne of lived experience. Outlined below is the rationale for implementing Advance Choice Documents, answers to some of the concerns around creating statutory provision, and implementation suggestions for those involved in law reform.



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About Advance Choice Documents [ACDs]

ACDs offer a number of benefits. First and foremost, they are a vital step towards ensuring that people living with mental illness have choice and autonomy over their care. Secondly, they resolve a fundamental inequality between physical and mental healthcare. While there is provision for those with physical health problems to use the Mental Capacity Act (MCA) to make advance decisions about their care (e.g. to refuse medical treatment), the same provisions are not legally binding for mental illness if the individual is admitted to a mental health hospital under the Mental Health Act 1983 (MHA). Thirdly, they bring the UK towards parity with other jurisdictions which have adopted similar changes, notably Scotland, Northern Ireland and India.

An example of how Advance Choice Documents could work in practice

Sam was diagnosed with Bipolar aged 21 and is now 40. He works in IT and has a partner and two children. Sam has experienced multiple episodes of very high mood (mania) and depression. When manic, Sam often spends vast amounts of money and behaves bizarrely in public including running around naked. When unwell he finds it difficult to engage with mental health services and has had multiple non-voluntary hospital admissions. It is difficult for Sam and his family to cope with the aftermath of these episodes, Sam is desperate to find a way to take control of his illness and its consequences.

Like many people with his mental health condition, Sam acknowledges his mental capacity to make decisions about treatment fluctuates depending on his mental health. When he is well, he works with his psychiatrist and partner to create an 'advance choice document', which includes early signs of relapse and loss of decision-making capacity. It also covers signs that show he is likely to need hospital admission to prevent the harm he fears, and in addition makes certain requests about treatment, including his preferred

medications and a refusal of a medication that has given him severe side effects in the past.

The next time Sam starts to become unwell, his partner alerts the mental health crisis team. This team have not met Sam before, but find the document helpful in creating Sam's care plan. Although Sam is compulsorily admitted to hospital, he receives his preferred medications and is discharged earlier than with previous admissions.

Reflecting on this episode, Sam and his family feel relief at having avoided some of the damaging behaviours Sam exhibits when unwell. Although still difficult, Sam found admission less distressing than on previous occasions. Sam feels more in control of his Bipolar and has more peace of mind that future crises can be managed well. Sam's relationship with mental health services is improved and he feels confident to contact them at an earlier stage in any future relapses. Sam and his team hope that this will reduce the number of future admissions to hospital and improve his general mental health.

The move to greater reliance on ACDs is not merely based upon principle. Current evidence suggests that:

a. There is service user demand for mental health advance decision-making

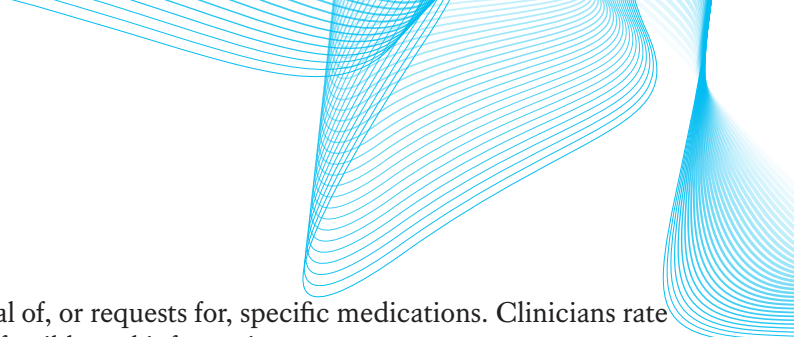
Surveys of people with severe mental illness as well as clinicians, consistently demonstrate the majority of both are in favour of provision for mental health advance decision-making.

b. The content of mental health advance decisions is clinically feasible

Studies examining what services users with severe mental illness want advance decisions to be about, in a variety of international contexts, consistently find that collaborative models are popular, total treatment refusal is rare and expression of preferences around



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treatment is common e.g. refusal of, or requests for, specific medications. Clinicians rate a large majority of decisions as feasible and informative.

c. Mental health advance decision-making holds potential to reduce compulsory admissions

Overall, mental health advance decision-making tools have been shown to reduce the number of compulsory admissions. Success in reducing compulsory admissions is likely to be dependent on process related factors such as clinical buy-in.

Anxieties around ACDs

Although many see ACDs as a timely response to stakeholder demand and human rights concerns, ACDs also raise a series of anxieties, particularly in light of similar policy changes in other countries.² These anxieties fall into three main ‘areas of tension’:



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1. The complexity of current provision which disincentivises use by clinicians and service users

The current complexity may contribute to the lack of confidence and knowledge amongst key stakeholders (service users, their friends and family, clinicians) who may benefit from the use of advance decision making. The addition of statutory ACDs may add a further layer of complexity into this picture. However, clear statutory rules, codes of practice and service user and clinical guidelines would reduce complexity, mobilise resources and help clinicians and service users feel more certain about ACD use.

2. Difficulties in creating separate provision for “psychiatric patients” vs “medical patients”

English and Welsh Law has implicitly differentiated between “medical” and “psychiatric” patients. The Mental Capacity Act 2005 (MCA) was built from case law around “medical patients” and medical decisions concerning physical health. For the “psychiatric patient” there was the legal concept of “unsound mind” and the MHA outlines the circumstances under which a person with mental disorder may be involuntarily detained and treated and their liberty safeguarded.

These legal distinctions may be unhelpful. We know, for instance, that “medical” and “psychiatric” problems frequently co-exist, for example when medical complications follow psychiatric treatments (e.g. metabolic syndrome) and when there are psychiatric complications arising from medical conditions (e.g. delirium). There are also ethical concerns over why someone’s status alone as a “psychiatric patient” should exclude the right to self-determination, as well as theoretical and practical problems with trying to separate the functions of the mind from the body.

However, certain dilemmas, particularly public interest concerns (discussed below), occur more commonly in mental health settings and demand tailored provision to ensure consistent and safe management.

3. Public Interests

There are three key areas of public concern that should be considered when introducing statutory ACDs. They centre around problems which may be caused by refusal of medical treatment for mental disorder. However, as outlined above,

evidence suggests refusal of all treatment is very rare, and this is an important aspect of public communication around ACDs.

i. **The potential for third party harm.** Overall this is a rare occurrence in mental health care contexts but demands consideration. For example, if a person with a history of exhibiting violent behaviour when unwell wished to use an ACD to refuse mental health treatment.

ii. **Public cost.** In some other jurisdictions, legislation which provides for refusal of treatment but does not permit refusal of hospital admission has resulted in cases of prolonged inpatient admission at significant public cost.

iii. **Ethical controversy.** Cases of advance refusal of treatment for suicide attempts arising in the context of mental health problems have raised particular ethical complexity and public concern.



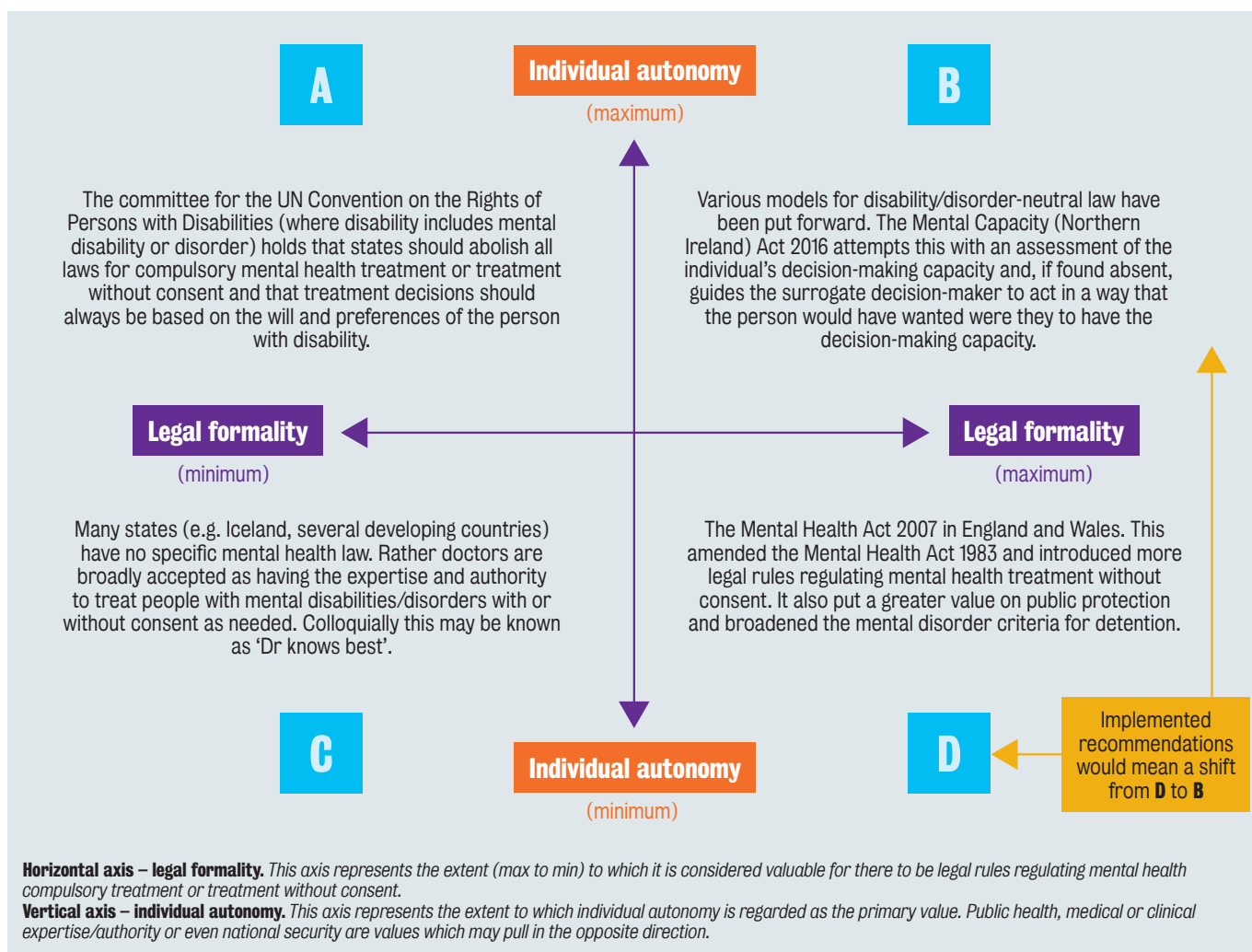
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The proposed safeguards for ACDs in England and Wales address these issues. Advance refusals would be respected by mental health services unless: (i) there is no other clinically appropriate treatment and a second opinion doctor is satisfied this is the case, or (ii) that the treatment is immediately necessary to prevent death, serious deterioration, violent behaviour, self-harm or serious suffering.

Competing values

Policy-making on advance decision-making in mental health takes place within a system where there are competing values: the extent to which legal rules should regulate mental health compulsory treatment, and the extent to which individual autonomy should be the primary consideration. Figure 1 illustrates these values and policy positions associated with them.

FIGURE 1: STRIKING THE BALANCE BETWEEN LEGAL FORMALITY AND INDIVIDUAL AUTONOMY



The recommendations in the next section aim to shift the balance towards maximising individual autonomy whilst retaining appropriate legal formality (from segment D to segment B in figure 1). In our view, such a shift allows for:

- ♦ More mental/physical health equality on advance decision-making without getting rid of specialist legislation for mental health contexts.
- ♦ More recognition of the role of clinical judgement in advance decision-making whilst introducing statutory provision and accountability.
- ♦ More service user autonomy whilst recognising that public interests exist.

Recommendations

Three key principles should underpin law reform for mental health advance decision-making

Reform in this area should:

1. Enable a culture change in relation to advance decisions made with capacity such that they are: (i) developed within mental health services, and (ii) involve joint working on mental health requests as well as potential refusals.

Historically, anti-psychiatry movements have been influential in shaping discussions of advance decision-making in mental health and this has emphasised advance refusal. However, evidence suggests that service users would like to make advance decisions in collaboration with mental health services. In addition, they would like to use documents such as ACDs as vehicles to request treatment that they know has been helpful to them in previous crises as well as make specific refusals.

2. Enable mental health Advance Decisions to Refuse Treatment (ADRT) with limitations reflecting legitimate public interests.

The current lack of parity between statutory provision for mental and physical health advance decision-making is ethically problematic and a human rights issue. ACDs which enable the refusal of medical treatment for mental disorder will be an important step towards reducing this inequality, but as noted above there may be particular concerns around this in mental health care contexts. Providing certain limitations around their contents can mitigate these concerns (see page 4).

3. Give service users more insurance that well thought-through advance decision-making documents will be respected.

Many people with severe mental illness experience fluctuating capacity (as exemplified in the case above). While they may lose the capacity to make treatment decisions during severe episodes of illness, when well they have full capacity to reflect on previous episodes of illness and use this experience to guide recommendations for future treatment. Fluctuating decision-making capacity can provide opportunities for well thought-through mental health ACDs borne of actual experience and responsive to learning. Formal provision for ACDs is required to assure service users and clinicians that making such detailed plans is worthwhile.



A range of stakeholders need to be involved to make ACDs a success

The government's review of the MHA creates an important opportunity to modernise advance decision-making for mental health. The introduction of statutory ACDs will be a vital step forward in achieving parity across mental and physical healthcare. However, it is unlikely that statutory change alone will be sufficient for a successful policy. For this we would further suggest that:

1. The MHA in its principles should reinforce the duty of **the NHS** to provide for mental health and include a reference to ACDs.
2. The MHA should empower a **specialised body for England and Wales** (similar to the Mental Welfare Commission in Scotland) to facilitate awareness of ACDs, provide case review and guideline development.
3. **Professional bodies** such as the Royal College of Psychiatrists, the Royal College of Nursing, the British Association of Social Workers and the British Psychological Society should be involved in the passage of the changes and take a lead in professional training and development.
4. The **Department of Health and Social Care** should provide Mental Health Trusts with up to date models of ACD implementation.
5. Leading mental health and service **user-led charities** should participate in the development of ACD templates.

References

1. More detail on these recommendations can be found in the following article which summarises the report submitted to the Independent Review of the Mental Health Act: G. S. Owen, T.Gergel, L. A. Stephenson, O.Hussain, L. Rifkin, A. Ruck Keene, Advance decision-making in mental health – suggestions for legal reform in England and Wales. *International Journal of Law and Psychiatry* (2019) 64; 162-177 (Open Access) <https://mhj.org.uk/2019/04/17/advance-decision-making-in-mental-health-suggestions-for-legal-reform-in-england-and-wales/>
2. <http://www.mentalhealthalliance.org.uk/news/2017-a-mental-health-act-fit-for-tomorrow.html>

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