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Perspective Piece

Mental health advance planning documents: complexities and considerations

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Abstract

This article addresses the questions of when mental health advance planning documents are created, the points when circumstances which they are intended to address arise and what consequences should flow when such a situation does arise. It addresses these points primarily from the perspective of what the law could/should be at a conceptual level. It looks at three stages: (a) creation of the document; (b) the period between the creation of the document and the point at which the intended circumstances arise; and (c) the point at which the intended circumstances arise. It does not purport to provide solutions at each stage, but rather to frame the dilemmas to aid discussion. In similar vein, it draws upon case studies from England & Wales, not to purport to dictate similarities of approach, but to flesh out dilemmas that have arisen to stimulate consideration.

Keywords: Human rights; mental disability; mental health

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Introduction

This article addresses the questions of when advance planning documents are created, the points when circumstances which they are intended to address arise and what consequences should flow when such a situation does arise. Whilst its observations are broadly applicable to all forms of advance planning documents, its particular focus is on the dilemmas that arise in the mental health context. The article addresses these points primarily from the perspective of what the law could/should be at a conceptual level. The primary focus of this article is upon unilateral instruments – that is, those documents prepared by the person in question and seeking in some way to provide the framework for what should happen to them at a point when (for whatever reason) they are unable to participate in the decision-making process at that point. The use of the term 'decision-making' here is intended to encapsulate decision-making on behalf of the person, if that is relevant, as well as decision-making by whoever it is (whether that be professional, informal carer, or family member) who has to act.

The sort of document with which this article is concerned could include categorical statements (e.g. refusals of specific interventions, or requests for the involvement of specific individuals in decision-making) or statements of wishes or values (i.e. focused less on specific decisions but the way in which the individual would like decisions to be taken). It could also include statements about how the person would wish their legal position to be characterised. For instance, a person could purport to give advance consent to admission to a facility where care and treatment is to be provided such that, at the point of admission, they are to be treated as consenting to it even if they are not presently able to do so – such might well then track through to whether they are to be regarded as deprived of their liberty. It may well be that the same considerations apply also to documents whereby the person seeks to give authority to another to stand in their shoes, but this is not the primary focus of this article.

The names given to such advance planning documents have varied across time and jurisdictions (Gloeckler *et al.* 2025). At present, in England & Wales (where the author is located), the preferred term in the mental health context is 'Advance Choice Document' (or 'ACD)', in part to draw a distinction with Advance Decisions to Refuse Treatment, the statutory term used in relation to decisions regarding to physical health treatment. An ADRT, made under the provisions of the Mental Capacity Act 2005, can only ever relate to a refusal of specified physical health treatment or treatments; an ACD, by contrast, can express a wider range of choices concerning admission and treatment for mental disorder, including requests for, as well as refusals of, interventions.

The article looks at three stages:

a. Creation of the document;
b. The period between the creation of the document and the point at which the intended circumstances arise;
c. The point at which the intended circumstances arise.

It does not purport to provide solutions at each stage but rather to frame the dilemmas to aid discussion. In a similar vein, it draws upon case studies from England & Wales, not to purport to dictate similarities of approach, but to flesh out dilemmas that have arisen to stimulate consideration.

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Creation

At the creation stage, there is a fundamental tension between formality and accessibility. The more formal the document, the more likely it is that it will not be subject to challenge at a later date – above all at the point when the creator will have wanted the document to take effect.

Conversely, the more formal the document, the less accessible advance planning documents risk becoming. There are (at least) two aspects to this: (1) cost; and (2) access (if relevant) to a person able to certify relevant matters such as the capacity of the person to create the document. These risks can be mitigated where advance plans are, in effect, integrated into care planning undertaken by statutory authorities. However, this is not a panacea because: (1) it does not mean that the exercise is cost-free – the cost is simply shifted from the individual to the organisation; and (2) it is not obvious that every person who might want to make an advance plan about aspects of their care and treatment will be in contact with statutory authorities.

It is also worth observing that an advance plan could, of course, be made other than in a document – by way of example, the Mental Capacity Act 2005 in England & Wales provides that an advance decision to refuse treatment (other than life-sustaining treatment) can be made orally. In my experience as a practising English barrister, however, the problems of identifying whether, when and how one was made are so significant that decision-making in the context of an asserted oral decision collapses almost inevitably into a 'presentist' analysis of the correct course of action.

Returning to the position where the person's plan is recorded in a document, I would also highlight a particular issue in relation to 'authentication' in relation to the capacity of the person to make the plan (in other words, confirmation that the person has the necessary capacity). This question will arise no matter: (1) whether 'capacity' is a relevant criterion for the plan to enter into force; and (2) what the components of that capacity are considered to be. Depending on one's perspective, authentication is either a sensible insurance policy or an unnecessary – and potentially discriminatory – departure from the presumption of capacity. This issue has caused considerable dissension in the context of the proposed introduction of ACDs into the Mental Health Act 1983 ('MHA 1983') in England & Wales, which further crystallises another issue: the significance of the weight to be placed upon formality is directly linked to the consequences which flow from the making of such a document. See in this regard this extract from the White Paper consulting upon the proposals advanced by the Mental Health Act Review which had reported in 2018 (Department of Health and Social Care 2021):

> Under the reformed Act, decisions made by people when they have the relevant capacity to make them will have a real power and influence over decisions and appeals regarding care and treatment. Any statements of preference in an ACD will, in most cases, be considered as equivalent to those made in real time by a patient with the relevant capacity.
>
> To remove the potential for doubt later as to whether the person had capacity to make the choices contained in an ACD, the review recommended that service users should seek to have their documents authenticated by a health professional. As part of this, the health professional would ensure that the patient understands the foreseeable consequences of an ACD, including the potential risks of refusing treatment; the circumstances in which treatment refusals can be overridden; and in what circumstances wishes and preferences may not be followed, for example, if preferred treatments are not available or clinically appropriate.
>
> While we agree an authentication process would be beneficial in ensuring that the patient is fully informed of the decisions they are making and in giving the responsible clinician confidence in the document's contents, we do not think that formal authentication should be necessary for the ACD to be valid. Instead, we think that for an ACD to be valid and have legal effect, it must have been made by someone who had the relevant capacity and apply to the treatment in question. This is the same approach as under the MCA. Authentication would be one way that an individual could seek to ensure that there is no doubt later about whether the statements were made with capacity. Otherwise, it would be for those concerned with the patient's care and treatment to consider whether the statements were made with capacity at the point when decisions need to be made.

Mental health law is an area in the United Kingdom which is legislated for separately in England & Wales, Scotland and Northern Ireland. The Department of Health and Social Care, responsible for the relevant parts of mental health law in England & Wales, consulted upon the proposal simply to align ACDs under the MHA 1983 with those under the Mental Capacity Act 2005 (where there is no authentication required). There were 1,278 responses to the question in the consultation: overall, 69% of consultation responses to the White Paper agreed/strongly agreed with the proposal, while 10% disagreed/strongly disagreed and 21% were not sure (Department of Health and Social Care 2021). Of relevance for present purposes are perhaps the contrasting positions of the Equality and Human Rights Commission and the National Survivors User Network recorded in the White Paper:

a. The EHRC 'recommend[ed] a requirement for ACDs to be authenticated by a health or social care professional to help ensure the patient understands their choices and the implications and to prevent any disputes about whether the patient had the relevant capacity and information at the time they made the decision'.
b. NSUN, by contrast, 'are concerned that the proposals in the White Paper may lead to a two-tier system, where those judged to have capacity and who have benefited from extended support and care will enjoy a significantly different level of autonomy to those who have not had such prior support'.

The Bill introduced into the Westminster Parliament (i.e. the legislative body for England & Wales) in the Autumn of 2024 provides, in its introduction of ACDs, that they must be made by a person with the requisite capacity. It does not require formal authentication, although this may, in fact, be achieved in a de facto fashion through the operation of the duties that will be imposed by the amended MHA 1983 upon the relevant public bodies to support relevant individuals to make ACDs. Discharging those duties may well include the public bodies (of their own motion) wishing to ensure that they are recording that they are supporting the relevant decision-making capacity.

The practical consequences of the absence of a requirement to include any 'authentication' in relation to advance decisions to refuse treatment in the Mental Capacity Act 2005 in England & Wales can be seen in *Re E (Medical treatment: Anorexia)* [2012] EWCOP 1639. In the absence of 'clear evidence establishing on the balance of probability' (paragraph 35) that E had the capacity at the material time to make the advance decision purporting to refuse force-feeding, the judge determining the case, Baker J (as he then was), concluded that the otherwise valid and applicable advance decision did not, in fact, exist. He went on to order that E was to be fed against her will. That case merits reading to test one's reactions: did the judge's overriding of the advance decision on the basis that

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he could not be satisfied that it had been made with capacity serve or harm E's interests? And, having read the case, it would be worth re-reading it in light of the fact that E has subsequently been identified as having been alive at least one year after the decision.

It is also perhaps worth highlighting for completeness that the same issues as regards 'authenticating' in respect of capacity will arise in respect of authenticating or otherwise confirming that the document is the product of the person's own free will.

Some may feel that different issues arise in respect of advance planning documents made for those in the mental health 'zone' to those in the physical health 'zone' – but an immediate challenge in this regard is as to the basis upon which any differential approach can be justified, so as not to amount to discrimination.

The period between creation and the intended circumstances arising

Two key issues arise at this stage: (1) recording of the fact of creation; and (2) the potential for time to elapse before the document is created and the intended circumstances arising.

A critical and immediate practical problem in relation to the creation of an advance document is whether (and if so, how) they should be stored in relevant records – whether medical, care or otherwise. The problems in this regard in relation to advance decisions to refuse treatment in Wales are vividly described in a 2016 report (Kitzinger and Kitzinger 2016) including situations in which treatment has been provided, often for considerable periods of time, against the recorded wishes of the person in an advance decision which has not been identified. And, in *NHS Cumbria CCG v Rushton* [2018] EWCOP 41, a person's attempts to ensure knowledge of her advance decision, including by giving a copy to her general practitioner to include in her records, did not prevent her being started with clinically assisted nutrition in hydration against the terms of that advance decision because of communication failures within a decentralised medical system.

Again, however, the greater the requirement for recording, the higher the potential burdens to accessibility. It is also always necessary to have a backstop in relation to any legal provision to cater for the situation where a person has made an advance planning document, but it has not (for whatever reason) made its way into the relevant records.

As to the second issue, the concept of advance decision-making has (in different forms) been around for many years, and it is now possible to start to see the potential problems caused in relation to 'old' documents. A case study from England & Wales is the case of *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52, concerning a 20-year-old advance decision to refuse treatment, apparently not revisited in the intervening years (and also not brought to the attention of the attorneys appointed by the woman in question to make decisions about her health and welfare). Under the relevant provisions of the MCA 2005, the age of the document did not, per se, affect its validity or applicability, but clearly weighed heavily in the mind of the judge. Put shortly: was he right to be concerned?

It should be noted that: (1) the more successful policies of supporting advance planning are; and (2) the more that the law relating to decision-making at the point where the person is unable to participate is predicated upon taking those documents into account, the more likely that, over time, there will be documents in existence which may have been around for some considerable period before they are relevant. Further, in the context of those with mental health conditions, a relatively short period of time may well see very considerable changes in their circumstances such that views that they have expressed in any advance plan no longer apply.

A similar, although perhaps less acute, dilemma arises in relation to the gap between the document being created and the intended circumstances arising to that which arises in relation to that at creation. The greater the degree of formality imposed (for instance, formal time limits to validity or formal requirements for review), the more inaccessible they become. Conversely, the greater the degree of informality, the greater the risk that those charged with deciding/acting at the relevant point will be troubled as to whether they should do so. And, arguably, the greater the argument that they should be so troubled because the more there is a prospect that the document no longer reflects the person's actual wishes.

The consequence when the intended circumstances arise

Two key questions arise at this point:

a. Whether the intended circumstances can or should be entirely 'self-directed?
b. Whether and under what circumstances it is legitimate not to follow a choice intended by the person to be a categorical one.

In respect of the first question, the traditional approach to advance planning has been contingent upon such documents taking effect at the point where the person does not have the capacity (however defined) to participate in decision-making. That determination is not made by the person themselves but by those who need to take action albeit it can be informed by statements made by the person in advance to help guide the process of assessment: see in this regard the 'PACT' advance planning documentation prepared as part of the Mental Health and Justice Project, which includes a section where the service user can set out signs that they may have lost capacity to make decisions about mental health treatment: see the template in the appendix to Stephenson *et al.* (2020).

The CRPD (or, more precisely, the Committee on the Rights of Persons with Disabilities) has thrown the traditional approach set out above into doubt, General Comment 1 to Article 12 providing that:

> The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity (General Comment 1, paragraph 17)

Suffice to say that such an approach to advance planning – taken to its logical extremes – is fundamentally incompatible with the governing legal frameworks for health and social care in most jurisdictions. These are based on a binary distinction between a person whose current actions or decisions are taken as having legal effect and a person whose current actions or decisions are not taken as having such effect.

The question of whether this approach to capacity is binding upon signatories to the CRPD is one that has generated much heat, but little light; I do not address it further here (but see Ruck Keene *et al.* 2023). With specific reference to the issue as it plays out in the context of advance planning, I note that, in favour of the Committee's interpretation might be thought to be the following:

a. It enables, in essence, unlimited self-direction as to the circumstances under which the advance planning document is intended to be effective. It could, therefore, include provisions for it to take effect at a point prior to the point that others might

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identify the person as having lost decision-making capacity. This could be particularly important for a person with a cyclic condition such as bipolar disorder, who may recognise the signs of an impending crisis in advance of those who do not know them and have very clear views as to what the most appropriate course of action to take at that point might be. These views could include nudging, persuading, or even compelling them to do something that, at that point in time, they are rejecting (for an argument in favour of this approach, although not predicated on the CRPD Committee's interpretation of Article 12, see Gergel and Owen (2015));

b. The Committee's approach appears to provide a clear answer to the dilemma of what to do where the person's past wishes (as recorded in an advance planning document) clash with the current manifestation of those wishes and feelings. Unless it is clear (according to whatever evidential standard is adopted) that the person's will as recorded in their advance planning document is that any current preferences contradictory to that will are to be ignored, all those concerned should proceed on the basis of the person's current desires.

Against this interpretation might be thought to be the following (over and above the incompatibility with current legal frameworks):

a. Making 'entry' and 'exit' solely contingent on the person's own decision raises the prospect of the person being held to a document which does not, in fact, represent their will at the time that action is required. This could have consequences which – at the limits – are fatal for the person concerned. It would also have consequences which are likely to give rise, at a minimum, to moral distress on the part of those who might be required to act upon the basis of that advance planning document;
b. If the sub-paragraph above suggests an extreme which may appear unpalatable, it is also important to note that, more broadly, the Committee's approach otherwise pushes to an extreme which feels equally unpalatable. With the exception of the scope for self-binding set out above, the heavy skewing of the Committee's approach towards the present position makes it much more difficult for those with degenerative conditions who hold to the importance of precedent autonomy to secure the essential interests which form the basis of that approach. Unless in every case they make expressly clear whether and under what circumstances their wishes and feelings were not to be determinative something which, decision-making would always proceed on the basis of those current wishes and feelings. Whilst it may be (relatively) easy for a person with a cyclical condition to have a sense of how they present when they self-identify as 'not being themselves', it is very much less easy for someone with a degenerative condition to project forwards to be able to predict precisely what they may do or say when their condition advances to the point that they might wish their advance planning document to take effect. Adopting the Committee's approach without further consideration of the potential impact upon such individuals would not easily sit with the 'nothing about without us' approach central to the Convention;
c. At a purely practical level, and without being unduly pessimistic, it is not unlikely that having entirely self-directed documents will generate uncertainty on the part of those who might need to take action (often rapid action) to secure what they consider to be the interests of the person as to the weight that they are to place upon the document. Further complications also potentially arise in respect of self-directed documents which move beyond statements of what the person would not want to statements of what the person would want. To take the example of an attempt to 'self-bind' to bring about admission to a facility in advance of a severe mental health crisis: assuming the reality that the places in such a facility are not unlimited, how are those charged with decision-making in relation to admission to weigh the demand of that person as against the position of the person who is currently in crisis?

The discussion above feeds into consideration of the second question – that is, in what circumstances it is legitimate not to follow a choice intended by the person to be a categorical one. The Committee appears to give a clear answer to this question: that is, only under circumstances when the person themselves has made clear that there is a 'let-out'. If this – very strong – approach does not appeal, then consideration will be needed as to the correct 'objective' test to apply. As noted above, the setting of this test will then have upstream effects in relation – above all – to the importance of formalities at the entrance point. In other words, the more limited the scope for those currently considering the person's position to proceed on a different basis to that set out in the advance planning document, the more important it is that that document can provide a secure basis – both legal and ethical – for them to do so. The concept of advance consent to confinement provides an example of the dilemma given that such will feed into the characterisation of whether the person is at that point to be considered to be deprived of their liberty, and thereby attracting (in countries to which the European Convention on Human Rights applies) the procedural safeguards required by the right to liberty protected by Article 5 ECHR. Put shortly, if a person is confined in a mental health setting, and currently unable to give consent to that confinement because of their mental health crisis, should they nonetheless be considered to be an 'informal' or a 'voluntary' patient because they have previously given consent to be so confined? Concerns as to the prospect of such individuals – in effect – opting out of those protections and remaining opted out of those protections on the basis of documents generated in advance of admission led the Independent Review of the Mental Health Act 1983 in England & Wales to a (rare) point where consensus could not be reached (see Wessely et al. 2018, at pages 81 to 83).

A separate issue would arise in relation to Article 14 CRPD (the right to liberty), which is arguably even starker if the Committee's approach to the Article is adopted. The Committee's approach suggests that consent forms the only basis upon which a disabled person could be admitted to circumstances of confinement. On the Committee's logic, it would therefore be possible to give binding consent to admission in circumstances of confinement and irrevocably commit oneself to the characterisation of that position as falling outside the definition of deprivation of liberty.

In relation to medical treatment, it is of note when comparing different regimes that the 'let-out' identified by the Court of Protection in *PW*'s case (in which the judge was statutorily permitted to take into account views expressed by PW after the point she was said to have lost capacity to make medical treatment decisions) is not available in the Republic of Ireland under its Assisted Decision-Making (Capacity) Act 2015. That Act enshrines a much harder-edged approach to precedent autonomy than does the MCA 2005 in England & Wales. The judge in *PW*'s case could rely upon s.25(2)(c) of the MCA 2005, which provides that an

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advance decision is not valid where the person has done anything else clearly inconsistent with the advance decision remaining their fixed decision ('anything else' being read in conjunction with s.25(2)(a), which talks of withdrawing the advance decision when the person has capacity; and (b), which talks of granting authority to an attorney to make the decision covered by the advance decision). By contrast, s.85(c) of the ADMCA 2015 expressly provides that the equivalent to the relevant statutory provision in s.25(2)(c) MCA 2005 only applies to 'clearly inconsistent' actions done at a point when the person had capacity to do so.

Despite the enormous amount of academic ink spilt on this question, it may be thought that this issue is – ultimately – one where attempts by the law to prescribe outcomes are both practically doomed and ethically unattractive. If so, then the true focus should be upon:

a. The processes by which decisions/actions in any given situation are approached;
b. the circumstances under which it is considered appropriate for dilemmas to be resolved informally; and
c. the circumstances under which formal resolution is required – including by whom.

Conclusion

Securing the ability to project a person's voice forward is a hugely important component of ensuring that decision-making about them comes as close to being with them at a point when they appear not to be able to speak for themselves. But it is not straightforward legally, ethically or practically, and this paper has sketched out some of the contours of those complexities for those wanting to recognise that ultimately, some of the principles in play may be irreconcilable.

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