

1347, 1856

Maudsley Debate

Should people with mental illness be able to commit themselves to future involuntary treatment?

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*Self-binding directives, which allow people with mental illness to dictate a compulsory treatment for themselves in the event of a future episode, could give them a degree of control and safety in decision making, say **Tania Gergel** and **Allen Frances**. But **Arun Chopra** and **Theo Van Willigenburg** argue that this takes advance planning too far and could worsen inequalities*

Yes—Tania Gergel and Allen Frances

Many people with severe episodic mental illness, such as bipolar disorder, know from past experience that their illness may well expose them to risk during future severe episodes in a way that they won't be able to control at that point. They may also recognise the likelihood that they'll resist treatment during such episodes—even though this is when treatment is most desperately needed.

These people understand, when they're well, the potentially catastrophic consequences of remaining untreated, even including risk to their lives given the high risk of suicide, particularly during the most severe depressive or “mixed” episodes of bipolar disorder. A self-binding directive (SBD) could provide them with a greater degree of control and safety for their future, by allowing those who wish to do so to explain how illness and risk manifest for them and to request treatment during the most severe phases of illness, even if they don't consent when a future episode occurs. [OK?]

Common concerns

SBDs are a form of advance request. They are not legally binding and would never lead to a clinician being forced to prescribe a treatment that went against their own clinical

judgment. They are not “directives” in the sense that [OK?] people would receive unnecessary or avoidable involuntary treatment or hospital admission. Rather, they harness the expertise of all stakeholders drawn from previous episodes, allowing clear indicators to be given for treatment and assessment, ensuring that treatment would be imposed only if the necessary clinical and legal criteria had been satisfied in terms of risk and lack of decision making capacity in relation to treatment.[1]

Of course, there are many people who wouldn't wish to create an SBD, and it's critical to provide safeguards to guard against undue influence or pressure. Ethicists worry that treatment might be imposed on someone before their illness had caused impaired decision-making capacity or that changes in a person's behaviour and views on treatment might be indicative of authentic changes of opinion as opposed to severe illness.

Until recently the debate about SBDs remained largely theoretical. However, a 2019 survey conducted in partnership with the charity Bipolar UK showed strong support for SBDs from people who used mental health services.[2] It also suggested that many of them viewed the transition to illness as clear cut: of the 463 participants (82%) who endorsed the idea of an SBD, 89% provided free text answers justifying this endorsement on the “grounds of a major determinate shift and distortion of thinking and decision making abilities when unwell.”[2]

To quote one response: “Because when I'm in a depressive state I want to die, when I'm not I don't. I'm a different person with different thoughts, feelings and reactions when I'm depressed or even manic, it wouldn't be fair if I'd stated in my care plan to persist in treatment to get better but was refused because of my depressed or manic state.”

Person centred care

The SBD approach may well be a “win-win” option in a seemingly impossible situation and could enhance both the person's autonomy and the model of “person centred care”—that is, ensuring that they're actively involved in decision making relating to their care and that their care is tailored more specifically to their individual needs. People can use their own lived experience of illness and treatment to inform others about the signs that they're severely unwell and at risk. Drawing on their past experience of treatment, they can suggest what they consider the most suitable treatment and, effectively, give advance authorisation for involuntary treatment—providing an opportunity for the person to exert some autonomy and control at a time when this won't be possible.[OK?]

Having an SBD can facilitate an increased sense of control and security for people navigating the difficulties of living with severe mental illness and may even provide

reassurance to the mental health professionals responsible for imposing involuntary treatment. In an ideal world, nobody would experience the trauma of involuntary treatment. However, the reality of many severe mental illnesses means that, no matter how good the care available, future health crises can't always be prevented, and some degree of coercive care may be required.

An SBD not only helps a person receive treatment but might also ensure that this care process [OK?] is better managed and less resource intensive by providing a pathway for earlier recognition and treatment of illness. It can also be used to inform healthcare providers of any elements of previous involuntary treatment that the person found particularly traumatic, so that this could be managed better during future illness. And through building greater awareness among the people who use mental health services, as well as carers and clinicians, it could even help to prevent illness from escalating to the point where involuntary treatment is needed.

No—Arun Chopra and Theo Van Willigenburg

At the Mental Welfare Commission we actively take steps to promote advance planning. We promote and monitor provisions in legislation that enable people to participate in their care when they might be unwell. However, self-binding directives (SBDs) are an over-reach—legally, clinically, and ethically—and developing them in law could lead to untoward consequences.

Currently, the right to refuse treatment can be over-ridden only through a legal process, and there are no rights to demand a service or a treatment. Under an SBD that specifies how a person must be compulsorily treated if they lose capacity to make the relevant decision, this basic premise of respecting a refusal (unless lawfully over-ruled) is changed to one of meeting a demand for treatment. A clinician could be compelled to follow a suboptimal plan, setting up a clash between clinical judgment and potential legal requirements.

Providing support for decision making is one way to realise the rights, will, and preferences of a person who may have reduced capacity, in keeping with the UN Convention on the Rights of a Person with Disabilities.[3] SBDs privilege only a person's precedent autonomy—namely, what they said in the past about how they must be treated. This could mean that efforts to understand, work with, and promote support for decision making, and creating alternatives to the use of restrictive practices, will be reduced.

This poses real risks to a person's rights. In practical terms, how would we guard against the undue influence of those (such as a family member or loved one) who would, even if well

intentioned, prefer that the person should accept treatment and compels them to make and then follow an SBD?

Incompatible with UK law

SBDs specifying compulsory treatment are incompatible with current mental health law in the UK. Particular risks must be demonstrated before a person can be subject to involuntary treatment. Proponents argue that SBDs would allow compulsory treatment to take place before such risks emerge. But this creates a dilemma: should we respect the SBD and continue a person's treatment in the absence of risk? Or should we acknowledge the lack of risk and require discharge from the compulsory treatment?

Alternatively, the SBD might require treatment only at a level of symptoms that results in risks that require compulsion—in which case the SBD itself becomes redundant.

In Scotland, the Mental Welfare Commission holds the register of advance statements. This register is skewed with an over-representation of people living in the more affluent areas of Scotland.[4] Among the service user respondents to a 2019 survey on SBDs, 93% were white and 72% were educated to degree level[2]—which is not representative of those who may be subject to compulsion in mental health services.

SBDs as an extreme form of advance planning could create two tiers of routes to treatment: those who trust services enough to create these instruments, who then get speedier entry to hospital on their own terms, perhaps in the absence of risks or before they emerge; and those who don't have as much trust, who don't then make these instruments and are then likely to remain subject to community compulsion for longer, accessing inpatient care only when the risks are high. As community-based compulsion is already disproportionately used with minority ethnic groups, SBDs could lead to a worsening of inequalities.

Instead, we need to make the current models of advance planning available to all. There is unrealised potential: in Scotland, for instance, only 6% of people detained under the Mental Health (Care and Treatment) (Scotland) Act 2003 had an advance statement.[4] We need to undertake statutory monitoring of how many people are offered advance planning, along with scrutiny when treatment refusals are not respected. And we need better mechanisms to involve other parties important to the person when determining wishes and preferences at times when that person has reduced capacity, recognising that we are individuals within communities.

Notes:

Views expressed are those of the authors and do not necessarily reflect those of their organisations. TG also has lived experience of using an SBD to manage her own treatment and was involved in a BBC Radio 4 podcast on the subject, *Bound to the Mast*.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare the following interests. AF and [AC] have no competing interests to declare. [Any competing interests for Theo Van Willigenburg?]

1 Gergel T, Owen GS. Fluctuating capacity and advance decision-making in bipolar affective disorder—self-binding directives and self-determination. *Int J Law Psychiatry* 2015;40:92-101.

2 Gergel T, Das P, et al. Reasons for endorsing or rejecting self-binding directives in bipolar disorder: a qualitative study of survey responses from UK service users. *Lancet Psychiatry* 2021;8:599-609.

3 United Nations. Convention on the rights of persons with disabilities (CRPD): Article 12—Equal recognition before the law.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

4 Mental Welfare Commission for Scotland. Mental Welfare Commission publishes two reports for consideration by the Scottish Mental Health Law Review.

<https://www.mwscot.org.uk/news/mental-welfare-commission-publishes-two-reports-consideration-scottish-mental-health-law>