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# A FINE BALANCE: RECONSIDERING PATIENT AUTONOMY IN LIGHT OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

JILLIAN CRAIGIE

#### **Keywords**

patient autonomy,
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#### **ABSTRACT**

The Convention on the Rights of Persons with Disabilities is increasingly seen as driving a paradigm shift in mental health law, particularly in relation to the understanding that it requires a shift from substituted to supported decisions. This article identifies two competing moral commitments implied by this shift, both of which appeal to the notion of autonomy. It is argued that because of these commitments the Convention is in tension with more general calls in the medical ethics literature for preserving patient autonomy through support. The competing commitments within the Convention also present a particular challenge in putting the support it requires into practice. A discursive control account of freedom is used to develop some practical guidelines for navigating this new moral territory.

#### INTRODUCTION

Despite the importance placed on respect for patient autonomy in medicine, there remains considerable uncertainty about what practices constitute a transgression of this principle. Recent years have seen the rise of calls in the medical ethics literature for greater involvement of healthcare professionals in patients' decisions, in the name of autonomy. This development has constituted a shift, to some degree, back towards a more traditional role for professionals in treatment decision-making, away from the minimal role in standard informed consent models. The United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup> represents an important development in the area of mental health law, and in this article I examine its implications for our understanding of what respect for patient autonomy requires, particularly in relation to decision-making support.

The CRPD has been widely interpreted as requiring a shift from legal structures that involve the transfer of personal decision-making (including treatment decisions) to a substitute decision-maker, on grounds of mental disorder or mental incapacity, to structures that instead

support the person in making their own decision.<sup>2</sup> Focusing on the concept of autonomy, I develop an account of the moral basis for this prescribed shift. This account points to an important difference between the evaluative commitments underlying the Convention, and those motivating the calls in the medical ethics literature for preserving patient autonomy through support. This difference means that the CRPD represents a new development in debates about patient autonomy, distinct from the shift already occurring in the medical ethics literature towards supported decision-making. The account also identifies a tension within the Convention, which presents a particular challenge in putting the support it requires into practice.

# THE CRPD: FROM SUBSTITUTED TO SUPPORTED DECISIONS

The current approach to preserving patient autonomy through the law in England and Wales, largely adopts a policy of non-interference in adults' treatment decisions,

Address for correspondence: Dr. Jillian Craigie, Department of Philosophy, University College, London WC2R 2LS. Email: j.craigie@ucl.ac.uk Conflict of interest statement: No conflicts declared

<sup>&</sup>lt;sup>1</sup> The Convention was adopted by the United Nations General Assembly in December 2006.

<sup>&</sup>lt;sup>2</sup> United Nations Committee on the Rights of Persons with Disabilities. General comment No 1 (2014) Article 12: Equal recognition before the law; Australian Law Reform Commission. Discussion Paper 81: Equality, Capacity and Disability in Commonwealth Laws 2014, ss. 2.69–2.80.

unless the person is judged to lack mental capacity in relation to the decision, or unless they have a mental disorder of a kind and degree that authorizes their detention and treatment in hospital. The first kind of case falls under the Mental Capacity Act 2005 (MCA), the second under the Mental Health Act 1983 as amended by the Mental Health Act 2007 (MHA). In both contexts the relevant decisions are transferred to a substitute decisionmaker, and under the MCA there is an explicit requirement that these decisions must be in the patient's best interests.3 The best interests assessment must take into consideration the person's past and present wishes, feelings, beliefs and values insofar as these are 'reasonably ascertainable'. However, the weight that can be placed on the their current wishes is limited by the fact that the starting point for the assessment is a judgment that the person's mental state means that they are currently unable to make the decision for themselves.<sup>5</sup>

This kind of approach to instances where a person's ability to make a personal decision is apparently impaired stands in contrast with that envisaged in the CRPD. The Convention adopts a social model of disability according to which a person's context plays a necessary part in explaining their disability. The preamble to the Convention describes disability as resulting from, 'the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (section e). Together with this background conceptual framework, Articles 12, 14 and 17 of the Convention have been interpreted as the elements that are particularly relevant to the MCA and MHA. Article 14 prohibits restrictions of liberty based, in part or whole, on mental disability; and Article 17 requires that the right to respect for one's own physical and mental integrity applies to people with disabilities on an equal basis with others.<sup>6</sup> However, most directly relevant to the substituted decision-making structures of the MCA and MHA, Article 12 provides that 'persons with disabilities enjoy legal capacity on an equal basis with others is all aspects of life' (12(2)); and requires states to 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.' (12(3))

The implications for law in England and Wales are yet to be established. However, commentators have suggested that compliance will require a shift, at least to some extent, from the binary substituted decision-making structures of the MCA and MHA towards a supported decision-making approach, in which treatment decisions are made by the patient with the help of others.<sup>7</sup> For example, Genevra Richardson writes that understood in its purist sense:

[Article 12] would demand that the law respect a person's decision, however disabled that person's mental powers might be, and however damaging the consequences of the decision. In practice, and in reflection of the social model, Article 12 would require the person to be supported in making her decision, and it would be the decision that emerged from this support that would attract legal effect.<sup>8</sup>

Adopting this interpretation of the Convention, in a report written for the Law Commission of Ontario, Michael Bach and Lana Kerzner propose that, 'the question can no longer be: Does a person have mental capacity to exercise their legal capacity? . . . Rather, the question is: What types of supports are required for the person to exercise his or her legal capacity?'9

### SUPPORTED DECISION-MAKING

In a General Comment on Article 12, the CRPD Committee defined support very broadly as encompassing 'both informal and formal support arrangements, of varying types and intensity', including peer support, advocacy, help with communication, and the deferral of decisions to a trusted person. 10 A number of supported decision-making models have begun to be developed in response to the CRPD, two prominent ones being Bach and Kerzner's model developed for the Law Commission of Ontario, 11 and the Supported Decision Making model trialled for the Office of the Public Advocate in South Australia.<sup>12</sup> In Bach and Kerzner's model, support aims to facilitate the person with a disability: (1) in formulating their values and aims, exploring the possibilities and making a decision; (2) in engaging other parties and giving a decision effect; and (3) in acting on decisions

<sup>&</sup>lt;sup>3</sup> This is not an explicit requirement of the MHA. See for discussion: G. Richardson. Capacity in the shadow of suicide: what can the law do? *Int J Law Context.* 2013; 9: 87–105.

<sup>&</sup>lt;sup>4</sup> Mental Capacity Act 2005, s. 4(6).

<sup>&</sup>lt;sup>5</sup> G. Richardson. Mental disabilities and the law: from substituted to supported decision-making? *Curr Leg Prob* 2012; 65(1): 333–351.

<sup>&</sup>lt;sup>6</sup> For discussion see previous note.

<sup>&</sup>lt;sup>7</sup> P. Bartlett. The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law. *Mod Law Rev* 2013; 75: 752–778; Richardson, *op. cit.* note 3.

<sup>&</sup>lt;sup>8</sup> Richardson, op. cit. note 5: 16–17.

<sup>&</sup>lt;sup>9</sup> M. Bach & L. Kerzner. A new paradigm for protecting autonomy and the right to legal capacity. A report prepared for the Law Commission of Ontario 2010; 58.

<sup>&</sup>lt;sup>10</sup> Committee on the Rights of Persons with Disabilities. *op. cit.* note 2: parra. 15. For a recent discussion of 'support' as conceived of in the CRPD, see sections 2.69–2.71 and 2.75 of the Australian Law Reform Commission Discussion Paper, *op. cit.* note 2.

<sup>&</sup>lt;sup>11</sup> op. cit. note 9.

<sup>&</sup>lt;sup>12</sup> M. Wallace. Evaluation of the Supported Decision Making Project. Adelaide: Office of the Public Advocate 2012.

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and meeting agreements that have been entered into.<sup>13</sup> Supporters are appointed by the person with a disability or by an administrative tribunal, within a legal structure that allows little room for substituted decisions,<sup>14</sup> and they may be friends, family or other parties.<sup>15</sup>

The model developed and trialed in South Australia focused more narrowly on supporting people with mental disabilities to access information and consider the potential consequences of the options – by acting as a 'sounding board' – before they made a choice (although supporters also sometimes acted as an advocate to help the person achieve their goals). Supporters were chosen by the person being supported, and were almost always family or friends. He model was conceived of as one element in a 'stepped' legal structure for decision-making in which substituted decisions remained a part. However, the trial involved support offered to people who were already making their own decisions, as well as support as an alternative to guardianship (substituted decisions) in selected cases.

On the face of it, these models seem to fit well with the increasing prominence in the medical ethics literature, of accounts calling for healthcare professionals to be more involved in patients' decisions. <sup>20</sup> The models developed as a result of the CRPD concern a broader set of decisions, and tend to focus on family and friends as supporters rather than professionals. <sup>21</sup> But both literatures recognize a positive role for others in personal decision-making. In the medical ethics literature, Marian Verkerk, for example, calls for the active involvement of healthcare professionals in patients decisions, on the basis that inter-

personal relationships can facilitate autonomy by 'enhancing the capacity of people to define who they are, to understand themselves and to direct their lives.'<sup>22</sup> Adopting a stronger line, Alisdair Maclean has argued that healthcare professionals, 'should be under a legal duty to persuade their patients to change their minds when they have made an apparently irrational decision'.<sup>23</sup> According to Maclean, this kind of involvement can help patients 'realise their goals and be consistent with their values and choices',<sup>24</sup> and such forms of intervention are justified because they therefore facilitate autonomous decision-making. Both Maclean and Verkerk argue that standard informed consent procedures run the risk of treatment decisions not being autonomous, and that this calls for a supported decision-making approach.

Like these accounts, the CRPD literature justifies support with reference to the importance of autonomy, holding, for example, that the support required by the Convention seeks to 'enable autonomous (not merely willful) decisions, encompassing reflection on and reasoning in light of one's values'. <sup>25</sup> However, a closer examination of the CRPD position on autonomy reveals a tension between the moral commitments expressed in the Convention, and those expressed in the calls for support by Verkerk, Maclean and others in the medical ethics literature. This tension is brought to light by distinguishing between two widely-recognized senses of autonomy, and the relative importance attributed to them in these two contexts.

### TWO SENSES OF AUTONOMY

The principle of respect for autonomy is traditionally understood to refer to the moral importance of not being governed by others: the *liberty* to make one's own decisions. However, it is also widely accepted that making

Apparently reflecting this understanding of the Convention, the South Australian model was designed to help participants exercise 'autonomy' as well as 'self-determination' in their lives. The final evaluation of the project found that support 'can build capacity to the extent that existing Guardianship Orders were revoked.' Wallace *op. cit.* note 12: 46.

<sup>&</sup>lt;sup>13</sup> Achieving these aims is described as potentially involving help with life planning, assistance in communication, advocacy in relation to wishes, the representation of the person with a mental disability as a person, relationship and community building, and making administrative arrangements. *op. cit.* note 9: 73.

<sup>&</sup>lt;sup>14</sup> Substituted decisions are replaced by what Bach and Kerzner call 'facilitated decisions'. *op. cit.* note 9: 91–93.

<sup>15</sup> op. cit. note 9: 78.

<sup>&</sup>lt;sup>16</sup> Wallace. op. cit. note 12: 4, 24.

<sup>&</sup>lt;sup>17</sup> The final report raises the possibility that community service organisations might be an alternative source of supporters. In the trial, the project leader took over the role of supporter for a number of participants. Wallace. *op. cit.* note 12: 24.

<sup>&</sup>lt;sup>18</sup> Wallace. op. cit. note 12: 6, 45–46.

<sup>&</sup>lt;sup>19</sup> The trial included only participants with an intellectual disability, acquired brain injury or neurological disease. People with a primary diagnosis of mental illness or degenerative dementia were excluded (Wallace. *op. cit.* note 12: 9–10). Selection for inclusion in the trial also required that the participant was not involved in serious conflict with family or friends (Wallace. *op. cit.* note 12: 15).

<sup>&</sup>lt;sup>20</sup> This can be seen, for example, in the General Medical Council's guidance on consent when it was updated in 2008 from a document entitled *Seeking patients' consent: the ethical considerations*, to *Consent: patients and doctors making decisions together*.

<sup>&</sup>lt;sup>21</sup> However, in the South Australian trial the project coordinator took on the role of supporter for a number of participants when their family or friend supporters withdrew from the trial for a range of reasons, for example see 'Alex's story' (Wallace *op. cit.* note 12: 22–24).

<sup>&</sup>lt;sup>22</sup> Verkerk argues for the particular importance of this kind of involvement by healthcare professionals when a person has a psychiatric disorder, on grounds of the difficulties this often brings in terms of the person's ability to sustain flourishing relationships. M. Verkerk. A care perspective on coercion and autonomy. *Bioethics* 1999; 13: 358–368: 367.

 $<sup>^{23}</sup>$  A. Maclean. Autonomy, consent and persuasion. Eur J Health Law 2006; 13: 321–338: 321.

<sup>&</sup>lt;sup>24</sup> Ibid: 337.

<sup>&</sup>lt;sup>25</sup> S. Wilderman. Protecting rights and building capacities: Challenges of global mental health policy in light of the Convention on the Rights of Persons with Disabilities, *J Law Med Ethics* 2013; 41(1): 48–73; P. Gooding. Supported decision-making: A rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law* 2013; 20(3): 431–451.

one's own decisions is not sufficient for autonomy. In the absence of interference, decisions can be more or less autonomous depending on the degree to which the choice is the product of, or consistent with, particular psychological features of the person – for example, reflectively endorsed beliefs or desires,26 their personality as a whole,<sup>27</sup> or their underlying and enduring commitments.<sup>28</sup> As Onora O'Neill expresses the idea, how autonomous a decision is depends in part on how genuinely it expresses 'the self or individuality of the person', however this is understood.<sup>29</sup> The full extent of the capacities that underpin autonomy in this self-expression sense is disputed, but those discussed include: reasoning that enables the coherent pursuit of current desires, reflection on and endorsement and rejection of desires, an ability to imaginatively project oneself into the future, planning and policy making, impulse control, and the ability to conceive of one's life as a whole.

It is this dimension of autonomy that is emphasized by Verkerk and Maclean, with Verkerk focusing on capacities for self knowledge and making life plans, and Maclean on capacities for reasoning. Their shared concern, which is one also expressed by O'Neill, is that the emphasis in medical ethics on protecting liberty – resulting in a focus on the need for informed consent procedures – overlooks the value of a choice being autonomous in this sense that distinguishes among freely made choices. The idea is that because self-expression can be augmented through the involvement of others in personal decision-making, laws and guidance that guard too strictly against the involvement of the healthcare professionals in patients' decisions in fact run the risk of obstructing autonomy.

The most straightforward way to understand the moral basis of this kind of position is to think of it as setting these two senses of autonomy against one another, so that a balance must be struck between them. According to such views, the balance has been tipped too far in favour of protecting liberty, at the cost of self-expression, and this should be redressed. However, using the concept of autonomy to understand the moral basis for the shift from substituted to supported decisions outlined in the CRPD, suggests that it reflects somewhat different evaluative commitments. The shift seems to require two distinct moral arguments which will be discussed in turn.

First, an argument is needed for the requirement that states must make support available when a person has a mental disability. As described above, the literature surrounding the CRPD – like the medical ethics literature – justifies support primarily with reference to the value of autonomy in the self-expression sense. 30 However, in the Convention the requirement for support is made in the context of a social model of disability, and this seems to buttress the requirement in the following way. Applying the social model to the concept of mental capacity suggests that that there are no answers to questions of mental capacity independent of a person's social and political environment. Context always forms part of the explanation for a mental incapacity, and this gives force to the requirement by implicating the state as partially responsible when support was not available due to its laws or policies. In this way, the social model of mental capacity implicit in the Convention further develops the arguments for supported decision-making that are found in the medical ethics literature.

A further argument, however, is needed for the proposed shift away from substituted decisions. The implementation of support fairly straightforwardly justifies a shift, to the extent that a person should be allowed to make their own decision when support enables them to meet existing capacity standards.31 However, the shift envisaged in the CRPD literature is often much more substantial than this. Prominent commentators interpret the Convention as requiring that the mental threshold for the right to make one's own decisions be significantly lowered – for example, to an ability to express an intention that can be understood at least by those who know the person.<sup>32</sup> This proposal reflects a much greater commitment to the importance of autonomy in sense of making one's own decisions, relative to existing law. Gerard Quinn, for example, 33 holds that the price of existing safeguards is too high to pay, because people with mental disabilities lose the opportunity to create their own life and to develop associated capacities, when lifeshaping decisions are made by others.34

<sup>&</sup>lt;sup>26</sup> A. Jaworska. Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philos Public Aff* 1999; 28(2): 105–138.

<sup>&</sup>lt;sup>27</sup> R. Dworkin. *Life's Dominion An Argument about Abortion, Euthanasia, and Individual Freedom.* New York: Vintage Books; 1994. pp. 191–192, 225–227.

<sup>&</sup>lt;sup>28</sup> A. Buchanan & D. Brock. *Deciding for Others*. Cambridge: Cambridge University Press; 1989. p. 41.

<sup>&</sup>lt;sup>29</sup> O. O'Neill. Autonomy and Trust in Bioethics. Cambridge: Cambridge University Press; 2002. p. 34.

<sup>&</sup>lt;sup>30</sup> I note, however, that elements two and three of Bach and Kerzner's model appear designed to give the person's will effect, however self-expressive the decision may be.

<sup>&</sup>lt;sup>31</sup> This appears to be the approach implemented in the South Australian model.

<sup>&</sup>lt;sup>32</sup> M. Bach. The right to legal capacity under the UN Convention on the Rights of Persons with Disabilities: Key concepts and directions form law reform, Toronto: Institute for Research and Development on Inclusion and Society; 2009. This requirement is far less demanding than the mental capacity test in the MCA, which refers to the ability to understand and weigh and use relevant information. See also Bach and Kerzner (op. cit. note 9).

<sup>&</sup>lt;sup>33</sup> G. Quinn. Seminar on Legal Capacity. European Foundation Centre, Consortium on Human Rights and Disability, Brussels: 4 June; 2009.

<sup>&</sup>lt;sup>34</sup> This second argument highlights an often invisible relationship between moral commitments and mental capacity standards. Mental

An important consequence of the significant value placed by the Convention on decision-making liberty, is that this constrains its endorsement of decision-making support. In contrast, the calls for support in the medical ethics literature demphasise the importance of decision-making liberty relative to self-expression, and this points to a central difference between these two literatures. Although both recognize the role that others can play in supporting self-expression, their divergent moral commitments suggest that they may yield very different advice regarding what constitutes appropriate support.

The tension within the Convention, between its commitment to decision-making liberty and its commitment to decision-making support, also presents a practical challenge.<sup>35</sup> It suggests that putting the support required by the Convention into practice involves a fine balance of facilitating self-expression without compromising decision-making freedom. Support always involves others playing a role that moves the person in the supporting role towards rather than away from clear cases of morally problematic influence.<sup>36</sup> However, the value placed on decision-making liberty in the CRPD makes

capacity tests set a threshold for the functioning that is necessary for a person to be considered minimally autonomous (self-expressive) in relation to a particular decision (Richardson, op. cit. note 3: 91). But autonomy in this sense comes in degrees. As suggested in the arguments made by Maclean and Verkerk, a person who under existing law has mental capacity, can nonetheless be helped to make a more selfexpressive decision through support. There is no bright line within this range of mental abilities – the legal boundary between mental capacity and incapacity is drawn on the basis of political commitments such as the value placed on decision-making liberty. And as a result, different societies (or the one society at different times) may draw the line in different places on the basis of divergent evaluative commitments. A. Buchanan. Mental capacity, legal competence and consent to treatment. J R Soc Med 2004; 97: 415–420. J. Craigie, L. Bortolotti. in press. Rationality, diagnosis and patient autonomy in psychiatry. In The Oxford Handbook of Psychiatric Ethics. Oxford: Oxford University

<sup>35</sup> In order to resolve this tension it might be argued that the commitment to liberty in the convention applies only to formal coercion (substituted decisions). However, it seems unlikely that the drafters of the CRPD were concerned only with interference in the formal sense, given the evidence for the way in which informal practices in psychiatry can also compromise decision-making freedom (K. Canvin, J. Rugkasa, J. Sinclair & T. Burns. Leverage and other informal pressures in community psychiatry in England. *Int J Law Psychiatry* 2011; 36: 100–106). Piers Gooding suggests that the relevant parts of the Convention are broadly concerned with respect for 'a person's sphere of freedom to exercise choice' (Gooding, *op.cit.* note 25: 436).

<sup>36</sup> This point is often raised as a concern about the Convention. See, for example: A. Ward. Abolition of all guardianship and mental health laws? *The Journal of the Law Society of Scotland*, 2014, online 14 Feb; N.A. Koln & J. Blumenthal. A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disabil Health J* 2014; 7(1): S40–S43. The CRPD Committee recognises this concern, commenting that 'Undue influence is characterised where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation.' *op. cit.* note 2: 5.

the balancing task in this context particularly precarious. The final two sections of this article set out the challenge, and explore one way of navigating it.

# SUPPORTING SELF-EXPRESSION WITHOUT UNDERMINING FREEDOM

Self-expression might be facilitated in a range at ways, which will be discussed here in the context of medical decisions. One role, or part of the role, that a supporter could play might be modeled on that of a genetic counselor, helping someone understand complex information such as the probabilistic results of a diagnostic test. This kind of role could plausibly be carried out in a way that does not constitute an attempt to influence the patient's decision, and under these circumstances it does not seem to threaten the freedom of the subsequent choice.

But support can also involve the giving of advice.<sup>37</sup> This kind of involvement does seem to count, more clearly, as an attempt to influence the decision. Yet intuitively it seems that this too could be done in a morally unproblematic way. This might be true of a case where the supporter strongly recommends a screening procedure for cancer, on grounds that early detection significantly increases the effectiveness of treatment. Even if someone who is initially reticent is persuaded to have the procedure, it seems possible to imagine this not involving improper influence.

However, some models of supported decision-making endorse the idea that engagement with the person's reasons for a choice can also facilitate autonomy, when this means that a decision is more deeply considered, the alternatives more fully explored. Alan Cribb and Vikki Entwistle suggest that sometimes the best way to support autonomy is by 'questioning or even challenging [the person's] expressed or apparent preferences'.<sup>38</sup>

The worry about all but the first kind of involvement is obvious, however, when considered in the context of a woman's decision about whether to have an abortion.<sup>39</sup> The arguments just outlined are often given, in one form or another, by pro-life organizations for making counselling a mandatory part of the consultation process prior to an abortion being performed. The concern is that proponents of counselling have a particular outcome in mind, based on their own evaluative stance, and a parallel concern arises in the context of a move from substituted

<sup>&</sup>lt;sup>37</sup> This will particularly be the case if a professional is in the supporting role, but I would suggest that people also often seek the advice from friends and family.

<sup>&</sup>lt;sup>38</sup> A. Cribb & V. Entwistle. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expectations* 2011; 14: 210–19: 213.

<sup>&</sup>lt;sup>39</sup> I thank Jonathan Glover for suggesting this contrast case.

to supported decisions. The issue was described by a standing committee of the New South Wales Parliament in the following way:

An appointed guardian has a statutory mandate to make decisions in the best interests of a person with a disability. Is an assisted decision maker helping a person to make the decision in accordance with his or her views and wishes or to make what the assisted decision maker may see as the 'best or right decision'? Many in the disability sector would argue that genuine autonomy includes the right to make poor choices or bad decisions.<sup>40</sup>

Given the value placed on decision-making liberty in the Convention, 'support' might be interpreted merely as giving the person's expressed wishes effect, however unwise or irrational they may be. But the CRPD literature clearly understands the purpose of support also as facilitating autonomy in the self-expression sense. To this extent it *does* endorse helping the person make a 'good' decision in a specific sense: part of the aim of support is to help the person make a self-expressive decision. The challenge, therefore, is how to do this while ensuring that the support does not undermine the person's decision-making freedom.

The solution that will be explored here is based on Philip Pettit's account of freedom as discursive control. <sup>41</sup> The account proposes that the involvement of others undermines decision-making freedom when it limits discourse about what the preexisting reasons relating to a decision require. It is developed by Pettit as a way of unifying two senses of freedom – one political, and one psychological – which map closely onto the two senses of autonomy discussed above. This unifying approach is helpful for addressing the challenge at hand, because what's required is an explanation of how decision-making liberty can be limited by others (limiting freedom in a political sense), in a way that seems to require a psychological explanation.

The discursive control account suggests that preserving decision-making liberty requires that that the supporter recognises the person being supported as a reason-giver and reason-taker; and in doing so, authorises them as an agent capable of engaging with these considerations.<sup>42</sup> Modeled in this way, support may result in a change in a person's beliefs or even their motivations, without compromising their decision-making liberty.

In what follows, threats as clear cases of attempts to influence that undermine decision-making liberty, are

used to explain how freedom is constrained on the discursive control view; and incentives are then considered in relation to threats. While threats are very unlikely to be recommended as a way of supporting decision-making in accordance with the CRPD, the possibility that support might be interpreted as involving an implicit threat should be a serious consideration. Incentives also seem unlikely to be endorsed as a way of supporting decisions in line with the Convention, but financial incentives are being trialed as a way of increasing compliance with antipsychotic medication. Therefore, in addition to serving the purpose of illustrating how certain modes of influence undermine decision-making liberty, the examination of threats and incentives has direct relevance for the evaluation of current psychiatric practice.

## A DISCURSIVE CONTROL SOLUTION

Threats present a puzzle because they appear to restrict decision-making freedom despite the person still being able to make a choice, and without the range of available options being restricted. In a discussion of informal coercive practices in psychiatry, Terry Carney and colleagues describe the effect that certain forms of social influence can have on human agency as constraining 'the size of the remaining decisional 'space' '.<sup>45</sup> Explaining how decision-making freedom (or the decisional space) is constrained, is essential for developing advice to help ensure that the support required by the Convention does not undermine decision-making liberty in this way.

The discursive control account explains the freedomundermining effect of a threat primarily in terms of its effect on the discursive relationship that can be had between the person who makes the threat, and its recipient. According to Pettit, threats limit discourse by '[rigging] the reasons by which I, a coercer, want you to be moved and show that I'm not content just to discourse with you about what the preexisting considerations require.'<sup>46</sup> The reasons are rigged in the sense that the threat increases the potential cost of not choosing a particular option. This constrains your ability to consider the

<sup>&</sup>lt;sup>40</sup> Standing Committee on Social Issues. 2010. Substitute decision-making for people lacking capacity, New South Wales Parliament Legislative Council. Sydney: s. 5.88.

<sup>&</sup>lt;sup>41</sup> P. Pettit. *A Theory of Freedom*. Cambridge: Polity Press; 2001. Chapter 4.

<sup>&</sup>lt;sup>42</sup> Ibid: 69.

<sup>&</sup>lt;sup>43</sup> For example see: K. Sheehan & T. Burns. Perceived coercion and the therapeutic relationship. *Psychiatr Serv* 2011; 62: 471–476.

<sup>&</sup>lt;sup>44</sup> D. Classon. Financial Incentives for antipsychotic depot medication, *J Med Ethics* 2007; 33: 189–193. One justification given for such interventions is that they support autonomy by helping people achieve their longer-term or more core goals. For a full discussion of this issue see: R. Ashcroft. Personal financial incentives in health promotion: where do they fit in the ethic of autonomy? *Health Expectations* 2011; 13: 191–200.

<sup>&</sup>lt;sup>45</sup> T. Carney, D. Tait & S. Touyz. 'Coersion is Coersion?: Reflection on clinical trends in use of compulsion in treatment of anorexia nervosa patients' *Legal Studies Research Paper* 2008, No. 08/09 Sydney Law School: 9.

<sup>46</sup> Pettit, op. cit. note 41: 74.

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preexisting reasons for choosing one option or another, making it more difficult for you to respond only to those features of the options. The degree to which a threat has this effect depends on the salience of the cost – how much you want to avoid the consequences. But whatever the cost, threats severely limit the conversation that can be had regarding the treatment options. It will be difficult, if not impossible, for the person who makes the threat to present themselves as a co-reasoner who is authorising the person being supported, as an agent.<sup>47</sup>

Using this account to consider incentives as an intuitively less problematic form of influence, further explores the proposal. The discursive control account provides an explanation for the intuition that incentives are less morally problematic than threats in terms of their impact on decision-making liberty. But it also suggests that this isn't necessarily the case. Where an incentive has been introduced, by not choosing in accordance with the incentive a patient incurs an opportunity cost – the cost of foregoing something desirable.<sup>48</sup> In general, threats have a more disruptive effect on a person's ability to engage with and respond to the preexisting features of the options, compared to incentives, because human psychology is more sensitive to costs than opportunity costs: it is a robust finding that people are more keen to avoid costs. 49 But while opportunity costs are generally more easily disregarded, it seems that extremely desirable incentives will have a disruptive effect that is equivalent to, or even greater than the effect of some threats.<sup>50</sup> A significant financial incentive offered to a person who is unable to earn money may make it very difficult for them to reflect on the decision in terms of the preexisting features of the options, for example to weigh the potential side-effects against the benefits of treatment.<sup>51</sup>

Despite this possibility, Pettit is relatively unconcerned about the potential impact of incentives on the discursive relationship, especially in cases where the incentive is aimed at helping the person make a decision that is in their declared interests.<sup>52</sup> However, considering incentives

in a context where the person making the decision has a mental disability, suggests that incentives will sometimes be much less benign that Pettit imagines. Even incentives that aim to facilitate self-expression send a message that calls into doubt the recipient's ability to engage in discourse about, or to act on, the pre-existing reasons for a decision. Recognition as a co-reasoner and authorisation as an agent is, to some degree, withheld. And against a background where the person being supported has struggled for recognition because of a mental disability, there is reason to think they may be particularly sensitive to this potentially discourse unfriendly signal.<sup>53</sup>

Pettit's discursive control account draws a connection between the discursive relationship and decision-making freedom at a particular moment in time. But it seems likely that a history of not being fully recognised as an agent will also have a more long-term impact, compromising the development of, or eroding the person's perception of themself as an agent, and therefore their capacities for self-respect and self-trust.54 These kinds of capacities are a central focus of relational accounts of autonomy, and the arguments for their importance are made in great detail in that literature.<sup>55</sup> In one influential account, Catriona Mackenzie argues that autonomy requires a person to regard 'herself as the legitimate source of authority – as able, and authorized, to speak for herself', and that, 'such attitudes towards oneself can only be sustained in relations of intersubjective recognition.'56

I suggest, in a commonsense way, that this will be an experience that is familiar to many people: that such capacities seem essential for the ability to assert oneself – one's beliefs, feelings, preferences or wishes. The proposed relevance of these capacities for decision-making freedom,<sup>57</sup> and the role played by recognition in developing and sustaining them, suggests that people with mental disabilities who are making a transition from substituted to supported decisions may be in a particularly vulnerable position – not because of a mental impairment

<sup>&</sup>lt;sup>47</sup> Pettit, op. cit. note 41: 75.

<sup>&</sup>lt;sup>48</sup> Pettit, *op. cit.* note 41: 75. An opportunity cost leaves the person no worse off if they do not choose in accordance with the offer. For a review of approaches to understanding the distinction between threats and offers see: G. Szmukler & P. Appelbaum. Treatment pressures, leverage, coercion and compulsion in mental health care. *J Ment Health* 2008; 17(3): 233–244.

<sup>&</sup>lt;sup>49</sup> D. Kahneman & A. Tversky. Choices, values and frames. Am Psychol 1984; 34.

<sup>&</sup>lt;sup>50</sup> Pettit, op. cit. note 41: 75.

<sup>&</sup>lt;sup>51</sup> Szmukler & Appelbaum, *op cit.* note 48. Furthermore, because the impact on decision-making freedom depends on the recipient's perception of the intervention, something that is intended as an incentive may be experienced as (and have the impact of) a threat, for example, if an 'offer' involves something that the person feels they are entitled to, or is in some sense already theirs (Ashcroft. *op. cit.* note 44).

<sup>&</sup>lt;sup>52</sup> Pettit. *op. cit.* note 41: 75.

<sup>&</sup>lt;sup>53</sup> Here I am borrowing Pettit's turn of phrase.

<sup>&</sup>lt;sup>54</sup> A loss of functioning, for example, due to dementia or during a severe depression may lead to an erosion of these capacities due to the withdrawal of recognition as an agent.

<sup>&</sup>lt;sup>55</sup> For example: P. Besnson. Free Agency and Self-Worth. *J Philos* 1994; 91: 650–658; P. Benson. Autonomy and Oppressive Socialization. *Social Theory and Practice* 1991; 17: 385–408; J. Anderson & A. Honneth. Autonomy, Vulnerability, Recognition, and Justice. In J. Christman, J. Anderson, editors. *Autonomy and the Challenges to Liberalism*, Cambridge: Cambridge University Press; 2005. 127–149; T. Govier. Self-Trust, Autonomy, and Self-Esteem, *Hypatia* 1993; 8(1): 99–120.

<sup>&</sup>lt;sup>56</sup> C. Mackenzie. Relational autonomy, normative authority and perfectionism. *J Soc Philos* 2008; 39(4): 512–533: 514.

<sup>&</sup>lt;sup>57</sup> 'Freedom' here is being used to refer primarily to the political sense of the word, described (following Pettit) in a psychological way. 'Freedom' could equally be substituted with 'autonomy' as discussed in earlier sections of the paper, referring primarily to autonomy as liberty.

(though this may also be the case), but because of their existing legal and social environment, and the impact that this may have had on their perception of themselves as an agent. An awareness of the importance of capacities for self-respect and self-trust, and a focus on their development through discursive relationships, therefore seems to be an important part of any move from substituted to supported decisions.

Gerard Quinn suggests that concerns about the support required by the Convention becoming improper influence are given too much weight, on grounds that we are all susceptible:

[We] tend to agonize over the hidden dangers of supported decision making – the ease with which the 'other' is not just invested in but absorbs the 'self'. Can we draw lines to ensure that supports do not become substitutes? Well, my point is that this affects all of us and not just those for whom a formalized system of support is put in place. Is there something about persons with intellectual disabilities that makes them maybe more prone to this 'capture'? Maybe the threat exists in a stronger form in the context of intellectual disability – but it is actually a threat we all navigate daily in our lives. Depending on the relationship in question we are all deeply impressionable.<sup>58</sup>

Quinn may be right that most of us are deeply impressionable. Nonetheless, the above analysis makes the case that there are (at least) two reasons to take this issue particularly seriously in the context of support required by the CRPD. One is the importance placed on decision-making liberty in the Convention. This makes implementing the support it requires a more challenging balancing act relative to the support endorsed more broadly in the medical ethics literature. Support will tip into improper influence more easily, because degrees or modes of influence that may more generally be considered acceptable, will be judged unacceptable as a way of implementing support in accordance with the CRPD.

Second, the discursive control account as further developed above, suggests that mental disability will be associated with a particular vulnerability to discourse-undermining forms of engagement. While Quinn frames this concern in terms of susceptibility due to a mental impairment, the above account focuses attention on susceptibility due to a history of interpersonal engagement where a person with mental disability has not been recognised as a legal agent; and how freedom may be undermined due to the impact of this experience on the person's perception of themselves as an agent.

# CONCLUSION

The CRPD forces a reconsideration of the principle of respect for patient autonomy in two ways. First, it challenges prevailing ideas about when the principle applies, by requiring that its scope be widened to include people with mental disabilities whose decisions are currently made by others. Second, its challenge to the concept of mental incapacity, and subsequent focus on support, will stimulate the existing debate about what respect for patient autonomy requires.

It was argued that the support required by the Convention is based on a valuing of autonomy in the sense of self-expression, but that this is combined with a very significant commitment to autonomy in the sense of decision-making liberty. This second evaluative commitment distinguishes endorsements of decision-making support in the CRPD literature from those in the existing medical ethics literature. And the combination of commitments expressed in the Convention (or at least in prominent interpretations of the Convention) identifies a particular challenge in putting its requirement for support in practice. <sup>59</sup>

The discursive control account described above offers a starting point for developing practical advice on how to navigate the territory between merely giving a person's expressed preference effect (which runs the risk of limiting autonomy in terms of self-expression); and the imposing of a decision in a patient's best interests (which denies autonomy in the sense of the liberty to make one's own decisions). It suggests that assessments of whether support jeopardizes decision-making freedom should pay attention to its effect on the person's ability to respond to the pre-existing features of the options; and the discourse that can be had between the supporter and the person being supported, regarding those features.

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Jill Craigie is a Lecturer in Medical Ethics in the Centre of Medical Law and Ethics, Dickson Poon School of Law, King's College London. Coming from a background in neuroscience and moral psychology she currently works primarily in the area of mental health ethics and law.

<sup>&</sup>lt;sup>58</sup> G. Quinn. Rethinking Personhood: New Directions in Legal Capacity Law & Policy. University of British Columbia: Vancouver, Canada; 2007; 57.

<sup>&</sup>lt;sup>59</sup> This is a challenge that is shared by all proposals for supported decision-making, to the extent that they value decision-making freedom.