Evaluating Trade-Offs between Autonomy and Wellbeing in Supported Decision Making

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A core challenge for contemporary bioethics is how to address the tension between respecting an individual’s autonomy and promoting their wellbeing when these ideals seem to come into conflict (Notini et al. 2020). This tension is often reflected in discussions of the ethical status of guardianship and other surrogate decision-making regimes for individuals with different kinds or degrees of cognitive ability and (hence) decision-making capacity (Earp and Grunt-Mejer 2021), specifically when these capacities are regarded as diminished or impaired along certain dimensions (or with respect to certain domains). The notion or practice of guardianship, wherein a guardian is legally appointed to make decisions on behalf of someone with different/diminished capacities, has been particularly controversial. For example, many people see guardianship as unjust, taking too much decisional authority away from the person under the guardian’s care (often due to prejudiced attitudes, as when people with certain disabilities are wrongly assumed to lack decision-making capacity); and as too rigid, for example, in making a blanket judgment about someone’s (lack of) capacity, thereby preventing them from making decisions even in areas where they have the requisite abilities (Glen 2015).

It is against this backdrop that Paterson, Karlawish, and Largent (2021) offer a useful philosophical framework for the notion of ‘supported decision-making’ as a compelling alternative for individuals with ‘dynamic impairments’ (i.e., non-static or domain-variant perceived impairments in decision-making capacity). In a similar spirit, we have previously argued that bioethics would benefit from a more case-sensitive rather than a ‘one-size-fits-all’ approach when it comes to issues of cognitive diversity (Veit et al. 2020; Chapman and Veit 2020). We therefore agree with most of the authors’ defence of supported decision-making, as this approach allows for case- and context-sensitivity. We also agree with the authors that the categorical condemnation of guardianships or similar arrangements is not justified, as this precludes such sensitivity. For instance, as the authors note, if a patient is in a permanent unaware/unresponsive state – i.e., with no current or foreseeable decision-making capacity or ability to exercise autonomy – then a guardianship-like regime may be the most appropriate means of promoting this person’s interests. A similar point can be made in relation to debates about intended human enhancement of embryos and children. Although some critics claim that such interventions violate the autonomy of the enhanced person, proponents may argue that respect for autonomy and consent do not apply in certain cases, for example, when

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dealing with embryos (see Veit 2018); alternatively, they may argue that interventions to enhance the (future) autonomy of a currently pre-autonomous (or partially autonomous) being can be justified on an enhancement framework without falling prey to such objections (see Earp 2019, Maslen et al. 2014).

An issue the authors raise, but do not discuss in detail, is the question of potential trade-offs between respect for autonomy (commensurate with the kind or degree of autonomy the agent has, either alone or as part of a supported decision-making unit) and the need to protect those who may not act in their own best interest due to compromised decision-making capacity. What should be done in cases where an agent’s decisions (i) seem not to reflect what is in their best interest and (ii) could be improved upon (in the sense of better promoting their wellbeing) through an intervention that restricts their autonomy (or exercise thereof)? These conflicts and trade-offs need to be made more explicit if we are to determine which surrogate decision-making regimes are best for different cases.

One point needs to be made right away. In general, respecting a person’s autonomy does not entail a conflict or trade-off with promoting their wellbeing. Instead, on various theories of human wellbeing, the very ability to make decisions about one’s own life without undue interference from others is a major component of, or at least contributor to, wellbeing. Thus, even if respecting someone’s apparently misguided decision (after all appropriate efforts to dissuade the person have failed) seems likely to bring adverse consequences for the decider in a specific domain, it will often still be the case that they should be left to make the putatively ‘bad’ decision: not only out of respect for their autonomy, but also on grounds of their overall well-being (for example, so that they can learn from their mistakes or otherwise develop their decision-making capacities over the long run). Importantly, this argument does not just apply to those people deemed ‘fully’ autonomous with respect to some relevant standard, such as a mature, neurotypical adult of sound mind; it also applies to those with ‘developing’ autonomy, such as children, whose very ability to become ‘fully’ autonomous will often require that their (primarily self-affecting) decisions be respected even when a different decision would be more prudent.

A similar lesson may apply to those with cognitive impairments, at least in certain cases. Specifically, when considering how to evaluate the decisions of someone “on the margins of autonomy” (Paterson et al., 2021), it is important not simply to assume that there is, in fact, a conflict between respecting their autonomy (again, commensurate with the kind or degree of autonomy they have) and promoting their wellbeing. In some cases, we suggest, allowing someone to make an apparently ‘bad’ decision (i.e., one that is not in their immediate best interests) will be justified both as a matter of respect for them as a person and as something that is compatible with, and may even promote, their overall wellbeing. By the same token, overriding someone’s decision(s) out of a concern for their best interests can sometimes, ironically, reduce their overall wellbeing, in part by undermining whatever autonomy they have.

That being said, there will undoubtedly be cases in which a person’s decision-making capacity (with respect to some domain or issue) is genuinely impaired, and where respecting their decision out of a concern for their – diminished – autonomy will in fact come at cost to their overall wellbeing, possibly to such an extent that the decision cannot in good conscience be allowed to
stand (e.g. allowing a ‘punch-drunk’ boxer to fight; Veit & Browning forthcoming). Of course, whether a situation falls under this description will often be a difficult judgment call, and we can’t hope to offer a general account of how to adjudicate such matters here. Instead, we simply want to flag two factors that should feed into such deliberations: (i) the need for case-sensitivity, with respect to which any genuine trade-offs between autonomy and wellbeing are made explicit, and (ii) the need to treat autonomy in a gradualist, rather than binary manner that reflects the cognitive diversity of actual agents. This is not to say that case-sensitivity will eliminate all disagreement, but that we will at least have a better understanding of what is at stake in particular situations when trying to find the best compromises between different desiderata.

Describing these trade-offs will in part require a clearer understanding of the reasons for giving weight to autonomy in the first place. Autonomy is typically taken to be valuable for a number of reasons, some of which plausibly reduce to its instrumental value in promoting wellbeing, but some of which do not. For example, autonomy can be valuable because it allows an agent to choose the ends which they recognize to be best for themselves (including ends other than happiness or wellbeing); and it may be objectively valuable or valuable in itself.

A potential constraint on the value of autonomy, however, is that should incline the decider toward choices that are, not random or whimsical, but rather, well-informed and rationally derived. According to this perspective, the value of autonomy declines as an agent becomes more cognitively impaired such that (i.e., as a result of the impairment) their ability to identify and choose those ends that really are best for them – even by their own lights – likewise declines. In such a scenario, the principle of beneficence may come to supersede autonomy in determining what is in a person’s best interest. It may also allow for an agent’s choices to be overridden in some cases without thereby treating the agent as mere means.

In any event, taking a case-sensitive approach requires that we cannot treat autonomy as equally relevant (or valuable) in all cases. Although this may seem evident in some circumstances, such as when considering the interests of comatose patients, autonomy is still often treated as a property that agents either have or lack, rather than something that comes in degrees (or as something which different agents may reasonably value to a greater or lesser extent). This seems to us to be a mistake. In the complete absence of decision-making capacity we must rely on considerations of wellbeing (or where possible, substituted judgment), but once there is some degree of autonomy this should be recognized and perhaps further enhanced, along the lines suggested by Paterson, Karlawish, and Largent (2021) in their proposal regarding supported decision-making.

It is also critical to keep in mind that an agent may continue to value their own (even diminished) autonomy, even if this makes their lives harder and decreases their quality of life. Accordingly, we may require methods of measuring an agent’s autonomy and how much they value it in order to clarify the trade-offs between autonomy and wellbeing where applicable and to help us determine which surrogate decision-making procedures are likely to be most appropriate. Autonomy may not be valued equally by all agents; and the degree to which one values it may also not covary precisely.

Utilitarians such as John Stuart Mill have long emphasized the importance of autonomy precisely because individual agents (albeit availed of advice from their relational networks) are typically better positioned to know what is best for them, rather than, say, the government. For further discussion with qualifications, see the section “Autonomy as an ethical tool” (p. 75) in Earp and Savulescu (2020).
with one’s capacity to exercise it. It is thus important to establish not only how much autonomy an agent with decision-making impairments has (or will have in the context of adequate support), but also how much they value their continued ability for self-determination.³

In the end, we believe we can advance the goals of supported decision-making by calling for a more pluralistic approach that recognizes the cognitive diversity of actual humans, while also emphasizing the need to make more explicit the process by which weights are assigned (ideally on a case-by-case basis) to considerations of autonomy and wellbeing insofar as these conflict.

References


Glen, K. B. 2015. Supported decision-making and the human right of legal capacity. Inclusion. 3(1): 2-16


³This parallels a discussion within the animal ethics literature, where certain kinds of freedom for animals are advocated without asking whether this is in their bests interests or what they value; in fact, different animals are likely to value control over their circumstances or other forms of agency in different ways and to different degrees, and this should inform how they are treated (Browning & Veit 2020; 2021).
Paterson, Karlawish, and Largent (2021) Supported Decision Making with People at the Margins of Autonomy. AJOB.

