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## Supported Decision Making with People at the Margins of Autonomy: Response to Commentaries

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### INTRODUCTION

Supported decision making is a model of decision making in which an adult with impaired capacity (the “beneficiary”) enters freely into an agreement with a closely trusted person or persons (the “supporter(s)”) who assist the beneficiary in exercising and enhancing self-determination. In our recent Target Article (Peterson et al. 2020), we argued that supported decision making, which has been used for transition-aged young adults with intellectual and developmental disabilities, is also ideal for individuals with dynamic cognitive impairments. Supported decision making facilitates a balance between the dual duties of enhancing self-determination and affording protections to vulnerable individuals, urged by the principle of respect for persons.

Thanks to the colleagues who submitted commentaries. Each thoughtfully engaged with our work. Here, we refine some of our positions, respond to select criticisms, and highlight valuable insights.

### IS A FORMAL SUPPORTED DECISION-MAKING AGREEMENT NECESSARY?

We argued supported decision making has three components: (1) an identification of the domains of decision making for support the beneficiary needs and desires; (2) an identification of the kinds of decision-making supports the beneficiary needs and desires; and (3) an agreement between the beneficiary and supporter(s) about the provision of support.

Several of our colleagues took issue with the third component. Supported decision making may be formalized through an agreement, but, they argue, this isn’t necessary. Kohn (2021),

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for instance, persuasively asserts there is little evidence that “formalized agreements increase the likelihood that such individuals are able to effectuate their will and preferences.” Likewise, Blumenthal-Barby and Ubel (2021) claim that “formalization may be practically difficult,” and that the goods of an agreement—including “clarifying expectations and abiding by them”—can be “achieved in most cases without formalization.”

We agree. At present, insufficient evidence exists to claim that formal *legal* agreements increase the likelihood that benefits would be conferred on the beneficiary. But this isn't what we intended to argue. We think the ambiguity of the term “formal agreement” created confusion. Our use of a legal document as an example certainly did not help to clarify our point. A strict interpretation would equate formal agreement with a *legal* agreement, whereas a more liberal interpretation equates it with an *explicit* agreement that can be appealed to by the parties to that agreement and also recognized by others. Importantly the latter is agnostic as to whether the agreement is legally recognized.

An explicit agreement is like a promise; breaking the promise would violate the trust of the relationship. This is what we have in mind when describing formalization and it is why, in our view, an explicit agreement is necessary for supported decision making. It memorializes the decision-making relationship, sets expectations, and provides important moral justification for the duties of the supporter and beneficiary. A decision-making relationship without an explicit agreement falls short.

## DOES SUPPORTED DECISION MAKING REQUIRE RETHINKING THE DOCTRINE OF INFORMED CONSENT?

Appelbaum and Trachsel (2021) argue there “is no need to modify the doctrine of informed consent for its application to supported decision making.” They cite the Texas Estates Code, which specifies that supporters should not impede the self-determination of beneficiaries. They then describe how each aspect of informed consent dovetails neatly with supported decision making.

We worry this analysis may be too thin. A puzzle arises when considering how supported decision making unfolds in practice relative to the idealized, individualistic decision making implied by the doctrine of informed consent. Consider the following scenario:

John is a supporter for his spouse Jane, who is experiencing moderate symptoms of dementia caused by Alzheimer's disease. Jane's physician recently discussed a new treatment called aducanumab (Aduhelm; Biogen) with her. The physician explains that aducanumab may improve Jane's daily functioning; however, it requires monthly intravenous infusions, could cause micro-bleeds or swelling in Jane's brain, and it is expensive. Jane listens while John takes notes. The couple leaves the visit with many questions and they agree to discuss the option over the next week.

John and Jane talk about aducanumab over their morning coffee and evening walks. John calls Jane's physician twice to ask follow-up questions. John and Jane's adult daughter, Eleanor, visits home and joins her parents in discussions; a professor

recently discussed the controversy surrounding aducanumab in her food and drug law course. The conversations are difficult, but Jane is supported throughout by her family.

At Jane's next appointment, her physician asks whether she'd like to go ahead with aducanumab. Jane glances nervously at John, who nods and mouths, "It's OK." Jane tells her doctor that she and her family have decided together to decline.

Appelbaum and Trachsel (2021) would likely argue that, even with the provision of support from her spouse and daughter, Jane made the decision for and by herself. This may suffice for a legal analysis, but does it suffice for an ethical analysis?

To us, the rich metaphysics of Jane's decision-making process is overlooked in Appelbaum and Trachsel's analysis—and we are not alone in this intuition. As Enck (2021) suggests, supported decision making can be temporally diffuse, occurring over many days or weeks, and distributed across agents (cf. Brown & Savulescu 2019). Likewise, Jaworska and Chiong (2021) emphasize how values can be distributed across relationships. These interpretations seem at odds with the metaphysics of decision making implied by the doctrine of informed consent. It's not that one patient, who is competent and informed, voluntarily makes a medical decision according to her own values at a discrete point in time. Rather, decisions are made *with* others through ongoing and complicated relationships.

We may find that, as Appelbaum and Trachsel envision, no further refinement of the legal doctrine of informed consent is needed for supported decision making. But it would remain an open question as to whether this would suffice for ethical claims about the decision-making process. In our view, one needs to engage faithfully with the metaphysics of supported decision making as it unfolds in the lives of persons living with dynamic cognitive impairments and their supporters. Appelbaum and Trachsel's analysis doesn't do this.

## WHAT IS THE ROLE OF A “LIFE VISION” IN SUPPORTED DECISION MAKING?

Francis (2021) persuasively argues that supported decision making should be buttressed with strong oversight mechanisms to assure the self-determination of the beneficiary is not undermined by overzealous or abusive supporters. She questions, for instance, what role a “life vision” should play in advancing supported decision making, and whether a life vision ought to be regarded as authentic to the beneficiary or instead a reflection of what supporters want the beneficiary to be.

Bigby et al. (2019)<sup>1</sup> identified a life vision—a broad set of goals that organize daily decision making—as a key theme among families who support adults with intellectual and developmental disabilities. They observe that “developing visions to guide life directions [is] a longstanding part of support practice with people with intellectual disability” as

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<sup>1</sup>Francis also questions our reference to Bigby et al. (2019). The article we refer to in our Target Article—incidentally, also Bigby et al. (2019)—is a review citing the primary study identifying “life visions” as a feature of supported decision making.

they organize “support provision and day-to-day decision-making commensurate with an individual’s preference” (Bigby et al. 2019, 405). Nonetheless, as Francis (2021) anticipates, Bigby et al. assert that a life vision “may be constructed primarily by family members rather than in collaboration with [the beneficiary]” (Bigby et al. 2019, 405).

This raises a practical question. How can we implement supported decision making without undermining the self-determination of beneficiaries? Even a well-intentioned supporter may become overbearing. Still, there may be relevant differences in how a life vision pertains to supported decision making for people with static versus dynamic impairments. A person diagnosed with cognitive impairments caused by Alzheimer’s disease is likely to already have a life vision, developed in the many decades prior to the onset of disabling symptoms. In such instances, a supporter doesn’t construct the life vision, but is rather its steward. This might assuage worries about the authenticity of a life vision when used in supported decision making for people with dynamic impairments.

Nevertheless, whether a life vision ought to factor in supported decision making is debatable. Caregivers and clinicians often speak of persons living with dementia as having two selves: the “then self” who existed prior to the cognitive problems, and the “now self” who presently exists. To which self should a life vision be tethered? A life vision seems to imply a continuity of self over time, but as many in the bioethics literature have argued, dementia can fracture the self into many pieces. Some days the person seems to be her “then self;” others, the “now self.” More work needs to be done to address the important questions raised by Francis to assure the self-determination of beneficiaries’ is protected.

## **SHOULD SUPPORTED DECISION MAKING BE USED IN CLINICAL RESEARCH?**

We were pleased to read that Bierer et al. (2021) have a favorable attitude toward using supported decision making in clinical research. As they note, U.S. regulations governing the conduct of research in vulnerable populations assert that additional protections are needed, but none is currently designed to safeguard autonomy, creating “a bias in favor of surrogate decision-making.” Incorporating supported decision making in clinical research might improve access to research participation among populations who would otherwise be excluded. Moreover, supported decision making might play a key role in longitudinal studies where the decision-making capacity of the study population changes over time, such as studies of persons living with dementia.

Practices roughly analogous to supported decision making are already used in many trials involving persons with neurodegenerative disease. A “study partner,” that is, a trusted friend or family member who accompanies a person with cognitive problems through a trial, can assist in research-related decision making, offer valuable insights into changing cognition and function, and help with logistics (e.g., monitoring adherence to medications, providing transportation to appointments). The term came out of the early studies of persons living with mild cognitive impairment for whom the assumption they had a caregiver seemed presumptuous.

The role of study partners is two-fold: to support their loved one and also to enhance the quality of the science. Study partners appear to be particularly important in enhancing self-determination in people with diminished capacity. In interviews of study partners and persons with Alzheimer's disease enrolled in a randomized trial of simvastatin, Karlawish et al. (2008) found that individuals judged not capable of providing consent participated in research-related decision-making just as much as individuals who could provide consent when their study partners were involved.

A key insight of Bierer et al. (2021) is that, while supported decision making in clinical research might be justified in theory, future work is needed to modify policies and practices within research institutions, as well as change the culture of "protectionism" endemic to institutional review boards. Using supported decision making in clinical research might therefore begin with modifications to ongoing practices with study partners or be used initially in research protocols that pose little risk, but have a high likelihood of clinical benefit.

## CONCLUSION

Supported decision making shows promise for persons at the margins of autonomy and their loved ones as they make decisions together. Yet, key questions, including but not limited to those we addressed here, require further investigation. We encourage bioethicists to continue thinking about these issues. We thank our colleagues for engaging in this critical discussion and look forward to further conversations.

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