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Using Supported Decision-Making to Promote Value-Aligned Research Participation

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Abstract

This article explores the potential of supported decision-making for helping individuals with intellectual or cognitive disabilities to make value-aligned or authentic decisions with respect to participation in clinical research. We argue that supported decision-making is valuable in this context not merely because it promotes self-determination, but also because it increases the likelihood that individuals' decisions align with what matters to them. To realize this potential, it is important to recognize and address situations in which individuals with intellectual or cognitive disabilities are at increased risk of making decisions that are contrary to their values. We focus on two such situations in particular: when the individual must integrate multiple, potentially competing values, and when the relevant values are insufficiently specified and require unpacking. These challenges can be met, we propose, by integrating dialectical support — a form of structured, dialogue-based assistance designed to help individuals explore and apply their values — into supported decision-making practices.

Keywords: supported decision-making; authenticity; dialectical support

1. Introduction

Consider the following hypothetical case:

> Mrs. Flores has participated in a natural history study for rare solid tumors for several years. The study, which involves annual CT scans, blood draws, and punch biopsies, is considered a minor increase over minimal risk, and requires annual reconsent. At the latest visit, the research team notices that Mrs. Flores struggles to retain information in short-term memory. As it turns out, she has recently been diagnosed with middle-stage Alzheimer's disease. A formal capacity assessment determines that Mrs. Flores is no longer able to provide informed consent herself, as she fails to demonstrate sufficient understanding of the study. With no court-appointed guardian, the research team consults her husband and next of kin, Mr. Flores. He attempts to discuss continued participation with his wife. However, the conversation proves difficult, and Mrs. Flores is unable to express a consistent preference. Mr. Flores feels discouraged, though not entirely surprised, as Mrs. Flores' difficulties with tracking conversations and making decisions have become more apparent in recent weeks. Believing that his wife would have chosen to continue, Mr. Flores provides informed consent on her behalf to remain enrolled.

Researchers are required to obtain informed consent from participants.[1] Such a requirement is grounded in the foundational principle of respect for persons.[2] This principle comprises two integral but separate obligations: first, to respect the autonomy of individuals capable of making decisions for themselves; and second, to protect those with diminished autonomy. In practice, this framework divides individuals into those who have capacity to make their own decisions, and those who lack it and therefore need additional safeguards.

Assessing capacity for a particular decision involves evaluating an individual's abilities to understand, appreciate, reason, and express a choice.[3] Importantly, these abilities exist on a continuum and are matters of degree. Yet in legal and regulatory contexts, "capacity" is a technical term designating a binary concept: that is, a person either has capacity or does not. Consequently, individuals with intellectual or cognitive disabilities (ICD) may be deemed to lack capacity, if their decisional abilities fall below a particular threshold.[4] Mrs. Flores is one such individual. Because she can no longer provide informed consent herself, her continued participation in research is governed by procedural safeguards, most notably the appointment of a surrogate decision-maker.

However, surrogate decision-making carries nontrivial ethical costs. Because it is a surrogate — her husband — who makes the decision, per current regulations and practice Mrs. Flores' involvement is reduced to simply assenting to or dissenting from a decision already made for her.[5] This practice limits Mrs. Flores' independence for the sake of her protection but can be *overly* protective. For example, consider that Mrs. Flores still holds opinions and preferences regarding her continued participation but, absent effective efforts to facilitate their expression, struggles to communicate them. In this case, relegating Mrs. Flores to a secondary role in the decision-making process appears normatively inadequate, for she is prevented from directly shaping a meaningful aspect of her life — contributing to the understanding of the rare disease that affects her — even though, with sufficient and appropriate support, she may well be able to do so. In this regard, it is not enough that Mr. Flores

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makes the decision that his wife would have made.[6] For the fact remains that, due to policy choices that prioritize protection over self-determination, Mrs. Flores is denied the opportunity to make that decision herself.[7]

We begin in this article by proposing *supported decision-making* as an alternative framework that better respects individuals like Mrs. Flores. Supported decision-making involves providing individuals with ICD-tailored assistance given their decisional needs, while preserving their role as ultimate decision-makers.[8] A key virtue of this approach, as commentators emphasize, is its recognition of the intrinsic value of self-determination.[9] In the words of the UN Convention on the Rights of Persons with Disabilities, supported decision-making affirms that individuals with ICD should "enjoy legal capacity on an equal basis with others."[10] As we explain below, while we share this general commitment, we stop short in this article of endorsing interpretations that would grant full decisional authority regardless of the severity of cognitive impairment.[11]

In this article, we highlight a distinct yet complementary virtue of supported decision-making: its potential to promote authentic decisions, namely those that align with one's own values. Specifically in the context of clinical research, supported decision-making has the potential to promote more value-aligned participation.[12] While surrogate decision-making can, in principle, achieve this goal, it relies on third parties' judgments about what the incapacitated individual would have preferred. By contrast, supported decision-making places the individual being supported at the center of deliberation. The onus is thus placed on supporters to offer tailored assistance given the individual's decisional needs and preferred modes of support. Such an approach, we suggest, offers greater chances for arriving at decisions that align with one's values.[13]

Our discussion develops two interrelated ideas about authenticity. First, authentic decision-making is a practical skill, one that requires the successful coordination of complex socio-cognitive capabilities such as self-reflection, value recognition, the ability to weigh options in light of one's goals and commitments, and so on. This skill varies among all decision-makers but may be especially challenging for individuals with ICD. In such cases, authenticity can be fostered through integrating into supported decision-making practices what we call "dialectical support": that is, structured, dialogue-based assistance that helps individuals to reflect on, access, and apply relevant values in concrete decision contexts.

Second, we propose that authenticity offers an especially valuable lens for evaluating the quality of decision-making regarding research participation. The requirement of informed consent primarily focuses on cognitive comprehension — understanding of risks, potential benefits, alternatives to research participation, and so on — as a procedural means to safeguard participants' autonomy and welfare interests. Consequently, if someone makes an informed decision to enroll, we can be reasonably confident that their decision does not work against their own interests. In comparison, authenticity shifts attention to deeper normative grounds of decision-making by highlighting the value of decisions that align with and potentially advance participants' broader goals and commitments beyond the research context. In this respect, authenticity helps to promote a more robust form of self-determination. Explicit attention to this value is of particular significance when it comes to individuals with ICD, whose broader goals and commitments are more likely to be overlooked when cognitive comprehension is treated as the primary or sole measure of decision-making quality.

Notably, advocating supported decision-making on the grounds of authenticity complicates the relationship between decisional authority and decisional capacity. On the standard view, authority stems from the possession of capacity.[14] As we discuss in the next section, supported decision-making can be useful for enhancing the relevant abilities of individuals. Yet the aim of any such ability-enhancing interventions is not to help individuals reach a particular threshold of decisional capacity, but rather to preserve their agency as the source of decisional authority. Indeed, in our view, supported decision-making can yield authentic decisions that are worthy of respect precisely by virtue of their being authentic.

This article proposes dialectical support, which is one form supported decision-making can take, as a useful intervention for promoting authenticity. Because dialectical support involves a collaborative process that helps individuals with ICD explore and reason with relevant values in concrete decision contexts, our focus is on individuals who can generally access, express, and converse about their values. Individuals with more severe cognitive impairments may not fit this characterization, and for them support may require interpretive work to discern their values.[15] Moreover, for individuals whose impairments are especially severe (e.g., those that preclude meaningful dialogue altogether), dialectical support in particular and supported decision-making more broadly may not be applicable or appropriate.[16] Our discussion is therefore limited in scope, targeting a subset of individuals with ICD who are capable of engaging in dialectical exchanges about their values. As can be expected, this population is far from uniform, encompassing individuals with varying trajectories and origins of disability that affect their decisional needs.[17] Nevertheless, dialectical support remains valuable despite these differences, though its specific form and implementation may vary.

2. Supported Decision-Making: A Shift in Perspective

Supported decision-making is a framework designed to assist individuals who might otherwise be unable to decide independently to make and communicate decisions about their own lives.[18] Support can be formal or informal, implemented in different ways and degrees of intensity, and provided by family members, friends, advocates, and other trusted individuals. Crucially, the role of supporters is not to decide on the individual's behalf, but to provide assistance tailored to the individual's specific decisional needs so as to help them reach decisions for themselves.[19] To this end, effective support can be as simple as providing written notes or reminders for someone with memory impairments.[20]

The recognition of decisional needs marks a significant shift in theoretical focus: that is, from viewing individuals with ICD as inherently unable to look out for themselves in managing their own affairs, to a more constructive perspective where tailored assistance is designed to meet specific, addressable challenges in decision-making. This shift underscores a chief advantage of supported decision-making as it relates to the social and interpersonal dimensions of decision-making.[21]

People rarely make decisions in complete independence from others, and using others' informational resources or reasoning skills does not automatically make our decisions any less our own. Indeed, our deliberative processes are often embedded within rich social networks where we seek advice, recommendations, and guidance from trusted others. This observation is especially relevant in research settings, where *un*supported decision-making is virtually non-existent for understandable reasons. Informed consent forms are frequently long and filled with medical jargon.[22] Meanwhile, clinical trial designs are becoming increasingly complex.[23] These challenges are in turn compounded by people's general

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difficulty with assessing risk under conditions of uncertainty.[24] It is hard, for instance, to grasp the seriousness of a study's unquantified risk of damage to liver function, and even harder to weigh that risk against one's desire to contribute to research, or the potential benefit for cardiovascular health. It is thus no surprise that research teams already routinely offer various forms of assistance — e.g., using plain language, providing information sheets, designing visual aids — that are meant to address participants' decisional needs during the informed consent process.

Yet when it comes to individuals with ICD, the fact that they too have decisional needs is often viewed as justification to question their decision-making capacity. This tendency, well-intentioned as it may be, diverts attention and resources away from devising strategies to support these individuals to deliberate effectively, and instead results in a strong bias toward conducting formal capacity assessments to determine whether someone else should make decisions for them. What this practice overlooks, however, is the fact that the difference between the decisional needs of individuals with ICD and those of their non-disabled peers is, by and large, a matter of degree rather than kind. In consequence, current practice can be unjustifiably discriminatory in its treatment of individuals with ICD. Whereas non-disabled participants are offered assistance when faced with decisional challenges, individuals with ICD are more likely to experience intrusive and potentially distressing questioning, to have their expressed preferences ignored or overridden, and even to be excluded from participation altogether.[25]

In facilitating tailored assistance, the underlying logic of supported decision-making is thus straightforward: like everyone else, individuals with ICD have decisional needs when making decisions about how they would like their lives to go. Providing them with appropriate support in this regard is therefore a matter of equality — in terms both of equal recognition of legal capacity, and of equal access to exercise that capacity effectively.[26] Furthermore, in the context of clinical research where individuals with ICD have historically faced discrimination and exclusion to their detriment, supported decision-making promises not only to rectify these injustices but also to facilitate their meaningful inclusion in research. Such inclusion enables them to gain greater access to valuable research outcomes and effective treatment options, as well as to contribute to the advancement of medical knowledge related to the conditions that affect their lives.[27]

More broadly, growing interest in supported decision-making has understandably focused on how to implement ability-enhancing interventions in order for individuals with ICD to make important self-regarding decisions effectively. Many such individuals, due to perceived or legally sanctioned incapacity, have lived much of their lives (only) being spoken for in areas crucial for their well-being and flourishing. In this regard, it bears clarifying that surrogate decision-making can be doubly harmful to the very individuals whom it aims to protect. First, as indicated earlier, responding to the decisional needs of individuals with ICD by simply placing them under the decisional authority of third parties disrespects their agency. But much more is at stake. After all, decision-making is a skill that can be improved with practice, including learning from decisions that turn out unfortunately. Yet surrogate decision-making can significantly limit valuable learning opportunities crucial for the improvement and refinement of that skill. This creates a troubling feedback loop, where the protective arrangement that surrogate decision-making places its protectees under ends up constituting its own justification for trapping them under that arrangement. Breaking this cycle thus demands an approach that acknowledges and fosters decision-making as a skill to be improved through practice.

3. Authentic Decisions, Authentic Decision-Making

This section offers a working account of authenticity and argues for its particular salience in the context of research participation. While promoting authentic decision-making is challenging for everyone, research with individuals with ICD poses heightened risks of making decisions that conflict with their values, making the development of authenticity-promoting support practices especially important.

Recall from the case of Mrs. Flores that cognitive impairment does not automatically preclude her from holding opinions and preferences about how she wants her life to unfold. To borrow a useful term from Agnieszka Jaworska, Mrs. Flores may retain "the capacity to value" despite her cognitive impairment.[28] It follows, as a general matter, that some decisions would align more closely with Mrs. Flores' values than others. Another notable feature of the case is Mrs. Flores' inability to *express* a consistent preference regarding continued participation. As should now be clear, this difficulty constitutes a target of decisional support, potentially addressable through, for example, augmentative and alternative communication.[29] Crucially, however, such communication assistance is of little use if Mrs. Flores, when unaided, struggles to *form* a consistent preference to begin with. In this context, then, support may also aim at helping her reflect on what matters to her and consider how her values bear on the decision at hand. Broadly speaking, assistance of this kind is what we mean by "dialectical support." It draws attention, we suggest, not only to the procedural aspects of decision-making, but also to the broader issue about the value of autonomy as self-determination.

In recent philosophical literature outside the context of supported decision-making, authenticity is increasingly viewed as a constitutive component of the value of autonomy.[30] From this perspective, autonomy as self-determination involves not only the independence or freedom to act, but also acting in ways that accord with one's own values. What values are, however, remains a contested issue across philosophy and cognitive science.[31] Here, we assume a broad and ecumenical conception of values as relatively stable mental representations of what matters, embedded within a cognitive network with dispositional connections to motivation and behavior. Schematic as it may be, this formulation helps to clarify values as an indispensable component of decision-making at every level. In choosing what to do, it is against the backdrop of our stored values that available options are appraised as more or less attractive. Moreover, the very aims and objectives that we pursue are themselves shaped by our underlying values. In this conceptualization, considerations of values are distinct from considerations of best interests, since values reflect what one finds meaningful or worthwhile, whether or not pursuing them is objectively beneficial. Thus construed, values need not always be explicitly articulated or consciously accessed to exert their influence. As research in cognitive science shows, values that operate under the level of conscious awareness can nonetheless shape perception, motivation, and decision-making.[32]

Values exert normative as well as motivational force in our practical lives. That is, not only do values underlie decisions in the causal sense, but they also constitute reasons for action by shaping the content and structure of our evaluative perspective. Someone who values altruism, for instance, is not only prone to help others in need; this person also counts considerations about others'

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interests and welfare as compelling reasons for action. In this sense, values help set the normative standards for what one ought to do. Indeed, it is hard to make sense of what it means to direct the course of one's life without understanding it as an activity guided by one's own values. That said, there is a risk of over-intellectualizing values by requiring values to have "narrative coherence" or positing an essentialist "true self" as their foundation.[33] In reality, the contents of one's representations of what matters often conflict with one another, and only some may survive careful reflection as what one "truly" values to serve as guiding principles for a life of overall integrity (assuming that one has this aspiration). Yet it would surely be mistaken to conclude that, until such conflicts are resolved, one lacks values or does not act based on reasons. What this observation suggests is the importance of distinguishing the values operative in actual decision-making from those invoked in a maximalist normative ideal.

In a similar vein, the notion of authenticity employed here is not an idealized one either, but first and foremost a feature of ordinary agency characterized by the alignment between decisions and values. Authenticity as value alignment captures the familiar idea that some decisions matter more — both to ourselves and to others — because they are genuinely our own, reflecting who we are and what we care about. Authenticity is, to that extent, an achievement in decision-making. Moreover, authenticity can be understood not only at the level of individual decisions, but also as a broader feature regarding the extent to which one's life course reflects value-guided self-determination.[34] On either understanding, authenticity is a graded concept, admitting of degrees along different dimensions. While here is not the place to develop a full account, it is plausible, for instance, that authenticity with respect to one's more central values carries greater normative weight.[35]

Construing authenticity as an achievement yields two suggestions relevant for devising strategies for promoting it. First, depending on the decision context, one's values may need to be articulated before they can effectively guide practical deliberation. In some cases, articulation means specifying abstract values at appropriate levels of detail. In others, reflection on one's beliefs, experiences, and affective attitudes may be needed in order to clarify what one's relevant values are in the first place, particularly in novel decision contexts. These considerations in turn lead to a second suggestion. Decision-making is a dynamic, temporally situated activity that unfolds in response to specific circumstances and task demands. While values tend to exhibit some degree of stability, they can evolve over time as learning and experience accumulate.[36] This temporal dimension adds further complexity to authentic decision-making, as will be explored in the next section.

Taken together, these two suggestions underscore that authenticity poses a challenge for all decision-makers. Successfully selecting or articulating relevant values with respect to a particular decision is no trivial task, as it often requires cognitive effort, reflection, and perhaps insight. That said, individuals with ICD may be at increased risk of making decisions that conflict with their values. Their vulnerability arises because authentic decision-making draws on a range of socio-cognitive capacities that may be impaired or inconsistently exercised in individuals with ICD.

To be clear, this vulnerability is not wholly *inherent* in the cognitive impairments of individuals with ICD but stems also from their limited experience — through no fault of their own — with making consequential decisions where authenticity is especially important, such as whom to marry, what career to pursue, or what major medical decisions to make. This is especially true for individuals with congenital or early-onset disabilities. These individuals often have had relatively limited opportunities to exercise their decision-making muscles, as the paternalistic protectionism widespread in society and among their caregivers tends to bypass rather than support their decision-making. Yet, as noted earlier, decision-making improves with practice. Thus, while making authentic decisions about research participation is often challenging for non-disabled individuals as well, they typically have years of experience honing decision-making skills and developing heuristics to rely on. By contrast, many individuals with ICD may have had comparatively less practice with making authentic decisions in complex and high-stakes contexts. Additionally, this vulnerability may be further compounded by individuals' psychological tendencies that interfere with authentic decision-making, such as the desire to please others or to feign understanding that they do not in fact possess.[37]

Individuals with acquired cognitive impairments may differ in this respect. Having developed their values and decision-making skills prior to the onset of disability, they may be able to more readily draw on some of those cognitive resources. Nevertheless, values changes that accompany acquired cognitive impairments will pose further challenges, a topic to which we return in the next section. And even when values remain unchanged, the cognitive demands of authentic decision-making are substantial. More specifically, identifying and articulating one's values, for instance, often requires introspection and access to autobiographical memory. Decisions involving long-term risks, which are not uncommon in the context of clinical research, further demand flexible temporal perspective-taking and emotional regulation. These tasks in turn place significant processing demands on working memory, since individuals must simultaneously hold multiple considerations in mind while evaluating their options. The cognitive challenge for authentic decision-making can thus be multifaceted for individuals with ICD.

Meanwhile, it bears emphasis that authenticity takes on particular importance for decisions to enroll in clinical research. Unlike decisions in clinical care, where considerations of concrete risks and benefits regarding treatment options tend to play a primary role given the central aim of promoting patients' health and well-being, decisions about research participation frequently involve more intricate, multidimensional trade-offs. In many cases, enrolling in a study offers no prospect of direct benefit to participants but instead serves the goal of contributing to generalizable knowledge that may benefit others. As such, participation may not significantly affect participants' well-being in the near term. Even for therapeutic studies that offer access to experimental treatments, considerable uncertainty often remains about whether such options are better than available alternatives. In both cases, then, decisions about research participation involve weighing personal costs — whether direct risks and burdens, or opportunity costs — against broader societal benefits. A particularly salient question thus becomes whether the aims of the research to which one contributes align with one's goals and commitments — in other words, whether one's decision to participate in research would be authentic.[38]

To be clear, the salience of authenticity in this context does not mean that participants' well-being is not important. A decision can be sufficiently authentic and yet unwise or even harmful to oneself. Here our point is that authenticity sharpens the relevant question with respect to participation in clinical research from simply whether the risks are acceptable, to whether the risks are acceptable *given what matters to the individual.* The relative weight that should be given to authenticity versus well-being considerations is an important question that merits careful examination, though likely

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not one that can be fully answered through abstract theorizing without attention to particular circumstances.

In this section, we have identified two sources of concern regarding authentic decision-making for individuals with ICD. These concerns establish why, in addition to information scaffolding or communication assistance offered to everyone thinking about research participation, individuals with ICD may need additional assistance — specifically, the kind of value-centered dialectical support discussed here. That said, the implementation details of dialectical support will likely vary considerably, as individuals' decisional needs depend on multiple factors. Congenital disabilities carry different implications for decision-making from disabilities acquired in adulthood. Likewise, the cognitive impacts of autism differ from those of Down syndrome, and variations in the severity of cognitive impairment across individuals are relevant as well. Moreover, even within a single person, decisional needs can shift across decision contexts. Therefore, our aim is not to offer a comprehensive taxonomy of decisional needs and support strategies. Rather, in the following two sections, we focus on two key challenges to authentic decision-making — situations where values require integration, and situations where they need unpacking — and propose that both may be addressed through dialectical support.

4. Integrating Values

One's values can change, and when they do, the changes reshape one's evaluative perspective. Subsequent to value changes, previously attractive options may lose their motivational pull, and new goals and commitments may emerge. These otherwise unremarkable observations are especially important in the context of supported decision-making. Medical or life events that result in acquired disabilities often affect one's values,[39] and receiving a formal diagnosis of a lifelong disability can also induce value changes.[40] In light of the possibility of value changes, the challenge of authenticity seems to lie in how to integrate, in a reliable and accurate way, the new values into value-aligned decisions. While this suggestion is correct, it is also incomplete. For even when values themselves remain stable, their relative salience in decision-making may shift over time.

To make the discussion concrete, suppose that Mr. Flores is correct in believing that he has made the decision that his wife would have made. This reasoning likely rests on the assumption that the decision accords with Mrs. Flores' long-standing values, as Mr. Flores understands them. Perhaps throughout her life Mrs. Flores has been eager to help others, or Mr. Flores knows his wife to value perseverance: finishing what she has started is something that matters deeply to her. Thus far in his reasoning, however, Mr. Flores has not begun to consider the potential impact of Mrs. Flores' Alzheimer's diagnosis. Now, while it is possible that the disease has not affected her values, it is equally likely that some of Mrs. Flores' values have changed. Since values shape both what considerations a person takes to be relevant and how those considerations are prioritized with respect to a particular decision, even subtle changes in Mrs. Flores' evaluative perspective may alter her preferences at this point. For this reason, a decision that once aligned with Mrs. Flores' values may no longer do so in her current state.

Consider the possibility that Mrs. Flores has become increasingly moody lately, due to frustrations resulting from memory loss and incontinence issues, and that, as a result, the value of helping others may no longer feel as salient to her as it once did. These shifts in Mrs. Flores' affect and evaluative perspective are worthy topics for Mrs. Flores' supporters — Mr. Flores being a natural candidate — to explore with her (using, as needed, other means of communication assistance), provided that Mrs. Flores is willing to receive dialectical support. As her supporter, Mr. Flores can take a more or less proactive approach depending on his wife's willingness and ability to engage. Suppose that Mrs. Flores may not want to or be able to discuss the possibility of value changes. Yet to the extent that Mr. Flores can identify altruism as a core value that has guided Mrs. Flores' previous participation in the study, it would be sensible for him to ask her whether helping others even at some personal cost *continues* to resonate with her. This kind of targeted inquiry, beginning with gentle prompting, engages potentially relevant values as they directly relate to the decision at hand. Likewise, given Mrs. Flores' cognitive and physiological changes, Mr. Flores might also ask his wife whether spending her remaining *good days* with loved ones, rather than participating in research, now holds greater appeal.[41]

The present point is not that engaging in these conversations will lead Mrs. Flores to a different decision from the one made by Mr. Flores. The scenarios are intentionally under-specified for reaching such a verdict. What is clear, however, is that it would be normatively inadequate to discard the possibility that Mrs. Flores' Alzheimer's has affected her current evaluative perspective. Whether — and if so, how — Mrs. Flores' relevant values have changed is an open question, but gaining clarity on this question is crucial for determining whether her continued participation would be authentic. Importantly, there is indispensable value in soliciting and respecting Mrs. Flores' own voice on this matter, not least because non-disabled individuals are often poor judges of how disability affects the lives of those actually living with it.[42]

At the same time, it would likewise be unwise to attend exclusively to Mrs. Flores' *post*-diagnosis evaluative perspective when supporting her authentic decision-making. The mood and cognitive acuity of patients with middle-stage Alzheimer's disease can fluctuate depending on factors as simple as the time of day, a pattern not uncommon among individuals with ICD. Suppose that during a moment of frustration Mrs. Flores manages to communicate that she no longer wants to remain enrolled because "it's all a waste of time." This expressed preference ought not to be dismissed. Yet good judgment is required in deciding how to respond. After all, the possibility that her statement stems from a genuine change in her underlying values must be weighed against the alternative possibility that it might simply express a transitory emotional state. Often, the most prudent course of action in such a case is to revisit the issue later when Mrs. Flores is more settled. At that point, Mr. Flores might remind his wife of the values that she has long upheld, such as altruism and perseverance, as a way of reintroducing considerations that might have become less readily accessible for her in the moment. This process begins with information and memory scaffolding, and the goal is to ensure that Mrs. Flores has access to her full range of relevant values when making decisions. Here the risk of undue influence arises, as the line between facilitating access to one's values and imposing those values can be perilously thin. We defer discussion of safeguards against undue influence until after presenting our proposal in full.

While Mrs. Flores' case first and foremost illustrates integration challenges arising from the possibility of value changes, it also implicitly reveals other challenges that we should now examine explicitly, namely those arising from cognitive and affective factors that distort *how* values are translated into value-aligned decisions, even when the values in question remain stable. This is where attention to individuals' psychological profiles becomes crucial.

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By helping individuals better understand their own cognitive and affective patterns, dialectical support can help address barriers that prevent values from being effectively translated into to value-aligned decisions.

To take a different example, in individuals with cognitive impairments associated with autism, traumatic brain injury, and dementia, episodic future thinking may be compromised.[43] These individuals may struggle to project themselves into future hypotheticals and evaluate the consequences of different options, often resulting in stronger tendencies to discount future outcomes in favor of immediate rewards. Consider, in the context of clinical research, someone who strongly values altruism and perseverance and so is motivated to contribute to research for the benefit of others. Yet when faced with an actual decision to enroll in a study that involves long-term follow-up and burdensome procedures, impairments in episodic future thinking may render their future-oriented commitments rather remote and uncertain. As a result, they may decline to participate, not because their core values have changed, but because the motivational link between those values and their future-oriented commitments is distorted. Here, although temporal discounting is not itself a value, it can reshape the relative attractiveness of different options, potentially leading to decisions that misalign with an individual's values.

To be sure, temporal discounting is not necessarily irrational and in need of correction. However, when steep temporal discounting results from cognitive or neurological impairments — whose influence individuals may not even be aware of — then the decisions thus shaped are more likely than not to be inauthentic. This possibility is therefore worth recognizing. That being said, it would be naïve to think that the mere recognition of these interfering influences is sufficient to correct for them. Our proposal is, rather, that fostering authentic decision-making requires, when appropriate, forms of dialectical support that draw on insights from research in decision and cognitive sciences.

Studies show, for instance, that imagining future scenarios in vivid detail can reduce temporal discounting by rendering future rewards more concrete and affectively salient.[44] Yet because episodic future thinking is already impaired in the individuals under discussion, the benefits of detailed prospection may only be realized through additional efforts, for example, by integrating into dialectical support empirically validated techniques such as memory cuing and scenario-construction prompts.[45] Through deliberate and carefully structured dialogue, supporters can then help individuals with episodic future thinking deficits construct vivid, detailed mental representations of the future that make distant possibilities feel more concrete.[46] Of course, implementing such evidence-based techniques effectively will require that supporters be equipped with specialized knowledge and skills. This in turn highlights an important opportunity for developing targeted training programs to bridge existing knowledge gaps.

These examples suggest several key principles about dialectical support. First, having this sort of conversation is not — and should not be — about second-guessing individuals' expressed preferences or overriding their decisions. It is rather about helping individuals grapple with the challenge of reaching value-aligned decisions in light of both newly emerging values (if any) and long-held values — in the latter case, values that individuals may still endorse, even if they do not surface readily in deliberation. However, promoting these goals without exerting undue influence on the individual's decision-making can be difficult, a critical concern to which we return at the end of the next section. Suffice it to note for now that there are no straightforward templates for how to proceed in such cases, and that at some point individuals' expressed decisions must be accepted and respected even if others have reason to believe that the decisions are not authentic. The challenges and uncertainties involved here must be lived with and managed rather than ignored. Second, dialectical support is not a recipe to follow or a checklist to complete, but a flexible framework that creates space and structure for reflection on values to guide decision-making. As such, dialectical support must be responsive to individuals' evolving cognitive abilities, decisional needs, and the particulars of the decision at hand. Finally, recognizing that even non-disabled individuals often require dialogue — whether within oneself or with others — to clarify and apply their values reminds us that the challenges of authentic decision-making are not unique to individuals with ICD. What varies, then, is not the nature of the task itself, but whether and how individuals are supported in navigating it.

In summary, our suggestions thus far for promoting authentic decision-making emphasize the importance of supporting individuals in balancing and integrating their longstanding values with their current evaluative perspective. Where appropriate, this effort can benefit from attention to the individual's psychological profile, especially their cognitive and affective patterns that shape how values are translated into decisions. Thus far, our discussion has focused on cases in which the relevant values are relatively clear. Authentic decision-making becomes more challenging, however, when the relevant values must first be unpacked or made explicit. It is to this challenge that we now turn.

5. Unpacking Values

Decision-making is difficult when we must choose among options with comparable expected outcomes. Choosing among job offers that differ in location but not overall appeal exemplifies this type of difficulty. Beyond such practical trade-offs, decision-making can be even more challenging when the objectives themselves are indeterminate or unclear, either due to a clash of seemingly incommensurable values, or because the relevant values are not yet sufficiently specified. An example of the former is choosing between two mutually exclusive careers, each desirable but for different reasons (e.g., prestige versus salary). As for the latter, challenges can arise because one's implicit or latent values have not yet been developed into explicit principles that can guide decision-making in novel contexts. Consider someone whose daily habits indicate a deep sense of care and respect for their local environment. Yet this person may still feel ambivalent about supporting broader climate initiatives, not because of internal inconsistency, but because they have not yet reflected on the more abstract and collective issue of environmental sustainability.[47]

In the context of clinical research, consider someone who explicitly endorses the value of helping others, but whose understanding of *others* has so far only encompassed concrete individuals within their immediate social circles, and not more abstract groups such as fellow citizens or future patients. Now facing the question of whether to participate in research that contributes to generalizable knowledge, this person may feel uncertain about how their commitment to helping others applies. Here, the difficulty in decision-making is not due to a lack of relevant values. The needed task is rather to unpack them in a way that bears directly on the decision at hand. In other words, another target of decisional support may be helping individuals reflect on and refine their existing commitments to better guide their decision-making. This point is especially relevant for individuals with ICD, who may have difficulty in clearly

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identifying and unpacking values at suitable levels of specificity without appropriate support and facilitation.

More broadly, individuals with or without disabilities may not have readily available, well-developed attitudes about research participation. Because most people go through life without direct engagement with the research enterprise, it can be difficult for them to determine how their values apply to decisions about participation in clinical research. This challenge exists independently of the fact, as discussed in section 2, that the significant epistemic gaps between investigators and participants, especially regarding technical aspects of the research, often complicate the translation of values into value-aligned decisions. Rather, the present point is that it will often be the case for participants' values to be in need of unpacking. To take another example, consider the value of independence. For some individuals, this value may incline them to oppose participating in research, because they dislike the idea of adhering to a strict, structured protocol. Yet others may decide to enroll in a study precisely because, upon reflection, independence means exercising the freedom to take personal risks in pursuit of altruistic goals. In both cases, the same value of independence is unpacked in ways that reflect the individual's unique perspective as well as the specific demands of the novel decision context. The resulting decisions are, for that reason, more authentic.

To illustrate how dialectical support can be used to address such unpacking challenges, consider Andrew, an autistic person who is in a supported decision-making agreement with several peer advocates in the domain of clinical research:

> Andrew is a young adult who was diagnosed with autism in childhood. For as long as he can remember, he has been living as a person with autism. He sees his autistic traits as including advantages in some areas and disadvantages in others. Being autistic, he believes, has its pros and cons, much like being non-autistic. A research team contacts Andrew about a study designed to evaluate a therapeutic intervention aimed at helping adults with autism better manage aversive sensory experiences, something from which Andrew has suffered not infrequently.

Whether to participate in this study poses a significant challenge for Andrew, particularly regarding the authenticity of the decision. Suppose, as seems plausible, that Andrew views his autism as a difference rather than a disability, and that he holds well-considered values related to neurodiversity and self-acceptance. However, these broader commitments do not straightforwardly entail a definitive position on enrollment in this particular study, which offers the potential of direct benefit. On the one hand, Andrew recognizes that sensory hypersensitivity has caused him discomfort and distress. On the other, he may view his aversive sensory experiences as inseparable from the broader set of autistic traits that constitute his identity.[48] From this perspective, participating in research aimed at reducing these experiences, or their severity, could feel like a rejection of that identity, especially if the study is framed as seeking a "cure," a characterization that might be anathema to Andrew. The complexity involved here illustrates that decisions to enroll in research are often not merely a matter of weighing risks and benefits, but also about whether participation meaningfully aligns with one's values. For Andrew, the crucial question is not just whether the intervention might help, but whether seeking such help and contributing to efforts to improve care for others cohere with his deeper values and sense of self.

Dialectical support can be particularly useful in this context for promoting authenticity. A productive dialogue may begin with Andrew's supporters helping him articulate, ideally in his own terms, the key tensions present in the decision. His supporters may offer framing suggestions or raise substantive considerations that Andrew might overlook. Ultimately, however, the dialogue is more likely to be effective if it aligns closely with Andrew's value system and worldview. In his case, making an authentic decision likely requires unpacking what neurodiversity and self-acceptance mean in relation to the study. Relevant questions include, for example, how Andrew understands the relationship between his identity and sensory hypersensitivity, whether seeking relief in that regard is compatible with embracing his full autistic self, and how the research team frames the goals of the intervention. By creating space for Andrew to consider these specific questions, in collaboration with trusted supporters, dialectical support enables Andrew to explore the relevance of his values in light of the specific decision context, making an authentic decision more likely. Notably, this approach can be implemented alongside other forms of tailored assistance, such as use of flowcharts and simplified lists of risks and benefits, to address any additional decisional needs that Andrew may have.

While Andrew's case illustrates unpacking values related to identity and self-concept, it points to a more general phenomenon about values, namely that they often are abstract idealizations admitting of varying degrees of open-endedness in scope and flexibility in content. As discussed earlier, the question of who counts as *others* in one's commitment to helping others does not necessarily have a fixed, predetermined answer. In this regard, values, as representations of what matters, resemble generic beliefs — such as *birds fly*, which remains true although not all birds do — in that they standardly contain tacit background assumptions and unstated qualifying conditions. In other words, they function as broad generalizations that capture what matters to us in general terms but often require specification when applied to specific decision contexts.[49]

To further illustrate the importance of value specification, consider Berta, who is in a supported decision-making agreement with her parents in several domains, including clinical research.

> Berta is an adult with Williams syndrome, a rare genetic condition with manifestations such as cognitive developmental delays, hypersociality, low muscle tone, and arterial stenoses.[50] She is offered the opportunity to participate in a study testing a cardiovascular intervention for her condition. The study requires several week-long hospital stays, and during these periods Berta's ability to engage in physical exercise would be limited. This aspect of the study unsettles Berta, as it conflicts with her strong commitment to physical independence, something of high value to her despite having faced lifelong motor challenges.

Berta's explicitly expressed value is physical independence. But this value is likely, in the case of Berta as well as in others in general, an abstract idealization with fuzzy background conditions that require specification before it becomes meaningfully applicable to specific decision contexts. For this reason, it is important for Berta, with the support of her parents, to carefully explore what physical independence means for her in the present context. For instance, it would be one thing if, as a result of traumatic childhood memories, what Berta has developed is a strong aversion to mobility-limiting environments. It would be quite another if what Berta values in physical independence has more to do with having opportunities to exercise her core muscles so as to maintain her fragile motor skills, for this need might be accommodated during the hospital visits. Indeed, in the latter case, what Berta values might be better described as physical health and its maintenance, rather than physical independence per se. If so, participating in a study from which Berta can potentially benefit along these dimensions not only seems to be consistent with that value, but may in fact help to promote it.

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To provide effective dialectical support for Berta aimed at unpacking her relevant values, a good starting point may thus be an open-ended discussion about what activities and past experiences have contributed to her sense of physical independence. Additionally, Berta may benefit from reflecting on how it feels to lack such independence, and how in the past she has navigated challenges in this regard. Another important question to explore may be whether sacrificing some physical independence temporarily could nevertheless remain authentic for her, if it occurred in the context of contributing to research. To complement this discussion, Berta's parents can present her with specific scenarios of the hospital stays, in order to help her concretely evaluate how her physical independence may be affected, and whether the study's mobility limitations can be managed in a way acceptable for her. Notably, the study team can contribute to Berta's parents' support effort by providing detailed, realistic information about the hospital stays and potential accommodations. Through this scenario-based dialogue, Berta can more effectively assess the implications of the study with respect to her valuing of physical independence and decide whether participation would be authentic for her.

Of note, because dialectical support involves probing an individual's relevant values and fostering their reflection, its effectiveness in promoting authentic decision-making may partly depend on how well supporters know the individual. The deeper this knowledge goes, the more likely it is that supporters can craft thoughtful questions and discussion points that facilitate productive deliberation. In Berta's case, for example, her parents likely possess valuable perspectives on Berta's valuing of physical independence. Meanwhile, the very familiarity that enables this kind of personalized support also raises concerns about undue influence. It is thus crucial that supporters do not impose their own values, or frame conversations in ways that steer decisions toward their own preferred outcomes, either intentionally or unintentionally.

Here we mention two strategies to mitigate the risks of undue influence. First, documenting the dialectical support process creates opportunities for independent oversight. For instance, high-level summaries of the discussion questions and the individual's responses can be made available for review by neutral third-parties or by the individual themselves, to identify potential signs of undue influence. Although documentation is retroactive in character, its very presence is as much a post hoc accountability mechanism as an ongoing reminder to supporters to remain mindful of their role and avoid overstepping boundaries. We note here that implementing such documentation requires careful attention to privacy protection (e.g., secure data storage) and protocols governing who may access these sensitive records. While the specific mechanisms for addressing these concerns are beyond the scope of this article, they represent important areas for future research and policy development.

Second, involving multiple supporters in iterative dialogues reduces the risk that any single supporter's biases will disproportionately shape the individual's decision-making. While supporters may hold differing views about the individual's values and priorities, such disagreements, when managed through careful facilitation, can prompt deeper deliberation and help ensure that important considerations are not overlooked. On this point, it is worth noting that in research settings, concerns about undue influence may more often apply to research teams, given their professional incentives, than to supporters. For this reason, whenever possible and with the prospective participant's permission, it is beneficial to involve supporters early in the study recruitment or consent process. Such involvement allows them to watch out for potential sources of undue influence, and to intervene if necessary. It also has the additional benefit of enabling supporters to develop a fuller understanding of the research, so as to strengthen the quality of the dialectical support that they provide.

6. Conclusion and Practical Implications

In this article, we have argued that authenticity is an important virtue of supported decision-making, one particularly worth promoting in the context of clinical research participation. We view authentic decision-making as a skill with complex socio-cognitive demands for successful execution. As such, it may often entail greater, though not unique, challenges for individuals with ICD. Dialectical support, as we have described it, offers a promising approach to addressing these challenges by helping individuals articulate and reflect on the relevant values in ways responsive to the specific demands of enrollment decisions. Given the diversity of disabilities and decisional needs, however, our discussion represents only an initial step. Implementing our suggestions on how to integrate and unpack values requires further work, most fruitfully pursued at levels closer to where support efforts are actually taking place.

Our discussion also raises broader implications relevant for research practice. Before closing, we briefly highlight several practical considerations as they relate to individual research teams, regulatory bodies such as institutional review boards (IRBs), and policymakers. For research teams, taking authenticity seriously means moving beyond merely treating informed consent as a procedural requirement focused primarily on cognitive comprehension. Instead, they should consider how the consent process can be enhanced to facilitate value-aligned participation. This shift will require understanding supported decision-making not only as a legal framework aimed at accommodating individuals with ICD, but also as a normative commitment of respect for persons. More concretely, research teams may take greater care to clarify, both in writing and in conversations with participants and their supporters, the aims of the research in accessible, value-oriented terms. Moreover, those conducting consent interviews can actively inquire about participants' values and, with tact, explicitly ask whether participation would align with those values.

Relatedly, IRBs may need to rethink what constitutes an adequate informed consent process as well. Beyond ensuring that participants are sufficiently informed, IRBs should consider implementing mechanisms that promote and assess the authenticity of enrollment decisions. Such mechanisms could include providing guidelines for incorporating, where appropriate, supporters into the consent process, requiring consent materials that explicitly connect research aims to potential participant values, and establishing review criteria for verifying that participation is value-aligned.

Some of these efforts — such as developing materials and training personnel to facilitate value-aligned decision-making — likely require additional resources as well as incentives to implement. Here is where policymakers can play an instrumental role by providing, for instance, funding and institutional support for training in dialectical support and value-centered communication techniques for research teams. Training and educational programs for supporters represents another important resource need, since they require specific skills (e.g., crafting thoughtful questions) and knowledge (e.g., in decision science) in facilitating value-centered conversations. At the broadest level, we urge policymakers to recognize value-aligned research participation as an important component of ethical research conduct, not merely an aspirational goal. Indeed, much of what we have said about authenticity and

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authentic decision-making applies broadly across different research settings and participant groups. While we have specifically proposed dialectical support as a targeted intervention for supported decision-making scenarios, it may be useful to aid the decision-making of all research participants.

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