



Supported Decision-Making: The CRPD, Non-Discrimination, and Strategies for Recognizing Persons' Choices About their Good

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ABSTRACT: People with cognitive impairments often have difficulties formulating, understanding, or articulating decisions that others judge reasonable. The frequent response shifts decision-making authority to substitutes through advance directives of the person or guardianship orders from a court. The Convention on the Rights of People with Disabilities defends supported decision-making as an alternative to such forms of supplanted decision-making. But supported decision-making raises both metaphysical questions—what is required for a decision to be the person's own?—and epistemological questions: how do we know what persons judge to be their good, when they have difficulty conceptualizing and articulating? It raises practical questions, too, such as protection against risks of exploitation. This article uses a non-discrimination account of legal personhood drawn from the CRPD to explore how common features of decisions employed by people without cognitive disabilities are important in supported decision-making too. These features include prostheses, guardrails, relationships, and social contexts.

KEY WORDS: CRPD, Discrimination, Supported Decision-Making, Cognitive Impairment, Agency, Guardianship, Cognitive Prosthesis

Introduction

People with cognitive impairments often have difficulties formulating, understanding, or articulating decisions that others judge to be reasonable. One common conclusion is that such people are incapable of making their own decisions and others must step in to make decisions for them. These substitute decision-makers

may be expected to follow one of several different decision-making models (Chaet 2017; Jaworska 2017). For people who have had had prior decision-making capacity, the model may be *advance direction*: decision-makers follow earlier directions for what should be done in the current circumstances. For people who have had prior decision-making capacity but have not made relevant prior prescriptions, the model may be *substituted judgment*: decision-makers decide as it seems likely that persons would have decided, given what is known about their values, preferences, and interests. For people who have never had decision-making capacity, decision-makers follow the *best interests* standard, relying on some mix of what is believed to be in the person's own interests or in the interests of human beings more generally.

These three models—advance direction, substituted judgment, and best interests—have been standard fare in bioethics and health law. But they are not uncontroversial. One important set of criticisms asks whether advance direction is an appropriate model to use for someone who has lost earlier cognitive capacities and may now seem to be a quite different person (Dresser 2018; Walsh 2020). At its fullest extent, this criticism holds that a later self, with altered cognitive capacities, is a different person than the former self and therefore decisions of the former should not bind the later. Another set of criticisms asks whether interests are to be understood subjectively, in terms of states of the individual subject, or objectively in terms of what is in general in the interests of similar persons (Cantor 2005). Criticisms of this kind doubt whether cognitively impaired subjects are the best judges of their own interests. These criticisms reflect controversies about which model of substitute decision-making should be followed in given situations.

Neither set of criticisms addresses a more fundamental challenge to substitute decision-making itself: whether the response to cognitive impairment should be shifting the locus of decision-making from the person with cognitive impairments to someone else. Nor do these criticisms take on additional philosophical questions about decision-making by a person with cognitive impairments. For example, what is required for agency, when a decision maker has limited cognitive capacity? How can we know whether a decision is someone's own, when articulation and communication are difficult for them? Transferring decision-making to a substitute bypasses these difficult metaphysical and epistemological questions. But the difficulty in answering these and related questions is not a sufficient reason for assuming that substitute decision-making of some form is a preferred response to impaired cognitive capacity. Instead, we might at least want to explore ways of enhancing agency or promoting understanding of people with cognitive impairments, rather than shifting the locus of decision-making away from them altogether.

My aim in this article is to make a start on how to retain the agency of someone with limited cognitive capacities. I do this by exploring how people with cognitive disabilities do not differ in decision-making processes from people without

these disabilities. I fully admit that this is only an incompletely theorized beginning. I hope, however, that it indicates at least some of the questions that would need to be asked and sketches at least some ways they might be answered, if fuller models of supported, rather than supplanted, decision-making are to be constructed.

Good reasons support retaining the locus of decision-making with cognitively impaired individuals themselves. First, it is the most direct reminder that they are the individual decisional subjects and that decisions should be individualized to them. It recognizes that they are where decisions start and ultimately end up. Second, impairments are not all-or-nothing, or even all or nothing for specific capacities. Some people with cognitive impairments may have intense perceptual skills, while others may have better communicative abilities. Some may need help with drawing the connections of abstract reasoning or calculation but understand the conclusions once the linkages have been made. Some may intuitively understand who is trustworthy and who is not, while others may have little social understanding of their vulnerability. Deficiencies in social skills are described as common for people with developmental disabilities (Devi 2013). For some, capacities may increase or decrease with the social or physical setting, or even with the time of day. Young adults with cognitive impairments may continue to develop skills while the capacities of others with progressive dementias may wane (Largent and Peterson 2021). Third, the exercise of capacities takes practice; people may improve in their decision-making skills as they engage in them. Or they may become increasingly passive when others seem to take over for them or not even listen to them. In sum, locating decision-making with individual themselves expresses respect for them as persons in myriad ways.

In the last few years, spurred by the Convention on the Rights of Persons with Disabilities (CRPD), supported decision-making has been gaining favor as an alternative to the legal transfer of decision-making authority to others through guardianship or other mechanisms (Kohn 2013). Much commentary has defended this approach as reflecting respect for persons with cognitive disabilities. Consider these words of Jenny Hatch, a woman with Down syndrome who has become a well-known advocate for supported decision-making after she was subjected to oppressive guardianship proceedings:

I want to tell you why Supported Decision-Making is very important to me. I love making decisions for myself. Sometimes I need some help to make good decisions. When I have help to make decisions, I can handle anything. (Martinis and Blanck 2019, 13)

But puzzles remain at the heart of supported decision-making about how decisions can be the person's own when capacities are limited. These puzzles loom especially difficult or pressing when people apparently lack understanding or coherent identity

(Burch 2017) or when they are at risk of significant personal harm (Largent and Peterson 2021). Consider these central questions about supported decision-making:

What is meant by someone's "own" good, rather than someone else's conception of their good?

How do we go about determining someone's "own" good when a person has difficulties processing information, conceptualizing, or communicating? Do we do this in the same ways that we would for people without such apparent difficulties?

Can supported decisions be wrong about whether a course of action will further the subject's own good? How can we know that this is the case? Is this different for supported decisions than for decisions made without support?

When are supported decisions unjustifiably paternalistic? Should questions about justifiable paternalism be answered in the same way for supported decisions as they are for decisions that are made without support?

These questions are not easy to answer. But grappling with them is critical to developing practices of supported decision-making. In this contribution, I hope to suggest some strategies for approaching these questions based on my earlier work on understanding the good by, with, and for people with cognitive disabilities (Francis and Silvers 2007). In developing these strategies, I will draw on three themes. The first is the role of what might be termed "cognitive prostheses." The second is the problematic nature of assumptions often found in liberal theory that people arrive at accounts of their good independently. And the third is the extent to which understandings of the good are social. I do not suggest that these strategies are solutions to all or even any of these challenging questions for supported decision-making. Rather, I think that they point to where the most difficult issues lie, how to make a start on thinking about them, and what might be some safeguards to incorporate into supported decision-making.

My exploration begins with the CRPD, the most powerful legal instrument providing impetus for supported decision-making. I draw on the CRPD for a non-discrimination approach to decision-making when people have cognitive impairments. This approach emphasizes similarities between decision-making by people who are not considered cognitively impaired, and people who have been determined to have significant cognitive limitation. Recognizing these similarities suggests ways of fostering agency that are common for most people, but that have been under-appreciated for people with cognitive disabilities.

The Convention on the Rights of Persons with Disabilities: Equality of Legal Personhood

The CRPD takes a definitive stance about the role of persons with cognitive impairments as decision-makers: they must remain full legal persons. Article 12 provides that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations 2006). To the extent that they are unable to formulate, understand, or articulate decisions, supports must be provided. This provision has spurred adoption of supported decision-making as an alternative to guardianship.

The General comment to Article 12 states that full legal personhood must be maintained for everyone, no matter the level or type of cognitive impairment (Committee on the Rights of Persons with Disabilities 2014). This comment has been interpreted by critics to mean that the CRPD requires supported decision-making even for people who have no or very limited interactive capabilities, such as people in permanent vegetative or minimally conscious states (Largent and Peterson 2021). This interpretation appears to founder with such limiting cases: how can the person be thought of as exercising their own decision-making when they apparently play a completely passive, non-interactive role? If agency requires some level of action, it seems that agency must be foreclosed in such limiting cases. I have argued elsewhere that that this interpretation of the General comment may be too strong. The principled basis of the comment is ensuring “the right to equality before the law for people with disabilities, on an equal basis with others” (Francis 2022, forthcoming). On this interpretation equality and non-discrimination are the touchstone for the understanding of legal personhood, rather than a single preferred process of decision-making. Along similar lines, commentators such as Scholten, Gather, and Vollmann (2021) read Article 12 as prohibiting discrimination in the recognition of equal legal personhood. These authors argue that for purposes of Article 12, non-discrimination should be understood as not imposing relative disadvantage based on membership in a disfavored group, such as being a person with a disability.

According to the General comment, equality and non-discrimination require that people not be stripped of legal rights such as the right to hold property or the right to participate in social life if they so choose. Support may take many forms, but should seek to generate the “best interpretation of will and preferences” rather than the best interests of the person (Committee on the Rights of Persons with Disabilities 2014, ¶17 and ¶21). Supports must guard against inappropriate paternalism that imposes others’ conceptions of their good on the supported person. The goal of support is to elicit the person’s own good rather than deciding what would be good for them. On the other hand, supports must also guard against undue influence or exploitation. Safeguards must thus be implemented to “respect the rights, will and preferences of

the person, including the right to take risks and make mistakes” (Committee on the Rights of Persons with Disabilities 2014, ¶22). Just as people without cognitive impairments should be permitted to engage in trial and error even at some risks to themselves, so should be people with these impairments.

This account of supported decision-making requires principled separation of the best interpretation of a person’s will and preferences from the person’s best interests, even when cognitive capacities are limited. Conceiving of subjects as acting on their own conceptions of their good must be differentiated from someone else’s conception of what would be good for them. Interests may of course be central to a person’s own will; the point is not that interests are irrelevant but that their relevance is part of the more general picture of someone’s will and preferences. But there is a delicate balance here, between eliciting someone’s individualized conception of the good and ensuring that this is not done in a way that unduly influences, coerces, or exploits. If people cannot assert their good on their own, how can we be sure that others are not imposing others’ conceptions of their good on them—or worse, manipulating them or disadvantaging them for others’ ends? The problems here are both metaphysical—what is it for a good to be a good of a person and not simply a good for a person?—and epistemological—how can we ascertain what is a good for a person who cannot articulate?

Importantly, Article 12 reminds us that these problems do not arise only for people with cognitive impairments. Rather, they arise for everyone. When they do arise, they must be handled in a manner that does not discriminate. On a non-discrimination account of Article 12, therefore the approach should not be to develop a different way of answering these questions for people with cognitive disabilities. Rather, we should look to how these problems arise, and may be addressed, in decision-making for anyone. To this end, I begin with a sketch of the complexities of decision-making, followed by some suggestions about how to navigate cross currents between these complexities and concerns about safety, harm, undue influence, and exploitation, primary concerns in decision-making for anyone but most particularly when there are questions about whether people are capable of self-protection. A concluding section examines some strategies that have been developed for supported decision-making in U.S law.

“Good” Decisions

In making decisions, people invoke different types of considerations. People have episodic wants or desires, for a piece of chocolate cake, a nap in the sun, or a one-night stand. They may have short term interests, such as a temporary job that can pay enough to live on during a summer when school is not in session. They may have “experiential” interests in pleasant sensations, more basic interests in things

such as money or health care than can enable them to achieve a wide range of goals, or “critical” interests in things central to their identity over time, such as relationships or careers (Dworkin 1993). They may have values: commitments to objects or states of affairs they regard as aesthetically or morally good. Decision-makers weigh these different kinds of considerations: wants, preferences, or desires against interests, shorter term interests against longer term interests, and a mix of wants, preferences, desires, or interests against values. And they may do this in different ways, at different points in time.

There are classic philosophical criticisms of some ways of weighing these considerations. For example, Aristotle has been interpreted as arguing that it is weakness of the will to give in to an episodic desire when so doing would not follow one’s reasoned judgment of what is best overall (Kraut 2018). This argument has generated extensive discussion of the force of a practical reasoner’s judgment about what is best for them to do. Ronald Dworkin defended advance directives for dementia that further critical interests—long-lasting interests over a lifetime—rather than present experiential interests (Dworkin 1993). This stance, in favor of the shape of a life over current experiences, is disfavored by those who believe that prior choices should not necessarily bind present selves. R. M. Hare described people who held to the pursuit of values over interests at all costs as “fanatics” (Hare 1963; Hare 1965). In his view, such people were outliers; most people, when asked to reverse their positions with those of others would recognize the need to take the interests of all into account in making decisions that affect people other than themselves. My discussion here does not pretend to explore these issues or defend any given solution to them. Rather, I wish to point out that people weigh these different kinds of considerations in different ways throughout their lives. Decision-making is pluralistic among experiences, desires, interests, and values. Following the principle of equality and non-discrimination of the CRPD Article 12 would seem to require that people with cognitive impairments should be no different than anyone else in this respect on account of their impairments.

Moreover, people do not acquire or weigh these different kinds of considerations in a vacuum. Relationships and social conditions shape whether different factors are experienced, realistically available, or endorsed. Theories of relational autonomy argue that autonomy does not require independence of or separation from others. Rather, autonomous decisions may be decisions that are taken in the recognition of relationships with others or in interaction with others (MacKenzie and Stoljar 2000; Christman 2004; Gómez-Virseda, de Maeseneer, and Gastmans 2019). Theories on which autonomy is socially constituted hold that social conditions must be considered in determining whether autonomy is possible. Under oppressive social conditions, even apparently happy acquiescence may not be freely given. Serene Khader (2020) argues that these ideal theories may be insufficient or misleading for non-

ideal situations in which people must deal with conditions of oppression and should not be subjected to unjustified paternalism in so doing. Again, without endorsing any set view about relational or socially constituted autonomy, in what follows I shall start with the assumption that people with cognitive impairments should be viewed as no different from others with respect to the significance of engaging in relational and social decision-making.

Supported Decisions

In this section, I outline non-discrimination strategies for addressing concerns that supported decision-making may yield decisions that are not the person's own, amidst cross currents among the complexities of decision-making and fears about safety, harm, undue influence, and exploitation. To do so, I draw on examples from my pro bono legal representation of people who are the subject of guardianship petitions. While my examples are admittedly anecdotal, I hope they will prove suggestive about how supported decision-making can be achieved in a non-discriminatory way.

My clients are people with very different cognitive impairments: developmental delays, brain injuries, mental illness, strokes, and dementias. The supports potentially needed in these cases differ widely. Some reflect the limiting cases cited by critics of the interpretation of Article 12 in General comment 1: people who have been severely impaired from infancy and never communicated through words, or who have been become comatose in accidents or through apparent drug overdoses. Others of my clients engaged in risky behaviors during adolescence that led state protective services to intervene; some but not all of these have grown beyond the most severe effects of the congenital conditions, brain injuries, or trauma and abuse that lay behind their earlier actions. Still others were college students before the onset of symptoms of schizophrenia. Many others have degenerative brain diseases or progressive dementia.

Prospective guardians in these cases nearly always seem to care about their proposed wards, but frequently manifest this care in ways that have led to conflicts with my clients about what would be good decisions. My clients want to take risks: with boyfriends or jobs if they are young adults or with continuing to live in their homes and communities if they are elderly. Their prospective guardians want to shelter them from harms, such as giving away money or spending it uncontrollably, becoming pregnant, or wandering and getting lost. My clients may have important reasons for wanting to take these risks, just as other people have reasons for risky behaviors in which they engage, from sky diving to starting new businesses. But there also are cases in which financial abuse appears likely. Some financial abuse comes from strangers: people met over the internet or on a telephone call. But there also are more intimate settings in which a prospective guardian lives with my client and has

been a long time and patient caregiver—but is also dependent on Social Security payments to my client. Sometimes, my client owns the home in which (nearly always) she lives with her caregiver and the caregiver has hopes of or believes (always) she has been promised to inherit the home.

To acquire guardianship, a petitioner must prove by clear and convincing evidence that my client is incapacitated. “Incapacity” is measured by functional limitations in the ability to “receive and evaluate information; make and communicate decisions; or provide for necessities such as food, shelter, clothing, health care, or safety,” and these limits must be such that the “individual lacks the ability, even with appropriate technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self-care.”¹ This is a very high level of proof that must be met separately for each area of decision-making that the prospective guardian wishes to have. Problematically, however, while this account of capacity explicitly relies on technological support, it does not mention the possibility of support from other people, even when my client would reach out for such support. Indeed, my clients often welcome support—but not if the support is compelled. They want to be recognized as making the decision to call on and rely on others. Arguably, my clients are not incapacitated in the statutory sense if they recognize the need to involve others in meeting essential requirements for self-protection and act to assure this involvement. In what follows, I consider how my clients might navigate cross currents of decision-making with supports that are commonly used by many people in three decision-making areas: money, health care, and social relationships. These supports are ways of supplementing, rather than supplanting, agency.

Cognitive prostheses and guardrails: Money. My clients are all pro bono, with limited financial resources. Their financial situations do not involve complex investment decisions. My clients likely receive Social Security disability or old age benefits, Supplemental Security income (SSI), Medicaid, and other supports such as case management or low-income housing vouchers. Money management for them typically involves these primary concerns: that basic bills are paid so the electricity is not turned off or they are not evicted from their living space; that they do not unwittingly acquire resources over the low ceiling set for continued eligibility for SSI, Medicaid, or other supports; that they do not lose cash or credit cards; and that they do not impulsively give away money to people who seem nice to them but whom they do not otherwise know.

People regularly use decision aids to address these concerns. Some aids are technological, such as a text reminder when bills are due or when a bank account is nearing a specified level. Bills can be paid electronically as they are received. These are technological *prostheses*. People cut up credit cards or leave them in safe places; they also set up automatic delays for larger expenditures to give themselves time to think twice. Such decision aids may be thought of as *guardrails*: ways to keep from

falling off a chosen path, at least without warning. Prostheses and guardrails are features of the ordinary lives of people without cognitive impairments. So are other decision aids for more complex financial transactions, such as tables of compound interest rates and required pension distributions. Many people do not make investment decisions on their own but rely on personal financial advisors or use packaged instruments such as annuities or money market funds. What may be different with supported decision-making is the need for help from others in setting up, acting on, or reviewing the functioning of these decision aids. But such need for help also is not unique to people with cognitive impairments; many others do not have the technological equipment or know-how to get online to set up automatic bill payments, for example. Calculators and computers are black boxes to many people who at best would be likely to notice if results seem wildly out of line, such as when a decimal point is misplaced. To be sure, people with cognitive impairments who lack calculative understanding might need to rely on trusted others to notice that \$1000 really should have been \$10 but here, too, it is unclear why the need to turn to a trusted advisor makes the decision different in kind, not the person's decision but someone else's. So far, there would seem to be no difference in principle between use of either technological or human help by people who are considered not to be cognitively impaired and people who are cognitively impaired. We do not think a decision is less someone's own because they rely on prostheses or guardrails to help, whether in the form of technology or human advice.

Nonetheless, important differences still may seem to remain about protection when cognitive impairments are in play. Even granting that assisted financial decisions are the person's own, concerns might be raised that they are not "good" decisions because they are unwise or present serious safety risks. One concern often voiced to me by prospective guardians is that people with cognitive disabilities are gullible and likely to give money away without understanding what they are doing. In principle, there should seem to be no more compelling reason to impose a supporter's judgment of what would be a wise expenditure on a supported person than there is to prevent anyone else from making silly decisions about money, however. People get pleasure from impulsive purchases or small gifts to others who may not be trustworthy, even if these expenditures seem improvident to others. It remains unclear why these experiential pleasures should not be "good" in the case of cognitive disabilities when they are unquestioned for others.

When larger expenditures are at stake, risks are greater. Risks are far greater when money is spent or given away to the extent compromises the ability to pay for necessities such as utilities or rent. Many potential guardrails can be set up against these risks, however, including carrying limited amounts of cash, leaving credit cards and checkbooks at home, or implementing arrangements for checks or withdrawals to be co-signed. Help may also be available to apply for assistance in paying

utility bills or in meeting the costs of housing, although these programs are chronically underfunded. Many of these prostheses or guardrails are in common use; their use is insufficient to show that people with disabilities are not functioning as agents.

Concerns about safety may seem most pressing if the person with cognitive impairments disregards advice about basic financial matters such as paying utility bills or rent. Yet supported decision-making statutes, as outlined below, are emphatic that arrangements may be terminated freely by any party and that supported persons remain free to act outside of the arrangements. These statutes allow people to put themselves at risk, even becoming unsheltered for extended periods of time. So questions about safety are pressing. Should these risky decisions be viewed differently in the presence of cognitive impairments? Does rejection of support show that a decision is not in a person's "good," or that paternalism is appropriate?

In answering these questions, it is important not to overestimate the likelihood of such situations of outright refusal. Many cases may be ones in which supports that would have been welcomed were not readily available. Some involve conflicts that could have been avoided by exploring forms of support rather than moving quickly towards imposition of control. Still others are ones in which there are conflicts about the appropriate persons to turn to for support. Some of my clients, for example, have values that are quite different from those of their parents and may wish to rely on supporters who are more reflective of these values. Non-discrimination would require that these differences be treated just as they are for people without cognitive impairments. Moreover, as described in the next section, there are models from fiduciary law to guard against fraud and abuse by chosen supporters.

Still, there will be cases in which people with cognitive impairments put themselves in severe danger, even when the impact of decision aids and human supports have been exhausted. Becoming unsheltered and living on the streets is a realistic outcome for too many. But the conclusions to draw in such cases about the person's good and the justifiability of paternalistic intervention are not obvious. It would be discriminatory under the General comment to Article 12 of the CRPD to draw different judgments about the good and the justifiability of intervention just because of the fact of cognitive disability, compelling people with cognitive impairments into shelter while continuing to respect the similarly risky choices of people judged not to be cognitively impaired. Non-discriminatory answers would be to intervene either in both situations or in neither. My point here is not to make a judgment about whether becoming unsheltered is or is not in someone's good. Rather, it is that further argument beyond the risks of becoming unsheltered is required to show that when all supports have been exhausted, cognitive impairment alone is the determining factor.

Relationships: health care decisions. Health care decisions present well-known challenges to accounts of the good in liberal theory that assume that individuals make decisions about their good independently of others. Perhaps not surprisingly,

health care is a decision-making area where my clients are readily willing to turn to others for help—at least when mental illness is not involved. The compulsion of guardianship is not required for my clients to involve others in their care. Like others, my clients recognize their need for help in understanding complex medical information. And they see their care decisions as intertwined with their relationships with loved ones.

Discussions in bioethics of the physician-patient relationship have attempted to address problems with patient understanding through what is called “shared” decision-making. In shared decision-making, clinicians and patients work together to evaluate the risks and benefits of care alternatives and make decisions about care based on the patient’s goals (Blumenthal-Barby et al. 2019). The model has become widespread in clinical practice as a method to avoid medical paternalism while helping patients to understand or process complex medical information when they are ill. Although the model has been promoted for informed consent and is even required for reimbursement for some high-cost procedures, it does not represent the kind of voluntary selection of a legally recognized, long-term decision-making partner or partners that is envisioned by supported decision-making. Indeed, in some supported decision-making statutes, health care providers are specifically prohibited from becoming supporters because of the role conflicts this might involve.

The problem that shared decision-making seeks to address is primarily cognitive: patients who lack medical knowledge or who are ill, in pain, or fearful, may have difficulty receiving or processing information critical to care decisions. As with financial decisions, trusted others can help people with cognitive impairments use information to draw connections. People do not have to understand the scientific accounts of why chemotherapy creates risks of infertility to understand that taking a recommended medicine may mean that they cannot have babies. While people who lack abstract reasoning abilities may find the full meaning of death difficult to comprehend, they may be able to understand that going without treatment means that they will no longer be able to feel anything or to be hugged by those they love. Supportive decision-makers can help to make such basic ideas comprehensible for people with cognitive impairments. (Parenthetically, these basic ideas may capture reasonably well the significance of infertility or death for many people who have not been diagnosed with cognitive impairments.)

In addition, criticisms of individualized models of healthcare decision-making go beyond the cognitive to also point out that people’s decision-making may be relational (Ells, Hunt, and Chambers-Evans 2011; Gómez-Virseda, de Maeseneer, and Gastmans 2019; Wright 2020). That is, people may be committed to working with others to make important life decisions or have conceptions of their good that are intertwined with the good of others. Supported decisions may provide practical

recognition of the role of relationships in health care decisions if the supporter and supported are in close relationships.

Emily Walsh (2020) has recently defended supported decision-making as an alternative to advance directives for patients who are undergoing significant changes in cognitive capacities. Walsh argues that changes in cognitive capacities may be transformative, altering the experiences people may have and the meaning of these experiences to them in ways they could not have imagined before the cognitive changes. If changes in cognitive capacities are transformative in this way, Walsh contends, people may have been unable before the changes to understand the decisions they would want to make after the changes. With support, she believes, people may be able to articulate conceptions of their good that better fit their current circumstances rather than being bound by epistemically flawed prior stipulations. Megan Wright (2021) has extended reasoning about the role of supported decision-making in end-of-life care to physician aid in dying, arguing that it violates equality for the opportunity to be available only to those who can attest to an implement their wishes on their own.

Thus conceptualized, health care decisions illustrate how supported decision-making can help not only with cognition but also with the recognition of relationships. But darker possibilities also loom. Persons in close relationships who act as supporters may have interests of their own that should not play roles in what is attributed to people with cognitive disabilities. These include not only financial conflicts—supporters may be dependent on the benefits of those they support and thus be inclined to err on the side of more treatment than would be the choice of the supported person, or supporters may stand to inherit if death comes more quickly—but also personal desires of the supporter. Supporters may find it difficult to face the deaths of those they love and let their own grief interfere with their decisions. Or supporters may have ethical or religious views that do not align with the practices of those they support. Supported decision-making statutes in the U.S. do provide protections for serious cases by incorporating obligations to report supporters' suspected abuse, as described in the next section. But many situations that may not rise to the level of abuse may still involve supporters apparently speaking for themselves rather than with the supported person.

As with financial decisions, moreover, safety issues may arise if persons with cognitive impairments choose to reject supports in making health care decisions. U.S. Supported decision-making statutes not only prescribe that either party may cancel agreements at any time, but also that agreements may limit access to medical information on the part of the supporter. It is with respect to access to information that prospective guardians raise the greatest safety concerns about my clients with mental illness whose decision-making capacities may be impaired. For example, parents petitioning for guardianship want to be sure that their children with mental

illness are continuing to see therapists, are staying on prescribed medications, or are protected from putting suicidal thoughts into action. Supported decision-making statutes provide that health information may be shared only with the consent of the supported person, consent that may be terminated at any time. Concerned parents often chafe at what they regard as the woeful inadequacy of these protections. On the other hand, non-discrimination requires that the presence of mental illness should not suffice to treat people differently from others. A nondiscriminatory conclusion to be drawn in such cases is that supporters should have the authority to intervene to protect their children with mental illness from danger to the same extent that they would have the authority to intervene to protect children without cognitive impairments from danger. The upshot of this conclusion might be more interference rather than less because the dividing line between permissible and impermissible interference is not mental illness but the extent to which the individual is protecting (almost always him)self from danger without support.

Social contexts: Choosing sex. A common theme in the guardianship proceedings brought by parents of young adult children is the risk of sexual exploitation. Not incidentally, in every case of this kind that I have had, the adult child was female. Also not incidentally, the most common specific concerns raised by parents were pregnancy or financial exploitation. In most cases, neither of these concerns were particularly realistic: my clients were using long-acting birth control and lacked significant financial resources. Rarely, parents did fear that their children would end up using drugs or on the street—concerns that might in some cases have been more realistic. Vaguer concerns went something like this: “her boyfriend isn’t good for her” or “she doesn’t understand what she’s doing.” Other more likely risks rarely surfaced, such as risks of sexually transmitted diseases, likelihood of domestic violence, possibilities that trust in the sexual partner would be unwarranted or concerns that my clients would be hurt if the relationship were to end.

Not surprisingly, many of these young adult clients oppose their parents as guardians. But they still do not oppose working with their parents on many important decisions, particularly involving finances or health care. Quite typically they say that they are happy to have their parents help them with these decisions which they find difficult to make. But they draw the line at personal relationships, defending the importance to them of having boyfriends or eventually moving in with them. Their parents reply with the worry that they do not know how to protect themselves. Their parents may also have different views about the morality of extra-marital sex than my clients do. Parents seem to view my clients as like young children acting out, while my clients seem to frame the conflicts as generational. My clients want to be able to date, have sex, get married and possibly have children, just like others

of their same age and social context. Their conception of their good differs their parents' with respect to their social lives.

Alexander Boni-Saenz (2015) has defended an account of sexual consent capacity that incorporates supported decision-making. He terms this account "cognition-plus." The account has three steps: whether the individual can express volition with respect to the act of sex; whether the individual can understand and reason about the nature and consequences of the decision to have sex; and, if not, whether "there is an adequate decision-making support network in place" (Boni-Saenz 2015). Boni-Saenz envisions an "adequate" network not just as a single supporter, but as a network consisting potentially of both family and friends. Such networks might seem more like what my clients hope for from supportive friends rather than overprotective parents.

My clients' desires to try—and possibly fail—at relationships suggest that their conceptions of their good involve the expectations they have formed in social contexts. These conceptions are not merely relational, they are social. Others such as Anthony Appiah (2005) have defended the role that social scripts play in identity. For my clients, these scripts are not externally imposed on them. Rather, they have been taken on through my clients' lived experiences with others.

Importantly, my clients' views about supports are not univocal. They may wish to call on different supporters for different kinds of decisions. For example, my clients often see their parents as appropriate supports for money or health care but not for developing friendships or relationships. Supported decision-making statutes allow these nuances to be recognized by allowing multiple supportive agreements, for different purposes and with different supporters, in a way that a single guardianship does not typically accommodate. Moreover, these statutes build in at least some protections in the form of duties to report suspected abuse by supporters and termination of the arrangements when abuse is substantiated. Once again, the question is whether, once supports have been exhausted, there are additional reasons not to respect supported individuals' judgments about their good that would not apply to people without cognitive impairments.

U.S. Law and Supported Decision-Making: Navigating the Conflicts?

In law, supported decision-making enables people with cognitive impairments to create formal instruments identifying partners in making specified decisions. Texas adopted the first statute in 2015 (Theodorou 2018); as of this writing, Supported decision-making has been adopted in some form in nine U.S. jurisdictions, typically as an alternative to guardianship. These agreements are completely voluntary on the part of both the maker and the supporter (Martinis and Blanck 2019; National Resource Center for Supported Decision-Making 2021). To ensure voluntariness and

authenticity, agreements must be witnessed or notarized. An important caution to how these support agreements function is sounded by Nina Kohn (2021), however, who points out that when supports are considered as alternatives to guardianship they may replicate the over-protective features of these arrangements. Beyond these basics, states have experimented with a variety of ways of structuring supported decisions to navigate the cross currents in decision-making I have described.

Several states have tried to give substantive guidance about the supporter's responsibilities, but these are quite minimal. Texas constructs the relationship as fiduciary, stating that this means the relationship "(1) is one of trust and confidence; and (2) does not undermine the decision-making authority of the adult."² Indiana says that the supporter must "support the will and preference of the adult, and not the supporter's opinion of the adult's best interests."³ Alaska states that the supporter is to "act with the care, competence, and diligence ordinarily exercised by individuals in similar circumstances."⁴ Statutes in Delaware, Nevada, and Rhode Island state that a guiding principle of supported decision-making is that the "values, beliefs, wishes, cultural norms, and traditions than an adult holds should be respected in managing an adult's affairs,"⁵ thus apparently recognizing the pluralism in decision-making described above.

Who can support. Statutes employ different methods to rule out potentially abusive support. Most basically, many statutes exclude people with certain criminal convictions such as for assault, sexual offenses, or theft from serving as supporters.⁶ Statutes also require people who deal with supporters to report any suspected abuse⁷ and provide for agreements to terminate with a finding of abuse.⁸

Drawing from fiduciary models, some statutes limit who can be a supporter based on concerns about potential conflicts of interest. These limits are primarily financial. For example, some statutes disqualify employees of the supported person unless they are immediate family.⁹ Some disqualify persons providing paid services to the supported person, also unless they are immediate family.¹⁰ Indiana does not allow supporters to be paid for the support although they can be paid for other services.¹¹ The District of Columbia excludes people other than immediate relatives who provide physical, mental, or behavioral healthcare services or disability services, owners of entities providing these services, or governmental entities funding these services.¹² Importantly, these statutes try to rule out financial conflicts of interest while allowing family members to serve as supporters. Yet although attention to financial conflicts is important to guard against risks of abuse, these protections are both too weak and too strong. As noted above, family members may have both financial and other conflicts of interest with those they support. Family members may rely on Social Security disability payments received by the supported person for shared household expenses. Personally, family members may have their own

views about the kind of life that is possible for the supported person or seek to be over-protective of them. Parents may be invested in the continuing safety of their adult children with cognitive disabilities, hovering over them in ways they would not for other children. Jenny Hatch's parents sought guardianship after she was involved in a biking accident, they claimed to protect her from what they judged to be likely harms but at costs of confinement that she found unacceptable (Martinis and Blanck 2019). The voluntariness of supportive agreements may not be enough to ward off these kinds of conflicts.

Supported decision-making statutes also impose limits designed against over-reaching by the supporter. Statutes provide that creating a support agreement is not evidence of the incapacity of the maker. They specify that even if people have entered supported decision-making, they are free to act outside of these arrangements. The scope of support agreements is limited to areas of decision specified in the agreement. Even when actions are within this scope, Wisconsin states that supporters have no authority to sign legal agreements on behalf of the supported person or to bind the supported person legally.¹³ State statutes also express concerns about informational privacy and stipulate that supporters may not access confidential information without the specific consent of the supported person, must keep information about the supported person confidential, and must not use information about the supported person for purposes other than support.¹⁴ As noted above, these provisions concern petitioners for guardianship who believe they need access to medical records to assure the safety of those they seek to protect.

What supporters can do. Statutes also have a variety of provisions regarding what should be done when support agreements are used. These provisions to some extent reflect uncertainty about the status of these agreements. Some statutes say that others should rely on agreements¹⁵ or give legal status to the supporter to participate in discussions with others.¹⁶ Other statutes, however, are silent about the legal status of actions under support agreements. At the same time, statutes are highly protective of those who may rely on the agreement, offering liability shields for good faith adherence to a supported decision.¹⁷ Wisconsin goes further, stipulating that health care providers relying on consent provided with a supported agreement are immune from actions claiming that the patient lacked capacity and so could not have given informed consent.¹⁸ Statutes also give specific deference to conscientious concerns of those confronted by supported decisions. For example, Delaware provides that supported decisions need not be followed if “the action proposed to be taken under the agreement is contrary to the conscience or good faith medical judgment of the person or to the written policy of a healthcare institution that is based on reasons of conscience.”¹⁹ Indiana provides a far-reaching liability shield for declining to honor decisions made pursuant to a supportive agreement unless the decline was fraud,

misrepresentation, reckless, or willful or wanton misconduct.²⁰ These provisions create more uncertainty about supported decisions than is likely to be the case about decisions made by persons acting without support. They thus may contribute to suspicions that these decisions are not quite to be trusted, without helping to provide substantive guidance about what might make these decisions trustworthy.

These legal structures are blunt instruments that are not well equipped to assess the quality of individual relationships. Nonetheless, some of these strategies are reasonable starting points for further development of what supported decision-making must do to elicit decisions that, as Jenny Hatch said, are “good.” At least, they may function in this way if they are seen as facilitative in the way that prostheses, relations, and social contexts function for others without cognitive impairments. Supported decision-making has only been recognized in the U.S. for six years; it will be important to collect data about the use of these devices and whether they are serving to enable and to protect in the non-discriminatory way envisioned by Article 12 of the CRPD.

Conclusion

Decision-making is complex for everyone. This is no less the case for persons with cognitive disabilities. In this article, I have sought to describe how, with supports, people with cognitive disabilities can negotiate apparent conflicts among experiences, interests, and values, along with concerns about safety. Supported decision-making statutes introduce a variety of safeguards, although it is by no means clear what their effects will be. What is clear is the importance of not moving too quickly to conclude that people with cognitive disabilities cannot decide their good and instead must be protected from themselves in circumstances in which such protection would not be judged appropriate for others.

ENDNOTES

- 1 Utah Code § 75-1-201(22).
- 2 Texas Estates Code § 1357.052(b), (c).
- 3 Indiana Code § 29-3-14-5(a)(1).
- 4 Alaska Stat. Ann. § 13-56-090.
- 5 Del. C. 16 §9402A(b)(4); Nev. Rev. Stat. Ann. § 162C.100(2)(d); RI Gen L § 42-66.13-2 (2019).
- 6 E.g., D.C. Stat. § 7-2132(b)(1)(B).
- 7 E.g., Texas Estates Code § 1357.102.

- 8 E.g., Texas Estates Code §1375.053.
- 9 Alaska Stat. Ann. §13.56.020(1); Del. Code 16 § 9406A(b)(1).
- 10 Del. Code 16 §9406A(b)(2). Alaska is to the same effect, but does allow payment just for the support, Alaska Stat. Ann. S 13.56.020(2).
- 11 Indiana Code § 29-3-14-5(c)(2).
- 12 E.g., D.C. Stat. §7-2132(a)(1), (2).
- 13 Wisc. Code §52.10(2).
- 14 E.g., Del. Code 16 §9406A(c)(2), (3); Wisc. Code §52.16(1); Alaska Stat. Ann. § 13.56.110(4).
- 15 Texas Estates Code §1357.101.
- 16 Del. Code 16 §9402A(a)(2).
- 17 Texas Estates Code § 1357.101.
- 18 Wisc. Code §52.30(4).
- 19 Del. C. 16 § 9408A(3). This provision is similar to, but possibly stronger than, the Delaware advance care directive statute, which provides exceptions for written policies of conscientious objection and for a directive that “requires medically ineffective treatment or health care contrary to generally accepted health-care standards applicable to the health-care provider or institution.” Del. Code 16 §2508(f).
- 20 IC § 29-3-14-11.

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