

PATERNALISM, SUPPORTED DECISION- MAKING, AND EXPRESSIVE RESPECT

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AMONG those who work in public policy to advance justice for people with cognitive disabilities, it is widely argued that supported decision-making must replace surrogate, or substituted, decision-making. From a legal perspective, surrogate decision-making is often decried as a human rights violation. From a moral perspective it is said to be an indefensible form of paternalism. Supported decision-making is the alternative that avoids these legal and moral failings.

In this paper, I will focus primarily on the anti-paternalistic argument in favor of supported decision-making. I will begin in section 1 by discussing recent debates within the paternalism literature to clarify the distinction between surrogate and supported decision-making, a distinction that is often underspecified or unclear in the legal, advocacy, and policy literature. I will rely on a distinction developed by Daniel Groll to argue that supported decision-making should be understood as treating the will of the agent as structurally decisive, whereas surrogate decision-making treats it, at best, as merely substantively decisive.¹ With the distinction between surrogate and supportive decision-making clarified, I will then turn directly to my main argument. At the heart of the rejection of surrogate decision-making is the belief that such paternalistic action *expresses* something fundamentally disrespectful about those upon whom it is imposed: that they are inferior, deficient, or childlike in some way. Contrary to this widespread belief, I will argue that surrogate decision-making often expresses more respect for people with lifelong, “severe” or “profound” cognitive disabilities than does the adoption of supported decision-making.² Specifically, in section 2 I argue that in some cases supported decision-making can arguably express that people with cognitive disabilities

1 Groll, “Paternalism, Respect, and the Will.”

2 The terms “severe cognitive disability” and “profound cognitive disability” are controversial and used very differently in different jurisdictions. There is no universal medical consensus on how they should be defined. There is certainly controversy in individual cases as to which category an individual may fit into. Rather than attempting to define

lack equal moral value. In section 3, I argue that supported decision-making for people with profound intellectual disabilities can arguably express that they lack complex and rich inner lives. In short, if our aim is to ensure our behavior and practices express respect for people with lifelong cognitive disabilities, then sometimes surrogate rather than supportive decision-making will be a much better option.

As this summary of my argument makes clear, I am concerned with the expressive dimensions of surrogate versus supportive decision-making. The expressive meaning of our actions (or omissions) matters, morally speaking. That view has had a profound influence on recent discussions of both paternalism and egalitarian political philosophy. For example, the recent focus on relational egalitarianism in political philosophy arose partly in response to the troubling expressive dimensions of more dominant distributive approaches to equality, particularly luck egalitarianism.³ One of the examples that Elizabeth Anderson famously used to illustrate these expressive concerns was the distribution of health care resources. She claimed that many luck egalitarians would distribute health care resources for paternalistic reasons. These reasons, she argued, fail to express respect for the so-called beneficiaries:

In adopting mandatory social insurance schemes for the reasons they offer, luck egalitarians are effectively telling citizens that they are too stupid to run their lives, so Big Brother will have to tell them what to do. It is hard to see how citizens could be expected to accept such reasoning and still retain their self-respect.⁴

Numerous philosophers working specifically on the issue of paternalism have recently developed arguments that resonate closely with these expressivist considerations. For example, Seana Shiffrin disputes that paternalism is about, or only about, an unjust interference with liberty. Rather, paternalism is characterized by the paternalistic motive: the distrust the paternalizer shows for the practical reasoning or will of the paternalized subject, and their belief about their own superior capacities in this regard.⁵ Paternalism, many now say, is first and foremost a failure of respect, specifically associated with how the paternalizer regards the paternalized subject as inferior or deficient in some regard, or can be arguably taken to express such an attitude.

the terms, my specific examples will make clear the nature and extent of the disabilities I discuss.

3 Anderson, "What Is the Point of Equality?"; Scheffler, "What Is Egalitarianism?"; and Wolff, "Fairness, Respect, and the Egalitarian Ethos."

4 Anderson, "What Is the Point of Equality?" 301.

5 Shiffrin, "Paternalism, Unconscionability Doctrine, and Accommodation."

The expressive meaning of our actions is also important in the sphere of disability, not least in the area of decision-making. This, of course, should surprise nobody: the disabled are a highly stigmatized social group and as such are routinely vulnerable to disrespectful behavior from others. Nevertheless, it will be argued in this paper that recent social and legal advocacy for people with cognitive disabilities has offered an oversimplified picture of how best to express respect for people with cognitive disabilities in the sphere of decision-making.

1. SURROGATE VERSUS SUPPORTED DECISION-MAKING

People with cognitive disabilities have historically been subject to paternalistic guardianship and surrogate decision-making. Recent legal and political developments have put increasing pressure on the acceptability of surrogate decision-making and have instead demanded that it be replaced with supported decision-making in most cases.⁶ Animating such demands are not only the great harms that have been inflicted on people through surrogate decision-making and guardianship arrangements, but also a rejection of the disrespect that is taken to be expressed by such arrangements—namely that some people have inherently deficient or inferior agential capacities.

Before being in a position to scrutinize such claims, it is necessary to get clearer about the exact difference between surrogate and supported decision-making. The distinction is not always as sharp as one might expect, for reasons I will explain in a moment. A discussion of some recent paternalism literature will enable me to clarify the core of the difference.

At its simplest, surrogate decision-making refers to a situation where a guardian is charged with making decisions for another person who is deemed to lack decision-making capacity. Within the policy-focused literature, different types of surrogate decision-making are usually distinguished from one another. Guardians can be legally charged with the responsibility to make decisions for another based either on best-interest standards or on the basis of what that person would have decided themselves (if they were not experiencing decision-making incapacity). I will say a little more about different types of surrogate decision-making in the next section, but the term refers to any situation whereby a guardian makes a decision for another who is deemed to lack decision-making capacity. In contrast, supported decision-making allows a person to make their own decisions. In recognition that some people may find making decisions more difficult, supported decision-making refers to various ways in

6 Cf. Bigby, Whiteside, and Douglas, "Providing Support for Decision Making to Adults with Intellectual Disability"; Kohn, "Legislating Supported Decision-Making"; and Series, "Relationships, Autonomy, and Legal Capacity."

which the decision-maker can be supported: for example, others can help them understand complex information, or their options, or the risks and benefits attached to various options, and so on. Depending on the disability, supported decision-making can also help a person articulate their decision.⁷ In short, the core distinction between surrogate and supported decision-making is that in one case a person does not get to make their own decisions and in the other case they do, albeit with some support.

While the distinction should be clear enough, in practice and advocacy it can get murky: often the issue of *who* makes decisions is conflated with other issues. For example, it is often assumed that supported decision-making respects the choices of individuals that surrogate decision-making fails to do, as evidenced by the central focus on “choice” in supported decision-making policy and academic literature.⁸ However, the issue of respecting a person’s choices is not the same as allowing her to be the decision-maker, as we shall see. Another common conflation occurs when it is claimed that supported versus surrogate decision-making is a difference between respecting choice as opposed to acting in a person’s best interests.⁹ But this obscures the fact that very often the best way to promote someone’s best interests is to respect their choices and preferences.¹⁰

A distinction developed by Daniel Groll allows us to more carefully home in on exactly what it means to be the decision-maker required by supported decision-making.¹¹ Groll’s distinction also allows us to disentangle what it means to respect the decision-making authority of a person from other issues with which it is often conflated, such as “respecting their choices.” A detour into the recent literature on paternalism leads us to Groll’s important distinction.

Paternalism has been most typically described as the interference in a person’s liberty for their own good.¹² More recently, some philosophers have cast doubt on this account of paternalism.¹³ One important reason is that there are common cases where a person is clearly subject to paternalism but does not

7 Further details of how supported decision-making can work in practice for even the most profoundly disabled are discussed in section 3 below.

8 Bigby, Whiteside, and Douglas, “Providing Support for Decision Making to Adults with Intellectual Disability”; and Office of the Public Advocate, “Supported Decision-Making in Victoria.”

9 Flynn and Arstein-Kerslake, “Legislating Personhood.”

10 Howard and Wendler, “Beyond Instrumental Value.”

11 Groll, “Paternalism, Respect, and the Will.”

12 Dworkin, “Paternalism.”

13 Begon, “Paternalism”; Groll, “Paternalism, Respect, and the Will”; and Shiffrin, “Paternalism, Unconscionability Doctrine, and Accommodation.”

have their liberty interfered with. For example, Shiffrin argues that paternalism can occur through omission, as when *A* refuses to help *B* build a bookcase because *A* believes *B* too often asks for help and would be better off developing their own confidence and carpentry skills by building the shelves on their own.¹⁴

Such cases have contributed to an alternative, motive-based account of paternalism. Motive-based accounts identify paternalism not in the act of interference as such, but in the motive of the paternalist.¹⁵ The paternalist, *A*, both distrusts the paternalized agent *B*'s judgment or will about her own good, and also believes that his own judgment is superior. Most of us share Shiffrin's view that there is a paternalistic motive at play in the bookcase example, even though *A* does not interfere with *B*'s liberty. Rather, what Shiffrin identifies as paternalistic is *A* substituting his judgment for *B*'s with respect to a sphere of decision-making that rightly belongs to *B*.

Exactly how to characterize the paternalistic motive is controversial. Shiffrin says *A*'s distrust of *B*'s judgment and a belief that his own is superior is paternalistic when it concerns matters legitimately within *B*'s control, whereas others count distrusting *B*'s judgment as specifically paternalistic when it concerns more narrowly a judgment about what is good for *B*.¹⁶ These differences are not of particular relevance to the arguments of this paper. What is directly relevant is that all such accounts believe that the paternalist expresses something fundamentally disrespectful and perhaps insulting about *B*. *A* expresses disrespectful attitudes when he treats his own judgment about what is good for *B* as superior to *B*'s own judgment on the matter—attitudes, for example, that *B* is deficient or childlike. The central objection to paternalism on motive-based accounts is based on the value we place on treating others with respect and expressing respectful attitudes in our behavior. Paternalism, it is said, is first and foremost a failure of respect.

Complicating matters, Groll argues that the paternalist motive can be present even when a paternalizer acts in accordance with the will of the paternalized subject, because the paternalized subject wills it. His central example concerns Bob, who needs a percutaneous endoscopic gastrostomy (PEG), a type of feeding tube, but refuses to have one inserted. Bob's decision-making capacity is not in doubt. Now imagine the surgeon takes it upon herself to decide what she ought to do. She weighs the fact that Bob might die without the PEG, but she also weighs Bob's sincerely avowed desire not to have one. Taking into account all of these factors, she decides that it would be bad for Bob to have the

14 Shiffrin, "Paternalism, Unconscionability Doctrine, and Accommodation," 2013.

15 Begon, "Paternalism."

16 Begon, "Paternalism."

PEG inserted as to do so against his wishes would cause far too much distress and anguish. So she tells Bob, "I have decided you won't have a PEG inserted because you don't want one." It certainly seems reasonable for Bob to be perturbed and indeed annoyed at this way of putting things. He is entitled to say to the surgeon, "What do you mean *you* have decided? It was not your decision to make!"¹⁷ According to Groll, the surgeon has acted on a paternalistic motive even though she does what Bob wants, and does it because he wants it.

Why is the surgeon acting on a paternalistic motive? Groll suggests that Bob's will should be authoritative, or what he calls "structurally decisive." What this means is that we should understand Bob as issuing something with the force of an order when he says he does not want a PEG. Here is how Groll puts it:

When Bob declares that he does not want surgery, his will is authoritative. This means that Bob, and in this case no one else, is the *de jure* ultimate decision maker in Bob's case. In other words, Bob's will grounds a legitimate demand that the surgery not be performed; he is effectively issuing an order that he not have the surgery, an order that only he is authorized to give. And it is in the conceptual nature of an order that it be treated as what I will call structurally decisive in determining what to do—it is meant to supplant the reason-giving force of other considerations not because it outweighs those other considerations but because it is *meant to silence, or exclude, those other considerations from the practical deliberations of the subject of the demand*, in this case Bob's doctor. . . . We can put this idea as follows: the force of the reason not to do the surgery that is grounded in Bob's demand is insensitive to considerations of Bob's good. . . . The normative force of Bob's demand is not properly assessed by determining what good (for Bob) comes from following it.¹⁸

Clearly the surgeon does not take Bob's wishes in the spirit of an order: rather, she weighs them highly, decisively so in the end, and decides to follow them because doing so is best for Bob. According to Groll, this is an instance of failing to respect Bob's will typical of the paternalistic motive we discussed earlier: the surgeon distrusts Bob's judgment about his own well-being and expresses this distrust when informing Bob that she has arrived at her own (superior) judgment about what is best for Bob, and decided accordingly.

Groll contrasts Bob's case with that of Carl. Carl also does not wish to have a PEG, but unlike Bob, Carl is deemed to lack medical decision-making capacity. The surgeon is aware that Carl's health will suffer seriously without a PEG

17 Groll, "Paternalism, Respect, and the Will," 707.

18 Groll, "Paternalism, Respect, and the Will," 700–701 (emphasis added).

but also that forcing an invasive medical procedure on Carl against his wishes can be extremely deleterious for his well-being. She also believes that though Carl lacks formal decision-making capacity, a good life for Carl includes the ability to direct his life according to his own wishes as far as possible. In the end, she decides that his overall well-being will be advanced by respecting his wishes. Even though Carl's wish not to have a PEG inserted is respected, his will is not treated as structurally decisive. While the surgeon takes into account Carl's wishes, they certainly do not silence other considerations concerning his well-being playing a part in her practical deliberations. Carl's will in this case is substantively decisive in the sense that his wishes end up carrying the most weight in the surgeon's deliberations. Groll argues that in this case there is nothing odd when she says to Carl, "I have decided not to give permission for the PEG because you don't want one."

The contrast between treating another's will as substantively versus structurally decisive allows us to home in more carefully on the distinction between surrogate and supported decision-making. It is clearly not helpful to contrast surrogate decision-making with respecting another's choices, because Carl's choices are respected even though he is subject to surrogate decision-making. *He* is not the decision-maker in this case, the surgeon is. Similarly, it is confusing to contrast respecting a person's choices with acting in their best interests, because the case of Carl demonstrates that we can respect a person's choices because it is in their best interests. Respecting a person's choices, in other words, can be done for paternalistic reasons. Carl's surgeon still exhibits a paternalistic motive. Her distrust of Carl's judgment and will drives the nature of her practical deliberations, and her belief that it is she, not Carl, who must be the ultimate decision-maker.

If the aim of supported decision-making is to avoid paternalism and the expression of disrespect it is said to entail, then supported decision-making is best understood as decision-making whereby the will of the subject is structurally decisive. Once a person has received sufficient support to make a decision, their decision should be treated as authoritative, as silencing others' practical deliberations about what they (those others) ought to decide. Those others have no decision to make. In contrast, surrogate decision-making refers to any situation where another person makes the decision for an individual: this can include surrogate decisions where the will of a person deemed to lack decision-making capacity is entirely discounted, but also those cases where it is treated as substantively decisive, as in Carl's case.

Within policy and legal literature, the archetype of "bad" surrogate decision-making occurs when the choices and preferences of the person subjected to guardianship are entirely ignored—they are not even consulted. In such

cases, it is presumed that a surrogate decision-maker can reach a judgment about the subject's best interests without taking into account their preferences and values.¹⁹ This is of course highly dubious in the majority of cases for a number of reasons, including those discussed by Groll: that very often what promotes a person's best interests is to respect their choices. Nevertheless, there is little doubt that historically this is precisely how surrogate decision-makers executed their role. To decide that a person lacked decision-making capacity was to assume their wishes lacked any kind of status or value. More recent "good" forms of surrogate decision-making—often referred to as substitute decision-making—explicitly direct surrogate decision-makers to make the decision the person would have made themselves had they not lacked capacity. For example, the UK Medical Capacity Act (2005) directs surrogate decision-makers to "encourage participation—do whatever's possible to permit or encourage the person to take part" and to "find out the person's views—including their past and present wishes and feelings, and any beliefs or values." The National Disability Insurance Scheme Act (2013) in Australia requires a guardian to "ascertain the wishes of the participant" in the insurance scheme even when they lack decision-making capacity. The recently updated Guardian and Administration Act (2019) in Victoria, Australia, directs surrogate decision-makers to "make a decision that gives all practicable and appropriate effect to the person's will and preferences, unless this would cause them serious harm." These examples are indicative of widespread changes from "bad" to "good" forms of surrogate decision-making that have occurred in countless jurisdictions.²⁰ For my purposes, however, they all count as forms of surrogate decision-making insofar as the person herself is not the decision-maker: her will is not treated as structurally decisive.

Groll assumes that it is appropriate that Carl is subject to surrogate decision-making given his cognitive disabilities.²¹ However, as I have indicated, such a view is no longer widely shared among disability scholars and advocates who call for the (near) abolition of all forms of surrogate decision-making in favor of supported decision-making. To a large extent, these claims are bolstered by the social model of disability that claims that much if not all of the incapacity associated with cognitive disability is due to incommensurable or

19 Flynn and Arstein-Kerslake, "Legislating Personhood"; and Howard and Wendler, "Beyond Instrumental Value."

20 Kohn, "Legislating Supported Decision-Making"; and Series, "Relationships, Autonomy, and Legal Capacity."

21 Howard and Wendler, "Beyond Instrumental Value."

unjust social arrangements.²² Within this framework, it is denied that there is a group of people who incorrigibly lack decision-making capacity. Rather it is believed that all (or very nearly all) people can achieve decision-making capacity and thus be accorded decision-making authority with the right kind of social accommodation—namely, decision-making support.²³ Those who advocate for supported decision-making for people like Carl do not imagine that we should assist Carl to work out and articulate his preferences in order that his guardian can make the decision that he would have made himself had he been able. The process of providing adequate support for Carl is to ensure that *he* can exercise his decision-making authority. So while “good” forms of surrogate decision-making may have been considered visionary only a decade or two ago, they too have been increasingly subject to criticism.²⁴

Supported decision-making has been given a considerable boost by recent developments in human rights law. While Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) might seem to suggest that people can lose the right to make their own decisions in extremely limited circumstances, the United Nations Committee on the Rights of Persons with Disabilities (2014) maintained in a General Comment that in fact Article 12 prohibits surrogate decision-making in favor of supported

22 Peterson et al., “Supported Decision Making with People at the Margins of Autonomy”; and Series, “Relationships, Autonomy, and Legal Capacity.”

23 Flynn and Arstein-Kerslake, “Legislating Personhood.”

24 Series, “Relationships, Autonomy, and Legal Capacity.” An anonymous reviewer raised the question as to how these recent legal, policy, and advocacy claims are related to the traditional philosophical distinction between “hard” and “soft” paternalism. In contrast to hard paternalism, soft paternalism does not interfere with choices that are fully autonomous, but only those choices that are not. It might be assumed that such interference does not express disrespect. I agree with others who argue that disrespect for people’s agential capacities is not confined to disrespect for their autonomy, and it is “agential capacities,” not “autonomy,” that I focus on in this paper: cf. Jaworska, “Respecting the Margins of Agency”; and Howard and Wendler, “Beyond Instrumental Value.” The large body of literature on supported decision-making also focuses on respect for agential capacities, and for good reason: whatever the merits of the philosophical distinction between soft and hard paternalism, as a matter of law, policy, and practice, “autonomy” is not the standard used for paternalistic interference. Indeed, interfering with choices that fail to meet any such high bar would, in practice, be considered quite offensive by most of us (Begon, “Paternalism”; Wall, “Self-Ownership and Paternalism”). In practice, as opposed to “ideal philosophy,” the focus has been on articulating much lower standards of “decision-making capacity.” Many defenders of supported decision-making simply deny that there is some group of people who incorrigibly lack all decision-making capacity (except perhaps those who are permanently unconscious). I certainly agree that we can express serious disrespect for the agential capacities of someone who is not fully autonomous, but in this paper I argue that both surrogate and supported decision-making can express such disrespect.

decision-making. Most disability scholars agree that the CRPD calls for the abolition of surrogate decision-making, even as some legal experts express skepticism about states' likely willingness to do this.²⁵ A number of scholars have argued that surrogate decision-making is a violation of human rights and the "backbone" or "lynchpin" in the restriction or loss of various other rights.²⁶

There are further reasons to be skeptical about the use and value of even "good" forms of surrogate decision-making, that is, surrogate decision-making that puts the will and preferences of the person concerned at the center. There can be no doubt that surrogate decision-making has been widely used where a person was in fact capable of making their own decisions, or would have been with appropriate support, including, not least, support for the development of agency at a young age. This has led not only to enormous frustration, but has robbed people of the opportunity to develop their agency, the exercise of which can boost self-esteem and the sense of personal well-being.²⁷ Surrogate decision-making has been regularly abused by surrogate decision-makers who misuse their power to promote their own interests as opposed to the interests, let alone the will, of the person they are supposed to be deciding for. Even when not intending to misuse their authority, surrogate decision-makers often fail to act in the interests of the person concerned, as their judgment is heavily clouded by their own interests, values, and beliefs.²⁸ Finally, the expressive dimension of denying an already highly stigmatized social group the right to make their own decisions about matters of personal and often intimate concern is thought to be morally troubling, to say the least. When such restrictions are enshrined in law and public policy the negative expressive force is arguably turbo charged.²⁹ It is these expressive concerns that are my focus in the rest of this paper. In contrast to prevailing opinion in disability scholarship and activism, I will argue in the next two sections that in some cases we can arguably express more disrespectful attitudes about people with severe, lifelong cognitive disabilities by adopting (or attempting to adopt) supported decision-making. I will argue that in some cases surrogate decision-making expresses more respect for people with severe or profound cognitive disabilities than does supported decision-making.

25 Series, "Relationships, Autonomy, and Legal Capacity."

26 Bach, "Inclusive Citizenship"; and Flynn and Arstein-Kerslake, "Legislating Personhood."

27 Bigby, Whiteside, and Douglas, "Providing Support for Decision Making to Adults with Intellectual Disability"; and Series, "Relationships, Autonomy, and Legal Capacity."

28 Bigby, Whiteside, and Douglas, "Providing Support for Decision Making to Adults with Intellectual Disability"; and Series, "Relationships, Autonomy, and Legal Capacity."

29 Anderson, "What Is the Point of Equality?"

2. EXPRESSIVELY DISRESPECTFUL SUPPORTED DECISION-
MAKING AND THE VALUE OF DISABLED LIVES

There are, of course, multiple ways in which we can express disrespect for others: expressing that others are deficient with respect to their agential capacities is but one domain. For example, Anne-Sofie Greisen Hojlund argues that sometimes avoiding paternalism conveys objectionable attitudes such as neglect and indifference, among other things.³⁰ Focusing on state action, she argues that the state can fail to treat its citizens as equals not only by failing to express that their agency is equally valuable to that of other citizens, but also by failing to express that their interests count equally. She invites us to see that standing idly by when a motorcyclist is about to careen down a steep and narrow road in rainy weather without a helmet “arguably conveys an attitude of indifference to their strong interests.”³¹ If this is so, then she argues we would need some way to weigh the objectionable expressive content of paternalistic action against the objectionable expressive content of non-paternalistic restraint, for which she offers a number of criteria.

Similarly, Viki Møller Lyngby Pedersen argues that sometimes people who avoid paternalism problematically express insouciance or indifference to the plight of others, which can also be a clear expression of disrespect for their equal status.³² She asks us to imagine Joe pranking Ben by telling him that he (Joe) will drink a cup of poison that will kill him. After discussion, Ben is satisfied that Joe is acting voluntarily so stands idly by while Joe drinks what Ben believes to be poison. Pedersen argues that Ben’s failure to save Joe is a morally dubious expression of insouciance or indifference to the plight of Joe. After having drunk the harmless substance Joe says “Come on Ben! Would you really let me do that?”³³ We can clearly make sense of Joe’s disappointment and his sense that Ben does not pay sufficient heed to the value of his life.

Neither Pedersen nor Hojlund argues that the morally troubling expressive meaning of avoiding paternalism always justifies acting paternalistically. They agree that paternalism can also involve expressing problematic attitudes about a person’s agency. Their main point is that both paternalism and refraining from paternalism can express problematic attitudes about others but that the literature on paternalism has exhibited a rather single-minded focus on the problematic expressive meaning of paternalistic behavior. Their position is

30 Hojlund, “What Should Egalitarian Policies Express?”

31 Hojlund, “What Should Egalitarian Policies Express?” 526.

32 Pedersen, “Respectful Paternalism.”

33 Pedersen, “Respectful Paternalism,” 430.

that there are a number of complex criteria that ultimately determine whether a paternalistic or non-paternalistic stance on each occasion expresses greater overall respect for the subject.

The arguments made by both Pedersen and Hojlund have particular force in cases of cognitive disability. I will develop this argument by discussing just one case with which I am familiar. Rose (name changed) was a fifty-year-old woman who developed severe lymphedema in her legs, making it difficult for her to walk and causing her serious pain. Rose was reluctant to seek medical attention, being terrified of doctors, although after receiving much support she agreed to do so. She was eventually diagnosed with lymphoma, a type of blood cancer. Rose refused any further medical treatment, even after a process of extensive support for her decision was provided. Numerous people close to Rose had conversations with her about the nature of her illness, what treatment would involve, and the consequences of not receiving such treatment. She remained resolute that she did not want treatment. When I spoke to Rose about her health, she told me that her legs were sore because every time she left the house people would shoot her in the legs. When I asked her if she would like to visit a doctor who could help her with the pain she told me adamantly that she did not like doctors and she just wanted people to stop shooting her in the legs. It was eventually decided by those involved with Rose's care that Rose had received extensive support for her decision and that it must be respected.³⁴ Rose eventually died from untreated lymphoma.³⁵

Did treating Rose's will as structurally decisive express sufficient respect for the value of her life or for her equal moral status? To clarify, I am not asking whether Rose's will should have been treated as substantively decisive, such that out of concern for her well-being her refusal of medical treatment should have been respected. I will return to that question shortly. At this point I am only focusing on the fact that surrogate decision-making was rejected in favor of treating Rose's will as structurally decisive. As Groll puts it, this silences or excludes considerations of Rose's good or well-being playing a role in the

34 Australia does not have formal or legislated supported decision-making, although, as noted above, much relevant legislation requires surrogate decision-makers to take into account or adhere to the will and preferences of the person. Most decision-making of this kind takes place on a very informal basis, between family and care providers. It is relatively rare for decision-making to be escalated to a formal authority and usually only happens when there is disagreement between informal parties. Rose's caregivers in this case believed they were morally and legally responsible for respecting Rose's will once she had been provided with extensive support.

35 Lest this be dismissed as a bad example of supported decision-making, Flynn and Arstein-Kerslake, proponents of supported decision-making, explicitly defend respecting the life-ending decision of a person in just such a case as this ("Legislating Personhood").

practical deliberation of others. I will argue that we have reasons to believe that morally troubling attitudes were expressed about the value of Rose's life when her will was treated as structurally decisive.

Rose quite clearly did not show a strong appreciation of some of the salient facts about her illness. She believed her pain was caused by being shot in the legs. I do not believe she understood what lymphoma is. She had only a limited capacity to grasp what treatment might involve, partly because of her overwhelming fear of doctors and hospitals. It was very questionable that Rose fully understood either that she would die without treatment or what it means to die. Having known Rose, I do not believe any level of support would have helped her resolve these deep misunderstandings. Let us contrast Rose to the case of Joe. The way Pedersen tells the story, Ben scrutinizes Joe's decision to drink the "poison." He asks Joe why he wants to do this, he checks and double checks that Joe understands that the poison will kill him and that Joe fully appreciates the finality of what this means. Once satisfied that Joe really does understand what he is doing and what the consequences will be, Ben refrains from intervening out of respect for Joe's agency. Despite this, we are invited to consider whether Ben expresses a morally troubling level of insouciance for Joe's moral worth when he refrains from swiping the cup from Joe's hand. If we feel the pull of this concern, then it is magnified in Rose's case where we have clear reasons to believe that she had an insufficient grasp of the facts that bore on her preferences. To conclude that respect requires that others exclude considerations of Rose's well-being from their practical deliberations seems to me to betray a paltry idea of what respect for Rose requires.

Agency is not the only thing that determines our worth or standing and how we should be valued by others. Agency is one dimension of persons that should be appropriately respected: so too should their lives, and their important interests. This point should be felt *forcefully* by those familiar with treatment of people with disabilities. It is not only the agency of people with disabilities that is undervalued or denied; so too are the full range of their interests and even their lives, especially so for those with cognitive disabilities. The evidence shows that people with cognitive disabilities are often stripped of the right to make decisions about highly personal and intimate matters that they would be perfectly capable of making with adequate support. Equally, the evidence also reveals high rates of medical neglect, failure of basic accommodations, failure to provide safe, high-quality housing, radical social exclusion, and so on.³⁶ Once we acknowledge that very basic interests of people with cognitive disabilities have been

36 Baladerian, "Sexual Abuse of People with Developmental Disabilities"; Horner-Johnson and Drum, "Prevalence of Maltreatment of People with Intellectual Disabilities"; Murphy and Bantry-White, "Behind Closed Doors"; and Troller et al., "Cause of Death

dismissed or discounted, including the interest in life itself, a single-minded focus on respect for agency is an oddly blinkered view about what we need to do to express fulsome respect for such people. Knowing as we do the history and ongoing contemporary evidence of the abuse and neglect of people with cognitive disabilities, it plausibly expresses morally troubling attitudes to treat their wills as structurally decisive when they make life-threatening choices, at least when their level of understanding remains very poor, despite extensive support. It is at least not implausible to suppose that such an anti-paternalist stance in Rose's case expresses morally troubling attitudes about the value of her life.

I will discuss two objections to my argument that treating Rose's will as structurally decisive expresses morally troubling attitudes about the value of her life. The first objection rejects the expressive meaning I attribute to treating Rose's will as structurally decisive, and the second turns on the supposed negative consequences of *failing* to treat Rose's will as structurally decisive.

First, a critic might deny the particular expressive meaning I attribute to treating Rose's will as structurally decisive. The people who decided that Rose's will should be treated as structurally decisive might claim they did so solely out of a strong conviction that respect for agency is of paramount importance and that they neither held nor intended to express any other attitudes, least of all about the lower value of Rose's life. Respect for Rose's agency, they might maintain, required of them that they excluded facts about Rose's well-being from their practical deliberations.

This response raises questions about how we determine the expressive meaning of people's actions or omissions, for which I will offer two brief suggestions.

1. The expressive meaning of our actions is not determined solely by the attitudes we sincerely avow or intend to express.³⁷ People can act on attitudes that they are not even aware that they have as the wealth of discussion on cognitive processes like implicit bias and stereotype threat have shown. To deny this is to assert that a person's actions cannot reasonably be read as expressing his problematic attitudes about race just because he sincerely believes he holds no such attitudes, or that his actions cannot reasonably be read as expressing problematic attitudes about women just because he sincerely believes he has no sexist attitudes. To the contrary, people of good will who are open to their own fallibility are aware that it is sometimes our very actions (or omissions) that should alert us to the possibility that we *do* hold morally troubling attitudes

and Potentially Avoidable Deaths in Australian Adults with Intellectual Disability Using Retrospective Linked Data."

37 Anderson and Pildes, "Expressive Theories of Law," 1513.

despite our sincerely held values. In light of the overwhelming evidence of how people with disabilities are treated in our society, it is more plausible than not to suggest that morally troubling attitudes about the value of the lives of people with severe cognitive disabilities are widespread. As such, it is not implausible to suggest that such attitudes are held and expressed by those who treat Rose's will as structurally decisive despite the extensive evidence of her limited levels of understanding. In any case, it is certainly not convincing to assert that no such attitudes are held or expressed just because the persons involved sincerely disavow that they hold such attitudes.

2. My second brief suggestion is to go further and deny that the meaning of a person's actions is solely determined by their attitudes (whether they are conscious of them or not). Here I follow Anderson and Richard Pildes, who assert that actions have public meanings.³⁸ Those who act in a certain way may not understand the public meaning of what they do, as when I hold up my middle finger to the face of another person believing that I am offering praise. This is a common enough occurrence when we are in an unfamiliar cultural environment. Indeed, Anderson and Pildes argue that the public meaning of an action is often not even determined by shared understandings of what it means. They offer the example of men complimenting women on their appearance in the workplace. Not long ago, few people recognized treating women as sexual or aesthetic adornments in the workplace as insulting.³⁹ But despite this meaning of the practice not being widely shared, that is indeed what it meant. The meaning of any action, according to Anderson and Pildes, is partly determined by how it "fits" with other practices and norms in the community: "Although these meanings do not actually have to be recognized by the community, they have to be recognizable by it, if people were to exercise enough interpretive self-scrutiny . . . a proposed interpretation must make sense in light of the community's other practices, its history and shared meanings."⁴⁰ What they convincingly suggest is that had the community engaged in interpretive self-scrutiny at the time they may have noticed that the practice contradicted norms of professional conduct among men, and also the various ways it slotted into the gendered hierarchy of labor, traditions of excluding women from positions of responsibility, and so on.⁴¹

In light of our community's other practices, our history and shared meanings around disability, treating the wills of people with severe cognitive

38 Anderson and Pildes, "Expressive Theories of Law."

39 Anderson and Pildes, "Expressive Theories of Law," 1525.

40 Anderson and Pildes, "Expressive Theories of Law," 1525

41 Anderson and Pildes, "Expressive Theories of Law," 1525.

disabilities as structurally decisive in life-threatening situations despite their clearly limited levels of understanding can be plausibly said to express troubling attitudes about the value of their lives and the weight we give to their pressing interests. Given the widespread disregard we have always shown toward the lives, well-being, safety, comfort, and security of people with cognitive disabilities, the meaning of treating their wills as structurally decisive in the face of life-threatening behavior can express troubling attitudes about the worth and value of their lives, even if some individuals who choose to treat such a person's will as structurally decisive hold no such attitudes.

A second objection to my argument that treating Rose's will as structurally decisive expresses morally troubling attitudes focuses on the purported negative consequences for Rose if we fail to treat her will as structurally decisive. Namely, it might be thought to follow from my argument that we should impose treatment on Rose against her will. That would be no small thing. Supposing that nothing we could do for Rose would resolve her terror of doctors and hospitals, that would likely subject her to distress. Moreover, the treatment for blood cancers is grueling by anyone's standards, involving months if not years of chemotherapy, radiation therapy, and sometimes surgeries. So apart from her terror, Rose would have to endure extensive physical, emotional, and social burdens. To inflict these on a person against her will seems unconscionable, even if we are right that her will is based on a serious misunderstanding of the basic facts. Am I really suggesting that forcing such treatment on Rose expresses greater respect for her than "respecting her wishes"?

I am suggesting no such thing. And talk of "respecting her wishes" is misleading. My concern about treating Rose's will as structurally decisive is based on the morally problematic meaning that is thereby expressed, not on the fact that she is allowed to die. It is based on the fact that treating Rose's will as structurally decisive is to ignore facts about her well-being for the purposes of our practical deliberation. As a *surrogate decision-maker* I might also "respect her wishes" and decide she should be allowed to die. It may well be that given Rose's intransigence, subjecting her to invasive chemical and radiation treatment would cause her intolerable levels of distress. Out of concern for her well-being I might decide to respect her wishes not to receive medical treatment. Considerations about her well-being, in other words, lie at the heart of my practical deliberations as a surrogate decision-maker. I would acknowledge that a tragic choice has to be made here: between taking action that fully respects the value of Rose's life on the one hand, and avoiding inflicting intolerable distress on her on the other. That is an honest appraisal of the nature of the tragic decisions that surrogate decision-makers must sometimes face. We express respect for Rose by acknowledging that we cannot act to preserve her valuable life without

causing her unacceptable levels of distress. What does strike me as disrespectful is to deny that such tragic choices exist by conceiving of our duties to respect Rose as being exhausted by treating her will as structurally decisive, so long as we have provided her with extensive support for her decision, and irrespective of how much basic misunderstanding she continues to display.⁴² Ignoring, or indeed refusing, to consider the well-being of a person in our practical deliberations when she remains deeply confused about matters of a life-threatening nature because of a cognitive disability is not a victory for expressive respect. As I have argued in this section, it is more plausible to suggest that it expresses morally problematic attitudes about the value of her life or her basic interests.

3. EXPRESSIVELY DISRESPECTFUL SUPPORTED DECISION-MAKING AND THE RICH INNER LIVES OF PEOPLE WITH COGNITIVE DISABILITIES

Rose was able to clearly articulate her preferences and more generally engage in fluent conversation with others. Some people with what are dubbed “profound” cognitive disabilities are not able to speak and apparently have very limited capacity to process language or to reason in ways we are familiar with. When people have lived their whole lives with such disabilities, we have little evidence that they are likely to have the complex beliefs and values that other people do, including people with less serious cognitive disabilities. How is supported decision-making supposed to work for them?

Supported decision-making, or something close to it, is possible for people with lifelong profound cognitive disabilities. Language is obviously not the only way that people can communicate with one another. All of us communicate extensively with gestures and sounds. Someone attentive to the communicative modes of a person who is nonverbal can often understand their wishes with respect to things like what they like to eat, whom they do and do not like living with, what activities they do and do not enjoy, which support workers they feel comfortable with and which they do not, and so on. With respect to most of these matters it should often be possible to treat the will of the person concerned as in some sense structurally decisive. If the person communicates that they do not enjoy a certain kind of food or certain music then in most situations the music should be changed and alternative food offered. Of course, such options will sometimes be more difficult when people live with others. The

42 I suspect that many proponents of supported decision-making within disability activism believe that a person provided with high-quality support will not continue to hold false beliefs or deep misunderstandings. Of course, quality support for decision-making will help eliminate misunderstandings. But to suppose that support can always do this betrays a naive view about severe intellectual disability (or just human nature more generally!).

point is that, insofar as these sorts of complications are not relevant, the wishes of the person concerned can and often should be treated as structurally decisive.

However, the range of matters that impinge on the lives of all people, including those with profound cognitive disabilities, is extremely wide. It includes not only matters about what we like to eat, what music we like to listen to, whom we want to spend time with, and so on, but also includes what religious practices, if any, we might engage in, how finances should be managed, whether to undertake grueling medical treatment, and so on. Like anyone else, a person with lifelong profound cognitive disabilities confronts many complex matters that can involve quite dramatic risks and benefits, yet it may not be clear how we could come to know their will. A parent might deny her son a COVID vaccination on the grounds that, according to her, he does not believe in vaccination; a Jehovah's Witness might declare that her daughter does not want a blood transfusion; yet another denies that her son wants a PEG inserted because of his love of food, even though it leaves staff at his residential facility having to call an ambulance on a regular basis when he experiences life-threatening choking episodes.

The obvious question is: How can a person claim to know the will of the subject in these cases? We cannot even consider the possibility of treating the will of the person as structurally decisive without first having grounds to be confident that we know what their will is.

I admit that I am skeptical about our ability to know what a person's will is in many such cases, partly because I am skeptical about the capacity of a person with lifelong, profound cognitive disabilities to develop a will in complex cases of this kind. But these skeptical concerns are not my focus here. Rather, I will discuss a number of concerning moral consequences of trying to apply supported decision-making in such cases, including the unacceptable expressive dimensions that arise when we display too much confidence in our ability to know the will of people with profound disabilities. I develop these criticisms by discussing an account of supported decision-making articulated by Leslie Frances and Anita Silvers.⁴³ Other defenders of supported decision-making for people with lifelong, profound cognitive disabilities have gestured at how the process could work: for example, Eilionóir Flynn and Anna Arstein-Kerslake suggest that the facilitator's role is to "imagine" what the person's will and preferences might be.⁴⁴ Silvers and Frances are alone in offering a detailed and

43 Frances and Silvers, "Liberalism and Individually Scripted Ideas of the Good"; and Silvers and Frances, "Thinking about the Good."

44 Flynn and Arstein-Kerslake, "Legislating Personhood," 95.

rigorous account of how the process of support for decision-making should work for people with lifelong, profound cognitive disabilities.

Silvers and Frances develop their view in the context of criticizing liberal political theory. While endorsing liberalism's commitment to diverse individual conceptions of the good life, they criticize what they take to be a widespread assumption that each individual must develop her conception of the good independently of others. They argue that we should accept not only diversity with respect to conceptions of the good, but diversity in the process by which different individuals arrive at their conception of the good. As they put it, there should be tolerance not only about the substance of the good, but also about how it is formed. Liberalism, they claim, fails with respect to the latter because it demands that the "proper process for arriving at and articulating the good specifies that individuals make determinations of their good on their own."⁴⁵ This, they argue, necessarily leads to the exclusion of people who are heavily reliant on others for formulating and articulating a conception of the good.

How then do people with profound cognitive disabilities form a conception of the good? According to Silvers and Frances they can do so by deploying a prosthetic reasoner, whom they call a trustee. As they put it:

We envision the trustee does not step into the subject's role in shaping a personalized notion of the good. Instead, as a prosthetic arm or leg executes some of the functions of a missing fleshly one without being confused with or supplanting the usual fleshly limb, so, we propose, a trustee's reasoning and communicating can execute *part or all* of a subject's own thinking processes without substituting the trustee's own idea as if it were the subject's own.⁴⁶

Silvers and Frances are clear that they see trustees as facilitating a conception of the good for even the most profoundly disabled people, hence the explicit reference to a trustee possibly executing *all* of a person's reasoning processes.⁴⁷ They say that people who cannot use language and who we have good reason to suppose are incapable of most conceptualizations and reasoning can use a trustee as a prosthetic in this way. Appealing to ideas of relational autonomy, they argue that using a trustee to execute the subject's reasoning and communication is just a matter, to a more extensive degree, of the ways all of us rely on interactions with others to develop our conceptions of the good. Or as they

45 Silvers and Frances, "Thinking about the Good," 477.

46 Silvers and Frances, "Thinking about the Good," 485 (emphasis added).

47 Perhaps they would exclude people thought to be "brain dead" or who show no demonstrable brain activity.

put it, “this prosthetic practice differs in extent and implementation, but not in nature, from commonplace social interactions that facilitate people’s development of their notions of the good.”⁴⁸

Much of what Silvers and Frances say about prosthetic reasoning is at a very high level of abstraction, as these quotes suggest. What does it consist in, exactly? I take it that they are not suggesting that trusteeship involves merely being responsive to a person’s unique way of communicating, and translating such communication into a form that others can also understand. If that is all they mean, then talk of a prosthesis seems entirely out of place. None of this common practice requires a prosthesis to *execute all of the reasoning and communicating* of the person—it does not require a prosthesis at all. It requires only the existence of others with a close relationship with the subject, who understand her way of communicating, and who have a deep commitment to ensuring her will is acted upon. This is a commonplace activity in high-quality relationships with people with profound cognitive disabilities.

Therefore, I assume Silvers and Frances have something more ambitious in mind: that the prosthesis’s unique role will be to execute the reasoning of the subject in forming a broader conception of the good, one that reaches beyond that much more limited range of matters that the person has clear preferences with respect to and can communicate herself (to those who understand her). One possibility here is prosthetic reasoning as a kind of *extrapolation*: that the trustee reasons on behalf of a person that because he has a great love of food, he rejects a PEG, or because he dislikes needles, he rejects medical treatment. Yet it is clear that these conclusions cannot be straightforwardly extrapolated from a person’s limited preferences about food and needles. I too love food and hate needles; nevertheless, when push comes to shove, I would almost certainly reevaluate or just dig deeper into aspects of my conception of the good to accommodate my changed circumstances. Similarly, Silvers and Frances make some rather oblique references to the connection between conceptions of the good and social scripts.⁴⁹ It is true that chunks of our conception of the good come from the social roles we inhabit: parent, teacher, Muslim, and so on. But very few of these social roles will be so tightly scripted so as to dictate clear answers to many of the quandaries that frequently arise in our lives, including the lives of people with profound cognitive disabilities, such as whether to accept a PEG. Moreover, the law and morality do not typically permit us to impose life-threatening or even life-changing aspects of social scripts onto people unless they have endorsed them, or at the very least not rejected them:

48 Silvers and Frances, “Thinking about the Good,” 495.

49 Frances and Silvers, “Liberalism and Individually Scripted Ideas of the Good.”

Jehovah's Witness parents do not have authority to deny their young child a blood transfusion, nor do members of religious groups have authority to marry off their young daughters. In cases such as these, we will have no evidence whatsoever as to whether a person with profound disabilities has endorsed, or merely rejected, such aspects that others claim are part of their socially scripted good.

What else, then, might prosthetic reasoning consist in, if not merely attending to what the person communicates about her likes and aversions, or straightforward extrapolation from such? It seems as though we are being invited to take a leap of faith: to accept that the reasoning conducted by the prosthesis on these complex issues is really the subject's own. It will involve sensitivity to the expressed wishes of the subject, and a degree of obvious extrapolation, but will clearly involve much more as well. We should accept that the "much more" really is the subject's own, when the reasoning is conducted by a diligent trustee. It is this ambitious idea that seems to make the most sense of the idea of a "prosthesis."⁵⁰

There are skeptical questions to raise here, clearly. As others have commented, prosthetic limbs do not have minds of their own, a key difference that raises genuine concerns about how someone executing all of the reasoning for another can exclude her own reasoning from the process, or even distinguish between her reasoning and the subject's.⁵¹

I want to sidestep these skeptical questions in order to home in on moral, rather than epistemic, concerns. For the sake of argument let us take the leap of faith and accept that a diligent trustee *can* execute the functions of another person's mind as deeply as prosthetic reasoning seems to entail. Would it be morally acceptable to do so? Most of us would forcefully reject someone presuming to take on such a role with respect to our own minds. Indeed, we very actively limit others' access to our minds. A degree of opacity, concealing large swathes of our inner lives, seems to be a basic need. Many of our desires, values, preferences, hopes, fears, and passions remain private, or are revealed only to some, when we deem it appropriate or desirable to do so. Moreover, when we do reveal information about our preferences and values, we do so with a degree of authorial control: we tend to carefully curate the way we present information

50 In a recent article, Leslie Frances uses multiple examples of prosthetic tools and "guardrails" that do not seem to have much relevance to people with profound cognitive disabilities, which is our focus here. She offers examples of text reminders, automatic bill payments, automatic delays for large expenditures, the use of financial advisors, and so on. The cases Frances discusses where these prostheses and guardrails can be deployed only reasonably concern people with less severe cognitive disabilities actively wanting to manage their own financial affairs, albeit with some support ("Supported Decision-Making").

51 Series, "Relationships, Autonomy, and Legal Capacity."

about our inner lives, for example by presenting a particular narrative about the origin or reason for some of our desires and values. None of us wants to be fully laid bare and it is highly unlikely our sense of dignity and self-worth would survive such exposure.

Does the ambitious idea of prosthetic reasoning as envisaged by Silvers and Frances appropriately respect the importance of opacity? It does not seem to. Someone able to execute all of the reasoning for another subject must be presumed to have very deep access to the subject's mind: it is not even clear whether on their account there are distinct minds to talk of. In any case, I assume they hold that such extensive prosthetic reasoning must be deeply informed by knowledge of the subject's desires, preferences, values, fears, and pleasures. The subject seems to have lost opacity altogether on this account.

Apart from the subject's dignity, there are other reasons to value opacity that are connected to vulnerability, and some of these reasons apply just as much to people with profound cognitive disabilities as to other people. We are vulnerable to anyone who is confident that they have unfettered access to our minds such that they can execute its functions. In such circumstances, the threat of inappropriate behavior if not outright abuse looms. If we imagine a case where the subject later experiences an improvement in her cognitive abilities it would be incoherent for her to claim that the decision made earlier was not her own, or even one she did not endorse.⁵²

These moral concerns about the idea of prosthetic reasoning are turbo charged by noting the subject's lack of control and authorization over "their" prosthesis. The runner exerts control over her prosthetic leg in a manner that is clearly disanalogous to the control a profoundly disabled person exercises over "their" prosthetic reasoner.⁵³ There is an obvious sense in which the runner authorizes the prosthetic limb to execute the function of running: she chooses to fix it on before she runs the race. How does the profoundly cognitively disabled person authorize or reject "their" prosthetic? What are the grounds on which we can be confident that her authorization has been provided?⁵⁴ It may

52 Series, "Relationships, Autonomy, and Legal Capacity." Indeed, a number of legal commentators have recently argued that supported decision-making can and has been misused in ways that bear striking similarity to the more familiar abuses of surrogate decision-making, and that there are aspects of various legal regimes that lend support to this problem (see Kohn, "Legislating Supported Decision-Making")

53 Wasserman and McMahan, "Cognitive Surrogacy, Assisted Participation, and Moral Status."

54 It is worth pointing out here that virtually all proponents of supported decision-making explicitly require that the person relying on the support selects and authorizes a support person or persons: cf. Bach, "Inclusive Citizenship"; Flynn and Arstein-Kerslake, "Legislating Personhood"; and Series "Relationships, Autonomy and Legal Capacity." This

be that in some cases she can clearly express her rejection of a prosthetic reasoner and communicator by expressing distress or rejection when the prosthetic attempts to engage with her. But presumably in more cases than not the person may express very little in this respect, so the question remains: What is our evidence that the person has authorized this prosthesis to access and execute the functions of her mind? When a full prosthetic reasoner takes on this role, with little to no evidence that the person controls or authorizes the process, then the attitudes being expressed about that person are troubling: that her authorization and control is not required before he, the trustee, presumes to enter her mind and execute its functions. It bears repeating: those of us without profound cognitive disabilities would never accept another person adopting such a role with respect to our own minds.

While these concerns are important, I think there is something more directly troubling with the idea of prosthetic reasoning. Up until this point, I have assumed for the sake of argument that a person *can* access another's mind to the extent that prosthetic reasoning seems to presuppose. But this assumption itself raises serious moral questions. Imagine a person, Ken, who takes it upon himself to speak for his partner whenever he can. In a range of professional, health, and social settings, he confidently tells others what her preferences and values are and therefore what she would like to be done as it concerns her own good or well-being. I suggest our indignation at Ken's behavior is not exhausted by the fact that he violates her privacy with respect to her own mind and renders her vulnerable to any misuse of the role he has taken upon himself to play. In addition, I would suggest that we might take offense at Ken's very assumption that he has the level of access to her mind that he claims to. Specifically, Ken seems to express morally troubling attitudes that his partner lacks a deeply rich and complex inner life that, by its nature, would render his access to it extremely limited. We might say that Ken fails to respect his partner as a separate person. I mean this not in the sense that Rawls did—namely, as a criticism of utilitarianism for trading off some individuals for the overall good—but rather, the sense in which Ken fails to appreciate his partner as a separate person refers to his failure to appreciate that she has a rich and complex mental life that is barely accessible to him. What access he does have should always be tempered by a respectful acknowledgement of how incomplete it is, and how any beliefs he has about her will are likely to be partial and often just wrong. Without this recognition and acknowledgement on Ken's part, why need he bother to wait for his partner to speak for herself? There may well

of course just raises the question of how this is to be secured in the case of people with lifelong, profound cognitive disabilities. There is little consistency on this point in the legal and policy literature on supported decision-making.

be reasons to do so, but that she knows her own mind far better than he could ever hope to would not be one of them.

I believe that the idea of prosthetic reasoning for people with profound cognitive disabilities fails to express appreciation for the subject as a separate person, one with a rich and complex inner life that is not simply there for a diligent trustee to access so as to execute its various functions. We express respect for other persons when we acknowledge this, and thereby concede that we have at best very limited access to their inner lives. Such epistemic humility directly expresses our appreciation for the rich and complex inner lives of people with profound cognitive disabilities despite their cognitive limitations, and an acknowledgement that they share this feature with all others. As such, their inner lives are no more accessible to us than Ken's partner's is to him.

It is important to labor this point because this is exactly the kind of respect that is all too often denied to people with profound cognitive disabilities, who are typically assumed to be simpletons with very little in the way of a complex inner life. I do not deny that people with profound cognitive disabilities almost certainly lack some of the complex cognitive capacities that people without such disabilities possess. Despite this, I think it is both false and pernicious to assume that they do not possess a very rich and complex range of likes and aversions, thoughts and perceptions, fears and comforts, that we can at best only guess at in many cases. Not all of these facts about a person's inner life will be easy to discern; some may be expressed very little, or in ways that circumvent even our best efforts to understand.

Silvers and Frances might object that on their view there is no reason a prosthetic reasoner cannot declare that in some situations they are unable to execute all of the reasoning for the subject. To make sense of this claim we would need to hear much more from them as to what grounds the prosthesis would have for making this claim, grounds that do not cast doubt on the whole idea of prosthetic reasoning. It cannot simply be on the basis that the subject does not express any likes or aversions on the matter at hand. I have already stated that a subject who *does* express likes and aversions toward some matter does not need a prosthetic reasoner, just someone who knows him well, including his mode of expressing his will, and who is committed to ensuring his wishes determine what happens to him. Nor will a simple process of extrapolating from expressed preferences be sufficient to answer many pressing questions we have about the person's preferences or values with respect to the complex matters that frequently arise in the lives of people with profound cognitive disabilities. Prosthetic reasoning—executing the reasoning for another with respect to her conception of the good—only seems to have a unique role to play where the subject appears unable to have preferences or values on the matter at hand or

is unable to communicate them. And where this is so, it remains mysterious on what grounds a prosthesis may claim serious limits to their ability to execute the reasoning of another without casting the whole notion of prosthetic reasoning into serious doubt.

One can speculate whether an assumption is being made that the complex mental functions of a person with profound cognitive disability can be executed by a diligent trustee because their inner life is at least to some extent a simulacrum of the inner life of the trustee. Think of a more familiar type of behavior, that of a person who believes she can execute and interpret her dog's cognitive processes because she assumes that to a large extent they match her own inner life. This is a very human-centric approach to how we might think of discerning the wills of animals, and it would certainly seem deeply human-centric to suppose we could execute their reasoning processes on their behalf. Not for a moment do I suppose the inner lives of people with profound cognitive disabilities are like those of dogs: they surely would not be, given their human embodiment and active participation in distinctly human practices and human forms of life. Nevertheless, one can query whether there is an "ableist-centric" approach to decision-making embedded within the idea of prosthetic reasoning—namely, that one can access the mind of another person and execute all of their reasoning because it is just like one's own mind, more or less. This, I argue, pays far too little heed to the facts of opacity and fails to express respect for the complex and somewhat ineffable inner lives of others, including those with profound cognitive disability.

Silvers and Frances might object that opacity affects surrogate decision-making as much as it does supported decision-making. If respect requires that we acknowledge that others have rich and complex inner lives to which we only have limited access, does this not also affect a surrogate decision-maker in the execution of their role, and limit what they can claim to know about another person's complex conception of the good?

There are certainly limits to what a surrogate decision-maker can know. But in contrast to prosthetic reasoning, there is nothing within the description and ambition of surrogate decision-making itself that necessarily suggests otherwise. The surrogate decision-maker can decide that they are unable to draw a clear determination as to what the subject really wants, or would want, and thereby revert to other ways of making a decision, including by reference to the person's best interests or well-being. Consider the case of Steve (name changed). Steve has a profound intellectual disability and a range of complex physical disabilities. He is also blind. Steve's greatest joy is food and eating. Despite ongoing attempts to engage him in other activities, Steve shows little active interest in anything other than eating. Unfortunately, he is progressively

losing the ability to swallow and is frequently experiencing life-threatening choking episodes. His doctor states that he must take nutrition through a PEG. This will likely prevent Steve from choking to death and ensure he receives adequate nutrition but will also deprive him of the one thing we are confident gives him great pleasure. Unlike Silvers and Frances, I do not believe that we can come to know much about Steve's conception of the good in this case, that is, whether he would value ongoing life more than the joy of eating and thus choose the PEG. I think it would also be deeply presumptuous to declare that the reasoning of the prosthesis (whom Steve may not have chosen or have any control over) has arrived at "his" (Steve's) decision. Rather, as a surrogate decision-maker for Steve I would explicitly state something like the following:

I am unable to draw any clear conclusions as to what Steve wants or values in this case. He does not appear to express anything on the matter, or what he does express does not lend itself to any clear interpretation. Therefore, we must try to work out what is in Steve's best interests, taking into account all those things about Steve that we do know more about, including his preferences and aversions. But we will never be completely sure that what we end up deciding is the right decision for Steve, or what he would have decided himself if he could.

In explaining their decision in this fashion, the surrogate decision-maker explicitly acknowledges the reality and importance of mental opacity and expresses appreciation for the complexity and ineffability of Steve's mental life. In contrast, supported decision-making for people like Steve assumes that a diligent trustee can come to know his will, or simply execute his reasoning for him, which can then be treated as structurally decisive. I have argued that this assumption rests on morally dubious attitudes about the nature of Steve's inner life and of the kind of relationship others may adopt toward it.

4. CONCLUSION

Replacing legal regimes and practices of surrogate decision-making with supported decision-making is a focus of considerable aspiration among disability advocates and legal scholars worldwide. The arguments of this paper add a philosophical and moral dimension to the cautionary concerns that some legal scholars have expressed about extending supported decision-making beyond where it has real value.⁵⁵ None of these authors, including me, are calling for a

55 Kohn, "Legislating Supported Decision-Making"; and Series, "Relationships, Autonomy, and Legal Capacity."

wholesale retention of surrogate decision-making. I accept that most people with cognitive disability would be capable of making most of their own decisions if appropriate supports were provided and initiated early in life. Supported decision-making in these cases not only respects the rights and interests of people with cognitive disabilities, but also expresses appropriate respect for them as agents. Nevertheless, I have argued that in some cases of severe or profound disability, practices of supported decision-making can express disrespect for people with cognitive disabilities in a number of distinct ways. In some cases surrogate, rather than supported, decision-making will express more respectful attitudes toward this highly vulnerable and stigmatized group of people.⁵⁶

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REFERENCES

- Anderson, Elizabeth. "What Is the Point of Equality?" *Ethics* 109, no. 2 (January 1999): 287–337.
- Anderson, Elizabeth, and Richard Pildes. "Expressive Theories of Law: A General Restatement." *University of Pennsylvania Law Review* 148, no. 5 (2000): 1504–75.
- Bach, Michael. "Inclusive Citizenship: Refusing the Construction of 'Cognitive Foreigners' in Neo-liberal Times." *Research and Practice in Intellectual and Developmental Disabilities* 4, no. 1 (2017): 4–25.
- Baladerian, Nora J. "Sexual Abuse of People with Developmental Disabilities." *Sexuality and Disability* 9, no. 4 (December 1991): 323–35.
- Begon, Jessica. "Paternalism." *Analysis* 76, no. 3 (July 2016): 355–73.
- Bigby, Christine, Mary Whiteside, and Jacinta Douglas. "Providing Support for Decision Making to Adults with Intellectual Disability: Perspectives of Family Members and Workers in Disability Support Services." *Journal of Intellectual and Developmental Disability* 44, no. 4 (2019): 396–409.
- Dworkin, Gerald. "Paternalism." *Stanford Encyclopedia of Philosophy* (Fall 2020). <https://plato.stanford.edu/archives/fall2020/entries/paternalism>.

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- Flynn, Eilionoir, and Anna Arstein-Kerslake. "Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity." *International Journal of Law in Context* 10, no. 1 (March 2014): 82–104.
- Frances, Leslie. "Supported Decision-Making: The CRPD, Non-discrimination, and Strategies for Recognizing Persons' Choices about Their Good." *Journal of Philosophy and Disability* 1 (2021): 57–77.
- Frances, Leslie, and Anita Silvers. "Liberalism and Individually Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency." *Social Theory and Practice* 33, no. 2 (April 2007): 311–34.
- Groll, Daniel. "Paternalism, Respect, and the Will." *Ethics* 122, no. 4 (July 2012): 692–720.
- Hojlund, Anne-Sofie Greisen. "What Should Egalitarian Policies Express? The Case of Paternalism." *Journal of Political Philosophy* 29, no. 4 (December 2021): 519–38.
- Horner-Johnson, Willi, and Charles E. Drum. "Prevalence of Maltreatment of People with Intellectual Disabilities: A Review of Recently Published Research." *Developmental Disabilities Research Reviews* 12, no. 1 (January/February 2006): 57–69.
- Howard, Dana, and David Wendler. "Beyond Instrumental Value: Respecting the Will of Others and Deciding on Their Behalf." In *Oxford Handbook of Philosophy and Disability*, edited by Adam Cureton and David T. Wasserman, 522–40. Oxford: Oxford University Press, 2020.
- Jaworska, Agnieszka. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value." *Philosophy and Public Affairs* 28, no. 2 (Spring 1999): 105–38.
- Kohn, Nina. "Legislating Supported Decision-Making." *Harvard Journal on Legislation* 58, no. 2 (2021): 313–56.
- Murphy, Kieran, and Eleanor Bantry-White. "Behind Closed Doors: Human Rights in Residential Care for People with an Intellectual Disability in Ireland." *Disability and Society* 36, no. 5 (2021): 750–71.
- Office of the Public Advocate (State of Victoria). *Supported Decision-Making in Victoria*. Melbourne, Australia, October 2020. https://www.publicadvocate.vic.gov.au/joomlatools-files/docman-files/general/Supported_Decision_Making_in_Victoria.pdf.
- Pedersen, Viki Møller Lyngby. "Respectful Paternalism." *Law and Philosophy* 40, no. 4 (August 2021): 419–42.
- Peterson, Andrew, Jason Karlawish, and Emily Largent. "Supported Decision Making with People at the Margins of Autonomy." *American Journal of Bioethics* 21, no. 11 (2021): 4–18.
- Scheffler, Samuel. "What Is Egalitarianism?" *Philosophy and Public Affairs* 31,

- no. 1 (Winter 2003): 5–39.
- Series, Lucy. “Relationships, Autonomy, and Legal Capacity: Mental Capacity and Support Paradigms.” *International Journal of Law and Psychiatry* 40 (May–June 2015): 80–91.
- Shiffrin, Seana. “Paternalism, Unconscionability Doctrine, and Accommodation.” *Philosophy and Public Affairs* 29, no. 3 (Summer 2000): 205–50.
- Silvers, Anita, and Leslie Pickering Francis. “Thinking about the Good: Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities.” *Metaphilosophy* 40, nos. 3–4 (July 2009): 475–98.
- Troller, Julien, Preeyaporn Srasuebku, Han Xu, and Sophie Howlett. “Cause of Death and Potentially Avoidable Deaths in Australian Adults with Intellectual Disability Using Retrospective Linked Data.” *BMJ Open* 7, no. 2 (2017): 1–9.
- United Nations. Convention on the Rights of Persons with Disabilities. 2515 UNTS 3. Adopted December 13, 2006; entered into force May 3, 2008.
- United Nations Committee on the Rights of Persons with Disabilities. General Comment No. 1, Article 12: Equal Recognition before the Law, 2014.
- Wall, Steven. “Self-Ownership and Paternalism.” *Journal of Political Philosophy* 17, no. 4 (2009): 399–417.
- Wasserman, David, and Jeff McMahan. “Cognitive Surrogacy, Assisted Participation, and Moral Status.” In *Medicine and Social Justice: Essays on the Distribution of Health Care*, 2nd ed., edited by Rosamond Rhodes, Margaret Battin, and Anita Silvers, 325–33. New York: Oxford University Press, 2012.
- Wolff, Jonathan. “Fairness, Respect, and the Egalitarian Ethos.” *Philosophy and Public Affairs* 27, no. 2 (Spring 1998): 97–122.