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Disability, Self-Representation, and Care: Nothing about Us without Us

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Abstract

In this paper, I examine the implications that the often-used slogan of disability rights, “Nothing about us without us,” has for our understanding of disability identity. I argue that externally labeling a person as disabled violates the principle of self-representation that is at the core of commitment to disability justice. But this concept of self-representation is complicated when we consider those deemed disabled who are incapable of communicating or perhaps even forming a disability identity. With these individuals in mind, I ask, How can self-representation be violated when a person is incapable of forming their own identity? What if external labeling is necessary for caregivers to provide care to their charges? In raising these questions, I seek to highlight how cases of noncommunicative individuals challenge us to rearticulate the meaning of self-identification and recognize the injustice of violating it, even when other obligations to them demand that we do so.

Keywords: disability studies, care ethics, disability identity, self-representation

1. Introduction

Self-representation is a central demand of the disability rights movement. The slogan “Nothing about us without us” has been meant to combat a history of marginalization and denied agency (Charlton 1998, 1). The movement’s commitment to the value of self-representation has implications for how we understand the very concept of disability identity. Externally labeling someone as disabled is not only an injustice; it stands in conflict with many of the core beliefs of those who are committed to disability justice. When considering this implication in relation to the fact that institutional labels are often required for the purpose of acquiring resources for those deemed disabled, a puzzle appears. Caregivers of disabled people are often put in a position where they must either impose an external label on the individual they are representing or fail to secure the basic resources that the individual needs. In this difficult situation, we must recognize the necessity of externally labeling individuals as disabled as an injustice—even if a necessary injustice—rather than seeing these coercive institutional norms as evidence of a person’s identity. The

principle of self-representation is important even when unjust circumstances force us to violate it.

This idea of self-representation becomes complicated when we consider individuals whose conditions make cognition and/or communication difficult or even outright impossible. Eva Kittay notes that demanding to have one's voice heard is simply not a reality for individuals with certain cognitive conditions. This is an important difference among individuals that get grouped together under the label of "disabled." Those who are unable to communicate or have severe cognitive conditions are far less likely to be represented or even taken into consideration by groups that advocate for disability rights because those groups are dominated by those who believe in self-advocacy (Kittay 2019, 7). It is for this reason that it is important to discuss the nature of disability identity and the ethical implications it has for individuals whose lack of communicative capacities has often left them overlooked in conversations about disability. The issue of communicative capacity also runs the risk of complicating the explanation of why external labeling is problematic in the first place. If labeling is problematic because it prevents individuals from conceiving and expressing their own identity and having that identity recognized, then it might seem that it would be permissible to externally label individuals who are incapable of their own expression of identity. This paper in part represents a response to this concern and attempts to clarify exactly how we can articulate an objection to labeling someone who appears incapable of forming their own identity.

2. Kittay's Care Ethics

Eva Kittay's account of care ethics in *Learning from My Daughter* is a useful starting point for the task at hand. To begin, it is important to discuss what I understand to be some of Kittay's underlying motivations in developing an ethics of care that is specifically attentive to those who are deemed cognitively disabled. She rightly points out that care is necessitated by the inevitability of biological limitations. She calls this reality the "register of inevitable human dependency" (Kittay 2019, 147). This is important because dependency is heavily stigmatized and often thought to be something that should be eliminated whenever possible. Kittay points to Romney's "47%" comment during the 2016 US presidential election as an example of this. Romney was filmed saying,

There are 47% of the people who will vote for the president no matter what . . . who are dependent upon government, who believe that they are victims. . . . These are people who pay no income tax. . . . And so my job is not to worry about those people. I'll never convince them that they should take personal responsibility and care for their lives. (quoted in Christoffersen 2012)

However, this notion that dependency is an intrinsically undesirable state that we should always seek to avoid is, as Kittay points out, clearly flawed. Not only is dependency inevitable, because we will all, at one point, be in a state of reliance on someone else, but valuable aspects of human culture and social life are only possible because we are necessarily dependent on each other. As Kittay (2019, 145) wittily notes, if we are to criticize the existence of modern social services and our dependency on them, we might as well criticize our dependency on oxygen.

Despite the persuasiveness of this response, there are more salient concerns about the notion of dependency, specifically in the context of disability. In many ways, the issue of self-representation, which I take to be core to the disability rights movement, can be articulated in terms of dependency. Those who are deemed disabled are often forced into states of extreme dependency because of the various ways society can be materially inaccessible. As Mike Oliver (1989, 8) argues, “The creation of dependency amongst disabled people is an inevitable consequence of the social policies that prevail in all modern industrial societies.” We can see why this would be a concern as it pertains to the voicelessness and powerlessness that those deemed disabled often experience. Anita Silvers claims that relationships of care further the marginalization of the individual who is made dependent on the other:

Far from vanquishing patriarchal systems, substituting the ethics of caring for the ethics of equality threatens an even more oppressive paternalism. We can grasp this by noting that helping relationships are voluntary, but asymmetrically so. Help-givers choose how they are willing to help, but help-takers cannot choose how they will be helped, for in choosing to reject proffered help one withdraws oneself from being helped, as well as from being in a helping relationship. To relate to others primarily by being helped by them, then, implies subordinating one's choices to one's caretakers, at least insofar as one remains in the state of being helped. (Silvers 1995, 40–41)

What we can surmise here is that because those deemed disabled are put in a situation where they are dependent on other individuals or institutions, they must accept whatever terms under which that help is offered. Susan Wendell offers a useful example regarding Deaf communities and their culture. Many Deaf individuals do not consider themselves disabled, but because medical and government authorities require them to be recognized as such, they are forced to defer to the label of disabled. This asymmetrical distribution of social power between the Deaf community and government institutions shows precisely the risk that dependency might create (Wendell 1996, 29).

I take these concerns about dependency to be well founded, but given that I also accept Kittay's idea that there is an inevitable condition of dependency, it becomes necessary to do what Kittay (2019, 162) calls "managing dependency," as people do when they recognize that they will inevitably have to rely on others in certain cases (some people more than others, depending on one's circumstances). Kittay gives the example of elderly individuals who accept help for tasks that they can accomplish on their own (but with great effort) because they wish to reserve energy for more meaningful tasks. She goes on to comment, "In the name of managing dependency, we can reorder our priorities and assert entitlements to care and support that are our due, not because in that way we can be independent and productive, but because our value derives from the chain of dependent relations that make all our lives possible" (Kittay 2019, 162).

How does one incorporate this need to manage dependency into an ethics of care? Kittay does so by defending what she calls the "completion of care." Care is often spoken of descriptively, counting an act as a form of "care" without any evaluative implications about the act; in a descriptive account of care, there is no implication that an act of care has succeeded at anything. Kittay instead conceptualizes care as a normative concept. To make this distinction, she examines the common phrase "caring too much." This is often used to describe a person who is so overly attentive that their actions become irritating and undesired. She then compares this to a normative concept such as justice. It would be strange for us to say that something is *too* just—that if there is an excess of justice, then it is not really justice at all. This is because justice can be an intrinsically positive good. Kittay argues we should think of care precisely in this way. If someone is "caring too much" to the point where the care is unwanted, then they are not actually caring in the first place. CARE, capitalized to distinguish itself from the descriptive concept, is a virtuous act that can only be completed if one's acts are taken as CARE by the recipient (Kittay 2019, 184). Here, Kittay challenges the idea that to be a recipient of care is to be passive and uninvolved in the process of caring (186). This notion, and even expectation, of passivity is precisely what puts those deemed disabled at risk of being marginalized and deprived of agency. Kittay argues that a necessary component of care is for the carer to be responsive to the "genuine needs and legitimate wants" of those they are caring for (174).

The requirement that care must be taken up as such is what enables Kittay's ethics of care to respond to concerns over dependency and its consequences for those deemed disabled. When disabled people's desires and values are disregarded, or not even considered, in the process of care, it is not actually care. Or in Kittay's terms, it is not an act of CARE. It is in fact a failure to care because those attempting care did not "take up the cares of people with disabilities, as the disabled understand them" (Kittay 2019, 157).

3. Disability Identity and Care

Here, however, is where the process of externally labeling someone as disabled come into tension with Kittay's view of CARE. To think of someone as disabled is to already presume some aspect of who they are. "Disability" is a term that is laden with historical and social context, much of which is unfortunately negative. Because disability has a negative connotation (the prefix "dis" has a morphologically negative meaning), being labeled "disabled" often results in normative assumptions being made about an individual. Imagine If I was describing an individual to you, and the only detail I provided is that they are disabled. What is this supposed to communicate to you? It does not inform you of any specific physical or mental conditions they might have, nor does it indicate what kind of accommodation or help the individual may need in a specific scenario. The only thing that this label seems to appeal to is a collective normative notion of what being "disabled" is like. Although this may be true of most, if not all, labels that we could imagine,¹ it becomes a particular problem as it relates to disability. This is the case, first, because the term "disability" bears a negative meaning and status. Rather than being potentially illuminating or offering relevant details about a person's life, disability as a label often only serves to indicate some kind of inferiority. Secondly, a disability label risks obscuring and marginalizing other aspects of a person's life and identity. Everett Cherrington Hughes (1945, 357) coined the term "master status" to refer to a trait or group membership that overpowers any other potentially relevant characteristic. While Hughes's original use of the term was describing race as a master status, the concept has been applied to disability as well (Omansky Gordon and Rosenblum 2001; Couser 2005; Kornasky 1996; Barnartt 2013). The disability label risks erasing every other aspect of a person's identity. Many people, including myself, have grown up knowing what it feels like to be thought of as the "disabled kid." Under this circumstance, regardless of what one might choose for oneself, disability becomes one's entire identity and shapes many, if not all, of one's social interactions.

Kittay herself clearly recognizes the potential concern about labeling others as disabled when early in her book she states, "To do justice to Sesha, I first need to introduce her. But I have already done her an injustice. I have introduced her as my disabled daughter" (Kittay 2019, 6). She continues by commenting that the way she would prefer to introduce Sesha is with a focus on her many positive attributes such as her smile and her love of music. Although we should not concede that disability is an intrinsically negative quality, at least in most cases, Kittay shows awareness of the

¹ Does this require us to reject all labels, such as *college student* or *immigrant*? While I think it might be the case that all external labels are unfitting, there can be external reasons that can justify using the label. I think it is the burden of those who wish to use the label to explain what would be lost without it.

fact that a disability label can come to consume and erase all other parts of an individual's identity or personality. While Kittay does not specify exactly what the nature of this injustice is, I argue it is strongly connected to how the disability label affects the way individuals are perceived by others. As Kittay (2019, 174) articulates about carers, "Self-reflection allows them to consider how their own desires might continue to obstruct their ability to be attentive and responsive to the other."

It is an injustice to identify Sesha as disabled because, by doing so, one is placing onto her an external label that is outside her own conception of self (Buttgereit 2022, 175). Kittay's descriptions of Sesha and her relationship to rationality and thought imply that we have no reason to believe that she has any formulated sense of self, and even if she has, she does not have a way to communicate such a sense to anyone. Therefore, much like the medicalized individual model of disability, the term "disabled" serves to mark people such as Sesha as passive recipients of judgements and values. This becomes especially concerning when we consider how precarious and harmful similar impositions of a notion of a good life have been for disabled people (Kittay 2019, 28). Allison Kafer (2013) offers a powerful example of how a grim and pessimistic future was imposed on her by doctors after she was injured in a house fire. As Kafer puts it:

In 1995, six months after the fire, my doctor suggested that my thoughts of graduate school were premature, if not misguided. He felt that I would need to spend the next three or four years living at home, under my parents' care, and only then would it be appropriate to think about starting school. His tone made it clear, however, that he thought graduate school would remain out of reach; it was simply not in my future (Kafer 2013, 4).

If we are to respect the value of self-representation, then we must accept the possibility that some individuals simply do not have a self-conception of their disability status. How is it then that we can justify the process of externally labeling an individual as disabled? It does not seem immediately apparent that we can justify it in terms of their physical or medical care, as specific diagnoses such as cerebral palsy, multiple sclerosis, and so on are more effective at illuminating what care an individual needs. It is also not clear that this labeling comes from a need for identity, because without the ability to form their own opinions and views of themselves, these individuals seemingly have no direct need for such a label as disabled. People like Sesha seem to be flourishing without such a self-conception. This leads me to believe that when we label someone who is noncommunicative with a cognitive medical condition as disabled, we are imposing our own sense of their life onto them. This is especially true in the cases of individuals who cannot communicate. Some may

respond to this concern about labeling by arguing that individuals can simply reject the label if it feels inappropriate for their identity. In fact, Dana Dunn and Erin Andrews (2015) have suggested that the best and easiest way to navigate labels regarding disability is to ask the individual their preference. But this solution becomes increasingly complicated when we consider someone like Sesha. She is incapable of communicating a preference, and one may also reasonably assume that she cannot form a preference. So, while the idea of seeking out preferences is good advice, if it is our only response to the issue, then we risk further marginalizing those for whom identity formation and the expression of preferences is not a possibility.

Another concern must be raised when we consider individuals who lack the ability to form or communicate a sense of identity. If I am correct that some people are capable of flourishing without any sense of identity at all, then imposing an identity is an act of disregard for their wants and needs. If someone like Sesha is incapable of caring one way or another about a disability identity, then we fail to care by imposing a label of “disabled” on to her. Kittay (2019, chap. 9) herself deals with a similar problem when she considers the case of Ashley X. Ashley X was a child who, due to her cognitive and physical condition, had many of her reproductive organs removed to make it easier for her parents to care for her. Kittay argues that this represents a failure to care but runs into a similar issue regarding Ashley’s own views on bodily integrity. She ultimately argues that this line of thinking potentially risks marginalizing and further discriminating against those with cognitive “disabilities.” She states, “If it is wrong to a person who does know the difference, that is, if it is justified in this case only because these people do not know the difference anyway, then . . . it is a wrong—whether or not a person is aware of what has been done to them” (Kittay 2019, 242). Added to this is the uncertainty that surrounds our ability to know if Ashley X or Sesha do have views on their own identity. Finally, as I have suggested above, the concept of disability itself is laden with judgements about an individual’s capabilities and their well-being. The types of futures available to them and our expectations for them are shaped and even warped by the assumptions that the disability label itself carries.

4. Speaking for Others

Although Kittay recognizes the injustice of introducing Sesha as disabled, she also offers a basis for the defense of the practice. As I mentioned in the introduction to this paper, self-representation is far from a simple and achievable ideal for many individuals deemed disabled. Speaking for others becomes necessary, and often desirable, when an individual is incapable of doing so for themselves. For this paper, let us imagine a very realistic situation in which a guardian or caregiver may label the individual that they are caring for as disabled. As mentioned before with the case of the Deaf, many aspects of government legislation such as the Americans with

Disabilities Act or the Social Security Disability Insurance program require that an applicant or beneficiary be recognized as disabled. This is a case in which one has good reason to label the person as disabled—which in practice means one will also tend to *think* of them as disabled—because doing so will grant access to resources and benefits that will make it easier to meet the person’s needs.

This response is compelling on the surface. It gives us reason to think that not only do we not fail to care when labeling someone as disabled, but doing so might be necessary for care to succeed. But this argument makes a mistake of conflating having a pragmatic reason to believe someone is disabled and the right kind of reason to do so.² The difference between these types of reasons can be seen, in an example used by D’Arms and Jacobson (2023, 781), by examining the reasons we might have to laugh at a joke. We may not want to laugh at a joke that we find to be insensitive due to timing or circumstance, or we may not want to laugh because others around us may react negatively to our doing so. D’Arms and Jacobson, however, argue that these are precisely the types of considerations that are irrelevant to the question of whether the joke itself is funny. I think the strength of this argument can be made even clearer if we consider the situation in reverse. Imagine a situation where you laugh at a joke you normally would not laugh at, with the intention of impressing or endearing yourself to the person who told it. The fact that you laughed is not evidence itself that the joke is funny, because the joke’s being funny was not the reason that you laughed. D’Arms and Jacobson (2023, 781) refer to this as the “conflation problem” because it makes pragmatic/moral reasons for feeling an emotion indistinguishable from reasons that bear on the emotion’s appropriateness.³ Not wanting to appear insensitive is a good reason not to laugh at a joke, but it is a mistake to conflate it with a reason for concluding that the joke is not funny.

Now we can begin to apply this concept to the issue at hand. I believe the conflation problem is relevant to the caregiver’s labeling of the individual for whom they are caring. A caregiver claims that they have a reason to call the individual they are caring for disabled, that reason being that they must do so for the individual for whom they are caring to be properly recognized by the relevant government officials. This is likely a good reason to do so, but it is not the right kind of reason for concluding

² Wlodek Rabinowicz and Toni Rønnow-Rasmussen (2004, 391) note that there is an influential view that states that for something to be valuable means that it is fitting to be an object of a pro-attitude: “If it is fitting to favor an object for its own sake, then, on this view, the object has final value, that is, it is valuable for its own sake. If it is fitting to have a pro-attitude toward an object for the sake of its effects, then its value is instrumental. And so on.”

³ Rabinowicz and Rønnow-Rasmussen (2004, 393) identify a similar phenomenon, which they call the “wrong kind of reasons” problem.

that the cared for individual is disabled. It is not a consideration that is relevant to the question of whether it is *fitting* to label them—and think of them—as such.

What does it mean then to have the right kind of reason? Pamela Hieronymi (2019, 37) notes that a reason is typically, though misleadingly, defined as “a consideration that counts in favor of an action or attitude.” In the case of disability identity, the fact that a caregiver can get the necessary medication or accommodations for the person they are caring for seems to count as a reason to believe an individual to be disabled because it is a consideration that counts in favor of an attitude—in this case, belief in them being disabled. But Hieronymi argues against this definition of a reason and seeks to show that it invites a conflation of different kinds of reasons. She argues alternatively that we should understand a reason as “a consideration that bears on a question” (Hieronymi, 2019, 38).

Hieronymi (2019, 35) asks us to imagine a butler who is accused of murder. You have been threatened with harm if you do not convince others that the butler is guilty, even though you do not believe them to be so. Now you have an external reason to believe the butler is guilty, and in fact, it is possibly a persuasive external reason. This is because it would be easier to convince others of their guilt if you yourself believed it. However, this is the wrong type of reason in favor of holding the attitude of belief because the fact that you are being threatened into believing the butler’s guilt does not bear on the question of whether they are guilty. Here, Hieronymi (2019, 35) distinguishes between a constitutive and an extrinsic reason. A constitutive reason is a consideration that bears constitutively on the question of an attitude, which in the butler case, is belief. By settling the question based on a constitutive reason, one thereby forms the attitude. It is the process of forming an attitude about something (such as belief in the butler’s guilt) that reveals what it is that matters to us. Extrinsic reasons bear on a different question that is separate from your initial belief. Rather than answer the question “Is the butler guilty?” extrinsic reasons offer an answer to the question of whether it would be good for one to believe that the butler is guilty (Hieronymi 2019, 35). You are better off believing that the butler is guilty because that will help you convince others. Turning to the case of disability, a caregiver may have an extrinsic reason to believe the person they are caring for is disabled, but the conflation problem occurs when we mistake the question of “is someone disabled?” with whether it would be good to believe they are disabled.

Ultimately then, the caregiver is right that institutional norms and expectations may produce a reason for them to think of the person they are caring for as disabled. However, these norms and expectations do not bear on the question of whether they really are disabled, which—given the value of self-representation—only they can determine. While the label may be necessary to care for them in one respect, it does not eradicate the injustice of externally placing an identity onto them.

5. CARES Coming into Conflict

The aim of acquiring government benefits by labeling someone “disabled” when they do not identify as such is the wrong kind of reason for believing them to be disabled. Insofar as a caregiver does not recognize it as a wrong kind of reason and thus *does* in fact believe the individual they are caring for to be disabled, they are exhibiting a failure to properly care. Even the caregiver who does recognize the problem with conflating different kinds of reasons can respond by saying that external circumstances force them to make the decision to label as disabled the person for whom they are caring. This creates a conflict between the identity (or lack of identity) of the cared-for and the accessibility of the resources necessary to provide for their other needs and wants when the government is demanding that an individual be recognized as disabled to receive accommodations or access to financial benefits. The result is that successfully caring in one respect necessitates failing to care in another. I am deeply sympathetic to this response and, in fact, believe that it highlights something important. Here, I must make clear that I am not suggesting that caregivers should forgo labeling the individual they are caring for to garner resources. However, I want to resist the idea that the fact that a caregiver still has a reason to label the person they are caring for serves as a justification for labeling them. To label the cared-for individual as disabled to get resources would be a failure to care just as denying them resources to avoid labeling them would be.

One might object that this is overly demanding and harsh toward a caregiver. How can we say that this would constitute a failure on the part of a caregiver when they are doing everything that they can to respond to the CARES of the individual they are attempting to care for? Kittay herself gives us the basis for understanding how an act can simultaneously succeed in caring in one way and fail in another. She argues that it is important to see the role that moral luck plays in the actual success of care. Moral luck refers to the fact that the moral warrant, or worth, of our actions can depend greatly on factors that are completely outside of our control (Kittay 2019, 213). We can see the role moral luck might play in terms of whether one’s actions will be taken up as CARE and thus complete the caring process. Imagine a parent who works extremely hard to care for their child and provide them with all the opportunities in life they might desire. The child may prove ungrateful and even resentful of their parents’ genuine effort. On Kittay’s account, this ultimately results in the act of care being unsuccessful. Care can also prove unsuccessful when certain background conditions that are necessary for care are absent. Kittay offers numerous examples of this, such as a parent who is impoverished and unable to feed their child or a nurse who is blocked from successfully executing their responsibilities to their patient by bureaucratic red tape (Kittay 2019, 169). Nirmala Erevelles (2012) adds that, in the case of nurses, care can be disrupted through the imposition of ableist

norms and assumptions onto patients; this serves as another example of how care is vulnerable to societal factors.

I argue that it is best to view this case of failure through the lens of a tragic dilemma. In *Moral Failure: On the Impossible Demands of Morality*, Lisa Tessman (2014) argues that there can exist impossible moral obligations. As moral agents, we can be placed into situations where we are required to do things that cannot be done without engendering moral failure. This creates a tragic dilemma in which either choice involves the sacrifice of something of incommensurable value (Tessman 2014, 39). Values are incommensurable when what is gained does not compensate for what is lost; choosing cake rather than cookies is not tragic because most people find them commensurable. A standard example of a tragic dilemma is taken from the novel *Sophie's Choice* (Styron 1976), in which a mother is forced by a Nazi soldier to choose which of her children to keep and which to hand over to him (Tessman 2014, 170). Regardless of what the mother chooses, the failure to protect one of her children understandably leaves behind a sense of moral failure. She was unable to protect and care for one of her children, and the sacrifice of this child cannot be made up for by the fact that she attempted to save the other child or the possibility that she made the “right” choice. For Tessman and other theorists sympathetic to the possibility of tragic dilemmas (Harris 2006; Nussbaum 2000; Stocker 1990; Williams 1981), dilemmatic choices further involve “moral remainders”—that is, moral wrongness that cannot be canceled even if one obligation is correctly judged to override the other.

Returning to the case at hand, where a caregiver is faced with the choice of labeling their charge as disabled or depriving them of financial or institutional benefits, we may naturally be tempted to think in terms of what they *should* do in this situation. This question of what should be done is what Martha Nussbaum refers to as, “the obvious question.” She writes, “The tragic question registers not the difficulty of solving the obvious question but a distinct difficulty: the fact that all the possible answers to the obvious question, including the best one, are bad, involving serious moral wrongdoing. In that sense, there is no ‘right answer’” (Nussbaum 2000, 1007). Tragic framing focuses less on concerns about whether a person should take the action and more on assessing the moral status of the action. Viewing this dilemma through the tragic frame, we can see that a wrong action remains wrong, even when the action must be done.

The value of this tragic view of care, and of Kittay’s discussion of moral luck, is that it allows us to focus less on blaming those attempting to care for others and, instead, focus on the unjust conditions that can prevent care from being successful. Kittay (2019, 215) herself notes that “it is often injustice and callous disregard for marginalized people” that makes it so that genuine attempts at care are unsuccessful. For Kittay, this is precisely why we must recognize that social and institutional

conditions can be such that caring for someone in one way unjustly forces one to fail to care for them in another way (215).

In “The Aptness of Anger,” Amia Srinivasan (2018) argues that the anger that one feels toward injustice is not rendered inapt (unfitting) even if the anger is ultimately counterproductive in terms of alleviating the injustice that produced the anger in the first place. She therefore rejects what she labels as “the counterproductivity critique” as a reason to dismiss the anger that racial minorities express in the face of injustice (Srinivasan 2018, 125). She recognizes that the counterproductive nature of anger might often override the reasons of fit that one has for expressing one’s anger, but in that situation, the inability to express one’s righteous anger must be recognized as a loss. In the case of anger, an oppressed racial minority might adopt an unfitting lack of anger in order to avoid political consequences, but that choice does not imply that outrage would have been an unfitting response to racial injustice. Similarly, a person deemed “disabled” might accept the label, not because it is a fitting expression of their identity, but because the government has provided them with an external reason to accept it—namely, access to resources and accommodations. Srinivasan rightly points out that having to face this forced choice between reasons of fit and practical considerations is, itself, an injustice. Regarding anger, those who are already marginalized face the problematic choice “between improving one’s lot and justified rage” (Srinivasan 2018, 136). In the case of disability, a caregiver of someone like Sesha is forced to choose between imposing on the cared-for an identity that is necessarily unfitting (because the cared-for cannot endorse any identity at all and so cannot be said to have any fitting identity) and sacrificing access to necessary resources.

This analysis of forced choice provides a clear avenue to respond to the caregiver’s criticism that they must label their charge as disabled. We can concede that the need to provide an individual with necessary resources can override the obligation to not impose an identity on them, but we must recognize that imposition as an injustice.

6. Self-Representation as a Negative Right

This paper has argued that the imposition of an external label of “disabled” onto others is not only an injustice but a violation. For most people who are deemed disabled, the notion of self-identification appears simple. As I mention earlier in this paper, many often default to a policy that entails asking if a person identifies as disabled. But this immediately raises difficulties for someone like Sesha, who would be unable answer that question. This presents a potential challenge for the principle of self-representation that disability justice calls for. Does holding up the importance of self-representation risk overfocusing on those deemed disabled who can communicate with others? If so, I believe that would be an unacceptable result; but I

argue we can, and must, redefine self-representation so it can better include the experiences of all people that are deemed disabled.

First, I want to examine a potential solution to this problem that I wish to reject. Some have responded to the challenge posed by certain cognitive conditions' impact on the ability to communicate by attempting to expand what is taken to count as communication. The most well-known and controversial example of this is the practice of facilitated communication. This practice involves a person, typically someone who cannot speak verbally or through any kind of sign language, pointing to images, letters, or objects presented through a communication board, with physical support coming from another person known as the "facilitator." The idea is that someone with limited cognitive or physical abilities can still communicate desires or thoughts with physical aid. But this practice has empirically produced very little evidence of accuracy in communicating the "disabled" person's desires and risks harmful consequences such as sexual abuse or exploitation on claims that consent was given (Hemsley et al. 2018).

Although not necessarily advocating for facilitated communication, Stacy Clifford Simpican (2015) has argued that what counts as political participation is fundamentally tied to ableist assumptions and beliefs about what proper communication and activism looks like. She argues we must interpret the everyday acts of those deemed disabled differently, in a way that recognizes their political potential. She shares an experience of being profoundly disappointed when first encountering a disability-based self-advocacy group (Simpican 2015, 1). She spent much of the night speaking to Charles, an individual deemed disabled, and she was disappointed that what seemed to count for political discussion was talk of the food at the event and how much soda Charles had drunk. She also remarks on being puzzled by a story that seemed to amount to a tale about a day when Charles did little else but get a good amount of sleep (1–2). However, upon reflection, Simpican concludes that this was in fact the result of ableist anxieties that we commonly have over what political speech is supposed to look like (2). She argues that, to counter these ableist assumptions, we must re-signify self-advocates' actions and come to understand them as representing political speech (5). As she states:

Although I failed to recognize it at the time, Charles was telling me a story about freedom. It took me over a year to understand the political significance behind his boasts about how many cups of Coke he drank, and another three years before I understood the import of his story about sleep. . . . I began to see an alternative account of political participation in the combined public presence of nondisabled staff members and people with intellectual and developmental disabilities. Even people with profound intellectual disabilities—that small class of

people who even the most ardent theorists of disability rights claim can only be served by surrogates—offer us ways to rethink democracy. (Simplican 2015, 6)

While I am troubled by the exclusion of those deemed disabled from political participation, the solution Simplican proposes is concerning. The suggestion that we should conceive of Charles's story as a "story about freedom" suggests placing a good deal of external meaning on his words. Yes, we can interpret his boasting about how much he ate and drank at the conference as an expression of being pleased about the autonomy he had in that moment, but we can just as easily justify interpreting it as him just enjoying his meal. While I agree with Simplican when she argues that the presence of those deemed disabled in a room can change the nature of a conversation, I am not sure that justifies the practice of reading political intent into actions and statements that are not obviously political. As Eva Kittay (2019, 7) suggests, we risk engaging in a form of ventriloquism where we are simply reading into their words and actions what we wish to be present. I think practices such as facilitated communication and liberal interpretations of everyday acts express a sort of discomfort with the idea of nonexpression. Namely, I think that they fail to recognize the difference between exclusion from social acts and nonparticipation. While it is often the case that nonparticipation is the result of exclusion, it is wrong to assume that is always the case. It is a mistake to try to replace a practice of excluding participation in such things as political advocacy or social identity with the idea that these things are mandatory or necessary. As I mentioned before, by Eva Kittay's account, her daughter Sesha lives a perfectly contented life without having a sense of social identity or engaging in political advocacy. I worry that the above views of cognitive disability not only struggle to accept this but also seem to imply that Sesha is worse off for a lack of social agency or political recognition. Rather than combat ableist assumptions, this view risks further pathologizing those who are incapable of robust forms of communication.

While I have rejected these possible solutions to making self-representation more responsive to individuals like Sesha, I do not believe we have to resort to abandoning self-representation as a value of disability rights. Instead, I argue we must conceptualize nonrepresentation as something that is protected by the value of self-representation. If this seems counterintuitive, it is likely because self-representation is often thought of as an active or positive expression that is intended by the individual. I argue we should instead think of self-representation as a form of negative right. Iris Marion Young (2000, 31) argues that domination is an injustice that reduces someone's capacity for self-determination and agency. In this way, I think we can conceptualize self-representation as a sort of negative right against domination. An individual has a right not to have an identity imposed on them by another, regardless

of whether they have formed an identity of their own. A good example of this is seen in the right to religious freedom, which equally protects the right to engage in religious practices and the right to not have any religious affiliation at all. We should be able to easily imagine this in the case of someone who can form and communicate their own identity. Someone may reasonably decide that they wish to have no ability identity at all, just as someone may wish to have no gender identity at all. I do not think that we should consider their right to a lack of identity any more substantial and important than a lack of identity that comes about through an inability to do so.

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