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AGENCY AND DISABILITY

Kevin Timpe

1 Introduction

There are a number of philosophical issues at play in any stipulative definition of agency. Lots of entities have agency; lots of kinds of things are able to exercise a distinctive kind of causal control that originates, at least in part, within them rather than just passes through them. In this chapter I focus only on human agency. By 'agency,' I mean both the complete set of capacities and abilities that humans have that enable them to do characteristic human activities (e.g., my capacity to make a double-shot of espresso) and the exercise of those capacities (e.g., my having just made and drank a double-shot of espresso). Many of these capacities and their exercise will be shared between humans and other organisms, such as the capacities for locomotion, nutrition, and various cognitive tasks. Other capacities and their exercise will be uniquely human; the exact boundaries between those that are uniquely human and those we share with other organisms need not concern us at present.

Agency is typically taken to involve a broad range of capacities and abilities: volition, intention, desire, sensation, emotions, proprioception, bodily control, and the abilities to evaluate reasons and guide one's behavior on the basis of those reasons. The use of 'behaviors' here should be construed broadly, including not only bodily movements but also mental acts. Bodily movements and mental acts are both behaviors in the relevant since they will be 'agentive when ... sensitive to reasons, that is, able to adjust flexibly its means and goals to varying constraints or opportunities' (Proust 2013, 209f). For each of these capacities or sets of capacities, there will be disabilities that impact the agent's having or ability to exercise those capacities. Here, I look at a number of ways that disabilities can impact agency. A central claim is that looking at how agency and disability relate can tell us something about human agency more broadly.

In Section 2, I clarify my approach to the nature of disability. This will make it clear why I think we must engage with the existing literature on a range of disabilities to see how disability affects human agency. Section 3 explores a number of examples. In Section 4, I draw a number of lessons about agency and argue that they apply not just to agents with disabilities, but to human agency in general.

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2 The nature and approach to disability

In the same way that the exact meaning and extent of 'agency' is contentious, so too is the exact meaning and extent of 'disability.' Licia Carlson refers to disability as 'the philosopher's nightmare' (Carlson 2010, 1), in part, though certainly not exclusively, because of the care needed to approach the topic well. History is full of examples of how thinking poorly about the nature of disability has led to significant harm against those with disabilities. Careful reflection on disability requires us to think about what disability is (or, better, what disabilities *are*). There are a number of different models of the nature of disability: the medical model; forms of the social model, both strong and weak (see Kahane and Savulescu 2009 for the claim that there is 'no single agreed formulation of the social model account of disability' (21)); critical realist models; moral models; the Nordic model; mixed models; the welfarist model; and others.

In *The Minority Body*, Elizabeth Barnes cautions against assuming from the outset that a particular model can apply equally well across the breadth of disabilities. In her book, she is only focusing on physical disabilities across. Even physical disability, she argues, is sufficiently complicated that we should not begin in a 'top-down' approach, seeking a general account or model. Doing so runs the risk of privileging an account of what disability is that may not accurately reflect the experiences of those the full range of disabilities that the account is supposed to include. Instead, Barnes suggests that we should work in a 'ground-up' way that begins with paradigmatic instances of disabilities and works from there toward an account of what disability in general is.[1] This will also be true not just for physical disability, but for disability in general.

Many treatments of disability, both within philosophy and elsewhere, fail to take seriously the diversity of disability. Like Barnes, I think we should begin our philosophical reflection by first exploring in detail specific disabilities before we seek to treat those disabilities in a unified or overarching way (see Barnes 2016, 4; for a similar approach see Kahane and Savulescu 2009). This approach begins by pointing to particular paradigmatic cases. One has first to decide which purported disabilities are in fact paradigmatic. But then two problems arise. First, if one ultimately endorses a revisionist account, what one originally took to be paradigmatic cases may fail to be paradigmatic, or even fail to be a disability altogether. Second, there's the question of how far the boundaries of the category 'disability' extend beyond those paradigmatic cases. It may be, as Barnes suggests, that there is no clear boundaries for whether or not a type of physical condition is a disability (Barnes 2016, 47). Fortunately, the conclusions I am aiming for do not require a full account of what all disability is, nor that we know exactly where to draw the boundaries around the concept.

One final clarification: social models of disability are especially influential in disability studies. In this field, as Ronald Berger's writes

> a discussion of definitional issues typically begins with a distinction between impairment and disability, whereby impairment refers to a biological or physiological condition that entails the loss of physical, sensory, or cognitive function, and disability refers to an inability to perform a personal or socially necessary task because of that impairment or the societal reaction to it.
>
> *(Berger 2013, 6)*

This distinction between impairment and disability is then used to argue that while impairment is biological or physiological, disability is 'something imposed on top of our

impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group' (UPIAS 1976, 4). The social model is extremely influential, both academically and politically. It is now codified, for instance, in the WHO's *International Classification of Impairment, Disability, and Handicap*. But this approach simply pushes the question of 'what is disability' back into the question of 'what is impairment' (Barnes 2016, section 1.4.1). Similarly, Shakespeare (2014, 22) argues that disability, understood as social, and impairment, understood as biological, are 'always intertwined.' Thus, we cannot extricate one from the other in the way that the social model often does. For these reasons, I only address disability and not impairment.

3 Specific disabilities

Given the 'ground-up' approach I have endorsed, exploring the impact of disability on agency requires looking at *specific* disabilities. Here, I investigate Parkinson's, a paradigmatic physical disability, a number of disabilities that impact an agent's emotions, and then briefly address some of the wide range of intellectual disabilities.

3.1 Parkinson's disease

The primary pathophysiologies for Parkinson's are tremor, rigidity, posture and locomotion disorders, and akinesia. While these pathophysiologies can't be isolated from each other in many individuals with Parkinson's, the present discussion will focus primarily on akinesia—the 'lack of movement or slowness of initiating and maintaining movement' primarily due to the disease's effect on neurons in the substantial nigra region of the brain, an area 'which is important for control and regulation of motor activity' (Weiner *et al.* 2001, 5). Akinesia makes it difficult to walk or engage in other whole body movements, particularly when they involve more than one action plan. (This is one of the reasons that the pathophysiologies in Parkinson's can't be separated from each other.) For those with Parkinson's, 'normal voluntary actions may be impaired by difficulty in initiation as well as slowness of movement, both of which may be apparent during most activities. In addition, sudden freezing or involuntary cessation of ongoing activity, which is referred to as kinesia paradoxa, may be seen' (Donaldson *et al.* 2012, 249). Most individuals with Parkinson's are able to briefly overcome, or at least mitigate, their akinesia or other motor control difficulties. However, the high levels of concentration required to do so can't be sustained, and thus the reprieve from akinesia is often short-lived.

The difficulty to initiate movements isn't consistent across contexts. The difficulty in self-initiating movement is significantly more pronounced than in response to external command by another agent, which is 'relatively well preserved' (Donaldson *et al.* 2012, 237). Furthermore, the difficulty initiating temporally disappears in certain environmental setting, such as the ringing of a fire alarm or a gunshot (Donaldson *et al.* 2012, 249).

This suggests that whether an individual is prevented from executing a particular task depends not just on the underlying disabling condition but also upon facts concerning one's environment. A similar conclusion can be raised from the examination of other physical disabilities.[2]

3.2 Emotional blunting and alexithymia

Let's turn to emotional disabilities. Numerous disabilities lead to emotional blunting or flattened affect, a decrease in the frequency or strength of emotions, both positive and

negative (Kim 2015). Emotional blunting is commonly associated with schizophrenic syndrome and frontotemporal dementia, or FTD (see Berenbaum *et al.* 1987, 57, and Williamson and Allman 2011, 104, respectively). In some cases, FTD's emotional and social impact may be more significant than the cognitive and neuropsychological deficits it causes. Decreased social tact and propriety, abulia, disengagement, and decreased behavioral regulation can all be rooted in FTD's effects on the emotions. Individuals impaired by FTD can become emotionally detached; have a decrease in autonomic emotional responsiveness; lose empathy and willingness to comfort others; and more frequently fail to comfort or help others in distress, even if they are family members or close friends (Mendez *et al.* 2006, 242–245).

Emotional blunting can impair other emotional responses, not just those involving empathy. Individuals with 2p15–16.1 microdeletion syndrome, which involves a deletion on the short (p) arm of chromosome 2, typically involves a number of physical affects (e.g., microcephaly, vision problems, kidney abnormalities); speech impairments; gross and fine motor control issues; and cognitive and developmental disabilities (2p15p16.1 microdeletion syndrome 2014, 4 and 7; see the longer discussion in Timpe 2016). It also typically involves mild to severe intellectual disability and problems with executive function, which can lead to both emotional blunting and alexithymia (Hancarova *et al.* 2013, 2).

Though not an official diagnosis in the *DSM-V*, alexithymia is 'marked by difficulties in identifying and describing feelings and difficulties in distinguishing feelings from the bodily sensations of emotional arousal' (Bird *et al.* 2010, 1517; see also Ricciardi *et al.* 2015). Alexithymia, like emotional blunting, has been clinically associated with reduced empathy (Bird and Cook 2013). While there's not as much evidence to be sure of this stronger claim, there's at least anecdotal evidence suggesting that some individuals with alexithymia may have difficulties experiencing certain emotions (e.g., shame, jealousy, or self-resentment) altogether. Individuals with Down syndrome often have difficulty identifying and labeling fear, anger, and surprise, and some individuals with autism show differences in emotional self-reports and expression (Kasari *et al.* 2012, 240 and 244). Insofar as human agency involves emotional regulation which contributes to agency (see Carla Bagnoli's chapter in this volume), we see here another range of influences of disabilities on agency.

3.3 *Intellectual disability*

Intellectual disability is a particularly challenging category to address. It is defined by the WHO as:

> a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.
>
> *(WHO 2010)*[3]

Similarly, the DSM-V points to deficits in both intellectual functions and adaptive functioning as a result of those intellectual functions as essential elements in the diagnostic criteria for intellectual disability. There are over 1,000 known etiologies of intellectual disability, and each 'differs from all the others in meaningful ways in virtually every aspect of functioning' (Burack 2012, 4). Furthermore, over half of individuals with intellectual disability show no known cause for their disability (Iarocci and Petrill 2012, 13).

Intellectual disability also ranges widely in terms of the particular capacities and abilities impacted, as well as the degree to which they are affected. All of the following are included by psychologists and neurologists as belonging to the set of capacities and abilities involved with intellectual disabilities: spatial mapping; attentional abilities; memory, both short and long term and working; cognitive flexibility; linguistic skills including vocabulary comprehension, expression, lexical and syntax skills, grammatical morphology, and pragmatics; literacy; conversational skills; and comprehension. Intellectual disabilities[4] can impact agential planning, learning, adaptive behavior, and social interaction. Intellectual disabilities can make it hard for an agent to exercise a range of other skills well and to plan well for the future. In some cases, those with intellectual disabilities might be 'unable to imagine that range of alternative possible futures that are, given their social circumstances, futures that it would be realistic for them to attempt to make their own' (MacIntyre 1999, 94).

Regarding the degree of impact, intellectual disability ranges from mild learning or developmental disabilities to anencephaly, where the neural tube fails to close during neonatal development resulting in the lack of a cerebrum. Most cases of anencephaly result in miscarriage, and those that are born alive usually die from cardiorespiratory arrest within days. The DSM-V specifies four levels of severity of intellectual disability: mild, moderate, severe, profound involving evaluation across conceptual, social, and practical domains. Unlike previous classifications, the DSM-V has moved away from primary reliance on IQ tests toward a combination of clinical assessment and standardized testing for diagnosis.[5]

There is a danger of focusing on the agential impact of intellectual disability, particularly in severe cases of intellectual disability, given the ways that those with intellectual disabilities have been mistreated, even to the point of institutionalization and forced sterilization in even not-too-distant history.

As indicated earlier, my discussion of physical, emotional, and intellectual disabilities isn't exhaustive of the ways that disabilities can affect human agency. All sorts of other disabilities not examined here have a wide variety of implications for agency. Depression, which according to the National Institutes of Mental Health is the leading cause of disability worldwide, impacts not only the emotions but also the motivational capacities involved in agency (for work on the connection between depression and moral psychology, see Ardal 1993; Caton 1986; Hansen 2004; Roberts 2001; and Silberfeld and Checkland 1999). Lesch-Nyhan syndrome causes an overproduction of uric acid that disturbs the nervous system causing cognitive, neurological, and behavioral abnormalities such as choreoathetosis and other involuntary movements, ballismus, and self-injurious behaviors (see Lloyd 1981). The discussion in this section is intended to merely be highlight a limited cross-section of the total impact of disabilities on agency.

4 Lessons from disability for agency in general

I want to draw three lessons about human agency on the basis of the disabilities canvased in Section 3, even though they don't exhaust the importance of disability for a full understanding of human agency.

Many scholars argue that agency, and moral agency in particular, should be understood as a degreed concept. For instance, Jeannett Kennett writes,

> Moral responsibility comes in degrees. The ordinary view implicitly recognizes both degrees of difficulty in the exercise of self-control (and indeed of judgement), and a distinction between those who are capable of synchronic self-control and those who must

> instead rely on diachronic techniques of control. Factors which impinge on the ease with which the capacity for self-control can be exercised mitigate responsibility. Some of those are obstacles to good judgement as well: for example, tiredness, emotional pressures, and lack of information.
>
> *(Kennett 2001, 182; see also Timpe 2016, particularly section 3)*

If tiredness can impact self-control, then surely disabilities can as well (for further discussion, see Timpe 2016). And self-control, like many other agential abilities, is best thought of as degreed (see Smith 2017). Volitional control, rationality, emotional regulation, bodily control, sensory awareness all are degreed. The facts that disabilities evidence considerable heterogeneity and that the same disability can manifest in such a wide range of agential impact (e.g., individuals with Down syndrome exhibit significant differences in terms of their degree of intellectual impairment) give us further reason to think that agency is a degreed concept. In part because we typically think of idealized agents rather than agents with disabilities, we can fail to take seriously enough the degreed nature of the capacities and behaviors involved in human agency. (I think a similar point is true of much philosophical reflection on mental illness and childhood development too, though I don't develop this line of inquiry here.)

Second, reflection on disability and agency reminds us that our agency is socially and ecologically dependent. Much contemporary philosophy seems to endorse an atomistic and individualistic approach to human agency. But reflection on disabilities shows that the social context of our agency matters. The capacities involved in human agency themselves might depend on the agent's social or environmental situation, so agency itself might depend, at least partially, on those social or environmental factors. On this understanding, we can change what the agent is able to do either by changing factors intrinsic to the agent or by changing the environment the agent is in. A slightly more modest claim is certainly true: the agent's exercise of those capacities depends on the social or environmental setting the agency takes place in. On this understanding, what the agent can do is just a function of the agent, but what they will do depends on the social or environmental situation and the number of supports that it provides (see Timpe 2019). Human agency can have a social scaffolding, 'the externalization of certain parts of the decision making process [or agency in general] that are not typically externalized,' and 'this externalization does not undermine the claim to autonomy' (DeVidi 2013, 193). Certain disabilities can decrease forms of autonomy, but not all disabilities do. Furthermore, it is not true that all disabilities completely undermine autonomy. The sorts of autonomy ruled out by disabilities are plausibly forms that aren't possessed by human agents even apart from disability.

As Alasdair MacIntyre has argued, no human is a 'fully independent practical reasoners' (see Clifton 2018; MacIntyre 1999). A danger in defining intellectual disability in terms of 'a reduced ability to cope independently' is that it wrongly suggests that human agents are more independent than they really are (see Clifton 2018, 131f). Overstating the independence of those without disabilities can increase the disenfranchisement of those with disabilities (Kittay 1998, 77). Even the independence that we do have develops in the context of our social environments.

Finally, the third related lesson is that there are degrees of difficulties involved even in successful human agency. Consider again the discussion of Parkinson's. An agent's ability to self-initiate movement depends on the degree of their condition's progression, how long they've been exerting this kind of control, and environmental variables. How likely they

are to succeed will vary with all these factors. Disabilities may increase the fallibility of an agents' abilities, but there are good reasons to think that abilities in general are fallible (see Smith 2017, section 3).

Furthermore, it seems that not just agency itself but also morally responsible agency is degreed. Dana Nelkin convincingly argues that the degree of difficulty can affect the amount of blameworthiness or praiseworthiness:

> For example, we often excuse people to an extent when doing the right thing would be very, very difficult. In turn, difficulty can be understood in at least two ways: on the one hand, it can be understood as requiring a great deal of effort, and, on the other, it can be understood as requiring a great sacrifice of one's interest. These often go together, but they might come apart.
>
> *(Nelkin 2014, 357)*

Disabilities can impact both of these ways of understanding the relevant sense of difficulty.

5 Conclusion

Much of recent philosophical work on agency focuses on instances of what might be thought of as 'typical' agency, concentrating on 'clear- cut paradigm' agents while bracketing issues related to developmental psychology, mental illness, or disability (Shoemaker 2015, 5). There is very little discussion of what Shoemaker calls 'marginal agents' even though these cases can teach us quite a bit. While this restriction and the related idealization of human agency might sometimes be justified, it can result in a skewed understanding of human agency. As I've tried to argue, we can learn about 'typical' agency and wander in the direction of 'the margins' insofar as there might be facts about human agency, such as its socially embeddedness, that we can recognize more clearly in cases involving disability. For instance, once we see that human agency is socially embedded, we can work to provide ecological structuring and social scaffolding that can lead to better expressions of human agency. (For examples of ecological structuring and social scaffolding, see Timpe 2019, particularly section 2.1.)

Finally, we ought not overly associate disabilities with challenges to successful agency. As indicated above, a wide range of disabilities can have this kind of impact. But some disabilities can also make a range of agential behaviors, in the sense spelled out in section 1, easier. For instance, some individuals with certain forms of autism spectrum disorders can have heightened focus and an increased range of executive function tasks, as well as increased sensitivity with respect to vision, hearing, or touch—all of which can impact the agent's behavior (see Crane and Goddard 2009). Similarly, an increased emotional attention and sensitivity has been found in individuals with Williams syndrome (Niccols *et al.* 2012). Further attention needs to be paid to these sorts of impacts as well so that we don't reinforce problematic stereotypes of disabilities.

Related topics

Agency, powers, and skills; Expert agency; Agency and emotion; Agency and responsibility; Agency and mistakes; Pathologies of agency: Agency and mistakes; Agency and autonomy.

Notes

1 My own skepticism of top-down approaches can be found in Timpe (2022). See also Barnes 2016: 3. Barnes isn't committed to the claim that there isn't a unified category of disability. Rather, on her view the mere fact that we use the word 'disability' with this range of modifiers doesn't entail that there is.

2 It is common to differentiate physical disabilities from, among other categories, intellectual disabilities. But the vast majority of the over 1,000 known etiologies associated with intellectual disability have physical consequences. Many intellectual disabilities are caused by genetic abnormalities; even with environmental causes, what they cause is changes in various bodily systems (e.g., lead ingestion, which is estimated to be the cause of approximately 10% of intellectual disability worldwide). Demarking physical disabilities from other subtypes is, in my view, significantly more vexed than often admitted.

3 According to Moss, Howlin, Oliver: 'the diagnostic criteria outlined by the DSM-IV-TR (APA 2000) and OCD-10 (WHO 1992) manuals may not be sensitive enough to distinguish between individuals who have not yet attained the appropriate level of development required to demonstrate a particular skill and those who show a genuine impairment in those skills' (Moss 2012, 293). For a discussion of criticisms of the WHO's approach to defining intellectual disability, see Buntinx 2014.

4 Licia Carlson and Eva Feder Kittay (2010, 1 note 1) write that 'We've chosen the term "cognitive disability" under which we include conditions like autism, dementia, Alzheimer's, and [what has historically been called] mental retardation, rather than "intellectual disability." The former is broader. Also, some forms of cognitive disability do not imply diminished intellectual capacity (e.g., autism)' (see also Carlson 2010). My interest here is specifically with intellectual disability, though the exact relationship between the two is complex. Furthermore, the distinction between them is not always held.

5 The history of IQ tests in general and specifically their role in evaluating intellectual disability is contested (see Harris 2006, particularly chapters 2 and 3).

Further reading

Barnes, Elizabeth. 2016. *The Minority Body: A Theory of Disability.* Oxford: Oxford University Press.
An excellent introduction into some of the philosophical issues surrounding specifically physical disabilities. Barnes argues that physical disabilities involve 'mere-difference,' not 'bad-difference.'

MacIntyre, Alasdair. 1999. *Dependent Rational Animals: Why Human Beings Need the Virtues.* Peru, IL: Carus Publishing Company.
MacIntyre's book focuses primarily on 'the virtues of acknowledged dependence' but canvasses a wide range of issues. Of particular relevance here are his arguments against overly idealized and atomistic conceptions of human agency.

Shoemaker, David. 2015. *Responsibility from the Margins.* Oxford: Oxford University Press.
While not specifically focused on disability, Shoemaker's book illustrates how reflection on 'non-standard' or 'marginal' cases of agency and responsibility can help us understand important facts about human agency in general.

Timpe, Kevin. 2019. "Moral Ecology, Disabilities, and Human Agency," *Res Philosophica* 96.1: 17–41.
This article argues that human agency is not simply a function of intrinsic properties about the agent, but rather depends on the ecology that the agent is in. In particular, it shows how, by paying deliberate attention to structuring the social environment around people with disabilities, we can mitigate some of the agential impact of those disabilities.

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