

RESPECT, COGNITIVE CAPACITY AND PROFOUND DISABILITY

ABSTRACT

According to one prominent form of moral individualism how an individual is to be treated is determined, not by considering her group membership, but by considering her own particular characteristics. On this view, so I shall argue, it is not possible to provide an account of why people with profound cognitive disabilities are owed respect. This conclusion is not new, but it has been challenged by writers who are sympathetic to the recommended emphasis. I aim to show that the conclusion cannot be avoided, and look at what is to be learned from an approach that leads us to this point. I suggest that any account of why profoundly disabled people are owed respect will have to supplement discussion of their particular capacities with a normative account of their humanity.

INTRODUCTION

Some profoundly disabled human beings do not exhibit rationality or autonomy, and whilst they have a life, theirs is not a life to lead. Their cognitive capacities are much lower than they are for almost all other human beings - lower, also, than for most other profoundly disabled people and for some higher functioning non-human animals. Why then, would anyone suppose that even the most profoundly impaired human beings are one of us; not only like us in being human but like us in that how they should be treated falls within the domain governed by the norms of the morality

of respect? This is what I suppose, but it is a supposition that is hard to defend, and on one influential account, endorsed by moral individualists, it is indefensible.

I shall assume that respect is owed to beings in virtue of a capacity for rational autonomy – that is, the capacity to reason, to act autonomously, to legislate rules for themselves and to be guided by these when they act; and I assume, also, that the requirements of respect impose the most stringent demands on how we must treat someone, demands that do not vary according to the expected harm or benefit to the person we treat. So, for example, it is equally wrong to kill an elderly patient with advanced Alzheimer’s disease as to kill a young woman in the prime of life. This is, of course, just one interpretation of respect; I adopt it because it is employed by the moral individualists whose work I discuss here, and who press the question whether people with profound disabilities really are owed respect in this sense.

I shall discuss the psychological capacities intrinsic to individuals, not because this is the only or the best way to approach the question of what is owed to profoundly disabled people but because I want to take seriously the influential assumption that ‘how an individual is to be treated is determined, not by considering his group membership, but by considering his own particular characteristics’ (Rachels 1990, 173).¹ My interest is directed towards the psychological capacities that we can both attribute to people with profound disabilities and which might help explain their inclusion in the class of human beings to whom respect is owed. However, it turns

¹ This view is characteristic of one prominent variety of moral individualism. Although there are many alternatives (see Crary 2016, 10-35) whenever I refer to moral individualism I have in mind the view expressed by Rachels (see also McMahan 2002 and Singer and Kuhse 2001). One important assumption, which Crary rejects, is that we can exclude moral characteristics from the empirically observable characteristics of human and animal lives (Crary 2016). For the purposes of argument I make this assumption too, although Crary’s argument deserves close attention.

out that no candidates suffice to provide the desired explanation; there just is no way that an approach focussed on psychological capacities intrinsic to individuals can avoid the conclusion that some profoundly disabled human beings fall below the threshold of respect. This conclusion is not new, but it has been challenged by writers who are sympathetic to Rachels' orientation. I aim to show that the conclusion cannot be avoided, and look at what is to be learned from any approach that leads us to this point. If the conclusion is thought to be unacceptable, as it is by me, we must find an alternative approach. In a concluding section I suggest that any account of why profoundly disabled people are owed respect will have to supplement discussion of their capacities with a normative account of their humanity.

AN ELUSIVE THRESHOLD

The two most authoritative diagnostic and classification systems in the United States – the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual on Mental Disorders (DSM-5) concur in conceiving intellectual disability as a developmental condition, characterised by 'significant sub-average' performance in intellectual functioning - as evidenced, for example, in her reasoning, problem-solving and practical understanding – and in her adaptive functioning, so that she is unable to meet the developmental and socio-cultural standards that allow for personal independence, social responsibility, and unconstrained participation in daily social activities (Tasse 2016). The onset of any intellectual and adaptive sub-average performance will be observed during the 'developmental period'; that is, between birth and the age of 18 (DSM-5; Shalock and Luckasson 2013).

Under the classification provided in DSM-5, intellectual disabilities are distinguished as 'profound' largely in virtue of judgments about adaptive functioning. An individual who is profoundly disabled in the conceptual domain is engaged with the physical world rather than with symbolic processes, and 'motor and sensory impairments may prevent functional use of objects'; the social domain is such that 'the individual has very limited understanding of symbolic communication . . . express[ing]. . . desires and emotions largely through nonverbal, non-symbolic communication'; and in the practical domain the 'individual is dependent on others for all aspects of daily physical care, health and safety'; (DSM-V 2013, 58, 61). The American Psychiatric Association (APA) and the AAIDD agree that anyone whose intellectual disabilities are profound will require constant care and support for every aspect of daily routines.

My interest here is confined to people with a profound congenital or developmental intellectual impairment (for brevity I often refer to these people as 'profoundly disabled'). This is a heterogeneous group, encompassing multiple disorders and syndromes, whilst the genetic aetiology of those with a genetic cause includes chromosomal abnormalities, copy number variants, single gene, mitochondrial and imprinting disorders (Foster et al 2015, 450). There are common features, including the need of constant care and dependency on others for help with such basic activities as toileting and feeding. But some people will be able to move independently within a secure space, play games, understand a few words, benefit from some education, reciprocate love and attention, and respond to and appreciate music. Others will be incapable of any of this, and show little sign of responding to

communicative behaviour, remain unable to use assistive technology, and, despite the best efforts of carers, spend large parts of any day asleep or unresponsive. The psychological profile of any one person may be uneven: she may exhibit no understanding of symbolic communication, although she gets the giggles when a clown's over-sized trousers fall down or a blob of gloop is stuck on his nose; or she may have perfect pitch and play a few lines of Bach on the piano and yet be unable to toilet herself or be left alone for a moment (Vorhaus 2016, 2107).

There are varying psychological capacities amongst profoundly disabled people, but this leads to the question how we can recognise the innumerable differences between the capacities of these human beings, and between all human beings for that matter, whilst insisting that what is owed to all is fundamentally the same. A familiar response is to suggest that anyone possessing capacities above a minimum threshold falls within a domain to which the requirements of respect apply, and that they apply equally to all those above the threshold, irrespective of any differences between them.

In his theory of justice Rawls distinguishes between a scalar property and a range property: a scalar property admits of degrees, and one has more or less of it, as one is more or less rational, loving and so on. A range property is not like this:

The property of being in the interior of the unit circle is the range property of points in the plane. All points inside this circle have this property although their co-ordinates vary within a certain range and they equally have this property, since no point interior to a circle is more or less interior to it than any other point (Rawls 1971, 444).

A range property R is related to a scalar property S, such that someone has R when she falls within a range on a scale indicated by S. Perhaps R is 'moral personality'; then someone with R may fall within the range set by the scalar properties of having a conception of the good and a sense of justice (Rawls 1971, 504-512). Someone may have an attenuated capacity for conceiving the good and a sense of justice, but so long as she meets a minimum threshold in respect of both she qualifies for moral personhood. The claim is that anyone who possesses moral personality is owed the guarantees of justice (Rawls 1999, 442).

Where to set the minimum threshold? Rawls insists that his demands of a conception of moral personality are 'not at all stringent' and represent only an 'essential minimum' (Rawls 1971, 506). Still, they demand more than some profoundly disabled persons are capable of, and Rawls recognises this: whilst 'no race or recognised group of human beings' lack moral personality there are 'scattered individuals [who] are without this capacity, or its realisation to the minimum degree' (Rawls 1971, 506). This is equally a problem for determining the domain of respect. If one sets the threshold as Rawls does, requiring the capacity for moral personality, or as Kant does, requiring that a person has the capacity to apprehend and respond to moral reasons, then some human beings, including people with congenital and acquired profound cognitive disabilities, will fall below the minimum. If, on the other hand, we are intent on not placing any human being below the threshold, or almost no human being below it, then we might opt, in the spirit of Bentham, to demand only the capacity for sentience or the capacity to suffer. This

may be the right place to set the threshold, but then we are bound to place not only almost all human beings above the threshold but almost all non-human animals too.²

At some point it will be necessary to explain why we should set the threshold at a point such that all human beings with profound disabilities fall on the right side of it. Before that though, a prior question: why stipulate a threshold in the first place, a thin dividing line that might make the difference as to whether or not a human being is protected by the requirements of justice or respect? What difference could there be, as between one human being and another, so great as to justify a distinction of this magnitude?³

Anencephalic infants are born with a congenital absence of the cranial vault, and the cerebral hemispheres are, typically, completely missing. There is no consciousness, no capacity for rationality or autonomy, and no potential to develop any such capacity. Perhaps anencephalic humans will fall below whatever threshold we set. However, this is a distinct group, and not one that falls under the category of profound disability. It is not any cognitive impairment that prevents the development of some capacity; there being no brain stem to support the existence of any such capacity there is no capacity whose development is impaired.

Anencephalic infants are a special case, and there may be a reason to distinguish what we owe to them from what we owe to everyone else. What about people with profound impairments? Suppose we follow Rawls in assuming that the basis of a

² Anencephalic humans would probably not meet this test.

³ See Arneson 1979 for discussion.

claim to justice is the capacity for moral personality, and that this includes the capacity to develop a sense of justice and a conception of the good life (Rawls 1972, 505). The sense of justice presumably includes some ability to identify and to act in accordance with the norms of fairness, but it is uncontroversial that people are variously able to do this. Whatever the sense of justice consists in, it includes abilities and dispositions that vary by degree, and the same applies to the capacity to form a conception of the good. Psychological capacities develop incrementally; hence, wherever we set the threshold, it will mark a point that corresponds to a developmental difference. But it seems indefensible to say, of someone who falls just below the line, that she is not owed the requirements of justice that are owed to someone else who falls marginally on the other side of the line. How can a marginal difference in capacity justify a life-determining difference in how someone is to be treated? This question applies equally to how we determine whether someone falls within the domain of the morality of respect; for the same difficulties arise once it is proposed that we set a threshold that distinguishes between human beings that fall above and below the dividing line.

I am assuming that the threshold will take the form of a 'thin' line, so that, for example, someone falls above or below the line depending on whether they achieve an average score of 49 or 50 on some battery of psychological tests. Those who score 49 fall below the line; those who score 50 fall above it. But the line may be thick, not thin: those who score under 20, say, fall below the threshold, whilst those who score 50 and above fall above it. Then the status of those whose scores lie between 20 and 49 remains indeterminate, and we stipulate that all those of

indeterminate status are to be treated just as we treat those who fall above the threshold, so minimising any risk of under-estimating anyone's capacity.

But here we require a justification for the stipulation that is not simply pragmatic. And in any case, it does not resolve the problem we started out with, which is how a slight difference in psychological capacity can justify a monumental difference in moral status. For, even assuming a thick line, those whose score is 19 will be subject to treatment that is fundamentally different to those whose score is 20.

We could decide to avoid the arbitrariness of a threshold by stipulating that all human beings are to be included within the domain of respect. We might then concede that some people do not have the capacities that warrant respect but insist on treating them as if they do have these capacities because, if we do not, and we single them out as fundamentally inferior and 'other', then – so history teaches us - this small number of exceptionally vulnerable people will be vulnerable to treatment that no one could justify. It may be a fiction that all human beings have the capacities that warrant respect, but it is not a fiction that, by treating them as if they do, we will likely avoid horrors that no human being should be exposed to and everyone has a right not to be subjected to.

This argument may prove decisive from a practical point of view, but it makes the assumption that some profoundly disabled human beings lack the capacities that warrant respect. Is this the best that we can do?

CAPACITY AND POTENTIAL

Although I have assumed that some people with profound disabilities do not have the capacities required for moral personality or rational autonomy, this may be a mistake, owing to an unimaginative conception of ‘capacity’. Since it is especially important to show generosity in thinking about what is possible for people with disabilities, I will explore this assumption further.⁴

I will take as an example the capacity for speech. Suppose that Alec is a young, profoundly disabled boy with a life-limiting condition who also suffers from Phelan-McDermid syndrome, a genetic condition caused by a deletion or disruption of a segment of chromosome 22. Symptoms include profound developmental delay, and absent or severely delayed speech.

Suppose that Alec never acquires the capacity to speak, and there is no prospect of doing so before he dies, although he would have regained this capacity were he to enjoy a longer life and to benefit from advances in medical science. We might then insist that he has a second order capacity to speak: that is, since he would develop the first order capacity to speak under the specified counterfactual conditions (longer life, scientific advance) he must therefore possess a second order capacity to develop the first order capacity. But this cannot be right. If he must have a second order capacity in order to develop a first order capacity then it follows that he must have a third order capacity in order to develop a second order capacity, and so on *ad*

⁴ The literature on capacities, otherwise referred to as ‘abilities’ and ‘powers’ is extensive. See, for example, Harre and Madden 1975, Prior 1985, Kenny 1989, DiSilvestro 2010.

infinitum. We need an account that does not lead to the proliferation of higher order capacities, and which allows us to recognise that capacities can be lost, irreversibly.

On the other hand we should not deny the existence of *all* higher order capacities.

Broad remarks of human minds that ‘they start with very few first-order powers, but rather with powers to acquire powers’ (Broad 1933, 267). However, these powers can be irreversibly lost, since ‘[i]f you injure a man’s brain in certain ways, his mind will lose certain powers, and there is no known way of restoring these powers to his mind’ (ibid). DiSilvestro denies that this is what we should say. There may be no known way of restoring these powers but that is not to say that ‘there is no way *at all* of restoring these powers’ (DiSilvestro 2010, 57. Italics in original.) Technologies of the future – genetic therapies, reconstructive brain surgery – may enable us to restore powers that at present we cannot restore, just as today we can restore powers that were unrecoverable in the past:

There are certain sorts of injuries to the brain that we can reverse with today’s technology, but that would have been irreversible a thousand years ago. If such an injury had occurred a thousand years ago, it would have been a mistake to claim that the injured organism did not have the power to regain the power to think. The organism did still have the power to regain the power to think. What was lacking was merely the technology to permit the higher-order power to be realized (DiSilvestro, 57-8).

The same general point applies to persons today who live with congenital disorders and impairments; the loss of any powers is only irreversible in the sense that we currently lack the technology to reverse it and this ‘tells us more about the state of our society’s medicine than it does about the state of our patient’s mind’ (DiSilvestro: 58).

This view, which I shall not accept, nevertheless encourages reflection on the conditions under which Alec has either the capacity to speak or - and as I prefer to say - the potential to develop the capacity to speak.⁵ I shall make two assumptions. First, Alec has the (first-order) capacity to speak only if he possesses the physical infrastructure – including the neurological structures – necessary to support this capacity. Second, he has the potential to develop the capacity to speak only if the development entailed by the realisation of any potential preserves identity. If the person whose potential is realised is not the same as the person who we identify as Alec then it is not Alec but someone else who has the potential to speak.

It seems clear that Alec does not have the capacity to speak. He has no ability to speak without assistance, and there is no known intervention or technology that would enable him to speak. This was not true of the physicist Stephen Hawking, who had amyotrophic lateral sclerosis. He used a speech-generating device, an infrared switch mounted on his spectacles to detect twitches in his cheek, and software that moved a cursor across a keyboard until it reached the desired word (as indicated by a twitch of the cheek). Hawking had the capacity to speak in the sense that his mental abilities enabled him to use technology so as produce aloud – using a speech synthesiser - the sentences and formulae he intended to communicate. Alec is not able to speak even with access to the most sophisticated augmentative and alternative communication technology. Lacking the neurological infrastructure that would enable unassisted or assisted speech, he cannot speak, *simpliciter*.

⁵ There are distinctions between 'potential', 'powers' and 'second order capacities' but these are not germane to the argument.

Whether Alec has the potential to develop the capacity to speak is a hard question, and I shall not offer an unequivocal answer. If, however, there is a sense in which he has the stated potential it turns out that it cannot provide a basis for respect.

Contrary to DiSilvestro we might suppose that, if Alec had been born 2000 years ago, he would have neither the capacity to speak nor the potential to develop the capacity to speak – contemporary therapies not having been dreamt of. But suppose that today we can administer genetic therapy following which his brain is stimulated to develop tissues in which the capacities essential for speech are developed.

Following speech and language therapy he develops the capacity to speak, and so we find him speaking English. Then Alec today has both the potential to develop the capacity to speak, and - but only after receiving therapy - the capacity to speak.

DiSilvestro, presumably, would go further: if this is what we can say of Alec today then we can say the same of Alec 2000 years ago: it is only the contingent state of knowledge and technology that prevents Alec at that time from speaking English; he too has the potential to do so.

We might observe that the pertinent difference between historical and contemporary Alec is extrinsic, taking the form of the administration of therapies and the importation of new genetic material. If what accounts for the capacity to speak is something extrinsic to Alec then this is not the kind of capacity which can be included in an account of respect, since respect – so we are assuming - is based on the possession of capacities that are intrinsic to individuals. Similarly, we cannot appeal to contemporary extrinsic developments to explain why historical Alec has the intrinsic capacities relevant to respect. Even if we allow that historical Alec has the

potential to speak, in the sense that he would have been able to speak had he been able to benefit from the administration of contemporary therapies, this again is to appeal to an extrinsic development, which is no part of the basis on which respect is owed to anyone.

The distinction between intrinsic and extrinsic potential is not clear-cut. The intrinsic potential to develop a capacity requires the presence of suitable external conditions. A young human being cannot grow without the presence of food and water. The capacity for language cannot develop in the absence of a community of language users. If the potential for maturation and language is intrinsic – a plausible view - then we must allow that potential can be intrinsic whilst dependent on the presence of propitious external conditions. One obvious suggestion is that potential is intrinsic if it would autonomously develop in its normal environment; given this environment nothing else is required for its development other than the absence of injury, insult, and so on. Assuming nutrition, warmth, accommodation and so on, an infant has an autonomous potential to grow into a child, having the physical infrastructure and disposition for maturation; the potential is not externally instilled by parenting or culture.

On this account neither historical nor contemporary Alec has the intrinsic potential to speak; even assuming the most supportive environment he will not autonomously develop the capacity to speak. He needs multiple therapies, and we can only include the administration of genetic therapy as part of his normal environment on the most elastic construal of 'normality'.

On the other hand we might insist that both historical and contemporary Alec *do* have intrinsic potential in at least one sense, that both are or would be receptive to the administration of therapy, a receptivity enabled by neurological structures present in both Alec past and Alec present. So long as Alec-plus-therapy is the same person as Alec-minus-therapy we can insist that he has the intrinsic potential to respond to the administration of the therapies that will provide him with the capacity to speak.

Whether owing to complexities in establishing the contours of a normal environment, or in determining how normality is sensitive to technology, it is notoriously difficult to secure a firm grip on the distinction between intrinsic and extrinsic potential. It is probably a matter of degree. In a typical case, all that is required for a human being to develop the intrinsic potential for speech is that he should be provided with nutrition, shelter and a human community. However, we can consider a range of cases arranged along a continuum, and in each successive case he requires a little more assistance from the external environment in order that he should develop the capacity for speech, including, at one end of the spectrum, assistance that takes the form of extensive surgery. There is no obvious point or threshold that distinguishes between cases of intrinsic and extrinsic potential (McMahan 2006, 91).

These questions deserve more attention than I can give them here, and I return to consider where they leave us later. But so as to avoid having to determine where intrinsic potential ends and extrinsic potential begins we might conceive 'potential' differently. Waldron treats potential as a range property:

[T]he primary understanding of the range property is not of potential as such. The underpinning of equality is understood first and foremost in terms of the capabilities and their exercise. Nevertheless, what we understand as the relevant range property is still seen as the realisation of potential . . . The capacity is understood as a realised potential. Its realisation is understood to have happened or to be happening organically; that is, it is something that has unfolded or is unfolding in time. And it is understood . . . as a fragile process, whose unfolding will in every instance be shadowed from beginning to end by a possibility of organic or genetic failure, damage, and decline (Waldron 2017, 250-1).

There are various relations we may have to a Waldron capacity: a new born baby is 'at the early stages of its unfolding'; the capacities of someone at the end of their life 'undergo their inevitable decline' (ibid, 251); and a profoundly disabled person 'may have suffered the misfortune of the unfolding of this capacity going badly wrong, leading to profound disability, in which case the individual concerned bears a tragic relation to the capability.' (ibid, 251). We can, then, distinguish 'different modes of participation in the basis of human dignity: full possession of the capacity, growing into the capacity, or growing out of it, or tragic consummation of the possibility of brokenness that exists or existed as a possibility in everybody's case (ibid, 251-2).

It is not easy to make sense of some of these claims. If actual capacity is conceived as the realisation of potential and that potential is not realised, what remains of the capacity? If as a young child I had the potential to play Mozart on the piano, but never achieved more than elementary proficiency, then my potential was unrealised and I never acquired the capacity to become a Mozartian. It might have been hoped that one day I would realise my potential, but there will come a point when this is no longer a realistic hope. I have a relation to a capacity only if there is a capacity to be related to, and in this case there just is no, realised, capacity. The capacity I am

related to must then be unrealised. But we do not have relations with all our unrealised capacities. I might be 'that talented boy who would have gone on to play Mozart if only he had applied himself', and I might think of myself as someone who never made the most of his talents. But I might also have developed the capacities that would have enabled me to become an athlete, bricklayer, librarian or mathematician. It is hard to give determinate sense to the idea that I have a relation with an almost limitless number of unrealised capacities.

The case of some people with profound cognitive impairments is especially difficult for Waldron, because they do not have the neurological infrastructure to support the development of many of the capacities he supposes they are related to. In cases of Angelman Syndrome, for example, the child's copy of the Angelman gene, UBE3A is often missing (deleted), and there is no active copy of the gene in the child's brain. In this case there is no genetic infrastructure to support the development of the capacity to sustain attention. It is a fiction to suppose that a profoundly disabled person bears a 'tragic' relation to a capacity such as this. It may be a tragedy that his life has turned out as it has, but it cannot take the form of a relation to capacities that he does not have and can never acquire.

Perhaps I have been unduly conservative in my approach to potential. Suppose, then, we allow that Alec has the potential to speak if he would have been able to speak had he lived long enough for technology to advance to allow for the administration of what he needs. Even assuming that any such expansive conception of potential is coherent, it cannot supply a basis for ascribing capacities which serve as the basis of respect. Who knows what Alec might have had the

potential to achieve following yet to be devised neuro-therapies? Which of innumerable counterfactual capacities does he have the potential for, assuming that he had lived for another 100 (1000) years? In what sense is some capacity his, if he never actually possesses the physical infrastructure to support it? And is the Alec who we suppose might one day have possessed this infrastructure and the capacities it supports one and the same person as the Alec we know today? Without some limiting conditions in respect of time, feasibility and identity the potential capacities that we might attribute to someone are limitless, and this only makes for an unserviceable conception of 'capacity'.

Moreover, the more generous we are in our conception of potential the more difficult it becomes to sustain a distinction between what we want to say about human beings and what we are bound to say about some other animals. McMahan has pressed the point that, if we allow that profoundly disabled people have the potential required for respect on the grounds that we can conceive scientific developments that would provide them with the capacities they would need to qualify for this status then we can conceive the same of high-functioning non-human animals. (McMahan: 2002, 2005, 2008). We might observe that, in order to provide the genetic basis for the development of capacities necessary for respect, what is required in the human case is merely the stimulation of dormant genes, whilst for non-human animals we would first have to insert any missing genes into existing genetic material. But, in the first place, there may be human beings who do not have all the genes that code for the requisite development. Secondly, whilst the insertion of missing genes is different from stimulating genes that were previously dormant it is difficult to see why this difference should warrant a categorical moral distinction as between all human

beings and all non-human beings, particularly if the outcome of the respective procedures is the same, in the sense that both groups are left with an equivalent set of capacities (cf. McMahan 2002, 311-312).

This argument could be defeated if we can sustain the view that human beings are the only creatures destined to develop the capacities that provide the basis of respect. Waldron asserts that, whilst human children are 'not born with mature intellectual capability . . . they are . . . *born to it*. They are destined for rationality' (ibid, 236). The teleology invoked here rests on what we know about the evolution of organic structures, and their role in contributing to the survival and reproductive advantage of the beings who possess them. What has evolved in the human species:

is not just a set of structures and mechanisms that enable speech and cognition but processes of individual growth and development for each individual of a set of structures and mechanisms that enable speech and cognition. Understanding them in this way, we can attribute a telos, *in an entirely naturalistic sense*, not only to the structures and mechanisms where they are fully developed but to the earlier stages of their organic development (ibid, 239. Italics in original).

If we subscribe to a teleological explanation of the development of psychological capacities we can assert, of some genetic failure in Alec, that it has prevented the growth of some organic structure which would otherwise have fulfilled the function for which it evolved. And we might then claim that, after all, Alec had the potential for speech and cognition but that this potential was damaged or frustrated (ibid, 241).

This is an appealing argument; but it invokes a type of explanation, functional explanation, that is particularly controversial. I do not have the means to defend such

an explanation here, nor is it prudent to rest the case for respect for people with profound disabilities on a type of explanation that is widely viewed with suspicion.⁶

In any event, the argument from potential, whether by appeal to teleology or otherwise, can prove too much. Bare potential, certainly, cannot suffice for respect. I might have become an internationally renowned pianist had I not early on abandoned the instrument, but my potential to become an acclaimed musician has no bearing on what is owed to me as an adult. Or I might have become a senior politician, with all the associated rights and privileges, but the mere potential for a life in politics goes no distance towards according to me rights that would have been mine had I succeeded in that career.

Now consider a foetus which dies during pregnancy owing to bleeding from the placenta. Here, there is an internal failure or malfunction, which prevents the growth of a baby whose organs and brain development would otherwise have supported the functions associated with the capacities for speech, rationality and so on. Even if we allow that in such cases as these the normal development of human potential is frustrated, it is a large step to the claim that frustrated potential suffices as the basis of respect. If a human being is owed respect in virtue of their relation to the processes of growth of structures that enable speech and cognition, are we not bound to show respect to a foetus in just the sense that applies to an adult human being? If we are bound to do this, what does this imply for the status of a foetus in cases in which the mother is seeking an abortion as a means of preventing serious injury or even of saving her own life? If frustrated potential is sufficient for respect,

⁶ For discussion, see, eg. Wright 1973 and Boorse 1976.

there is no basis for distinguishing between what we owe to born and unborn human beings, including unborn human beings at the very earliest stages of human development.

In any case, if someone is born without the physical infrastructure to support the development of the capacity to speak in what sense is his capacity to speak frustrated? It would be frustrated if, having the capacity, or possessing the infrastructure to support it, life intervenes to impede or prevent any (further) development. But without the infrastructure there are no developments to impede or prevent. We might say that Alec belongs to a human kind, and the typical or normal development of members of this kind includes development of the capacity to speak. His capacity to speak is then frustrated in the sense that he is not able to develop a capacity that develops in most members of his kind. But whatever we make of this appeal to membership and norms of a kind, it is not an appeal we can make here, since we are bound by the constraint of looking only at capacities intrinsic to Alec. Whilst most human beings have the potential to develop the capacity to speak, and this is the norm for the species, nothing that we can say about most other people should settle what we can say about what is intrinsic to *him*. Others have this potential; Alec does not.

Disability activists are right to insist that we should aim at generous conceptions of potential: time and again disabled people have undertaken and achieved far more than many people would have believed possible; disabled people have to reckon with ignorance, error and prejudice, the imposition of ableist norms and an overly medicalised conception of disability. But allowing for all this, we are still forced to

conclude that many people with profound disabilities do not have the capacities required to meet the threshold at which respect is owed to them. They will not develop an autonomous will or a capacity to respond to reasons, and if they have any potential to do so it is not potential in a sense that can explain why they are owed respect.

RESPECT AND HUMAN RIGHTS

We should go back to the question I started out with: why include someone in the domain governed by norms that characterise the morality of respect, if they not only lack the psychological capacities required to belong in this domain, but also lack the potential to acquire these capacities on any conception that is not implausibly generous? If we confine attention to the psychological capacities of individuals we have no good reason for doing so. But I will now suggest that if we confine attention to the capacities of individuals we will also struggle to account for widely held normative views about the status of people with profound disabilities. I will take as an example the view that profoundly disabled people are, and ought to be included in the class whose treatment is governed by the norms specified by human rights. Why do (many of us) take this view?⁷ We might think it enough to state the obvious, that they are human beings, but this is precisely the kind of speciesist claim that moral individualists object to. In any case we can say a lot more about the capacities of people with profound disabilities than that they are human beings, and this will go some of the way towards providing the desired explanation. But not all the way; even on this largely uncontroversial question we find that confining attention to the

⁷ Some moral individualists, of course, may not.

psychological capacities of individuals will prevent us from accounting for why we acknowledge people with profound disabilities as bearers of the rights we want to insist on. Since we have good reason to uphold human rights for profoundly disabled people we have reason to reject the view that the basis for recognising their human rights lies exclusively in individual psychological capacity. This gives us a reason for reaching the same conclusion on the matter of how we should justify a principle of respect for profoundly disabled people.

The human being with profound impairments is not only a human being; she is, let us suppose, a young girl, with a name – call her Hanifa – and someone who smiles a lot, is often grumpy, and becomes anxious in the presence of strangers. Hanifa is someone with her own character; ‘she’s the smiley-grumpy’ one, as we say.

Watching Hanifa at play we might see a child who likes to be teased, who is constantly re-arranging the coloured objects in a favourite wooden box, who seeks out the eyes of her favourite teacher; a child who wears thick glasses, whose hair is braided, and who has a runny nose; a child who cannot walk, or talk or sit up without assistance; a child prone to fitting and who is often unexpectedly subdued; someone who needs constant re-assurance from loved ones; and someone who has good days and bad.

Some of what is distinctive about Hanifa is what she is *not* capable of – using language, toileting herself, recognising danger. These incapacities give rise to dependencies; she is much more dependent than most on other people to sustain a life that preserves her health and well-being. And she is dependent on other *people* for such a life: no other animals will provide the care and consideration she needs.

Her incapacities give rise to distinctively human dependencies, and a distinctively human predicament, as being in need of especially high levels of care and assistance from other people.

The capacities we take account of are not only those we observe at any one moment but also those included in her life as a whole. Hanifa is a child, and how we treat a child is shaped by our expectation that she will grow into an adult. If Hanifa gives evidence of being able to achieve some independence so that one day she might live in sheltered accommodation, there is a responsibility on her carers to help her develop the capacities she will need to do that. If Hanifa gives evidence that she will benefit from formal teaching, now, or later, then we will consider that she is owed an education, not only because she can benefit as a child but also because of what we owe her as someone who will grow into adulthood. The capacities we acknowledge, therefore, include those she has now and those we expect her to develop in the future, and this acknowledgement informs her preparation for adulthood, and the duties we are bound by in the way of her care and education.

No one, or almost no one has only the 'bare species characteristic of simply being human' (Nozick 1997, 308). Profoundly disabled human lives include all the psychological complexity sufficient for the development of character and individuality. Hanifa and people like her are each individual children; their lives have trajectories, and the capacities we take account of are understood in a context that includes what we expect of their likely course.

It is not necessary that Hanifa, as I have described her, should have the capacity for rational autonomy. The capacity to form a plan of life or develop a conception of the good is not a prerequisite for the capacities required to develop her own character, form loving relationships, and learn how to play with paint. Nor is it necessary that she is capable of judgement sensitive preferences, formulating rules and maxims, or directing her life in accordance with these. Even so, our longitudinal understanding of Rachel's distinctively human life goes some way towards explaining why she is not to be excluded from the class of human beings protected by human rights.

There is, of course, room for disagreement as to which rights are human rights, and which rights have application in the case of profoundly disabled people. But for at least a significant category of rights there is little dispute: those designed to avoid the worst that human beings can do to one another. Shue suggests that human rights concern the "lower limits on tolerable human conduct" rather than 'great aspirations and exalted ideals' (Shue 1996). In so far as human rights are designed to avoid the worst, they apply to profoundly disabled people just as they apply to anyone else, and no more argument is required to explain their application to this group than for anyone else. If, on the other hand, we take the view that how someone is to be treated is determined by considering their own particular characteristics, then more argument *is* required, and far from confirming an initial presumption in favour of according human rights to profoundly disabled people, further argument only serves to undermine it.

Profoundly disabled people are bearers of human rights, and all of us have a duty to treat them accordingly. How to explain this? If we adopt the premises of moral

individualism, there can be no appeal to a principle of respect since we have seen, and moral individualists anyway affirm, that profoundly disabled people fall below the threshold of respect (McMahan 2002, 260). But if we are not required to respect people with profound disabilities it may prove impossible to explain the stringency of the requirements and prohibitions that characterise their human rights – why, for example, degrading and inhuman treatment is *absolutely* prohibited - and we will also struggle to explain why some human rights should have any application to profoundly disabled people in the first place.

Some rights will be easier for moral individualists to defend than others: the right not to be tortured may be explained by appealing to the universal human interest in not being subject to the unconsented-to deliberate infliction of extreme pain. Here there is an appeal to the capacity to suffer. In other cases we can appeal to the capacity to benefit. One reason why the right to education should apply to very nearly every profoundly disabled child is that we can assume that very nearly every such child has the potential to learn something worthwhile. A defence of both rights can be made with reference to the morality of interests, interests generated by the psychological capacities of individuals. But other human rights – as with the rights not to be subjected to degrading treatment, servitude and arbitrary interference with privacy - require an appeal to ideas of dehumanisation and objectification. There are ways of treating Hanifa that she may be happy with and which in no way constrain her capacities; we hold her in servitude but treat her benignly. Although she may be a ‘contented slave’ this is no way to treat a young girl. Without any recourse to a principle of respect, and to the related ideas of treating someone as an object, or as

a mere minion, it may prove impossible to explain why we regard servitude as an abomination.

In my account of Hanifa, I made some attempt to avoid any reliance on the idea that she is a human being, *qua* member of the human species, having in mind the charge of speciesism. But it may be objected that I did not and could not succeed in that attempt. Why assume that Hanifa should never be treated like a dog? One answer is: because these are ways of treating Hanifa that are incompatible with how any human being ought to be treated. 'You can't do that to her - she's a human being' is often thought to provide reason enough to refrain from some action without the need for any further elaboration. We may have no objection to leaving a dog in a spacious kennel for a period, with food and water, and some litter in a tray. If Hanifa was happy enough to be left in a similar condition why not do the same with her? She might remain blissfully unaware of her leash whenever we let her out, and be quite content to obey instructions normally reserved for canines ('Hanifa, Sit!'). A moral individualist will struggle to explain why we could have any objection to this without having recourse to the idea that no human being should be treated like a (well treated) dog.

Up to this point I have not discussed human relations and practices, but these are integral to understanding the kind of creatures human beings are. In any case, it may fairly be said that I *have* implicitly made appeals to the importance of relations and practices: 'Hanifa' is a name, and naming is a social linguistic practice; she seeks the eyes and the arms of people she trusts; she smiles on seeing someone she recognises, she becomes anxious in the presence of strangers; and some people

have undertaken to care for her and are now under a duty of care corresponding to her right to their care.

I do not mean to deny that some human rights are sensitive to capacities that many profoundly disabled people do not have. The value of free speech is related to the importance we attach to human reasoning and personal autonomy. If these are not possible states for some human beings, it looks as if there is no connection between what we are trying to explain – their right to freedom of opinion and expression – and what we are offering up as an explanation of this right as it applies to *them*. It is hard to see how we can explain their right to freedom of speech without appealing to any of the capacities that this right is designed to protect. Freedom of speech, we might say, has no application to many people with profound disabilities.

It does not follow, however, that we should deny this group their right to freedom of speech. It is one thing, to acknowledge that someone does not have the capacity to reason, another, to enshrine in human rights law an exemption which formally declares that this person has no right to express an opinion. The exemption conveys the message that there is nothing that she could possibly want to say or give voice to, or that anyone would want to, or ought to hear. This message is stigmatising, not in the eyes of those with no right to speak, who will likely lack awareness, but in virtue of how they are regarded, singled out as fundamentally unlike and inferior to everyone else. Hanifa and her peers are to be forever shut out of the conversation; if they are silent anyway, they are to be kept that way. Even allowing that there are people who will never offer an opinion on anything, this amounts to rejection: a refusal to admit any profoundly disabled person into the class of human beings who

are permitted, now or in the future, to have any kind of public voice, not even as expressed on their behalf by a guardian. Stigmatisation and rejection are reasons not to deny the human right of freedom of opinion and expression to people who will never be able to make use of it.

If we are to explain why Hanifa should have the rights that many of us think she should have we are bound to introduce such considerations as these, considerations that are not confined to detailing her psychological capacities. It may have appeared that, when I introduced Hanifa, I was merely profiling her capacities, but when we assert that she, too, is a bearer of human rights, it turns out that we must consider these capacities alongside her humanity if we are to have any hope of explaining our view. If we have good reason to assert these rights on behalf of profoundly disabled people, then the resources of moral individualism appear to be explanatorily inadequate, making no allowance for the significance of belonging to humanity and leaving no room for a principle of respect. The two deficiencies are related: it is because there can be no appeal to the significance of belonging to humanity that the moral individualist is unable to include profoundly disabled people within the sphere governed by the norms of respect.

ONE OF A KIND

It is not only the moral individualist whose theoretical adequacy is in question. I have recently appealed to the fact of being human, relations to other humans and belonging to the human species. The first appeal must face the charge of speciesism; the second the objection that how we are related to others is no more

than of marginal significance to our moral status; the third that only by a process of moral alchemy can the question of how we should treat a profoundly disabled person depend on how others members of the species are to be treated, when their characteristics are fundamentally different to hers.⁸

Yet these objections must be overcome if we are to make sense of some idea of humanity as a basis for the claim that Hanifa is owed respect just as any other human beings are owed respect. They must be overcome, then, if we want to offer an argument that goes like this. We do not deny that there are large differences between profoundly disabled people and less disabled and other people, differences that extend to some of the most basic human capacities. However, we recognise that Hanifa and people like her are each individual children, born to and raised by human beings, and their lives, however curtailed and impaired, we conceive of as distinctively human, lived under human culture and sharing in our common life (Mulhall 2002). The differences are not so great as to justify a fundamental difference in how the two groups are to be treated; rather, the commonalities explain why Hanifa is, essentially, one of us, or sufficiently like one of us to be deemed one of us, and she is to be treated as such.

This is, of course, only the beginning of a long argument, and there is anyway a question whether this line of thought can extend to include *all* people with profound disabilities, for it assumes the presence of capacities that are not universally present in human beings. A small fraction of profoundly disabled people do not have the

⁸ McMahan presses these charges to powerful effect (2002, 2005, 2008).

capacities that allow them to develop anything much in the way of individuality or to engage in relationships with other people. Where do we go from here?

Even the most profoundly disabled human beings are not human beings in only a biological sense: each one is some mother's child (Kittay 2005); we see their lives under terms that take their bearings from our understanding of the human life cycle; there are times of birth, dying and death, marked by the formalities recognised under human culture; and almost no one would think of killing these people for food, or eating them, or keeping them in cages like animals in a zoo (Diamond 1978). These last actions are absolutely ruled out because even the most profoundly disabled human beings are members of our human kind, a kind subject to a distinctive morality that includes the morality of respect.

It is this last anthropocentric claim, of course, that is most in need of defence. The greater the extent of profound disability, the closer we move towards the condition of anencephaly, the more any argument will appear to rest on the sheer fact of being human. It should be clear how much weight is put upon this fact, on any additional facts about human beings, and on claims about the human kind and the norms that apply to it, claims which should reckon with ableist assumptions about human bodies, minds and life-cycles.

However we choose to explain what we owe to profoundly disabled people the moral individualist will rightly insist that we should include *some* reference to psychological capacity; psychological capacities and the physical infrastructure necessary for their development are what help to make human beings the creatures we are. If we have

a license to float free from any reference to capacities we can begin to entertain narratives that lead to views that are darker or more far-fetched than anything we have considered here.

Nevertheless, it is not possible to make out a case for respecting people with profound disabilities without reaching for resources besides those that reside in their psychological capacities. We cannot eschew an appeal to membership of the human kind, the importance of being human and the norms that attach to our understanding of a human life; that is, we will have to offer a thoroughgoing normative account of the kind we call 'humanity'. This requires a series of ambitious commitments, commitments which have long taxed those who are sympathetic to them, and towards which moral individualists are predictably sceptical; but for those of us intent on establishing more on behalf of profoundly disabled people than the moral individualist can admit, there is no alternative.⁹

⁹ Sympathisers include Mulhall 2002, Diamond 1978, Kittay 2005 and Crary 2016. McMahan has relentlessly attacked the commitments introduced in this last section (2002; 2005; 2006).

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