Respecting Autistics and Preventing Autism: Exploring a Tension in the Allocation of Public Resources

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Abstract. It has increasingly been argued by proponents of the ‘neurodiversity movement’ that society should change to accommodate autistic individuals – autistics – rather than trying to prevent or cure autism. Underlying this is a movement to re-conceptualise autism as neurodiversity, rather than as a disorder requiring a cure. In this paper I consider the tensions that arise in the context of people who oppose the claims of the neurodiversity movement – and seek to prevent and cure autism – in terms of the allocation of public resources to address autism. These tensions are difficult to neutralise or navigate. I examine two possible strategies to address this tension. The first involves narrowing the scope of the re-conceptualising to include only high-functioning autistics (HFA) and individuals with Asperger’s Syndrome (IAS), excluding low-functioning autistics (LFA). The second proposes addressing the co-occurring symptoms of autism, while leaving its essential characteristics untouched. The aim of this paper is to see if a space exists between the two extremes of rejecting the claims of the neurodiversity movement, or completely removing funding for the prevention and cure of autism. Hopefully, the difficulties of finding such a space will enable a fuller appreciation of the costs involved in the re-conceptualisation of autism.

1 CONTEXT

Two claims are present within the ‘neurodiversity movement’.2,3 The first is an ontological claim:

ND1: Autism is not an illness.

Rather, autism is part of the normal range of variation in neurological structures – it is neurodiversity. Autism is not a state deviant from the “proper” state of the brain, but simply another way the brain can be wired. This comes with certain payoffs, but also costs. This is not unlike how typical brain wiring – in neurotypical people – also comes with payoffs and costs. For instance, neurotypical individuals are unable to attain the same, high levels of perceptual capabilities that autistics are able to [4, 9]. The atypical brain wiring that allows for these capabilities also contribute to the poor social skills in autistics. However, rather than seeing this as involving trade-offs in different capabilities, people tend to focus only on the low levels of social capabilities and functionings when they think of autism. This, to proponents of the neurodiversity movement, is to adopt an erroneous picture of autism. First, it commits what some theorists have called the ‘sin of synecdoche’ – inspired by the literary device in which a part of something is used to refer to the whole. In this context, it is to see autism only in terms of the costs of atypical brain wiring, instead of also taking into account the payoffs that come along with it [10]. Second, deeming autism as an illness is to be mistaken about the ontological status of autism. This is explained using the enactive model of mind [11, 12, 13, 14]. On this model, the disabling behavioural traits associated with autism – and which motivates people to deem autism as an illness – do not find their cause simply in biology, but in the interaction between individuals and their environments [15]. This is contrary to the conclusions of an account in which illness – and its disabling effects – is explained simply by biology. In this context, autism is not an illness, since its effects are not explainable simply by biology.

This is related to the second claim, which is a political claim:

ND2: Society should allocate resources to accommodate the different needs of autistics, rather than trying to prevent and cure autism.

If autism is currently an illness, it is not the result of biology but of society not doing enough to accommodate the different needs of autistics [16]. Here, accommodation of autism is seen in contrast to curing it. The latter involves trying to “remove” autism in order to restore the autistic to “health”. Instead of that, the former involves trying to address the different needs of autistics by changing society – either in terms of physical structures, or institutions that manage resources for addressing those needs [17].

Proponents of the neurodiversity movement argue that while society has accommodated the costs of neurotypicality, it has not done the same for autism. For instance, we address the consequences of poor memory via accommodation (especially invention). People with poor memories who need to constantly check their electronic devices are excused from stigmatisation, as long as they continue to achieve certain functionings. The same, however, cannot be said for society’s treatment of autistics. And ND2 seeks to change this.

Both these claims are hotly contested. Against ND1, people insist that autism is a disability. Against ND2, people argue that society should instead allocate resources to prevent and cure autism.

In this paper, I examine the tensions that arise from these opposing claims, in the context of the allocation of public resources to address autism. I first clarify the tension by considering two “first-pass” attempts to negotiate the tension and why they do not succeed in navigating the tensions. Next, I examine two possible strategies. The first is by Pier Jaarsma and Stellan Welin, who propose narrowing the scope of the claims of

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2 For some survey articles, see [1, 2, 3, 4, 5].
3 The first use of this term is inconsistently credited to both Harvey Blume and Judy Singer. See [6, 7, 8].
the neurodiversity movement to include only high-functioning autistics (HFA) and individuals with Asperger’s Syndrome (IAS), excluding low-functioning autistics (LFA) [18]. The second proposes addressing the co-occurring symptoms of autism, while leaving its essential characteristics untouched. I argue that both strategies are not successful. The aim is to see if a space exists between the two extremes of rejecting the claims of the neurodiversity movement, or completely removing funding for the prevention and cure of autism. Hopefully, the difficulties of finding such a space will enable a fuller appreciation of the costs involved in the re-conceptualisation of autism.

2 CLARIFYING THE TENSION

I clarify the tension by considering two “first-pass” attempts at negotiation, and why they do not succeed. In so doing, I flesh out the claims on either side of the tension as and when is necessary to assess the success of the attempts. In seeing how these two attempts are inadequate, we can get a better picture of the reasons that support both positions, and how we can subsequently navigate the tension.

2.1 Waiting for science

The first attempt (A1) suggests that we wait for science to give us an answer to the ontological status of autism. That way, we can resolve the dispute over the ontological claim (ND1). If it turns out that autism is an illness, then it means that we should cure it, rather than accommodate it. In this way, we can take a stand on the political claim (ND2) as well.

However, this erroneously assumes that ND2 turns on the success of ND1. Proponents of the neurodiversity movement can still push for ND2 even if the ND1 does not succeed. To give an analogy: we know that myopia is an illness – in that its cause is located in terms of biology. Yet that does not stop us from allocating resources to accommodate the needs of people afflicted with myopia, nor does it commit us to allocating resources to prevent and cure myopia. The conclusions of science leave open what we ought to do regarding ND2 – appealing to science cannot resolve ND2. 4 A note: this appears to run counter to the current debates over autism. A fair bit of the debates appear to hinge on whether autism is an illness. Proponents of the neurodiversity movement put up valiant efforts to protect ND1. Are they conflating the ontological claim with the political claim? We shall discuss this in detail later.

Moreover, A1 misses out on the fact that we cannot wait for science – in the sense that a pragmatic decision needs to be made, even without a final answer from science. So, even if making a pragmatic decision now risks “getting it wrong”, we still have to go on. The demand for negotiating between the opposing claims is urgent. Our situation is like a Beckettian character – “I can’t go on, I’ll go on” [19].

2.2 Satisfying both political claims

The second attempt suggests that we just try to satisfy both political claims. This attempt finds its basis in pointing out that the political claim of those who oppose ND2 leaves open whether we should allocate resources to accommodate the needs of autistics. Strictly speaking, they do not contradict each other. It appears that we can both allocate resources to accommodate autistics, as well as prevent and cure autism. The first response is to point out that it is not likely we can do both given the constraint of scarce resources. This is especially so given that research to cure autism, institutions and mechanisms to prevent autism, and to accommodate autism all require a lot of resources. In trying to do both, it is likely that we will fare poorly in both.

More importantly, however, this attempt at negotiating does not work because of how ND2 is argued for. ND2 does not seek accommodation, simpliciter, but strives for something more. We clarify this, negatively, by considering a case dis-analogous to autism. Jonathan Wolff discusses the case of an activist who claims to celebrate his quadriplegia, arguing that we should not understand the remarks as indicating that he wants to bring more quadripilegics into the world, or that since quadriplegia is to be celebrated we should neglect safety or disapprove of people who seek to cure it. Rather, we should understand the activist as trying to make another, quite different, point with a political intent. A society which has adjusted itself to accommodate quadriplegia by means of suitable transport and education policies, tolerant social attitudes, and other imaginative steps, is good for all of us. [17, p. 131]

Here, we accommodate quadriplegia without simultaneously treating it as part of the normal variations in human forms – we deem quadriplegia abnormal. The accommodation of quadriplegia is compatible with trying to prevent and cure it. However, this is not what ND2 seeks. Rather, ND2 seeks accommodation of the different needs of autistics, without attempting to prevent or cure autism. This dis-analogy can be explained by looking to the claims of some autistics that trying to prevent and cure autism is to be disrespectful to them [1-9]. There are three locations of disrespect that we can extract from the claims that have been made.

The first location of disrespect is in terms of mis-identifying what autism is. In wanting to prevent or cure autism, the stand taken is that autism is an illness – which is a mis-identification of what autism is. An analogy here can be drawn to homosexuality. In deeming homosexuality as an illness or affliction, we mis-identify what it really is. This mis-identification constitutes a form of disrespect [20] to homosexual individuals. A note: this is one way that ND1 can be, and is, linked to ND2. In this way, the political claim hinges – albeit loosely – on the success of ND1.

Second, trying to prevent and cure autism disrespect autistics in ignoring how autistics understand autism as central and integral to the ways their lives unfold. In taking autism to be something undesirable that ought to be eradicated (prevent and cured), we not only belittle the importance and fruitfulness of autism as a core element of individuals’ identities, but also contribute to the perpetuation of unfairly negative portrayals of it [21, 22]. The analogy with homosexuality also holds in this aspect.

Third, the disrespect stems from ignoring the obligations that are owed to autistics, in terms of allowing them to pursue their

4 I later argue for a stronger conclusion – that the way which science unfolds turns on how the conflicting political claims are negotiated. But the weaker conclusion is sufficient for the claim that we cannot wait for science.
life plans. As earlier mentioned, autism plays a central role in how autistics see their lives, and features correspondingly in their life plans. Employing John Rawls’ framework, we have to ensure that the arrangement of the basic institutions of society do not prevent or unfairly disadvantage autistics from pursuing their life plans. To fail to do so would be to not seriously take autistics as equal citizens whose life plans ought to be taken into consideration in the design and arrangement of the basic institutions. Trying to prevent and cure autism, when in fact autism features as a central element in the life plans of autistics (in the neurodiversity movement) is to be disrespectful to them in just this way.

Returning to the point, these three locations of disrespect contribute to the rejection of trying to accommodate the needs of autistics while trying to prevent and cure autism. Even if we put aside the first claim about what autism really is – for its success contributes little to ND2 – we still have two more to contend with. While they are not conclusive, they point to the difficulties of trying to satisfy both political claims. I now put aside the two ‘first-pass’ attempts, and move to consider two strategies that seek to negotiate the tension.

3 NARROWING THE SCOPE OF THE NEURODIVERSITY MOVEMENT

The first strategy involves narrowing the claims of the neurodiversity movement. Instead of attempting to account for all cases of autism on the spectrum, we should restrict ourselves only to high-functioning autistics (HFA) and individuals with Asperger’s Syndrome (IAS). This strategy appears to have some following among parents who seek to cure their autistic children. Lenny Schaefer, publisher of the popular Schafer Autism Report, wrote that ‘[i]f those who raise their opposition to the so-called oppression of the autistic would simply substitute their usage of ‘autism or autistic’ with ‘Asperger’s,’ their arguments might make sense’ [1].

3.1 Reconstructing Jaarsma and Welin

In what follows I discuss this strategy in relation to Pier Jaarsma and Stellan Welin, who argue that ‘[o]nly a narrow conception of neurodiversity, referring exclusively to high-functioning autists, is reasonable.’ [18, p. 20] Jaarsma’s and Welin’s strategy is motivated by two main kinds of considerations – one purporting to benefit of the low-functioning autistics (LFA) and the other for the high-functioning autistics. I first reconstruct their arguments as best as I can, before addressing them in turn. Because of space constraints, I only address their arguments from the perspective of seeking to benefit the LFA – though I think that their arguments from the perspective of the HFA also do not succeed.

The considerations seeking to benefit the LFA begin from the intuition that there are some characteristics of autism resistant to re-conceptualisation. These characteristics – such as intellectual disability or not being fully toilet-trained – appear to be clearly deficits whose reality cannot be changed by any amount of rhetoric [2]. Of course, the success of such a claim turns on whether these characteristics are indeed clearly deficits that should be cured, rather than those addressable by changing society to accommodate them. Many characteristics have been discussed, but I consider only two apparently obvious ones – cognitive disability, and the inability to lead independent lives.

Jaarsma and Welin claim that there ‘seems to be a partial consensus on this distinction [between HFA and LFA]: if autists have an IQ in the normal range (or above) they usually are said to have high-functioning autism’ [18, p.21]. Those who do not fall within that range are considered LFA. To date, LFA is taken as akin to mental retardation in terms of its impact on individuals [23]. This conclusion is backed up by several studies. When tested on the capacities to perform certain cognitive tasks, LFA fare similarly to the cognitively disabled. With less-developed cognitive capabilities, they are unable to manage many of the functionings that neurotypical individuals are able to. Rather than having society accommodate individuals who are only able to function at lower cognitive levels, we should instead seek to cure the cognitive limitations.

Jaarsma and Welin also argue that LFA are unable to lead independent lives. In addition to, and perhaps as a result of, less-developed cognitive capabilities, LFA are also unable to perform routine activities that are crucial for everyday life. These activities include going to the toilet by themselves, cooking, or even driving – and are crucial aspects of leading independent lives. In this regard, LFA are unable to lead independent lives in ways similar to neurotypical individuals [18, p.28]. As with cognitive disabilities, Jaarsma and Welin claim that we should cure these deficits rather than changing society to accommodate them.

At first glance, these characteristics do appear to require a cure, rather than accommodation. Jaarsma and Welin leverage on this prima facie plausibility to point towards a ‘paradox’ that would arise if the claims of the neurodiversity movement were extended to include LFA. Specifically, ‘[i]f neurodiversity is accepted by society as a special culture, the autists that need care may face a hard time getting it, because their state of being will be regarded as just a natural variation.’ [18, p.27]. The worry is that the rhetoric of autism being a natural variation may make it difficult for those who need medical care to get them – which ends up being detrimental to the well-being of the LFA. They do not elaborate on this claim, but we can perhaps see it as pointing to our treatment of left-handed people. Though we used to, we do not currently see them as having special learning needs that need to be cured. In this way, the claims of left-handed people to address their special learning needs become illegitimate. Though the analogy I provide is not tight, we may nevertheless see Jaarsma and Welin as intending something close to it.

In resisting extending the claims of the neurodiversity movement to include the LFA, Jaarsma and Welin also put forth arguments from the perspective of seeking benefit for the HFA. These arguments turn on the earlier claims that LFA are clearly deficit in some crucial ways. First, they argue that to put Asperger’s Syndrome ‘in the same category together with low-functioning autists may be regarded by some of the persons with Asperger’s as an even worse stigmatization.’ [18, p.25]. Here, the worry is that grouping IAS, and HFA, together with LFA may not be genial to the self-respect of the former two. This is not simply because the former will be grouped together with individuals who are not alike, but also because the latter group possesses certain deficits that will be detrimental to how the former see themselves, and how people outside the group see them.
In fact, Jaarsma and Welin proceed to argue that the claims of the movement are only reasonable if seen as stemming from a culture. We need ‘a restrictive view of the autistic culture, only including high-functioning autists, to get a potentially independent culture’ [18, p.27]. It is this independent culture that will ground the claims of the movement. Including the LFA – individuals who are not ‘usually able to manage on their own’ [18, p.27] – within the neurodiversity movement may actually be detrimental to the HFA – it jeopardises the latter’s claims to a culture, and to the group rights and resources that come along with it. This claim is not further explained, but is presumably because people may be so distracted by the deficits of the LFA that they reject that the group they are in can be genuinely considered as a culture. This is intended to bolster the claim that grouping the LFA with the HFA and IAS is not productive.

If their arguments succeed, and a line can successfully be drawn between HFA and IAS on the one hand, and LFA on the other, then Jaarsma and Welin would have negotiated the earlier mentioned tension. We would be able to grant members of the neurodiversity movement their self-respect, yet continue to allocate public resources to prevent and cure autism. However, I doubt we can sensibly draw such a line. My responses will primarily centre on the various difficulties of doing so.

3.2 Responding to Jaarsma and Welin

Assume that public resources are in fact put into preventing and curing autism. One obvious response lies in a worry that in preventing and curing cases of autism on the lower end of the spectrum, we simultaneously prevent and cure autism on the higher end of the spectrum. If so, the earlier mentioned tension arises again – there will simply be no agreement on whether prevention and cure should proceed, even for LFA. This worry assumes that all cases of autism share a common cause, which when addressed will have implications for how it manifests in individuals. However, this picture does not cohere with the increasingly common suspicion of finding a common cause of autism [24]. Perhaps, as more research is done, we may find that ‘autism’ may break down into a family of different, related phenomena [1]. This also coheres with what members of the neurodiversity movement mean when they say that ‘[w]hen you know a person on the [autism] spectrum, you know one person on the spectrum’ [2]. Given this, it is possible to cure autism that leads to LFA, without affecting HFA and IAS. I recognise that this is a possible way out of the tension, but argue that not much can be made of an argument like this at this point. We do not currently know enough of autism – especially the connections between how it manifests differently across cases – to conclusively reject or accept drawing a line between HFA and IAS on the one side, and LFA on the other. But we cannot wait for science – the decisions that have to be made now cannot be postponed. Pointing to a possible future solution does not solve the tension that we now face.

Much else can still be said about Jaarsma and Welin’s arguments; I now respond to them directly. First, their argument from the partial consensus on separating LFA from HFA on the basis of cognitive capabilities omits to mention that the consensus is difficult and problematic. Because of space constraints, I only gesture towards two ways the consensus is problematic. First, many standard tests for intelligence only test for some cognitive capabilities not representative of the full range. In construing intelligence on the basis of a narrow set of cognitive capabilities, all that these IQ tests can tell us is that autistics simply fare worse than non-autistics – and not that they are intellectually deficient [25]. The second is that even for those capabilities that are being tested for, current methods are ill-suited to autistics [26]. For instance, it has been argued that the Wechsler Intelligence Scale for Children requires competences in capabilities – such as speaking – that autistics fare worse at.

The alternative is to go for a test that avoids smuggling in these requirements from other capabilities. The Raven Progressive Matrices is cited as better suited for autistics, while being neutral for some cognitive capabilities not representative of the full range [4, 26]. Moreover, even if we did not rely on these arguments, merely pointing at individuals who have been described as LFA, but whose intellectual capabilities are clearly not absent or diminished, should already give us an indication our conclusions about who qualifies as LFA, and what counts as LFA, are suspect. The most famous example must now be autistic activist Amanda Bagg. Even though described as LFA, she was able to produce and upload a video to YouTube that contains cogent arguments on how neurotypical individuals have misunderstood autistic individuals [27]. Clearly, she is not intellectually disabled.

Second, that those described as LFA have difficulties with independent living not only determines less than what Jaarsma and Welin seem to intend, but is also crucially blind to the point of the neurodiversity movement. That LFA face these difficulties does not bring us immediately to the claim that they therefore require a cure. In the context of the tension we wish to examine, merely pointing out that LFA have difficulties with independent living leaves open the question of what we should subsequently do in addressing these difficulties. While curing autism in an option, it is only one possibility.

This points us back to one of the central claims of the neurodiversity movement – society unfairly catering to the costs of neurotypicality, while neglecting those of neurodiversity. Part of what is sought, is getting society to change in order to accommodate those costs that arise from atypical brain wiring, in the same ways that it has done for typical brain wiring. The earlier example on accommodating bad memory point us to the reality that even neurotypical individuals employ prostheses in everyday life. Paying attention to how these prostheses support and cater to certain types of (diminished) capabilities, and how their use has been normalised, is important if we do not want to obscure the reality of our capabilities’ dependence on the environment to bring about functioning. But why is it not the same for those capabilities of autistics that require addressing [23]? In thinking about how autistics have difficulties with toilet training, we will do well in thinking more closely about the reasons for why we do not deem these as requiring accommodation, but instead needing a cure. Jaarsma and

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5 I leave aside the issue of whether using public resources to fund research on autism is disrespectful to autistics, especially in terms of singling autism out.

6 Many thanks to an anonymous reviewer who pointed out that given the unsettled controversy surrounding IQ testing, the arguments from IQ testing do not fully support my conclusion that it is problematic to draw a line between HFA and LFA. Unfortunately, I do not have space to address the issue fully.
Welin’s arguments that autistics face difficulties with independent living may well succeed. But if they do, they must be on the basis of detailed arguments about why society should not accommodate these difficulties, and why they are best addressed via curing autism.

Moreover, thinking that neurotypical individuals are capable of independent living is to neglect the fact of their dependences and inter-dependences on others to achieve the functionings that independent living may well succeed. But if they do, they must be on the basis of detailed arguments about why society should accommodate these difficulties, and why they are best addressed via curing autism. As Martha Nussbaum and other disabilities theorists have argued, non-disabled individuals function in the world within a network of interdependences [28]. Again, the question is not whether autistics can have independent lives, but whether society is prepared to protect the atypical kinds of dependences that autistics require for their functioning.

Third, the connection between the acceptance of the neurodiversity movement, and autistics’ ease of access to care has been overlaid by Jaarsma and Welin. Their claim omits to mention that we can deem a characteristic as belonging to natural variation, while thinking that it requires special care. One obvious example is the case of pregnancy. Deeming it a natural variation in human forms does not commit us to the subsequent claim that pregnant individuals do not need special care. Focusing on their actual phrase, that ‘autists that need care may face a hard time getting it’ [18, p.27], does not help their case either. To use the case of pregnancy again, the fact of natural variation does not even point us to any increase in the probabilities of people deeming it as not requiring special care.

Assume we understand Jaarsma and Welin as making a sociological, rather than analytic, claim. The connection we seek is then filled in with reference to empirical information about how things are in the world. Perhaps, it is the case that in accepting autism as part of natural variance, while thinking that it requires special care. The decisions about what autism is, is on the basis of how things are. While the sociological reading of their claims avoids the obvious leap in reasoning, it commits them to ignoring the people they seek to help.

All that said, there is another line of consideration concerning Jaarsma and Welin’s proposal. It is that a crucial internal inconsistency may be introduced into the neurodiversity movement if a line were indeed to be drawn between HFA and IAS on one side, and LFA on the other. Stepping back, we see that the line was drawn on the basis of a comparison to certain types of characteristics and functioning that are either present in, or analogous to those of neurotypical individuals. As earlier mentioned, a central claim of the neurodiversity movement is that society has catered unfairly for neurotypical, but not neurodiverse, individuals. Drawing a line in this manner between HFA and IAS, and LFA would mean that society now caters to some neurodiverse individuals, but not others. It is not clear that catering only to those who are not so different – or even similar – from neurotypical individuals coheres well with the spirit of the neurodiversity movement – which is at its heart a call for society to cater to those who are different. In doing so, what we are doing is merely ‘postpone’ or relocate the original tension from one residing between members of the neurodiversity movement and neurotypical individuals, to one existing within members of the neurodiversity movement.

4 CURING CO-OCCURRING TRAITS

Related to the earlier point – of curing some cases of autism but not others – is a different strategy. This strategy proposes that we seek to prevent and cure only the co-occurring, or comorbid, deficits associated with autism, and leave the essential characteristics of autism untouched. In this context, co-occurring deficits are other medical conditions that exist simultaneously with, but independently of, autism. For example, we may address the issue of intellectual disability via medicine, but leave the rest to society to accommodate. In doing so, we can occupy a space between the demands of the neurodiversity movement and the wishes of parents who seek to cure their autistic children. I put aside the issue of whether such a claim directly rejects the neurodiversity movement’s claim that what we think of as deficits are actually the costs of having an atypically wired brain.

It appears that we cannot yet make an adequate assessment of whether this strategy is plausible, at this point where we have so little information about autism. However, I want to argue that even if we had the necessary science that points us to the causes of all the different characteristics and behavioural traits associated with autism, the problems we face nevertheless remains. I hope to gesture towards the claim that the debate cannot be resolved purely or easily by the progresses of science.

Assume that science already has located the causes of all the different characteristics – including capabilities and deficits – that are manifest in autistics. For instance, the causes of RRBIAs, peaks in perceptive or other cognitive processes, and the like, have been identified. The next question is: what is the “core” of autism, and what is merely contingently related to it?

To answer that, we first have to decide on what autism is. And the decisions about what autism is, is on the basis of grouping certain characteristics together. The context for this claim is found in how autism is identified and diagnosed. Currently, autism is identified on the basis of behavioural criteria. The fifth, and current, edition of the Diagnostic and statistical manual of mental disorders (DSM-5) sets fairly strict criteria on what behavioural characteristics must be present before an individual is considered autistic – for example, he or she must possess three characteristics of deficits in social communication and social interaction not accounted for by general developmental delays, together with two of four identified instances of RRBIAs [29]. Currently, there is some degree of fungibility in terms of the behavioural characteristics that are taken as constituting autism – the absence of one characteristic can be ‘made up for’, so to speak, by the presence of another – as long as the set number of characteristics are present.

The question of what should be included as the “core” of autism can be elaborated on, via considering the example of Asperger’s Syndrome. In the fourth edition of the Diagnostic and statistical manual of mental disorders (DSM-IV-TR), Asperger’s Syndrome was considered a separate entity from autism – and lies outside what is now termed the Autism Spectrum Disorder (ASD) [30, 31]. What motivated the change in how Asperger’s Syndrome is understood? In part, this is due to the decision that language delays are not essential to autism – an answer in the affirmative rules out Asperger’s as a kind of autism [32]. That the DSM-5 now deems Asperger’s as a kind of autism along the spectrum indicates a corresponding shift in the understanding of autism and what is essential to it. The question we want to ask: for what reasons was it decided that language delays were or
were not essential to autism? We do not have any agreed-upon standard on the basis of which we can decide which characteristics and behavioural traits ought to be constitutive of autism. This change in how we understand Asperger’s Syndrome is controversial – and still the subject of much heated debate. In fact, discussions about whether language delays are essential to autism are often quite fraught with the tension arising from people who just understand autism differently from each other. For instance, parents who are interested in curing their autistic children resist the current understanding of autism, for fear that it may affect their prospects of getting resources to address language delays in their children, on the basis of autism alone.

More generally, what can we say about why any of the other characteristics are currently identified either as essential or associated with autism – and will these reasons by agreed to by people on both sides of the issue of re-conceptualising autism? Returning to the strategy of wanting to cure co-occurring symptoms while leaving core characteristics untouched, we see that the question is left open as to which characteristics are essential and which are merely co-occurring – even upon identification of all the causes of all the characteristics associated with autism. And as we have seen in the case of Asperger’s Syndrome, the discussions about whether one single characteristic is essential to, or co-occurring with, autism are the subject of much heated debate. I suspect – though I cannot argue further – the same may apply to the other characteristics currently associated with autism. For example, parents interested in curing their autistic children may argue that RRBIs are merely characteristics that co-occur alongside the different distribution of cognitive capabilities manifest in autistics, whereas members of the neurodiversity movement may argue that they are essential to autism. I suspect, though I cannot argue for it further here, that people who want to reject the claims of the neurodiversity movement will have vested interests in arguing that many characteristics and behavioural traits are not essential to autism, and ought to be cured. The idea – or maybe, hope – is that in curing all these co-occurring symptoms, they manage to get at a neurodiverse individual who is in all respects similar to a neurotypical individual.

Returning to the point. Even if there were a consensus between the two opposing parties that co-occurring deficits ought to be cured, rather than accommodated for, there still looks to be no resolution in sight. That we agree with this strategy – which is at a high level of generality – does not give us a way of negotiating the disagreements that occur at the level of whether any single characteristic is essential to, or co-occurring with, autism. The disagreement between the two parties run deep, and it is not likely that this strategy will be of much help.

5 CONCLUDING REMARKS

I began with a question of examining the tension that arises from respecting autistics while trying to prevent and cure autism, in the context of the allocation of public resources to prevent and cure autism. I considered two “first-pass” attempts, and two strategies that purported to negotiate the tension. None of them appear to be satisfactory in allowing us to negotiate the tension. In outlining the difficulties they run into, I partly clarified the nature of the tension. I hope this clearer understanding of the sites of disagreement paves the way for future work to find strategies – theoretical or practical – that can negotiate this disagreement.

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