

PAPER

Conceptualising well-being for autistic persons

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ABSTRACT

In the philosophy of well-being, there is hardly anything written on the lives of people with autism or on the question whether existing philosophical theories of well-being are suited for understanding how well the lives of autistic persons are going. This paper tries to make some progress towards filling this gap. I start by giving a concise account of autism, which highlights the huge heterogeneity among autistics. I discuss some basic features of autism, ask whether there are good reasons why we would need an account of well-being specifically for autistics and what philosophical well-being research could learn from being informed by autistic experiences and phenomenology. I then investigate to what extent the capability approach gives us a helpful theory of well-being for autistics, and what looking through an autism lens can contribute to the further development of the capabilitarian well-being. In particular, I show that some capabilities that are crucially relevant for autistics are also relevant for the lives of non-autistic people. The final part of the paper looks at an important difficulty in using the capabilitarian account of well-being for autistics, namely: should the normative focus be on achievements (functionings) or real opportunities (capabilities)?

INTRODUCTION

Autistics, like all other people, want to live good lives. Their family members and friends generally also care deeply about their well-being. Among these groups, many believe that most autistics have, all other things equal, lower levels of well-being than non-autistic people, and, consequently, that much more should be done to try to improve their quality of life. Yet such judgements must rely, at least implicitly, on an account of well-being. Similarly, the terms 'well-being' and 'quality of life' are often used in policymaking and in educational and therapeutic settings. In those areas too, references to 'well-being' are often made without reference to a proper theory of well-being. Still, this seems to be the first question to ask when thinking about the well-being of autistics: What do we mean when we refer to 'the well-being of people with autism'? Is there an account of well-being that is suitable for thinking about how well the lives of autistics are going?

Unfortunately, the current state of academic research does not offer a satisfying answer to this question. There is a huge empirical literature on well-being and a lively philosophical literature, but the two are poorly connected.¹ There are empirical studies using quality-of-life instruments to study the lives of people with autism² and some work in

disability studies focusing on the quality of life of autistics,³ but these measurements are generally not based on any philosophically robust theory of well-being. As a consequence, it is often unclear in empirical assessments whether these accounts entail constituents of well-being, or rather their proxies, or the determinants of well-being, or the resources needed for well-being. It is also unclear whether important dimensions are missing. There is thus a *prima facie* reason to believe that the empirical literature would benefit from some more philosophically robust foundations. Unfortunately, while there is a huge literature by moral philosophers working on the philosophy of well-being, there is virtually no work on the conceptualisation of well-being for people with autism. There is some limited work on the question of which account of well-being is most suited for disabled people, but this work tends to prioritise either physical disabilities or cognitive disabilities.⁴

This paper will try to make some progress by analysing philosophical theories of well-being, and in particular, the capability approach to well-being, from the perspective of people with autism. What, if anything, do we need from the current philosophy of well-being in order to have a helpful account of the well-being for people with autism? My strategy in answering this question will be the following. In the next section, I will first give a concise account of autism, highlighting some of its core features. I subsequently briefly introduce philosophical theories of well-being. I then focus on the capability approach to well-being and investigate how it should be adapted in order to fully include people with autism. This will lead to two conclusions: first, that the capability approach gives us a promising basis to develop an account of autistic well-being, and second, that developing such an account teaches us something about the items that a capabilitarian account of well-being *for all people* should contain. Asking what makes for a good account of well-being for autistics therefore will be helpful for our personal decisions or policy-making aiming to improve the lives of autistics, and also will give us some insights into the general development of the capabilitarian account of well-being.

Before proceeding, a terminological note is in order. There are different views on whether the best term is 'a person with autism' or rather 'an autistic' or 'an autistic person'.⁵ I will assume in this paper that all sides in this debate have good reasons to believe that their preferred term is the most respectful. I will therefore use these terms interchangeably and postpone a full analysis of the question which terminology is most appropriate.



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AN ACCOUNT OF AUTISM

It is hard, given space constraints, to present a sufficiently subtle account of autism in a mere few pages. Autism is a condition that manifests itself in many different ways, and hence is hard to get a decent grip on. Asking what autism is and how it should be understood has led to claims that psychiatric labels are not the right way to classify neurodiverse people,⁶ that autism is a social construction and that we should get rid of the autism label altogether,⁷ and that autism research is too much focused on the neurobiological basis of autism and should instead focus on experiences of impairment, distress and particular behaviours.⁸ While these are important and highly interesting discussions, they fall beyond the scope of this paper. Here, I will simply attempt to describe autism as brief as I can without making a caricature of the condition and highlight those aspects that are important for thinking about the well-being of autistics.

Autism is a term we use for a condition that is generally taken to be a pervasive developmental disorder.^{9 10} It is an umbrella term that is used to describe several different subgroups of autism, including most prominently classical autism, Rett syndrome, Pervasive Development Disorder—Not Otherwise Specified and Asperger's syndrome. Although there is strong evidence that autism has a genetic basis, so far no genetic or biological 'core' of autism has been identified. Instead, there are speculations that up to 1000 genes are implicated in autism.¹¹ Since there is no biomarker or gene that can be attributed a causal role, the diagnosis of autism is fully based on behavioural features.

Following the most recent diagnostic criteria, as laid down in the DSM-V, in order to be diagnosed with autism, one needs to have persistent deficits in social communication and social interaction across multiple contexts, as well as restricted, repetitive patterns of behaviour, interests and activities. Autism scholars recognise that there are some other features that are central to autism, but that are not part of the DSM-V criteria. One important criterion is atypical language development and abilities, which was a core feature included in DSM-IV. Other features are motor abnormalities. A recent meta-analysis by Meng-Chuan Lai, Michael Lombardo and Simon Baron-Cohen does not mention sensory oversensitivities and undersensitivities as a core feature.¹¹ This is surprising, given the strong arguments given by Temple Grandin¹² that it should be key to our understanding of autism, as well as the experiences of many people with autism and their caregivers.

In addition, a large percentage of autistics are suffering from co-occurring conditions. About 45% has an intellectual disability, and other often observed co-occurring conditions include attention deficit hyperactivity disorder (ADHD), gastrointestinal problems, immune dysregulation, sleep disorders anxiety, depression, oppositional defiant disorder, aggressive behaviours and self-injurious behaviour.¹¹ This long list of co-occurring conditions only complicates the task of a better understanding of autism itself and also explains why autistic individuals make up such a heterogeneous group.

Autism manifests itself in many different ways among autistic individuals. All autistics have ways of interacting that are not in line with how the vast majority of people in society interact. Most people with autism have 'atypical' ways of communicating, yet this 'atypical communication' may manifest itself in very different ways. Some autistics—often referred to as 'low-functioning autistics'—have hardly any speech or no speech at all, and can only communicate very basic things, like a desire to go for a walk, or can only communicate with intensive help of facilitators and technology. Others master speech, reading and writing excellently, but still are considered 'non-normal'; for

example, in the rather formal use of language by people who have Asperger's syndrome. Autistics generally have a hard time understanding bodily communication (like facial expressions of anger or irritation), they are generally quite bad at picking up social cues, they may not look others into the eyes or instead keep staring at people when social norms would tell us that we ought not to do so. Autistics often have difficulties with understanding jokes, but this need not mean that they do not like humour; instead, they may develop their own forms of humour, which neurotypicals have a hard time to grasp. More generally, they have a hard time understanding the relevance of social context for expectations and social norms.¹³

At the concrete level, the behaviour of autistics and the challenges they face vary dramatically. Some autistics try to avoid the presence of other people. Others love the company and attention of others, but may not have the intuitive understanding of social codes and thus may need to learn those explicitly to the best of their abilities. Some autistics may become anxious, aggressive or self-injurious if they are confronted with sudden changes or disruptions; others may just need a minor heads-up for a change to a new activity, after which they cope well with such transitions. Most autistics have strong preoccupations, like items they collect and like to order, or a particular hobby that absorbs all their attention. This is also one of the sources of autistic talent since they are exceptionally motivated to work on the things that fascinate them most—which could turn them into excellent artists or scientists.

Some autistics are extremely sensitive to certain food tastes and textures or suffer from gastrointestinal problems that severely restrict what they can eat, which in turn may impact on their social lives. Other autistics have food preferences and allergies that are in no way different from the average population. Some autistics do not feel hunger and need to be reminded by an alarm or a personal helper that it is time for them to eat, and sometimes also how much they should eat. All these challenges also apply for other sensory sensitivities, such as light, noise or the feeling on one's skin. Due to their different neurological processing of visual input, autistics often also see the small parts, but not the bigger picture, for which they need to make an explicit effort to piece it together. Yet their attention to detail, their talent in systematising and their often exceptional memory also may lead to major talents and even savant skills.¹⁴

According to some, autism is a disorder or a psychiatric disability, whereas for others it would be better to understand it as an identity of people who are 'neuroatypical'.¹⁵ It is possible to highlight the disability and disorder aspects, or instead the identity and difference aspects.¹⁶ The choice of stressing one aspect rather than another may depend to some extent on how autism manifests itself. Some autistics need 24 h care, develop no speech during their lives, and are self-harming and aggressive. It is hard, perhaps even wrong, not to see them as disabled. Others can become successful professionals, have families and lead fully flourishing lives; they refuse to be seen as disabled, but rather want to stress neurodiversity. This wide variety within the group of autistics is not making it much easier to develop a good understanding of autism. One strategy has been to use the metaphor of the 'autism spectrum' or by making a distinction between low-functioning and high-functioning autistics. Yet both strategies can be criticised for insufficiently appreciating the ambiguities and multiple dimensions in the lives of autistics. Autistic students may be doing fine in pursuing their educational careers, but they may be suffering from bullying teachers or classmates, or suffering from social isolation.¹⁷ An autistic scholar may be married with children and extremely

successful in his research, but he may suffer from anxiety attacks and experience regular social expectations as heavy burdens.

With this brief description of autism in mind, we can now ask whether philosophical theories of well-being are suitable for autistics as much as for non-autistics, and what, if anything, can be learnt when we analyse accounts of well-being from an autism perspective.

THEORIES OF WELL-BEING IN PHILOSOPHY

The philosophical literature on well-being is huge.¹⁸ This paper will assume that readers are somewhat familiar with basic debates in the philosophy of well-being.¹⁹ Although there is a lively debate on which typology makes most sense, the most influential one remains the typology of philosophical theories of well-being introduced by Derek Parfit, who distinguished hedonistic theories, desire fulfilment theories and objective list theories.²⁰ For hedonistic theories, well-being is the presence of pleasure and the absence of pain. For desire fulfilment theories, well-being is the degree to which our desires are fulfilled (and these desires could be required to be fully informed and 'authentic'). Objective list theories conceptualise well-being as the presence of certain goods that are taken to be objectively good for us. That is, those goods are at least to some extent independent of our own subjective views on those goods. Typical goods included in an objective list account are health, knowledge and friendship. It is also possible to construct hybrid theories, for example, where 'happiness' is part of the goods that are regarded as objectively good.

In philosophy, there is a huge literature with defenders and critics of all those theories. There are many debates in the philosophical literature on well-being that could benefit from being analysed from an autism perspective; and there are many contributions that could be made based on insights from the philosophy of well-being literature in thinking about how to improve the quality of autistic lives. But since none of this has happened so far, we need to start with limited aims.

Ultimately, a more ambitious project should analyse for each theory of well-being whether they have a plausible justification, ask to what extent they can serve as a pure philosophical theory or rather can also serve as a practical theory of well-being that can be used in applied conditions and policy circumstances, and then compare how these various theories do in terms of including autistics. In this paper, I will only take one step of this larger project. First, I am interested in theories that have a sound philosophical basis but can also be used for applied work. That is, I am interested in practical (and hence action-guiding) accounts that do not rely on idealising and counterfactual conditions, such as that people's desires are 'authentic'. If we are searching for an account of well-being that can guide our actions (both individually and institutionally), then we need a theory of well-being where either the constituents of well-being or the determinants of well-being can be the object of intervention.

Second, I will limit myself in this paper to analyse one theory of well-being from the point of view of autism. I chose the capability approach to well-being because it is a plausible candidate given earlier support for this theory in disability ethics and given the central role attached to human diversity in the conceptual architecture of the capability approach. When Amartya Sen introduced the capability approach in his critique on both utilitarianism and the Rawlsian social primary goods as 'all purpose goods', he stressed the importance of human diversity and used the example of the disabled as an argument against those two views.²¹ Many philosophers have hinted at, or argued, that the capability approach may be particularly suited for understanding

the well-being of human beings, and of those with disabilities in particular.^{22 23} Similarly, prominent disability philosophers such as Eva Kittay have suggested that the capability approach is a helpful view to think about the lives of the cognitively disabled.²⁴ When Martha Nussbaum tried to show that her capability theory of justice is stronger than Rawls's Justice as Fairness, she invoked its ability to include three groups that are marginalised from Rawls's theory, one of which being the disabled.²⁵ And in his recent book on mental disorders, Jonathan Glover suggested that an Aristotelian account of human flourishing could help to make sense of how to think about autism, and in particular, the claim whether autism should be seen as a disability that would better be cured or rather as an identity that merely requires respects and accommodation.²⁶

My aim in the paper is to answer the question whether the capability account of well-being is a helpful theory for autistic well-being. However, as we shall see, a by-effect of that analysis is that it also adds further insights on the strengths and limits of the capability approach to well-being itself.

THE CAPABILITY ACCOUNT OF WELL-BEING

The capability approach is a general normative framework claiming (among other things) that people's well-being should be conceptualised as a set of functionings that they have reason to value.²⁷ Functionings are beings and doings, for example, having friends, being knowledgeable, being secure, ... Functionings can include negative functionings (whose presence would then indicate ill-being), for example, being stressed, being anxious. Within the capability approach, well-being is distinguished at two different levels: achieved levels of well-being and the freedom one has to achieve well-being. Well-being freedom is given by people's capabilities—their real opportunities to achieve the corresponding functionings.

The distinction between well-being achievement and well-being freedom is absent in much of the philosophy of well-being. Yet it is highly interesting since it prompts the question if (and to the extent that) we care about someone's well-being, should we care about her well-being *freedom*, or rather about her well-being *achievement*? There is disagreement among capability scholars whether as a normative default we ought not to care about people's achieved well-being, but about their well-being freedom.²⁸ The main reasons for focusing on capabilities (freedoms, opportunities) rather than functionings (achievements) are anti-paternalism considerations and respect for human agency: we do not force people into certain modes of being and doing, but subscribe to the moral imperative to give them access to genuine opportunities or freedoms, and respect their choices of those opportunities they want to realise. However, there are reasons why we could legitimately focus on achieved functionings rather than capabilities, such as age (infants should not make their own decisions), severe cognitive impairment or particular specific capabilities where *many or all* persons tend to make bad decisions, like the decision whether or not to drive without a safety belt or long-term financial decisions such as how much to save for your pension. As we will see below, the decision when the focus on achieved functionings rather than capabilities is legitimate is deeply normative and contested, and is likely to pose the biggest challenge for using the capability approach to improve the well-being of autistic persons.

HOW USEFUL IS THE CAPABILITY APPROACH FOR AUTISTICS?

The capability approach can be used as the conceptual foundation for an applied or practical account of well-being. The first

strength of the capability account of well-being is its multidimensional nature. In contrast to monistic accounts of well-being, the capability approach claims that well-being consists in many different dimensions, which should not be assumed to be commensurable. Monistic accounts of well-being, such as the balance of pleasures and pains, will always be able to rank different individuals with respect to their well-being. Since a monistic account by its very nature aggregates all the constituents of well-being to one overarching value, it is not possible for a monistic account to *not be able* to rank the levels of well-being of person A and person B. In contrast, on a pluralistic account such as the capability approach, it is possible to say that person A is better off than person B with respect to the well-being dimension 1, but worse off with respect to dimension 2. If our point of departure is life as we know it, and we do not allow for counterfactuals or counterfactual information in our account of well-being, then pluralism seems to be a very desirable property of a well-being account. Counterfactuals, such as fully informed preferences, or preferences that are not influenced by morally impermissible processes such as groups-based prejudice, should not be used in a practical account of well-being since by definition we cannot know what those counterfactuals would be. Therefore, theories of well-being that are based on counterfactuals cannot inform our present actions. In life as we know it, the comparison of two individuals often leads us to the conclusion that one is better off in one dimension of well-being, but worse off in another dimension. We may think that the successful manager is well off in terms of the intellectual challenges and autonomy she finds in her work, and the material standard of living that her salary enables her, but at the same time her heavy workload may make her relatively deprived when it concerns the time she can spend with significant others like her children or friends, or for having leisure activities.

This pluralistic nature of the capability concept of well-being is important because the lives of autistics are extremely diverse and often contain both (severe) deprivations on some dimensions, but at the same time high levels of well-being on other dimensions. Autistics can be fully flourishing in the activities that are their preoccupations, which may turn them into gifted musicians, writers, gardeners, artist, scholars, and so on, but they may at the same time have low achievements in terms of their psychological or social well-being. Or they may flourish in their hobbies, but due to an autism-unfriendly labour market be long-term involuntarily unemployed. A multidimensional or pluralistic account of well-being is able to capture this, whereas a monistic account cannot do this. In addition, most capability thinkers have argued that the different capabilities are incommensurable, that is, they cannot be traded off: a bit more of well-being dimension A cannot be regarded as compensation for a shortfall in well-being dimension B.²⁹

A second strength of the capability approach is that human diversity is one of its core features, which any capability account includes.³⁰ Human diversity, including diversity related to abilities and impairments, is a conceptual cornerstone of the capability approach, and hence one would expect that this implies that its conceptual architecture should facilitate the study of autistic well-being. This implies that we would expect that we do not need to adapt the capability theory to create a separate account of well-being, but rather that the capability theory of well-being, when properly informed and conceptualised, should include neurodiversity. As I will show below, this is indeed the case.

A third strength of the capability approach for thinking about the well-being of people with autism is that it resonates with the

phenomenological accounts that can be found in (auto-)biographies and narrative accounts. When describing elements of well-being and ill-being, such accounts are not primarily talking about preferences or desires not being fulfilled, but about functionings (and their shortfalls) and capabilities (both how they are expanded and how they are—often unnecessarily—constrained). Of course, in those descriptions there is often a preference for that functioning or capability to be present and secured—but the stress in those accounts is more on the enabling or disabling effects of the aspects of one's being and the possible actions or activities (doings) from which one can choose. Due to space limitations, I will have to merely claim this third advantage to the capability account of well-being and postpone a full defence of the claim. However, let me offer a few examples merely to illustrate the claim. Temple Grandin describes that not having control over loud sounds that suddenly go off (alarms, hand dryers in public restrooms) cause her pain comparable with a dentist's drill.³¹ Not having to be exposed to such noises would be a significant improvement to her well-being. Garry, a college student who reflects on his youth, writes about the "constant teasing, bullying and worst of all rejection of the young teenagers to whom I was an outcast", as well as the teachers who would lower his self-esteem by making degrading remarks.³² Garry is very well able to point out exactly what was making his life miserable at that age. Of course, one could also say that ultimately what autistics want is being happy—but that claim does not give us many handles on what to do to improve their well-being.

So we have identified three major strengths of the capability account of well-being for autistics. However, there are also two major challenges. The first challenge is to specify the capabilities that matter; the second challenge is whether to focus on achieved functionings rather than on capabilities. These challenges will be analysed in turn.

WHICH DIMENSIONS?

Each application of the capability approach needs to take a stance on how to select the relevant capabilities. In the capability literature, a variety of answers to this question of the selection of capabilities has been offered.³³ A complete and detailed selection of capabilities for a notion of well-being for autistics is beyond the scope of this paper. However, in order to make some progress, I will do two things. I will ask which capabilities should be added to those that are often listed in the literature if we look at well-being from an autism perspective. As we will see, this exercise will generate some interesting insights about well-being for autistics and the content of a capability well-being concept for the entire population—including non-autistics. Second, I will make a procedural suggestion for a comprehensive selection of capabilities for well-being for autistics.

One caveat is in order. Many lists of dimensions that have been proposed in the literature, including the well-known list by Martha Nussbaum, are not constructed as an account of well-being. For example, Nussbaum's list aspires to be a list of fundamental political entitlements that every human being should have.³⁴ This list is thus part of a theory of justice rather than a list of constituents of an account of well-being. Yet given that Nussbaum justifies her list by reference to human flourishing, the list makes sense as a *prima facie* account of well-being. Similar qualifications need to be made for other dimensions suggested in the literature.

None of the capabilities suggested in the literature are irrelevant for autistic persons. Nussbaum's 10 (aggregated) capabilities—life; bodily health; bodily integrity; being able to use the

sense, imagine and think; experiencing emotions; practical reason; affiliation; living with other species and the world of nature; being able to play; and having control over one's environment—are all relevant for people with autism. Similarly, dimensions that have been suggested like others, such as my suggestion (in the context of the assessment of gender inequality) to include control over one's time-use as a normatively relevant capability, are equally relevant for people with autism.³⁵ Of course, this should not surprise us at all. It would be wrong to assume that people with autism always and categorically do not need (or are not interested in) some of those capabilities. It may be that particular autistics have no interest in certain capabilities, but that can hold as well for non-autistics. But given the two-layered structure of the capability approach, that does not pose a problem as long as the target is capabilities (opportunities) rather than functionings (outcomes or achievements).

Second, there will be autistics who do not have genuine access because they do not have the innate characteristics that are needed to truly enjoy some of these capabilities; but that holds for non-autistics who do not have certain innate characteristics as well. Furthermore, this problem is more prominent if we are looking at very specific capabilities. A person with autism may not enjoy the capability of driving a car (a specific capability), but can enjoy mobility (a more general capability) if others drive him around. Wasserman and Asch have made this point in the context of physically disabled persons: a blind person may not be able to enjoy looking at paintings, but if the relevant good is 'enjoying aesthetic experiences' then surely she is able to enjoy that good in other ways. Nevertheless, it would be implausible to conclude that two persons who both can enjoy *some* specific capability that falls under the more general capability of 'enjoying aesthetic experience' are both enjoying the same well-being if one of them has access to 10 specific capabilities within the aesthetic domain while the other has access to only 2–3.

Take an autistic person who is oversensitive to sounds and visual stimuli, and becomes very anxious in public spaces. As a consequence, he cannot enjoy theatre, concerts, museums, movies and most other cultural products and performances. Still, because he can enjoy listening to some soft music in his own room, he does have *some* aesthetic capability. Wasserman and Asch rightly point out that an objective list account of well-being should not lead to claims that the more goods we are able to enjoy, the higher our well-being is. That is, a view that a minimal number of goods needs to be present seems much more plausible. Within one general capability (like aesthetic experience), a certain number of more specific capabilities each increase well-being, but there may well be a decreasing marginal contribution of each additional specific capability to overall well-being, and at some point that marginal contribution may be zero or even negative (in cases where too many options cause psychological burdens of having to choose).

The second question to ask is whether there are any capabilities missing in the existing capability literature, which are particularly important when we discuss well-being from an autism point of view. Which are the capabilities that draw our attention if we examine them from the point of view of autistic lives?

First, for autistics, a very important dimension of well-being is the absence of sensory overload. Autistics can greatly suffer from certain sounds or visual stimuli. This may imply that it is imperative to remove a fly from a room in which a person with autism is learning or working, or it can imply that a family needs to replace their porcelain plates because the sound of a knife scratching over the plate hurts an autistic family member.

To some extent, the harms created by sensory overload are a subcategory of the capability to 'avoiding non-beneficial pain', which is included in Nussbaum's list, as can be the case with the autistic who feels pain if he hears a knife scratching over a porcelain plate. But there are aspects of sensory overload that do not manifest themselves as pain. Rather, they may lead to excessive fatigue. It may also have other negative effects on well-being that are not yet properly understood. Thus, 'avoiding sensory overload' should be added explicitly to any capability account of well-being. Yet it follows that it should be added to Nussbaum's list too since her list explicitly aims to be inclusive towards all human beings, including the disabled and those with disorders and atypical conditions. Note also that it is not only people with autism for whom this specific capability is important. Sensory oversensitivities are also present among non-autistic people. They can also be important for people who suffered from certain illnesses or conditions, for example, someone who is recovering from a burnout.

A second dimension of well-being that is crucial for autistic persons is being able to communicate. The seventh cluster of capabilities on Nussbaum's list includes 'to engage in various forms of social interaction'. One could argue that 'communication' is a form of interaction, and hence that this capability is duly included. However, there are other forms of interaction, like cuddling, which can be seen as *some form* of social interaction, but still a rather limited form. It may be especially important for autistics to have 'communication' *made explicit* in addition to other forms of interaction since enabling communication for autistics often requires special efforts, both in terms of training caregivers in how autistic people think and communicate and in terms of investing in the development and accessibility of communication technologies.

Closely related to this capability to communicate is the capability to be properly understood, which is not mentioned by Nussbaum, or, to the best of my knowledge, anywhere else in the capability literature. This is a hugely important capability for autistic people. Many autobiographical accounts of autistic people describe how autistics do not feel properly understood.³⁶ Promoting this capability would require, for example, training police officers, social workers and other officers who interact with the public, on what autism precisely entails and how they should interpret the behaviour and interactions of autistic persons. For example, a pupil or coworker without autism may be seen as not making a significant effort, or as insufficiently contributing to picking up the slack in the organisation, whereas for autistics exactly the same behaviour could mean an inability or having to work in an autism-unfriendly organisation. Similarly, autistic children with severe speech impairments are often assumed to be cognitively impaired and not able to understand, whereas some are perfectly able to understand, but have severe challenges in making themselves properly understood by others. Note that here, too, this capability is important for other neurodiverse people, such as people who are cognitively extremely gifted or people with dyslexia. Their neuroatypical interests, way of thinking and ultimately their behaviour are also often interpreted in a neurotypical way, which at best leads to misinterpreting them, but may also lead to various forms of harm.

A fourth crucially important capability for autistics, especially the so-called 'low-functioning autistics' as well as autistic children, is being able to be properly cared for, which includes being loved and given enough and appropriate forms of attention. For various reasons, most autistics do not have many friends, even though they may well care as much about

friendship as any other human being. And while friendship and love are not resources that can be bought and redistributed, individuals and communities can do something about the fact that many autistics are not having access to as much love and friendship and attention as non-autistics do. For example, the government may give autistics and their supporters access to suitable meeting places where they can get together on their own terms and organisations could set up days that are exclusively for autistics with volunteers who are committed to spend a day with them once a month. More generally, people could volunteer to be part of such initiatives or could just make a greater effort to reach out to families with autistic members.

What can we conclude about existing lists of valuable capabilities in the philosophical literature? Existing lists, such as Nussbaum's, contain many of the elements that are important for autistic lives. However, as the above analysis pointed out, in order to be *useful* for our understanding of well-being of autistic persons, one would need to *specify* in greater detail what these capabilities *entail* and what policies, practices or institutions are needed to support those capabilities. Otherwise, there is too great a risk that some crucial dimensions are left out of the list of goods that make up well-being. I have argued specifically that being protected from sensory overload, being able to communicate, being properly understood and being loved and given sufficient attention are capabilities that are very important in the lives of autistic people. On the most charitable reading, one can argue that they are not sufficiently highlighted and made explicit on Nussbaum's list, though it is also plausible to conclude that these dimensions are simply missing from her account.

These dimensions should be added to *any* well-being account for human beings. In fact, there are good reasons for wanting one comprehensive, integrated account for both neurotypicals and neuroatypicals. The first reason is that this will prevent us from putting the bar to low in our well-being assessment of people with autism. We will also assess their well-being in domains that we may overlook if we specifically focus on domains where people with autism are facing challenges, such as psychological dimensions of well-being. But surely if there are other dimensions of well-being that we believe to be important for humans in general, then *mutatis mutandis* they are also important for autistics. Second, if it is true, as is increasingly believed by scientists studying autism, that traits and characteristics of autism are also prevalent under the non-autistic population, then we may want to pick those up if we assess the well-being of people who do not have an autism diagnosis or who do not self-identify as autistics.

In this section, a first step has been taken to develop a capability account of well-being that is particularly sensitive to the lived experiences of people with autism. Still, if one were to continue the development of such an account in more detail, it would be important to add a stronger procedural element to the selection in order to avoid biases that are always a risk in the construction of the content of such accounts of well-being.³³ The capability account of well-being for autistics should start from the lives that people live, hence from the phenomena and the experiences. Given the huge diversity among people with autism, it is imperative that the further development of such an account include the voices of many different people with autism. If they are severely cognitively disabled, this could be via their friends, caretakers and therapists. Note that this procedure would give us an account of capabilities, and hence well-being *freedom* (or the entitlements to achieve well-being). What make up the basic constituents for the well-being achievement

of a particular individual would have to be determined by that person herself.

TWO CHALLENGES FOR THE CAPABILITARIAN ACCOUNT OF WELL-BEING

We now turn to two challenges that are related to question whether the normative priority should be given to capabilities rather than functionings. Recall that capabilities are *real* opportunities—that is, they require not merely non-interference, but demand that the provision of resources and the design of the environment is such that if the person wants to have the functionings, they can have it (assuming that their innate characteristics are permitting the functioning). Hence, it does not suffice to allow autistics equal access to higher education, but rather requires that the lecture rooms are not causing them sensory pains, that the lecturers understand how they should interpret what they might otherwise interpret as 'odd' or 'inappropriate' questions, and that groups-work will require additional instructions for the fellow students of an autistic student.

I have argued recently that given the arguments made in the capability literature, it cannot be said that the capability approach always gives normative priority to capabilities over functionings.³⁰ Nevertheless, there are good reasons why we will often want to focus on capabilities. However, using capabilities rather than functionings as the normative default may be problematic in some cases. The reasons for this claim are particularly relevant for autistic lives, yet they may be relevant for other people too.

The first challenge is that the focus on capabilities rather than functionings can only be justified based on the assumption that a certain threshold level of the capacities for agency is present (being able to make choices in an autonomous way, having control over actions, being able to oversee the consequences of one's action). We know that these idealised accounts of agency do not apply to us all of the time, but they may even apply less for people with psychiatric disorders who do not have the same level of control over their deliberated decision-making. In the case of autism, there are at least three reasons to be worried. The first is that most people with autism have strong preoccupations, which may lead them to become very single minded in the activities they pursue, sometimes leading to self-neglect. While some forms of self-neglect should not worry us since they are primarily related to social norms that do not constitute any objective self-harm (eg, never having a haircut or not caring about how one looks like), other forms of self-neglect can be argued to be objective forms of self-harm or potential risks of illness such as never taking showers, not eating sufficiently healthy, never going outdoors in fresh air or not taking a minimal amount of physical exercise. The second reason is that many people with autism also suffer from other disorders (co-occurring conditions), which includes impulsive behaviour, aggression towards others or self-injury. As a consequence, for some autistics there may be reasons for their carers to be paternalistic. They could, for instance, try to steer them away from always focusing on one particular function where this harms their well-being in other domains (such as becoming literate or being well-fed or enjoying enough sleep). Or they could steer them away from situations that will elicit anxiety, depression or aggression. The third reason is that sensory oversensitivities may impede the ability to make good choices from one's capability set. For example, there are cases of people with autism who do not experience sensations of (not) being hungry, and thus they would forget to eat properly, or, reversely, would not know when to stop eating when having a meal.

Importantly, note that the structure of this argument applies to *all human beings*, but if we combine this normative argument with the empirical premise that autistics are *significantly more prone* to being strongly preoccupied with one activity or being at risk of self-neglect, then this issue will be a more prominent challenge for practices and decisions where the well-being of autistics is at stake.

The second challenge is that, from a life-course perspective, we sometimes *now* need to choose particular functionings that we do not prefer or desire in order to keep capabilities open for the future. With neurotypical children, we generally believe that it is justified to nudge or gently coerce them into doing certain things that go against their short-term impulses or preferences. For example, we coerce them to learn mathematics or a foreign language, whereas many may not choose to do so if they were given the option to not study mathematics or a foreign language. So this worry concerns *all children*, not just autistic children—and it has often been acknowledged in the capability literature that there are good reasons to focus on children's functionings rather than on their capabilities and letting them do the choosing themselves. The appropriate pedagogical model is surely to gradually increase the domain of freedom we give to children when they grow up. Yet there may be reasons why in the case of the autistic child the increase in the domain of freedom will be bumpier, and parents, caregivers and therapists will be more inclined to nudge or even coerce the child into certain functionings. One could argue that this is often based on good reasons, related to limited control over impulses and pre-occupations that may greatly influence how choices are made. However, this prolonged and possible more intense limitation of the scope of freedom may cause more pain and stress for children with autism than neurotypical children since they may be more sensitive to psychological stress, are more likely to not feel properly understood and may suffer from problems in communication with those who make decisions for them. Moreover, autistics may be fully aware that they are more being constrained in their freedom than their neurotypical siblings, which they may experience as a great injustice. Due to their limitations in being self-reflexive, they may be unable to appreciate or understand their difficulties with controlled decision-making.

These brief remarks show that parents, caregivers, teachers, friends and therapists will constantly have to walk a fine line between providing true options (capabilities) and leaving the choice with the autistic, or instead either restrict the options to particular functionings that are deemed desirable and/or try to influence the choice process in the direction of those functionings. This constraining of options or the attempts at influencing our decisions happens with all of us from time to time—as when our spouse deliberately puts the chocolate out of sight, or our friend tries to convince us to get off the couch and join her to her yoga class or for a walk outdoors. The normative point is that this is likely to happen much more with autistic persons than with neurotypical persons. And the very difficult question will always be whether this reflects a genuinely well-informed attempt at improving the flourishing of the autistic person, a well-intended but badly informed attempt at improving the autistic's well-being or mere prejudice and/or inability or unwillingness to respect the autistic person *as autistic* and put *their* interests central. To my mind, this serious practical complexity does not make the capabilitarian account of well-being any less valid or useful for autistics; it merely shows that we need to start from the complexities, ambiguities and challenges of the lives of people with autism, and makes sure our notion of well-being reflects the realities of those lives.

CONCLUSIONS

In this paper, I have argued that the capability approach provides a promising foundation for an account of well-being for people with autism. Still, much more work is needed to further develop a neurodiverse capabilitarian account of well-being, and enquire what is needed to enhance human well-being. Some of the capabilities that I highlighted—such as the capability to be properly understood—need much more unpacking and detailed examination. Similarly, so does our understanding of what would be needed in terms of policies to guarantee those capabilities. In striving for this, we also need to analyse what can be done to avoid potential conflicts between the capabilities of autistics and those of their carers, relatives and other persons who are directly affected. Finally, and importantly, the question of when the normative focus should be on well-being achievements (functionings) and when it should be on genuine well-being opportunities (capabilities) is one that requires further philosophical analysis.

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REFERENCES

- Rodogno R. Well-being, science and philosophy. In: Søraker J, Van De Rijt JW, De Boer J, et al., eds. *Well-being in Contemporary Society*. Berlin: Springer, 2015:39–40.
- van Heijst BF, Geurts HM. Quality of life in autism across the lifespan: a meta-analysis. *Autism* 2015;19:158–67.
- Robertson SM. Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disabil Stud Q* 2010;30. Open Access at <http://dsq-sds.org/article/view/1069/1234>
- Wasserman D, Asch A. Understanding the relationship between disability and well-being. In: Bickenbach JE, Felder F, Schmitz B, eds. *Disability and the Good Human Life*. Cambridge: Cambridge University Press, 2013:139–67.
- Salomon A. *Far from the Tree*. London: Chatto and Windus, 2013:274.
- Hacking I. *Lost in the Forest*. *Lond Rev Books* 2013;35:7–8.
- Cushing S. Autism: The Very Idea. In: Anderson J, Cushing S, eds. *The philosophy of Autism*. Lanham: Rowman & Littlefield, 2013:17–45.
- Verhoeff B. Fundamental challenges for autism research: the science-practice gap, demarcating autism and the unsuccessful search for the neurobiological basis of autism. *Med Health Care Philos* 2015;18:443–7.
- Baron-Cohen S. *Autism and Asperger syndrome*. Oxford: Oxford University Press, 2008.
- Frith U. *Autism. A very short introduction*. Oxford: Oxford University Press, 2008.
- Lai MC, Lombardo MV, Baron-Cohen S. Autism. *Lancet* 2014;383:896–910.
- Grandin T. *The Autistic Brain. Exploring the Strength of a Different Kind of Mind*. London: Rider, 2013.
- Dewey M. Living with Asperger's syndrome. In: Frith U, ed. *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press, 1991:184–206.
- Happé F, Frith U. *Autism and Talent*. Oxford: Oxford University Press, 2010.
- Jaarsma P, Welin S. Autism as a natural human variation: reflections on the claims of the neurodiversity movement. *Health Care Anal* 2012;20:20–30.
- Salomon A. *Far from the tree*. London: Chatto and Windus, 2013.
- Prince-Hughes D. *Aquamarine blue. Personal stories of college students with Autism*. Athens: Ohio University Press, 2002.
- Fletcher G. ed. *The Routledge handbook of philosophy of well-being*. New York: Routledge, 2016.
- Tiberius V. Prudential value. In: Hirose I, Olson J, eds. *The Oxford Handbook of Value Theory*. Oxford: Oxford University Press, 2015:158–74.
- Parfit D. *Reasons and Persons*. Oxford: Oxford University Press, 1984.

- 21 Sen A. Equality of what? In: McMurrin S, ed. *The Tanner Lectures on human values*. Salt Lake City: University of Utah Press, 1980:197–220.
- 22 Sen A. Capability and well-being. In: Nussbaum M, Sen A, eds. *The quality of life*. Oxford: Clarendon Press, 1993:30–53.
- 23 Terzi L. What metric of justice for the disabled? Capability and disability. In: Brighthouse H, Robeyns I, eds. *Measuring Justice. Primary Goods and Capabilities*. Cambridge: Cambridge University Press, 2010:150–73.
- 24 Kittay Feder E. *Love's labor*. New York: Routledge, 1999.
- 25 Nussbaum M. *Frontiers of Justice. Disability, Nationality, Species Membership*. Cambridge, Massachusetts: Harvard University Press, 2007.
- 26 Glover J. *Alien Landscapes? Interpreting Disordered Minds*. Cambridge, Massachusetts: Belknap Press, 2014:218–34.
- 27 Sen A. Capability: Reach and Limits. In: Chiappero-Martinetti E. *Debating global society: reach and limits of the capability approach*. Milan: Feltrinelli, 2009:15–28.
- 28 Robeyns I. Capabilitarianism. *J Hum Dev Capabilities* 2016;1–18,
- 29 Nussbaum M. *Women and human development. The capabilities approach*. Cambridge: Cambridge University Press, 2000.
- 30 Robeyns, capabilitarianism.
- 31 Grandin, *The Autistic Brain*, 69.
- 32 Price-Hughes D. *Aquamarine Blue*, 3.
- 33 Robeyns I. Selecting capabilities for quality of life measurement. *Soc Indic Res* 2005;74:191–215.
- 34 Nussbaum M. *Creating capabilities*. Cambridge, Massachusetts: Belknap Press, 2011:33–4.
- 35 Robeyns I. Sen's capability approach and gender inequality: selecting relevant capabilities. *Feminist Econ* 2003;9:61–92.
- 36 Higashida N. *The Reason I jump*. Translated into English by Yoshida KA and Mitchell D. London: Sceptre, 2013.