

Neurodiversity, Advocacy, Anti-Therapy

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Abstract

This chapter provides an overview of the origins and theoretical stance of the neurodiversity movement, and then explores the implications in terms of what, if any, treatments for autism are appropriate. We outline some of the key arguments and critiques made by neurodiversity proponents, and as a case study we focus on the controversy around Applied Behaviour Analysis (ABA) – the most widely used approach in North America. We discuss four distinct issues: efficacy, normalisation/social control, trauma/wellbeing, and autonomy. After examining each, we argue that a significant element of contemporary ABA practice requires abolition or reform, and suggest that whether or not ABA can be rehabilitated in the eyes of its critics remains to be seen. We further suggest that the debate around ABA has implications for the practice and research around all forms of autism therapy. In particular, we propose that more discussion between neurotypical and neurodivergent people needs to take place to establish what goals and outcomes are beneficial for whom, and for what purpose, and in what context.

Keywords: Neurodiversity; Applied Behaviour Analysis; ethics; bioethics; autism treatment

At one time, autism advocacy was largely associated with parents and doctors advocating for greater autism awareness, increased funding for services, and more research into treatment and therapy (Feinstein, 2010). Roughly from the early 1990s onwards, autistics began to gain more recognition advocating for themselves. In contrast to earlier advocacy, they increasingly pushed against the idea that autism was necessarily a tragedy (Sinclair, 1993) and became more interested in autism acceptance. Out of this grew the neurodiversity movement, a social justice movement that began among autistic self-advocates but which has since become associated with a paradigm shift regarding cognitive and developmental disability more generally (Chapman, 2019; Singer, 1999; Walker, 2012).

Prior to the rise of the neurodiversity movement, autism advocacy had tended to assume that autism should be viewed as a medical condition – be this psychiatric or neurological. In contrast to this medical paradigm, neurodiversity proponents were influenced by the broader disability rights movement and their politicisation of disability. Because of this, they viewed autistic disablement and distress more as a broader social and political issue (Chapman, 2019a; Singer, 1999;). The arguments made by neurodiversity proponents are varied, and it is important to note that the movement has mostly grown online in blogs and social media more rapidly than through scholarly journals. While there have been influential figures, the movement has nothing like a textbook or leader at the time of writing. Still, the movement's politics are underpinned by some core philosophical and ethical arguments. Perhaps most centrally, it is relatively common for autistic neurodiversity proponents to challenge the depiction of psychological disabilities as inherently pathological. This is usually done by drawing on constructivist models of disability that explain disablement as socially and culturally produced. At the individual level, many autistic individuals have come to see autism as an inherent part of their selfhood, and even a political identity, rather than a disorder to be treated or cured (Chapman, 2016; Sinclair, 1993). Hence autistic people tend to use identity first language (i.e. "I am an autistic person") rather than person first language ("I am a person with autism"). We shall adhere to this preference here. In turn, at the group level, neurodiversity proponents reframe autism and other similar disabilities as "neurominorities" rather than as mental disorders (Walker, 2012). On the neurodiversity perspective, society has been mainly built for and by "neurotypicals", in such a way that its dominant notion of "normality" inevitably disadvantages, devalues, and disables

neurodivergent individuals and neurominority groups. Autistics as a neurominority thus form a marginalised and oppressed group, somewhat akin to minority ethnicities or sexual orientations.

To the extent that this reframing is feasible, it raises significant ethical issues when it comes to therapeutic or clinical practice, not to mention public policy. On the one hand, if it is true that autism is a medical pathology that causes significant harm to autistic individuals and others around them, then it seems right to try and treat, cure, or prevent it. Arguably, to not do so would be wrong, just as it would be wrong to refrain from trying to treat cancer. This, implicitly at least, has been the orthodox view of autism since it was first described in the 1940s. By contrast, if the neurodiversity perspective is convincing, then such attempts may be just as bad as trying to “cure” being gay. That is, they would be deeply unethical and based on a catastrophically misguided undue pathologisation of a minority way of being. Indeed, for many neurodiversity proponents, the proliferation of genetic investigations, often explicitly justified as raising the possibility of preventing autism, is reminiscent of eugenics, and must be resisted at all costs.

Here we will outline some of the key arguments and critiques made by neurodiversity proponents before turning to the issue of treating or curing autism. Our more specific focus here is the controversy around Applied Behaviour Analysis (ABA). This method is the most widely used for autism in North America and is often described as the gold standard, yet is hotly contested by many autistics and in particular neurodiversity proponents, who see it as akin to conversion therapy. After reviewing the existing evidence of both the harms and benefits associated with ABA, we pose a challenge to the ABA industry with respect to autism: Either concede that the wholesale application of ABA to autism lacks moral permissibility, or provide evidence that there is at the very least a subsection of the autistic population who benefit, bearing in mind the associated risks we discuss below. More broadly, we challenge all approaches to autism intervention and research to consider the notion of ‘benefit’ in terms of well-being and autonomy, as defined in terms consistent with perspective of autistic people and those closest to them, as well as being foundational principles in bioethics.

The Medical and Social Models

Traditionally autism, like other disabilities, has been viewed through what is sometimes called the 'medical model' of disability. Although there are many variations of this model, what they share is that they frame disability chiefly as a problem that primarily stems from an individual's impairments. When it comes to autism and other neurominorities, the explicit claim of the medical model (e.g. in the DSM) is that the behavioural problems must stem from the dysfunction within a person, rather than from a mere clash with external conditions such as societal norms (American Psychiatric Association [APA], 2013). While this model does take into account how external issues, such as stigma or poverty, can also affect the lives of disabled people, it is distinguished by its framing of disability as being primarily caused by *individual* biological or psychological impairments or dysfunctions.

On this model, autism is viewed as a spectrum disability identified in light of social and communication issues coupled with highly restricted and repetitive habits, actions, and routines and sensory sensitivities (APA, 2013). These are seen as harmful deficits, stemming from underlying dysfunction at the psychological and biological levels (Wakefield, 1992). Some theories have associated autism with impairments in empathy or cognition, which are both taken to have a largely biological basis and in turn to cause autistic disablement. In this view, autism is something that an individual *has*, much as one can have cancer. A cancer patient is not described as "cancerous", because cancer is viewed as an unwanted addition to the person rather than part of them. Similarly, by saying someone "has autism", the implication is that autism is an add-on, and a problematic one, rather than being regarded as merely a different way of being.

While the medical model is still dominant, in the 1970s disabled self-advocates began to challenge this by developing the 'social model' of disability (Oliver, 1990). This model also has many variations, but the key difference is that it distinguishes between "disability" and "impairment", and frames disability as often, or in large part, being caused by societal unwillingness to accommodate impaired individuals. By distinguishing between impairment and disability, disabled self-advocates were able to frame the related distress that disabled individuals experience as being primarily caused by broader social pathology, rather than by their impairments.

The social model was initially mainly applied to physical disability, leading to important social reforms in countries where it has been implemented (Oliver, 1990). For instance, the

implementation of ramps and disabled parking spaces stemmed from shifting the focus from the individual to the environment. However, neurodiversity proponents have applied the social model to autism, highlighting how attitudes, practices, and structures contribute to autistic disablement (Chapman, 2019a). For instance, when it comes to physical structures, it may be that workspaces are designed in such a way that they are disabling to autistic individuals with heightened sensory sensitivity (Booth, 2016). And when it comes to practices, how we organise and teach in classrooms is designed for neurotypical processing styles and may exclude autistics, especially those with further cognitive disabilities (Goodley, 2018). Social norms and attitudes are also relevant. Mitz (2008) argued that “the identification of autism with self-loss, otherness and dehumanisation pervades the dominant, medicalised discourse of autism” (p. 21). In line with this, Cage et al. (2018) found that autistic people were associated with higher levels of dehumanisation than neurotypicals.

Building on the theorising of autistic self-advocates, the social model has also been applied to autistic wellbeing. While autistic well-being is, on average, lower than the average, neurodiversity proponents have argued in detail what we can understand this as stemming in significant part from external factors (Robertson, 2010). In line with this, Renty and Royers (2006) found that well-being was predicted by how well supported autistic individuals felt rather than by how impaired they were taken to be. More recently, Frost and Botha (2018) studied autism using the minority stress model, which had previously been applied to sexual and ethnic minorities in order to explain mental and physical health issues as arising from disparities between minority and majority groups. In the autistic population, they found that “Minority stressors such as victimization and discrimination, everyday discrimination, expectation of rejection, outness, internalized stigma, and physical concealment of autism consistently predicted diminished well-being and heightened psychological distress” (2018, p. 27).

To be clear, in making the shift to the social model, neurodiversity proponents do not claim that there are *never* any impairment effects associated with autistic cognitive (Ne’eman, 2010; Chapman, 2020). Kapp et al. (2013) found that while most autistic neurodiversity proponents were against trying to cure autism as such, they did not find ameliorating specific more disabling impairments to be a problem. Walker (2012) has

argued that neurodiversity proponents are more concerned with cognitive variations that underlie different forms of selfhood. Hence, something pervasive such as the sensory differences associated with autism should not be “treated” since they are constitutive of a “way of being” (Sinclair, 1993). By contrast, epilepsy, gastrointestinal issues, and other problems associated with autism (co-occurring conditions, or “specifiers” within the DSM) should be considered genuine medical problems, and hence the subject of medical intervention.

Autism Knowledge Production

Importantly, neurodiversity proponents do not just disagree with the idea that autistic impairments are the key cause of autistic disablement and distress. They also challenge how autism is characterised and defined. On the medical model, framing autism has typically been defined in light of deficits. At the cognitive levels, this includes empathy deficits, weak context processing, and sensory processing impairments. At the behavioural level, diagnosis is only framed in terms of problems. Neurodiversity proponents have criticised the medical model as leading to a depiction of autism based too heavily on deficits rather than benefits (Dinishak, 2016). They have also challenged the “tragedy” narrative they associated with the medical-deficit view, which they take to be misleading and harmful for the autistic population (Sinclair, 1993). Recent advances in neurodiversity theory also challenge the notion of “impairment” due to issues in its conceptualisation (Chapman, 2020).

Here the critique of knowledge production in the autism industry is key. According to Walker, the fundamental axioms and assumptions underlying what he terms the “pathology paradigm” (2012) are normatively and ideologically laden in such a way that will be reflected in the results of autism science. By this he means that if a scientist’s starting-point is that difference is a sign of dysfunction – rather than being simply a different form of functioning – then any findings that demonstrate difference will serve as proof of a problem, rather than merely an indication of divergence. In line with this, autism scientist Laurent Mottron (2011, pp. 34-5) noted a bias in autism research towards undue negativity:

“researchers who study autism can display a negative bias against people with the condition. For instance, researchers performing functional magnetic resonance imaging (fMRI) scans systematically report changes in the activation

of some brain regions as deficits in the autistic group — rather than evidence simply of their alternative, yet sometimes successful, brain organization. Similarly, variations in cortical volume have been ascribed to a deficit when they appear in autism, regardless of whether the cortex is thicker or thinner than expected. When autistics outperform others in certain tasks, their strengths are frequently viewed as compensatory of other deficits, even when no such deficit has been demonstrated empirically.”

Autistic sociologist Damian Milton (2014) has written extensively on how autistic individuals have been “frozen out” of the processes of knowledge production on autism. This in turn undermines the “ethical and epistemological integrity” of autism research. It has meant the focus has been driven by neurotypical norms and concerns; the assumptions of the scientific paradigm may already exclude the possibility of seeing autism in a less negative light. Given such worries, Walker (2012) endorses the trend to turn to a “neurodiversity paradigm” instead of the “pathology paradigm” when conceptualising autism. This seeks to frame autism in its wider social-ecological context, rather than by reducing it to biomedical deficit compared to an elusive neurotypical norm.

This is important when it comes to conceptualising the dysfunctional element, and in turn the target for intervention. On the medical model, the dysfunction is primarily conceived of as a biologically-based dysfunction internal to the autistic individual. By contrast, the neurodiversity research paradigm frames the dysfunction in at least two different ways. The first is as a two-way relational dysfunction between autistics and non-autistics. Whilst autism has traditionally been associated with impairments in empathising, neurodiversity proponents have reframed autistic social and communication problems in light of how the empathy deficit goes both ways between the autistic and neurotypical populations (Chapman, 2019b; Milton, 2012). Moreover, autistic individuals have often noted that they can empathise with other autistic individuals (Chapman, 2019b) and neurotypicals (Brewer & Murphy, 2016). Second, the dysfunction may be a relational one between the autistic and their society, whereby society has been ordered and designed in a way that devalues and disables the autistic form of life. While this view does not deny that some limitations will primarily stem from the autistic individual, neurodiversity proponents thus reconceptualise the dysfunction by looking at the

wider context. This has important implications for attempts to remedy social and communication issues, shifting the emphasis and responsibility away from a sole focus on autistic people.

Opposition to Therapy : ABA Case Study

Viewing autism as difference rather than dysfunction, and awareness of the social model of disability, combine to raise important questions about what – if any – therapy offered to an autistic child or adult is helpful and legitimate, as opposed to harmful and oppressive. Within the neurodiversity movement there is a range of perspectives on the value of therapy. The call for acceptance and acknowledgement of strengths, and indeed for socio-cultural changes to make the world more autism-friendly, need not negate the fact that many autistic people will seek or need individually-targeted assistance and support. What is called into question, though, is what kinds of support are truly helpful. Awareness of the neurodiversity movement's concerns require important questions to be asked by all who seek to intervene therapeutically: What is the purpose of therapy? What is the nature of the therapy? What are the outcomes – both intended and unintended?

In some cases, a broad consensus is easily achieved that a particular approach is harmful. Medical-model and social-model sympathisers agree about the harm linked to certain interventions, such as packing (Amaral et al., 2011), and holding therapy (Fleming et al., 2015). Far more controversial are those therapies that some hold as beneficent and others hold as harmful. Behaviourally based approaches to autism are probably where opinion is most sharply divided. They have respectability in some quarters and are loathed in others, and are the focus of particular attention from the self-advocacy movement. In the following section we explore the controversy, propose areas of discussion that remain outstanding and where some resolution could be found, before finally outlining the areas that remain uncharted across all therapeutic domains

Although there are many delivery models within the field of ABA, the dominant form that is often cited by the neurodiversity movement is the UCLA Model, based on the early work of Lovaas and colleagues (Lovaas, 1987). Thus, Wilkenfield and McCarthy (2020) describe a typical ABA programme as involving 25-40 hours per week of intense one-on-one therapy, “in which the autistic child is rewarded for engaging in activities that make him more

normal” (p. 37). Lovaas-style Early Intensive Behavioural Intervention (EIBI) with regard to autism is given particular examination both because it was the first to be widely disseminated in North America, and because it is equated in the eyes of some with an attempt to eliminate all signs of autism – even to the point of “recovery”. Lovaas’ reference to his autistic patients as “not persons in the psychological sense” (1974, p. 76) reflects a dehumanising view of autistic people.¹ Unlike some other approaches, the Lovaas model of intervention is criticised for failing to accommodate autistic characteristics, instead choosing to wage “all out war against them ” (Cohen, 1998, p. 106) . For those in the neurodiversity movement who hold that autistic behaviours such as stimming are fundamental, that autism is key to someone’s identity, and further that it confers a collective identity, this reads as “all out war on the autistic person” or “all out war on autistic people”. We now tackle these issues in turn, testing the validity of the allegations, and then propose areas in which there may be room for mutual accommodation.

Evidence and Efficacy

A standard claim made by the behaviour analytic community is that theirs is a discipline rooted in science and that it uses systematic evidence at its base - in contrast to other interventions that are held be less evidence-based, and less rooted in scientific principles (Shreibman, 2005, p. 133). This claim requires unpacking, because references to the evidence base of ABA can mean two different things. One relates to how individual practice is rooted in a cycle of continually-reviewed empirical testing. The other relates to what large-scale intervention trials may or may not tell us about the comparative impact of ABA versus other approaches. Both will now be addressed in turn.

ABA adopts an individual-based ‘before and after’ approach, in which stimuli and consequences are systematically recorded and manipulated so that it is possible to identify precisely what component of an intervention is helpful or impactful. It is argued that this makes it possible to identify quickly if an approach needs to be adjusted. It puts the onus on the teacher or therapist to make learning as motivating as possible for the learner, and to be

¹ This was in an interview with Psychology Today in 1974. The full quote is as follows: “You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense — they have hair, a nose and a mouth — but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but I you have to build the person.”

accountable for failures to learn. The additional advantage of such an approach, it is argued, is that it can be individually-tailored, according to the particular circumstances of each person – building on their passions and interests, and requiring the teacher/therapist to make adjustments if the individual is struggling. The additional justification for the origins of ABA is that it avoids the excesses of psychological interventions that are based on subjective, unreliable/partial narrative-based accounts, overlaid with non-proven psychoanalytic theories. The rejection of mentalism in favour of reliance on the observable and measurable has an integrity and rigour at its roots.

The ideal of individually-tailored practice is, however, undermined significantly in the case of those EIBI interventions that adopt rigid curricula and are dominated by an aim to remove or mask someone's autistic behaviour. And more generally, there is a danger within all BA practice that the emphasis given to precision data and research validity takes precedence over any incidental change that has not been directly observed or measured. The need for data integrity may be a safeguard against charlatans or wasteful and ineffective therapeutic interventions, but it may also overlook influences and outcomes that are not considered by the therapist as relevant and/or measurable at the point of intervention. By avoiding subjective measures or qualitative research methods, limits are placed on what areas of enquiry and knowledge can be explored within behaviour analytic discipline. This inhibits curiosity in areas beyond the observable and measurable, which in turn may limit the practitioner's orientation towards any hidden or longer-term influences of the therapy – some at least of which may be adverse.

The second pillar of the BA community's claim to being evidence-based rests on intervention trials that purport to indicate effectiveness, often in comparison with alternative interventions (Foxy, 2008). But the status of this evidence is widely disputed. Just as the original Lovaas studies were subjected to methodological criticism, so have subsequent trials been noted for falling short of optimum design (Reichow et al., 2018). Thus, Dawson's influential attack "The Misbehaviour of Behaviourists" was strongly linked to a rights-based position that standards of research on autistic subjects should be as robust they are for anyone else (Dawson, 2004). She also pointed out, as others have done, that relatively weak evidence has been promoted as if it were conclusive, in order to boost a

commercially-driven business approach to autism therapy, or - one could add - a competitive approach from research centres driven by the quest for academic reputation.

Normalization

For some critics, all forms of ABA, not just the dominant EIBI approach, are likely to be rejected by virtue of the intellectual basis of behaviourism (Sparrow 2018). The highly-publicised excesses of some of its applications further taint its reputation – for example attempts to reduce homosexual behavior. Some autistic self-advocates hold that EIBI is equivalent to this. In attempting to steer someone away from their core identity because it clashes with restricted and oppressive social norms, the issue is that ABA seeks to normalize autistics instead of helping them achieve self-actualization.

ABA is inherently vulnerable to the charge that it is a vehicle to enforce social conformity. The profession defines itself as operating within social norms: “using scientific principles and procedures discovered through basic and applied research to improve socially significant behaviour to a meaningful degree” (Association of Professional Behaviour Analysts, n.d.). Key texts refer to how ABA can steer behaviour to what is “socially important”, aiming to influence behaviors for the “better state of society” (Baer, Wolf & Risley, 1968, p. 91). This then implies an underlying belief that an individual’s own interests can be furthered by adhering to what wider society holds to be important, *and/or* that it is permissible to deny a person their own preferences and interests in order to fit in with the wider interests of society as a whole. While some influential behaviour analysts have given consideration to the issues around social validity, (Baer & Wolf, 1987; Wolf, 1978) few subsequent approaches to ABA with regard to autism have fully addressed this challenge as matter of priority.

A number of pressing questions arise here. Who decides what is socially important? And in any case, should a helping professional aim to promote what is socially significant, or rather, aim to address particular issues that are of distress and relevance to an individual? If people are socially anomalous, what is the rationale for forcing social compliance? Clearly, what is judged to be socially significant or socially important is open to wide interpretation, and is very far from being self-evident. In the eyes of many autistic critics, ABA has entailed a slavish and unquestioning adherence to norms dictated by a neurotypical (NT) majority.

One response from within the discipline of ABA has been to imply that the needs of the individual are best met if they conform to behaviours that NT society holds as significant. While this may be true in some cases (addiction or criminality, for example,) it is far more questionable regarding autism. Shreibmann (2005, p. 238) justifies an attempt to redirect stims as a way of promoting wellbeing via social acceptance - reducing the risk of being stigmatised and ostracised. Yet in the case of some aspects of typical autistic behaviour, such as stimming, the counter argument is that these are neither disadvantageous to society nor to the individual – they are simply different or actually vital to the autistic person’s identity and wellbeing (Rudy,2018). Autistics are forced to comply in a way that is not only actively damaging to them, but also does not in any case bring about societal improvement. Indeed, from the autistic perspective, this makes society worse, by reinforcing the stigmatization of autistic behaviours more broadly. In response to the suggestion that a reduction in atypical behaviour may minimise the stigmatisation or bullying of the individual, the counter-argument holds that bullying is the aberrant behaviour and that the person in need of a behavioural programme is the bully. As such, ‘all out war on autism’ runs counter to the idea that behaviour change – if it is required – should not be uni-directional, but, rather, entail reciprocal adaptations to be made by the NT majority.

Trauma and Wellbeing

In making the case for the use of ABA, comparisons have occasionally been drawn between treating autism and conducting surgical operations to address a serious illness, for example, Frederikson (2013). The language used points to a fundamental category-error identified by self-advocates who argue that their identity and way of being is in no way analogous to a serious operable condition. The error gives room for therapists to justify uncomfortable features of their practice: If autism is deemed to be pathological, then ‘treatment’ that is considered necessary may be painful and distressing yet justifiable by a longer-term goal of ‘recovering’ from the pathology. But if a condition is not considered equivalently harmful or dangerous, then any uncomfortable or distressing features of the intervention are questionable at best. And, further, if the condition is experienced as integral to a person’s identity, then intervention to eliminate it has significant moral implications. Thus Dawson (2004) states that “failing to detect that people with differences have abilities and worth, because they fail to be like those self-designated as exemplifying capability and worth, is a

denial of basic human rights”. The neurodiversity movement has also aligned itself with human rights more broadly, for example the slogan “Autistic rights are human rights” (ARGH, 2014).

The internet is awash with forums and first-person accounts of autistic people who describe their experience of receiving ABA as traumatic and harmful (Asasumasu, 2013; Kirsty, 2017). The trauma relates not only to how ABA was practised on them – for example the use of aversives that characterised early ABA programs - but also to the feelings of being powerless and regarded as essentially flawed by virtue of being autistic. At the same time, it has been found that adverse effects have been seriously understudied in research on autism interventions, so there is little evidence to the contrary (Bottema-Beutel et al 2020).

Preliminary – and highly controversial – research by Kupferstein (2018) indicated that the incidence of PTSD was far greater amongst those who had received ABA as children than amongst those who did not. The Kupferstein study was quickly criticised by Leaf et al (2018) for its methodological limitations. In turn Chown et al (2019) pointed out that the vested interests of Leaf et al and endorsed the Kupferstein findings as requiring further investigation. In line with Chown et al’s suggestion, a recent thematic analysis of the perspectives of twelve autistic adults who had experienced ABA for more than six months found that they tended to associate ABA both with trauma and with a long term negative impacts on their sense of self (McGill and Robinson 2020). While this is based on a small sample, it is worth noting that more robust research found that the extent to which people camouflage signs of autism in order to emulate being NT correlates with suicidality (Cassidy et al., 2019) and depression (Cage et al., 2017) among autistic adults. While correlation does not equate with causality, it is also notable here that the contrasting practice of ‘autism acceptance’ - which refers to accepting autism as an intrinsic and valuable part of the individual, and therefore adjusting environments and expectation accordingly - is not associated with trauma. In fact, as an alternative to trying to treat autism, autism acceptance has recently been found to help increase wellbeing in both autistic individuals (Cage et al., 2017) and family members (Da Paz et al., 2018).

Autonomy and Identity

Autonomy, conceived as the capacity for self-governance, is widely seen as a fundamental part of the good human life. Another reason ABA is taken to be permissible is that it enhances autonomy, which is often taken to be diminished in the autistic population due to the effects of cognitive processing differences associated with the autistic population. Furman and Tuminello (2015), for instance, argue that ABA is vital for allowing autistic individuals to be able to live good lives in large part because it can increase autonomy. In their words, ABA may:

“assist the child with autism to develop his scientific reasoning skills—by breaking problems down into manageable units—until he can autonomously discover/ justify truths inductively or deductively.” (p. 260)

In line with this, some parents of multiply-disabled, non-verbal autistic individuals have argued that ABA has led to significantly increased efficacy in individual autonomy. Examples include the teaching of basic skills that mean less external support is required, by redirecting and reducing behaviours that are perceived as dangerous, such as extreme self-injury or pica, and by promoting communication that in turn increases the range of opportunities to express preferences and make choices (Abaa4all, n.d.). The following observation by Wendy Webster (2020) about Simon, her autistic son’s learning, in contrast to that of his NT siblings Oliver and Lucy, is typical of how many parents feel:

The emphasis was always on teaching Simon skills that would help him have more control in his life—either by being better able to communicate his wants and needs or by being more independent.

Thanks to ABA, I have learned to be a much better teacher so that I could teach Simon some of the same skills that I had taught Oliver and Lucy, such as buttoning his shirt and tying his own shoelaces. In our world, ABA has opened lots of doors and I do think that Simon has an infinitely better quality of life thanks to it. I don’t feel that we’ve tried to make him more neuro-typical via ABA. On the contrary, the more we’ve taught him, the more he’s been able to develop his own areas of interest. For example, he can search for highly unusual (to me) videos on Google.

In contrast others have argued that ABA may in fact unduly subvert autonomy, when directing a child's behaviour away from their passions or their stims. Perhaps the strongest reiteration of this criticism comes from a recent article by Wilkenfeld and McCarthy (2020). They argue that what is at stake is a "systematic violation of fundamental tenets of bioethics – those of justice and nonmaleficence, and of autonomy". While they recognise that children do not have capacity at a young age to be authoritative decision-makers on several issues of importance, they suggest that ABA offers a particular violation because it seeks to alter the formation of a person's identity in a way that is misaligned with their underlying preferences, passions and pursuits: "ABA coercively *closes off* certain paths of identity formation. This undermines children's autonomy, and it fails to provide the kind of autonomy support necessary for good caregiving" (Wilkenfeld & McCarthy, 2020, p.47). According to this view, then, what seems like an increase in autonomy might actually be a decrease of autonomy in a more fundamental sense. Moreover, ABA is thereby at its most harmful when it is at its most effective.

While this may be so in some cases, it is important to note that their critique is based on a Lovaas-style model of EIBI, which in many cases has been superseded. Also, some have questioned connotations between identity and autonomy in bioethical debates (McKenzie, 2020). In some cases, it may be that external influence on identity formation is not necessarily autonomy-undermining. In the case where a child learns new skills or to avoid self-injurious behaviours only, and is simultaneously supported in autism acceptance, it is possible that autonomy is advanced without subverting individual identity. Still, even if the case forwarded by Wilkenfeld and McCarthy is overstated, it is vital to recognise that teaching skills, *if* done in a way that relies on total compliance, may itself undermine the development of autonomy in other ways. For instance, some autistic people who have experienced ABA have reported that they were implicitly "taught to be compliant without question" and that this "ultimately made it more difficult for them to say "no" as adults, even when that "no" would protect them in a potentially dangerous situation" (Gardner, 2017). In line with this, Sandoval-Norton (2019) recently reviewed literature concluded that ABA often "created prompt dependent adults who lack in self-motivation and self-esteem" (p. 4). While ABA may be help develop autonomy-enhancing skills for some individuals, it has often been applied in a way that may undermine autonomy.

Can ABA be Reformed?

It is important to recognise that the context in which ABA is practised may influence how it is delivered and to what purpose. While some ABA practitioners do aim at extinguishing autistic behaviours, others focus on issues that they believe can improve quality of life – such as tooth-brushing, self-management of medication, and learning to use augmentative communication devices. These are in keeping with what Wilkenfeld and McCarthy (2020) refer to as developmental skills which they acknowledge are not inherently problematic as therapeutic targets (p.56.), and which others (including ABA-sceptics) have maintained are actively helpful (Pantazakos, 2019). It is also probably fair to say that while some parents and practitioners might seek the shorthand outcome of ‘recovery’, others are aiming to help autistic and learning disabled children acquire some core learning strategies - strategies through which they can achieve in areas that will be helpful to them, without undermining their self-esteem or attempting to change their diagnostic category.

Given that the practice of ABA is highly variable in terms of goals, context, approaches and client group, some members of the neurodiversity movement have recognised that there are relevant distinctions in how it is applied across the autistic population. Murray (2020) refers to “British version nicey-nice ABA”. This falls short of an endorsement, but it does recognise as relevant the distinction between different ways of implementing ABA. Despite the critics’ focus on attempts to extinguish stimming or special interests, these examples are not necessary features of all ABA approaches to autism, where passions and interests are encouraged and a focus on communication – spoken or through alternative means such as signing and PECS - works with, rather than against, the child.

Just as ABA practice is not homogenous, there is also a dramatic heterogeneity within autism. The possibility that Autism Spectrum Disorders is an umbrella of varying subgroups (Waterhouse & Gillberg, 2014); Muller & Amaral, 2017) reinforces the adage that in any kind of therapeutic or educational approach “one size does not fit all”. Statistical trends in large group studies may hide valuable data about diverse individual responses across all types of therapy. To assert that ABA is harmful for some autistic people does not exclude the possibility that it is helpful for some other autistic people, perhaps especially some of those whose autism intersects with additional disabilities (although equally it could be more harmful for some specific intersections). Any treatment can be extremely harmful when

forced or applied to the wrong trait, individual, or population, but beneficial for a small number of people when applied appropriately, and there is not yet sufficient evidence to conclude that ABA is necessarily harmful as such.

However, some autistic self-advocates have criticised attempts to distinguish between “good” and “bad” kinds of ABA, arguing that all applications express the same underlying attitudes to normalisation (Asasumasu, 2017) or because of issues in the conceptual foundations of behaviourist principles (Sparrow, 2018). It is also notable that, at the time of writing, research just published in the *Journal of Applied Behaviour Analysis* still classifies autistic stims including as hand flapping as “problem behaviours” (Frank-Crawford et al., 2020). The multiple testimonies of those for whom the experience of ABA has been extremely negative therefore need to be taken very seriously by the ABA community. The evidence of damage cited previously (Cassidy et al., 2019; Kupferstein, 2018)) – not to mention the benefits associated with autism acceptance – all point to the need to engage with self-advocates about the features of receiving ABA that they find particularly distressing. While the Kupferstein sample is non-random, this does not undermine the existence of the distress also attested to by multiple autistics who have experienced ABA first-hand.

Importantly, Behaviour Analysts can look to discussions within their own discipline to recognise ways in which subjective views and priorities require attention. Wolf wrote as far back as 1978 that “... we must develop systems that allow our consumers to provide us feedback about how our applications relate to their values...” (Wolf, 1978, p. 213). This is an important statement made by an influential behaviour analyst, before the work of ABA became so linked with a particular type of autism intervention. Likewise, the ABA literature has offered reflections around the ethical issues of autonomy, consent and best interests when the clients are children and/or people with limited capacity (Goldiamond, 1974). ABA practitioners and academics should also be willing to take on board the insights of the social model of disability, and be willing to critique some of the assumptions underlying a drive to reduce autistic symptoms. This too lies within the tradition of reflective ABA practice: “A proper appreciation of context always implies that we are not merely studying or managing it, but also are part of it and therefore are being managed by it” (Baer et al., 1987)

Drawing these arguments together, then, a summary of where conversation across the divisions may start is as follows. If some ABA clinics and practices adopt an approach that is hostile to autism and to autistic people, by attempting to camouflage their autistic difference, then the neurodivergent (ND) advocates are unequivocally right to protest. For ABA proponents to establish a case for moral permissibility, ABA practice needs to focus on therapeutic targets that are considered relevant to and -- where capacity allows -- by the individual. This reflects the broader point made elsewhere (e.g. Bovell, 2020) that it is not autism in toto that should be targeted, but rather specific issues that autistic people themselves would like help with. Where parents and family members are involved in decisions affecting children and adults with intellectual disabilities, the same principles apply. Bearing all this in mind, if ABA proponents can show that ABA can increase well-being and autonomy without causing trauma for some subsection of the autistic community, then it will have shown that ethical reform is possible and that ABA is not just morally permissible but also a significant good in some cases. But if such evidence is not produced, then working towards abolition in favour of alternatives seems to be the only morally permissible option.

Implications for all Autism Therapies

It should be stressed that several of the neurodiversity movement's concerns about ABA actually apply to *all* therapies that target the individual, insofar as they chiefly operate within the medical model of disability. Most of the helping professions focus on individuals, regardless of any broader social critique that their members may have.

“If any disvalue of ASD stems from societal forces, placing the full burden of rectifying this situation on autists is unjust” (Wilkenfield & McCarthy, 2020, p. 53)

This comment concerning ABA is therefore of broader significance. It does not invalidate the potential value of therapy, but it raises important questions about what kinds of therapy are helpful, for whom, and for what purpose, and it takes forward the principle that NT and neurodivergent people should be engaged in a project of *mutual and reciprocal* conversation and behaviour change. All participants in the conversation need to recognise that different goals may apply to different individuals, in different contexts. Within this, it will be important for the ND movement to engage more closely with parents about what they may wish for their children. While “recovery” may be held out as a possibility to some

parents, many others seek therapeutic intervention as something that can promote their child's welfare without taking away their autism or indeed their intellectual disability.

At the same time, comparative intervention trials should move away from testing global targets, and instead explore specific goals that are both less controversial and less general; for example, the acquisition of expressive communication tools (spoken or otherwise), or learning to tolerate nutritious foods. Such interventions are unlikely to be necessary across an entire cohort of autistic children or adults, but will be relevant for particular subgroups who have distinct challenges in these kinds of areas.

Practitioners and researchers, in collaboration with autistic people and/or their advocates, therefore need to identify and adopt relevant measures when conducting comparative research trials. They need to move away from standardised measures such as autism symptoms that dominate intervention studies (Provenzani et al., 2019), and tackle the under-representation of autistic people with intersecting learning disabilities in the bulk of autism research (Russell, et al., 2019). Likewise, longitudinal markers regarding economic status or type of living arrangement (Howlin et al., 2013) need to be questioned in terms of their relevance, in contrast to other outcomes that may be more accurate as a measure of quality of life or wellbeing across the autism spectrum.

This in turn opens up a wider question about what kinds of outcomes are truly positive as opposed to merely fitting in with social conventions. The whole terrain of what kinds of lives autistic people prefer, want and need is under-researched and under-discussed. Given the heterogeneity of what is practical and desirable, according to the kinds of attributes and additional issues facing a person (including the DSM "specifiers" about severity, communication and intellectual ability) there will need to be a whole matrix of potential signifiers for a good autistic life, defined in terms decided by the autistic individuals - either expressly -- or by advocates who know them well.

While such shifts would be welcome, at this point in time, whether or not ABA can be rehabilitated in the eyes of its critics remains to be seen. Currently, one of the co-authors veers towards abolitionism, while the other veers towards reform. Regarding therapy more broadly, only further enquiry can establish the impact of contrasting approaches in terms of harms and benefits, where – crucially - these are framed as far as possible in terms of

perspectives on wellbeing described and observed among autistic people themselves and those close to them, and taking into account the potential for significant variation across a range of different intersecting disabilities.

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