

The autism worldview dilemma: to normalise or not to normalise, that is the question

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Editorial comment

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This paper should be read by all who live and work with autistic children and adults. It serves to question the perspective we take and the potential outcomes. Three perspectives or paradigms are described – the medical model, radical behaviourism and the neurodivergent-affirmative model. Each derives from a different view of autism and so differ in their methods, with little common ground, termed by the authors as the ‘autism worldview dilemma.’ The authors argue that the most respectful and positive paradigm in terms of process and outcome is the neurodivergent perspective. This is gathering momentum as autistic communities and other neurodivergent groups take to social media and have greater visibility in research and the workplace. There is also now more effective and frequent consultation with autistic people on decisions which affect them. The Editor welcomes papers from those who have changed their perspective over the years giving their rationale and commentary for the journey they have taken.

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Introduction

For many years in the field of autism, the actions, skills and responses of autistic people were often described as abnormal, maladjusted or deficient. So, the goal of many interventions was to teach autistic children and adults to behave like their non-autistic peers as evidenced in approaches designed to teach (neurotypical) social skills, (neurotypical) communication and in programmes designed to modify behaviour to make autistic people appear neurotypical. This approach – which sees autistic behaviour as aberrant and without purpose and thus aims to remove this behaviour – is described as normalisation.

We challenge this view from a neurodiversity-affirmative perspective, querying the assumed lack of purpose in autistic behaviour as well as examining the impact on autistic people in the deliberate removal of autistic behaviour.

Normalcy is defined as the condition of being normal and normalisation as the process of bringing or returning something to a normal condition or state. Chappell and Jeppsson (2023, authors’ emphasis) discuss the normalcy bias they consider that psychiatry suffers from, whereby:

“clinicians consider it medically necessary to make psychiatric patients more normal through treatment, and where they do so even if it clashes with harm-reduction and function-enhancing goals and/or is not wanted by the patient.” (p.2)

We feel that there is confusion over normalcy/normalisation in relation to autism because so-called ‘normal’ behaviour is understood to mean neurotypical behaviour that is foreign to autistic people.

If human beings are just a cluster of behaviours – as proposed by those who believe in radical behaviourism – human behaviours are either normal or abnormal. Under this paradigm, certain behaviours specific to autism would be considered as abnormal and could justifiably be targeted for eradication by intervention. From a radical behaviourist perspective this would be considered as **normalisation** as such intervention simply involves eradicating what is regarded as abnormal behaviour to achieve **normalcy**. The radical behaviourist perspective may not be too far removed from the medical model paradigm view of autism. The medical model – as reflected in the diagnostic manuals – regards autism (known as autism spectrum disorder) as a mental disorder. Proponents of the medical model argue that autism is a disorder caused by genetic defects or environmental factors, that, despite the strengths that can be associated with autism, most autistic people would be better off if they were not autistic. Supporters of the medical model hold that normalisation cannot eradicate autism, only the outward behaviours of autism. While the medical model does not regard normalisation as cure – as radical behaviourism does – in principle it does not object to the use of normalisation as autism is regarded as a disorder. Thus far we see that normalisation of autism is generally either seen as essential (radical behaviourism) or acceptable (medical model).

Neurodiversity paradigm

However, those who believe in the neurodiversity paradigm have a radically different attitude to normalisation of autism both in terms of whether normalisation as generally understood is acceptable and how normalisation of autistic people should be defined. Under this paradigm autistic behaviours are regarded as being **normal**

for autism. Any eradication of behaviours regarded as normal for autism would only be **illusory normalisation** (involving **forced masking**) as the behaviour eradication would camouflage aspects of autism giving only an illusion of neurotypicality. Under this paradigm, when autistic people mask their autistic behaviour, they do not become less autistic or more neurotypical, but simply adapt foreign ways of behaviour that are antithetical to their true autistic selves. There is significant evidence that masking, in this sense, is harmful to autistic people which we will discuss later in this paper. There is also evidence that interventions aimed at so-called normalisation of autism can be harmful, despite the radical behaviourist view that there is only normal and abnormal human behaviour and that eradication of the latter can only be beneficial as greater normality is considered positive. Henderson, Wayland and White (2023, authors’ emphasis) write as follows about what they refer to as compliance training but which is clearly another name for normalisation of the autistic person:

“There are countless adults who have felt traumatized by compliance training. Unless there are safety concerns, the autistic must be on board with the goals of any intervention (and not solely to please other people or fulfill their or another’s wish to ‘be normal’), and they also must be reasonably comfortable with the process of any intervention. If the process is overwhelming or distressing, there must be collaborative problem-solving to reassess the plan and create a sense of safety.” (p.280)

Autism worldview dilemma

But it is not just that understandings of autism differ between the various paradigms (e.g. medical model, neurodiversity, radical behaviourism); opinions about autism also vary within the autistic community as they do for the wider autism community. Most autistic people are adamant that they should be allowed to be their autistic selves and not be pressured to behave in ways that are foreign to them. However, some autistic people do not celebrate their autism. Some would accept a cure for their autism if one were available. They feel it is important to ‘fit in’ to neurotypical society and be able to act like the neurotypical population, as it can be difficult to survive, let alone thrive, as an autistic person in a society that for the most part is not accepting of autism and places barriers in their way.

These autistic people may be willing to undergo normalising interventions to improve their chances of avoiding the downside of autism. Another nuance is that some autistic people who support the neurodiversity paradigm would have difficulty making the choice if they could live their lives again either as autistic or neurotypical in a world that is not accepting of autism.

Holders of differing views about autism will not agree on what autism is, let alone on what the appropriate response to autism should be. We call this the **autism worldview dilemma**. In all likelihood, this is a dilemma without any chance of a resolution. Adherents of the various perspectives on autism will continue to argue in favour of their chosen perspective and against the others. It is highly unlikely that any of the tools available for resolving disputes, such as the “healthy conflict” approach (Springs, 2018), will be effective in a situation where there is a fundamental disagreement over the ontological status of the subject matter. Where does this leave things? Our response to this question is to place the intractable ontological issue aside and focus on what we regard as achievable. In this paper we will focus on arguments for and against normalisation, summarise the autism worldview dilemma, and then propose practical steps that we consider should be taken to protect autistic people.

What is being normalised?

Behaviours that are associated with autistic behaviour that are frequently targets for enforced normalisation include “*echolalia, perseveration, and stereotypy*” (Yergeau, 2018, p. 98). It is important to distinguish between the behaviour being normalised and the person undergoing normalisation. For example, we see perseveration behaviour at a continuous rate across the population and, indeed, frequently celebrate high-level interests and specialism in the non-autistic population. But in the autistic person, perseveration is considered obsessive, anti-social, and aberrant. It is therefore important to note what we are talking about when we talk about normalisation. Is normalisation targeting **specifically autistic behaviour** (as a specific pattern of behaviour that is inherently autistic)? Or is normalisation targeting the **autistic behaving** (where that behaviour is behaviour that occurs across the human population)?

We would argue that much focus of enforced normalisation centres on normalising behaviour in this second sense, simply because it is the autistic person behaving. On this reading, it is the person being autistic that makes people see the behaviour as deviant and in need of normalisation as opposed to there being something intrinsically deviant in the behaviour. Take stereotypy, all humans might engage in bodily movements to display moments of happiness, worry, or excitement. Bodily displays of emotion are not themselves considered irregular or aberrant. However, in an autistic person, the extent and frequency of such displays can make the behaviour a target for normalisation. Henderson, Wayland and White (2023) draw attention to the importance of stimming to autistic people and argue against attempts to normalise this behaviour:

“Countless autistic individuals have been encouraged, told, forced, or shamed into giving up their stims. However, advocacy from many autistics has shown that stims serve important purposes, whether they include movement, use of objects, or sensory experiences.” (p.275)

There are different ways in which autistic people might encounter normalisation. The authors identify three main categories under which normalisation can be seen to interact with the lives of autistic people and these will be referred to in our discussion (see *Table 1*).

Arguments for and against normalisation

This section will consider some of the pros and cons of enforced normalisation and possible alternatives. The autistic community often refer to acting ‘normal’ to avoid harm, as ‘masking’, and this may be done consciously but is usually subconscious. The authors do not see normalisation and masking as synonyms however, and a distinction needs to be made between behaviour that (consciously or unconsciously) tracks that of the prevailing dominant culture and enforced normalisation. As social beings, everyone is engaged in cultural / social absorption and as Tomasello’s cultural learning theory points out, humans are distinct in their unique ability for imitation. Tomasello refers to a cultural ratchet which allows human infants to rapidly absorb the accumulated prevailing human culture (Tomasello, 1999). As neurominorities within a

Table 1: Three areas where normalisation interacts with the lives of autistic people

	Cultural /social absorption	Enforced normalisation	Skills training
Description	Organic adaption of majority cultural values from living in a society with established norms.	Purposeful attempts to eradicate behavioural traits that are considered anti-social or aberrant compared to a desired norm.	Purposeful interaction with vulnerable groups to enhance understanding of majority norms and teach self-preservation to groups who may be vulnerable in certain social environments due to being perceived as different.
Impact	This occurs to everyone living in a social group to a greater or lesser extent. Minority or less celebrated groups are likely to experience greater exposure, and pressure to adapt, to majority norms and prevailing celebrated values.	Permanent reduction of behaviour patterns to mimic the prevailing celebrated norms of behaviour (e.g., neurotypical behaviour).	The choice to temporarily adapt majority (neurotypical) behavioural patterns and minimise behaviour that could put one at risk in certain situations and environments.

wider culture where the prevailing dominant culture is not reflective of, and frequently not appreciative of, autistic behaviour, there are benefits accrued from abiding by the rules and norms of dominant culture. Through masking less desirable behaviour, gains can be made in terms of social status, connections, relationships, and work.

Recent research on masking in both autism and ADHD has suggested that females may have a greater proclivity towards masking. Borg Skoglund (2020) puts this, in part, down to the fact that at a group level, early development in the female brain will enhance social and linguistic functioning and so allow autistic and ADHD girls to better absorb and understand social norms and codes. Essentially, at a group level, this will make it easier for autistic and ADHD females to mask. This absorption of dominant cultural norms, while different from the enforced normalisation of behavioural programs, such as compliance training, is often seen to contribute to delayed diagnosis in autistic and ADHD females. This indicates that cultural / social absorption alone, can, to some degree, have a filtering impact on how autistic people (consciously or unconsciously) adapt their behaviour to prevailing norms.

Some may argue that masking is done by everyone and that there are frequent gains to concealing less desirable behaviour and in promoting more socially acceptable

behaviour. Masking is not always normalisation as it can be the result of cultural / social absorption or consciously chosen to better access social goods. Non-autistic people do not need to mask in everyday life as much as autistic people (Miller et al., 2021) as the world is designed by and for them, so non-autistic masking cannot be regarded as normalisation. The literature on autistic masking is relevant to this section as trying to normalise autistic people is essentially teaching them to mask. Enforced normalisation of an autistic person is enforcing extreme masking.

‘Fitting in’

Some autistic people yearn to ‘fit in’ to society as they blame their differences for their problems in achieving their life goals. If we take the examples of finding friends and employment as an example:

It can be hard to make friends if you are viewed as ‘weird’; and many employers look to recruit people who will ‘fit in’ at their workplace, so there is certainly logic to wanting to fit in and successful ‘normalisation’ facilitates this. Recent research suggests that autistic individuals who disclose autism during the application process are less likely to be offered work (Flower, Dickens and Hedley (2019), highlighting the real world incentive to minimise behavioural patterns associated with autism for entry to social goods, such as work.

The authors argue however, that it is not ‘fitting in’ that brings the benefits, it is acceptance. People are accepted easily into groups when they ‘fit in’. Acceptance in a greater number of environments would be advantageous for finding employment and friends. Constant rejection can be painful and damaging to a person’s self esteem. However, the benefit of achieving acceptance by normalisation is likely to be short term (Rose, 2017) and may be offset or even nullified by the high cost to mental health which will be discussed later. There are also alternatives to normalisation. If we change the goal of ‘fitting in’ to ‘acceptance’, we can look for communities that are more accepting of difference. The growing neurodiversity movement has enabled the formation of groups of people who have neurological differences. The diversity of those who identify as neurodivergent may mean one still feels different to peers, but there is an increased chance of acceptance amongst people who themselves have experienced ostracization and who advocate for the benefits of neurodiversity. The drawback to restricting the places where you can look for work and friends is becoming less problematic as the neurodiversity movement expands and the growth of social media makes it easier than ever to find like-minded people.

It should be noted that ‘masking to fit in’ is also likely to have a negative effect on the positive promotion of autistic behaviour in society. Where autistic people associate success in, for example, the workplace, with minimising autistic behaviour, there will be less visible autistic behaviour in such spaces. Nordell (2021) highlights the cumulative impact of visible ‘role models’ from minority or under-represented groups to dismantle homogeneity in workplaces. Under-representation of autistic people in workplaces is highlighted by the abysmal figures for autistic employment in the UK today with fewer than 30 per cent of autistic people in employment, where autism is diagnosed or disclosed and/or data is available (ONS, 2021). Where access to workplaces is determined by an individual’s ability and willingness to mask their autistic self, it comes at the cost of autistic people perpetuating the devaluation of autistic behaviour and further decreases the visibility and association of autistic behaviour as compatible with success.

Safety

The feeling of safety is a privilege rarely afforded to autistic people, particularly those at the intersection of other forms of oppression such as gender or race (Onaiwu, 2017). The world is currently full of environments that are hostile to any form of difference and so it is unsurprising that many believe normalisation is the route to a better life. Of course, the preferred solution to this problem is societal change. Why should autistic people have to adapt themselves to stay safe? As societal change is a long-term goal and not under the immediate control of any individual, it is to be expected that autistic people sometimes need to use strategies to keep themselves safe. ‘Normal’ behaviour may lead to less frequent bullying and discrimination and therefore increase both emotional and physical safety. As mentioned, this is even more pertinent at the intersection between autism and race as Onaiwu (2017) captures in an account of conversations she has with her children regarding interaction with police after the shooting of Walter Scott:

“[F]orget everything I have taught you about how forced eye contact is a bad thing... Do it anyway, even if it hurts. Speak in a soft gentle tone. Keep your hands where they can see them at all times. No sudden or unexpected movements and ABSOLUTELY no stimming or fidgeting or flapping as it might be perceived as attempting to strike someone. (Onaiwu, 2017, p.146).

Given the many hostile environments that autistic people may find themselves in, an alternative to ‘enforced normalisation’ could be to teach people behaviour that may feel unnatural to them but keeps them safe for the times where they are unable to avoid danger. If taught by other autistic people as a strategy, rather than by non-autistic people who may frame it as the desired or correct way to behave, then it is not the same as the ‘social skills courses’ that might be used as interventions. It could be taught alongside the risks that come with masking, which means autistic people can make fully informed decisions in the moment on whether the benefits of being true to themselves outweigh the risks. In this case, masking is being used as a tool. It allows the autistic person to keep themselves safe while maintaining their autonomy and the risks to mental health are lower, as they can be managed with strategies such as allowing recovery time in safe spaces.

This could be seen as temporary, apparent normalisation that is completely in the autistic person's control. Rather than neurotypical social behaviours being framed as a 'skill' that autistic people need to learn, the 'skill' would be maintaining one's autistic identity, while learning to navigate majority neurotypical spaces. There are numerous examples of how such strategies are cultivated and shared among autistic people, either through in-person exchanges or through online communities (see for example, Horlock, 2019).

Autonomy

Enforced normalisation removes a person's autonomy. If a person feels entitled to interfere in another person's life decisions, perhaps because of their perception of the individual's ability to make their own decisions, they are denying them their liberty (Späth and Jongsma, 2022). Späth and Jongsma cite Berlin's (1963) concept of negative liberty – if a person has negative liberty they are free from interference in their life.

Enforced normalisation without critical reflection on the necessity or the ability of the person to make the decisions for themselves could be considered a form of interference rather than support, which would ultimately lead to reduced autonomy. This is particularly the case as many examples of enforced normalisation seek to 'mainstream' young autistic children at the earliest point, before the behavioural patterns associated with autistic behaviour have become fixed and exclusion from societal spaces (such as mainstream schools, education, workplaces) is seen as inevitable (Yergeau, 2018). However, at such a young age, children are unable to provide informed consent or agree to either the normalisation or the potential secondary harms to mental health.

Wilkenfield and McCarthy (2020) argue that if, hypothetically, an autistic person could be taught to behave in a 'normal' way on a superficial level, then their autonomy is being disrespected because their coerced behaviour will misalign with their internal feelings and desires. If the coerced normalisation goes deeper and the person's internal thoughts and preferences are normalised, then it interferes with the formation of their identity. They highlight the number of autistic people who consider autism a part of their identity, despite the stigma, and argue that a 'respect for autonomy' means that all should have the option of doing so.

Mental health and wellbeing

There are numerous reasons why autistic people mask including unconsciously, by habit, for their safety, or because of the negative consequences of not masking (Hull et. al, 2017). One participant in Miller et al.'s (2021) study blamed being unable to mask as the reason for being a target for bullies. So, some would argue that normalisation has the potential to improve wellbeing and mental health by allowing greater inclusion into society. This has historically been an assumption as outcome measures for normalising interventions have rarely included measures of autistic wellbeing. Instead, they have looked at factors which non-autistic people consider to be indicators of wellbeing, such as 'number of friends' or 'wide variety of interests'. In recent years, an emerging body of literature contradicts the assumption that normalising autistic people leads to their improved wellbeing (e.g., Miller et al., 2021; Pearson and Rose, 2021; Wilkenfield and McCarthy, 2020).

Masking has been shown to contribute to suicidality (Cassidy et al, 2018), poor mental health (Lai et al., 2021; Pearson and Rose) and burnout (Raymaker et al (2020). While masking is not unique to autistic people, and is exhausting to all, in Miller et al.'s study (2021) only autistic people described it as making them feel suicidal. So, although the reasoning for normalisation may appear to have some merit (to improve life for the autistic person), research shows that the negative impact of normalisation can be extremely high – as such there is a strong chance that it will not improve the life of the autistic person.

Concluding comments and recommendations

We have referred to the three main perspectives on the nature of autism: the medical model, radical behaviourism, and the neurodiversity paradigm. These three viewpoints result in widely varying understandings of autism from a disease or disorder (medical model), a set of aberrant behaviours to be eradicated (radical behaviourism), and natural human difference with autistic behaviours being normal for autism and serving valuable purposes for autistic individuals (neurodiversity paradigm). Because these perspectives on autism are so very different in terms of an ontological understanding of autism, it is highly unlikely that any common ground will be found between

the various perspectives, which we call the **autism worldview dilemma**. The entire autistic population is left in an unfortunate limbo where they may be exposed to the possibility of interventions aimed at normalising those of their behaviours that proponents of perspectives other than the neurodiversity paradigm regard as abnormal. This demonstrates the importance of bringing the dilemma out into the open so that it can be the subject of reasoned debate between the respective parties. But where does this leave autistic individuals?

There is increasing evidence of the harm that interventions involving normalisation may do to autistic people; we have discussed some of these. Capuano and Killu (2021) remind their readers that:

“Ensuring that parents and clients are fully informed of the risks and benefits of treatments before they agree to pursue them is ... an aspect of informed consent.” (p.254–255).

While these authors were writing about what they refer to as pseudoscientific practices, their statement must apply to **all** treatments. We therefore encourage researchers to continue to investigate possible intervention harms in the hope that at some point in the not-too-distant future there will be clarity over whether, and to what extent, interventions involving normalisation harm autistic people. We also recommend that researchers study settings and practice which reflect the wishes of the autistic community and/or adopt a neurodiversity-affirmative approach. Practitioners could design and deliver training that assists autistic people to develop their ability to understand where and how neurotypical behaviour differs from autistic behaviour. Ideally, we would also like to see a legal requirement to require intervention practitioners to inform parents and other carers making decisions about the use of such interventions of the latest research findings to enable them to make informed decisions. However, as this is unrealistic under current circumstances, we set out an initial attempt at developing a set of indicators that will enable parents and carers to determine whether a particular intervention is aimed at either normalisation or acceptance of autism (see *Table 2*). We hope that other researchers will develop this framework further.

Table 2: Indicators of a normalisation approach versus an acceptance approach

Interventions focused on normalisation	Interventions focused on acceptance*
The intervention will not be described as neurodiversity-affirmative	The intervention may be described as neurodiversity-affirmative**
The intervention will seek to change behaviours associated with autism e.g. increase eye contact and reduce stimming	The intervention will never seek to change behaviours just because they are associated with autism. Change is only acceptable where it prevents harm to the autistic person or others (but it must be genuine harm; for example, embarrassment because someone is stimming is not harm).
The intervention will work on the basis of false or generic assumptions about autism	The intervention will be person-centred and avoid stereotypes of autism
The practitioner may not have received training in autism and will probably not understand differences such as in attention, eye contact, interests and stimming	The practitioner will have received training in autism and understand differences such as in attention, eye contact, interests and stimming
The practitioner will be focused on specific intervention techniques and may not adjust these to reflect differences in autism	The practitioner will use a thorough understanding of autism gained through training and/or professional experience
The intended outcome of the intervention will be to make an autistic person appear neurotypical	The intended outcome of the intervention will be to improve the life of the autistic person

*Acceptance of autism from a neurodiversity-affirmative perspective means seeing autism as an aspect of natural human difference. In the context of interventions, acceptance simply means not seeking to normalise an autistic person.

** It is recognised that an intervention may not be described as neurodiversity-affirmative but may still be focused on acceptance.

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