Autistic Knowledge: A Discussion from a UK Context

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Abstract

Being, knowledge, society, politics and powers all intersect in the construction of the concept of autism. In this article, I will present the changing and complex concept of what it means to be autistic and how societal structures, and the socio-political context affect some autistic individuals within the UK. Critical autism studies will be used as a theoretical approach that interrogates power structures and enables autistic lived experience to inform autistic knowledge within research. Neuro-affirming practice will be used as a philosophical lens to demonstrate that values and beliefs are interconnected with autistic knowledge and being.

Keywords: *autism, critical autism studies, neuro-affirming practice, epistemic injustice, social justice*

Introduction

This article aims to encourage theoretical and philosophical discussion in critical autism studies by using neuro-affirming practice as a lens through which to view autistic researchers and autistic research.

I begin by describing the societal landscape regarding the dominant conceptualisation of autism. Then I present theoretical framing of critical autism studies and why this is a suitable and neuro-affirming approach. I then introduce neuro-affirming practice as a philosophical lens and how this is linked to autistic knowledge and being. The term epistemic injustice is then discussed from an educational perspective. Finally, I present current autistic research demonstrating neuro-affirming practices and how we can embrace autistic knowledge within and outside of research.

(Re-)Conceptualising Autism

Over the past 80 years, the concept of autism has largely been framed by medical and psychiatry discourse, with the DSM-5 and the recent revision, DSM-5 TR (APA, 2013; 2022) being dominant contributors. The DSM-5 TR, which expands the criteria set in the DSM-5, provides the current working definition for autism diagnosis (APA, 2022). These criteria can be understood as differences in communication and social interaction (National Autistic Society (NAS), 2024b; APA, 2022). These differences are sensory differences; restricted and repetitive behaviours and

interests (RRBs) (described by some autistic people as self-soothing or self-regulating behaviours- or stimming, Kapp et al., 2019); and focused and dedicated interests, such as monotropic behaviours (Murray et al., 2005; Murray, 2018). These differences will be defined later on within the article.

Autism has been understood predominately through an objective and “value-free” lens of empirical studies from the medical and psychiatry field, which is also known as the medical model (Botha, 2021; APA, 2022). This deficit thinking presents many autistic individuals as “lacking” in cognitive function and social communication, leading to many individuals believing their experiences and worldviews are less than or maladaptive (Leekam et al., 2011; Baron-Cohen, 2012). These previous diagnostic classifications have led to restricted and limited framing of individuals with these differences (Russell, 2021). But recently there has been a social shift in autism awareness, where more individuals are seeking diagnosis as a validating tool to make sense and gain an understanding of what being, processing and behaving differently within the world can encompass (Russell, 2021; Blastland, 2025). Leading academics recently stated the aim of the DSM-5 TR diagnostic criteria was to reduce stigma by expanding the criteria to include less severe social communication difficulties and expanding the classification to include a wider spectrum of differences (Hens, 2018; Russell, 2021). As a result, the concept of autism began to better reflect a more heterogenous population, with more females and adults being diagnosed, compared to just children and males (Russell, 2021).

In response to the dominant thinking of the medical model of autism (APA, 2022), the social model of autism emerged in the UK in the 1980s (Oliver, 1990; Oliver, 1997). This political movement was different and empowering, as it was led by disabled individuals who challenged and interrogated society’s barriers and involvement in contributing to disabilities within the UK. This movement reframed disability from being solely situated as an individual’s deficit, to disability being considered a product of social construction (Olivier, 1990; Barnes & Sheldon, 2007). Importantly, the development of the social model has led to disability studies emerging as its own field of study within academia (Oliver, 1990; Barnes & Sheldon, 2007). Aligned with the social model of disability led by disabled activists, autistic activists and community have led the theorising and coining of the term neurodiversity (Botha et al., 2024)

Neurodiversity describes the variation apparent in neurocognitive functioning throughout the whole of the human species, acknowledging both neurotypical and neurodistinct individuals (Botha et al., 2024; Shaw et al., 2024). The term neurodivergent describes individuals who differ or vary from the societal norm of what is perceived to be dominant mind and brain functioning, also known as neurotypical (Chapman, 2020). When referring to neurodivergent autistic individuals, I will use the term neurodistinct, as this reflects my neuro-affirming position in this article and the variance of all human diversity, not just difference from the societal norm (Chapman, 2020). Neurodistinct, is used to describe someone who perceives, processes, or thinks in a distinctly different way to neurotypical or neuronormative thinking and experience (Morrow, 2021). The term

neuronormative relates to the idea of normality, where majority neurotypical thinking, assumptions, norms, and experiences are considered dominant or superior to neurodistinct thinking and experiences (Rosqvist, Chown & Stenning, 2020; Catala, 2023).

Being neurodistinct means an individual is shaped by the neurodivergent community and not defined by their difference and societal difference. One is still an individual within it. We do not have to display all behaviours and traits, as we are all unique and distinct (Morrow, 2021).

As discussed, autism is a contested term, but I will be viewing autism as a difference rather than a deficit (Chapman, 2020; Shaw et al., 2024). However, I do acknowledge that being autistic is a very subjective experience to each person, and what can be considered a difference for one person, can be very disabling for another (Hughes, 2020). I am an autistic PhD researcher, and I was inspired by autistic academic and researcher Monique Botha (2021) to define and situate my own being and position within this research article. As Botha (2021:6) states ". . . all research is driven by values, and instead it is not the presence of values which biases research, but the transparency of said values." My values are embedded within my research and not separate from my daily life as being autistic. By being transparent and acknowledging my privileged position as an autistic researcher, I have the ability to add to the emerging field of autistic researchers and inform autistic research (Botha, 2021). This position will allow me to amplify other autistic voices and capture experiences who have not had the access or opportunity to be heard (Botha, 2021; Green and Shaughnessy, 2023; Ryan and Milton, 2023).

Unfortunately, stigma around autistic people is still prevalent within society (Blastland, 2025). Western media's framing of autistic individuals is a key example of this problem.

Autistic Rhetoric within Society

Neurodistinct autistic individuals continue to face harmful rhetoric from Western media and from powerful individuals who influence how communities are perceived and included (Schreiber, 2025). We have just finished Autism Acceptance Month in the UK, which falls on April 2025. Throughout this month, we saw a series of campaigns dedicated to accepting autistic behaviours, values and being. However, this year's celebrations were met with the announcement of cuts to welfare reform and disability benefit for the most vulnerable people within UK society (Department of Work and Pensions, 2025). This is highly worrying as only three in 10 autistic adults are employed, and autistic people generally face significant social barriers getting into employment (National Autistic Society, 2024a). Disability benefit is an important and vital need for many autistic individuals to live and function within society. Yet the narrative and harmful rhetoric that autistic individuals are an economic drain on society remain prevalent (Lavelle et al., 2014). I argue an important counter-narrative is adopting critical autism studies as a theoretical tool and starting from a neuro-affirming position. This values autistic experience as valid and important knowledge in society (Botha, 2021).

Critical Autism Studies

Critical autism studies (Davidson and Orsini, 2013; Woods et al., 2018; Ryan and Milton, 2023) is an emerging field that acknowledges and embraces the intersection of autistic lived experience. It seeks to break down the societal barriers that have hindered the development of autistic knowledge informed by autistic individuals, and thus embraces different ways of knowing (Ryan and Milton, 2023; Naylor, 2023). Critical autism studies' emancipatory paradigm is rooted in highlighting and explaining the social structures and powers that enable or disable an individual within society (Oliver, 1990; Barnes & Sheldon, 2007). This worldview encourages an iterative dialogue between disabled people and researchers, and intends for research to make a difference to disabled people's daily lives. In doing so, the approach aims to empower disabled people rather than objectify them (Barnes & Sheldon, 2007).

Controversy around what constitute true participation and collaboration involving autistic experience characterised the field's early conception (Freeman Loftis, 2023). Early publications claiming to capture autistic experience were critically challenged by many autistic activists as well as autistic scholars for containing no true autistic voice, resulting in a misalignment of the field's purpose (Freeman Loftis, 2023; Ryan and Milton, 2023). Responding to these debates, Davidson and Orsini (2013) offered the initial conceptualisation of critical autism studies. This consisted of three parts: medicalised tenets of autism could be challenged by allowing for autistic experience; power structures could be interrogated; advancements in autism research could allow for autistic methodologies and frameworks to inform autistic knowledge and understanding. Ryan and Milton (2023) expand the conception of the term by adding a fourth part; that autistic academics, advocates and change-makers are part of the core of the field.

Societal and power structures that have an impact on autistic people and families are now the focus, moving the stigma away from autistic individuals (Ryan and Milton, 2023). This lens allows for expanding society's experiences and perceptions to drive social change and accept many more differences in worldviews and in how human beings differ within the world (Woods et al., 2018; Ryan and Milton, 2023).

Critical autism studies encourages activism within academia, empowering researchers to reflect not just on perspectives and standpoints, but also to challenge values and beliefs (Elsherif et al., 2022). Much of objective empirical autistic research has tried to separate values and beliefs from the research process (Botha, 2021; Ryan and Milton, 2023). However, values and beliefs are very much embedded within the research process, from shaping to disseminating research. Questions such as what can be considered knowledge and who is participating in the research are important (Fletcher-Watson et al., 2019; Botha, 2021). Cultural bias and limitations influence the construction of how we, as diverse humans, are "to be" in the world (Wood et al., 2018; Botha, 2021). This theoretical approach explicates power relations and considers these influences when analysing who we are within society, ultimately allowing differences in worldviews that can enable social change (Oliver, 1990; Barnes & Sheldon, 2007). It is important for research to make a

difference to the lives of autistic individuals and to be part of constructing the research process (Fletcher-Watson et al., 2019). Participatory research practices within the autism field have led to the establishment of guidelines to involve autistic individuals in research. For example, Fletcher-Watson et al. (2019) conducted a series of seminars focusing on presenting the positive outcomes of participatory research rather than the barriers that many autistic individuals face (Fletcher-Watson et al., 2019). An important contribution to the field is that participatory research can be shaped by autistic lived experiences and be ethically conducted, without autistic individuals experiencing tokenism (Fletcher-Watson et al., 2019). Furthermore, academic rigour and validity is central to constructing autistic knowledge and this consists of not just solely from an autistic standpoint but also includes reflexive and informed evidence from neurotypical researchers as well as autistic researchers and lived experience (Fletcher-Watson et al., 2019; Kapp et al., 2019; Ryan and Milton, 2023).

While critical autism studies is an important emancipatory theoretical framework, it is important to acknowledge this approach is based on a Global North perspective of neurodiversity (Nair et al., 2024). From a decolonial lens, it can be argued that autistic knowledge continues to be constructed from the Global North, mainly the UK, USA and European context, which presents a narrow understanding of autistic lived experiences and knowledge (Nair et al., 2024). Canagarajah (2023) argues the gaze of the neurodiversity paradigm in the Global North focuses on the individual and communication, whereas the Global South places more emphasis on ethical and moral beliefs and attitudes when understanding neurodivergent individuals. Building on Canagarajah's (2023) thinking, Nair et al., (2024), argues the Global South centres the gaze on relation of community, ethics and morals rather than deficit in skills and knowledge of the individual, and this needs to be acknowledged and included in the construction resulting in plurality of global autistic knowledge (Nair et al., 2024). However, progress is being made within the Global North as more autistic research is starting to position ethical and moral practices as an important part of autistic research practice (Hens et al., 2018; Fletcher-Watson et al., 2019; Hughes, 2020; Botha, 2021). These studies have begun to acknowledge the value, standpoint, and positionality of autistic knowledge and perspective (Hens et al., 2018; Fletcher-Watson et al., 2019; Hughes, 2020; Botha, 2021).

Neuro-Affirming Practice as a Philosophical Approach

Neuro-affirming practice as a philosophical approach treats being autistic as meaningful and different rather than as a deficit (Naylor, 2023). This philosophical approach is not a clearly defined framework with clear structures. Rather, just like the term "neurodiversity", it embraces all variations, strengths, weaknesses, and differences of neurotypes (Chapman, 2020; Naylor, 2023). This philosophical approach involves more than just an academic stance and application of a

model; it involves living and lived realities, values and beliefs imparting and shaping the discourse (Woods et al., 2018; Naylor, 2023; Ryan and Milton, 2023; Green and Shaughnessy, 2024).

A recent study from Russell et al. (2019) supports the stance of neuro-affirmation. This qualitative study involved interviewing 24 adults about their neurodistinct autistic experience. The findings from this research suggest that autistic traits, which can manifest as behaviours, such as complete concentration of an interest, are experienced as both a strength and a weakness (Russell et al., 2019). These behaviours can be perceived as highly focused on an interest, which can in turn demonstrate determination and perseverance. In addition, these behaviours align with the theory of monotropism (Murray et al., 2005).

Monotropism is an autistic theory and is conceptualised as being completely concentrated on a task while channelling or blocking out other external influences (Murray, 2018). Viewed through a neuro-affirming lens, monotropism is about starting from an autistic person's interest. However, these traits also fall under the criteria of the DSM-5 TR (APA, 2022) as highly restricted and abnormal focus resulting in the exclusion of others. These findings are important for steering the field of neuro-affirming practice forward, as they signify strengths and weaknesses of neurodistinct autistic being and behaviours, and both deeply intersect with context and society (Murray et al., 2005; Murray, 2018). For example, within society, focused behaviours by neurotypical individuals can be perceived as determined and disciplined while focused and concentrated behaviours by autistic individuals can be perceived and received as "abnormal" and "intense" (Murray, 2018; Kapp et al., 2019; APA, 2022). Therefore, I support Botha (2021) in arguing that being autistic is linked to what is socially and culturally acceptable. Rather than starting from a deficit-based position, research should be approached from a strength-based position (Russell et al., 2019; Botha, 2021; Elsherif et al., 2022).

The validity of autistic knowledge is a deeply embedded value of this approach, meaning equality and fairness in how all knowledge is received and perceived (Ryan and Milton, 2023). As a concept, autism is highly contested and is continuing to change, and conflicting understanding has led to autistic knowledge being disputed, divided, and misrepresented (Shaw et al., 2024; Ryan and Milton, 2023). Within the context of social theory, knowledge can be supported and argued for by expertise, including lived expertise (Milton, 2014). But for many autistic individuals, autistic knowledge—which can manifest as difference in social communication—is assumed to represent a deficit and has led to the common assumption that there is a cognitive deficit and "lack of empathy" (Baron-Cohen, 2012; Griffiths et al., 2019). A difference in social communication is not to be understood as lack of knowledge, but a difference in how knowledge is displayed. This misunderstanding and misperception are due to the label and social status that is conferred onto autistic individuals (Milton, 2014). Knowledge is intertwined with power and social structures. This means knowledge is affected by how much an individual varies and deviates in social communication from the accepted social norm, which ultimately determines how one is accepted within society (Milton 2012; Milton, 2014).

I argue that due to differences in social communication and behaviour, autistic sociality is interpreted as lacking and therefore misunderstood as non-social compared with dominant social norms, resulting in epistemic injustice (Milton, 2014; Botha, 2021).

Epistemic Injustice

Fricker (2013) and Legault et al. (2024) define epistemic injustice as the exclusion of a person or individual based on how they interpret, demonstrate, and exhibit knowledge within society. The UK education system is perpetuating this act of injustice by not recognising differences in social communication and meaningful ways of learning, thus leaving no space for neuro-affirming practice (Wood, 2021). This is evident from teacher- inspector training to practices within schools (Timpson et al., 2019; Wood, 2021; Syal & Adams, 2025; Scottish Assembly of Parents and Carers, 2025). Evidence suggests within some schools in the UK; autistic knowledge is not valued and is stigmatised. A recent report of 144 parents and carers of disabled and neurodistinct children state that within some educational settings in Scotland, there are stigma, societal assumptions, and status conferred onto some neurodistinct disabled children (Scottish Assembly of Parents and Carers, 2025). The report calls for an education culture to be built on beliefs and values that view disabled children, including neurodistinct autistic children, as individuals and not as “badly behaved” children (Scottish Assembly of Parents and Carers, 2025).

There have also been reports of exclusion from education. The Department of Education reported that children with special educational needs and neurodistinct autistic children are more likely to be excluded from schools in the UK (Timpson et al., 2019). Another report conducted in Scotland, titled *Not included, not engaged: not involved, a report on the experiences of autistic children missing school,* wanted to establish why some autistic young people were missing school (Children in Scotland et al., 2018). Based on 1417 parental responses, the report found 34% of autistic children were unlawfully excluded from school (Children in Scotland et al., 2018). More recently, the National Autistic Society criticised the 2025 OFSTED manual for training teaching inspectors in the UK for its use of discriminatory language and narrative towards young autistic people within UK schools, further stigmatising neurodistinct autistic behaviours (Syal and Adams, 2025).

In response to the stigmatised framing of neurodistinct autistic behaviours and knowledge within the education system, a drive towards positive social change is emerging with focus in examining support and intense interests within schools (Woods, 2021). Wood’s (2021) research findings indicate that when autistic young peoples’ focused interests are enabled and supported as informing the learning environment, they can be a positive teaching tool to access the wider curriculum and positively affect well-being.

Aligned with Wood’s (2021) findings, a new knowledge partnership at the University of Birmingham and Sheila Coates foundation led by Professor Laura Crane aims to improve

educational experiences for autistic young people. This project aims to break down the social barriers within schools that restrict many autistic young people (University of Birmingham, 2025). As well as driving social change within the field of education, neuro-affirmative research methodologies are also emerging.

Neuro-Affirming Research Methodologies

A recent study introduces autistic phenomenology (Green and Shaughnessy, 2024), which explores how autistic individuals perceive and experience the world from their own lived experience, and how this can be adopted in clinical settings. This implicates recent autistic research, as it challenges the stigmatisation of societal autistic experiences within research (Kinnear et al., 2016; Kapp et al., 2019; Morris et al., 2025). Building on this research is the reframing of autistic perceptions of "stimming": self-regulatory behaviours that are repetitive (Morris et al., 2025). The autistic community through reclamation and lived experience, has reframed these negative behaviours as positive "stimming" behaviours (Kapp et al., 2019; Morris et al., 2025). These behaviours are linked to positive sociality and connection with others and have important meaning for self-regulation and well-being (Kapp et al., 2019; Morris et al., 2025).

An ethical responsibility and implication then arise for autistic researchers to challenge and reframe deficits as differences. Botha (2021), an autistic activist and researcher, calls for autistic researchers to inform and shape autistic knowledge within academia. I also interrogate the power structures within society and academia and call for more autistic researchers to have an active participatory voice in producing their own research while also working together with neurotypical researchers (Fletcher-Watson et al., 2019; Botha, 2021; Ryan and Milton, 2023). Recent work discussing neurodivergent researchers within academia highlights the challenges faced due to academia's output-driven framework (Azevedo et al., 2022; Elsherif et al., 2022). Both Azevedo et al. (2022) and Elsherif et al. (2022) suggest that we can reduce these challenges and barriers by adopting inclusive spaces for neurodistinct academics to thrive, such as hybrid learning spaces. In addition, training that highlights the effects of power structures, positionality, and standpoints needs to be provided within academic institutions. Elsherif et al. (2022) further explains the complexities and difficulties faced by some neurodivergent researchers, as disclosing one's individual disability can be met with stigma. Additionally, Diversity Equity and Inclusion (DEI) policies do not always translate into actual teaching and practice. However, an intersectional lens can challenge and reduce barriers and exclusionary practices (Elsherif et al., 2022).

Methodological approaches and understandings of positionality are also being redefined. More careful attention to research design and conduct is starting to inform autistic research (Fletcher-Watson et al., 2019). For example, a recent study from Kapp et al. (2019) was co-designed with autistic participants as well as non-autistic academics. Through focus groups and interviews, autistic participants were empowered to describe their lived experience of "stimming"

behaviours. A recent mixed method study involving autistic parents and autistic children also demonstrated co-production of autistic research and experiences (Crane et al., 2021). This involved reflexive feedback from autistic parents on the design of the survey used in the quantitative phase. Both studies by Kapp et al. (2019) and Crane et al. (2021) demonstrate the importance of methodological intent and approach involving autistic people, as it validates autistic lived experience and expertise, informing and building an ethical and responsible research process. This co-produced approach serves the autistic community with more meaningful research done with autistic individuals rather than research being "done to" autistic individuals, resulting in interventions and approaches to support day-to-day autistic life (Barnes & Sheldon, 2007; Fletcher-Watson et al., 2019; Kapp et al., 2019; Crane et al., 2021; Russell, 2021).

As well as co-produced research practices and autistic experience, autistic-led theories are also expanding and enriching autistic knowledge. Monotropism, an interest-led theory, described as lived experience of autistic processing being completely focused and concentrated on a task (Murray et al., 2005; Murray, 2018). This theory is constructed and conceptualised with neuro-affirming positioning and views this autistic trait as a difference rather than a deficit. This implicates how future theories are conceptualised and how the standpoint of autistic lived experience informs the conceptualisation of a strength-based term, while still acknowledging the weaknesses and implications intense focus can bring for autistic individuals (Murray et al., 2005; McDonnell and Milton, 2014).

Aligning with other autistic scholars (Botha, 2021; Woods et al., 2019; Ryan and Milton, 2023), I propose that this critical theory and philosophical lens is not about eliminating or devaluing the roots of what it means to be autistic. This combined approach highlights barriers within society and academia and demonstrates effective co-production within autistic research by stating positionality and using autistic informed participatory research methods (Fletcher-Watson et al., 2019; Kapp et al., 2019; Crane et al., 2021; Morris et al., 2025). I have discussed the complexity and changing conception of autism and how this is reflected in society within the UK. As researchers, we have a moral and ethical duty to reflect the complexity and blurriness of the changing diagnostic culture of autism within society (Hens et al., 2018; Fletcher- Watson et al., 2019; Blastland, 2025). We can achieve this by informing autistic research from not only the perspective of neurotypical researchers but also that of autistic researchers and autistic participants (Hens et al., 2018; Fletcher- Watson et al., 2019; Crane et al., 2021). Autistic research calls for more focus on the intersections of race, gender and autism (Nair et al., 2024; Botha et al., 2024). This is crucial for social justice and informing a more plural landscape in what it means to be autistic (Fletcher-Watson et al., 2019; Botha, 2021; Ryan and Milton, 2023; Nair et al., 2024).

The autistic research landscape is starting to change. Leading academics are demonstrating this change by listening, embracing and including autistic voices, behaviours, and difference (McDonnell & Milton, 2014; Fletcher-Watson et al., 2019; Kapp et al., 2019; Botha, 2021; Crane et al., 2021; Ryan & Milton, 2023). Society needs to enable access and opportunity to allow

autistic researchers, neurotypical researchers, and autistic participants to come together to enrich the autistic episteme and embrace neurodiversity and the varied reality of human experience.

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