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CRITICAL AUTISM STUDIES
An introduction

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The importance of critical autism studies was clearly signalled in 1992 with the creation of the Autism Network International by a small number of autistic activists who sought to create an autistic space for autistic people. This early activism lay the foundations of critical approaches to autism and, importantly, was driven by the experiences of those so defined. Despite this development the term ‘critical autism studies’ only started to gain currency in academic studies following a workshop focused on this subdiscipline organised by Joyce Davidson and Michael Orsini in Ottawa, Canada, in 2010. Davidson and Orsini’s (2013) initial conceptualisation of critical autism studies had three core strands: advancing enabling narratives of autism to challenge deficit-focused constructions; a focus on power relations within the autism field; and a commitment to developing new analytical frameworks and theoretical approaches to study the nature and culture of autism. They call for social science research which “demands sensitivity to the kaleidoscopic complexity of this highly individualised, relational (dis)order” (2013, p. 12). This edited volume seeks to explore the development, importance, application, and insights offered by critical autism studies. It draws on the three core conceptual strands identified by Davidson and Orsini and further develops them with the addition of a fourth strand to the original conceptualisation of critical autism studies which locates the work of autistic academics, activists, and professionals at the centre of the discipline.

What is this thing called autism?

Autism remains a contested term or descriptor which is conceived on multiple levels of description, from a biologically based biomedical disorder to a cultural identity. Verhoeff (2012) posed the question “What is this thing called autism?” and a decade later we still have much to learn, particularly from autistic worlds (Davidson and Orsini 2013). Autism has an unusual or even mysterious (McGuire and Michalko 2011) intensity generated by the potential, imaginings, controversy, resistance, and tensions it variously incorporates, engages with, or resists. It has been discursively constructed in different historical, social, political, economic, and cultural contexts, originating as a clinical term, and expanding beyond the clinical realm to mean different things to different people. It is brilliantly and impossibly diverse in terms of experiences, characteristics, ‘symptoms’, possible biological markers, and social contexts. Controversial and contradictory, it has been perceived as an economic burden (Lavelle et al. 2014), something to be eradicated

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(Krcek 2013), and a strength (Milton 2017). At the same time, it is an important life experience that is highly charged and can have devastating consequences for the autistic individual and their families within contemporary cultural contexts (Hirvikoski et al. 2016). Indeed, as Hodge et al. (this volume) ask, how can we somehow undo or avoid the hurt autistic people have often experienced from childhood into adulthood?

The politics and ontological foundations of biomedical research, with its quest for secure, fixed and ‘scientific’ research outcomes remain strong, with vast sums of money and potential profit available to big pharma. In 2018, for example, around 40% of the US government research funding for autism was spent on biological studies with only 10% on lifespan issues and services (Dattaro 2021). A fundamental schism exists between considerations of the historical, cultural, and social context of the production of autism knowledge, and a biomedically based focus which examines autism through an ableist lens of deviance and inferiority (see, for example, Verhoeff 2012). For McGuire and Milchalko (2011), the use of a puzzle symbol to typically represent autism signifies the idea that there is a currently missing solution to be found, that autism is somehow knowable (and again potentially curable). At the same time, it remains unknown, which implies mono-dimensional manifestations. We should be embracing the ways in which, conceptually, autism always exceeds and confounds, and how it is always ‘yet to know’, rather than seeking to cure and potentially eradicate it. Most importantly, at the heart of the autism narrative are the experiences of those so defined. This schism in the way that autism is conceptualised is remarkably enduring, and speaks to the commodification of the label, not least given how the cause continues to elude researchers despite the time and resources invested in seeking to discover it. The dominance of the biomedical model has also led to a significant gap between funded research topics and the questions that autistic people would like researched (Milton and Bracher 2013; Milton 2014; Pellicano et al. 2014; Fletcher-Watson et al. 2019). A recent systematic review of studies that report on key stakeholder priorities for autism research found the importance of prioritising initiatives that will result in real life changes for autistic people (Roche et al. 2021). The authors underline the importance of the continued involvement of autistic people and communities in priority-setting research, arguing this is imperative for achieving change in people’s lives and for progressing autism research in an ethical and effective way.

The tensions within critical autism studies

These controversies and contradictions extend to the field of critical autism studies, which has been differently interpreted and appropriated by autistic and non-autistic academics and activists, although the power to define autism has long been held by non-autistic or neurotypical clinical professionals and researchers (Evans 2013; Milton 2014). In the Global North there has been a growing community or communities of autistic activists and academics, family members, and allies challenging negative perceptions of autism, facilitated by emerging social media platforms, an increasing number of autistic activist-academics, and interest around critical autism studies within the wider and established field of disability studies (Woods et al. 2018).

The strength of this development has been in part due to resistance to the unwavering dominance of the deficit-laden model which informs biomedical research. Indeed, neurodiversity has become a preferred conceptual paradigm for many autistic people as it is considered to be both socially situated and more value-neutral than medicalised models of autism (Botha et al. 2020). At the same time, embedded within the space of critical autism studies are deeply personal positions on what autism means to different people, whether they are autistic, family members, or the wider public. This includes questions around who has the epistemic authority
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to research and write about the experiences of being autistic (Milton 2014; Hens et al. 2019, Botha 2021), as well as concerns about the rewriting of the narrative around the development of critical autism studies and the original critical autism studies autistic leadership (Woods et al. 2018). There is strong criticism about the lack of recognition of the importance of epistemological validity and integrity generated by the centrality of autistic input and expertise (Milton 2014; Woods et al. 2018, Gillespie-Lynch et al. 2017), and the importance of critical autism researchers taking seriously a commitment to research that avoids reproducing hierarchical relations with marginalised groups has been highlighted (O’Dell et al. 2016). Critiques of ‘cultural imperialism’ levelled at neurotypical researchers by autistic researchers and activists (Milton, 2016, Woods et al. 2018) speak to the territorialisation of critical autism studies and the accompanying ‘linear containment of thought’ (Mercieca and Mercieca 2010). Recent challenges to conventional academic knowledge production by autistic researchers include an account of the impact of experiencing ‘scientifically sound’ dehumanising accounts (Botha, 2021) and consideration of neurodiverse epistemological communities (Bertilsdottir Roqvist et al. 2019). Without epistemological validity, questions are raised around how meaningful research can be. Indeed, Pellicano et al. (2014 p. 1) argue that “the lack of a shared approach to community engagement in UK autism research represents a key roadblock to translational endeavours”.

An alternative position is taken by some activist scholars who provocatively argue that the core questions we should be asking are whether the diagnosis of autism is scientifically valid or useful to autistic people or their families (Runswick, Mallett and Timimi, 2016). It is important to recognise the fluidity (or outright rejection) of autism identity for some and the reasons why such positions are taken up (O’Dell et al. 2016, Runswick-Cole et al. 2016).

There is some evidence of shifting power within the autism research arena. A new study, Spectrum 10K, was launched in the United Kingdom in August 2021 to considerable national media interest. The project, co-led by Simon Baron Cohen from the University of Cambridge and Daniel Geschwind from the University of California Los Angeles aims to “investigate the genetic and environmental factors that contribute to autism and related physical and mental health conditions to better understand well-being in autistic people and their families”. After the launch, questions were immediately asked by members of the autistic community and their allies about the lack of involvement of autistic people in the study design. There were also strong concerns around the proposed collection of DNA samples from autistic people and their family members. Despite explicit claims on the project website that the study will not look for a cure or aim to eradicate autism, an autistic-led group, Boycott Spectrum 10K, was founded, and the campaign work of this group and others led to the suspension of the study within weeks. A consultancy firm has been commissioned to conduct retrospective engagement with autistic people and family members to repair the damage caused by the lack of awareness and foresight of the study team and strengthen the research design. As Natri (n.d.) suggests, it is unprecedented for a large-scale study to be paused because of ethical concerns raised by members of the marginalised group targeted by the research.

So what does critical autism studies do?

For us, critical autism studies is a cross-disciplinary endeavour which highlights the constraints of social environment, structures, and cultures. It is essential to recognise and act on these constraints if we want to change things to generate better health and well-being for autistic citizens and their families. Critical autism studies offers the opportunity to have an impact on people’s lives. It takes the focus off the autistic person and their ‘personal troubles’ and recognises the
socially situated nature of public issues facing autistic people and their families (Wright Mills 1959).

It creates a space to relieve some of the tensions that percolate around autism and autism research, enabling respectful, open dialogue and discussion. Critical autism studies engages with the use of language and highlights the dangers associated with functional labels which are not only ableist but can generate barriers to appropriate support (Bottema-Beutal et al. 2021). The activist turn within and beyond the autistic community and academia has added anger, clarity, and a hope for pragmatic and meaningful change. From theory to practice, we want this to be practically meaningful and to unsettle positions of power when they are built on shaky, unevi-
denced grounds, or grounds that have been shown to have a detrimental effect on people.

The production of understandings that perpetuate how we understand phenomena because of the ways in which our research practices are underpinned by the imperialism of common sense – shaped and influenced by the strength of conformist thinking (Guattari 1988) – is, we argue, magnified in a field in which research is dominated by non-autistic researchers and academics. A linear status quo is maintained, reducing space for imagination and opportunities to critically think and do things differently (Deleuze, 1997). There is some irony that this cultural imperialism can be demonstrated through an autistic researcher-led analysis of the referencing of work within critical autism studies (Milton 2018). Authors citing autistic critical theorists in Disability and Society are typically other autistic authors, which suggests a systematic sidelining of, or superficial engagement with (Botha et al. 2020), autistic scholarship – a peculiar ‘talking over’ in the process of writing about the importance of collaborative research and engagement.

Whilst there is a drive towards co-production and interdisciplinarity, with a few notable exceptions, it is autistic scholars who are most likely to cite each other. For critical autism studies to change this, a more participatory and emancipatory ethos is necessary. The contributions and forms of expertise needed (Milton 2014) for such efforts require both autistic and non-autistic scholars and activists, not the erasure of their voices and efforts within the field. Indeed, a compelling case for inclusion on ethical and epistemological grounds has been made (Milton and Bracher 2013; Milton 2014; Gillespie-Lynch et al. 2017; Chown et al. 2017; Fletcher-Watson et al. 2019). We have seen a welcome counter-focus on participatory autism research in the UK (Fletcher-Watson et al. 2019; Milton and Bracher 2013; Milton 2014; Gillespie-Lynch et al. 2017; Chown et al. 2017).

In producing this Handbook, we have embraced how working across these subcultures is possible, productive, and beneficial to all concerned. Critical autism studies offer potential and possibilities to continue to seek the emancipation of autistic people, focus on intersectionality and injustices, and for academics who are autistic and non-autistic to work together in producing important scholarship that has reach and impact. Meaningful collaborative engagement is key and can be demonstrated by the development of a ‘neurodiverse collective’ in which autistic and non-autistic people (researchers and participants) work together (Bertilsdottir Rosqvist et al. 2019); working in partnership, increasing the inclusion of autistic voices, and revising or reducing the non-autistic voices. Meaningful engagement is a core part of robust research and yet the power relations in the field of autism studies remain unbalanced. We support the summary of autism research advocated by the autistic community (Bottema-Beutal 2021 p. 19): “Accessible, inclusive of autistic participation and perspectives, reflective of the priorities of the autistic community, of high quality and written in a way that doesn’t contribute to the stigmatisation of autistic people”. Critical autism studies involves the reclaiming of the narratives of autistic people and the centring of these experiences.

There is a strong bias in this volume towards the Global North. The idea of a wider autism spectrum is a Northern European and American concept which means there are fewer autistic
people in other parts of the world (Zeidan et al. 2022). In many countries, there is no term for autism, there is no concept of autism as we would define it, and there is a tendency for the Anglo-American representation of autism to be viewed as universal (see Crosbie, this volume). In terms of funding knowledge production and research into autism, there is a highly Americanised weighting. In 2010, for example, the United States spent 89 times more on autism research than the UK (Pellicano, Dinsmore, and Charman 2014). Although there is growing interest in autism across the globalised world and in the spread of information and ways of conceiving issues, in many societies autism still seems a rare disorder of severe learning disability. Autistic activists are often in a difficult position although they are beginning to organise and form autistic activist and family-led groups. This is very early, however, and a strong stigma remains in some parts of the world, related to a strongly medicalised interpretation. Medical clinicians still have the power to label and frame people with more severe learning disabilities and make decisions about people’s lives.

Book aims and structure

A key aim of this book is to coalesce the split subcultures within critical autism studies in one place by including contributions from a wide range of perspectives, including autistic and non-autistic activists, academics, practitioners, and professionals. This speaks to the concept of the ‘autism wars’ (Orsini 2016) and competing meanings generated by autistic knowledges (generated by autistic people) and knowledges of autism (the knowledge of professionals, parents, and academics) (see Bertilsdottir and colleagues, this volume). This coalescence will provide people – activists, scholars, professionals, students, and others – with a connection to critical voices on the matter of autism, highlighting points of connection with which to build their own activism with, ideas of what to take on and what to disregard as irrelevant, and potential starting points. There is strength in linking theory and practice and improving activism and thereby generating change in people’s lives. The collection of authors in this volume gives activism a legitimised voice, a level of respect that activism is often not granted. Indeed, too often activism is not listened to or considered to be part of the academic evidence base.

In terms of structure, the book is divided into four sections: Conceptualising autism; Autistic identity; Community and culture; Practice.

Part 1: Conceptualising autism

In the opening sections, authors conceptualise autism in diverse ways which capture the fluid meaning of the term. In Chapter 2, Larry Arnold traces the movement from disorder to identity as autistic people engage with the concept and generate new meanings. For Arnold, ‘self’ can be viewed as a set of constructions based on contingency and circumstance. He reflects on whether the identity is useful, real, or a mechanism to establish a sense of self. In Chapter 3, Charlotte Brownlow, Lindsay O’Dell, and Ding Abawi consider how autistic people are positioned within the dominant discourses of developmental psychology and other psy-disciplines and explore what normative models of development mean for understandings of autism and autistic individuals. The authors highlight the dominance of Western understandings and the powerful role that they have played in constructing ‘normal’ and ‘non-normal’. They further demonstrate how three key developmental concepts manifest within the autism literature are invoked to identify differences, serving to marginalise those labelled. In Chapter 4, Dinah Murray makes a strong call for injustices to be exposed as widely as possible, in order to create the passion that is necessary for truly different attitudes towards people who are unable to speak for themselves.
For Murray, language and the power of words are central to this endeavour. In Chapter 5, Patrick Dwyer presents an introduction to clustering analyses and, like Brownlow et al., demonstrates how what may be perceived to be an objective process of subgrouping relatively similar autistic people is subjective and can have deleterious consequences, such as reducing support or fracturing communities. In Chapter 6, Richard Woods carefully takes us through the process of how the social construction of Pathological Demand Avoidance (PDA) led to the adoption of PDA as a form of autism. For Woods, PDA provides disability studies scholars with an unusual opportunity to study how phenomena are constructed. He again explores the impact of impact of PDA on those assigned with the label. Monique Botha completes this section in Chapter 7 by proposing reparations for the gross institutional violence experienced by autistic and other people. Unpacking the presumed neutrality of psychologists, Botha describes how the history and present of autism knowledge is one marked by violence, such as eugenics, dehumanisation, and objectifying narratives, and has rarely fully involved autistic people. Botha suggests Community Psychology could provide a road map for addressing this violence.

**Part 2: Autistic identity**

Part 2 includes contributions around autistic identity that cover critical race theory, motherhood, gender, and secondary schooling. Autistic identities cut across other, more established identities and this is demonstrated in recent research with studies focusing on gender (Kourti and McCloudf 2019, Mandy and Lai 2017), sexuality (Kourti 2021), and race (Brown et al. 2017). Melissa Simmonds makes a strong case for the existence of racism in the autistic community and wider society in Chapter 8, demonstrating that it is important to focus not on what it is like to be autistic but what it is like to be Black and autistic. She asks what we are going to do to write the wrongs in the field of autism. In Chapter 9, Francesca Bernardi draws on a Gramscian perspective in her qualitative study of Italian mothers of autistic children to highlight hierarchical positions maintained in medical proceedings and contexts, producing practices of control disguised in language as rigour. Her work resonates with contributions from Part 1, including Brownlow et al. and Botha. Bernardi further identifies how the interview space enabled mothers the opportunity to begin to recognise, articulate, and counter marginalisation, ableism, and social distinctions. Chapter 10 stays with mothers, as Magdalena Mikulak focuses on the intersection between gender diversity and autism. Drawing on a qualitative study of the experiences of mothers of young trans and gender-diverse children, she asks what ideas and understandings of both gender diversity and autism are reproduced when the two are held together and analysed in relation to one another. In Chapter 11, Emma Rice Adams demonstrates an understanding of how the self can be presented in varying social contexts to influence the perceptions of others. She uses the example of young autistic adolescents and the school environment and demonstrates how her findings act as a counter to deficit-focused characterisations of young autistic people. In the process, she illustrates how the sense of self of the autistic young people involved is both conceptualised and negotiated within the social world. Finally, Damian Milton offers a personal account of neurodiversity, academia, and activism in Chapter 12. In this chapter Milton examines the power differentials between researchers and autistic people, introduces the reader to the Participatory Autism Research Collective (PARC), a network promoting participatory work within autism studies, and offers advice for others setting out on the path of autistic scholar-activism.

**Part 3: Community and culture**

Part 3 shifts the focus to community and culture and takes us from a vision of ‘utopia’ to the Moulin Rouge (or the Rouge Moulin) in Paris, to the reality-TV programme *Love on the
Spectrum, ending with sunflowers at Manchester airport. **Luke Beardon** starts this section with the presentation of a vision for autistic acceptance and belonging in a future dimension – ‘autopia’ – in Chapter 13. He returns to the theme of harm that is done to autistic people by narrowly defined normative expectations, arguing that the problems autistic people experience are the result of lack of knowledge, of understanding, acceptance, willingness to listen, and of change. In Chapter 14, **Peter Crosbie** uses the example of France to question the idea that there is a single, universal representation of autism that is understood across all cultures. He challenges the notion that the only way forward for these societies is to adopt the Anglo-American representation of autism as their own. **Hanna Bertilsdotter Rosqvist** and co-authors discuss competing autistic knowledges in Chapter 15 and conceptualise these claims to knowledge and rights of interpretation in terms of struggles for authority within and between different epistemological communities. This again speaks to the aim of this volume, which is to bring together the different subcultures within critical autism studies. **Mitzi Waltz** returns to parents in Chapter 16 with a hard-hitting exploration of the pressures parents experience. She takes us back to the Child Guidance Movement with its focus on the ‘maladjustment’ of children, which developed in the early 20th century in the UK and the United States, and the subsequent commercialisation of autism. **Allison Moore** brings us back to the present with an examination of the intersection of representation of autism, sex, and intimacy in a US-based reality-TV programme, *Love on the Spectrum*. Using Pierre Bourdieu, Moore demonstrates how it is necessary to move beyond individualised accounts of love and romance, to the structural inequalities autistic people face in the dating world. Finally, in Chapter 18, **Katherine Runswick-Cole and Dan Goodley** provide a biopolitical reading of a story about the use of a sunflower lanyard and the subsequent conversation the authors had about this experience. This allows a consideration of the biopolitics not simply of autism but of life itself and what it means to be human.

**Part 4: Practice**

The final section in this volume focuses on practice and offers ideas for improving the well-being of autistic people. Chapter 19 by **Chloe Farahar** documents the two ‘autisms’ – autism as a medical disorder and autism as difference – before going on to highlight the importance of an autistic identity as a ‘social cure’ and the importance of autistic spaces as places of refuge and healing, generating well-being. **Hodge and colleagues** use critical autism studies as a methodological tool in Chapter 20 to analyse how the apparently mundane and ordinary chatter in classrooms conceals and reproduces dominant disabling discourses that deny autistic children personhood and position them as a problem. The chapter is based on a digital story made by Hodge as part of the Re•Storying Autism in Education project. In Chapter 21, **Steven Kapp** compares four attribution models of moral responsibility for the causes of and solution to problems: moral, medical, enlightened, and neurodiverse. He argues the neurodiversity model offers the strongest approach to improving autistic people’s lives as it is empowering and encourages people to seek support on their own terms. In Chapter 22, **Joseph Long** considers the insights critical autism studies has to offer autism support services, drawing on his experience of a service-providing organisation, Scottish Autism. For Long, practices and discourses within support services can reflect social norms that have historically marginalised autistic people, but engagement with critical theory has the potential to transform the way services operate. **Rebecca Wood** returns to education practice as she explores communication in the classroom. Like Hodge et al., she presents evidence of the denial of the value of autistic communication in the classroom, drawing on her doctoral study, which leads to diminished agency on the part of the children. Wood makes the
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argument for setting aside the unquestioned association between autism and communication to allow children to reclaim their agency and show, themselves, the conditions for communicating more fully. Wood here highlights the values that underpin this volume: a resistance to normative conformity and obedience and an acknowledgement that autistic individuals can stand to gain more from silent resistance. Finally, in Chapter 24, Waldock and Keates complete this volume with a chapter that underlines a consistent theme running through the contributions: the colonisation of this thing called autism by non-autistic people and what this has meant for autism ‘knowledge’. Examining Arnstein’s Ladder of Citizen Participation, the authors underline the importance of the autistic voice in autism research and provide a checklist for autism researchers to use.

References

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