



**A critical reflection on the development of the Participatory  
Autism Research Collective (PARC)**

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## **A critical reflection on the development of the Participatory Autism Research Collective (PARC)**

### **Abstract**

#### **Purpose**

The Participatory Autism Research Collective (PARC) was initially set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise.

#### **Approach**

This article explores the development of the PARC network, reflecting upon its activities and ethos within current Higher Education (HE) practices and structures.

#### **Findings**

In supporting autistic individuals in their attempts to establish themselves within academic systems that may not always be considerate or accommodating, the existence of PARC creates a structure with which autistic people can influence social change. PARC serves as a network of support, strengthening the presence of autistic scholars in academia. It also provides a structure through which autistic people are able to demonstrate helpful practices with which to engage more broadly.

#### **Value**

The PARC network is the first autistic-led venture of its kind in the UK to have a sustained impact. PARC is growing to become an important element in the field of autism studies both by supporting the emerging autistic academics and by promoting ethical and participatory research methods and practices.

**Keywords:** Autism, Participation, Higher Education, Social networks

**Article Classification:** Viewpoint

### **Introduction**

The Participatory Autism Research Collective (PARC) was initially developed at London South Bank University (LSBU) by Dr. Damian Milton and Professor Nicola Martin, with the first meeting being held in April 2015. PARC was set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise. This article explores the development of the PARC network, reflecting upon its ethos within current Higher Education (HE) practices and structures.

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3 Although the PARC project was initially based at LSBU (where PARC has held a number of events  
4 since and will continue to do so), the group has also expanded to holding events across a variety of  
5 sites, including Birmingham, Sheffield and Nottingham. Initially however, just five people attended  
6 the very first meeting of the PARC group at LSBU in April 2015, three of them autistic scholars and  
7 two non-autistic researchers, one from LSBU and one from another University. The initial aims and  
8 objectives of PARC were set out as to:  
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- 11 - Address the isolation felt by many autistic researchers
- 12 - To ensure that research carried out by autistic people can be found and used
- 13 - To raise the reputation of participatory research methods in the field
- 14 - Critically comment on autism research which does not empower autistic people
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17 In order to achieve these aims it was suggested that PARC would:

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- 19 - Encourage autistic people starting out in research
- 20 - Provide peer feedback on research and support with accessing funding
- 21 - Holding meetings and events
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#### 24 **Influences on the formation of PARC**

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26 The initial inspiration for the PARC group had come from several sources. Previously to the PARC  
27 group, a number of early members had been part of an autistic-led 'grassroots' endeavour called the  
28 'Theorising Autism Project' (Greenstein, 2014, Ridout, 2014), which had held two workshop days,  
29 one in 2012 at the University of Birmingham on the theme of education and another in 2014 at  
30 University College London (UCL) on the theme of participation. Also in 2012 saw the launch of an  
31 autistic-led open access journal called 'Autonomy: the Critical Journal of Interdisciplinary Autism  
32 Studies' where future PARC members were part of its editorial board. The future chair of PARC  
33 Damian Milton had also helped to develop and then chair a conference on the topic of participation  
34 for the National Autistic Society's (NAS) 'Ask autism' project in 2014, and had co-authored a critical  
35 article on this topic a year earlier (Milton and Bracher, 2013).  
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#### 38 **The activities of PARC**

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40 Running parallel to the work of PARC was a seminar series set up led by Liz Pellicano at UCL (who  
41 had hosted one of the Theorising Autism Project events), where Damian Milton was a co-applicant,  
42 called 'Shaping Autism Research UK' and was funded through the ESRC (Shaping Autism Research,  
43 2017; Fletcher-Watson et al., 2018). This had a similar ethos to PARC, but was 'researcher-led' and  
44 followed a report that had been written regarding autism research in the UK entitled 'A future made  
45 together' (Pellicano et al. 2013). This report highlighted a great dissatisfaction from autistic people  
46 and their families regarding the research produced in the UK and its impact (or lack of it) on their  
47 everyday lives (or indeed at times negative impact). The report found that the majority of research  
48 funding was spent investigating the biological and genetic aspects of autism, with just 1% of research  
49 spend being in the area of 'social research'. The seminar series looked into autism policy and  
50 practice as well as wellbeing within a social context, and participation as key themes. This seminar  
51 series had a good deal of input from autistic scholars associated with the PARC group, and the  
52 project also produced useful resources, such as a toolkit on participatory research practice (Fletcher-  
53 Watson et al., 2018). Whilst this project was a funded three-year project that has now come to an  
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3 end, the PARC group has been unfunded, yet has continued to hold meetings and events.  
4 Importantly however, colleagues from the Shaping Autism Research project helped with the setting  
5 up of a website for the PARC group which went live in the spring of 2017 and has attracted a good  
6 deal of interest since through the announcing of events and critical blog posts regarding research  
7 and practice in the field.  
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10 During 2016 the PARC group held a number of meetings involving invited speakers, some autistic  
11 activists and scholars and some early-career researchers. These activities led to PARC being  
12 shortlisted for an NAS award early in 2017 for 'Most Creative Community Project'. This was followed  
13 by a number of meetings held at LSBU with established researchers in the field such as Dr. Wenn  
14 Lawson and Dr. James Cusack (research director at the charity Autistica). Over the last year PARC  
15 events have also expanded to Birmingham, Sheffield, and Nottingham, with initial informal meetings  
16 and plans forming at the University of Kent and recently held its first conferences in Birmingham and  
17 London.  
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20 The PARC group has inputted into a number of funded projects, firstly a project looking into  
21 mentoring services for autistic adults that members of the PARC group were employed to work on at  
22 LSBU, as well as the National Autism Project funded by the Shirley Foundation. In 2017 PARC also  
23 managed to access a share of a very small amount of funding from LSBU as a crucial part of the  
24 newly formed Critical Autism /Disability Studies Research Group headed by Professor Nicola Martin.  
25 LSBU and other universities also support PARC with access to facilities such as meeting rooms. If  
26 funding room hire was factored in PARC would be unable to meet. LSBU opens PARC events to MA  
27 Education / Autism students and regards the arrangement as a win-win situation.  
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31 In 2017 PARC established itself in the West Midlands with initial events held at Birmingham City  
32 University (BCU), where it launched by inviting a student Seb Stafford-Cook, to talk about Wellbeing  
33 and his early experiences in compulsory education prior to moving to Higher Education (HE) and  
34 receiving mentoring support. Highlighting the issues of imposed outsider terminology and bullying  
35 and their impact on him, Seb's talk led to discussion between autistic and non-autistic students,  
36 mentors and practitioners around what constituted an enabling environment or, conversely, a  
37 disabling environment in HE (Ridout and Edmondson, 2017). There was much criticism of a lack of  
38 even basic autism awareness among staff, and other critical issues raised focused on: the  
39 importance of an individual approach; understanding the sensory impact of busy spaces, especially  
40 entrances; and the need for quiet spaces to allow an individual to regain control of anxiety (Ridout,  
41 2016; Graby, 2015; Moon, 2014; Murray 2006). These points are often overlooked when planning  
42 support and are in addition to helping individual autistic students engage with their course and  
43 understand its requirements. Perhaps even more problematic is that the quality of mentoring and  
44 disability support varies between universities, so a change of course or university can effectively  
45 mean a new start that is difficult to manage (Ridout, 2018).  
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50 The West Midlands branch of PARC then moved to its second home at the University of Birmingham  
51 (UoB), where people attending the first session took part in small group discussions under the  
52 overarching theme of 'Identity and Violence' to decide on the theme and purpose of future sessions.  
53 As a result, the themes of 'Sexuality', 'Institutionalised Violence' and 'Gender' emerged. The events  
54 are inclusive of all, and it is encouraging that young autistic speakers are finding this a welcoming  
55 space to present at alongside more experienced autistic and non-autistic researchers. Future  
56 sessions also have exciting plans for joint writing and presentation ventures. This format allows  
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3 people to reflect on learning points and encourages thoughts about the shaping of future events,  
4 and it is arguably this inclusive approach that points to the national and growing success of PARC to  
5 date.  
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7 November 2017 saw PARC spread its reach north to Sheffield, with the workshop 'PARC Publish'  
8 being held in collaboration with Sheffield Hallam University. The aim of this workshop was to bring  
9 together writers and researchers from both within and outside of academia, along with members of  
10 autistic and autism communities with an interest in the publishing of autism-related literature, in  
11 order to discuss the current state of the field, and to explore aims and goals for the future, and the  
12 potential roles PARC may play in this. A lively and engaged discussion session was structured around  
13 four key themes: (1) Literature review – material that has been useful, and that which may be  
14 considered problematic; (2) Representation and inclusion – how can we ensure that autistic and  
15 autism communities are represented in, and have access to, literature on autism? How can we  
16 incorporate diversity of expression and communication in autism publishing?; (3) Collaboration –  
17 how can we work together and share skills and resources at our collective disposal?; and, (4) The  
18 future – what do we want to see in the field of autism publishing? What topics do we wish to see  
19 covered? What working methods do we wish to engage?  
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23 Key points coming out of the discussion included the role of autism literature in shaping and  
24 strengthening the identities of autistic people, in a similar way to that discussed by Bagatell (2007),  
25 and in influencing the trajectories of autistic and non-autistic researchers. Conversely, the 'offensive'  
26 tone of some research on autism was experienced as problematic by some. Access to published  
27 material was highlighted as an issue, with the impact of academic 'paywalls' and other barriers being  
28 highlighted as having a negative impact on community inclusion and activism. Topics identified as  
29 important for future publications included employment support, access to healthcare, ageing, and  
30 sexualities. Participants indicated a keenness to develop supportive writing groups, and forums to  
31 share work, with social media being identified as an important platform, to enable confidence and  
32 empowerment, and to assist in navigating interaction while accommodating a wide range of  
33 communication and processing needs and preferences. The role of established writers, researchers,  
34 and publishers was highlighted as being significant in supporting those at earlier points in their  
35 career who did not have access to the same range of supportive networks and resources.  
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40 A novel aspect of the PARC Publish workshop was the use of social media to facilitate participation  
41 and engagement on an international level. This included the use of the 'Buffer' application to pre-  
42 prepare tweets, which contained slides detailing the questions being discussed at the workshop.  
43 These tweets were then timed to be sent from the organiser's Twitter account at the same time as  
44 the topics were being discussed in the room. The use of this strategy, along with the 'hashtag'  
45 #PARCPublish meant that those unable to attend the event in person were able to participate in the  
46 discussion, and to continue this after the event; it also facilitated additional 'processing' and  
47 communication time for those, primarily autistic, participants who experienced 'real-time' face-to-  
48 face interaction as a barrier to participation, adding a level of inclusivity and accessibility to the  
49 event. The fact that discussion coalesced around a hashtag meant that discussion was captured and  
50 is now easily located and identified. The workshop proved very popular, with a replication of the  
51 event being held subsequently in Plymouth. It is envisaged that the points raised in the workshop  
52 may be incorporated into future publishing plans, both for PARC, and for the wider autistic and  
53 autism communities.  
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3 In early 2018, PARC partnered with the Department of Psychology at the University of Nottingham to  
4 hold a workshop day concerning the 'double empathy problem' as initially theorised by Milton  
5 (2012). This brought together researchers and theorists such as Nick Chown, Brett Heasman, and  
6 Noah Sasson to discuss this growing area of research interest. Another event held at LSBU involved  
7 students from New York University visiting the UK and a talk from the US-based autistic academic  
8 Stephen Shore. In July 2018 PARC held a 'Critical Autism Studies' conference at LSBU attended by  
9 some sixty guests.  
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12 Activities through the PARC group have also led however to a partnership with Pavilion Press and a  
13 number of publications (Milton et al. 2016; Milton and Martin, 2016; Milton and Martin, 2017;  
14 Milton, 2017; Ridout, 2018) addressing practical issues as well as theoretical. The PARC group has  
15 also organised and chaired a stream for the last two years at the Learning Disability Today  
16 conference and in September 2018, chaired a stream on the theme of 'Neurodiversity' at the Centre  
17 for Disability Research Conference at Lancaster University, and organised the speakers for one of the  
18 platforms at the 'Autism Show's' in 2018 with members Damian Milton, Susy Ridout and Leo Capella  
19 running a workshop in advance of the event to assist people with presentations. Plans for the future  
20 of PARC also include the renewal of an autism practice journal, and a series of workshop days. The  
21 above activities show that PARC has worked very well in terms of increasing collaboration and  
22 communication between autistic people and the research community, as well as leading to  
23 publications, dissemination and sharing of research, and providing peer support, thus showing a  
24 great deal of 'real world impact' and going a long way to meeting its initial aims.  
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### 28 **PARC and the wider HE context**

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31 Becher and Kogan (1992) suggested that HE systems contain four tiers: central authorities (such as  
32 research councils), individual institutions, basic units (such as departments) and individuals. Within  
33 these structures however, a number of commentators have suggested that the processes governing  
34 Higher Education have come to reflect a neoliberal agenda and managerialism (e.g. Davies and  
35 Peterson, 2005a; Zepke, 2017). Such concerns are not entirely new either, if one takes into account  
36 the 'instrumentalist pedagogy' noted by Scrimshaw (1983) or Ritzer's (1996) McDonaldisation of  
37 education thesis. When one looks at how the 'impact' and 'quality' of research is assessed within the  
38 Research Excellence Framework (REF), and the mechanisms and structures through which funding is  
39 allocated, one can easily depict a highly competitive and hierarchical model, even 'elitist'. Within the  
40 context of autism research, the vast majority is funded through the Medical Research Council, often  
41 framing autism as a disorder to be remedied. Social research is sparse, and where there had been  
42 two research charities dedicated to autism, one has recently closed down operations regarding  
43 funding future projects. The journals with the highest impact factor in the field of autism studies  
44 both have a history of preferring scientific and medical model approaches. Thus, as the PARC  
45 network are part of an autistic community that rallies behind the slogan 'nothing about us, without  
46 us', this scenario presents something of a problem. This issue is not just one we facing personally as  
47 autistic academics however, but a common feature for many and could be considered a 'public  
48 issue' (Mills, 1956). Furthermore, the fluidity of 'identity' as a concept is often not recognised within  
49 HE structures, so for those of us who identify as neurodivergent the issue becomes problematic with  
50 us being even more labelled and compartmentalised to suit the whims of funding bodies and  
51 outsider research communities to the detriment and exclusion of our other identities.  
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3 The Teaching Excellence Framework (TEF) is a government initiative introduced in 2017 as a  
4 framework whereby undergraduate students can now assess quality of teaching and academic  
5 support along with subsequent progression into employment (Bhardwa, 2018). Linked to this is a  
6 need for HE institutions to understand and reflect social mobility, diversity and choice, and with a  
7 focus on flexible and inclusive teaching, resources and assessment forms which challenge the  
8 limiting nature of setting rigid goals (Garvey et al., 2009). The unpredictability of life and social  
9 circumstances can act as barriers to achievement (Ridout and Edmondson, 2017; ARGH and HUG  
10 2011), so the TEF encourages practice, which it can be argued are represented in the social research  
11 values embedded in PARC.  
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15 Within this climate of competition for resources and status, the notion of research 'impact' has  
16 become increasingly important in the way academic work is evaluated, but also in terms of public  
17 responsibilities being recognised such as 'engagement', often assessed via various forms of metrics  
18 regarding citations within a field and the quality of peer review the work had been subjected to.  
19 Traditionally, autistic scholars have sometimes struggled to acquire sustainable work, or perform  
20 within normative or highly competitive frameworks and structures, thus exacerbating the rift  
21 between autism researchers and the autistic people they research or autistic scholars promoting a  
22 participatory agenda (Milton and Bracher, 2013; Milton, 2014; Gillespie-Lynch et al., 2017; Chown et  
23 al., 2017). It is interesting to note then, how the PARC network without funding has been able to  
24 build a strong research network, with increasing impact in a number of areas, providing knowledge  
25 sharing activities, increasing visibility of research outputs, effectively utilising digital media, and  
26 extending networks nationally (and more recently internationally through invited visiting guests or  
27 via online means). Despite PARC members having good and improving metrics through such work,  
28 many are in unstable employment, or with limited access to academic resources or funds. Indeed,  
29 accessing funding through partnerships with established academics, coupled with peer support and  
30 mentoring (Martin, 2017; Ridout, 2018), may be the best way to address this anomaly within current  
31 constrained systems. This is a critical issue for consideration as the majority of mentors, many of  
32 whom are themselves neurodivergent, are often employed on flimsy and demeaning zero hours  
33 contracts, with little or no respect for their skills and abilities and with no prospect of promotion.  
34 Worryingly, many mentors have no support unlike line management embedded in contracted  
35 positions, and many are unfamiliar with their co-mentors. This raises concerns as to their support  
36 network and wellbeing within the work environment and identification of the responsible party for  
37 this (Miller, 2002), and even more so raises questions as to the monitoring of agencies and whether  
38 they understand the requirements of mentees and how to appropriately match people on their  
39 agency list with students (IES and REAP, 2015). Mentoring too often falls foul of an agency's or  
40 university's need to meet performance criteria set by auditors, and this will inevitably become a  
41 number-crunching exercise as role descriptors of mentors is confused and the realistic picture of  
42 student support requirements are overlooked (SFE, 2016).  
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50 An issue explored by Archer (2008) is the construction of professional academic identities, drawing  
51 from interview data with 'younger' academics within UK universities to consider how they position  
52 themselves in relation to notions of 'authenticity' and 'success'. Archer (2008) argues that feelings of  
53 inauthenticity and exclusion are exacerbated through the performative ethos favoured by current  
54 research assessment processes and institutional structures, as well as by inequalities of age,  
55 ethnicity, class and gender (as well as the structure of temporary contracts of employment). Archer  
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3 (2008) suggests that as well as going through a process of 'becoming' an 'authentic' academic,  
4 researchers also lived with the threat of 'unbecoming' or precariousness and related inauthenticity  
5 of academic status. In relation to the development of the PARC group it is interesting to note that  
6 intersections of disability (let alone neurodiversity) did not enter in the frame of Archer's (2008)  
7 research, yet the very same issues could be said to be even more exacerbated for such populations,  
8 further disabled by the neoliberal structures and processes they contend with in academia (Davies  
9 and Peterson, 2005a). Within the field of autism studies there is also a significant divide between  
10 disciplinary territories and boundaries (Becher and Trowler, 2001; Henkel, 1997), characterised by  
11 one autistic scholar as a 'silo mentality' (Arnold, 2010). Archer (2008) cites Bourdieu, in suggesting  
12 academia can be characterised by competing individuals and groups, vying for recognition, status  
13 and value – subject to competing paradigms, representations, constructions and claims to truth. As  
14 Archer (2008) asks the question as to what extent younger academics were able to feel legitimate  
15 and successful within their identities, and finding a precarious positionality, this can be reflected to  
16 an even greater extent when considering autistic academics and scholars and the opportunities that  
17 have been afforded them in what could be described as an institutionally ableist neoliberal academic  
18 culture. PARC in contrast, has been able to step in as a collective and demonstrate inclusive practice  
19 to the field more generally.  
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24 For Davies and Peterson (2005b) the pressure for 'performance' within neoliberal discourse  
25 produces people as a set of outcomes, and reduces them to exchangeable products, a Foucauldian  
26 'technology of self' acting within and between contradictory agendas. However, by marginalising  
27 autistic academics and their potential output, such systems give rise to activist academia, such as  
28 that seen within the field of 'critical disability studies'. The PARC group can be said to be positioned  
29 within such wider social currents as the neurodiversity movement (Walker, 2014), the social model  
30 of disability, and a participatory / emancipatory research ethos (Barnes, 2001).  
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34 Nicola Martin (2017), co-founder of the PARC network interviewed disabled academics working  
35 within UK universities in order to explore their experiences and draw out recommendations for  
36 improvements in practice. Martin (2017) found a number of barriers to encouraging and developing  
37 disabled leaders within HE that included: stereotyping, the invisibility of role models, limited  
38 strategic change at managerial levels, ableist assumptions, and disorganised processes. In order to  
39 meet these challenges, Martin (2017) recommended strategic responses, inclusive design and  
40 reasonable adjustments, leadership development and recruitment, peer support and mentoring  
41 networks, and promoting a culture that celebrates rather than problematises diversity. Whilst the  
42 PARC group is a significant step in addressing such issues, it is but a small activist group when  
43 compared to the current structures that govern and implement research within the UK. Given its  
44 small stature in this regard though, the network has significantly added to the collaborative 'impact'  
45 of the work of its members.  
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### 50 **Forming an autistic academic community**

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52 Part of the process of forming PARC is and has been the formation of an autistic academic  
53 community that is supportive and empowering (Ridout and Edmondson, 2017; Research Autism,  
54 2015). This has been one of the initial aims for PARC and its importance should be considered not  
55 only in terms of connecting academics with similar research interests, but also in supporting autistic  
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3 individuals in their attempts to establish themselves within academic systems that may not always  
4 be considerate or accommodating. From our personal anecdotal conversations with each other, and  
5 with autistic individuals working in the autism field more broadly, we are aware of a vast array of  
6 issues that we share and with which we need support. These may apply more broadly to many  
7 autistic autism professionals and/or activists but are contextualised in a different way within  
8 academia.  
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11 One important aspect of being an autistic academic is the vast amounts of emotional labour that one  
12 has to go through. Emotional labour is defined as the process of dealing with other peoples' feelings,  
13 a core element of which is the regulation of one's own emotions (James, 1989). There are many  
14 ways in which an autistic academic has to manage profound emotional labour in academic spaces. It  
15 begins with constantly engaging with a huge amount of violent predominant autism discourses,  
16 based on dehumanising and infantilising medical models. Autistic professionals also have to manage  
17 a world where the "outside-in" description of their abilities often disregards the amount of effort  
18 they put in order to stay and survive ableist academic spaces that are not prepared to address their  
19 needs in any significant way (Milton and Moon, 2012). This extends to the relationships and  
20 networking we have to do, which is an integral part of academia. As autistic academics, we often  
21 must engage in predominantly non-autistic autism discourses as well as non-autistic colleagues  
22 whilst managing our own emotions regarding the dominance of non-autistic autism discourse which  
23 harms us personally, autistic academics collectively and the autistic communities more broadly and  
24 handle our colleagues' unhelpful practices in a tactful way. This requires an immense amount of  
25 emotional labour in and of itself, which is only aggravated by the constant need of having to re-  
26 evaluate our beliefs and alliances.  
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32 The examples above demonstrate a few instances of emotional labour involved in being an autistic  
33 academic. Therefore, from a community-building standpoint, the very existence of PARC creates a  
34 structure with which we can begin to create change for ourselves and others as members of a  
35 "community of coping" (Korczynski, 2003). The idea of a community of coping was first introduced  
36 by Hochschild (1983), to refer to the unofficial structures which workers create to deal with work  
37 situations that require them to display significant amounts of emotional labour. Korczynski (2003)  
38 elaborates in the ways which communities of coping can act in ways which are useful with the  
39 structures that surround them, by reducing, for example, staff turnover, as well as inform acts of  
40 resistance from management directives. In an academic context, PARC serves both of those roles.  
41 Given the significant lack of any meaningful support towards autistic academics, PARC serves as a  
42 network of support for each other in our efforts of continuing our work and strengthening our  
43 presence in academia. It also provides a structure through which we are able to demonstrate helpful  
44 practices with which to engage both autistic academics and autistic communities more broadly, by  
45 its firm commitment to participatory autism research. Therefore PARC is growing to become an  
46 important element in the field of autism studies both by supporting the emerging autistic academics  
47 and by promoting ethical and participatory research methods and practices.  
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## 51 52 **Conclusion**

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54 The PARC group has been successful and continues to grow, yet to be living up to its name it will  
55 need to find ways of widening participation for those with more considerable communication or  
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3 intellectual impairments, or from autistic people who also occupy intersecting marginalised  
4 identities. One advantage to being largely a network of 'outsider researchers' is the lack of managing  
5 the risk of 'unbecoming' an academic if one has never been seen as legitimately so to begin with,  
6 affording a critical scrutiny others set within a hierarchical and competitive system may enjoy. The  
7 PARC group and others like it are thus essential for academia to sustain some of its classical ethos  
8 within a neoliberal context.  
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## A critical reflection on the development of the Participatory Autism Research Collective (PARC)

### Abstract

#### Purpose

The Participatory Autism Research Collective (PARC) was initially set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise.

#### Approach

This article explores the development of the PARC network, reflecting upon its activities and ethos within current Higher Education (HE) practices and structures.

#### Findings

In supporting autistic individuals in their attempts to establish themselves within academic systems that may not always be considerate or accommodating, the existence of PARC creates a structure with which autistic people can influence social change. PARC serves as a network of support, strengthening the presence of autistic scholars in academia. It also provides a structure through which autistic people are able to demonstrate helpful practices with which to engage more broadly.

#### Value

The PARC network is the first autistic-led venture of its kind in the UK to have a sustained impact. PARC is growing to become an important element in the field of autism studies both by supporting the emerging autistic academics and by promoting ethical and participatory research methods and practices.

**Keywords:** Autism, Participation, Higher Education, Social networks

**Article Classification:** Viewpoint

### Introduction

The Participatory Autism Research Collective (PARC) was initially developed at London South Bank University (LSBU) by Dr. Damian Milton and Professor Nicola Martin, with the first meeting being held in April 2015. PARC was set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise. This article explores the development of the PARC network, reflecting upon its ethos within current Higher Education (HE) practices and structures.

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3 Although the PARC project was initially based at LSBU (where PARC has held a number of events  
4 since and will continue to do so), the group has also expanded to holding events across a variety of  
5 sites, including Birmingham, Sheffield and Nottingham. Initially however, just five people attended  
6 the very first meeting of the PARC group at LSBU in April 2015, three of them autistic scholars and  
7 two non-autistic researchers, one from LSBU and one from another University. The initial aims and  
8 objectives of PARC were set out as to:  
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- 12 - Address the isolation felt by many autistic researchers
- 13 - To ensure that research carried out by autistic people can be found and used
- 14 - To raise the reputation of participatory research methods in the field
- 15 - Critically comment on autism research which does not empower autistic people
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18 In order to achieve these aims it was suggested that PARC would:

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- 21 - Encourage autistic people starting out in research
- 22 - Provide peer feedback on research and support with accessing funding
- 23 - Holding meetings and events
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### 26 **Influences on the formation of PARC**

27 The initial inspiration for the PARC group had come from several sources. Previously to the PARC  
28 group, a number of early members had been part of an autistic-led 'grassroots' endeavour called the  
29 'Theorising Autism Project' (Greenstein, 2014), which had held two workshop days, one in 2012 at  
30 the University of Birmingham on the theme of education and another in 2014 at University College  
31 London (UCL) on the theme of participation. Also 2012 saw the launch of an autistic-led open access  
32 journal called 'Autonomy: the Critical Journal of Interdisciplinary Autism Studies' where future PARC  
33 members were part of its editorial board. The future chair of PARC Damian Milton had also helped to  
34 develop and then chair a conference on the topic of participation for the National Autistic Society's  
35 (NAS) 'Ask autism' project in 2014 and had co-authored a critical article on this topic a year earlier  
36 (Milton and Bracher, 2013).  
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38 There have been a number of similar initiatives to PARC in terms of promoting participatory research  
39 in the field of autism studies (Nicolaidis et al., 2011; Fletcher-Watson et al., 2018), although until  
40 recently have tended to assume a separation between researcher and community and a period of  
41 mentoring into specific research roles. PARC on the other hand is simply an open network, led by  
42 established and aspiring autistic academics and allies from numerous disciplines, but open to all to  
43 contribute to through numerous and varied activities.  
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### 45 **The activities of PARC**

46 During 2016 the PARC group held a number of meetings involving invited speakers, some autistic  
47 activists and scholars and some early-career researchers. These activities led to PARC being  
48 shortlisted for an NAS award early in 2017 for 'Most Creative Community Project'. This was followed  
49 by a number of meetings held at LSBU with established researchers in the field such as Dr. Wenn  
50 Lawson and Dr. James Cusack (research director at the charity Autistica). Over the last year PARC  
51 events have also expanded to Birmingham, Sheffield, and Nottingham, with initial informal meetings  
52 and plans forming at the University of Kent and recently held its first conferences in Birmingham and  
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5 The PARC group has inputted into a number of funded projects, firstly a project looking into  
6 mentoring services for autistic adults that members of the PARC group were employed to work on at  
7 LSBU, as well as the National Autism Project funded by the Shirley Foundation. In 2017 PARC also  
8 managed to access a share of a very small amount of funding from LSBU as a crucial part of the  
9 newly formed Critical Autism /Disability Studies Research Group headed by Professor Nicola Martin.  
10 LSBU and other universities also support PARC with access to facilities such as meeting rooms. If  
11 funding room hire was factored in PARC would be unable to meet. LSBU opens PARC events to MA  
12 Education / Autism students and regards the arrangement as a win-win situation.  
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16 In 2017 PARC established itself in the West Midlands with initial events held at Birmingham City  
17 University (BCU), where it launched by inviting a student Seb Stafford-Cook, to talk about Wellbeing  
18 and his early experiences in compulsory education prior to moving to Higher Education (HE) and  
19 receiving mentoring support. The West Midlands branch of PARC then moved to its second home at  
20 the University of Birmingham (UoB), where people attending the first session took part in small  
21 group discussions under the overarching theme of 'Identity and Violence' to decide on the theme  
22 and purpose of future sessions. As a result, the themes of 'Sexuality', 'Institutionalised Violence' and  
23 'Gender' emerged. The events are inclusive of all, and it is encouraging that young autistic speakers  
24 are finding this a welcoming space to present at alongside more experienced autistic and non-  
25 autistic researchers. November 2017 saw PARC spread its reach north to Sheffield, with the  
26 workshop 'PARC Publish' being held in collaboration with Sheffield Hallam University. The aim of this  
27 workshop was to bring together writers and researchers from both within and outside of academia,  
28 along with members of autistic and autism communities with an interest in the publishing of autism-  
29 related literature, in order to discuss the current state of the field, and to explore aims and goals for  
30 the future, and the potential roles PARC may play in this. In early 2018, PARC partnered with the  
31 Department of Psychology at the University of Nottingham to hold a workshop day concerning the  
32 'double empathy problem' as initially theorised by Milton (2012). This brought together researchers  
33 and theorists such as Nick Chown, Brett Heasman, and Noah Sasson to discuss this growing area of  
34 research interest. Another event held at LSBU involved students from New York University visiting  
35 the UK and a talk from the US-based autistic academic Stephen Shore. In July 2018 PARC held a  
36 'Critical Autism Studies' conference at LSBU attended by some sixty guests. Such activities have  
37 established links between autistic and non-autistic researchers across disciplinary backgrounds  
38 forging links that have led on to publications in the field.  
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46 Activities through the PARC group have also led however to a partnership with Pavilion Press and a  
47 number of publications (Milton et al. 2016; Milton and Martin, 2016; Milton and Martin, 2017;  
48 Milton, 2017; Ridout, 2018) addressing practical issues as well as theoretical. The PARC group has  
49 also organised and chaired stream for high profile conferences such as Learning Disability Today, the  
50 Centre for Disability Research Conference at Lancaster University, and the 'Autism Show's'. Plans for  
51 the future of PARC also include the renewal of an autism practice journal, and a series of workshop  
52 days. The above activities show that PARC has worked very well in terms of increasing collaboration  
53 and communication between autistic people and the research community, as well as leading to  
54 publications, dissemination and sharing of research, and providing peer support, thus showing a  
55 great deal of 'real world impact' and going a long way to meeting its initial aims.  
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60 **PARC and the wider HE context**

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3 Becher and Kogan (1992) suggested that HE systems contain four tiers: central authorities (such as  
4 research councils), individual institutions, basic units (such as departments) and individuals. Within  
5 these structures however, a number of commentators have suggested that the processes governing  
6 Higher Education have come to reflect a neoliberal agenda and managerialism (e.g. Davies and  
7 Peterson, 2005a; Zepke, 2017). Such concerns are not entirely new either, if one takes into account  
8 the 'instrumentalist pedagogy' noted by Scrimshaw (1983). When one looks at how the 'impact' and  
9 'quality' of research is assessed within the Research Excellence Framework (REF), and the  
10 mechanisms and structures through which funding is allocated, one can easily depict a highly  
11 competitive and hierarchical model, even 'elitist'. Within the context of autism research, the vast  
12 majority is funded through the Medical Research Council, often framing autism as a disorder to be  
13 remedied. Social research is sparse, and where there had been two research charities dedicated to  
14 autism, one has recently closed down operations regarding funding future projects. The journals  
15 with the highest impact factor in the field of autism studies both have a history of preferring  
16 scientific and medical model approaches. Thus, as the PARC network are part of an autistic  
17 community that rallies behind the slogan 'nothing about us, without us', this scenario presents  
18 something of a problem. This issue is not just one we are facing personally as autistic academics  
19 however, but a common feature for many and could be considered a 'public issue' (Mills, 1959).  
20 Furthermore, the fluidity of 'identity' as a concept is often not recognised within HE structures, so  
21 for those of us who identify as neurodivergent (divergent from social standards of neurological  
22 normalcy) the issue becomes problematic with us being even more labelled and compartmentalised  
23 to suit the whims of funding bodies and outsider research communities to the detriment and  
24 exclusion of our other identities.  
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33 The Teaching Excellence Framework (TEF) is a government initiative introduced in 2017 as a  
34 framework whereby undergraduate students can now assess quality of teaching and academic  
35 support along with subsequent progression into employment (Bhardwa, 2018). Linked to this is a  
36 need for HE institutions to understand and reflect social mobility, diversity and choice, and with a  
37 focus on flexible and inclusive teaching, resources and assessment forms which challenge the  
38 limiting nature of setting rigid goals (Garvey et al., 2009). The unpredictability of life and social  
39 circumstances can act as barriers to achievement (Ridout and Edmondson, 2017), so the TEF  
40 encourages practice, which it can be argued are represented in the social research values embedded  
41 in PARC.  
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45 Within this climate of competition for resources and status, the notion of research 'impact' has  
46 become increasingly important in the way academic work is evaluated, but also in terms of public  
47 responsibilities being recognised such as 'engagement', often assessed via various forms of metrics  
48 regarding citations within a field and the quality of peer review the work had been subjected to.  
49 Traditionally, autistic scholars have sometimes struggled to acquire sustainable work, or perform  
50 within normative or highly competitive frameworks and structures, thus exacerbating the rift  
51 between autism researchers and the autistic people they research or autistic scholars promoting a  
52 participatory agenda (Milton and Bracher, 2013; Milton, 2014; Gillespie-Lynch et al., 2017; Chown et  
53 al., 2017). It is interesting to note then, how the PARC network without funding has been able to  
54 build a strong research network, with increasing impact in a number of areas, providing knowledge  
55 sharing activities, increasing visibility of research outputs, effectively utilising digital media, and  
56 extending networks nationally (and more recently internationally through invited visiting guests or  
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3 via online means). Despite PARC members having good and improving metrics through such work,  
4 many are in unstable employment, or with limited access to academic resources or funds. Indeed,  
5 accessing funding through partnerships with established academics, coupled with peer support and  
6 mentoring (Martin, 2017; Ridout, 2018), may be the best way to address this anomaly within current  
7 constrained systems. This is a critical issue for consideration as the majority of mentors, many of  
8 whom are themselves neurodivergent, are often employed on flimsy and demeaning zero hours  
9 contracts, with little or no respect for their skills and abilities and with no prospect of promotion.  
10 Worryingly, many mentors have no support unlike line management embedded in contracted  
11 positions, and many are unfamiliar with their co-mentors. This raises concerns as to their support  
12 network and wellbeing within the work environment and identification of the responsible party for  
13 this (Miller, 2002), and even more so raises questions as to the monitoring of agencies and whether  
14 they understand the requirements of mentees and how to appropriately match people on their  
15 agency list with students (IES and REAP, 2015). Mentoring too often falls foul of an agency's or  
16 university's need to meet performance criteria set by auditors, and this will inevitably become a  
17 number-crunching exercise as role descriptors of mentors is confused and the realistic picture of  
18 student support requirements are overlooked (SFE, 2016).  
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25 An issue explored by Archer (2008) is the construction of professional academic identities, drawing  
26 from interview data with 'younger' academics within UK universities to consider how they position  
27 themselves in relation to notions of 'authenticity' and 'success'. Archer (2008) argues that feelings of  
28 inauthenticity and exclusion are exacerbated through the performative ethos favoured by current  
29 research assessment processes and institutional structures, as well as by inequalities of age,  
30 ethnicity, class and gender (as well as the structure of temporary contracts of employment). Archer  
31 (2008) suggests that as well as going through a process of 'becoming' an 'authentic' academic,  
32 researchers also lived with the threat of 'unbecoming' or precariousness and related inauthenticity  
33 of academic status. In relation to the development of the PARC group it is interesting to note that  
34 intersections of disability (let alone neurodiversity) did not enter in the frame of Archer's (2008)  
35 research, yet the very same issues could be said to be even more exacerbated for such populations,  
36 further disabled by the neoliberal structures and processes they contend with in academia (Davies  
37 and Peterson, 2005a). Within the field of autism studies there is also a significant divide between  
38 disciplinary territories and boundaries (Becher and Trowler, 2001; Henkel, 1997), characterised by  
39 one autistic scholar Larry Arnold as a 'silo mentality'. Archer (2008) cites Bourdieu, in suggesting  
40 academia can be characterised by competing individuals and groups, vying for recognition, status  
41 and value – subject to competing paradigms, representations, constructions and claims to truth. As  
42 Archer (2008) asks the question as to what extent younger academics were able to feel legitimate  
43 and successful within their identities, and finding a precarious positionality, this can be reflected to  
44 an even greater extent when considering autistic academics and scholars and the opportunities that  
45 have been afforded them in what could be described as an institutionally ableist neoliberal academic  
46 culture. PARC in contrast, has been able to step in as a collective and demonstrate inclusive practice  
47 to the field more generally.  
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55 For Davies and Peterson (2005b) the pressure for 'performance' within neoliberal discourse  
56 produces people as a set of outcomes, and reduces them to exchangeable products, a Foucauldian  
57 'technology of self' acting within and between contradictory agendas. However, by marginalising  
58 autistic academics and their potential output, such systems give rise to activist academia, such as  
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3 that seen within the field of 'critical disability studies'. The PARC group can be said to be positioned  
4 within such wider social currents as the neurodiversity movement (Walker, 2014), the social model  
5 of disability, and a participatory / emancipatory research ethos.  
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8 Nicola Martin (2017), co-founder of the PARC network interviewed disabled academics working  
9 within UK universities in order to explore their experiences and draw out recommendations for  
10 improvements in practice. Martin (2017) found a number of barriers to encouraging and developing  
11 disabled leaders within HE that included: stereotyping, the invisibility of role models, limited  
12 strategic change at managerial levels, ableist assumptions, and disorganised processes. In order to  
13 meet these challenges, Martin (2017) recommended strategic responses, inclusive design and  
14 reasonable adjustments, leadership development and recruitment, peer support and mentoring  
15 networks, and promoting a culture that celebrates rather than problematises diversity. Whilst the  
16 PARC group is a significant step in addressing such issues, it is but a small activist group when  
17 compared to the current structures that govern and implement research within the UK. Given its  
18 small stature in this regard though, the network has significantly added to the collaborative 'impact'  
19 of the work of its members.  
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### 25 **Forming an autistic academic community**

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27 Part of the process of forming PARC is and has been the formation of an autistic academic  
28 community that is supportive and empowering (Ridout and Edmondson, 2017). This has been one of  
29 the initial aims for PARC and its importance should be considered not only in terms of connecting  
30 academics with similar research interests, but also in supporting autistic individuals in their attempts  
31 to establish themselves within academic systems that may not always be considerate or  
32 accommodating. From our personal anecdotal conversations with each other, and with autistic  
33 individuals working in the autism field more broadly, we are aware of a vast array of issues that we  
34 share and with which we need support. These may apply more broadly to many autistic autism  
35 professionals and/or activists but are contextualised in a different way within academia.  
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40 One important aspect of being an autistic academic is the vast amounts of emotional labour that one  
41 has to go through. Emotional labour is defined as the process of dealing with other peoples' feelings,  
42 a core element of which is the regulation of one's own emotions (James, 1989). There are many  
43 ways in which an autistic academic has to manage profound emotional labour in academic spaces. It  
44 begins with constantly engaging with a huge amount of violent predominant autism discourses,  
45 based on dehumanising and infantilising medical models. Autistic professionals also have to manage  
46 a world where the "outside-in" description of their abilities often disregards the amount of effort  
47 they put in order to stay and survive ableist academic spaces that are not prepared to address their  
48 needs in any significant way (Milton and Moon, 2012). This extends to the relationships and  
49 networking we have to do, which is an integral part of academia. As autistic academics, we often  
50 must engage in predominantly non-autistic autism discourses as well as non-autistic colleagues  
51 whilst managing our own emotions regarding the dominance of non-autistic autism discourse which  
52 harms us personally, autistic academics collectively and the autistic communities more broadly and  
53 handle our colleagues' unhelpful practices in a tactful way. This requires an immense amount of  
54 emotional labour in and of itself, which is only aggravated by the constant need of having to re-  
55 evaluate our beliefs and alliances.  
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3 The examples above demonstrate a few instances of emotional labour involved in being an autistic  
4 academic. Therefore, from a community-building standpoint, the very existence of PARC creates a  
5 structure with which we can begin to create change for ourselves and others as members of a  
6 “community of coping” (Korczyński, 2003). The idea of a community of coping was first introduced  
7 by Hochschild (1983), to refer to the unofficial structures which workers create to deal with work  
8 situations that require them to display significant amounts of emotional labour. Korczyński (2003)  
9 elaborates in the ways which communities of coping can act in ways which are useful with the  
10 structures that surround them, by reducing, for example, staff turnover, as well as inform acts of  
11 resistance from management directives. In an academic context, PARC serves both of those roles.  
12 Given the significant lack of any meaningful support towards autistic academics, PARC serves as a  
13 network of support for each other in our efforts of continuing our work and strengthening our  
14 presence in academia. It also provides a structure through which we are able to demonstrate helpful  
15 practices with which to engage both autistic academics and autistic communities more broadly, by  
16 its firm commitment to participatory autism research. Therefore, PARC is growing to become an  
17 important element in the field of autism studies both by supporting the emerging autistic academics  
18 and by promoting ethical and participatory research methods and practices. Whilst PARC opens up  
19 opportunities for connection and progress in the development or participatory work, there are also  
20 risks to contend with, primarily the lack of funding for core activities, and in developing  
21 opportunities for those autistic people who traditionally have not been best served within autism  
22 research. Recently we have received news however of funding for projects at the University of Kent  
23 exploring the sensory needs of autistic people with high support needs and at London South Bank  
24 University into the needs of older autistic people, both of which will have input from PARC members  
25 in their development. We very much hope to see such initiatives continue to flourish into the future.

### 33 34 **Implications for wider service provision**

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36 Whilst there have been many experiences to reflect upon regarding the continuing development of  
37 PARC, these experiences also pertain to wider service provision for meeting the needs of autistic  
38 people. Most strikingly this is the case in terms of support and mentoring services for autistic people  
39 in Further and Higher Education. The experiences of PARC would lend added insight into the  
40 constrained opportunities afforded to autistic students and graduates and the potential benefit of  
41 peer support and pointing in the direction of the benefit of ‘working with’ rather than ‘doing for’  
42 marginalised groups. We would conceive of participation however to be an ongoing effort and ethos  
43 rather than a definable outcome, meaning that striving for inclusion, participation and co-production  
44 can never be perceived as a given or as fully accomplished. This is also true for the activities of PARC  
45 itself which will need to further diversify in order to broaden its impact and reach. Meanwhile, the  
46 translation of research to practice can only be furthered by continuing efforts for fruitful  
47 partnerships across neurological dispositions and academic disciplines.

### 52 53 **Conclusion**

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55 The PARC group has been successful and continues to grow, yet to be living up to its name it will  
56 need to find ways of widening participation for those with more considerable communication or  
57 intellectual impairments, or from autistic people who also occupy intersecting marginalised  
58 identities. One advantage to being largely a network of ‘outsider researchers’ is the lack of managing  
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3 the risk of 'unbecoming' an academic if one has never been seen as legitimately so to begin with,  
4 affording a critical scrutiny others set within a hierarchical and competitive system may enjoy. The  
5 PARC group and others like it are thus essential for academia to sustain some of its classical ethos  
6 within a neoliberal context.  
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## A critical reflection on the development of the Participatory Autism Research Collective (PARC)

### Abstract

#### Purpose

The Participatory Autism Research Collective (PARC) was initially set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise.

#### Approach

This article explores the development of the PARC network, reflecting upon its activities and ethos within current Higher Education (HE) practices and structures.

#### Findings

In supporting autistic individuals in their attempts to establish themselves within academic systems that may not always be considerate or accommodating, the existence of PARC creates a structure with which autistic people can influence social change. PARC serves as a network of support, strengthening the presence of autistic scholars in academia. It also provides a structure through which autistic people are able to demonstrate helpful practices with which to engage more broadly.

#### Value

The PARC network is the first autistic-led venture of its kind in the UK to have a sustained impact. PARC is growing to become an important element in the field of autism studies both by supporting the emerging autistic academics and by promoting ethical and participatory research methods and practices.

**Keywords:** Autism, Participation, Higher Education, Social networks

**Article Classification:** Viewpoint

### Introduction

The Participatory Autism Research Collective (PARC) was initially developed at London South Bank University (LSBU) by Dr. Damian Milton and Professor Nicola Martin, with the first meeting being held in April 2015. PARC was set up with the purpose of bringing autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise. This article explores the development of the PARC network, reflecting upon its ethos within current Higher Education (HE) practices and structures.

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3 Although the PARC project was initially based at LSBU (where PARC has held a number of events  
4 since and will continue to do so), the group has also expanded to holding events across a variety of  
5 sites, including Birmingham, Sheffield and Nottingham. Initially however, just five people attended  
6 the very first meeting of the PARC group at LSBU in April 2015, three of them autistic scholars and  
7 two non-autistic researchers, one from LSBU and one from another University. The initial aims and  
8 objectives of PARC were set out as to:  
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- 12 - Address the isolation felt by many autistic researchers
- 13 - To ensure that research carried out by autistic people can be found and used
- 14 - To raise the reputation of participatory research methods in the field
- 15 - Critically comment on autism research which does not empower autistic people
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18 In order to achieve these aims it was suggested that PARC would:

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- 21 - Encourage autistic people starting out in research
- 22 - Provide peer feedback on research and support with accessing funding
- 23 - Holding meetings and events
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### 26 **Influences on the formation of PARC**

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28 The initial inspiration for the PARC group had come from several sources. Previously to the PARC  
29 group, a number of early members had been part of an autistic-led 'grassroots' endeavour called the  
30 'Theorising Autism Project' (Greenstein, 2014, ~~Ridout, 2014~~), which had held two workshop days,  
31 one in 2012 at the University of Birmingham on the theme of education and another in 2014 at  
32 University College London (UCL) on the theme of participation. Also ~~in~~ 2012 saw the launch of an  
33 autistic-led open access journal called 'Autonomy: the Critical Journal of Interdisciplinary Autism  
34 Studies' where future PARC members were part of its editorial board. The future chair of PARC  
35 Damian Milton had also helped to develop and then chair a conference on the topic of participation  
36 for the National Autistic Society's (NAS) 'Ask autism' project in 2014, and had co-authored a critical  
37 article on this topic a year earlier (Milton and Bracher, 2013).  
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41 There have been a number of similar initiatives to PARC in terms of promoting participatory research  
42 in the field of autism studies (Nicolaidis et al., 2011; Fletcher-Watson et al., 2018), although until  
43 recently have tended to assume a separation between researcher and community and a period of  
44 mentoring into specific research roles. PARC on the other hand is simply an open network, led by  
45 established and aspiring autistic academics and allies from numerous disciplines, but open to all to  
46 contribute to through numerous and varied activities.  
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### 49 **The activities of PARC**

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51 ~~Running parallel to the work of PARC was a seminar series set up led by Liz Pellicano at UCL (who~~  
52 ~~had hosted one of the Theorising Autism Project events), where Damian Milton was a co-applicant,~~  
53 ~~called 'Shaping Autism Research UK' and was funded through the ESRC (Shaping Autism Research,~~  
54 ~~2017; Fletcher-Watson et al., 2018). This had a similar ethos to PARC, but was 'researcher-led' and~~  
55 ~~followed a report that had been written regarding autism research in the UK entitled 'A future made~~  
56 ~~together' (Pellicano et al. 2013). This report highlighted a great dissatisfaction from autistic people~~  
57 ~~and their families regarding the research produced in the UK and its impact (or lack of it) on their~~  
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3 everyday lives (or indeed at times negative impact). The report found that the majority of research  
4 funding was spent investigating the biological and genetic aspects of autism, with just 1% of research  
5 spend being in the area of 'social research'. The seminar series looked into autism policy and  
6 practice as well as wellbeing within a social context, and participation as key themes. This seminar  
7 series had a good deal of input from autistic scholars associated with the PARC group, and the  
8 project also produced useful resources, such as a toolkit on participatory research practice (Fletcher-  
9 Watson et al., 2018). Whilst this project was a funded three-year project that has now come to an  
10 end, the PARC group has been unfunded, yet has continued to hold meetings and events.  
11 Importantly however, colleagues from the Shaping Autism Research project helped with the setting  
12 up of a website for the PARC group which went live in the spring of 2017 and has attracted a good  
13 deal of interest since through the announcing of events and critical blog posts regarding research  
14 and practice in the field.  
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19 During 2016 the PARC group held a number of meetings involving invited speakers, some autistic  
20 activists and scholars and some early-career researchers. These activities led to PARC being  
21 shortlisted for an NAS award early in 2017 for 'Most Creative Community Project'. This was followed  
22 by a number of meetings held at LSBU with established researchers in the field such as Dr. Wenn  
23 Lawson and Dr. James Cusack (research director at the charity Autistica). Over the last year PARC  
24 events have also expanded to Birmingham, Sheffield, and Nottingham, with initial informal meetings  
25 and plans forming at the University of Kent and recently held its first conferences in Birmingham and  
26 London.  
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30 The PARC group has inputted into a number of funded projects, firstly a project looking into  
31 mentoring services for autistic adults that members of the PARC group were employed to work on at  
32 LSBU, as well as the National Autism Project funded by the Shirley Foundation. In 2017 PARC also  
33 managed to access a share of a very small amount of funding from LSBU as a crucial part of the  
34 newly formed Critical Autism /Disability Studies Research Group headed by Professor Nicola Martin.  
35 LSBU and other universities also support PARC with access to facilities such as meeting rooms. If  
36 funding room hire was factored in PARC would be unable to meet. LSBU opens PARC events to MA  
37 Education / Autism students and regards the arrangement as a win-win situation.  
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41 In 2017 PARC established itself in the West Midlands with initial events held at Birmingham City  
42 University (BCU), where it launched by inviting a student Seb Stafford-Cook, to talk about Wellbeing  
43 and his early experiences in compulsory education prior to moving to Higher Education (HE) and  
44 receiving mentoring support. ~~Highlighting the issues of imposed outsider terminology and bullying  
45 and their impact on him, Seb's talk led to discussion between autistic and non-autistic students,  
46 mentors and practitioners around what constituted an enabling environment or, conversely, a  
47 disabling environment in HE (Ridout and Edmondson, 2017). There was much criticism of a lack of  
48 even basic autism awareness among staff, and other critical issues raised focused on: the  
49 importance of an individual approach; understanding the sensory impact of busy spaces, especially  
50 entrances; and the need for quiet spaces to allow an individual to regain control of anxiety (Ridout,  
51 2016; Graby, 2015; Moon, 2014; Murray 2006). These points are often overlooked when planning  
52 support and are in addition to helping individual autistic students engage with their course and  
53 understand its requirements. Perhaps even more problematic is that the quality of mentoring and  
54 disability support varies between universities, so a change of course or university can effectively  
55 mean a new start that is difficult to manage (Ridout, 2018).~~  
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3 The West Midlands branch of PARC then moved to its second home at the University of Birmingham  
4 (UoB), where people attending the first session took part in small group discussions under the  
5 overarching theme of 'Identity and Violence' to decide on the theme and purpose of future sessions.  
6 As a result, the themes of 'Sexuality', 'Institutionalised Violence' and 'Gender' emerged. The events  
7 are inclusive of all, and it is encouraging that young autistic speakers are finding this a welcoming  
8 space to present at alongside more experienced autistic and non-autistic researchers. ~~Future  
9 sessions also have exciting plans for joint writing and presentation ventures. This format allows  
10 people to reflect on learning points and encourages thoughts about the shaping of future events,  
11 and it is arguably this inclusive approach that points to the national and growing success of PARC to  
12 date.~~

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17 November 2017 saw PARC spread its reach north to Sheffield, with the workshop 'PARC Publish'  
18 being held in collaboration with Sheffield Hallam University. The aim of this workshop was to bring  
19 together writers and researchers from both within and outside of academia, along with members of  
20 autistic and autism communities with an interest in the publishing of autism-related literature, in  
21 order to discuss the current state of the field, and to explore aims and goals for the future, and the  
22 potential roles PARC may play in this. ~~A lively and engaged discussion session was structured around  
23 four key themes: (1) Literature review — material that has been useful, and that which may be  
24 considered problematic; (2) Representation and inclusion — how can we ensure that autistic and  
25 autism communities are represented in, and have access to, literature on autism? How can we  
26 incorporate diversity of expression and communication in autism publishing?; (3) Collaboration —  
27 how can we work together and share skills and resources at our collective disposal?; and, (4) The  
28 future — what do we want to see in the field of autism publishing? What topics do we wish to see  
29 covered? What working methods do we wish to engage?~~

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34 Key points coming out of the discussion included the role of autism literature in shaping and  
35 strengthening the identities of autistic people, in a similar way to that discussed by Bagatell (2007),  
36 and in influencing the trajectories of autistic and non-autistic researchers. Conversely, the 'offensive'  
37 tone of some research on autism was experienced as problematic by some. Access to published  
38 material was highlighted as an issue, with the impact of academic 'paywalls' and other barriers being  
39 highlighted as having a negative impact on community inclusion and activism. Topics identified as  
40 important for future publications included employment support, access to healthcare, ageing, and  
41 sexualities. Participants indicated a keenness to develop supportive writing groups, and forums to  
42 share work, with social media being identified as an important platform, to enable confidence and  
43 empowerment, and to assist in navigating interaction while accommodating a wide range of  
44 communication and processing needs and preferences. The role of established writers, researchers,  
45 and publishers was highlighted as being significant in supporting those at earlier points in their  
46 career who did not have access to the same range of supportive networks and resources.

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51 A novel aspect of the PARC Publish workshop was the use of social media to facilitate participation  
52 and engagement on an international level. This included the use of the 'Buffer' application to pre-  
53 prepare tweets, which contained slides detailing the questions being discussed at the workshop.  
54 These tweets were then timed to be sent from the organiser's Twitter account at the same time as  
55 the topics were being discussed in the room. The use of this strategy, along with the 'hashtag'  
56 #PARCPublish meant that those unable to attend the event in person were able to participate in the  
57 discussion, and to continue this after the event; it also facilitated additional 'processing' and  
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~~communication time for those, primarily autistic, participants who experienced ‘real-time’ face-to-face interaction as a barrier to participation, adding a level of inclusivity and accessibility to the event. The fact that discussion coalesced around a hashtag meant that discussion was captured and is now easily located and identified. The workshop proved very popular, with a replication of the event being held subsequently in Plymouth. It is envisaged that the points raised in the workshop may be incorporated into future publishing plans, both for PARC, and for the wider autistic and autism communities.~~

In early 2018, PARC partnered with the Department of Psychology at the University of Nottingham to hold a workshop day concerning the ‘double empathy problem’ as initially theorised by Milton (2012). This brought together researchers and theorists such as Nick Chown, Brett Heasman, and Noah Sasson to discuss this growing area of research interest. Another event held at LSBU involved students from New York University visiting the UK and a talk from the US-based autistic academic Stephen Shore. In July 2018 PARC held a ‘Critical Autism Studies’ conference at LSBU attended by some sixty guests. Such activities have established links between autistic and non-autistic researchers across disciplinary backgrounds forging links that have led on to publications in the field.

Activities through the PARC group have also led however to a partnership with Pavilion Press and a number of publications (Milton et al. 2016; Milton and Martin, 2016; Milton and Martin, 2017; Milton, 2017; Ridout, 2018) addressing practical issues as well as theoretical. The PARC group has also organised and chaired a stream for ~~the last two years at the~~ high profile conferences such as Learning Disability Today, conference and in September 2018, chaired a stream on the theme of ‘Neurodiversity’ at the Centre for Disability Research Conference at Lancaster University, and organised the speakers for one of the platforms at the ‘Autism Show’s’ in 2018 with members Damian Milton, Susy Ridout and Leo Capella running a workshop in advance of the event to assist people with presentations. Plans for the future of PARC also include the renewal of an autism practice journal, and a series of workshop days. The above activities show that PARC has worked very well in terms of increasing collaboration and communication between autistic people and the research community, as well as leading to publications, dissemination and sharing of research, and providing peer support, thus showing a great deal of ‘real world impact’ and going a long way to meeting its initial aims.

### **PARC and the wider HE context**

Becher and Kogan (1992) suggested that HE systems contain four tiers: central authorities (such as research councils), individual institutions, basic units (such as departments) and individuals. Within these structures however, a number of commentators have suggested that the processes governing Higher Education have come to reflect a neoliberal agenda and managerialism (e.g. Davies and Peterson, 2005a; Zepke, 2017). Such concerns are not entirely new either, if one takes into account the ‘instrumentalist pedagogy’ noted by Scrimshaw (1983) ~~or Ritzer’s (1996) McDonaldisation of education thesis.~~ When one looks at how the ‘impact’ and ‘quality’ of research is assessed within the Research Excellence Framework (REF), and the mechanisms and structures through which funding is allocated, one can easily depict a highly competitive and hierarchical model, even ‘elitist’. Within the context of autism research, the vast majority is funded through the Medical Research Council, often framing autism as a disorder to be remedied. Social research is sparse, and where there had been two research charities dedicated to autism, one has recently closed down operations regarding

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3 funding future projects. The journals with the highest impact factor in the field of autism studies  
4 both have a history of preferring scientific and medical model approaches. Thus, as the PARC  
5 network are part of an autistic community that rallies behind the slogan 'nothing about us, without  
6 us', this scenario presents something of a problem. This issue is not just one we are facing personally  
7 as autistic academics however, but a common feature for many and could be considered a 'public  
8 issue' (Mills, 19596). Furthermore, the fluidity of 'identity' as a concept is often not recognised  
9 within HE structures, so for those of us who identify as neurodivergent (divergent from social  
10 standards of neurological normalcy) the issue becomes problematic with us being even more  
11 labelled and compartmentalised to suit the whims of funding bodies and outsider research  
12 communities to the detriment and exclusion of our other identities.  
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17 The Teaching Excellence Framework (TEF) is a government initiative introduced in 2017 as a  
18 framework whereby undergraduate students can now assess quality of teaching and academic  
19 support along with subsequent progression into employment (Bhardwa, 2018). Linked to this is a  
20 need for HE institutions to understand and reflect social mobility, diversity and choice, and with a  
21 focus on flexible and inclusive teaching, resources and assessment forms which challenge the  
22 limiting nature of setting rigid goals (Garvey et al., 2009). The unpredictability of life and social  
23 circumstances can act as barriers to achievement (Ridout and Edmondson, 2017; ARGH and HUG  
24 2011), so the TEF encourages practice, which it can be argued are represented in the social research  
25 values embedded in PARC.  
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30 Within this climate of competition for resources and status, the notion of research 'impact' has  
31 become increasingly important in the way academic work is evaluated, but also in terms of public  
32 responsibilities being recognised such as 'engagement', often assessed via various forms of metrics  
33 regarding citations within a field and the quality of peer review the work had been subjected to.  
34 Traditionally, autistic scholars have sometimes struggled to acquire sustainable work, or perform  
35 within normative or highly competitive frameworks and structures, thus exacerbating the rift  
36 between autism researchers and the autistic people they research or autistic scholars promoting a  
37 participatory agenda (Milton and Bracher, 2013; Milton, 2014; Gillespie-Lynch et al., 2017; Chown et  
38 al., 2017). It is interesting to note then, how the PARC network without funding has been able to  
39 build a strong research network, with increasing impact in a number of areas, providing knowledge  
40 sharing activities, increasing visibility of research outputs, effectively utilising digital media, and  
41 extending networks nationally (and more recently internationally through invited visiting guests or  
42 via online means). Despite PARC members having good and improving metrics through such work,  
43 many are in unstable employment, or with limited access to academic resources or funds. Indeed,  
44 accessing funding through partnerships with established academics, coupled with peer support and  
45 mentoring (Martin, 2017; Ridout, 2018), may be the best way to address this anomaly within current  
46 constrained systems. This is a critical issue for consideration as the majority of mentors, many of  
47 whom are themselves neurodivergent, are often employed on flimsy and demeaning zero hours  
48 contracts, with little or no respect for their skills and abilities and with no prospect of promotion.  
49 Worryingly, many mentors have no support unlike line management embedded in contracted  
50 positions, and many are unfamiliar with their co-mentors. This raises concerns as to their support  
51 network and wellbeing within the work environment and identification of the responsible party for  
52 this (Miller, 2002), and even more so raises questions as to the monitoring of agencies and whether  
53 they understand the requirements of mentees and how to appropriately match people on their  
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3 agency list with students (IES and REAP, 2015). Mentoring too often falls foul of an agency's or  
4 university's need to meet performance criteria set by auditors, and this will inevitably become a  
5 number-crunching exercise as role descriptors of mentors is confused and the realistic picture of  
6 student support requirements are overlooked (SFE, 2016).  
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10 An issue explored by Archer (2008) is the construction of professional academic identities, drawing  
11 from interview data with 'younger' academics within UK universities to consider how they position  
12 themselves in relation to notions of 'authenticity' and 'success'. Archer (2008) argues that feelings of  
13 inauthenticity and exclusion are exacerbated through the performative ethos favoured by current  
14 research assessment processes and institutional structures, as well as by inequalities of age,  
15 ethnicity, class and gender (as well as the structure of temporary contracts of employment). Archer  
16 (2008) suggests that as well as going through a process of 'becoming' an 'authentic' academic,  
17 researchers also lived with the threat of 'unbecoming' or precariousness and related inauthenticity  
18 of academic status. In relation to the development of the PARC group it is interesting to note that  
19 intersections of disability (let alone neurodiversity) did not enter in the frame of Archer's (2008)  
20 research, yet the very same issues could be said to be even more exacerbated for such populations,  
21 further disabled by the neoliberal structures and processes they contend with in academia (Davies  
22 and Peterson, 2005a). Within the field of autism studies there is also a significant divide between  
23 disciplinary territories and boundaries (Becher and Trowler, 2001; Henkel, 1997), characterised by  
24 one autistic scholar [Larry Arnold](#) as a 'silo mentality' ([Arnold, 2010](#)). Archer (2008) cites Bourdieu, in  
25 suggesting academia can be characterised by competing individuals and groups, vying for  
26 recognition, status and value – subject to competing paradigms, representations, constructions and  
27 claims to truth. As Archer (2008) asks the question as to what extent younger academics were able  
28 to feel legitimate and successful within their identities, and finding a precarious positionality, this  
29 can be reflected to an even greater extent when considering autistic academics and scholars and the  
30 opportunities that have been afforded them in what could be described as an institutionally ableist  
31 neoliberal academic culture. PARC in contrast, has been able to step in as a collective and  
32 demonstrate inclusive practice to the field more generally.  
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40 For Davies and Peterson (2005b) the pressure for 'performance' within neoliberal discourse  
41 produces people as a set of outcomes, and reduces them to exchangeable products, a Foucauldian  
42 'technology of self' acting within and between contradictory agendas. However, by marginalising  
43 autistic academics and their potential output, such systems give rise to activist academia, such as  
44 that seen within the field of 'critical disability studies'. The PARC group can be said to be positioned  
45 within such wider social currents as the neurodiversity movement (Walker, 2014), the social model  
46 of disability, and a participatory / emancipatory research ethos ([Barnes, 2001](#)).  
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50 Nicola Martin (2017), co-founder of the PARC network interviewed disabled academics working  
51 within UK universities in order to explore their experiences and draw out recommendations for  
52 improvements in practice. Martin (2017) found a number of barriers to encouraging and developing  
53 disabled leaders within HE that included: stereotyping, the invisibility of role models, limited  
54 strategic change at managerial levels, ableist assumptions, and disorganised processes. In order to  
55 meet these challenges, Martin (2017) recommended strategic responses, inclusive design and  
56 reasonable adjustments, leadership development and recruitment, peer support and mentoring  
57 networks, and promoting a culture that celebrates rather than problematises diversity. Whilst the  
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3 PARC group is a significant step in addressing such issues, it is but a small activist group when  
4 compared to the current structures that govern and implement research within the UK. Given its  
5 small stature in this regard though, the network has significantly added to the collaborative 'impact'  
6 of the work of its members.  
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### 9 **Forming an autistic academic community**

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11 Part of the process of forming PARC is and has been the formation of an autistic academic  
12 community that is supportive and empowering (Ridout and Edmondson, 2017; ~~Research Autism,~~  
13 ~~2015~~). This has been one of the initial aims for PARC and its importance should be considered not  
14 only in terms of connecting academics with similar research interests, but also in supporting autistic  
15 individuals in their attempts to establish themselves within academic systems that may not always  
16 be considerate or accommodating. From our personal anecdotal conversations with each other, and  
17 with autistic individuals working in the autism field more broadly, we are aware of a vast array of  
18 issues that we share and with which we need support. These may apply more broadly to many  
19 autistic autism professionals and/or activists but are contextualised in a different way within  
20 academia.  
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26 One important aspect of being an autistic academic is the vast amounts of emotional labour that one  
27 has to go through. Emotional labour is defined as the process of dealing with other peoples' feelings,  
28 a core element of which is the regulation of one's own emotions (James, 1989). There are many  
29 ways in which an autistic academic has to manage profound emotional labour in academic spaces. It  
30 begins with constantly engaging with a huge amount of violent predominant autism discourses,  
31 based on dehumanising and infantilising medical models. Autistic professionals also have to manage  
32 a world where the "outside-in" description of their abilities often disregards the amount of effort  
33 they put in order to stay and survive ableist academic spaces that are not prepared to address their  
34 needs in any significant way (Milton and Moon, 2012). This extends to the relationships and  
35 networking we have to do, which is an integral part of academia. As autistic academics, we often  
36 must engage in predominantly non-autistic autism discourses as well as non-autistic colleagues  
37 whilst managing our own emotions regarding the dominance of non-autistic autism discourse which  
38 harms us personally, autistic academics collectively and the autistic communities more broadly and  
39 handle our colleagues' unhelpful practices in a tactful way. This requires an immense amount of  
40 emotional labour in and of itself, which is only aggravated by the constant need of having to re-  
41 evaluate our beliefs and alliances.  
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48 The examples above demonstrate a few instances of emotional labour involved in being an autistic  
49 academic. Therefore, from a community-building standpoint, the very existence of PARC creates a  
50 structure with which we can begin to create change for ourselves and others as members of a  
51 "community of coping" (Korczyński, 2003). The idea of a community of coping was first introduced  
52 by Hochschild (1983), to refer to the unofficial structures which workers create to deal with work  
53 situations that require them to display significant amounts of emotional labour. Korczyński (2003)  
54 elaborates in the ways which communities of coping can act in ways which are useful with the  
55 structures that surround them, by reducing, for example, staff turnover, as well as inform acts of  
56 resistance from management directives. In an academic context, PARC serves both of those roles.  
57 Given the significant lack of any meaningful support towards autistic academics, PARC serves as a  
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3 network of support for each other in our efforts of continuing our work and strengthening our  
4 presence in academia. It also provides a structure through which we are able to demonstrate helpful  
5 practices with which to engage both autistic academics and autistic communities more broadly, by  
6 its firm commitment to participatory autism research. Therefore, PARC is growing to become an  
7 important element in the field of autism studies both by supporting the emerging autistic academics  
8 and by promoting ethical and participatory research methods and practices. Whilst PARC opens up  
9 opportunities for connection and progress in the development of participatory work, there are also  
10 risks to contend with, primarily the lack of funding for core activities, and in developing  
11 opportunities for those autistic people who traditionally have not been best served within autism  
12 research. Recently we have received news however of funding for projects at the University of Kent  
13 exploring the sensory needs of autistic people with high support needs and at London South Bank  
14 University into the needs of older autistic people, both of which will have input from PARC members  
15 in their development. We very much hope to see such initiatives continue to flourish into the future.

### Implications for wider service provision

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23 Whilst there have been many experiences to reflect upon regarding the continuing development of  
24 PARC, these experiences also pertain to wider service provision for meeting the needs of autistic  
25 people. Most strikingly this is the case in terms of support and mentoring services for autistic people  
26 in Further and Higher Education. The experiences of PARC would lend added insight into the  
27 constrained opportunities afforded to autistic students and graduates and the potential benefit of  
28 peer support and pointing in the direction of the benefit of 'working with' rather than 'doing for'  
29 marginalised groups. We would conceive of participation however to be an ongoing effort and ethos  
30 rather than a definable outcome, meaning that striving for inclusion, participation and co-production  
31 can never be perceived as a given or as fully accomplished. This is also true for the activities of PARC  
32 itself which will need to further diversify in order to broaden its impact and reach. Meanwhile, the  
33 translation of research to practice can only be furthered by continuing efforts for fruitful  
34 partnerships across neurological dispositions and academic disciplines.

### **Conclusion**

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42 The PARC group has been successful and continues to grow, yet to be living up to its name it will  
43 need to find ways of widening participation for those with more considerable communication or  
44 intellectual impairments, or from autistic people who also occupy intersecting marginalised  
45 identities. One advantage to being largely a network of 'outsider researchers' is the lack of managing  
46 the risk of 'unbecoming' an academic if one has never been seen as legitimately so to begin with,  
47 affording a critical scrutiny others set within a hierarchical and competitive system may enjoy. The  
48 PARC group and others like it are thus essential for academia to sustain some of its classical ethos  
49 within a neoliberal context.

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