



**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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