



# Kent Academic Repository

**Milton, Damian (2018) *An introduction to the Participatory Autism Research Collective (PARC) and to Critical Autism Studies (CAS)*. In: PARC 2018 Critical Autism Studies Conference, 18 July 2018, London, UK. (Unpublished)**

## Downloaded from

<https://kar.kent.ac.uk/67683/> The University of Kent's Academic Repository KAR

## The version of record is available from

<https://participatoryautismresearch.wordpress.com/2018/06/28/parc-critical-autism-studies-conference>

## This document version

Presentation

## DOI for this version

## Licence for this version

CC0 (Public Domain)

## Additional information

## Versions of research works

### Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

### Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in **Title of Journal**, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

## Enquiries

If you have questions about this document contact [ResearchSupport@kent.ac.uk](mailto:ResearchSupport@kent.ac.uk). Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).



# Welcome to #PARC2018

- Some general guidance for the day:
- Sticking to time!
- Accessibility issues
- 'Flappause' and general levels of noise
- Asking questions of speakers
- Respectful debate please!

# The Participatory Autism Research Collective

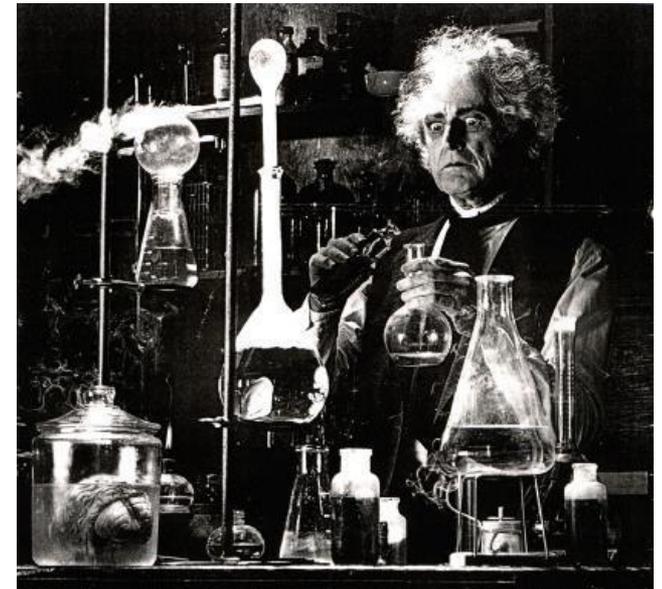
- The Participatory Autism Research Collective (PARC) was set up to bring autistic people, including scholars and activists, together with early career researchers and practitioners who work with autistic people.
- Our aim is to build a community network where those who wish to see more significant involvement of autistic people in autism research can share knowledge and expertise.
- Not just for researchers!

# Participation and insider knowledge

- “...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.” (Williams, 1996: 14).

# The autistic voice and the production of knowledge

- People on the autism spectrum rarely in the role of researcher, traditionally seen as passive subjects.
- The ‘glass sub-heading’ (Milton and Bracher, 2013).
- “Of over \$314 million in research funding, only 3% went to research into services, supports and education and less than 1% went to research into the needs of adults.” (Ne’eman, 2011).



# Participatory research

- A range of theoretical and methodological approaches.
- Yet with the main objective of handing power from the researcher to research participants, who are often community members or community-based organisations.
- In participatory research, participants have control over the research agenda, the process and actions taken.
- Most importantly, participants themselves are the ones who analyse and reflect on the information generated, in order to obtain the findings and conclusions of the research process.

# Activity of the PARC group

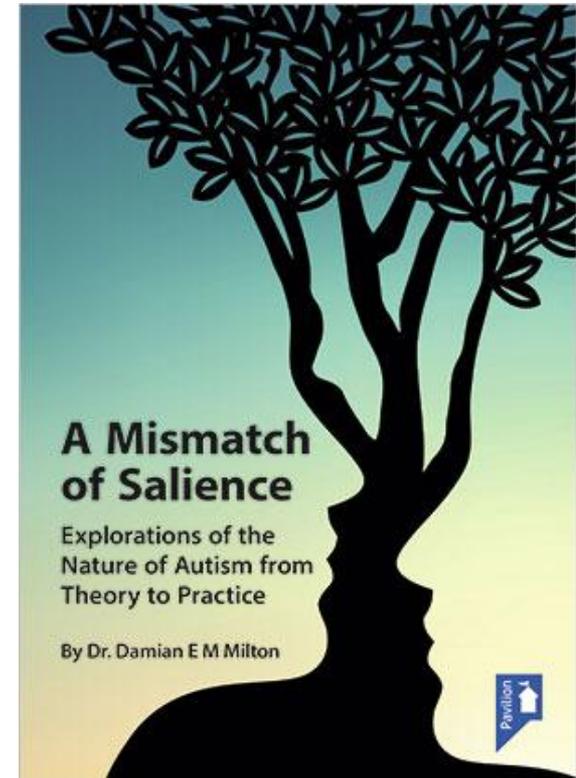
- The website for PARC continues to attract interest: [www.PARCAutism.co.uk](http://www.PARCAutism.co.uk)
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Expanding to other regions – events held in London, Birmingham, Sheffield and Nottingham. Discussions held in Edinburgh and Kent.

# Conference streams

- Damian Milton and Nicola Martin from the PARC group will again be chairing a stream at the Learning Disability Today conference.
- We have been asked to chair a stream on 'Neurodiversity' at the next Centre for Disability Research Conference at Lancaster University in September 2018.

# Publications

- Special edition of the Scandinavian Journal of Disability Research (SJDR) regarding a critical dialogue on Neurodiversity.
- Special edition of Advances in Autism (AIA), work in the field of education and autism.
- Invited to write an article for the Tizard Learning Disability Review.
- Partnership with Pavilion Press.



# Reinvigorating the ‘Theorising Autism Project’

- A series of workshop days
- One of these workshop days has already looked at research regarding the ‘double empathy problem’. Another is likely to look at ‘monotropism’ and related theory and research.
- Presenting workshop – potential for more events of this kind.
- Publishing workshops
- ‘Hacking the system’ workshop suggested.

# Critical Autism Studies (CAS) – the early years

- Workshop held in Toronto in 2010 followed by a seminar day in Sheffield in Jan 2011.
- Autonomy first edition published in 2012.
- Worlds of Autism (Davidson and Orsini, 2013).
- Re-thinking Autism (Runswick-Cole et al. 2016).

# Differing definitions

- “...about critical thinking, new perspectives and a channel for further debate in future.” (Arnold, 2013).
- For Davidson and Orsini (2013) CAS is about scrutinising power relationships in autism research and practice; promoting positive accounts of autism that confront prevailing negative views; and the development of theoretical and methodological approaches that are inclusive and valuing.
- For Runswick-Cole et al. (2016) CAS is about examining whether a diagnosis of autism is scientifically valid, and whether such a diagnosis is useful in the lives of those so ‘labelled’.

- A broader and more inclusive definition however was provided by Waltz (2014):
- *“The ‘criticality’ comes from investigating power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce ‘disability’”* (Waltz 2014, p 1337).

# The citation survey (Milton et al. yet to be published)

- Event held at LSBU last year, concerns raised regarding power differentials involved.
- The motivation for holding a PARC conference on the theme this year.
- A citation survey was piloted in 2017 and then was completed in 2018 regarding these core texts and works in the field of CAS within relevant journals.

# Cross-citations within key texts

Texts	RT-A	WoA	Autonomy
RT-A	46	33	3
WoA	8	49	14
Aut	5	17	21

# Most cited authors in Disability and Society

Authors	Text	Citations in D&S CAS articles
Dan Goodley	RT-A	12
Katherine Runswick-Cole	RT-A	10
Damian Milton	Autonomy	8
Rebecca Mallet	RT-A	6
Charlotte Brownlow	WoA	5
Jim Sinclair	Autonomy	5
Larry Arnold	Autonomy	5

# Number of articles published in D&S by author

Name	Number of articles in D&S	Name	Number of articles in D&S
Damian Milton	6 (1)	Hanna Bertilsdotter Rosqvist	2
Nick Chown	2 (1)	Richard Woods	2 (0)
Charlotte Brownlow	2	Mitzi Waltz	2
Lindsey O'Dell	2	Anne Lindblom	2
Katherine Runswick-Cole	1	Carmel Conn	2
Michael Orsini	1		
Frances Ortega	1		

# Crossref citations

Author	Article	CrossRef Citations	Text
Milton (2012)*	On the ontological status of autism: the 'double empathy problem'	31	Autonomy
Runswick-Cole (2014)	'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times	14	RT-A
McWade, Milton and Beresford (2015)*	Mad studies and neurodiversity: a dialogue	9	Autonomy
Bertilsdotter Rosqvist, Brownlow & O'Dell (2012)	Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces	8	WoA
Chown (2014)*	More on the ontological status of autism and the 'double empathy problem'	5	Autonomy

- Highest Altmetric scores were all authored or part-authored by autistic scholars, and four of the five most viewed papers.
- Cross citations in articles in D&S between the authors of the initial texts:

Texts	RT-A authors in D&S	WoA authors in D&S	Autonomy authors in D&S
RT-A authors in D&S (2)	7	6	0
WoA authors in D&S (2)	1	6	0
Autonomy authors in D&S (8)	4	0	17

## Questions to think about and to return to later:

- The most cited CAS articles are also the least cited by some working within CAS! What to do about the subcultures forming within CAS?
- How to relate such work to traditional research organisations based mainly within a medical model framework – e.g. Autistica and the AIMS-2 project?
- How can we increase participation and the autistic voice within autism research – e.g. less represented groups?
- What kind of scrutiny might we be able to bring to the field working cooperatively and internationally?

# Dr. Michael McCreadie – a tribute

- Health Psychologist with over twenty-five years experience in the field
- Provided clinical support, advice and consultancy in the UK and beyond
- Promoting a focus on well-being and meeting holistic needs in service delivery
- Worked with Studio3, Scottish Autism, and most recently was a director of AT-autism
- Supported PARC and contributed to the LDToday conference stream and annual last year
- Exemplified the concept of the ‘reflective practitioner’ and will be sadly missed



**Any questions?**

# THE UK'S EUROPEAN UNIVERSITY



[www.kent.ac.uk](http://www.kent.ac.uk)

University of  
**Kent**