# Who benefits from autism research? And to what extent is it participatory and/or emancipatory?: A brief follow-up to Pellicano, Dinsmore and Charman (2014)

**Author Details.**
Nick Chown
Independent scholar
npchown@gmail.com

Several years ago, the *A Future Made Together* report on autism research in the UK (Pellicano, Dinsmore and Charman, 2013), including a survey of the autism community in the UK, pointed out that despite the welcome increase in the amount of research on autism, and the amount of funding provided for autism research, "there was a clear disparity between the United Kingdom's pattern of funding for autism research and the priorities articulated by the majority of [survey] participants" (Pellicano, Dinsmore and Charman, 2014: p. 756). More recently, in an editorial in *Autism,* Liz Pellicano and various other colleagues announced a new era for autism research following the recommendation of the US Government's Interagency Autism Coordinating Committee (IACC) that "autism-related research funding in the United States should increase further still, doubling by 2020" (Pellicano et al., 2018). These authors pointed out that the IACC called for more research that directly affects the lived experiences of autistic people. Although the IACC call was not for research in areas prioritised by the autism community, if the call is heard and acted upon there should be a greater focus on what is important to the community. There has been no US equivalent of Pellicano, Dinsmore and Charman's 2014 study, nor is there a UK equivalent of the US government body's call for more research of direct benefit to autistic people.

Milton and Bracher (2013: p. 66) write that the "meaningful involvement of autistic people in understanding autism – including (but not limited to) the employment of appropriately trained autistic people in research teams … would increase the epistemological integrity of studies that seek to explore important questions relating to the wellbeing of autistic people." Later, Milton stated a stronger view that social autism research could not claim epistemological (or ethical) integrity in the absence of the involvement of autistic scholars. Woods and Waltz (2019, n.p.) write that "it is unsustainable to ignore the case for autistic parity with other stakeholders in autism knowledge production" and call for a debate on autistic parity. All these contributions relate to the "double empathy" hypothesis, whereby it is contended that non-autistic people have as much difficulty understanding autistic people as vice versa, i.e., the communication difficulties between the neurotypes are bi-directional in nature.

I wanted to investigate the extent to which current autism research is: (a) focused on matters of potential direct benefit to autistic people; and (b) participatory and/or emancipatory. I undertook a simple, although structured, search of the Google Scholar academic database for reports of autism research (articles and Doctoral theses, any national origin) between 1997 and 2016. Across this period, 129 reports were found that could be included in my study. All reports were reviewed to identify those with the potential to have a direct benefit for autistic people. The reports were also evaluated in relation to a framework of criteria for participatory/emancipatory research (Chown et al., 2017). Despite the use of a method that may not be considered fully 'scientific'[1], I believe my approach is adequate to enable preliminary indications to be drawn from the data.

Of the 37 studies involving either autistic adults or parents of autistic individuals, only four (11%) were linked with one of the priorities identified by the autistic participants in Pellicano, Dinsmore and Charman (2014): 3% of the full dataset. Only one of the 37 studies was even partially compliant with the criteria for participatory and emancipatory research (1% of the full dataset). As I have only

---

[1] The 'scientific' standard associated with university-based research should not necessarily be expected of an individual, unfunded, independent researcher (Chown et al., 2019).

considered a small sample of the vast corpus of autism research, it is not possible to draw hard and fast conclusions regarding my research question. Nevertheless, I think that the findings that only 3% of the studies reviewed were linked with a UK community research priority, and that only 1% were partially compliant with the participatory/emancipatory research criteria (no study was fully compliant), are indications of the challenge ahead.

Not long after the original version of this letter was submitted, research undertaken on behalf of Autistica was published. The Autistica study rightly stresses that “We need to represent every autistic person in research.” The absence of any mention of the need for autistic scholars in research teams undertaking social research in autism is a missed opportunity. Despite the limitations of my study, I did my best to consider the extent of autistic researcher participation[2]; none of the 129 items in my study appeared to be compliant in this respect.

Autistica state in their report that: “In 2016, **27%** of UK autism research funding was spent on the top 10 community priorities.” My study found that only **3%** of studies published worldwide during the chosen period and accessible via Google Scholar were linked with the research priorities identified by Pellicano, Dinsmore and Charman (2014). I only excluded items that were neither articles nor doctoral theses, and duplications. The Autistica researchers searched the Dimensions research grant database developed by ÜberResearch. Their report discusses use of “exclusion terms” but does not list the terms they adopted. I posed two questions to Autistica in relation to their study.

*Question 1*
How would you describe the difference between the research priorities informing your study in comparison to those informing the [PDC] study?

*Response*
Autistica stated: ‘The six major differences were: 1) We were interested in how funding related to research priorities established in our JLA: https://www.autistica.org.uk/our-research/our-research/your-research-priorities), 2) we were interested in what groups of people were excluded from autism research (according to age, cognitive ability etc.), 3) we were interested in where, geographically, money on autism research was spent, 4) we were interested in when in a person's career they were awarded funding, 5) we also did this work as part of an exercise to look at funding across different nations (to be published later this year) and 6) five years had passed since *A Future Made Together* and so we were interested to see whether there had been a move towards addressing community priorities” (personal communication, James Cusack, 10 July 2019).

*Question 2*
What "exclusion terms" did you adopt for your study?

*Response*
Autistica stated: “Exclusion/limitations: Using Uber Research it is not possible to identify all autism research funding (particularly funding localised within universities). There is also an element of decision making required regarding whether something is or is not autism research. The method for making these decisions is detailed in our scoping report (https://www.autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf). We made decisions

---

[2] The framework used (Chown et al., 2017) includes a criterion requiring that identification and definition of matters to be investigated be undertaken or confirmed by a member of the autistic community and/or an autistic researcher. The known involvement of an autistic researcher might not have been reported, although it seems unlikely that a research team would not have drawn attention to such a beneficial development unless the individual concerned did not wish to disclose. In this latter regard, I think it more likely that an individual would not disclose to their establishment, rather than having disclosed to their employer, not be willing to disclose further.

using more than one person and by following approaches established by others - such as the mental health research charity, MQ" (*ibid.*).

There are various reasons why a direct comparison cannot be made between the percentages in the Autistica study (27%) and my study (3%), including:

(i) Mine was focused on the priorities in *A Future Made Together*, whereas Autistica focused on their own JLA priorities;
(ii) What we classified as "autism research" differed;
(iii) It is not clear what "exclusion criteria" were adopted by Autistica but the indications are that they were more extensive than mine;
(iv) Autistica considered only UK research (and it is clear that the UK has made some strides in comparison with the worldwide picture);
(v) Other aspects of our research methods differed.

There is a need to ensure that autism research priority studies like these are meaningful and replicable. My view is that an initial study based on an agreed standard, updated annually, would be a very worthwhile project. Is it impractical for all the various stakeholders to develop a standardised approach for these studies? At the very least, research method transparency is essential to ensure that research can be understood and replicated.

Yours sincerely,

Nick Chown
Independent researcher

## References

Chown, N., Hughes, E., Leatherland, J. & Davison, S. (2019) "Response to Leaf et al.'s critique of Kupferstein's finding of a possible link between applied behaviour analysis and post-traumatic stress disorder," *Advances in Autism*. doi: 10.1108/AIA-01-2019-0002.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L. and MacGregor, D. (2017) "Improving research about us, with us: A draft framework for inclusive autism research," *Disability & Society*, *32*(5): 720-734. DOI: 10.1080/09687599.2017.1320273

Milton, D.E. (2014) "Autistic expertise: A critical reflection on the production of knowledge in autism studies," *Autism*, *18*(7), 794-802. doi: 10.1177/1362361314525281.

Milton, D. and Bracher, M. (2013) "Autistics speak but are they heard?," *Medical Sociology Online*, *7*(2): 61-69. Retrieved from: *https://kar.kent.ac.uk/id/eprint/62635*

Pellicano, E., Dinsmore, A. and Charman, T. (2013) *A Future Made Together: Shaping Autism Research in the UK*. London: Institute of Education.

Pellicano, E., Dinsmore, A. and Charman, T. (2014) "What should autism research focus upon? Community views and priorities from the United Kingdom," *Autism*, *18*(7): 756-770. doi: 10.1177/1362361314529627.

Pellicano, L., Mandy, W., Bölte, S., Stahmer, A., Lounds Taylor, J. and Mandell, D.S. (2018) "A new era for autism research, and for our journal," *Autism*, 22(2): 82-83. doi: 10.1177/1362361317748556.

Woods, R. and Waltz, M. (2019) "The strength of autistic expertise and its implications for autism knowledge production: A response to Damian Milton," *Autonomy*. Retrieved from: http://www.larry-*arnold.net/Autonomy/index.php/autonomy/article/view/CO2/html*