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Beyond tokenism: the participation of autistic people in autism research

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In recent years there has been an exponential rise in the amount of autism research that has been undertaken, yet much of the narrative created has been at odds with voices from the autistic community following the 'neurodiversity paradigm' which could be loosely described as applying a social (or post-social) model of disability to autistic (and other 'neurodivergent') experiences. As an autistic social scientist, ever since moving into the field of autism research I have championed the need for greater participation of autistic people throughout the research process from design to interpretation and dissemination (see Milton, 2017). Echoing the views of autistic and wider disability activists for 'nothing about us, without us', I and many others have sought to make a difference in this regard often in the face of strong opposition. A similar sense of tokenism is often felt among autistic people regarding their representation by organisations set up 'for' autistic people who often have limited input from autistic people themselves.

"...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).

Within social science there has long been debates about the usefulness of insider and outsider perspectives on any given issue, as one can see in concepts from positionality, to situated knowledge, habitus and disposition.

Divides and controversies over what exactly autism is and therefore how best to support autistic people marginalised within society often with limited life chances largely stem from differences with seeing autism as a medicalised set of deficits to be remediated in some way and describing a variety of ways of being in the world that need accommodation and understanding. These issues have a direct bearing on what outcome measures are used in autism research and how useful they are in practice.

In the production of knowledge within the field of autism, autistic people have been traditionally seen as subjects of research, rather than in the role of researcher. This is slowly and thankfully beginning to change. Yet autistic researchers are still a distinct minority within the academy and a participatory ethos more generally can often be held back by financial and bureaucratic constraints. This means that most autism research would not be viewed as having more than tokenistic participation (on a scale such as that devised by Arnstein, 1969). In order to break the cycle a more collaborative approach is needed in setting the research agenda as well as the design and development of support strategies and methodologies.

Rather than a prescriptive 'how to' guide, it is argued here that participatory research should be conceived of as an ethos or ideal, and often one that is fraught with difficulties in actual practice. Participatory research can therefore relate to a wide range of theoretical and methodological approaches, yet with the aim of ceding power from the researcher to the research participants, with participants in control of the agenda, processes and interpreting analysis of information generated.

There are however many barriers to the inclusion of autistic people in research, not least of which being the heterogeneity of autistic experiences and positionalities. The cognitive or linguistic demands of a method may impair the full involvement of autistic people with learning disabilities. Often proxies for autistic perspectives are taken from those close to them, yet this can sometimes

be problematic. Yet, just because something is difficult does not mean it should not be attempted. Indeed, given what is at stake ethically and epistemologically one could see it as essential to do more toward the participatory ideal.

As example of this one-step-at-a-time ethos, I was involved in a project called 'Transform Autism Education' (<https://www.transformautismeducation.org/>). This project involved teams from the UK, Italy and Greece sharing educational practice ideas through building a community of practice. I was originally part of the project team as a consultant yet by the time the project had finished I was employed as a part-time Research Fellow on the project and alongside others on the project team such as Rebecca Wood gradually increased autistic participation as the project developed, from holding events and workshops with autistic speakers and co-produced workshops to helping recruit autistic consultants in Italy and Greece.

Another project I worked on was as a Research Assistant at London South Bank University. This project was piloting mentoring for autistic adults, but involved mentor training developed by autistic people, autistic and neurodivergent members of the project team and advisory groups, as well as some of the mentors who worked on the project, with all involved feeding into the process as a whole and goals for the mentoring process set by the mentees (Martin et al. 2017). Whilst such examples are increasing in number, there remain many obstacles to participatory research with autistic people. As an example, with some notable exceptions such as the work of Susy Ridout, Anat Greenstein and Sally Brett, few projects successfully involve autistic people with significant learning disabilities.

A significant factor in participatory research with autistic people is what I have previously referred to as the 'double empathy problem' (see Milton, 2017). This concept at its most basic is to suggest that rather than framing autism as a social deficit within the autistic mind, that breakdowns in interaction are more to do with a mismatch of salience (what is perceived as meaningful and important within a given context) and interactional expertise (or 'know-how'). Problems in empathy being a 'two-way street' have been commented upon since the origins of autistic activism, yet recently research from a range of disciplines have been furthering understanding of such interactional issues. Similarly, work in the area of monotropism or an 'interest model' of autism is finally getting some needed attention (see Murray, 2019), along with recent discussions on how these ideas intersect with neuroscientific concepts such as predictive coding. Working collaboratively, however difficult that may be is the only way such work has been able to flourish at all, plus such efforts increase mutual interactional expertise.

Effort toward promoting a participatory agenda within autism research has not been without success. The 'Future Made Together' report (Pellicano et al. 2013) examined the spread of autism research within the UK and beyond and the priorities of various stakeholder groups. Needless to say; there was a disparity regarding the aims and objectives of research. Not perhaps in the reduction of basic science, but with the need to increase funding into more participatory and social research with everyday impact. Following on from the 'Future Made Together' report came the ESRC funded 'Shaping Autism Research UK' seminar series (see Fletcher-Watson et al. 2018). This series looked to bring together autistic people with academics, family members and practitioners. Perhaps unsurprisingly the topic of participation was high on the agenda and was also one of the planned seminar themes. Preceding these developments there were events and meetings on the subject led by autistic-led groups. I also currently chair an open network called the Participatory Autism Research Collective or 'PARC' (www.PARCautism.co.uk). The PARC group was set up in 2015 initially at London South Bank University (LSBU) but has grown to be a network with international interest. This network was set up for those who wish to see more significant input from autistic people in

autism research could share their work, to reduce the isolation of autistic people in academia, and raise the profile of participatory approaches (Milton et al. 2019).

“Traditional methods of consulting and working in partnership may not always be effective, and new avenues for connection may need to be sought, however when collaborative ventures are pursued, and when people on the autism spectrum feel included and empowered, the ability to live as one chooses greatly increases.” (Milton, 2014).

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