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The future I'd like to see.

National Autism Project.

Dr. Damian E M Milton

<http://nationalautismproject.org.uk/the-future-id-like-to-see-dr-damian-milton>

I originally became involved in the National Autism Project as support for Dr. Dinah Murray's involvement in the project strategy board and then as a member of the Project's autistic advisory panel. As an autistic academic and father to an autistic son, the recommendations that come from such reports and how they are interpreted and acted upon are of great personal importance. The report highlights many of the issues faced by autistic people and their families, and offers some wise areas for investment, including in research. Of particular relevance are the four core principles of the National Autism Project: personalised actions, choice and control, addressing inequalities, and a life-long perspective.

The previous commentary from Dame Steve Shirley rightly indicates the need for greater investment in research. However, controversies will remain as to what interventions should be aiming for, and how one should go about measuring the consequences of such interventions. In the previous commentary from Jude Ragan, both the what, why and how of educational interventions was called into question and practical alternatives offered. These debates need to be broad and inclusive and place the views of autistic people and their families in a central position.

In 2013, the 'A Future Made Together' report (Pellicano et al. 2013) was released which surveyed current research in the UK in the field of autism and asked autistic people, family members, and practitioners to comment on current research priorities. This report highlighted both the need for more participatory research with autistic people and families, but also a dearth of research into social issues and service provision, the areas often strongly highlighted as in need of more research. This report led on to the 'Shaping Autism Research UK' seminar series (<http://www.shapingautismresearch.co.uk>), in which I was part of the research team that led the series. This series brought together academics (both autistic and non-autistic), autistic non-academics, family members, and practitioners to explore key aspects of autism theory and practice. I co-led seminars on the themes of participation and wellbeing, and it is these areas which I would like to see developed further in autism research in the future.

Many assumptions can be made as to what a 'good outcome' or 'social wellbeing' may look like for an autistic person (Rodogno et al. 2016), often with the autistic person having little choice in such matters, particularly in regard to research objectives. Many researchers assume that such things may come from lessening autistic 'symptoms', yet the accounts of autistic people consistently show this to be a false claim (at least in such a general sense). In addressing autistic wellbeing, a small project I was involved in (Milton and Sims, 2016) suggested that the needs of autistic people in regard to wellbeing were in general terms of 'beings and doings' (Robeyns, 2016), often little different to anyone else, although objective measures can hide more nuanced issues such as social

alienation. What did differ markedly were accounts of the social barriers people faced in navigating everyday life and having autistic enabling environments to fulfil their capabilities, such as gaining and sustaining employment, or other indicators of 'life chances'. Key difficulties highlighted were discrimination and misunderstandings from other people, resultant stigma and social isolation, whilst, recognition and understanding of one's need and positive social connections were key to improving feelings of wellbeing. This would suggest that along with increasing research spending, we also need to look at the framing of research questions.

Recently, the James Lind Alliance published findings from a stakeholder consultation exercise to list the top ten priorities for autism research. First on this list was looking at ways to help the mental health of autistic people. This is but one example of how for too long research and practice have focussed primarily on interventions concerning change by the individual autistic person, rather than wider social change. Often interventions are not person-centred or even adjusted for autistic sensibilities generally, and do not attend enough to the social dynamics that autistic people find themselves in. It should not take a sociologist to figure out that high rates of self-harm and suicide within a population are suggestive of a social issue, likely social isolation and marginalisation.

In my PhD thesis, I examined the tensions and common ground in educational priorities for autistic children, between and within stakeholder groups (Milton, 2016). These findings found that whilst autistic people often held a radical and critical view of educational practices and the need for a more pupil and interest led approach, non-autistic parents often held a more remedial view. When looking deeper at some of the reasoning for this difference however, it was not that these parents wished to 'normalise' their children, but rather build resilience in their children in the face of an unforgiving world and a lack of services. In order for tensions and controversies to be reduced and common ground to expand, such a deeper understanding and communication is needed for all concerned.

There are many gaps in knowledge and service provision that adequately meets the needs of autistic people and their families. In many cases this can lead to horrendous consequences (see Milton, 2014). Therefore, the future I would like to see is one where autism is not neglected in terms of research, but where research, and the practice that it helps inform, is fully involving autistic people in its design and delivery. To this end, I am chairing a network of autistic people and early career researchers (autistic or not) involved in such work and wanting to share ideas and promote such practices called the 'Participatory Autism Research Collective' or 'PARC' for short (PARCautism.co.uk). This group has managed to hold meetings and events, be involved in research projects and publications, but is only just beginning to potentially attract a small amount of funds. It is projects such as this which need to be fully supported and funded as we move forward. Such work needs to have an impact on policy and practice however, in order to see real social and cultural change, and where instead of working against a person's 'autism', practitioners can work with autistic people and their families with mutual respect.

References

Milton, D. (2014) Moments in time

Milton, D. (2016) Educational discourse and the autistic student: a study using Q-sort methodology [doctoral thesis]. Birmingham: University of Birmingham

Milton, D. and Sims, T. (2016) How is a sense of well-being and belonging constructed in the accounts of autistic adults. *Disability and Society*, Vol. 31(4): 520-534

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

Robeyns, I. (2016) Conceptualising well-being for autistic persons, *Journal of Medical Ethics*, Vol. 42: 383-390

Rodogno, R., Krause-Jansen, K. and Ashcroft, R. (2016) 'Autism and the good life': a new approach to the study of well-being, *Journal of Medical Ethics*, Vol. 42: 401-408

Participatory Autism Research Collective (PARC)

Shaping Autism Research UK