

## Autistics speak but are they heard?

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### ABSTRACT

In this article, we argue that the exclusion of autistic people from meaningful involvement in research is both ethically and epistemologically problematic, and constitutes a significant barrier to research impact. By the term 'meaningful', we refer to the inclusion of different autistic voices not merely as sources of empirical material, but as active participants in the production of knowledge on autism. We discuss two trends in research that are of concern: firstly, the failure to explore and engage fully with the lived experiences of participants in social research; secondly, imposition of problematic narratives on autistic experiences, linked to partial or complete absence of engagement with the diverse work of autistic authors. We conclude by pointing to some contemporary developments and intellectual exchanges that serve as exemplars which increase the ethical and epistemological integrity of research on the lived experiences of autistic people.

**Keywords:** Autism, participation, wellbeing, exclusion, research ethics.

### INTRODUCTION

The majority of published research in autism has emerged from areas allied to clinical practice; a consequence of which has been an almost exclusive focus on the condition as involving only deficits. While there are indications (Baron-Cohen et al., 2009; Mottron et al., 2006), that this is beginning to change - and that an appreciation of autism as involving a range of potential strengths and limitations is emerging - the view that still dominates mainstream research is that of autism as consisting exclusively of deficit. This has a range of implications: one of which is the exclusion of autistic voices from processes of knowledge production. We argue that this produces ethical and epistemological problems that are interrelated, such as the tendency to pathologise behaviours that may be seen as 'bizarre' or 'strange' to the observer without exploring their subjective rationale. In addition, there is also a lack of exploration of variation and contingency in the lives of autistic people (in particular adults), which stifles the development of more ecologically grounded understandings of autistic people's lives. However, some emerging developments in research participation may help overcome these limitations, and these are discussed in the final section of the paper.

### Framing Autism

Autism Spectrum Conditions are commonly understood as involving difficulties in social communication, social interaction, and social imagination (Baron-Cohen, 2008, 1; NAS, 2011). Social communication difficulties can include problems with facial expressions and body language, or with conveying implicit meaning in written or spoken language (Baron-Cohen, 2008, 58). Many autistic people also experience the world differently from non-autistic people, in terms of their sensory and perceptual experiences of, for example, light

levels or patterns, sounds, particular smells, colours, textures or tastes (Bogdashina, 2003, 44-83). This can affect the quality and/or intensity of what is experienced, resulting in hyper/hyposensitivities (i.e. a more or less intense experience of stimuli than the range typical in non-AS people), that tend to be multimodal (i.e. taking different experiential forms and occurring in different sense domains) and pervasive) (Kern et al., 2006; Klintwall et al., 2011; Leekam et al., 2007; Samson et al., 2011; Tomchek & Dunn, 2007).

How autism manifests can vary significantly between individuals and this is socially mediated, via a process of constant interaction with changing environments. For example, even within a setting where an annoying sound is present, a person may be able to persevere in their intended actions, if the social environment is conducive and/or their awareness is directed significantly away from the noise (Bogdashina, 2001, 4-7). However, if the social context and/or environment presents other issues, perhaps sensory (for example, too many sounds or lights) or social (for example, anxiety in the presence of unfamiliar company) then this can affect a person's threshold of tolerance (Bogdashina, 2001, 4-7). While problems with social and environmental aspects of the everyday world are common features of life for people on the spectrum, 'being autistic' should not be framed purely through a deficit model lens (Baron-Cohen et al., 2009; Gernsbacher et al., 2006; Milton, 2012). Indeed, there is evidence that autistics routinely outperform non-autistics in a range of perceptual, reasoning and comprehension tasks. However, these appear less likely to be reported, or are reported as further evidence of deficit rather than an associated strength (Dawson et al., 2007; Gernsbacher et al., 2006). Conversely, for many people, autistic experiences are central to their wellbeing and sense of self, and social and cultural constraints mediate the extent to which they can freely experience these ways of being (Gernsbacher et al., 2006; Milton & Moon, 2012a; Milton, 2012). This is not to argue that AS-related differences are reducible to either social or cultural factors; rather to emphasise that individual experiences of 'being AS' are inextricably linked to the conditions in which lives are lived (Molloy & Vasil, 2004).

Despite evidence in the autistic population of a range of neurodevelopmental differences when they are compared with non-autistics (Schroeder et al., 2010), autism remains a condition that is defined and diagnosed through observation. There exists no definitive account of its development, and current research points away from a single 'cause' towards a range of potential neurodevelopmental differences (Happé et al., 2006) - to say nothing of variations in social and cultural circumstances in which autistic people live. Hacking (1999) frames Autism in terms of an interface between biology and culture, where factors relating to each domain are necessary but not sufficient to explain or even define observed differences between autistic and non-autistic people. Further, he argues that, in autism, biological factors appear to interact with classifications through social processes, giving rise to what he terms an 'interactive' phenomenon (Hacking, 1999). Classifying an object as a table does not change anything about its material properties (Hacking refers to this as a 'flat effect' that is unchanging). However, classifying human beings can alter both the conceptual and material conditions of what is observed, which can then, in turn, affect classifications, through what Hacking (1999) terms a 'looping effect'. For example, he observes that variations in institutional and interactive responses to those classified as 'autistic' can change the context in which features identified with autism may arise (Hacking, 1999). Setting up AS as a generalised deficit in sociality, for example, may frame social encounters with people categorised in such a way that breaches in interactions become more visible or more likely (e.g. in programs of therapy, support services, or changes to educational, study and workplace environments).

### **Exclusion and marginalisation of autistic voices – historical and contemporary examples**

Given these conditions, distributions of power and opportunities to speak in the process of knowledge production on autism matter very much in terms of how it is understood, and how autistic people are seen and treated by non-autistic others.

*...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).*

Talking about autism was, for many years after its emergence in the work of Leo Kanner (Feinstein, 2010; Grinker, 2008), the exclusive preserve of clinicians and researchers, where autistic people were objects of inspection, rather than active participants in the creation of knowledge relating to their own experiences. While the emergence of self-advocacy movements and the entrance of academically-trained autistic researchers into knowledge production has begun to challenge these conditions (for example: Arnold, 2010; Dawson et al., 2007; Graby, 2012; Milton, 2012; Murray et al., 2005), these tend to be the exception.

Obtaining the views of disabled people is now a requirement of policy legislation, both nationally and internationally (Pellicano & Stears, 2011; U.N., 2006). Yet this remains tokenistic when policies and research concerning people with a particular disability fail to include them in a meaningful way in agenda setting in both research and service provision. Such a situation is reflected in the lack of involvement and representation that autistic people have in organisations with stated aims that include the support of autistic people (Milton et al., 2012). In particular, the experiences and needs of autistic adults are often poorly understood by service providers, and the experiences of adults are under-researched (Allard, 2009; Rosenblatt, 2008). Financial pressures may, of course, play a role in this, as Ne'eman observes:

*Of over \$314 million in research funding, only 3% went to research into services, support and education and less than 1% went to research into the needs of adults (Ne'eman, 2011).*

Consequently, research does not address the conflict between the groundswell of autistic voices and efforts of self-advocacy, on the one hand, and those espousing a discourse of deficiency and dependency on the other (Milton et al., 2012). Although many within the autistic community have adopted the political slogan of: 'Nothing about us, without us' (for example: ASAN, 2013), research in autism continues to silence autistic voices within knowledge production, also side-lining potential valuable insights from research that engages with lived experiences. Failure to acknowledge and explore the different personal and social conditions in which autistic people live and implications for their wellbeing is therefore a significant barrier to impact in contemporary research.

The answer does not lie simply in funding research that engages with lived experience (although this is undoubtedly an important issue), but there is a need to explore how autistic people can be involved as participants in the processes of knowledge production. All too often, autistic participant contributions to social research are quarantined beneath what we refer to as a 'glass subheading', treated only as empirical material for inspection and analysis by non-autistic researchers, and thus opportunities for mutual reflection and exploration are missed. This is significant because it means that understandings of wellbeing - what makes life liveable and everyday worlds inhabitable for different autistic people - are framed by third-person observers. For example, Jennes-Coussens et al. (2006) explored the quality of life of 12 young AS men aged 18-21 through measures based upon the World Health Organisation's Quality of Life measure, with little discussion of how these factors

might play out within the lives of specific participants. The authors claim at one point that 'results [relating to satisfaction with physical health] may relate to clumsiness of movements or to sensory hypersensitivity' (Jennes-Coussens et al., 2006, 410). However, they do not appear to have followed up on this point with participants in their semi-structured interviews, limiting the specificity and scope of this claim. In Lawrence et al.'s (2010) investigation of the transition to adulthood, the authors' use of Maslow's hierarchy of needs to frame important areas limits their engagement with first person narratives in their review of literature. While they emphasise 'self-actualisation' as important for maintaining quality of life, they give no examples of how this might be achieved by specific people, nor do they discuss what this might mean for different autistic people in different contexts. Elsewhere, Portway and Johnson (2005) explored the 'risks of a non-obvious disability' for adults diagnosed with Asperger Syndrome. Here the unqualified description of the behaviours of their participants as 'odd' or bizarre' means that they neglect to explore the potential meaning or significance of these activities as legitimate and valued experiences, or as important strategies for coping with social and/or sensory issues (2005, 80).

The failure to engage fully with first-person experiences in exploring the lives of autistic people is both ethically and epistemologically significant in the context of contemporary research, because wellbeing does not simply mean the absence of difficulty, but also the ability for individuals to be involved in their communities, and to pursue happiness, as underscored by the World Health Organisation's (WHO) definition of 'mental health':

*Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community (WHO, 2011).*

In the case of autistic people, wellbeing also relates to a person's ability to experience ways of being that are compatible with their dispositions, without being forced to mimic non-autistic behaviours that can be confusing or bewildering to them (Bogdashina, 2001; Milton, 2012). It is known that autistic people - in particular adults - suffer high levels of social isolation, unemployment, and economic difficulties, as well as physical and mental ill health, and that this is attended by variable and often poor understanding of their needs (Allard, 2009; Rosenblatt, 2008). Therefore, it is crucial that researchers explore the subjective significance of AS related experiences in relation to wellbeing, as this may not be immediately apparent to non-AS observers.

### **Imposing narratives – ethical and epistemological consequences of dis/engagement with autistic authors**

Another worrying aspect of some academic publications that are positioned within or draw on theoretical and methodological resources from social science, is the imposition of narratives that produce a distorted picture of life experience - in part due to a failure to engage with the writings of autistic people. In their book *The Myth of Autism*, Timimi et al. (2010) argue that the changing history of the autism spectrum, and failure to provide clear etiological explanations indicates that the diagnostic label is of no scientific, clinical or social value, and should therefore be abolished. They claim that this would be a desirable outcome for those currently diagnosed as being on the spectrum - a bold step for which they provide worryingly little evidence or discussion in terms of concrete ethical implications (Bracher & Thackray, 2012). More troubling in the context of the present discussion, however, is the authors' failure to engage with a diversity of accounts of experience from autistic people themselves. This is problematic not only in epistemological terms, but also ethically. Much of the existing writing from autistic authors is critical of current diagnostic categories; something

which casts further doubt on the ethical and intellectual integrity of many contemporary arguments.

Where autistic voices have been integrated into discussions by non-autistic academics, these tend to involve problematic interpretations of the source material, an example of which comes from Ruud Hendriks' (2012) *Autistic Company*. In this book, Hendriks explores how autistic and non-autistic people navigate a shared existence, and considers how one can talk about the unusual forms of interaction that take place (Hendriks, 2012). In so doing, the author approaches a topic not only of paramount importance within the field of autism studies, but also medical sociology more generally, in terms of how to build interactions and relationships with neurodiverse populations (Hendriks, 2012). His main focus is on the forms of living that autistic and non-autistic people establish together, and he suggests that the metaphors commonly used to describe autistic people underestimate commonalities; that dispositional differences are not irreconcilable extremes (Hendriks, 2012). Here, the reason for autistic people being outsiders in society is formulated as a lack of insight in context-related meaning. Hendriks concludes that a shared existence is dependent on the widening of companionship to include physical as well as mental connections (Hendriks, 2012).

However, Hendriks' selective engagement with the works of autistic authors leads to some highly questionable suggestions. For example, he suggests that a stimulus-free and controlling environment is the only way to help autistic people connect with others, and that 'leaving autistic people alone' will lead to them becoming lost in the world (Hendriks, 2012). This reifies behaviourist modification techniques to stimulate 'normal development' and reduce 'autistic behaviour' - techniques that are highly criticised by some autistic self-advocates (Dawson, 2004; Milton & Moon, 2012b). While one would not recommend neglect for any child, building reciprocity requires mutuality of understanding rather than the one-sided imposition that Hendriks appears to advocate. As Ryan and Räisänen (2008) have observed, autistics are often very aware of the conditions of life 'over there' in the non-autistic world; and in a way that is not often reciprocated. Elsewhere, Ochs and Solomon (2010) have indicated that adjustments in dispositional alignments in parent/child interactions can help to alleviate some of the difficulties inherent in autistic/non-autistic interactions.

Hendriks asks how to prevent a non-autistic interpretation from 'gaining the upper hand after all' (Hendriks, 2012, 149). Co-researching and co-writing with an autistic writer or scholar might provide a useful starting point. If interactional expertise is to be gained, it is essential that normative assumptions and impositions of non-autistic meanings are deconstructed. Instead, Hendriks' examination of autistic autobiographies ends up being an exercise in 'quote-mining' to fit the claims being made; claims that are often critiqued by some of the authors cited by Hendriks (such as Sinclair and Baggs) (Hendriks, 2012, 18-19, 149-150, 178). Despite seeking to position his research in the disability studies literature (Arnold, 2010; Goodley, 2011; Meekosha et al., 2013), Hendriks is not attuned to the anti-normative stance that characterises this body of work and end up working against the activist rallying cry of 'nothing about us, without us'. Indeed, if Hendriks' conceptualisations were valid, the social awareness required in order to enable collaboration between the autistic and non-autistic authors of the current paper could not have been achieved.

### **Possible alternatives**

Despite the prevalence of exclusion in contemporary research, examples of good practice do exist, such as the *Autism Asperger Partnership in Research and Education (AASPIRE)* - a group that carries out research projects in collaboration with academic communities, 'relevant to the needs of adults on the spectrum' (Nicolaidis et al., 2011; Nicolaidis et al.,

2012). This group advocates the use of 'community based participatory research' or 'participatory action research', where autistic people engage as equal partners throughout the research process (Nicolaidis et al., 2011; Nicolaidis et al., 2012). Some of the principles of this style of research are: to build on the strengths and resources of the community; to facilitate co-learning and 'capacity' building between participant; and to disseminate results to all partners. Parallel aspirations have been expressed by the autistic community in Britain: for example, the 'Autescape' conference in 2011 included a presentation concerning the 'owning' of autism research, providing advice with regard to how research is carried out and highlighting challenges to address when considering participation (Autescape, 2011; Kalen, 2011). More recently, an autistic run academic journal (Autonomy, 2013) has been established, and a project - entitled 'Theorising Autism' (Milton & Moon, 2012b) - has been set up with the aim of bringing autistic academics together, in order to bolster collaborative efforts.

Meanwhile the agenda of the majority of autism research continues to be dominated by concerns relating to finding a 'cause', normalisation through behavioural modification, and 'hopes of a cure', - wrapped in a rhetoric of 'scientifically supportable evidence-based practice' (Post et al. 2012). In order for there to be a significant shift in the research agenda, the silencing of autistic voices and tokenistic practices must be replaced by meaningful involvement of autistic people in understanding autism – including (but not limited to) the employment of appropriately trained autistic people in research teams. With such involvement, the research agenda would be broadened, rapport with research participants might improve, dissemination of findings would be less offensive to the autistic community, and autistic people would be less alienated from knowledge produced in the field. Crucially, such developments would increase the epistemological integrity of studies that seek to explore important questions relating to the wellbeing of autistic people.

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