

Inside Out Conference: Speaker biographies and talk abstracts

#InsideOutAutism #PlayingApart

Thursday 4th July

10:30 – 11:30 Aphra Theatre

Welcome & Presentations

Dr Damian Milton and Dr Schaubroeck

Chaired by Dr Shaun May

Dr Damian Milton

Damian works part-time for the Tizard Centre, University of Kent as a Lecturer in Intellectual and Developmental Disabilities and for the National Autistic Society (NAS) as Autism Knowledge and Expertise Consultant. Damian also teaches on the MA Education (Autism) programme at London South Bank University and has been a consultant for the Transform Autism Education (TAE) project and a number of projects for the Autism Education Trust (AET). Damian's interest in autism began when his son was diagnosed in 2005 as autistic at the age of two. Damian was also diagnosed with Asperger's in 2009 at the age of thirty-six. Damian's primary focus is on increasing the meaningful participation of autistic people and people with learning disabilities in the research process and chairs the Participatory Autism Research Collective (PARC).

Participatory research: perspectives, issues and ethics

Traditionally autistic people have been treated as research 'subjects'. More recently however autistic scholars have become engaged in researching autism, alongside calls for greater participation generally. Rather than being a prescribed set of conventions, participatory research is presented here as an ethos, or an ideal to work toward. Covering a wide range of theoretical and methodological approaches, the main objective of participatory research is to cede power to the research participants from research design to the interpretation of findings. Such an ethos is essential to answer calls by autistic activists of 'nothing about us, without us', but also comes with associated difficulties. Reflecting upon projects such as Shaping Autism Research UK and the Participatory Autism Research Collective (PARC), this presentation will contextualise participatory research as complementary to the goals of autistic advocacy and the neurodiversity movement, review the research priorities of autistic people, as well as highlighting the difficulties associated with trying to implement participatory ideals, and practical advice for increasing the participation of autistic people in research.

Dr Katrien Schaubroeck

Katrien Schaubroeck is senior lecturer at the Philosophy Department of the University of Antwerp. Her research interests are in moral psychology and meta-ethics, with publications on love, rationality and moral responsibility. She co-authored with Kristien Hens and Ingrid Robeyns 'The ethics of Autism' (Philosophy Compass, 2019).

Philosophers on autism: problems with empathy and knowledge

Drawing on collaborative work with members of the Autism Ethics Network I will explain two moral problems with standard ways in which autistic people are said to lack some or other capacity. First, they are often described as having a defective theory of mind, therefore a defective capacity for empathy. Second, their epistemic authority is questioned on the grounds of attributed difficulties in mental state attribution. These views of autism are to be found in various sources, including philosophical discussions on social cognition and self-knowledge. Both views have strong implications with regard to the moral responsibility and the credibility of autistic individuals. There is therefore all the more reason to scrutinize these views and be sceptical of their unreflected distribution. I will point to resources in philosophical discussions on social cognition and self-knowledge that support this scepticism and that pave the way for a more inclusive and accurate reflection on autism in philosophy.

12:30– 13:30 Lumley

Panel 1: Researching Differently

Dr Helen Kara, Dr Laura Crane and Professor Jonathan Green

Chaired by Dr Hannah Newman

Dr Helen Kara

Dr Helen Kara has been an independent researcher since 1999 and writes and teaches on research methods. She is the author of *Creative Research Methods in the Social Sciences: A Practical Guide* (Policy Press, 2015). She is not, and never has been, an academic, though she has learned to speak the language. In 2015 Helen was the first fully independent researcher to be conferred as a Fellow of the Academy of Social Sciences. She is also a Visiting Fellow at the UK's National Centre for Research Methods. Her latest book is *Research Ethics in the Real World: Euro-Western and Indigenous Perspectives* (Policy Press, 2018).

Title: A critique of participatory research

Dr Laura Crane

Laura Crane is an Associate Professor at the Centre for Research in Autism and Education (at UCL Institute of Education), where she holds the role of Acting Director. At CRAE, Laura's research focuses on supporting autistic people in the fields of education, healthcare and criminal justice. Laura is a strong advocate of community engagement in research, for which she was awarded a UCL Provost's Prize for Public Engagement (2018), the UK research charity Autistica's inaugural Community Engagement Award (2018) and a British Academy Rising Star Engagement Award (2017). Laura is on the steering group of UCL's new Centre for Co-Production in Health Research, is Chair of the Pan London Autism Schools Network Research Group (fostering partnerships between specialist autism schools and academic researchers) and also serves as Social Media Editor at *Autism: The International Journal of Research and Practice*, where she leads all community engagement initiatives (e.g., podcasts, lay abstracts, social media) at the journal.

In the autism research field, there is growing recognition of the need to conduct research 'with', as opposed to 'on', 'about' or 'for', autistic people and their families (see Pellicano, Charman & Dinsmore, 2014). Despite calls for greater autistic participation in research (e.g., Fletcher-Watson et al., 2018), there is much uncertainty regarding the practicalities and utility of such an approach. In this talk, Laura will discuss how the Centre for Research in Autism and Education (CRAE) strive to adopt participatory approaches within their research, in terms of dissemination (telling people about research), dialogue (engaging in two-way discussions about research) and partnership (shifting the power balance of research).

Professor Jonathan Green

Jonathan Green is *Professor of Child & Adolescent Psychiatry at the University of Manchester and Honorary Consultant Child and Adolescent Psychiatrist at the Royal Manchester Children's Hospital.*

Jonathan trained in Medicine at Cambridge, Paediatrics in London and Psychiatry in Oxford before coming to Manchester and establishing his clinical and academic teams. He has a long standing clinical and research interests in autism and other aspects of social development in children. Clinically, he runs a regional specialist Social Development Clinic at the Royal Manchester Children's Hospital, which undertakes assessment and treatment innovation with ASD and other impairments of social development in children.

Jonathan has developed and tested, with colleagues, interventions that work with parents of children with autism to help their development. He has led a number of prominent international treatment trials in Autism in the last 15 years. These include the MRC Preschool Autism Communication Trial (PACT), the first to show a sustained impact of intervention over 6 years after the end of treatment. He also led the first randomised pre-emptive trial of intervention for infants at high likelihood of developing ASD, showing sustained impact of the intervention over 2 years. PACT intervention is being taught in 12 countries to date and is the first evidenced autism intervention to have been specifically adapted and tested in a low-income context in South Asia using non-specialist therapy workers.

Jonathan was part of the UK NICE guideline group for autism treatments and on an MRC methodology research group into process and causal analysis in clinical trials. He is a National Institute for Health Research Senior Investigator.

Website and Contact – jonathan.green@manchester.ac.uk
<http://research.bmh.manchester.ac.uk/socialdevelopment/>

Autism, intersubjectivity and relatedness

I begin from the idea of autism development as individual difference within the broader context of neurodiversity. Given this, the development of autistic children (like all development) happens in transaction with their environment; I think that understanding these two-way transactions gives us a good way into making sense of strengths, difficulties and possibilities for intervention....

This approach is relevant at any age; it links in my mind to Damian Milton's idea of the 'double empathy' problem.

The intervention work I've done with young children with autism and their parents is based on this idea. It deals with early transactions in the family and education; its goal is to give the autistic children the best possible experience of early social reciprocity and relatedness in the context of ordinary development. Partly I hope this will improve their later sense of well-being and emotional connectedness; also it may reduce their social difficulties in development, and we have some evidence for that.

In addition, this kind of early transaction links to the experience of inter-subjectivity. Inter-subjectivity has many dimensions – from lived experience of thinking and feeling with others, to entrained synchrony at the neuroscience level.

It also links to how neuro-typical clinicians and researchers (and research methods) can relate authentically and creatively to neuro-diverse experiences. How do we need to adapt to best understand each other and work together?"

15:30 – 16:30 Aphra Theatre

Panel 2: Exploring an Interest Model of Mind

Dr Damian Milton, Dr Dinah Murray, Jo Bervoets and Dr Philip Barnard

Dr Damian Milton

For Bio see above

In workshops recently held in Edinburgh, Glasgow and London, autistic scholars have been meeting with neuroscientists and other researchers to explore the potential links between theories such as monotropism (an interest model of mind) and the double empathy problem with work in cognitive neuroscience, particularly in regard to embodied cognition, predictive coding and related concepts. This panel brings together a wide range of speakers whose work can help build further connections and debates regarding fundamental questions in autism research.

Dr Dinah Murray

Dinah Murray is an independent researcher with a PhD on the topic of Language and Interests (1986); a campaigner and a former support worker for people with varied learning disabilities including autism. The PhD was the basis of an interest account of mind using ecological modelling of interest/ attention as a scarce resource.

She first published about autism with "Attention tunnels and Autism" in 1992, a conference paper, and most recently in Monotropism, an interest based account of autism in ed Volkmar, 2018. Dinah's autism-related research interests have included the nature of the human being, with a particular focus on the distinctive pattern of interests in autism. She has been assessed as autistic, and if growing up today would certainly have attracted an autism diagnosis.

Dinah Murray's talk will be a lightning survey of the concept of interest from the micro in the light of predictive processing's parallels with the interest model, to the macro, in the light of thinkers from Rousseau to Thunberg via Marx.

The ecological model of interests developed by Murray with Mike Lesser in the 90s nicely fits with recent predictive coding (see especially Friston, Parr & deVries, 2017). We propose that the long recognised intensity of autistic interests, and the extremely uneven skills profiles, follow from an energy or attention distribution that can be roughly summed up in terms of expressive contribution of more to the current interest, less to orthogonal ones.

Jo Bervoets

Affiliations: University of Antwerp/Katholieke Universiteit Leuven/Autism Ethics Network

Jo Bervoets holds Masters in Philosophy, in Artificial Intelligence (Cognitive Sciences) and in Sciences (Electronic Engineering). He worked for 25 years in the technology sector, as engineering and product manager. After a burn-out, Jo was formally diagnosed with autism in 2017. To get back on track he pursued his lifelong obsession with philosophy studying it at the University of Antwerp. Jo graduated in 2018 summa cum laude writing his thesis on the moral implications of asking “What is autism?”. This allowed him to make a fresh start as a full-time PhD researcher in the ERC project “NeuroEpigenEthics” focusing on Tourette Syndrome. Jo presented his autism research at various conferences and he co-authored a paper on the autistic self. Jo actively contributes to the Autism Ethics Network, is scientific collaborator of the Brain & Cognition lab in Leuven and founded “LAVA”, a group of autistic adults promoting participatory autism research in Flanders.

Beyond the Catch-22 of autism research and diagnosis.

Autism research seems stuck between the essentialist exact sciences treatments of it and human sciences social constructionist readings of it. At the same time autistic people try to construe autism as a positive practical identity under the umbrella of neurodiversity whilst the public continues to see it mainly as a psychiatric disorder. The Catch-22 of diagnosis is nowhere more apparent than in the DSM-5 requiring dysfunctioning as criterion for autism diagnosis. This talk proposes to go beyond these binary categorizations by keeping focus first and foremost on *understanding* the lived experience of autistic people.

Dr Philip Barnard

Philip Barnard is a retired cognitive psychologist and Honorary Member of the MRC’s Cognition and Brain Sciences Unit, University of Cambridge, UK. His long-term research programme focused on theorizing about how memory, attention, language, body states and emotion all work together. He developed Interacting Cognitive Subsystems (ICS) as a conceptual framework for understanding normal and dysfunctional cognitive–affective relationships and their modification. ICS has been applied to depression, schizophrenia and eating disorders. He has collaborated with choreographer Wayne McGregor and arts researcher Scott deLahunta to develop productive and applicable synergies between choreographic processes and our knowledge of cognitive neuroscience (Wellcome Trust ‘Thinking with the Body’ Exhibition, 2013). He is the coauthor with John Teasdale of *Affect, Cognition and Change: Re-modelling Depressive Thought* (1993); co-edited with Nicola Shaughnessy *Performing Psychologies: Imagination, Creativity and Dramas of the*

Mind. He has written numerous papers for a wide range of science and humanities journals.

Paying attention to meanings about the self, the world and others in atypical ways

The architecture of the human mind enables us to pay attention, not just to the physical and social world around us but also to visual and auditory verbal images in the mind's eye and ear. We can also selectively attend to meanings – ideas, interests and feelings. We learn how to pay attention to meanings and develop attentional habits of mind that govern not just what we think but how we think it over time. One useful analogy is with musical scores that indicate what should be played and how it should be played. I work with an architecture of mind that argues that we humans have two mental meaning systems – one conceptual (called *Propositional* meanings) and one that integrates conceptual meanings with the products of immediate visual and auditory perception *and* embodied feelings (called *Implicational* meanings). People who ruminate in depressed states have habits of mind or *attentional scores* with particular properties that, alongside negative mental models of self, can adversely impact their day-to-day intellectual and social functioning. I have argued that internal mental dialogues between the two meaning systems are typified by *attentional scores* that pay too little attention to *Implicational meanings* and any personal discrepancies they encapsulate. Here I will briefly examine the conjecture that autism could be linked to specific early challenges in the formation of *Implicational meanings* and, over a developmental time course, lead to atypical meaning systems and rich varieties of *attentional scores* for managing them.