

AUTISM

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Summer Newsletter

Welcome to the summer 2017 edition of the autism@manchester newsletter. In this edition you will find:

- Summaries of the findings of recent autism research studies (pages 4-9)
- An interview with the autism@manchester chair, Dr Emma Gowen (pages 10-13)
- Details of opportunities to take part in research (page 14)

For more information about our research community visit:

<http://www.autism.manchester.ac.uk/>

NEWS

PACT- G awarded

Professor Jonathan Green and the team conducting the PACT-G study were the winners of the 'Outstanding Benefit to Society Through Research' award for their work on the early parent-mediated communication intervention for autism at the [Making a Difference for Social Responsibility awards ceremony](#). The team were also winners for 'Outstanding Innovation' at the SEE Changemaker Recognition Awards 2017 held at the University of Oxford.



Dr Catherine Aldred, Olivia Mitchell & Dr Shruti Garg (left to right) collecting the Outstanding Benefit to Society award from the University of Manchester chancellor Lemn Sissay

Grant success

The [Time Perception lab](#) and [The Body Eyes and Movement lab](#) in the Division of Neuroscience and Experimental Psychology have been awarded a three year grant from the Economic and Social Research Council. This is an exciting project investigating the perception, experience and understanding of time in Autism. Dr Emma Gowen and Dr Daniel Poole will be working on this project.

Grant success (continued)

Dr Emma Gowen was also awarded an National Institute for Health Research award to contribute towards the further development of the autism@manchester expert by experience group. This is an advisory group to help researchers to consider the perspectives of autistic people and their families when planning research studies.

Autism awareness week

Members of autism@manchester attended the Autism Conference 2017 at Salford Quays which coincided with autism awareness week. Peter Baimbridge and Dr Jo Bromley presented at the event. Dr Daniel Poole, Martin Casassus and Andrius Vabalus ran a stall with Professor Tony Long (University of Salford) raising awareness of autism research in Greater Manchester and the work of SalfordAutism



Public engagement at the Autism Conference 2017, Salford

International Meeting for Autism Research

The [International Meeting for Autism Research](#) (or IMFAR) is the major global scientific meeting for the dissemination of autism research held each May. This year, IMFAR was held in San Francisco, USA. Professor Jonathan Green and members of the [Social Development Research Group](#) presented 3 oral, 2 poster presentations and 1 press release.

Publications

Fayette & Bond (2017) A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences.

European Journal Of Special Needs Education.

Garg et al. (2017) Autism spectrum disorder and other neurobehavioral comorbidities in rare disorders of the Ras/MAPK pathway. *Developmental Medicine and Child Neurology*

Green et al. (2017) Randomised trial of a parent-mediated intervention for infants at high risk for autism: longitudinal outcomes to age 3 years. *Journal of Child Psychology and Psychiatry* ([open access](#))

Poole et al. (2017) Similarities in autistic and neurotypical visual-haptic perception when making judgements about conflicting sensory stimuli. *Multisensory Research* ([open access](#))

The Autism Spectrum Disorders Working Group of The Psychiatric Genomics Consortium (2017) Meta-analysis of GWAS of over 16,000 individuals with autism spectrum disorder highlights a novel locus at 10q24.32 and a significant overlap with schizophrenia. *Molecular Autism.* ([open access](#))

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LATEST FINDINGS

PAEDIATRIC AUTISM COMMUNICATION TRIAL – GENERALISED (PACT-G) UPDATE



PACT-G builds on the clinic based PACT therapy which involves working with parents to improve the social communication of preschool children with autism. PACT therapy involves the coaching of caregivers using video-feedback to interact with their child using strategies which facilitate communication development. This approach was found to be very effective in increasing the quality of parental communicative responses to the child, which in turn led to an increase in communications with the parent which were initiated by the child. The original PACT study was one of the [major autism intervention studies](#) to be completed internationally, formed part of the evidence base behind the [NICE guidelines on autism treatment](#) and has received widespread [press coverage](#).

However, children with autism can find it difficult to transfer skills learned in one context into another. Although improvements in social communication were observed in the home, these improvements did not extend to the child's communication with adults outside their family. Moreover, autism is a lifelong, developmental condition and as such, further interventions may be required later in development.

PAEDIATRIC AUTISM COMMUNICATION TRIAL – GENERALISED (PACT-G) UPDATE



PACT-G develops on the effective elements of PACT, but is aimed at children of a wider age range and looks to extend the parent-child therapeutic model to also work in the education setting. The therapy begins with the parents at home and is integrated into everyday routines to assist the generalization of these skills across the home setting. This is later widened so that education staff are included in the training so that the intervention can be continued within the child’s school or nursery.

To examine how effective this intervention is the PACT-G study follows a rigorous methodology. The child’s interactions with their parents or teachers, and a measure of autism symptoms will be taken before, during and after the intervention is administered. This will involve measures across the clinic, home and in education, which allows detailed study of whether the child can generalise the skills across different contexts. As the PACT-G intervention is appropriate for middle childhood the data can be analysed alongside the previous PACT studies to test the impact of the intervention across childhood. It is anticipated that training both parents and education professionals will provide a consistency which will be beneficial to the child and help them use any new skills which are adopted more widely.

Recruitment for the PACT-G study opened in January 2017. There are currently 79 families recruited to the study and the team are working with 64 partner schools. For more information visit the [PACT-G website](#).

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LATEST FINDINGS

THE AUTISTIC COMMUNITY'S OPINIONS AND EXPERIENCES OF RESEARCH



Peter Baimbridge



Thomas Bleazard



Dr Emma Gowen



Dr Anat Greenstein



Dr Daniel Poole

In recent years there has been a marked increase in the amount of published research investigating aspects of autism. However, it has been noted that there is a disconnect between the autistic community and those conducting the research. Autistic adults and their families do not feel engaged in research and feel that research does not focus on the issues which are important to them ([Pellicano, Dinsmore & Charman, 2014](#)).

In January 2016 we arranged a series of workshops in an effort to bridge this gap. These workshops included a number of recorded discussions (called focus groups) with 10 autistic adults and 14 parents of autistic children. A further 13 autistic adults were later recruited at [Autscope](#) (which is a conference for autistic people, organised by autistic people).



The 'Building Bridges' workshop

THE AUTISTIC COMMUNITY'S OPINIONS AND EXPERIENCES OF RESEARCH



Peter Baimbridge



Thomas Bleazard



Dr Emma Gowen



Dr Anat Greenstein



Dr Daniel Poole

Participants in this study indicated that they considered autism research to be something which was important and relevant to their lives. In particular, participants identified research participation as a means of post-diagnosis support, representing an opportunity to learn about themselves and give something back. However, they did not feel that they were able to access the findings of autism research, find out how to take part in research studies, or influence the direction of research. Participants raised a degree of distrust in the motivations of many researchers. The importance of moving beyond a 'medical' understanding of autism and towards an appreciation of the social and cultural experience of being autistic was underlined.

We are currently writing up the findings of this study for publication alongside some of the workshop participants to encourage researchers to explore new ways of improving engagement with the autistic community.

More information about outcomes from the workshops are available on the Autism@Manchester website, including [videos of autistic adults discussing some of their experiences](#).

TRANSITIONS: INVOLVING YOUNG PEOPLE WITH AUTISM IN PLANNING FOR ADULTHOOD



Rainart Fayette



Dr Caroline Bond

Previous studies suggested that poor adult outcomes for individuals with Autism Spectrum Condition (ASC), such as difficulties in gaining employment or lack of independent living skills, are linked to poor experiences during their transition from school to adulthood ([Knapp, Romeo & Beecham, 2009](#)).

According to the Special Educational Needs Code of Practice ([DfE, 2014](#)), students should be involved in planning for their transition to adulthood and should be supported by their parents, school staff and relevant professionals such as careers advisers and/or educational psychologists. However, previous studies have found that pupils with ASC were less likely to actively participate in this process due to barriers such as difficulties in conceptualizing the future ([Beresford et al., 2013](#); [Hewitt, 2011](#)).

This study explored two specialist schools' processes of eliciting the views of young people with ASC when planning for their transition to adulthood. Staff members from both schools who were involved in transition planning were interviewed and a transition to adulthood planning meeting in one of the schools was observed.

TRANSITIONS: INVOLVING YOUNG PEOPLE WITH AUTISM IN PLANNING FOR ADULTHOOD



Rainart Fayette



Dr Caroline Bond

The authors found that both of the schools placed the students at the centre of their planning processes by making sure that they were involved. These processes comprised three phases:

- 1. Getting to know the young people*
- 2. Supporting pupils to make informed choices by explicitly letting them know that they are free to make choices, turning abstract concepts to concrete one and jointly evaluating choices*
- 3. Eliciting the views of the students through their preferred communication media*

This study's findings also indicated that practitioners and researchers must work together to actively promote the belief that eliciting the views of young people is not as an end in itself, but a means to an end of meaningful participation in the decision-making process. Furthermore, the development and delivery of training packages about transitional issues that affect young people with ASC will benefit school staff and relevant professionals who work with young people during their transition. This could be further enhanced by having input from individuals with ASC who have experienced transitioning from school to work placements about the barriers and supports required to effectively improve the transitioning process.

WHO ARE YOU?

My name is Dr Emma Gowen. I am a Senior Lecturer at the University of Manchester and co-director of the Body Eye and Movement lab.

I founded, and am chair of, autism@manchester and have been conducting research in the autism field for 13 years.



My time is divided between research, teaching and administrative duties. I teach on the undergraduate Optometry degree and supervise Undergraduate, Masters and PhD student projects. During an average week, I could be teaching, examining, interviewing, writing papers or grant applications, giving talks, commenting on ethics applications, organising autism@manchester activities, talking to members of the public about my research....it's a very diverse role.

I research how we use sensory information (e.g. vision, touch) to control movements. Performing everyday actions such as eating, walking and typing seems relatively effortless but involves a complicated set of brain processes. You can get an idea of how difficult such control is when we see children learning to walk or pick up objects or when people have a brain injury and can no longer perform simple actions. I am particularly interested in understanding why some autistic people have problems with motor control such as poor eye hand coordination, unusual walking styles and unstable balance.

My husband and I have recently adopted a little boy and my spare time is mainly taken up spending time with them. We like walking, nature watching, getting muddy....

WHO ARE YOU?

WHAT MADE YOU BEGIN RESEARCHING AUTISM?

My first research position following my PhD was at The University of Birmingham studying motor control in autism. Up to that point my research had focussed on eye movements and I had little knowledge about autism. I soon realised that although autism was a vast and complex research field, there was relatively little work on the motor aspects of autism. I decided to stay in this field as there was so much to find out and I also really enjoyed meeting autistic people. I have never been particularly keen on the pressure many of us feel to fit into society norms and talking with autistic people gives me a refreshing sense that difference can be valuable and valued.

HOW WOULD YOU DEFINE THE AUTISM SPECTRUM?

We are all tuned to have a different sensory, motor and cognitive experience of the world around us. For people on the spectrum, their “tuning” may be less well suited for how societies are often organised and presented. This can lead to difficulties in learning how to make sense of the world around us.

IS IT POSSIBLE TO CARRY OUT RESEARCH IN YOUR FIELD WHICH APPLIES TO ALL ASPECTS OF THE AUTISM SPECTRUM?

As autism affects people in many different ways (e.g. sensory issues, digestive problems, difficulties in getting employment, psychological issues such as depression and anxiety...) it would be difficult to carry out research in one particular field that could have implications for all areas of the autism spectrum. Having said that, researching motor difficulties could have wider implications than one might think. For example, poor motor skills are linked to anxiety as well as reduced ability to carry out daily living tasks that allow independence (e.g. eating, dressing, walking about). Good motor skills also support social functioning by facilitating opportunities to participate in social activities and there is now quite a bit of evidence that we use the motor regions in our brain for interpreting and predicting the actions of others.

WHO ARE YOU?

IS IT POSSIBLE TO CARRY OUT RESEARCH IN YOUR FIELD WHICH APPLIES TO ALL ASPECTS OF THE AUTISM SPECTRUM? (continued from page 10)

So, if we can understand why motor difficulties are present in autistic people and come up with some suitable therapies we might be able to help with some aspects of anxiety, independence and social interaction.

HOW VALUABLE DO YOU EXPECT YOUR RESEARCH TO BE TO PEOPLE WITH AUTISM?

As I mentioned previously, it is possible that understanding more about motor issues in autism can have a number of real life implications. However, this type of research can take many years before tangible benefits are seen (such as an actual therapy). In the meantime, by providing small pieces of evidence we can add to the collective weight of knowledge around a theory. This can then be used to make changes. For example, if we can add to the body of evidence suggesting that motor difficulties are a common issue in autism and can contribute to difficulties with social interaction, a case could be made to screen for motor difficulties at diagnosis. We are also working on whether movement patterns can be used to help with the diagnostic process which might be particularly useful for adults where diagnosis can take a long time. Another area, where I hope that I am having immediate benefit is through autism@manchester where we are connecting members of the autistic community to researchers to allow greater involvement of the autism community in the research process. This has included some successful initiatives such as our expert by experience groups, this newsletter and co-authored research papers (where autistic people have contributed to the writing of papers). I hope that people are finding these small steps valuable...!

WHO ARE YOU?

WHAT RESEARCH IDEA WOULD YOU LIKE TO PURSUE IF FUNDING WAS NO BARRIER?

I would love to direct a large project covering a number of questions relating to sensorimotor control in autism. This would include whether movement could be used to screen for autism using very detailed sensors that monitor a wide range of people's movement (e.g. walking, interacting with others, upper body movements). A related but unanswered question is whether the motor difficulties seen in autism are the same as those with developmental coordination disorder or whether autistic people have a unique set of movement difficulties. The study would also look at the use of bespoke movement games (virtual reality games or using devices such as Xbox Kinect) to improve motor control and what impact this might have on social ability and aspects of wellbeing. A further area about which nothing is known is what impact motor difficulties might have on autistic people as they age. We know that falls are a big concern for older people, but if you already have poorer motor skills are you more at risk of falls and associated consequences?

THANK YOU EMMA

If you have any comments on this newsletter, please contact Dr Daniel Poole (daniel.poole@manchester.ac.uk)



Andrius Vabalas

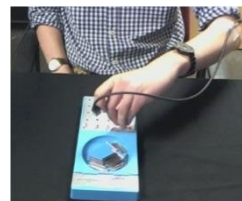
Autism is primarily identified by differences in social and communication ability. However, a substantial body of evidence indicates that motor difficulties such as clumsiness, unstable balance and unusual walking style are also common in autism. Research in motor functioning is important because motor difficulties cause practical difficulties with daily tasks such as eating, dressing, and performing skilled movements, as in sports.

We are running a study in which we are asking autistic adults to copy different movements and perform simple movement tasks. We are doing this to find out more about why autistic people have motor difficulties and whether they can be used to help diagnose autism and to design therapies.

We are looking for volunteers with a diagnosis of Autism or Asperger's Syndrome:

- Aged between 18-45
- Have no history of eye disease or of psychological illness
- Speak English as a first language

Experiments will take place over two visits lasting approximately three hours in total. All experiments are non-invasive. If you decide to take part you will be asked to observe and copy different actions while your own actions are recorded with a sensor. You will also be asked to perform other simple movement actions. While you are doing these experiments, we may also measure where you are looking using an eye tracker on the table in front of you.



All volunteers will be reimbursed for their time and reasonable travel expenses. If you would like more information about this study, or would like to take part, please contact Andrius at: andrius.vabalas@manchester.ac.uk