



Winter Newsletter

Welcome to the winter 2021 edition of the Autism@Manchester newsletter.

At the time of writing Manchester has been in some form of lockdown for over 300 days in the last year. This has been an incredibly challenging time for autistic people and their families: <https://www.autism.org.uk/what-we-do/news/coronavirus-report>

Wishing everyone safety and good health.

In this edition of the newsletter you will find:

- The latest findings from our research community (pages 3 – 10)
- An interview with K Leneh Buckle (pages 11 – 13)
- Elizabeth Le-luan discusses her experiences of Patient and Participant Involvement in research (pages 14 – 17)
- Opportunities to take part in research in our group (pages 18 - 19)

NEWS

- The University of Manchester is planning to run a masters course (MRes) in Autism Theory, Research and Practice. If you would be interested, or would like to find out more, please could you complete this short survey (<http://www.autism.manchester.ac.uk/study/mres-autism-theory/>). We would love to know what you think!
- Recordings from our 2020 webinar series are available on the Autism@Manchester YouTube channel:
<https://www.youtube.com/channel/UCgBGgPRCvjD6FF5N1uSFxrA>

Grant success

- Sophie Langhorne and colleagues have obtained a grant from the University of Manchester – Melbourne seed fund (<https://www.manchester.ac.uk/collaborate/worldwide/collaborations/manchester-melbourne-research-fund/>) to collaborate on the secondary analysis of a large autism and language communication dataset which has been accrued through research at both Universities.
- Daniel Poole was awarded a New Investigator grant from the Economic and Social Research council to investigate distraction in autism. You can read more about this project here: <https://gtr.ukri.org/projects?ref=ES/V002538/1>

Publications

- Evans & Bond (2021) The implementation of Lego-Based Therapy in two English mainstream primary schools. *Journal of Research in Special Educational Needs*.
- Gowen et al (2020) Collinear facilitation and contour integration in autistic adults. Examining lateral and feedback connectivity. *Vision Research*
- O'Hagan, S., Bond, C., & Hebron, J. (2021). What do we know about home education and autism? A systematic review. *Research in Autism Spectrum Disorders*
- Poole et al (2021) "No idea of time": Parents report differences in autistic children's behaviour relating to time in a mixed methods study. *Autism*
- Tomlinson, Bond & Hebron (2021) The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education*.



By Daniel Poole

**Division of Neuroscience & Experimental Psychology,
University of Manchester**

What was the study?

The ability to organise ourselves in time is valuable for many everyday behaviours: including co-ordinating ourselves with others, planning and waiting for things to happen.

A sense of time gradually mature across childhood development. This is complimented with formal learning about time (e.g. how to read and use clocks).

Accounts from autistic people and those who live and work with them have described difficulties relating to time. In a recent [review](#), we found that the research evidence investigating time in autistic and non-autistic samples is mixed, with some studies suggesting autistic people have a diminished sense of time, other studies suggesting there is no difference from non-autistic people and others suggesting autistic people have a superior sense of time.

We also noticed that most of the research that has been conducted so far has used lab based experiments which were designed non-autistic participants and do not directly relate to timing in everyday life.



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LATEST FINDINGS

TIME MANAGEMENT IN AUTISTIC CHILDREN

What was the study?

In this study we aimed to

- a) Assess the extent to which timing management impacts the daily lives of autistic children
- b) Better understand *how* time management is different in autistic children

What did we do?

This study focused on children aged between 7 - 12 who were educated in a mainstream education setting. 113 parents of autistic children and 201 parents of non-autistic children completed an online survey which included a questionnaire used to measure children's time concept and management, and five open-ended questions about their child's experiences of time.

The materials in this study were designed with input from the Autism@Manchester [expert group](#). Autistic participants were recruited via Autistica's family database <https://www.autistica.org.uk/asd-uk> and the advisory panel gave further direction on study design.

What did we find out?

Questionnaire ratings were substantially reduced in the autistic group suggesting autistic children's concept of time was reduced compared to non-autistic children. Reports in the open ended questions suggested that problems related to time were a issue for many autistic children. Most of the parents described getting ready to get to school on time as a considerable challenge which was stressful for their children and themselves.

We used [thematic analysis](#) to identify patterns (themes) in what the parents had said.

We identified three key themes in the data:

Time knowledge

Parents described problems their children had with learning time concepts, such as how to read a clock, which were not in keeping with their educational level. The children's awareness of these challenges encouraged an intense focus on punctuality, leading to increased anxiety.

Prospection

Parents described challenges their children had when thinking about the uncertainty of the future which they managed by developing fixed and often inflexible plans. Where these plans were not in line with what subsequently happened, it could be a considerable cause of distress.

Monotropism

This theme relates to an [existing theory](#) about how attention may function in autistic people. In the context of the present study, autistic children viewed their time as extremely precious and time spent on activities unrelated to their preferred interests was often seen as wasted. Accordingly, they often placed a high value on punctuality in others

What does this mean?

This work suggests that differences in timing are relevant in autistic children's everyday lives and can have a considerable impact on their well-being. Analysis of the open-ended questions have highlighted some topics which should motivate further research in particular why autistic children may be struggling with learning about time and whether they later catch up with non-autistic children.

This is only one study, it is important to collect the opinions of autistic children themselves and teachers and other professionals who work with these children, but this work has possible implications in an educational and clinical context. For instance, this work suggests that many autistic children may be at a severe disadvantage when completing timed assessments (such as exams) with extra time not sufficient to level the playing field. Additionally, clinical interventions could be directed towards supporting parents with managing their child's anxieties around time.

I discussed these findings and the larger timing project in a recent webinar (from 23:55):

<https://youtu.be/jd9XdE6Y09w>



EMPOWER-ASD: A NEW GROUP FOR PARENTS OF CHILDREN RECENTLY DIAGNOSED WITH AUTISM



By Kathy Leadbitter

**Division of Neuroscience & Experimental Psychology,
University of Manchester**

The Need

1% of UK children receive a diagnosis of autism. Parental responses to the diagnosis are diverse and complex. Some parents (we use the term ‘parent’ to include all those with a parenting role) experience considerable stress, anxiety and disorientation around this time. Many parents are desperate to understand more about autism and the best ways to help their child. Parents of autistic children face many additional practical, emotional and social challenges. Therefore, supporting parental mental health and resilience could bring long-term benefits for the parent, their children and the whole family.

Developing the programme

We set out to develop a programme that:

- addresses the diverse needs of parents after receiving a diagnosis
- provides up-to-date information about autism and lots of practical strategies
- takes a neurodiversity-positive approach and offers hope and empowerment
- allows parents to share advice and support with each other
- gives parents time and space to reflect on the diagnosis and their parenting experience
- helps parents feel emotionally well and have strategies to deal with stress



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LATEST FINDINGS

EMPOWER-ASD: A NEW GROUP FOR PARENTS OF CHILDREN RECENTLY DIAGNOSED WITH AUTISM

Developing the programme

We worked in collaboration with many professionals, parents and autistic people to develop the programme. We drew upon two existing approaches: (1) an autism workshop developed within Central Manchester NHS and (2) a therapeutic programme developed in Australia based on Acceptance and Commitment Therapy (ACT). The resulting programme, called EMPOWER-ASD, consisted of five 3-hour sessions.

Piloting the programme

We recruited a diverse sample of 29 parents/carers of children (aged 2-15 years) recently diagnosed with autism from a Manchester NHS autism clinic. Participants were invited to one of three intervention programmes (two in-person; one online) run by NHS practitioners. We evaluated attendance and satisfaction ratings to see whether parents liked the programme. We also gathered feedback through feedback forms and interviews.

Findings

Attendance was satisfactory: 22 of the 29 participants attended 3 or more sessions (out of 5). Three participants attended fewer than 3 sessions and 4 participants attended none. Non-attendance was due to external circumstances (illness, caring responsibilities, employment).

Satisfaction was excellent: 72% of sessions were rated as 'very satisfied' and 28% as 'satisfied'. No sessions were rated as unsatisfied/very unsatisfied.

EMPOWER-ASD: A NEW GROUP FOR PARENTS OF CHILDREN RECENTLY DIAGNOSED WITH AUTISM

Findings

Feedback: All participants interviewed described the programme as a positive experience. They liked the therapeutic approach and focus on their wellbeing. Participants benefitted from meeting and sharing experiences with other parents. They learnt a lot and gave nice examples of how they were using what they learnt in daily life. They became more confident. There was also some constructive criticism (e.g. some parts felt rushed) which was used to improve the programme.

Quotes from the parents:



My name is K Leneh Buckle I am a PhD student which means that I am training to be an autism researcher.

My research interests are: autistic inertia and movement disorders.

I spend a lot of time with autistic people at [Autscope](#) (an annual meeting for autistic people arrange by autistic people) and when we get together, we don't talk about the ways others might define autism: social problems, inflexibility etc. The things that affect us are sensory issues, getting along with NTs (neurotypicals, i.e. non-autistic people) and this problem with inertia.

Inertia is a problem doing things when we want to. This can mean problems with starting, stopping or switching what we are doing. Some people call this a problem with executive functioning (and this may be part of it), but I'm interested in whether autistic inertia is related to movement disorders like catatonia. Catatonia is a problem where people get frozen in place and can't move for extended periods. We find it hard to explain what this problem is and call it 'difficulty doing stuff': Some people can't do something because they find things overwhelming but some people find themselves stuck, just physically stuck. I want to help people have the language to explain what the problem is and what might help.

Work related to autism and looking after my family take up most of my time, but I also enjoy playing strategy games – at the moment I am playing Cities Skylines.

WHO ARE YOU?

WHAT MADE YOU BEGIN RESEARCHING AUTISM?

Most importantly, I am autistic and so are most of my family. The reason I started a PhD was that I have these problems with initiating things. I really wanted somebody to research this and lots of other autistic people were talking about wanting somebody to investigate this thing that we call autistic inertia. Although lots of autistic people have been talking about it, nobody has been researching it and there is nothing that has been written on it, so somebody had to do it! I seemed to be in a good position to do it and eventually it became obvious that I was the one... Also, I was on an advisory panel of autistic people and all my friends there have PhDs and get letters after their names!

HOW WOULD YOU DEFINE THE AUTISM SPECTRUM?

I see autism as too much of a good thing! Processing differences that would be an asset in small amounts, for example intense focus, but autistic people have so much of these traits that it gets in the way and creates problems.

IS IT POSSIBLE TO CARRY OUT RESEARCH IN YOUR FIELD THAT APPLIED TO ALL AREAS OF THE AUTISM SPECTRUM?

At the moment I am only working with people who can explain their own experiences (by talking or writing) because I need to find out what the experience is like. But it almost certainly applies to people who aren't as able to express themselves as easily.

A lot of the things I find in my research are the same as what non-speaking people have written about in their experiences of autism.

WHO ARE YOU?

HOW VALUABLE DO YOU EXPECT YOUR RESEARCH TO BE TO AUTISTIC PEOPLE, OR SOCIETY AT LARGE, AND WHY?

I expect this to be really valuable to autistic people because we need inertia to be recognised as part of autism which can cause problems for many people. It's not currently recognised as part of what autism is or what autistic people need support with. When I have this work published (I hope part of it will be soon) autistic people can point to this and say this is a real thing, it's not just me. That should help people to get understanding, adjustments and support.

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

My research is more limited by time and knowledge because this is a completely new area. One of the things I would ultimately like to find out is if there are some things that cause autistic people to be more likely to get these problems, e.g. if certain medications trigger it. That would require first defining inertia really clearly, which I'm working on doing and hope others will too, and then looking at what things go along with it, like if there are certain autistic traits, life stresses, medical conditions or medications that people with these problems are more likely to have had. If we could figure that out we could make it less likely that autistic people get the most severe types of problems like this in the first place.

THANK YOU LENEH!

WHAT ABOUT PATIENT AND PUBLIC INVOLVEMENT?

Elizabeth Le-luan talks to us about her experience of involving autistic people in her research on social communication.



By Elizabeth Le-luan
Division of Neuroscience and Experimental Psychology,
University of Manchester

I am a PhD researcher interested in social communication, with a particular interest in our ability to predict upcoming information and our sensitivity to indirect communication.

As an example:

Paul and Jane are friends. Paul asks Jane “How did you do on your chemistry test”? Jane replies, “The exam was not fair”.

It is not immediately obvious in this scenario what Jane means here and requires the reader to search for the hidden meaning within the text. Many of us will pick up on the fact that it is likely Jane did not do well on her exam and wishes not to talk about it.

Previous research has shown that non-autistic readers are sensitive to this information and that it is picked up on rapidly during reading. As the research literature describes the autistic population as having poor social communication skills, the logical next step for my research was to investigate these sensitivities in an autistic sample. However, before I began running a full-fledged experiment, I thought I should get some expert advice first and I am glad I did!



WHAT ABOUT PATIENT AND PUBLIC INVOLVEMENT?

How did Patient and Public Involvement change your understanding?

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), a core symptom of autism is impaired social communication and interaction. Many autistic individuals believe that findings confirming social deficits do not reflect the individual variability evidenced across the spectrum. It can be frustrating to feel stereotyped and stigmatised for a very broad core symptom that is not well understood. This often leads autistic individuals feeling others are unable to look beyond their diagnosis ([Cooper et al., 2020](#)).

Through PPI, I can confirm that, although unconscious, I was also using autistic diagnosis as a means to study my interests rather than the interests of autistic people. What I learned from discussions with individuals from the expert group was that my research interests aligned with theirs but the way I was framing this was not in the autistic community's best interest. I went from being interested in social communication deficits to a much more open-minded approach. This included not looking at any differences between autistic and non-autistic participants as a deficit but rather simply a difference in understanding.

I have learned autistic people often feel their deficits are not as profound as research suggests and that research does not seem to represent the wide spectrum of autistic individuals. It is important for the data to be framed in a way that benefits the participant, in my case autistic people. Therefore, investigating what aspects of social communication autistic people complete well is just as important as investigating which processes are impaired.

WHAT ABOUT PATIENT AND PUBLIC INVOLVEMENT?

Why should researchers use PPI in their research?

For me, PPI has highlighted a fundamental principle of research. We cannot expect autistic people to blindly complete study after study when they feel it is not relevant to them or that their efforts go unappreciated. I assure you from conversations within my own PPI journey autistic participants do feel like this. Our research should be important not just to us but those in which we are investigating. By providing a debriefing session in which the participant had opportunities to ask questions, but also to feel involved and invested in current and future work, I was able to hear how important it was for participants to know what aspect of their communication was being studied as well as how important it was for them to be included in the discussion.



As I mentioned before, autistic participants can often feel defined by their autism at their individual expense. Therefore, it is important to treat every participant as an individual and PPI can help a researcher achieve this. Through pre-testing PPI sessions over email with expert group members, I was reminded of this early on in the process. Therefore, I was able to quickly adapt my experiment to be quite flexible with a number of aspects, something I may not have been able to do without the feedback I received through the PPI process. PPI has served to dispel some of my own misconceptions and improved my understanding and communication with the autistic community.



WHAT ABOUT PATIENT AND PUBLIC INVOLVEMENT?

PPI has been an invaluable tool in creating a study that satisfies my needs but also those of the participants I'm investigating, autistic people. If you are a researcher thinking of whether PPI is useful for your study, I would say the answer is always yes! As researchers we often think we have thought of everything and planned our studies well. While this may be the case, PPI will always provide some new insight that can only benefit your study.

I shall end by saying a very big thank you to the members of the Autism@Manchester expert by experience group who provided their knowledge and time to make my experiment the best it could be.

Find out more

For more information and guidance on working with autistic participants please see the Autism@Manchester guidelines for conducting research studies with the autism community ([Gowen et al. 2019](#)).

If you are interested in finding out more about Elizabeth's study, or taking part please contact Elizabeth (elizabeth.le-luan@postgrad.manchester.ac.uk) and/or see the poster in the "opportunities to get involved" section of the newsletter.

TAKE PART

How can autistic adults be supported to age well?



Rebecca Aitken

I am Rebecca Aitken and I am completing this project as part of a doctoral degree in Clinical Psychology at the University of Manchester.

I am being supervised for this project by Dr Emma Gowen, Dr Laura Brown and Professor Katherine Berry.

I am aiming to interview autistic adults who are 45 years and older to find out their thoughts on what it means to age well, what care and support needs they think autistic adults have and what they think other services or individuals can do to support the ageing process. We have chosen the cut off age as 45 years as it has been suggested that age related changes begin to become more important in this group of autistic adults, this age group have also typically been under recruited in research involving autistic adults.

I hope that I can use these findings to help other people know what individual support and changes to society autistic people may need as they get older and to build on the strengths that autistic people have.

Participants will be asked to complete some questionnaires and take part in an interview either via online video, online chat, via the telephone or face to face (subject to social distancing rules no longer being in place). Participants will be paid for their time and any reasonable travel expenses will be reimbursed.

If you are autistic, aged 45 years or older and are interested in taking part please feel free to contact Rebecca (student researcher) on Rebecca.aitken@postgrad.manchester.ac.uk. Please note we have yet to receive ethical approval for this study so we are not currently recruiting, but if you express an interest we will retain your contact details and make contact with you when we are ready to recruit. We anticipate beginning our recruitment in March or April 2021 and ending in approximately November 2021.

Autistic participants sought for reading study



Elizabeth Le-luan

Autistic participants are sought for a study investigating how autistic individuals mentally represent information while reading. In order to be eligible, you need to:

- Be aged between 18-55
- Be diagnosed with autism
- No known reading disability (e.g. dyslexia, specific language impairment)
- Have English as your first language
- Have normal to corrected normal vision

Participants will be asked to complete a short demographic questionnaire, read short narrative stories from a computer screen at their own pace answering comprehension questions throughout. Additionally, participants are requested to complete 2 cognitive tests and 2 questionnaires.

Testing will be completed whilst on a Zoom meeting with the researcher. Portions of the Zoom session will be recorded. All data will be stored in accordance with data protection standards.

The study is anticipated to take up to, approximately, 2 hours and you will receive compensation for your participation.

This can be done in one sitting or over two sessions. The participant information sheet (available on request) provides in depth detail of what you can expect from each portion of the testing session.

If you would like to participate or would like further information, please email Elizabeth Le-luan elizabeth.le-luan@postgrad.manchester.ac.uk