

## Summer Newsletter

Welcome to the summer 2020 edition of the Autism@Manchester newsletter. It has been an extremely challenging year. Research activity, like all activity, has been impacted by the pandemic, but we are finding ways to (safely) continue producing high quality work with meaning for autistic people. Wishing everyone safety and good health.

In this edition you will find:

- The latest findings from our research community (pages 3 – 8)
- An interview with Dr Kathy Leadbitter (pages 9 - 14)

### NEWS

- We are running public seminars virtually this year as webinars (see ad page 2). You can sign up using the Eventbrite link: <https://www.eventbrite.co.uk/e/autism-manchester-webinar-series-tickets-120004028279>
- On 28<sup>th</sup> July, Autism@Manchester chair Dr Emma Gowen gave a presentation to Live with Scientists. This presentation is freely available to view online: <https://youtu.be/kDe6qi4Dy3E>
- Dr Gowen has been awarded grant funding with Dr Ellen Poliakoff to collaborate with Professor Timothy Welsh (University of Toronto) for a project investigating the interaction between action, perception and imagination in autistic and non-autistic people

### Publications

- Leadbitter et al. (2020) Parent perceptions of participation in a parent-mediated communication-focused intervention with their young child with autism spectrum disorder. *Autism* ([open access](#))
- Vabalas et al. (2020) Applying machine learning to kinematic and eye movement features of a movement imitation task to predict autism diagnosis. *Scientific Reports* ([open access](#))



Tuesday 6<sup>th</sup> October  
Tuesday 13<sup>th</sup> October  
Tuesday 20<sup>th</sup> October



Free tickets on Eventbrite: "Autism @ Manchester Webinar Series"

<https://www.eventbrite.co.uk/e/autism-manchester-webinar-series-tickets-120004028279>



Autism at Manchester



AutismAtMCR

### WEBINAR 1: TUESDAY 6<sup>th</sup> OCTOBER, 5-6pm

**Dan Poole**

Time perception and autism



### WEBINAR 2: TUESDAY 13<sup>th</sup> OCTOBER, 5-6pm

**Kathy Leadbitter, Louisa Harrison,  
Ceri Ellis, June Gilbert & Amelia Pearson**

The development and piloting of EMPOWER-ASD: a post-diagnostic programme for parents of children recently diagnosed with autism



### WEBINAR 3: TUESDAY 20<sup>th</sup> OCTOBER, 5-6pm

**Alex Sturrock**

Language and communication profiles of autistic females without intellectual impairments: strengths and weaknesses and impact on life



**Sophie Langhorne**

How the complexity and diversity of the language parents use affects young children's language development



### RADICALISATION AND ACCESS TO RADICAL MATERIALS FOR YOUNG AUTISTIC PEOPLE



By Sarah Leonard, Florian Walter and Jenny Shaw

Division of Psychology & Mental Health, University of Manchester

There are very few resources for educators, parents/carers and autistic people that look at how autistic people engage with topics which are linked to terrorism, and how to support safe engagement with these materials. There is also no guidance to help people recognise whether this engagement is an interest, or whether the person is developing radical ideas, and how Autism may play a part in developing these ideas. This study aimed to address this knowledge gap, whilst also ensuring that safeguarding and wellbeing of people with Autism is a priority.

#### What was the study?

We interviewed 34 professionals and young people about radicalisation and access to radical materials by autistic people. All young people had an Autism diagnosis and professionals were clinicians, police officers, educators and researchers who work with autistic people who have accessed radical materials and/or developed radical ideas.

Interviews focused on identifying potential signs that a young autistic person may be at risk of developing radical ideas and how to respond appropriately to these risks.



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## LATEST FINDINGS

### **RADICALISATION AND ACCESS TO RADICAL MATERIALS FOR YOUNG AUTISTIC PEOPLE**

#### **What was the study (cont.)**

We also asked the young people about their experiences of interacting with others online and how this differs from the offline world.

Before starting the project, we presented our study idea to the Autism@Manchester expert by experience advisory group. The guidance received from this group helped us to develop our interview guides, plan how the interviews would be conducted, and how to communicate our study findings.

#### **What did we find out?**

All participants agreed that having an Autism diagnosis does not make a young person more likely to develop radical ideas, but that there are some key traits of Autism which may make them vulnerable. Interviewees also described external factors (for example environments and social situations) which may add to this vulnerability. These descriptions allowed us to write a report for educators which can act as a guide for how to safeguard young people with Autism from developing radical ideas. We were also able to gather examples of how to help young autistic people who already have radical ideas. Interviewees made it clear that any intervention to help these young people should be personalised to meet their individual needs rather than a one-size-fits-all approach.

#### **What does this mean?**

Our study is the first to look into the development of radical ideas in young autistic people. We hope that our report and recent research article act as a first step to help parents, educational staff and care professionals to safeguard young people who are at risk of, or have developed, radical ideas.

### THE IMPACT OF SUBTLE COMMUNICATION DIFFICULTIES ON MENTAL HEALTH AND RELATIONSHIP BUILDING FOR AUTISTIC GIRLS AND BOYS



**By Alexandra Sturrock**

**Division of Human Communication Development & Hearing,  
University of Manchester**

**This study focused on the impact of subtle communication difficulties on autistic children without learning disability. This is a group who are often reported to have language skills within normal limits, although this typically refers to the individual's competence in vocabulary and sentence level grammar. More subtle difficulties impacting on communication; for example, word finding, narrative skills, inference and pragmatic/communicative behaviours, are identified in the wider literature but little has been done to explore the interaction between those difficulties and the individual's social and emotional well-being.**

**In addition, recent studies have identified differences in the presentation of autism between girls and boys, and this has included differences in language and communication skills (see <https://link.springer.com/article/10.1007%2Fs10803-019-03920-6>). This study focuses on the impact of subtle communication difficulties for both autistic girls and boys without learning disability. It also provides some preliminary data on gender differences that might exist.**



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## LATEST FINDINGS

### **THE IMPACT OF SUBTLE COMMUNICATION DIFFICULTIES ON MENTAL HEALTH AND RELATIONSHIP BUILDING FOR AUTISTIC GIRLS AND BOYS**

#### **What was the study?**

**This study focuses on the impact of subtle communication difficulties for both autistic girls and boys without learning disability. It also provides some preliminary data on gender differences that might exist.**

**Six girls and six boys (aged 9 to 14 years) were interviewed by a trained speech and language therapist using carefully designed interview schedules and adaptable and individualised interview protocols.**

**All materials were designed in collaboration with members of the autistic community and parents of the interviewees (including members of Autism@Manchester), in order to achieve rich self-report. Interviews lasted around one hour. All transcripts were analysed with a data analysis team comprising: an autistic researcher, autism researcher and a qualitative researcher (30% contributions each). The prioritisation of the autistic researcher in the analysis team was to manage known researcher biases and neurotypical overshadowing while interpreting the child's accounts.**

#### **What did we find out?**

**The overarching result was that autistic children, from as young as 9 years old, could be engaged in in-depth conversations and add insight into their own communication difficulties. They highlighted problems with word-finding, listening (particularly in groups), narrating an event, starting and maintaining a conversation, and explaining their emotions to others.**





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## LATEST FINDINGS

### THE IMPACT OF SUBTLE COMMUNICATION DIFFICULTIES ON MENTAL HEALTH AND RELATIONSHIP BUILDING FOR AUTISTIC GIRLS AND BOYS

#### What did we find out?

They identified clear links between language and communication difficulties and problems with social interactions:

*“In groups ... everyone’s talking at the same time and I can’t follow the conversation”*

*“I couldn’t talk about toys without them talking about makeup. It felt like someone had taken out a few of my vocal chords”*

They also described vividly the impact of communication breakdown on their emotional wellbeing:

*“[Teachers tell me to] ‘just say something’, and I am getting all wound up and I don’t know what to do”*

*This research indicates a significant impact of even subtle language and communication difficulties for this group of children.*

The group identified particular problems explaining their emotions to others, and that this was exacerbated when they were in a state of arousal; demonstrating a complex relationship between emotions and communication breakdown.

There were gender differences in the experience and reporting of difficulties, as well as the coping strategies undertaken.



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## LATEST FINDINGS

### THE IMPACT OF SUBTLE COMMUNICATION DIFFICULTIES ON MENTAL HEALTH AND RELATIONSHIP BUILDING FOR AUTISTIC GIRLS AND BOYS

#### What does this mean?

These findings suggest that support needs to be aimed at the subtle social communication difficulties experienced by this group. This should be differentiated by gender and according to individual needs.

Support should also include developing strategies that allow the individual to explain emotionally sensitive information in a way that is meaningful and helpful for them.

Overall, this research finds that this group of children can and should be involved in self-reporting of communication difficulties, which could help guide assessment and therapy planning. More research is required to isolate the impact of language on social interaction and emotion and to develop better tools for measuring skills in language of emotion.

#### Can you help?

The research team are aiming to raise funds to develop the children's quotes into a series of informative images and potentially a public facing information booklet. If you would be interested in donating or could share the link with a group, this would be gratefully appreciated:

[https://www.justgiving.com/crowdfunding/aspire-femaleautismnetwork?utm\\_term=7jqWZjr9b](https://www.justgiving.com/crowdfunding/aspire-femaleautismnetwork?utm_term=7jqWZjr9b)



## WHO ARE YOU?

**My name is Dr Kathy Leadbitter. I am Research Fellow at the University of Manchester. This means that I work on specific externally-funded research projects, including two large clinical trials of autism interventions, one in the UK and one in India. I also supervise Masters and PhD students.**



**My research interests are everything related to autism and Neurodiversity; ways in which to support parents to understand and connect with their autistic child; communication and language development in autistic children; good mental health, wellbeing and quality of life in autistic people and their families; developing and testing intervention programmes including those that are deliverable within the NHS and within low and middle income countries; developing research measurement tools, such as questionnaires. Outside of work I am mum to my 6-year old daughter and two cats. I enjoy swimming, camping baking (and eating) cakes and trying to grow things in the garden.**

## WHAT MADE YOU BEGIN RESEARCHING AUTISM?

**I studied child language development at Glasgow University and became fascinated by how children with neurodevelopmental conditions learn to talk and communicate. After graduating, I worked in schools and with families supporting autistic children. I loved the children's individuality, determination, and humour. I also saw how the people around the children, including myself, struggled to always understand their world and know how best to help them develop and learn. I also witnessed how services were underfunded, patchy, un-evidenced and not always autism-positive. I wanted to do my bit to change that.**

## WHO ARE YOU?

### WHAT MADE YOU BEGIN RESEARCHING AUTISM?

I completed a Masters and PhD at Lancaster University studying communication development in verbal children with autism. I always enjoyed the research interactions with the young participants but I learnt the hard way about being realistic in my research questions and organised in my data-handling! During this time, I also volunteered at a social group for autistic adults; this opened my eyes to the inequalities and marginalisation that many autistic people face and this made me even more determined to try to address some of these issues through research.

More recently three close family members of mine have been diagnosed with autism – I sometimes wonder if I found an affinity with autism because of characteristics within family members (or myself)! This family connection to autism has further boosted my passion and resolve to make a difference to the lives of autistic people through research.

### HOW WOULD YOU DEFINE THE AUTISM SPECTRUM?

Wow, to be honest, I don't know where to start! I would need to write thesis of 80,000 words to explore this properly! I am keen on a neurodiversity angle to thinking about autism, that is, that all brains are different and autism is one way of defining and grouping together particular kinds of brain differences that affect how a person responds to and interacts with the world. These brain differences are unique to the individual and result in constellations of characteristics around communication, interaction, thinking styles, sensory processing, and emotional and energy regulation, amongst other things. Some of these characteristics are strengths; some are the cause of difficulties or disability; some are both these things depending on the situation (and who you ask!).

## WHO ARE YOU?

### HOW WOULD YOU DEFINE THE AUTISM SPECTRUM? (cont)

The constellation is totally unique to the individual but each autistic person may share certain things in common with other autistic people. According to this viewpoint, the autism spectrum is definitely not a two-dimensional continuum. We also know that autism can present very differently depending on factors like gender, age and intellectual ability. This can lead to missed or mis-diagnosis, for example, in girls and women. It can also present very differently within one person depending on the context and environment. The conceptualisation of autism has also evolved over time, as we have come to understand how autism fits amongst other diagnoses and how it presents differently across people.

I think the neurodiversity angle is a good one because it moves us away from a stigmatising narrative which situates the 'problem' in the autistic individual and towards one which promotes a shared responsibility to create a world that is accessible to and embracing of people with all neurotypes (all kinds of brains).

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

I am interested in many aspects of the autistic spectrum and in any research that could bring potential benefit to the lives of autistic people. One of my particular areas of expertise lies in intervention development and testing. I use the term 'intervention' in its broadest sense to mean any kind of programme, service, technology, support framework or strategy that could potentially help autistic people or those people around the autistic person. My research involves working with stakeholders including autistic people, family members and clinical colleagues to co-produce manualised interventions. This includes finding out whether those interventions are feasible (deliverable) and acceptable (liked).

## **WHO ARE YOU?**

### **IS IT POSSIBLE TO CARRY OUT RESEARCH IN YOUR FIELD THAT APPLIED TO ALL AREAS OF THE AUTISM SPECTRUM? (cont)**

I also have expertise in subjecting interventions to gold-standard evaluation through randomised controlled trials – a hugely complex and intensive task but one which produces really robust evidence about whether or not an intervention is worth bothering with. I would be more than happy to continue applying this expertise to any avenue that might ultimately help autistic people.

Another area of my research concerns measurement tools (like questionnaires, interviews and assessments). One of the big problems faced by autism researchers concerns the measurement tools that are at our disposal. On one hand, we are faced with a huge array of different tools which measure similar things (for example lots of observational scales for measuring joint attention in autistic children). This means that different researchers use different scales and it is really hard to compare and contrast the findings. On the other hand, there is a real dearth of tools to reliably measure the things that really matter to autistic people and their families, such as wellbeing, quality of life, happiness, autonomy etc. Trials have traditionally focussed very much on outcomes such as IQ and autism ‘symptoms’, but I am really keen on incorporating measurement that relates to the things that matter to autistic people themselves. To this end I developed with colleagues and stakeholders a questionnaire to measure family experience and quality of life which is now being used within several autism trials around the globe; it can be accessed here:

<https://link.springer.com/article/10.1007/s10803-017-3350-7>



## WHO ARE YOU?

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

My absolute passion is research that has direct real-world impact for autistic people. I have been fortunate enough to work as part of the 'PACT consortium' since 2006 and together we have produced high quality evidence for a video-aided intervention approach which helps parents to understand and communicate better with their autistic child (called Paediatric Autism Communication Therapy - PACT). I approved of the approach from the start due to its focus on changing the way in which parents relate to their autistic child, rather than attempting to change aspects of the child or their autism. This work has already proved valuable. The trial produced some exciting findings (website: <http://research.bmh.manchester.ac.uk/pact>; the papers can be accessed here: <https://www.sciencedirect.com/science/article/pii/S0140673610605879> and <https://www.sciencedirect.com/science/article/pii/S0140673616312296>).

The intervention is now being implemented in several countries around the world and in several areas of the UK, including Greater Manchester. It takes time for this impact to happen: this work started in 2000 and it is only within the last couple of years that the true real-world implementation has occurred on any scale. We are also running a trial to see whether an intervention based on PACT can be delivered by health workers in Delhi, India (<http://www.sangath.in/compass/>) so we hope that this work could make a difference in India too, as well as in other low-resource countries.

Another current research trial of ours looks at a group-based programme for parents and carers of newly-diagnosed children. The programme aims to help parents/carers understand autism and have ideas for helping their child in day-to-day life.

## WHO ARE YOU?

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

It also offers parents time, space and strategies to process any difficult emotions or stresses they may have (in life generally or specifically related to their child's condition). I feel this is the most important first step to helping young autistic children: for parents and carers to 'get' their child, to know how best to help them, and to be emotionally OK – both generally and specifically with regards to their child's autism. We really hope this programme proves to be valuable and the trial will tell us whether or not it is. If it does prove to really help people, we can push for the programme to be delivered within the NHS.

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

Another great question! I would like to build on my current research to look at specific groups of parents who are struggling practically or emotionally, for whatever reason, and the best way to provide targeted support to them. I would also love to develop and test a programme for children and young people to understand autism as it presents in themselves and in other people, to meet other autistic young people and autistic adults, and to learn about the ways in which other autistic people have found ways to thrive and be happy and well.

If funding were no barrier, my ultimate dream would be to have consistent, timely, NHS-funded implementation of evidence-based interventions across the UK. Producing the evidence base is one challenge, but turning evidence into practice is quite another!

THANK YOU KATHY!