

## Winter Newsletter

Welcome to the winter 2018 edition of the Autism@Manchester newsletter. In this edition you will find:

- Findings from research taking place in Greater Manchester (pages 4-11)
- An interview with Dr Shruti Garg (pages 13-16)
- Details of upcoming events to raise awareness of autism in females (page 17)
- Opportunities to take part in research with autism@manchester (pages 18-19)

### NEWS

#### New Autism Intervention Trial in India

Professor Jonathan Green and autism researchers from the University of Manchester are embarking on a large clinical trial of a communication-focussed intervention in India. The trial has arisen out of a longstanding collaboration between the Manchester team and Vikram Patel, Gauri Divan and researchers in Goa and New Delhi.



The trial will evaluate whether local health workers can successfully deliver the intervention to parents of autistic children in the community and the impact of the intervention on parent-child communication and the intensity of the child's autism features. The project will also develop app technology to help

deliver the intervention to more rural communities.

This will be the first large-scale autism intervention trial outside high-income countries. Read more about our previous work with colleagues in India

<http://research.bmh.manchester.ac.uk/pact/PASS/>

### Films

In 2016, Autism@Manchester produced a series of films to raise awareness about what it is like to live with autism. These are still available online:

<http://www.autism.manchester.ac.uk/connect/get-involved/autism-survey/>

We would be grateful if people could click on the link to watch the film, then fill out the short survey (the whole activity should take ~10 minutes). Please forward on to anyone that you think might benefit.

### Researcher guidelines

Autism@Manchester has produced some guidelines for conducting research with the autistic community. This guidance covers the considerations that researchers should take into account when conducting research with the autistic community and is particularly valuable for those researchers who are just starting out in the autism field or would like to increase active involvement of autistic people in their research. You can download the guidelines here:

<http://www.autism.manchester.ac.uk/research/projects/research-guidelines/>

**Publications**

Gowen et al (2017) Optometric and orthoptic findings in autism: a review and guidelines for working effectively with autistic adult patients during an optometric examination. *Optometry in Practice*. [This article was co-authored with members of the autistic community]

Gowen et al (2017) Guidelines for conducting research with the autism community (<http://www.autism.manchester.ac.uk/research/projects/research-guidelines/>)

Hayes (2017) Sensorimotor learning and associated visual perception are intact but unrelated in autism spectrum disorder. *Autism Research*.

Leadbitter et al (2017) The autism family experience questionnaire (AFEQ): An ecologically valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention, *Journal of Autism and Developmental Disorders* ([open access](#))

Li (2017) Applying machine learning to identify autistic adults using imitation: an exploratory study, *PLOS ONE* ([open access](#))

Robinson (2017) A UK and Ireland survey of educational psychologists' intervention practices for students with autism spectrum disorder. *Education Psychology in Practice*



By Dr Kathy Leadbitter,  
Research Associate, Division of Neuroscience and Experimental  
Psychology, University of Manchester

Research into interventions for children with ASD often focusses on whether the intervention brings improvements to children's communication and language skills, play, IQ, or behaviour. These are important child-centred goals. However, these are the intervention priorities set by researchers and clinicians. What changes do parents want from early autism interventions? And is it possible to measure changes in these key areas within an intervention trial for autistic children and their parents?

#### What was the study?

We identified the intervention priorities of parents of children with ASD through focus groups and an online consultation through the National Autistic Society website. We then developed a questionnaire, the Autism Family Experience Questionnaire (AFEQ), which reflected these priorities.

We used the AFEQ questionnaire within a large autism intervention clinical trial called the [Pre-school Autism Communication Trial](#) (PACT). Half of the 152 parents in the trial received PACT intervention during the first year of the trial; the other half did not. Parents completed the AFEQ questionnaire at the start of the trial, after 1 year and again after 6 years.





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## LATEST FINDINGS

### THE AUTISM FAMILY EXPERIENCES QUESTIONNAIRE

#### What did we find out?

Parental priorities fell into three areas:

1. Changes for themselves as parents, such as having realistic milestones for their child's development and not having to continually fight for the right support for their child
2. Changes for the child with ASD, such as their child being happier and getting invited to birthday parties.
3. Changes for the whole family, such as being able to go to family events together and making home routines more manageable. Parents also emphasised the relationship between their autistic child and siblings, but we were unable to keep items about siblings in the questionnaire as they could not be answered by parents with only one child.

We put the priorities together into a questionnaire with 48 items that were answered from 1 (always) to 5 (never).

We looked at the AFEQ data from the PACT trial. We were reassured that the AFEQ was measuring important constructs, as it mapped well onto other well-established measures of child independence and parental wellbeing. We found that parents who had received the PACT intervention had significantly better total AFEQ scores at the end of intervention and that this relative improvement over the control group was sustained 6 years later when the families were seen for follow-up.



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## LATEST FINDINGS

### THE AUTISM FAMILY EXPERIENCES QUESTIONNAIRE

#### What does this mean?

The Autism Family Experience Questionnaire is a tool that can be used to measure the effects of an early autism intervention on the things that matter most to parents. It reflects aspects of family, parental and child wellbeing and quality of life, areas often overlooked within autism research.

We had already established that the PACT intervention brings about improvements to parent-child interaction and the intensity of the child's autism features. By developing and using this questionnaire we were also able to establish that this intervention has a positive effect on critical aspects of family wellbeing and experience.

For more information:

You can read more about the wider work of our research group at:

<http://research.bmh.manchester.ac.uk/socialdevelopment>

The full questionnaire can be downloaded here:

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

welcome others to use it: please contact [Kathy.Leadbitter@manchester.ac.uk](mailto:Kathy.Leadbitter@manchester.ac.uk).

The PACT research articles are available from:

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)60587-9/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)60587-9/abstract)

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)31229-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)31229-6/abstract)

### **SPEAKING THE SAME LANGUAGE? COMPARING THE LANGUAGE AND COMMUNICATION SKILLS OF FEMALES AND MALES WITH AUTISM**



**By Alexandra Sturrock,  
Clinical Lecturer Speech and Language Therapy and PhD researcher,  
Division of Human Communication, Development and Hearing,  
University of Manchester**

**Females who meet criteria for Autism Spectrum Condition (ASC) are diagnosed in fewer numbers than males. There is some evidence that this is because females present differently from their male peers, but there has been no in-depth investigation into sex-differences in language and communication. In many of the studies females with ASC (FwASC) perform better when compared to male with ASC (MwASC), but lag behind females with typical development (FwTD).**

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

**We assessed 14 females and 14 males with autism, and matched them with typically developing peers. All participants were 9-11 years old, with IQ in the typical range and attending a mainstream school. Participants completed a range of language assessments and asked to complete tasks such as figuring out what happened in a story, or telling a story themselves. The assessments were used to develop a language and communication profile of the children, i.e. understanding and expression at the level of words, sentences, narrative, language of emotion and language in context (pragmatics).**

### SPEAKING THE SAME LANGUAGE? COMPARING THE LANGUAGE AND COMMUNICATION SKILLS OF FEMALES AND MALES WITH AUTISM

#### What did we find out?

Over all we found that there were differences in the profiles of the four groups. In particular

- In our *pragmatic tasks*, such as asking the children to work out what happened in a story from its implied meaning, MwASC performed worst and FwTD performed best while FwASC and MwTD performed similarly. This pattern also occurred in other pragmatic tasks; understanding figurative language (i.e. irony or rhetorical questions) and story-telling (where the children were judged on their ability to link important elements of a story together). Finally, the same pattern was also found in a semantic word generation task; where children are asked to think of as many words as possible from a category (i.e. food and occupations) in 60 seconds.

Item 6



Mum and Chris came home from a long day shopping.

‘We just got a few things’ said mum.

**Example 1. What does Chris’s mum mean when she says ‘we just go a few things’?**



### SPEAKING THE SAME LANGUAGE? COMPARING THE LANGUAGE AND COMMUNICATION SKILLS OF FEMALES AND MALES WITH AUTISM

#### What did we find out (cont.)

- There were also group differences in the children's *language of emotion*. MwASC spontaneously produced less emotional words than FwTD when telling a story. All groups performed similarly when asked to match an emotional label (i.e. embarrassed) to a choice of four pictures. However, the MwASC were more likely to pick incorrect pictures that were widely wrong, while FwASC made closer errors. When the children were asked to tell a story both females with either ASC or TD generated a similar number of emotional words and this was more than males with either ASC or TD, suggesting performance here was dependent on sex not diagnosis.



*Example 2. Match an emotion to the pictures*

#### What does this mean?

Language and communication is an important area for investigation because it makes up a core feature within autism diagnosis. It is also an area where evidence-based adaptations in therapy services might be particularly beneficial. We hope the study will add to the growing information about differences in the presentation of females and males with autism, and that this will support better differentiated diagnostic and therapeutic guidelines.

Read more at Alexandra's blog: <https://communicationautism.wordpress.com/>

### THE FANTASTIC AUTISTIC: IDENTITY AND ENABLEMENT OF NEURODIVERSITY IN FANTASTICAL FICTIONS



By David Hartley,  
Creative Writing PhD student, University of Manchester

As [Stuart Murray](#) and [Mark Osteen](#) have shown, representations of autism in popular culture have long been considered inadequate and, at times, offensive by those in the autistic community. The popularity of figures like Raymond Babbit from *Rain Man* (1988) and Christopher Boone from *The Curious Incident of the Dog in the Night-time*, have created a narrow and unrepresentative cultural image of a highly complex and frequently misunderstood condition. In the fantastical genres (which typically includes science fiction and fantasy, but also horror, folktale, myth, and the Gothic) autism rarely makes an appearance at all. And yet, after spending time with people from the autistic community, it has become apparent that there is a high incidence of autism among the fandom of fantastical genres, where autistic communities have formed around a shared interest in a vision of the future, or a fantasy world.

However, this study has discovered that autistic identification with fantastical worlds is predicated on far more than just a sense of community. The use of fantastical characters and locations are frequently associated with autism, in both negative and positive ways. Autistic people often note that they feel *alienated* from a neurotypical society, as if they were travellers from a different planet. This was most famously articulated by Temple Grandin in her interview with Oliver Sacks, where she described herself as ‘an anthropologist on Mars’ (which subsequently became the title of [Sacks’ publication](#)). This sense of alienation and otherness, however, has also been used as a badge of pride, as seen on the autistic-run forum, [WrongPlanet.net](#).

### THE FANTASTIC AUTISTIC: IDENTITY AND ENABLEMENT OF NEURODIVERSITY IN FANTASTICAL FICTIONS

The characters and situations of fantastical narratives often offer radical explorations of what it means to feel alienated and othered, so it is perhaps no surprise that autistic people have increasingly found a more productive sense of cultural identity among these genres. Neuro-atypical aliens and cyborgs, such as Mr Spock from *Star Trek* (1966-1969), Data from *Star Trek: The Next Generation* (1987-1994), and The Doctor from *Doctor Who* (1962-) can provide what [Leslie Manning](#) has called a ‘an heroic representation of difference for a person with ASD.’ It has become clear that while the fantastical genres rarely include characters labelled as autistic, the presence of neurodiversity has long been a staple feature.



Recent characters from fantastical narratives claimed by autistic fans include [Dr Jillian Holtzmann](#) from the *Ghostbusters* (2016) reboot, [Drax the Destroyer](#) from *Guardians of the Galaxy* (2014, 2017) and [Sylvia Tilly](#) from *Star Trek: Discovery* (2017-). This study aims to further explore these ‘manifestations’ of autism to ask; what radical potential does this act of claiming contain for autistic identity? And, how might the illumination of the presence of autism impact upon the understanding of the fantastical genres themselves?

Progress on this project can be followed on Twitter at [@Fantastic\\_Aut](#) and interaction is encouraged. Are you an autistic person who finds kinship with fantastical characters? Why do you think science fiction and fantasy are useful to autistic identity?

**My name is Shruti Garg. I am a child clinical psychiatrist and lecturer at the University of Manchester.**

**I am involved in clinical work diagnosing children with autism and also do research. Outside of work a lot of my time is taken up as a practicing Buddhist. I follow a particular philosophy which emphasises dignity of life, respect for all people and oneness with the self and environment. This means that your environment is a reflection of who you are.**



**In my research, I study neurofibromatosis type 1 (NF-1) in the context of autism. NF-1 is a genetic disorder which is caused by a 'spelling mistake' in one of the genes which means that some of the brain pathways become over active. NF-1 causes lumps which can affect the nervous system and the children will often have splodges on their skin called 'café au lait'. However, parents of children with NF-1 commonly tell you that the biggest problems for their children are social problems, clumsiness, attentional problems and learning problems. As such, NF-1 shares a lot of traits in common with autism. As we have a good understanding of the genetics and brain biology of NF-1, it is a useful model for autism; we can develop treatments for NF-1 which may also prove useful for people with autism too.**

## WHO ARE YOU?

### WHAT MADE YOU BEGIN RESEARCHING AUTISM?

I fell into autism research by chance. When I started my research work with children with NF-1 I found that parents were often telling me that the children had problem with friendships and for them , these seemed to be the biggest concern. These problems seemed to increase as the children became adolescents. In peer relationships, anxiety and getting on with their lives. This caused them problems everyday.

This led to me studying these problems a bit more in an attempt to understand what these problems were about. That's where I became interested in autism. I have always studies autism in the context of NF-1, but I have become more interested in autism in general.

### HOW WOULD YOU DEFINE THE AUTISM SPECTRUM?

Being a clinician, I always have a clinical understanding of what autism is in my head! Problems with communication, social interaction, a need for similarity, problems arising from sensory sensitivity etc. However, I would define autism as a way of understanding oneself and the world, which is different from the understanding of the majority of people around you.

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

Autism is such a spectrum condition. There are lots of different aspects to the condition communication, social issues, and motor problems. Our understanding of what autism is about is really very limited and the more research there is into the causes of autism and developing treatments, the more questions we have. As such, I don't think it's possible for one person to carry out research which can encompass all aspects of autism. We need collaboration with lots of talented scientists working alongside individuals affected by the condition to understand all the different aspects of autism.

## WHO ARE YOU?

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

Despite many decades of autism research, we have not moved much further in developing effective interventions. In my role as a clinician, there is an acknowledgement in the parents that I see, that we can offer the diagnosis, but we can't offer any treatment. They see their child struggle on a day to day basis and ask 'what do we do now?' I think we cannot progress with interventions without basic science research. The brain is a very complex organ and we know very little about the brain biology of autism. The reason for trying to understand this better is that if we don't understand what the underlying effects of autism are (in the brain) then we don't know how to offer effective treatments.

I'd like to think I will make a small contribution to improving our understanding of autism by the time I end my career. In particular, I hope that I can further our understanding of autism in the context of the genetic disorder I study, NF1, which contribute to an understanding of autism in itself.

I hope by using a model of NF-1 we might develop new interventions, including biological interventions which could sit alongside the current psychosocial interventions. By biological interventions I mean things like drug treatments, which might target the differences in brain biology and function in order to treat some aspect of the autism e.g. rigidity in thought causing problems with learning. The end goal would be to improve the quality of life for people with autism, who feel like they need that.

## WHO ARE YOU?

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

**My dream project would involve a personalised precision medicine based approach to offering treatment for people with autism. Autism is very varied and no two people with autism are alike, so why should the treatments that you offer be the same for everyone? The research project could take the form of a clinical trial, incorporating a mix of approaches stemming from basic science all the way to translational clinical work. For instance, using stem cell technology to study brain cells in a petri dish, which could help us to understand the brain functioning of a given individual and a uniquely tailored approach to intervention for that person.**

**THANK YOU SHRUTI**

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

## TAKE PART

### AUTISM IN WOMEN AND GIRLS

Autism@Manchester invites you to join us for two events that aim to enhance connections between the autism and research communities and to raise awareness about autism in women and girls. These events are free and open to all: autistic people, family members and friends, practitioners, academics and researchers. Please register using the links below. For more information about either event, please contact: [Kathy.Leadbitter@manchester.ac.uk](mailto:Kathy.Leadbitter@manchester.ac.uk)

### Seminar and Workshop: Postcards from an Aspie World

Hayden Larder, Helen Larder and Dan Redfearn

Mon 26<sup>th</sup> March 2018, 10:00am – 12:30pm (Registration from 9:30am)

Kanaris Lecture Theatre, The Manchester Museum

Hayden, Helen and Dan will give a presentation about their autism training resource for practitioners. The training resource is based on a series of postcards created by Hayden and her mother Helen that offer an insight from Hayden's life as a young woman with autism (see Hayden and Helen on ITV news [here](#)). Following the presentation, attendees will be given the opportunity to draw their own postcards documenting thoughts, emotions or struggles around all aspects of autism (but particularly the female perspective). These postcards will be documented on the Autism@Manchester website. For more information and to register, please visit our Eventbrite page: [Postcards from an Aspie World](#).

### Seminar and Poster Session: Uncovering Hidden Autism in Females

Hannah Belcher (Anglia Ruskin)

Monday 21st May 2018, 1:00 - 3:30pm (Registration from 12:30pm)

Kanaris Lecture Theatre, The Manchester Museum

Females with autism face longer waiting times to receive their diagnosis and many are not identified at all. Increased social motivation and social mimicking strategies are thought to be behind these difficulties in identification. This talk, given by Hannah Belcher who herself is diagnosed with autism, will discuss evidence supporting this theory and speculate on what research needs to uncover to improve the lives of females affected by autism (see more about Hannah's work [here](#)). Following the seminar, attendees will be able to talk to Autism@Manchester researchers and find out about their research. This will take the format of a 'poster session' where researchers display some of their work on large posters. For more information and to register, please visit our Eventbrite page: [Uncovering Hidden Autism in Females](#).

Following the seminar, attendees will be able to chat to Autism@Manchester researchers during a poster session where researchers display some of their autism research.



### GIVE EXPERT FEEDBACK ON A WORK-IN-PROGRESS FANTASY NOVEL



David Hartley

As a Creative Writing PhD student, I am currently in the process of writing a contemporary fantasy novel about autism and I am keen to have input from the autistic community. As much of my research for the novel has centred on representations of autism in works of science-fiction and fantasy (see 'Latest Findings' above), I am particularly aware of the challenges faced in faithfully and carefully depicting autism in fiction, especially as I am writing from my non-autistic perspective. Volunteers would be required to read a full draft of the novel and provide feedback on their reaction to the story, the characters and the writing style. Full instructions will be given, and only minimal amounts of feedback are expected.

The first full draft of the novel will be ready to read by the 31<sup>st</sup> March 2018. It will be approximately 125,000 words long and is intended for an adult audience as it contains some adult themes. Here is a little synopsis of the story, to whet your appetite...

#### Own World

*After the death of their mother, Leo Roberts moves back into his childhood home to look after his autistic sister, Teresa. It is a responsibility he has been expecting, but he's not ready for it, not quite yet. He shuts down his life, accepts his destiny, but there is one thing he cannot let go of.*

*Leo works for a secretive organisation who send him into the afterlife to rescue ghosts who have become stuck. He specialises in autistic ghosts and he enjoys his work more than anything else in his life. So, when an arrangement is made so that he can return to his job, he is overjoyed. But, as he crosses back over the threshold to the world of the dead, something has changed. Something is very, very wrong indeed.*

All participants will be given a copy of the draft in whichever format they prefer; printed or digital, along with a feedback questionnaire and further information about the expectations of the feedback. The timescale for feedback is flexible, however I would appreciate completion of the task by the end of May 2018.

If you would like further information about this task, or would like to take part, please contact me at [david.hartley@manchester.ac.uk](mailto:david.hartley@manchester.ac.uk). If the novel is eventually published, all chosen participants will receive a free, signed copy and an acknowledgement in the book.



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](mailto:andrius.vabalas@manchester.ac.uk)