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Winter Newsletter 2020

NEWS

Upcoming presentations

- Caroline Bond will present her inaugural professorial lecture on 'Educational psychology: bridging the research – practice gap in autism and education' at 17:00 on Thursday 13th February in the Cordingley Lecture Theatre, Humanities Bridgeford Street
- Emma Gowen will be presenting at Café Scientifique Thursday 2nd April 18:30 - 20:30

Grant success

- Alexandra Sturrock awarded £2000 from the Faculty of Biology, Medicine and Health Engaging Communities Fund for a project titled 'In their own words: When communication breaks down for children with autism'. Details of the event to be announced later this year.
- Salford Autism have received 12 months of funding from Salford Clinical Commissioning Group to: 1) deliver autism training to all health and social care workers and managers working in Salford 2) develop self-advocacy in Salford's autistic community

Publications

- Gowen, E. et al (2019) Instructions to attend an observed action increases imitation in autistic adults. *Autism*
- Sturrock, A. (2019) Observational and reported measures of language and pragmatics in young people with autism: A comparison of respondent data and gender profiles. *JADD*. [Open Access](#)
- Vabalas, A. et al (2019) Kinematic features of a simple and short movement task to predict autism diagnosis. *IEEE*



By Ketan Parmar, PhD student,
Division of Neuroscience and Experimental Psychology
University of Manchester

What was the study?

Visual sensory symptoms and eye conditions in autistic adults are poorly documented in the research literature. It suggests a greater need for spectacles and a higher number of eye-coordination problems, but this has been conducted on autistic children, mostly those with learning disabilities.

This study aimed to explore:

- what visual issues and symptoms are experienced by autistic adults and how these impact daily life;
- coping strategies for these visual experiences;
- the experience of an eye examination from an autistic person's point of view.

What we did

18 autistic adults (25-67 years, 6 females), without learning disabilities, took part in a focus group. Most wore spectacles, and there were some who had eye conditions.

We asked four key questions, related to our aims, during each focus group.



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LATEST FINDINGS

Investigating optometric and visual sensory symptoms in autism

What we found

- **Q1: Does anybody feel that they experience any visual problems or unusual visual symptoms?**

Participants expressed visual sensitivity issues related to light, colours, patterns, motion, and fine detail which varied from person to person. Discussions suggested, the greater the participant's understanding about the normal phenomena of the eye, the less stressed they felt about some aspects of their vision and eye health.

- **Q2: Do you feel you can do anything to improve these symptoms?**

Participants explained that visual symptoms usually occur as part of a multisensory experience. Strategies to cope with visual symptoms included avoiding visually cluttered environments, preferring certain types of spectacle frames and lenses, light alterations, but ultimately to endure these.

- **Q3: How do your visual issues impact your daily routine?**

Participants described negative impacts of visual experiences on their physical, mental and emotional wellbeing. These can also impact their home life, social life, ability to visit public places and travel. Although most participants explained the disadvantages of their visual issues, some described advantages. For example, sensitivity to detail was seen to be beneficial for fine arts.

Participants were generally disappointed with the public's understanding and perception of sensory issues that autistic people experience.

- **Q4: What are your experiences of eye examinations?**

Participants described the importance of accessible layouts and services in an optometric practice, and preferred to book appointments online. Practitioner continuity is strongly recommended, and they should be attentive, compassionate and understanding so that they can build a good rapport with the patient. Some participants expressed that optometrists need to provide clearer information and have a robust questioning technique.

Investigating optometric and visual sensory symptoms in autism

What we found (cont)

Participants said that information about what to expect prior to their eye examination would better prepare them for each stage of their visit. Practitioners should ensure that patient queries are fully addressed to avoid unnecessary stress.



Fig 1. An eye examination.

Autistic adults are largely dissatisfied with their vision, and experience a range of visual symptoms, which vary from person to person. Autistic adults employ a variety of strategies to overcome these visual experiences, which can have both positive and negative impacts on daily life. Eye examinations are currently not very accessible for many autistic individuals; improvements can be made to make these more “autism-friendly”.

What we are doing next

This study has formed the groundwork for the next part of this project which will explore the types of eye conditions present in an autistic adult population and how treating these may impact vision, visual symptoms and quality of life. We will be providing eye examinations for autistic adults at the University of Manchester for this. Please see page 11 for more details.



By Siobhan O'Hagan,
Trainee Educational Psychologist,
University of Manchester

School can present many challenges for autistic girls such as understanding unwritten social expectations and navigating peer relationships which with age become increasingly complex. Girls may be more likely to internalise their feelings and appear to be able to manage and cope within the learning environment. Therefore, their difficulties can go unnoticed by school staff until behaviours such as *emotionally based school avoidance* (EBSA) arise. It is important that education professionals are aware of how girls can be supported to return to school, integrate with their peers and meet their academic potential.

What was the study?

The aim of the study was to explore the supportive factors that have helped autistic girls who have experienced EBSA return to and thrive in school. We interviewed three autistic girls from different high schools who had successfully re-engaged in formal education following a period of EBSA, their parents and their key adult in school. We identified themes of supportive practice in schools.



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LATEST FINDINGS

Autistic girls emotionally based school avoidance

What did we find out?

This was the first study to explore the supportive factors for autistic girls who have successfully re-engaged with mainstream education following EBSA. A shift of research focus onto autistic girls who have overcome barriers to education and who are thriving in school has highlighted pathways to successful re-engagement. Psychological factors which support re-engagement include a sense of belonging, identity, safety, acceptance and motivation which are developed through trusting staff and student relationships, pupil participation, psychoeducation, social skills teaching, friendship and good autism practice including safe spaces and a flexible approach.

What does this mean?

Positive staff and peer relationships appear to underpin good educational experiences for autistic girls. Friendship was important to all the girls in this study and they benefited from feeling connected to others and having a sense of belonging to the school community. The relationship between the young person and key adult provided a secure foundation for which the young person's skills could be developed. This relationship was key to pupil participation and more in-depth social skills and mental health support being successful. The supportive factors for autistic girls to re-engage in education following EBSA are likely to also be preventative factors to EBSA and may be considered as good practice in autism education.

WHO ARE YOU?



I am Dr Jaleel Miyan. I am a Senior Lecturer in Neuroscience. This means that I study the central nervous system and brain.

My research interests include Cerebrospinal fluid and its essential role in development of the cerebral cortex. Cerebral folate metabolism and how this goes wrong in conditions affecting the brain.

Outside of work I enjoy riding my motorcycle, walking over the hills and countryside as well as aircraft and flying.

What made you begin researching autism?

Initially it was my interest in cerebral folate metabolism and the role of cerebrospinal fluid in some aspects of folate metabolism and transport around the brain. There is increasing evidence that certain types of autism are rooted in a cerebrospinal fluid problem and associated folate problem. [Recent publications](#) demonstrate that babies born with accumulation of fluid around the outside of their brain, which resolves by 2-3 years of age, develop autism over the same time course. [Other research](#) demonstrates that autistic children show improved language and social abilities with high dose natural folate supplements.

In addition, my research on neuro-immune connections has demonstrated that the brain receives information about host challenge way before the immune system and is involved in coordinating the response through activation of the bone marrow and/or by release of memory cells from lymph nodes.

WHO ARE YOU?

What made you begin researching autism? (cont.)

It seemed to me that the two areas of research came together with a bit of light bulb moment in thinking about how the differently developed autistic brain may then produce a susceptibility (as we all probably have) to specific host challenges which then cannot be eliminated and result in a chronic change in behaviour. This hypothesis forms the basis of a grant application we have just submitted to test the idea. The underlying host challenges may be embedded in the co-morbidities that individuals with autism commonly have.

More recently, I have been working with colleagues at Manchester Metropolitan University who have personal interest in autism through their children and have been investigating some new avenues of biomedical research that show links to this condition.

How would you define the autism spectrum?

Based on the above, I would define Autism as a complex picture of phenotypes based in developmental events that shape the behaviour of, and responses of individuals on the spectrum. I believe it may be that this complex picture is a consequence of developmental events throughout development of the central and peripheral nervous system, most particularly the gut nervous system and the connections between cortical and sub-cortical structures in the brain. These will have an impact on peripheral neural control of all organ systems including metabolism in the liver, cardiovascular health, physiological health and haemopoiesis and immunity.

WHO ARE YOU?

Is it possible to carry out research in your field which applies to all aspects of the autism spectrum?

I believe so but we will know better after the research project to test the association of neuro-immune issues underlying comorbidities in autism.

How valuable do you expect your research to be with autistic people, or society at large, and why?

Our understanding of the cerebral folate system and its key role in development of the cerebral cortex is now ready for translation into a human trial of cerebral conditions, including, we hope, Autism, through maximising and optimising the development. Most cerebral conditions, including hydrocephalus, autism, schizophrenia, bipolar etc, have not been successfully assigned to genetic factors. More likely they are based in epigenetic errors which comes back to folate insufficiency/imbalance since folate is the methyl donor for these processes. Moreover, environmental toxins seem to affect the folate-methylation pathway more than any other biochemical process. I am really excited to take our treatment into a population study to assess which conditions respond to folate supplements.

What research idea would you like to pursue if funding was no barrier?

To test the idea that cerebral conditions are based in a cerebral folate issue elicited by a cerebrospinal fluid drainage problem. This could have occurred through development, or at any time in life through infection, inflammation or trauma that affected the drainage cells and thereby resulted in a cerebral folate condition. Trialling of our treatment would be a great way to identify those conditions that respond and those that don't at a population level.

Thank you Jaleel

TAKE PART

Join the Expert by Experience Virtual Group

There are opportunities to join the Autism@Manchester Expert by Experience Virtual group. The group aims to connect the autism community with researchers by sharing information about research projects online. Members of the virtual group are asked to provide comments on materials that researchers send via a LISTSERVE mailing list (email). As the aim of the group is to get advice from people with a lived experience of autism, group members consist of autistic adults, parents, carers and family members of children or adults with autism.

To become involved, please contact Dr Emma Gowen

(emma.gowen@manchester.ac.uk) after downloading and reading the induction pack found here (click on the virtual tab):

<http://www.autism.manchester.ac.uk/connect/expert-by-experience/>



TAKE PART

Autistic adult volunteers needed for a study looking at vision and eye conditions



Ketan Parmar

Researchers at the University of Manchester are looking for autistic individuals to take part in a study which is looking at vision and eye conditions in autistic adults. These conditions include visual sensory issues (e.g. hypersensitivity/sensory overload), problems with level of vision, the need for spectacles and issues with the coordination of the eyes (e.g. a lazy eye). To be eligible you need to:

- Have a diagnosis of autism, without a diagnosis of learning disabilities
- Be aged 18 year or over
- Able to travel to the University of Manchester

IMPORTANT: You do not need to have an existing eye condition to take part. If you think your eyes and vision are okay, we would still like to see you.

This study involves completing a series of questionnaires and undergoing a full eye examination by a fully qualified Optometrist. It will take place at the Carys Bannister building at the University of Manchester and on completion of the eye examination you will receive a personal portfolio containing your spectacle prescription and other eye care information relevant to you. You will also be given any required treatment (spectacles or eye exercises). Thereafter, you will be required to attend for additional visit(s) at which you will either undergo some eye tests or complete further questionnaires.



TAKE PART

Autistic adult volunteers needed for a study looking at vision and eye conditions

All participants will be required to attend two visits for this study, the first lasting approximately 3½ hrs (excluding optional breaks) and the final lasting approximately 40 mins. Those participants who are given treatment may be required to attend up to an additional 6 visits depending on the treatment given.

This study is being conducted by Ketan Parmar, a fully qualified Optometrist, under the supervision of Dr Emma Gowen, Prof Christine Dickinson and Dr Catherine Porter. For more information or if you would like to take part, please contact:

Ketan Parmar: Ketan.parmar@postgrad.manchester.ac.uk

This project has been reviewed and approved by the NHS research ethics committee, reference: 271545

If you have any comments on this newsletter,
please contact
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