This is the first autism@manchester newsletter. In this edition you will find:

- A summary of findings from recent studies investigating social inclusion and wellbeing in autism. (page 2-3)
- Professor Neil Humphrey answers a number of questions which were pre-selected by some of our contacts in the autistic community (pages 4-5)
- Details of opportunities to take part in research (pages 6-7)

For more information about our research group visit: http://www.autism.manchester.ac.uk/

AUTISM@MANCHESTER

Autism at Manchester are a network of researchers, practitioners and individuals from the autistic community based within Greater Manchester. The group is chaired by Dr Emma Gowen, who is on parental leave. Peter Baimbridge is current acting chair.

The steering committee of autism@manchester are:

You can find out more about the steering committee at http://www.autism.manchester.ac.uk/about/people/

NEWS

On 15.2.17 at 5pm Dr Caroline Bond will be presenting an open lecture on the topic of:
70 years of autism education research: where are we now?
In the Ellen Wilkinson building at the University of Manchester. If you would like to attend please email us on autism@manchester.ac.uk

Paper published:
Poole, Gowen, Warren & Poliakoff (2017) Brief report. Which came first? Exploring crossmodal temporal order judgements and their relationship with sensory reactivity in autism and neurotypicals. Journal of Autism and Developmental Disorders. This article is open access and free to download from:
Statistics show that children with Autism Spectrum Conditions (ASC) are more likely to experience social rejection and bullying than their mainstream peers and children with other Special Educational Needs.

In 2016 the National Autistic Society launched a campaign to promote awareness raising of ASC including assembly and lesson materials for primary and secondary schools. Although awareness raising strategies are important in promoting positive peer attitudes, research also shows that teaching peers’ key skills to enable them to interact successfully with pupils with ASC alongside awareness raising strategies are needed (Humphrey & Symes, 2011). The ‘Saturation Model’ (Morewood, Humphrey & Symes, 2011) is a good example of how whole school awareness raising activities can be supplemented by more formalised peer support strategies in the context of a mainstream secondary school.

The lead author recently developed a peer support intervention for use in mainstream primary schools, which aims to raise awareness of ASC and teach peers key skills to interact with pupils with ASC. The initial piloting of this intervention with a pupil and his peers in one school has shown promising outcomes for the pupil and peers and was well received by school staff. The research also supports previous research findings which have shown that when introducing peer support interventions it is important to plan collaboratively with pupils, parents and staff so that the intervention is individualised and issues such as pupils’ awareness of their own diagnosis, parents’ views and staff awareness of ASC can be managed sensitively.
Happiness, wellbeing and quality of life are all subjects of interest that have been researched extensively in the general population. There is little to no research however in these areas in terms of adults with an autism spectrum condition (ASC) diagnosis despite a global acknowledgement in the importance of them for humankind to live a good, meaningful life.

87 participants with a diagnosis of ASC completed questionnaires that looked at varying aspects of happiness, joy, quality of life and loneliness. 25 participants also partook in in-depth interviews to share their experiences of wellness, happiness and joy.

A particularly interesting finding was that wellbeing for adults with ASC is conditional on the quality of social relationships as well as the quality of communication with other people. This will probably come as no surprise to many people, especially those with ASC. Fundamentally the needs of adults with ASC with regards to wellbeing, happiness and joy are no different to neurotypical adults. There are the same internal and external desires for collective support and companionship, however the barriers to achieving this seem to be down to the ability for all, both those with ASC and neurotypicals, to embrace difference, accept that everyone has their own quirks and peculiarities to personality and be open to experiencing difference. What needs to be considered more deeply in future research is that the main predictors of quality of social relationships and communication is the ability for all to be tolerant, accepting and open to difference.

There is a lot more to be shared but hopefully this first insight will help to open to the mind to how all can support everyone to achieve a better quality of life and higher levels of well-being. This study has been highly dependent on the willingness and openness of the participants to share so poignantly their experiences of life.
Neil: When I went to secondary school in the early 1990s Autism and Asperger’s were not particularly well known. We had a friend of the family who was about my age who had Autism and profound learning difficulties, so I was aware of autism at a time when most people were not aware of the condition. Also, I was a volunteer befriender for the National Autistic Society (NAS) early in my career. They have a scheme where you are matched up with somebody with autism and you develop a relationship with them. I was matched with a young man who had a special interest in academia and university. That was a nice match as that was my job! He used to come into my office sometimes and we’d have a chat over a coffee. These experiences raised questions for me that have influenced my work. For instance, issues around when diagnosis happens, whether diagnosis is helpful or a hindrance. There are people who work in the academic community who are dead against labels for autism and consider it damaging, but there are many individuals who consider their diagnosis an essential part of their identity. Those early experiences have fed into that understanding that there is no simple answer to those questions.

WHAT MADE YOU BEGIN RESEARCHING AUTISM?

Neil: One of the useful definitions I have come across is the idea that people with autism might struggle to make sense of the world around them. That may be the social world, or the sensory world, but its about how people make sense of the world which is external to them and how that relates to them as an individual.

Also for me, I have come to think about autism in terms of strengths. We tend to focus on the difficulties, but I think there is a real need to think about what the strengths are that we often see in children that identify as being on the autistic spectrum. They are not present in every individual and they expressed in different ways, but we can talk about how autism can enable people to achieve things that they could not do without it. There is a famous phrase “if you’ve met one person on the autism spectrum, then you’ve met one person on the autism spectrum.” I think that’s an important thing to understand. There is a general set of characteristics which you will read in a book, but actually that is a very small starting point as each individual is so different. I increasingly try and keep neutral terminology in my writing which reflects this conceptualisation of autism. For instance referring to people who identify as being on the autistic spectrum rather than autistic spectrum disorder as I think that ‘disorder’ has a judgement attached to it.

My definition is therefore one which I would hope is quite a balanced view. Which recognises there are social challenges, but also there are strengths which are brought by autism.
Neil: Good question. I suppose the short answer is no. What we can do very well in autism research is add incrementally to our knowledge about autism, but by necessity that focus means that there are some things which you cannot take account of. That is, therefore, the beauty of having a community of researchers, like we have here at Manchester, but also across the UK and the world. Everyone is doing focused bits and collectively, there is a body of knowledge which comes together.

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

Neil: I hope its valuable, or I wouldn’t do it! I think where my work would be valuable to the autism community is shedding light on experiences of young people. For instance, when we started a study of inclusion of children on the autism spectrum in 2008 at that point it was the first study to focus on large numbers of children who were being ‘included’ but nobody was really looking at their experiences. I think we helped to kick start a focus on the experiences of children on the autism spectrum surrounding education more generally. Hopefully we are giving autistic children a voice, and one of the key things we’ve done is making sure that the perspectives of young people with autism are at the forefront of our work. To date, the most highly cited paper I have written is a study I did with 20 or so teenagers who were on the autism spectrum who were being educated in mainstream school and they told me about their experiences, things that went well, things that didn’t. Hopefully that gives them a voice they would not have otherwise.

I think it is an important thing that the voice of the autism community is always directly included in research. I think that comes through with critical autism studies and work from actually autistic researchers. I think this brings real value for teachers, policy makers and people who are determining provision for people on the autism spectrum on how to support people with autism well and things that were not immediately obvious if you don’t work in the field of autism minor, but important adjustments that may be needed and can make a huge difference to a child on the autism spectrum in that classroom. So I hope that my work has value in that sense.

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

Neil: At the moment I think there is a gap in the research in terms of looking at the transition from compulsory education to moving to the adult world whether that is further study, employment or just sitting at home. I think there is a huge gap there in terms of knowing what happens to people and how people can be best supported. If you look at the statistics about the number of autistic people who are engaged in gainful employment or further study those are very worrying. We have a system where autistic people ‘age out’ beyond compulsory education and are considered an adult there is a gap which young people can fall into. There might be a lack of continuity where they go from being well supported during secondary school to having no support in the adult world. I think a lot of the negative outcomes we see in adults with autism, whether that be employment or mental health, I suspect that will have roots in that transition from being a young person in education to an adult in the adult world and how well that transition is managed. If funding was no object and time was not an issue I’d love to do a study looking at these issues.
We are a team of researchers from the University of Bolton with a keen interest in emotion understanding in individuals with Autism Spectrum Condition. More specifically, we are interested in gaining a better understanding of the processes associated with correctly identifying emotions from a number of stimuli such as pictures and spoken sentences. We hope that by doing so we may contribute to a better knowledge of the factors contributing to atypical social skills in Autism.

We are looking for participants with a diagnosis of Autism Spectrum Condition, without sensory difficulties (i.e. reduced vision or hearing), who are willing to come to University of Bolton to take part in our study. Participants of all ages and gender are welcome.

Participation involves completing a couple of questionnaires on cognitive and behavioural profile (should not take more than 15 minutes) and watching and listening to a number of stimuli and identifying the emotion being portrayed (should not take longer than 30 minutes). Should you require additional information, please contact Pedro Vital: Tel: 01204903685 email: p.vital@bolton.ac.uk

Are you an adult diagnosed with autism? Are you a parent or carer of a child diagnosed with autism? Do you have an interest in autism-related research?

Autism@Manchester is keen to develop its ‘experts by experience’ group, which act as an advisory group for research studies to help researchers consider the perspectives of people on the autism spectrum and their families when planning research.

The group meets monthly for discussions, presentations and research updates.

If you are interested in getting involved, please contact autism@manchester.ac.uk
We are running a study to investigate how people with autism spectrum condition respond to viewing different types of visual stimuli in the world around them, which could help explaining some of the sensory symptoms in autism.

To be eligible, we need volunteers with a diagnosis of autism or Asperger’s Syndrome with the following criteria:

• Be aged between 18-45
• Have English as your first language
• Have no history of any eye conditions, such as squint or lazy eye (glasses or contact lenses are fine)
• Have no psychological illness

What will you be asked to do if you take part:

Some tasks involving looking at patterns on a screen:

An IQ test:
(this is used to match up non-autistic controls with those in the autistic group)

All volunteers will be reimbursed for their time and reasonable travel expenses. If you would like more information about the study, or would like to take part, please contact Sabrina at:
nursabrina.subri@postgrad.manchester.ac.uk

If you have any comments on this newsletter, or would like to contact the steering committee, you can email us on autism@manchester.ac.uk