

# ASD-UK and Dasl<sup>n</sup>e Research Newsletter Spring/Summer 2017



## The databases support research leading to improved clinical services

### Blue Room Treatment

A treatment designed by Dr Jeremy Parr and colleagues at Newcastle University has shown to lead to improvements in tackling fears and phobias for children with ASD aged 7-17. The Blue Room Treatment provides an immersive virtual reality setting in which a therapist works with a young person on strategies to help deal with their specific anxiety, without needing goggles.

Examples of situations and phobias that have been treated in the Blue Room include fear of dogs, going shopping and crossing a bridge. A video showing the treatment can be found at [bit.ly/videoblueroom](http://bit.ly/videoblueroom)

The Blue Room Treatment is provided by the Complex Neurodevelopmental Disorders Service (CNDS) for Children and Young People. It is now available as an NHS service, with referrals accepted from all over the UK. For more information visit [www.ntw.nhs.uk/CNDS](http://www.ntw.nhs.uk/CNDS) or email [NTAWNT.cnds@nhs.net](mailto:NTAWNT.cnds@nhs.net)



### PACT Follow-Up



The Pre-school Autism Communication Trial (PACT) tested a parent-mediated therapy that aimed to help parents adapt their style of

communicating with their child with severe autism. It was shown to bring about positive changes in the way that the parent and child interacted with each other.

A recent follow-up study found that for children who received this therapy at age 2-4 years, the beneficial effects on symptoms and communication continued 6 years later, with children showing less severe overall symptoms, improved social communication and reduced repetitive behaviours.

The results of this follow-up study indicate that healthcare professionals should consider early psychosocial therapy for young children with autism, in line with NICE guidance. Read more about the findings of this study at: [bit.ly/PACT7-11](http://bit.ly/PACT7-11)

## More than one family a day joins ASD-UK and Dasl<sup>n</sup>e!

ASD-UK is the national research database of children with ASD across the UK. Dasl<sup>n</sup>e is the research database of children with ASD living in the North East of England. These are two separate but linked databases - families join one or the other, based on their location. We are delighted that more than **4000 families** of children with ASD have the opportunity to take part in research that aims to answer important questions about ASD, and which has the potential to lead to significant advances in the care and treatment of children with ASD.

- ⇒ **Over 2200 families** from across the UK have registered and consented to take part in **ASD-UK**
- ⇒ **Over 1900 families** from Northumberland, Tyne and Wear have registered and consented to take part in **Dasl<sup>n</sup>e**

This map shows you the number of families taking part in ASD-UK and Dasl<sup>n</sup>e in different regions across the UK.



## Studies recruiting participants

### What is the relationship between attention and learning?

Investigating the relationship between attention and learning for children with and without an Autism Spectrum Disorder

Miss Emily Grew, Dr Debbie Riby and Dr Mary Hanley, Durham University



Understanding how to support children in achieving their full potential at school is a vital part of education. To do this, we first need to understand what factors influence academic success. Research suggests that some cognitive abilities are related to academic

achievement – for example, children who have good attention skills may achieve higher grades at school compared to those who have poor attention skills. For children with an Autism Spectrum Disorder (ASD), this relationship is less understood. We know that children with an ASD can experience cognitive and behavioural problems that may impact upon their experience in school, and subsequently, their academic achievement.

The researchers at Durham University would like to investigate the relationship between cognitive ability and academic achievement in children with a wide range of abilities, both with and without ASD between 6 and 16 years of age. The study will involve completing five standardised assessments of cognitive ability and academic

achievement with each child. They also ask each child's parent or guardian to complete four questionnaires relating to the child's social behaviour, symptoms of anxiety, and their sensory experiences. The researchers are looking for children and young people with an Autism Spectrum Disorder aged from 6 to 16 years who are able to use simple phrases or speak in sentences. For more information about the study, please contact Emily Grew ([e.e.grew@durham.ac.uk](mailto:e.e.grew@durham.ac.uk)). **Recruiting in the North East of England.**



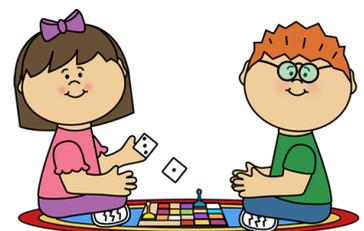
### Does your child process the world in a different way?

Autism: A look Behind the Scenes

Ms Jennifer Glennon, Professor Annette Karmiloff-Smith and Professor Michael Thomas, Birkbeck, University of London

For a child to be given a diagnosis of autism, they must show evidence of social and communication difficulties, and restricted, repetitive behaviour. There is, however, much more to autism than is clinically considered. Behind the scenes, autism is associated with greater attention to detail and a unique visual preference for objects over people. Indeed, it seems that individuals with autism process the world in a different way.

The researchers at the Centre for Brain and Cognitive Development (CBCD, Birkbeck, University of London) are using eye tracking and electroencephalography (EEG) technologies to explore visual and brain processes in children with moderate to severe autism aged between 6 and 10 years of age. They want to improve our understanding of what's going on behind the scenes. They hope that insights gained will inform intervention practices, promote earlier diagnoses and, ultimately, improve quality of life for children with autism. If you would like to take part or hear more about the study, please contact Jennifer Glennon ([jglenn01@mail.bbk.ac.uk](mailto:jglenn01@mail.bbk.ac.uk)). **Recruiting in London and the surrounding areas.**



## What is the role of sleep in memory consolidation?

### **SleepSmart**

*Dr Victoria Knowland and Dr Lisa-Marie Henderson, University of York*



Sleep difficulties occur in approximately 70% of children with ASD, who exhibit a broad range of language abilities. SleepSmart is the first investigation into whether atypical sleep patterns relate to individual differences in language development in children with ASD as well as those with language learning impairments (LLI) without ASD.

The researchers aim to recruit 30 typically developing children; 60 children with ASD (30 with co-occurring language impairment) and 30 children with LLI but without ASD between 8 and 12 years of age. Children are assessed in a location most convenient for the family. The assessments include cognitive and language ability, ASD diagnosis, and memory tasks. Tests of memory for will be applied after periods of both sleep and wake. Test sessions last no more than an hour.

Parents are asked to complete a series of standardised questionnaires about their child's autism symptoms, communication ability, behaviour and sleep habits, along with a brief sleep diary during the week of the experiment.

Sleep patterns are recorded in children's homes using a portable polysomnography (PSG) unit on the night following training to enable correlations between overnight changes in learning and aspects of sleep. Before this session, participants are introduced to all parts of the equipment and set up.

A short video is available to participants in which a PSG setup is demonstrated:  
<http://www.york.ac.uk/psychology/research/facilities/slam/sleep-smart-study/>.

If a child is found to be anxious regarding the PSG monitoring, alternative options are discussed with parents (e.g. wearing an actiwatch without accompanying PSG). To take part in the study, children should be able to communicate in at least simple sentences.

For more information about the study, please contact Victoria Knowland ([sleepsmart@york.ac.uk](mailto:sleepsmart@york.ac.uk)). **Recruiting within 50 miles of York.**



## What could help children with eating, drinking and swallowing difficulties?

The National Institute of Health Research (NIHR) is funding a research study that aims to investigate interventions for children with eating, drinking and swallowing difficulties. This research is being carried out by the members of the Neurodevelopment and Disability group at Newcastle University, together with national partners.

More information about this study will be available from late Summer 2017.



Pictured: Dr Jeremy Parr and Dr Lindsay Pennington, Newcastle University

## The ASD-UK and Dasl<sup>ne</sup> Team



### Back row, from left

Dr Jeremy Parr (ASD-UK Lead)  
Alison Mulvenna (Dasl<sup>ne</sup> Co-ordinator)  
Ann Payne (ASD-UK Administrator)  
Dr Alex Petrou (ASD-UK Co-ordinator)

### Front row, from left

Dr Faye Buckingham (ASD-UK Programme Administrator)  
Prof Helen McConachie (Dasl<sup>ne</sup> Lead)  
Richard Hardy (ASD-UK & Dasl<sup>ne</sup> IT and database support)

## ASD-UK and Dasl<sup>ne</sup> Team Updates

After 12 marvellous years, the Dasl<sup>ne</sup> co-ordinator Mary Johnson (pictured right) is retiring. Alison Mulvenna (pictured above) is taking over the role. Welcome Alison! ([daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk))

In November 2016, Faye Buckingham (pictured above) took over as ASD-UK Programme Administrator ([asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk))



## James Cusack, Director of Science, Autistica



James recently wrote an editorial article for the journal 'Autism', in which he discusses the importance of involving people on the autism spectrum and their families in research, in order to ensure that studies are relevant and reflect what the autism community wants from research. He writes that by working together in this way, there is greater opportunity to achieve the aim of providing longer, happier and healthier lives for autistic people and their families.

You can read this article online at [bit.ly/JamesCusack](http://bit.ly/JamesCusack)

## Joining ASD-UK or Dasl<sup>ne</sup>

If you have not yet had a chance to complete your consent form & questionnaires so you can take part in either ASD-UK or Dasl<sup>ne</sup>, please contact us if you need another pack, or join online at:

**[www.asd-uk.com](http://www.asd-uk.com)** (for families across the UK)  
or  
**[www.daslne.org](http://www.daslne.org)** (for families in NE England)

If you would prefer not to take part, or receive newsletters, please let us know and we will remove your details from the list of families who have contacted us. If you would like to take part in the future, please do contact us. We would like to hear from you.

## Contact ASD-UK

Institute of Neuroscience  
Henry Wellcome Building  
Newcastle University  
Framlington Place  
Newcastle upon Tyne  
NE2 4HH

**Tel:** 0191 282 5965 **Email:** [asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk)

## Contact Dasl<sup>ne</sup>

Institute of Health and Society  
Newcastle University  
Sir James Spence Institute  
Royal Victoria Infirmary  
Newcastle upon Tyne  
NE1 4LP

**Tel:** 0191 282 1400 **Email:** [daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk)

 Autism Spectrum Database—UK

 @asd\_uk2011 #asduk

 Dasl<sup>ne</sup>



**Moving House? Have you changed your email address recently? Please help us make sure we have the correct contact details for you, otherwise we can't easily get in touch with you about research. Please fill in the form below and send it to us, or email [asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk) or [daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk)**

**Child's Name:** \_\_\_\_\_ **Telephone No:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Postcode:** \_\_\_\_\_

**Email:** \_\_\_\_\_