

ASD-UK and Dasl^{ne} Research Newsletter Autumn 2016



More than one family a day joins ASD-UK and Dasl^{ne}!

ASD-UK is the national research database of children with ASD across the UK. Dasl^{ne} 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 over **3750 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.

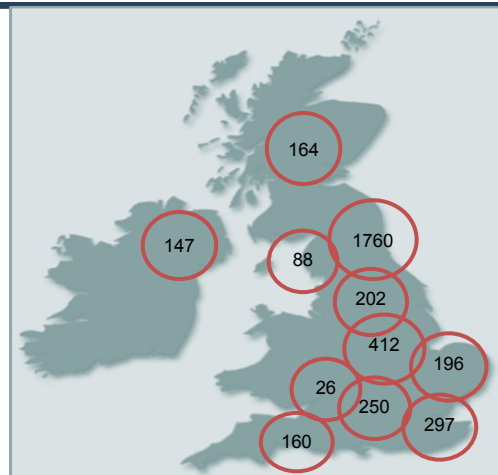
ASD-UK Update

⇒ **ASD-UK now has over 2000 families** who have registered and consented to take part across the UK

Dasl^{ne} Update

⇒ **Dasl^{ne} has over 1750 families** who have registered and consented to take part from Northumberland, Tyne and Wear

This map shows you the number of families taking part in ASD-UK and Dasl^{ne} in different regions across the UK



Royal College of General Practitioners - ASD is a Clinical Priority

Parents' experiences of GPs varies—some are knowledgeable about autism and some are not. Dr Carole Buckley, The Royal College of General Practitioners (RCGP) **Champion for Autism**, tells us what the RCGP is doing to address the problem.

RCGP made ASD a clinical priority for three years in April 2014. A survey of GPs revealed that 40% had had no training in autism at either undergraduate or postgraduate level. Despite this, the GPs who were surveyed scored well in their knowledge of autism; however, they lacked confidence in their ability to support patients with a diagnosis of autism and were very critical of the lack of specialist service provision.

As part of action on the clinical priority, the RCGP has endorsed an **Autism charter**, and created tools and resources that are "GP friendly" to support GP practice staff in becoming more accessible to patients with autism. The resources are aimed at both improving the pathway to diagnosis and highlighting the reasonable adjustments practices need to make. Training materials have been developed, with help from the Autism Alliance, available to cascade to all practice staff.

The Department of Health sponsored an information resource pack, which was delivered to 7000+ practices in England in May 2016. This resource pack included information and a poster about **ASD-UK**.

All the resources described above have been collated into an **Autism toolkit** which is freely available on the RCGP website (www.rcgp.org.uk/asd). There are also links to other useful websites, and it is hoped it will become a 'one-stop-shop' for GPs and practice staff when they have queries related to autism. RCGP is now evaluating the impact of the work by registering website visits, collating feedback, and conducting a survey of practices to measure the use of the resource pack. The work to maintain understanding of ASD in GP practices will be on-going, with a greater presence of autism in the GP training curriculum, and the toolkit will remain available.

Studies recruiting participants

How does your child see the world?

Seeing the world differently

Prof Liz Pellicano, UCL Institute of Education, London.



When most people process information coming into our senses, we relate what we see, touch, and hear to our past experience. The research team are looking at whether the sensory sensitivities experienced by children with ASD might be a result of differences in the way that they interpret this incoming information. They are testing this possibility within a fun science club called Brain Detectives. These are half-day workshops which give children and young people with autism a chance to take part in on-going research, including the 'Seeing the World Differently' project, and at the same time learn about how the brain and mind work. The research team are still recruiting as they want to try and reach their target number of participants. If you know somebody who would like to take part, you can find out more here: bit.ly/1u9ZGNP or you can email the team at BrainDetectives@ioe.ac.uk. **Recruiting in London and surrounding areas.**

Is your child good at planning and remembering?

The think and do project

Catherine Wen and Dr Jacqui Rodgers, Newcastle University

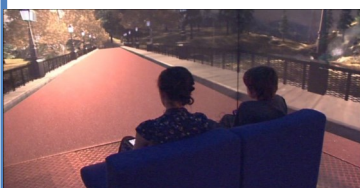


'Executive function' is a term used to describe a wide range of everyday abilities considered to be necessary for day to day living. It includes skills like being able to plan tasks and activities, pay attention to and remember important information. Children with autism spectrum disorder (ASD) are often reported to experience executive function difficulties, which can result in having trouble concentrating on chores and schoolwork or getting used to new situations. The research aims to provide information on the executive functions which may underlie everyday behaviours and ASD characteristics in children with ASD, and potentially could inform new educational strategies. The researchers are looking for children with ASD, aged between 6 and 11 years old, who don't have learning disability (LD) and/or attention deficit hyperactivity disorder (ADHD) - and their parents/ carers. If your child may be interested in answering some questions and completing some games on the researcher's computer, please email y.wen4@ncl.ac.uk.

Recruiting in the North East of England

The Blue Room study—what happened next.

In 2012, several Daslⁿe families took part in a study to see whether virtual reality could help children to overcome specific fears or phobias (such as dogs, pigeons or speaking to a shop assistant). The young person sits inside the 'Blue Room' with a therapist while images are projected on the walls, floor and ceiling of the Blue Room which replicate the young person's individual situation-specific anxiety, increasing the difficulty in small steps. A video showing the therapy can be seen at <https://www.youtube.com/watch?v=9U-rRC8jc28>.



The therapy has been shown to have a lasting effect – from the research and clinical information available at present, most children who benefit continue to do so after 12 months. A larger study with 32 children years has been taking place, and the results will be known early in 2017.

The therapy is available now within the NHS, for children aged 7 to 17 years, through the Complex Neurodevelopmental Disorders Service, Northumberland, Tyne & Wear NHS Trust. Referrals should be sent from GP or child health team, by email: CNDSadmin@ntw.nhs.uk. More information is available at: <http://www.ntw.nhs.uk/sd.php?l=2&d=9&sm=37&id=276>.

Study findings

British Autism Study of Infant Siblings (BASIS)

Prof Mark Johnson, Birkbeck, University of London



Many people on the autism spectrum show a skill for noticing details; for example, the autistic artist Stephen Wiltshire draws highly accurate representations of cityscapes from memory. The **STAARS** study aims to find out whether those perceptual skills are present early in infancy, before the appearance of symptoms of autism.

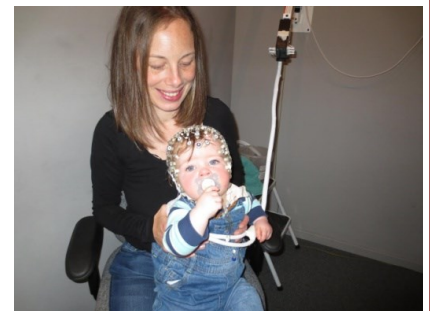
To answer this question about early perception, the research team took advantage of the fact that infants will spontaneously look towards anything that stands out in a visual scene, for example, the letter S in a group of X's. To test the infants' perceptual skill, we placed them in front of an eye-tracker. The eye-tracker measures where infants look as they are presented with arrays of letters on a screen. What the team found was that, when they were 9 months and again at 15 months of age, those infants that later received an ASD diagnosis were better at spotting the odd one out letters. They also found that this skill predicted children's later ASD symptoms, but was not related to whether they might have symptoms of ADHD.

These findings suggest that detail-focused perception is a central feature of autism. It is indeed the sensory aspects of social interaction, but also of many other events of daily life, that people with autism often report as distressing. The team hopes this study and others will increase understanding of why this is the case, and whether detailed perceptual skills can be used for benefit without affecting people's lives in a negative way. Please contact mark.johnson@bbk.ac.uk if you would like further information.

One family's experience of taking part in STAARS

Following my son M's autism diagnosis, I decided that I really wanted to support research into autism. I feel that research is the best way to enhance both our understanding of autism, and the life experiences of people with autism, and their families.

Apart from joining Daslⁿe, my first opportunity to participate in research came when I saw an advert in the National Autistic Society's 'Your Autism' magazine for the STAARS project. STAARS is studying the development of infants between the ages of 5 months and 3 years, with a full sibling or parent with an autism or ADHD diagnosis. At that point my second son T was 8 months so I thought, this is for us!



After establishing our eligibility, the process has so far involved two visits to the Babylab at Birkbeck, University of London, when T was 10 and 15 months old. Visits involved spending around one day at the University (although timings and everything about the visit is tailored to suit you and your baby). T was observed completing tasks such as playing games, and watching faces and animations on a screen. During some tasks, T's eye movements were tracked using an eye-tracker; temperature was measured using a special babygro suit; and brain activity recorded using a sensor net. T was not too keen on wearing the sensor net, but that was not a problem; the researchers understand that children don't always cooperate, and they put the needs of the child and parent first. We also completed a number of questionnaires prior to both visits, and also when T was 2 years old (we couldn't attend the 2 year visit due to ill health).

If I am completely honest, there have been both positives and negatives to taking part in STAARS. The whole research team are lovely, the trip was really well organised and everyone was great with T. My partner and I also enjoyed being able to spend a little bit of time in London. T and I enjoyed our visit to the Babylab; both days were fun and interesting. On the downside, it was tiring to travel to London from Newcastle with a baby, and I found it difficult to find the time to complete the questionnaires. We also tried to take M with us for the first trip, but that did not work very well. Overall though, we have thoroughly enjoyed participating in STAARS, and I'm pleased we have contributed to this important project.

The ASD-UK and Dasl^{ne} team



Back row, from left

Richard Hardy (ASD-UK & Dasl^{ne} IT and database support)
Jane Tilbrook (ASD-UK Administrator)
Debbie Wilde (ASD-UK Programme Administrator)
Sarah Nolan (ASD-UK Administrator)
Dr Jeremy Parr (ASD-UK Lead)

From left, front row

Mary Johnson (Dasl^{ne} Coordinator)
Dr Alex Petrou (ASD-UK Coordinator)
Prof Helen McConachie (Dasl^{ne} Lead)

James Cusack, Research Director, Autistica

Autistica are very pleased to have led a recent project that identified the most important topics for autism research. Parents of children with autism and autistic adults and their relatives worked together with health and education professionals and researchers to come up with a 'Top Ten' list of important research questions. Some of these questions are: 'Which interventions improve mental health or reduce mental health problems in autistic people?'; 'Which interventions are effective in the development of communication /language skills in autism?'; 'How can parents and family members be supported/educated to care for and better understand an autistic relative?'



The full list can be found at: <https://www.autistica.org.uk/research/top10/>. Autistica and other research funders will now use this list of priorities to help decide what research to fund in the coming years.

Joining ASD-UK or Dasl^{ne}

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^{ne}, please contact us if you need another pack, or join online at:

www.asd-uk.com (for families across the UK)
Or
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

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Newcastle University
Framlington Place
Newcastle upon Tyne
NE2 4HH

Tel: 0191 282 1380 **Email:** asd-uk@ncl.ac.uk

Contact Dasl^{ne}

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Newcastle University
Sir James Spence Institute
Royal Victoria Infirmary
Newcastle upon Tyne
NE1 4LPT

Tel: 0191 282 1400 **Email:** daslne@ncl.ac.uk

 Autism Spectrum Database—UK

 @asd_uk2011 #asduk

 Dasl^{ne}



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 or daslne@ncl.ac.uk

Child's Name: _____ **Telephone No:** _____

Address: _____ **Postcode:** _____

E-Mail: _____