

# ASD-UK and Dasl<sup>n</sup>e Research Newsletter Autumn 2015



## Over 3300 families have now registered with 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 databases - families join one or the other, based on their location. We are delighted that over **3300 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.

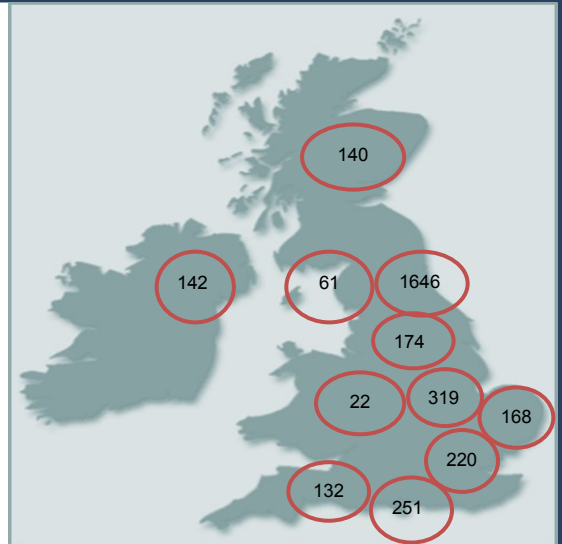
### ASD-UK Update

- ⇒ **ASD-UK now has nearly 1700 families** who have registered and consented to take part across the UK

### Dasl<sup>n</sup>e Update

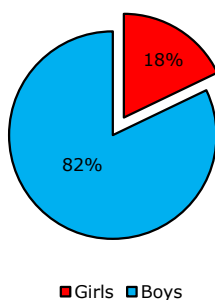
- ⇒ **Dasl<sup>n</sup>e has over 1600 families** in Northumberland, Tyne and Wear

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

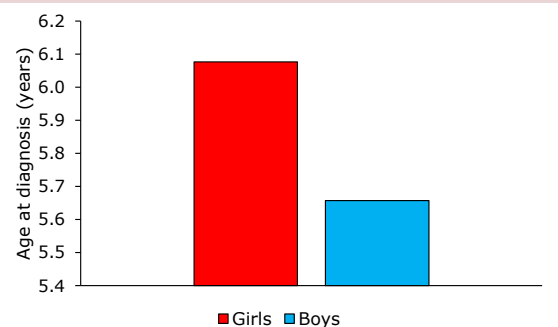


## Girls and Autism

Autism is known to affect boys more than girls. However, in the coming months, researchers at Newcastle University will be exploring what the differences are between girls and boys with autism and whether autism characteristics present differently in girls. Topics to explore will include whether there are gender differences in language ability, IQ, problem behaviours and coping.



As expected, there are about 4 boys to every 1 girl who are registered with ASD-UK and Dasl<sup>n</sup>e.



Age at diagnosis is, on average, rather similar between girls and boys who are registered with ASD-UK and Dasl<sup>n</sup>e.

## Studies currently recruiting families from ASD-UK and Dasl<sup>n</sup>e

**PREDICTORS: Parent Resources for Decreasing the Incidence of Change Triggered Temper Outbursts — Update — Dr Kate Woodcock, Queens University Belfast.** Temper outbursts are a common form of challenging behaviour shown by children with ASD and associated with negative outcomes. Many of the outbursts are triggered by changes to children's routines or expectations. This project will pilot an intervention led by caregivers which aims to reduce such outbursts by signalling changes; the study tests the feasibility of this approach for evaluation in a clinical trial. Participants will be 50-60 children with an ASD (7-16 years), and their caregivers. **Recruiting UK-wide.**



**Seeing the world differently — Update — Dr Liz Pellicano, University of London.**

When we process information coming into our senses, we make sense of that information based on our past experience. In the 'Seeing the World Differently' study, we are looking at whether the sensory sensitivities experienced by children with autism might be a result of differences in the way that they interpret this incoming information. We 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. If you know somebody who would like to take part, you can find out more here: [bit.ly/1u9ZGNP](http://bit.ly/1u9ZGNP) or you can email the team at [BrainDetectives@ioe.ac.uk](mailto:BrainDetectives@ioe.ac.uk). **Recruiting in London and surrounding areas.**

**Testing emotion recognition in autism spectrum disorder online — Update — Sarah Griffiths, University of Bristol.** Researchers at the University of Bristol are recruiting young people aged 6-16 from the ASD-UK database to take part in a study of emotional facial expression recognition. The study is run over the internet so that people from anywhere in the country can take part. The study focuses on how young people with and without autism, deal with subtle emotional information from facial expressions. Participants are asked to complete an emotional expression labelling task, as well as verbal and non-verbal IQ measures. This is in order to understand how verbal and non-verbal reasoning skills are linked to the ability to make judgements about emotions. The researchers have tested 46 participants so far and are aiming to test 100 by December 2015. The results of this study will help in the design of better materials for teaching those who struggle with emotion recognition. If you are interested in taking part or have any questions about the study, please contact [sarah.griffiths@bristol.ac.uk](mailto:sarah.griffiths@bristol.ac.uk). **Recruiting UK-wide.**



**STAARS—Studying Autism and ADHD Risk in Siblings — Professor Mark Johnson, Birkbeck University of London.** The team at Birkbeck University London are interested in the developmental pathways between autism and attention deficit hyperactivity disorder (ADHD) in order to move towards earlier diagnosis and more effective intervention. This 5 year longitudinal study will assess infants at high familial risk for ASD and ADHD, because they have a first-degree relative with the disorder. They will use multiple measures at 5, 10, 14, 24 and 36 months to study the earliest signs of autism and ADHD in brain, cognition and behaviour by using methods such as eye-tracking, brain imaging, and a range of behavioural measures, questionnaires, and genetic samples. Analyses will focus on infant measures in relation to measures of ADHD and ASD symptoms at age 3 years. Results will allow the researchers to address critical issues about the extent to which ASD and ADHD share developmental causal paths, and to what extent selected infancy measures associate with specific diagnostic outcomes. If you are interested in taking part or have any questions about the study, please contact [mark.johnson@bbk.ac.uk](mailto:mark.johnson@bbk.ac.uk). **Recruiting UK-wide.**



**Parental Perceptions of Health Care Experiences and Future Needs for Children/Young Persons with Autism — Alison Bratt, The Universities of Kent and Greenwich at Medway.** Children and young people with autism have a higher need for medical support from a wide range of health care professionals throughout the course of their development than children and young people without ASD. There is no research to date to show either how frequently children/young people with autism access all types of health care provision or the perceptions of their parents/carers regarding how satisfied they are with the healthcare support they have received. This pilot project proposes to survey the views of parents/carers concerning their past experiences of health care provision for their children/young people with ASD in order to assess if care is appropriately and adequately tailored to the specific needs of autistic individuals. If you are interested in taking part or have any questions about the study, please contact [amb54@kent.ac.uk](mailto:amb54@kent.ac.uk). **Recruiting UK-wide.**



## Summaries of findings: Studies which recruited from ASD-UK and Dasl<sup>ne</sup>

### Ups and Downs — Sarah Wigham and Jacqui Rodgers, Newcastle University

Children with ASD often experience high anxiety, which can have a significant impact on many aspects of their lives. The way in which anxiety may present in children with ASD might differ from anxiety in children without ASD but no methods of assessing anxiety have been specifically designed for young people with ASD. This research, funded by the Baily Thomas Foundation, working with young people with ASD and their parents aimed to address this gap.

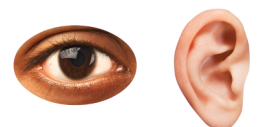


A widely used measure to assess anxiety in typically developing children is the Revised Child Anxiety and Depression Scale (RCADS). The goal of this study was to adapt the RCADS to make it suitable for use with young people with ASD. This was done first by talking to parents of young people with ASD about the content of the original measure and the researchers ideas about the inclusion of some new items to assess anxiety related to uncertainty, sensory issues and phobias. Having taken their advice , the researchers then developed an adapted measure which was sent to children with ASD and their parents, for completion alongside a range of other questionnaires. Over 170 families responded. This enabled the team to undertake analyses of these responses and develop the first anxiety measure specifically developed for young people with ASD.

The new measure, the **Anxiety Scale for Children - ASD (ASC-ASD)** has four anxiety related subscales: Performance anxiety, Separation anxiety, Anxious arousal and Uncertainty. Two versions of the measure were developed: One for completion by parents and one for completion by young people themselves if they are over the age of 8. Preliminary evidence shows the ASC-ASD is valid and reliable for measuring anxiety in children with ASD. This is important because it will facilitate better assessment, guide treatment, and enhance evaluation of therapies. The measure is freely available to researchers and clinicians soon via the cargo-ne website ([www.research.ncl.ac.uk/cargo-ne/measures.html](http://www.research.ncl.ac.uk/cargo-ne/measures.html)). The team is very grateful to all of the families who participated in the study.

### Sensory hotspots in children — Magdalena Glod, Newcastle University

Individuals with autism spectrum disorder (ASD) experience many sensory difficulties. We were interested in exploring sensory experiences within families, looking at similarities and differences in touching, smelling or seeing between children with ASD and their parents.



We asked parents of 44 children with ASD and 30 typically developing (TD) children, aged between 3 and 14 years, about their personal and their children's sensory experiences. Parents of children with ASD, compared to parents of typically developing children, reported that their children experienced significantly more sensory difficulties than typically developing children. We found many similarities between parents and their children in both groups in how they respond to everyday sensory information. However, we found that only within ASD families were there similarities in experiencing visual and auditory information. These findings suggest that some of the sensory difficulties might be shared more within ASD than TD families. Further work is needed to explore how sensory difficulties develop in ASD.

For more information about the above projects please contact:

**ASD-UK - Website:** [www.asd-uk.com](http://www.asd-uk.com), **Tel:** 0191 282 1380 or **email:** [asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk)  
**Dasl<sup>ne</sup> - Website:** <http://daslne.org/>, **Tel:** 0191 282 1400 or **email:** [daslne@ncl.ac.uk](mailto:daslne@ncl.ac.uk)



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

#### Back row, from left

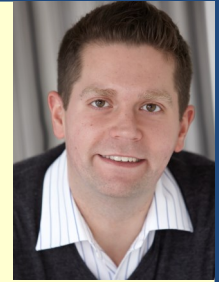
Richard Hardy (IT and database support for ASD-UK & Dasl<sup>ne</sup>)  
Jane Tilbrook (ASD-UK Administrator)  
Debbie Wilde (ASD-UK Programme Administrator)  
Sarah Nolan (ASD-UK Administrator)  
Dr Jeremy Parr (ASD-UK Lead)

#### From left, front row

Mary Johnson (Dasl<sup>ne</sup> Coordinator)  
Dr Alex Petrou (ASD-UK Coordinator)  
Prof Helen McConachie (Dasl<sup>ne</sup> Lead)

### Jon Spiers, Chief Executive of Autistica

I am the new Chief Executive of Autistica, Jon Spiers. I have already had the opportunity to speak with various organisations to see how we can work together to change the lives of those with autism and their families. Alongside this we have continued with our existing research strategy and two main research initiatives.



#### Identifying Top Research Priorities

An amazing 1213 people responded to our recent survey which asked individuals, family members and professionals for their top questions for autism research to address. This resulted in 3,331 questions being submitted. Responses represented the community well with 23% being individuals on the autism spectrum, 52% family members and caregivers and 25% clinicians and professionals. In a few months we will ask people to vote on a longlist before holding a final priority-setting workshop. The final top 10 will be published in April 2016.



Anxiety and depression are ten times more common in people with autism than in the general population and yet no autism specific treatments have been developed for those experiencing these debilitating problems. Having consulted with 1000 families (many through ASD-UK), we know that mental health is their top priority. As a result, we have launched a multi-centre programme of research. You can watch our 'casting light' film available on YouTube which showcases the work, hearing from families and researchers. For more information on all of our projects, visit our website: [www.autistica.org.uk](http://www.autistica.org.uk)

### 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

ASD-UK, Institute of Neuroscience  
Henry Wellcome Building  
Newcastle University  
Framlington Place  
Newcastle upon Tyne, NE2 4HH.

**Tel:** 0191 282 1380 **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 4LPT

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

Autism Spectrum Database—UK

@asd\_uk2011 #asduk

Daslne



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

**E-Mail:** \_\_\_\_\_