



# ASD-UK and Dasl<sup>ne</sup> Research Newsletter Spring 2016



## Over 3500 families have now registered with ASD-UK and Dasl<sup>ne</sup>!

ASD-UK is the national research database of children with ASD across the UK. Dasl<sup>ne</sup> 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 **3500 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 1800 families** who have registered and consented to take part across the UK

### Dasl<sup>ne</sup> Update

⇒ **Dasl<sup>ne</sup> has over 1700 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 both ASD-UK and Dasl<sup>ne</sup> in different regions across the UK.



## Has Age at Diagnosis of ASD Reduced?

Autism and ASD have been in the news a lot. Along with increased public awareness, there have been efforts to improve ASD diagnostic services for children in the UK. So has the average age at diagnosis of ASD in children reduced over the past few years? Data from 2134 children aged 2-18 years from Dasl<sup>ne</sup> and ASD-UK were used to examine this question. The median age at diagnosis was 4 years 7 months for all children with ASD, ranging from 7 months of age to 18 years 6 months. Against expectation, it was found that the average age at ASD diagnosis did not reduce between 2004 and 2014.

Since early intervention is likely to improve some outcomes for children and families, these findings are important for parents and clinicians. Sometimes there are good reasons to 'wait and see' before diagnosis. But it is often the case that though parents may detect ASD symptoms early on, the diagnosis is delayed due to long delays between the parents' initial concern and services making referral, and undertaking assessment.

An academic paper about this topic came out in April 2016, and can be found at: <http://tinyurl.com/zdqk8lj> or for a summary, see: <http://tinyurl.com/huv7kyj>

## Would you like to take part in autism research?

### Take a trip to London



#### STAARS—Studying Autism and ADHD Risk in Siblings

Professor Mark Johnson and his team at Birkbeck University, London, are interested in the development of autism and attention deficit hyperactivity disorder (ADHD) in order to move towards earlier diagnosis and more effective intervention. This 5 year study will assess infants with raised likelihood of 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. The study aims to relate measurements made in infants to the likelihood of ASD and ADHD symptoms and any 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**

### Looking for better treatments



#### LEAP and SynaG — Hannah Hayward, King's College London.

Children and adults with ASD have difficulties in social interaction, in communicating with others and often engage in repetitive behaviours (for example lining up objects) or pursue special interests. Despite a lot of progress in autism research, more effective treatments and interventions for ASD are needed. A major challenge in developing new treatments lies in the fact that the spectrum is very broad: some people with ASD are highly intelligent, others have a learning disability, some have medical conditions, while others do not. It is therefore likely that a particular treatment may only be effective for some people with ASD or may only work at certain ages. Therefore, this study is recruiting a very large group of people with ASD from 6 years to 30 years with a wide range of abilities. The overall goal is to develop treatments that help alleviate core symptoms of autism in different groups. Participation involves both your son/daughter and yourself (i.e. one parent). You will be asked to each fill in an (online) questionnaire booklet at home. Then you and your son/daughter will be invited to the Institute of Psychiatry, South London on 1-2 occasions.

If you are interested in taking part or have any questions about the study, please contact [hannah.hayward@kcl.ac.uk](mailto:hannah.hayward@kcl.ac.uk). **Recruiting UK-wide**

### How does your child see the world?



#### Seeing the world differently — Update

*Dr Liz Pellicano, University of 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.

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.**

## Summaries of findings: Studies which recruited 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.*

The PREDICTORS Study is a study aimed at parents of children aged 7-16 years old, who display temper outbursts when there is an unexpected change to their routines/plans or expectations. Children taking part have also been diagnosed with ASD or other developmental disorders (e.g. Prader Willi Syndrome, Fragile X or Intellectual Disability). 51 families (parent and child) were eligible to take part in the study from those recruited, having temper outbursts triggered by change. Caregivers completed a structured interview about their child's temper outbursts before proceeding to the first stage of data collection. During this interview they were asked to identify the frequency, duration and intensity of both change and non-change triggered temper outbursts, as well as the behaviours they observed during their child's outbursts. Caregivers were then asked to begin keeping a behaviour diary accessed online and using a smart phone, where they reported the frequency, duration, intensity and component behaviours of their child's temper outbursts as they occurred. The design process for the diary included holding focus groups with parents and professionals who emphasised the need to ensure the diary gathered the right information about temper outbursts but was also user friendly and quick to access and complete (2-5 minutes each entry).



Caregivers will soon start to engage with online training resources over a period of one month. Training includes demonstration videos of the training tools in use which were filmed with the help of a child actor. The aim of the resources is to equip caregivers with tools that will help decrease the severity and/or incidences of their child's change-triggered temper outbursts. After this training phase, parents will start implementing what they have learned and continue to report temper outbursts using the online behaviour diary. The study aims to assess the efficacy of resource efficient training tools for parents of children who have difficulties dealing with unexpected changes to routines/plans or expectations. The overall results of the study are due at the end of 2016. For more information about the study, please contact Dr Kate Woodcock (Tel: 028 9097 4886, [k.woodcock@qub.ac.uk](mailto:k.woodcock@qub.ac.uk)) or Dr Clare McGeady (Tel: 028 9097 4623, [c.mcgeady@qub.ac.uk](mailto:c.mcgeady@qub.ac.uk)).

### 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.*

This was a questionnaire based study surveying the experiences of parents / carers of children and young people with autism (0-18 years) of contacts with healthcare services across 4 main sectors (General Practitioner, Hospital Paediatric, Child & Adolescent Mental Health (CAMHS), and Hospital Accident & Emergency Services) in the UK. Through ASD-UK parents were invited to participate and thus could remain anonymous within the data collection process. The questionnaire collected both quantitative data (how frequently health care support was accessed), and qualitative data (parental perceptions of satisfaction with services). 101 parents / carers participated, providing data for 117 children with autism. Many parents reported difficulties accessing support and services. Satisfaction ratings were highest for GP and A & E services, and poorest for secondary care with paediatricians, and tertiary care with CAMHS. However, parents / carers receiving more appointments with paediatricians and CAMHS had higher satisfaction scores. Neither the presence / absence of challenging behaviour nor co-morbidities in the young people with autism affected parental healthcare satisfaction ratings. Significant concerns were repeatedly identified, such as a need for raising knowledge and understanding of autism among health care providers, increasing global family support, decreasing waiting times for referral to services, and providing individualised autism care plans. When questioned about the use of Hospital Passports for children / young people with autism, more than three quarters of the respondents were not aware of this possible aid; however 97% thought that health passports could be useful in facilitating individualised care. Hospital passports may be beneficial to the provision of well integrated and individualised healthcare services for young persons with autism and could be more widely publicised to parents / carers possibly at the point of diagnosis. For more information about the study, please email Dr Alison Bratt [amb54@kent.ac.uk](mailto:amb54@kent.ac.uk).



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



### Back row, from left

Richard Hardy (ASD-UK & Dasl<sup>ne</sup> 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<sup>ne</sup> Coordinator)  
Dr Alex Petrou (ASD-UK Coordinator)  
Prof Helen McConachie (Dasl<sup>ne</sup> Lead)

## James Cusack, Research Director, Autistica

Parents are helping to guide the future of autism research. You may remember that, last year, Autistica launched a survey asking individuals, family members and professionals for their top questions for autism research to address. The next step was to narrow down the shortlist of 40 questions to a shorter list of 25. This list will go to a workshop in late April 2016 to decide on a final top 10 unanswered questions.



The results will help autism research funders treat families' views as a priority.

[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

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

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

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