ASD-UK and Dasl^{n}e Research Newsletter
Autumn 2014

The UK charity Autistica fund ASD-UK and Dasl^{n}e for the next three years

ASD-UK is a national research database of children with ASD across the UK. Dasl^{n}e is a 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 to announce that the autism research charity Autistica has provided funding for both databases until 2017!

ASD-UK Update

⇒ **ASD-UK now has over 1350 families** who have registered and consented to take part.

⇒ 72 NHS trusts have now joined ASD-UK, meaning more families have the opportunity to take part in ASD research.

Dasl^{n}e Update

⇒ **There are now 1500 families registered with Dasl^{n}e** in Northumberland, Tyne and Wear.

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

9* 35* 1500 137 150 49 246 146 200 115 221
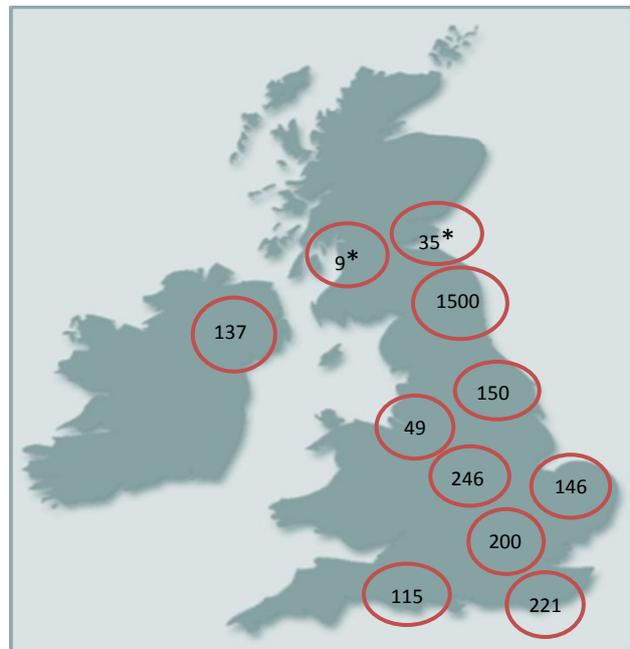
* Families first approached in Autumn 2014

Evidence for ASD Recurrence Rates and Reproductive Stoppage:

A new study has been published that looks at the recurrence rate of ASD in families, using data from both ASD-UK and Dasl^{n}e databases.

Dr Jeremy Parr, who is the lead for ASD-UK, explains what the results of this study mean:

"One of the questions I am often asked by parents is about the chance of them having another child with ASD in any future pregnancy. The study of information provided by ASD-UK and Dasl^{n}e families shows that 10% of families have more than one child with ASD (one in ten families); 90% of families have one child with ASD. The study also shows that following the diagnosis of ASD in one of their children, some parents choose to have no further children and therefore have a smaller family than they originally intended."

Reference: Wood, C. L., Warnell, F., Johnson, M., Hames, A., Pearce, M. S., McConachie, H. and Parr, J. R. (2014), Evidence for ASD Recurrence Rates and Reproductive Stoppage From Large UK ASD Research Family Databases. Autism Res. doi: 10.1002/aur.1414

ASD-UK and DasIⁿe support the recruitment of families of children with ASD to many research studies. The following research projects are currently recruiting around the UK:

Research Studies recruiting across the UK

Measuring Anxiety in ASD — *Dr Sarah Wigham, Newcastle University*

A research team at Newcastle University are currently developing a measure of anxiety especially for children with ASD aged 8-16 years. This is important because it will enable accurate assessment, and improve the evaluation of therapies.

Sensory Hotspots — *Magda Glod, Newcastle University*

This study is interested in finding out how children with autism and Williams syndrome (a rare developmental disorder) react to a range of everyday sensory events, such as different sights, sounds, tastes and textures, and how these responses might change with age. The research team hope this research will benefit the families of children with ASD and Williams syndrome (aged 4 - 16 years) by providing a wider understanding of how children experience the world, and that this will influence future interventions.

Research Study recruiting in London and Kent

Seeing the world differently — *Dr Liz Pellicano, University of London*. This project is interested in the way that children with autism (aged 6-14.5 years) might see things differently from children who don't have autism. Autism can affect a person in important ways; for instance where senses can work too well, e.g. being averse/sensitive to florescent light, or not well enough, e.g. being drawn to spinning things (such as washing machines, fans). These differences can have a huge effect on children's everyday lives. This project wants to know why these behaviours occur.

Research recruiting around Reading, Milton Keynes, Slough, Northampton, Gloucester

Repeating words and sentences — why do some children find it hard? — *Hannah Hobson, University of Oxford.* Some children have problems repeating words and sentences, including children with developmental disorders such as autism spectrum disorder or specific language impairment. This project is looking at whether some children (aged 8-12 years) do better if information is presented by a computer, rather than by a person, and if children's ability to copy words is related to their ability to copy movement. It is also looking at whether an ability to repeat words and sentences relates to children's attention to different kinds of sounds.

For more information about these studies contact ASD-UK

Tel: 0191 282 1380 or email asd-uk@ncl.ac.uk

Research Studies recruiting in the North East

Virtual Reality —*Dr Morag Maskey, Newcastle University*
Young people with ASD seem to be particularly at risk of developing anxiety that affects their daily life. This research explores whether 'virtual reality' scenes presented on computer screen are helpful as part of a psychological treatment process for specific anxiety (for example, about supermarkets or dogs) in young people with aged 8-14 years.

My Way of Doing Things — *Caroline Joyce, Newcastle University*
The study aims to find out more from young people on the autism spectrum (aged 14 to 18 yrs) about how they feel and the links to what they do (for example, what underlies repetitive behaviours).

Colour Perception in Children with ASD—*Matt Cranwell, Newcastle University*
Parents often mention that their children's behaviour is affected by particular colours. This study aims to find out more about colour perception in children with and without ASD aged 8 - 16 years.

For more information about these studies please contact DasIⁿe
Tel: 0191 282 1400 or email daslne@ncl.ac.uk
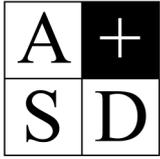
ASD Plus, Dr Beena Koshy, Newcastle University This recent research study involved families from ASD-UK and Daslⁿe, and was conducted by Beena Koshy at Newcastle University's Institute of Neuroscience. It explored the co-existing conditions often faced by children with autism. Co-existing conditions are additional difficulties, such as sensory problems, or struggling with attention or selective eating. Parent report questionnaires were used to help identify the range and severity of the difficulties. Results showed that it was very common for children with autism to have co-existing conditions.

⇒ Almost half of participating children (42%) had 3 or more conditions to a significant degree, which had a major impact upon their lives and that of their family

⇒ Many parents thought they were not given enough support by services to help them manage the effects of their child's additional difficulties, particularly in the case of challenging behaviour.

Dr Koshy concluded that it is important for professionals to look beyond the diagnosis of ASD, focus on what disrupts family life and evaluate whether additional support and services could reduce the impact of co-existing conditions on people's lives.

Technology and Autism, Dr Sue Fletcher Watson, Edinburgh University

Many children (and adults) with autism enjoy using technology - games consoles, computers and other devices. Parents often report that children pick up new skills from using technology, and it can be used to improve both concentration and interaction with other people. However, with so many different devices available it can sometimes feel hard to choose the right type. ASD-UK and Daslⁿe families took part in this online survey and a further small group of parents also met to discuss issues in more detail. This research has led to evidence based guidelines for parents, so that they and their children can get the most out of technology and avoid any associated risks. Parents' top tips for choosing hardware, for choosing software, and for managing screentime are practical and helpful.

The guidelines booklet can be downloaded from the link below:
http://daslne.org/research/projects/autism-technology (Summary of Findings)

The National Autistic Society has summarised these guidelines at http://www.autism.org.uk/technology

In our next research newsletter, we will summarise the results from projects looking at managing repetitive behaviours in young children with ASD, and children's understanding of questionnaire scales.

The ASD-UK and Daslⁿe team

From left, back row

Richard Hardy (IT and database support for ASD-UK & Daslⁿe)

Sarah Nolan (ASD-UK Administrator)

Jane Tilbrook (ASD-UK Administrator)

Prof Helen McConachie (Daslⁿe lead)

Dr Jeremy Parr (ASD-UK Lead)

Mary Johnson (Daslⁿe Coordinator)

Denise Brett (ASD-UK Coordinator)

Christine Swabey, Chief Executive of Autistica

Research into autism, its causes, how to diagnose the condition earlier and what interventions work, is absolutely vital to support individuals and families who are living with the condition day by day. Research also helps raise awareness and understanding and we know from consulting with families how strong the interest is in taking part in research studies. That is why Autistica is delighted to continue our support for ASD-UK. By joining ASD-UK, you not only enable more research to take place, but the information you provide will help us learn more about real experiences of autism, to help drive future research and influence how services are provided. For Autistica, ASD-UK is a key part of our new Research Strategy, which you can find by visiting our website at www.autistica.org.uk

As the UK's leading autism research charity, we are committed to funding research that will address the high priority areas for families; including early diagnosis and interventions; addressing mental health conditions so many face; and considering how we can best ensure a good quality of life throughout adulthood and into old age. If you would like to learn more, you can sign up to our newsletter on the website, or email us on info@autistica.org.uk; we would love to hear from you.

Joining ASD-UK or Daslⁿe

If you have not yet had a chance to complete your consent form & questionnaires so you can take part in either ASD-UK, or Daslⁿe, 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 the North East)

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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Contact Daslⁿe

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Royal Victoria Infirmary
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Email: daslne@ncl.ac.uk

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: _____