

ASD-UK and Daslⁿe Research Newsletter Spring 2015



Over 3000 families have now registered with ASD-UK and Daslⁿe!

ASD-UK is a national research database of children with ASD across the UK. Daslⁿe 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 that now over **3000 families** of children with ASD have the opportunity to 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.

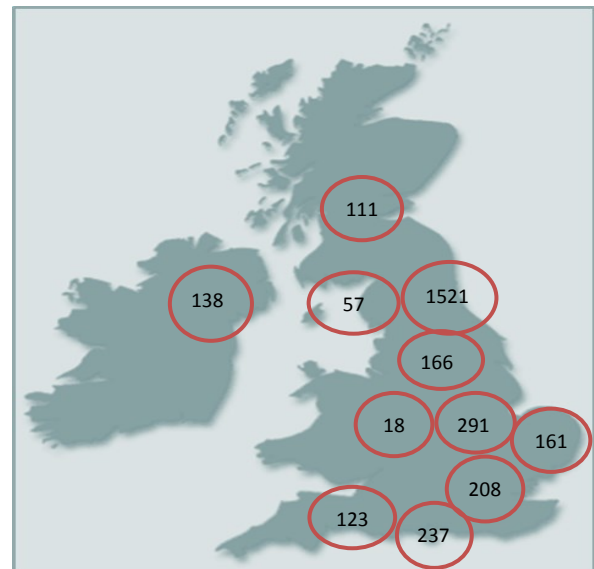
ASD-UK Update

- ⇒ **ASD-UK now has over 1500 families** who have registered and consented to take part across the UK

Daslⁿe Update

- ⇒ **Daslⁿe has over 1500 families** in Northumberland, Tyne and Wear.

This map shows you the number of families taking part in both ASD-UK and Daslⁿe in different regions across the UK.



The Adult Autism Spectrum Cohort — UK:

Newcastle University has now launched an exciting new programme of research, funded by Autistica, into the life experiences and health of adults with autism, including into old age. We are recruiting 500 adults with autism, aged 16 or over, and 500 relatives of adults, who are willing to take part in research studies.

The resulting cohort will enable research into life stories, what helps or reduces quality of life, what skills increase or diminish over time, what supports work best, and what services are needed by individuals and their families. Some families registered with ASD-UK and Daslⁿe will have children with ASD aged 16 or over. This study may play a significant role in determining the future services and support provided to adults and relatives in the UK, so we ask you to please consider joining this project so your opinion is heard.

For more information please visit the website www.autismspectrum-uk.com

Email: adultautismspectrum@ncl.ac.uk Telephone: 0191 282 1380.

Studies currently recruiting families from ASD-UK and DasIⁿe

PREDICTORS: Parent Resources for Decreasing the Incidence of Change Triggered Temper Outbursts— *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.**

Recognition of emotional expressions of varying intensity in children with and without autism spectrum disorder—*Sarah Griffiths, University of Bristol*: Many people believe that children with ASD have difficulty recognising emotion from facial expressions, but the research evidence is mixed. The aim of this study is to understand how individuals with an ASD (aged 7-16) recognize facial expressions that vary in emotional intensity. The researchers want to develop better materials for teaching those who struggle with emotion recognition. If you decide to take part, your child will be asked to complete three tasks online. Each of the three tasks takes around 20-30 minutes to complete. **Recruiting UK-wide.**

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 fluorescent light) or not well enough (e.g. being drawn to spinning objects such as washing machines, fans). Such differences can have a huge effect on children's everyday lives. This project studies why these behaviours occur. **Recruiting in London and surrounding areas.**

**For more information about the above projects please contact ASD-UK
Telephone: 0191 282 1380, email: asd-uk@ncl.ac.uk**

Reducing anxiety in young people with ASD through 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 using virtual reality is 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 who are attending child mental health services. **Recruiting in the North East.**

**For more information about this study, please contact DasIⁿe
Telephone: 0191 282 1400, or email dasIⁿe@ncl.ac.uk**

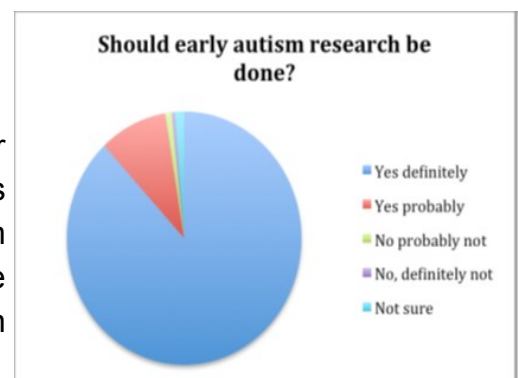
Results from studies that recruited from ASD-UK and DasIⁿe

Engaging in Autism Research

Dr Sue Fletcher-Watson, Edinburgh University

A survey conducted in the summer of 2014 asked people for their opinions about autism research focused on toddlers and infants, which aims to identify the early signs of autism and develop supports for the early age group. A huge number of people took part: 2381 from 11 European countries, and 271 from the UK alone!

One question was about how to describe early autism research; 'infants with a higher chance of developing autism' was preferred to 'infants at risk of autism'. The areas of early autism research that the majority agreed are important include understanding the genetic basis of autism, and describing the earliest signs of the condition. Interestingly, although developing supports was also a key issue, 40% of participants were still interested in taking part in studies which don't offer an intervention.

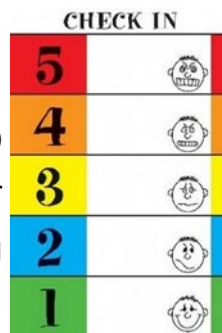


More results from studies that recruited from ASD-UK and Dasl^{ne}

Use of self-report rating scales in children with an Autism Spectrum Disorder

Dr Laura Tavernor, Newcastle University

Rating scales are often used in questionnaires in health and education settings, but little is known about which scales are best for collecting responses from children. Research indicates that young children (under 8) are significantly more likely to demonstrate 'extreme scoring' than older children. This is when a child chooses the highest or lowest option of a rating scale, thus giving less information. The researchers expected that children with ASD would tend to use 'extreme scoring'.



Nineteen Dasl^{ne} families were recruited for the study. The children had a diagnosis of ASD, were aged between 6 and 11 years, and attended mainstream school. Younger children were more likely to use 'extreme scoring', but unexpectedly the children with ASD had the same pattern of scoring as typically developing children. It was clear that children prefer vertical rating scales, with colour or cartoons, to the usual horizontal presentation of scales.

Illustration from 'The Incredible 5-Point Scale: The Significantly Improved and Expanded Second Edition; Assisting students in understanding social interactions and controlling their emotional responses' by Kari Dunn



Managing Repetitive Behaviours in young children with ASD

Dr Victoria Grahame, Northumberland, Tyne and Wear NHS Trust

This study looked at a new parent group course for understanding and managing repetitive behaviours in children with autism. Forty-five families took part in the study, with children aged 3-7 years. Half were offered the course straight away, and half after 6 months. Managing Repetitive Behaviours[©] involves eight 2-hour group sessions with two course leaders. Parents are helped with identifying what happens before, during and after repetitive behaviours, so as to plan strategies to manage behaviours which are disruptive. A group of expert clinicians assessed the effectiveness of the group course from all the assessments and questionnaires. They found reductions in certain types of repetitive behaviours, such as very focused interests and limited play. For the parents, there was an increase in the number of positive behaviour management strategies they used, as well as improved confidence in using these. In terms of overall progress, 57% of children whose parents attended the course immediately were rated as improved, compared to 25% for those whose parents attended later. This new intervention for managing repetitive behaviours in young children with ASD appears to have encouraging potential benefits.

In our next newsletter we will report findings from the 'Ups and Downs' project to adapt a questionnaire about anxiety for children with ASD.



The ASD-UK and Dasl^{ne} team

From left, back row

Richard Hardy (IT and database support for ASD-UK & Dasl^{ne})

Sarah Nolan (ASD-UK Administrator)

Jane Tilbrook (ASD-UK Administrator)

Prof Helen McConachie (Dasl^{ne} lead)

Dr Jeremy Parr (ASD-UK Lead)

Mary Johnson (Dasl^{ne} Coordinator)

Denise Brett (ASD-UK Coordinator)

Christine Swabey, Chief Executive of Autistica

Autistica's funding and support for ASD-UK is integral to our 5 year Research Strategy. Autistica's role is to bridge the gap between research and the autism community. We are committed to funding research that will address areas that have the greatest impact on the quality of life for those with autism, which is why, this year, we are leading on a James Lind Alliance Priority Setting Partnership for Autism. This is an independent, collaborative project, working with a coalition of charities and other interested parties to define a Top 10 list of research questions. A survey will be sent to individuals with autism, carers and clinicians to identify their research priorities in the field of autism. The initiative is well-respected by the National Institute for Health Research (NIHR) and other research funders, so we expect it to significantly increase funding from government.



Families will be receiving information about the James Lind Alliance Priority Setting Partnership for Autism soon, and we hope many of you will consider taking part. We're keen to keep you updated on this project, and other autism news, so please sign up to our mailing list at the bottom of [Autistica's homepage](#) to stay connected.

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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Contact Dasl^{ne}

Institute of Health and Society
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Sir James Spence Institute
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Newcastle upon Tyne
NE1 4LP
Tel: 0191 282 1400
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: _____