

By the end of January 2013, 650 families had joined ASD-UK!
Thank you to all families for supporting ASD-UK

Progress More than 1000 families have contacted ASD-UK about taking part. Over 650 families have returned their consent form and the questionnaires we sent, and can now be contacted about research projects they might like to take part in!

NEWS!

Online Registration: Families can now register with ASD-UK online.

By going to www.asd-uk.com and following the link, families can now register online. When families register, they are asked to give a small amount of information. They will then be emailed a unique password. After entering their email address and the password, families will be able to complete the consent form and the parent questionnaire – this will take just 20-30 minutes.

We send a second questionnaire by post once the consent form has been submitted - this takes about 10 minutes to complete. The questionnaire will include a return envelope. Any medical or education reports parents/carers are sending can be posted with the questionnaire in the return envelope; this is all explained in the letter we send with the questionnaire.

Families who prefer to complete the consent form and questionnaire by hand and post back to us, can still do so.

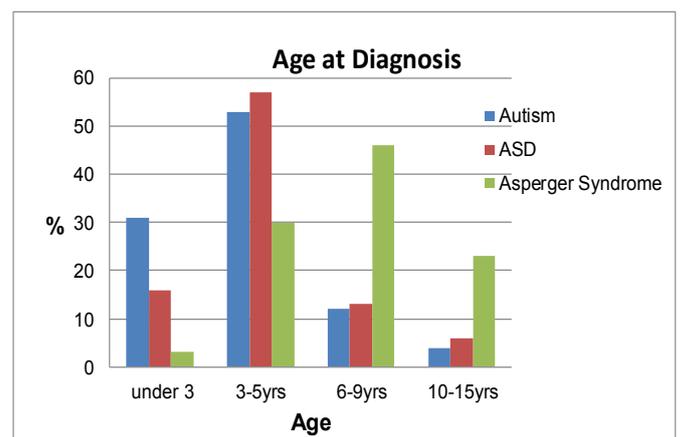
If you already have a consent form and questionnaires but have not filled them in, you can register on-line if you prefer to complete the forms this way. Just follow the link on the website. A member of the ASD-UK team will contact you once you have registered.

Please go to www.asd-uk.com and click on 'ASD-UK Register' to join via the website.

What we can tell you from the information families have sent

We ask parents to tell us the age their child was diagnosed. Early diagnosis of ASD is desirable to give parents appropriate advice as early as possible and start interventions that may improve children's developmental progress.

We can now show that children with a diagnosis of 'autism' were more likely to be diagnosed earlier than children with 'ASD' or Asperger Syndrome. The age of diagnosis between boys and girls is similar.



How representative is ASD-UK of all children with ASD in the UK?

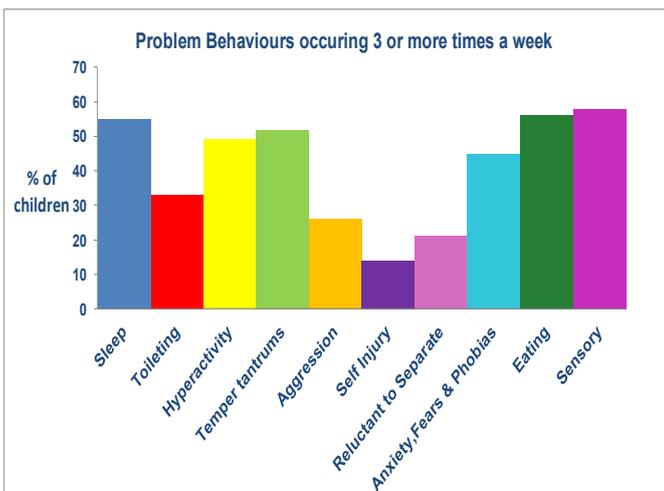
For high quality research, it is important that the children taking part in ASD-UK are as similar as possible to all children with ASD in the UK.

We have compared the children on ASD-UK to the regional ASD database in North East England (Daslⁿe), as we know that Daslⁿe families are similar to UK children with ASD. We compared the children's age at diagnosis, the type of school attended and the numbers of children with a learning disability and found that children registered with ASD-UK are similar to Daslⁿe children. This means that the findings of research carried out through ASD-UK will show what is happening in the wider ASD population.

Do you have any questions you would like us to answer about the information you give us? We would like to hear from you – please contact us with your questions. As we receive more information from families, we can produce more reports about topics that we think families would like to know about. This information will go on to the ASD-UK website www.asd-uk.com.
Here is an example question: What are the most common emotional and behavioural problems in children with ASD?

Remember – we only ever release information about group data, never about individuals.

Research



In our Spring 2012 newsletter we reported on the frequency of 10 common behaviour problems experienced by ASD-UK children. The most 3 most common problems were sleep, eating and sensory issues.

Since then we have published a paper with other colleagues at Newcastle University about the frequency of these behaviour problems.

The paper, *Emotional and Behavioural Problems in Children with Autism Spectrum Disorder*, can

be read by clicking the link on the ASD-UK website: www.asd-uk.com/links.html.

Here is a summary of the paper:

ASD-UK works closely with a regional ASD database; Daslⁿe (Database of children with ASD living in the North East of England). Families who take part in Daslⁿe are asked the same questions about problem behaviours as ASD-UK families. The paper looked at the information of 863 Daslⁿe families who reported on the emotional and behavioural problems of their children with ASD. Parents reported a high rate of behaviour problems, with 53 % of children having 4 or more types of problems, 3 or more times a week.

The following problems were more common in children with lower language level and attending special school: **sleep, toileting, eating problems, hyperactivity, self injury and sensory difficulties**. However, **anxiety, tantrums and aggression towards others** were frequent in children no matter what their age, ability or type of school. It is important to understand the frequency of behavioural problems in children with ASD when providing support services for children and families.

Other UK ASD research initiatives



This UK initiative for autism and related conditions like epilepsy, has been set up at Oxford University. One approach to understanding these conditions is through brain research. When scientists can explain how and why the brain functions differently in autism, it will be possible to develop scientific methods for diagnosis and targeted interventions to help.

To find out more visit: www.brainbankforautism.org.uk or phone 0800 089 0707

ASD-UK are now inviting researchers to apply to recruit families to their projects.

Two studies have been adopted by ASD-UK so far:

Indian Fellowship: Dr Beena Koshy is a Consultant Paediatrician from India who is working with ASD-UK for 2 years to develop the work that has already been done on behavioural problems in children with ASD (see page 2). Beena will be contacting ASD-UK families this Spring to find out more about these emotional and behavioural problems, and what services families are receiving.

Autistica are funding Beena's research fellowship. For more information you can visit the ASD-UK website; www.asd-uk.com/research.html

Autistica Survey: In Autumn 2012, we worked with the UK research funding charity **Autistica** to consult with parents of people with ASD about:

1. what they think are important areas for autism research
2. how they would like to receive new information about ASD.

We contacted those families registered on ASD-UK who have given an email address.

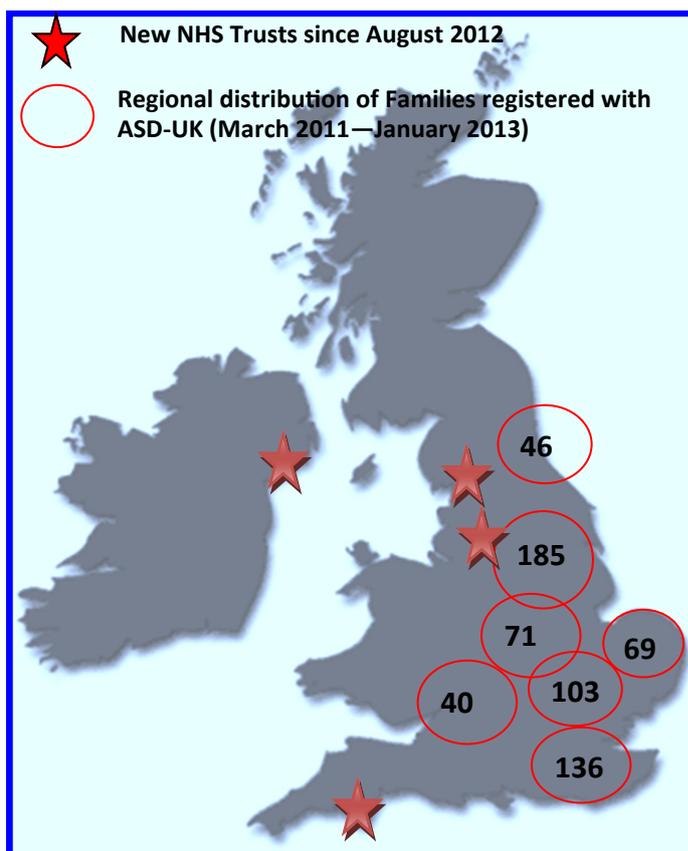
Autistica will use the answers to help prioritise some of their future research funding.

Over 400 people took part in the survey and a summary of the results will go onto the **Autistica** website and be included in a future ASD-UK newsletter

ASD-UK is expanding! We have invited more child health centres from other parts of the UK to help recruit families.

Over the next few months at least 20 more NHS Trusts will join ASD-UK so that families in other areas can have the opportunity to take part in ASD research. We now have Trusts in North West England, Yorkshire, the Midlands, the South West and Northern Ireland as well as more Trusts joining us in Derbyshire, South Thames & East Anglia.

This map shows you the locations of the new NHS Trusts and the number of families who are taking part from different regions throughout the UK. In addition, just over 100 families from other parts of the UK have contacted us themselves about taking part.



Welcome to the ASD-UK team



Frances Warnell is the coordinator for the ASD-UK project at Newcastle University. She worked with families of children with ASD as a health visitor in Durham and Newcastle before joining the ASD-UK team.



Helen McConachie is Professor of Clinical Child Psychology at Newcastle University and leads a similar ASD database in the North East www.dasline.org. Helen researches the effectiveness of interventions for children with ASD and their families, and how best to measure children's progress and outcome.



Jeremy Parr is a Consultant Paediatrician in Newcastle and leads the ASD-UK project. Jeremy sees children and young people with ASD in clinics. He works closely with ASD researchers in the UK and other countries and is involved in a number of studies

Padmini Ramesh recently joined the ASD-UK team as a research volunteer. For the last two of years Padmini has worked in a children's research unit as a data manager and has experience working on a number of different projects.

How to contact us

ASD-UK co-ordinator: Frances Warnell

 ASD-UK, Sir James Spence Institute, 3rd Floor, Royal Victoria Infirmary, Queen Victoria Road, Newcastle Upon Tyne, NE1 4LP

 0191 2825965 Email: asd-uk@ncl.ac.uk

Do you know anyone who would be interested in joining ASD-UK? Please pass on this newsletter

If you have moved, or changed any of your contact details, please can you complete the form below and send to the address above, or send us an email at: asd-uk@ncl.ac.uk



ASD-UK change of details

Child's name.....

Parent's name.....

Address

.....

Phone.....

Email address.....