

Spring 2012

The Autism Spectrum Database (ASD-UK) recruited its first family in March 2011

In the last 12 months, over 600 families have contacted us about taking part. More than 350 families have returned the consent form and the questionnaires we sent, and can now be contacted about research projects!

We have lots of other families planning to take part, and look forward to reaching 1000 families in the next year or so

Thank you to all families for supporting the ASD-UK project

What is ASD-UK?

ASD-UK is a national research database for families of children with ASD. The first 2 years of ASD-UK are being funded by the UK autism charity, Autistica. ASD-UK means that

- families are more able to take part in research
- it will be easier for researchers to recruit families to important research studies about Autism Spectrum Disorders (ASD)
- we can collect information to help us answer important questions about ASD

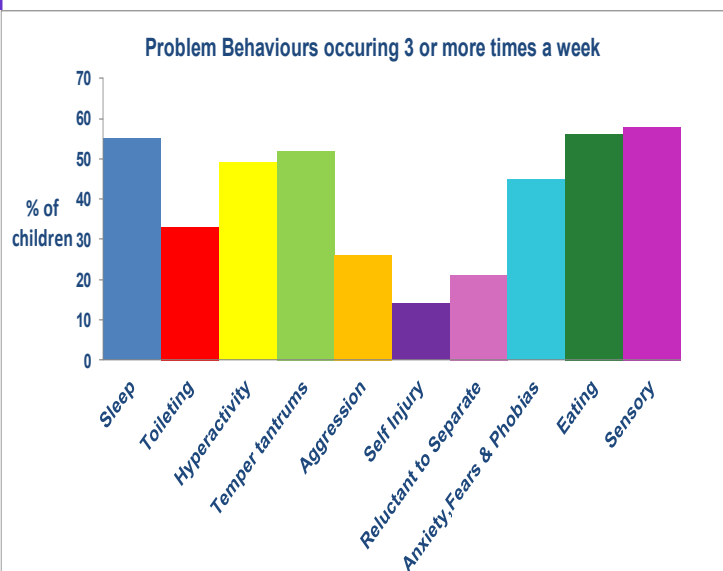
What parents say about ASD-UK

Many parents we have spoken to have expressed their enthusiasm about taking part. One parent said recently 'I am very excited about taking part in ASD-UK'. Another parent commented: 'I'm all for research and anything that can help families'. Parents have also said that they want to know what is going on in the world of autism research.

The three parents on our steering group stress that 'there is a lot of pressure on parents' time - research must be relevant and have impact so that parents want to take part'.

Progress so far

At the end of the first year we have over 350 families taking part. The data that parents have given us already shows some very useful information. For example, parents were able to tell us which problem behaviours affected their child and how often these occurred.



This chart shows the percentage of children who have each of the behaviour problems 3 or more times a week. The behaviour problems most commonly reported are sensory issues, (eg. sensitive to noises, textures, smells & tastes), eating & sleeping difficulties.

Over half of children have 4 or more behaviour problems, 3 or more times a week. This is a lot for children and families to cope with! It highlights the amount of support that parents need to help them cope with and manage their child's behaviour problems.

What happens next?

We are continuing to recruit families with the support of the child health teams across the UK. About 40 families a month contact ASD-UK about taking part. In 2012 more child health teams will join ASD-UK so that more families can join. The more families who take part, the more chance of supporting research that could answer important questions about ASD.

We will soon be contacting families who are taking part in ASD-UK, about research projects they may like to join. Projects that recruit families from ASD-UK will be listed on our website.

When a project is finished, a summary of the results will be available for families to see.

How you can take part in research studies

A steering group, that includes parents, will look at applications from researchers who want to recruit ASD-UK families for their studies. The ASD-UK team will send you information about studies so that you can decide if you would like to take part.



Your information is safe

The information you send us about your child is stored on a database that is only accessed by the ASD-UK team.

All paper documents (your questionnaires and medical/educational reports) are locked in a secure office. **Your information is not shared with anyone outside the ASD-UK team.**

Do you have an ASD-UK pack and want to take part?


If you have received a pack from us with the consent form and questionnaires but have not sent them back, we would love to hear from you.

Once you send us your completed consent form and questionnaires, you will be able to take part in ASD research studies. **If you need a new pack, let us know and we will send you one.**



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 @ asd-uk@ncl.ac.uk

We would like to hear what you think about ASD- UK. Please write to us or email us with any comments or thoughts about the idea of this research database for families.

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



Child's name.....

Parent's name.....

Address

.....

Phone.....

Email address.....