

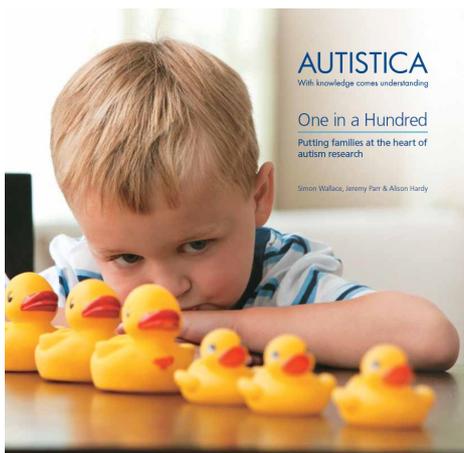
Our 1000th family joined ASD-UK in October!

Over 60 NHS child health teams in the UK have now joined ASD-UK, meaning more families have the opportunity to take part in ASD research. This map shows you the number of families taking part in different regions across the UK. In addition, there are a number of families from other areas of the UK who have contacted ASD-UK independently about taking part.

The red stars show the new areas that will be recruiting families in 2014.



Autistica Survey: One in a hundred — Putting families at the heart of autism research. *Simon Wallace, Jeremy Parr and Alison Hardy*



Autistica conducted a survey in 2012 that included the views of parents and individuals from ASD-UK. Thank you to those who took part. The 'One in a Hundred' report includes the results of the survey with almost 1000 parents and individuals with autism, and the results of telephone interviews and focus groups.

The 2013 report is a first step in an on-going process by Autistica to look at greater engagement with families and improve communication between families, researchers and medical practitioners in order to set research priorities.

This is a summary of the findings. The full report can be found at: http://autistica.org.uk/document_downloads/Reports/Autistica-1-100-Report.PDF

Information was collected in 4 key areas:

Living with autism

94% of parents worry about the future of their child with autism

72% of parents reported being judged/misunderstood

62% of felt isolated from those around them

66% of parents felt the experience of autism had given them a perspective on what really matters in life

Experiences of the UK health system

75% of adults reported no specific help in the months after diagnosis

74% of adults would have liked interventions to help reduce worry and stress

61% of adults wanted help with social skills

55% of parents reported not receiving enough information on autism after diagnosis

80% of parents would have liked to receive an intervention within the first month after diagnosis

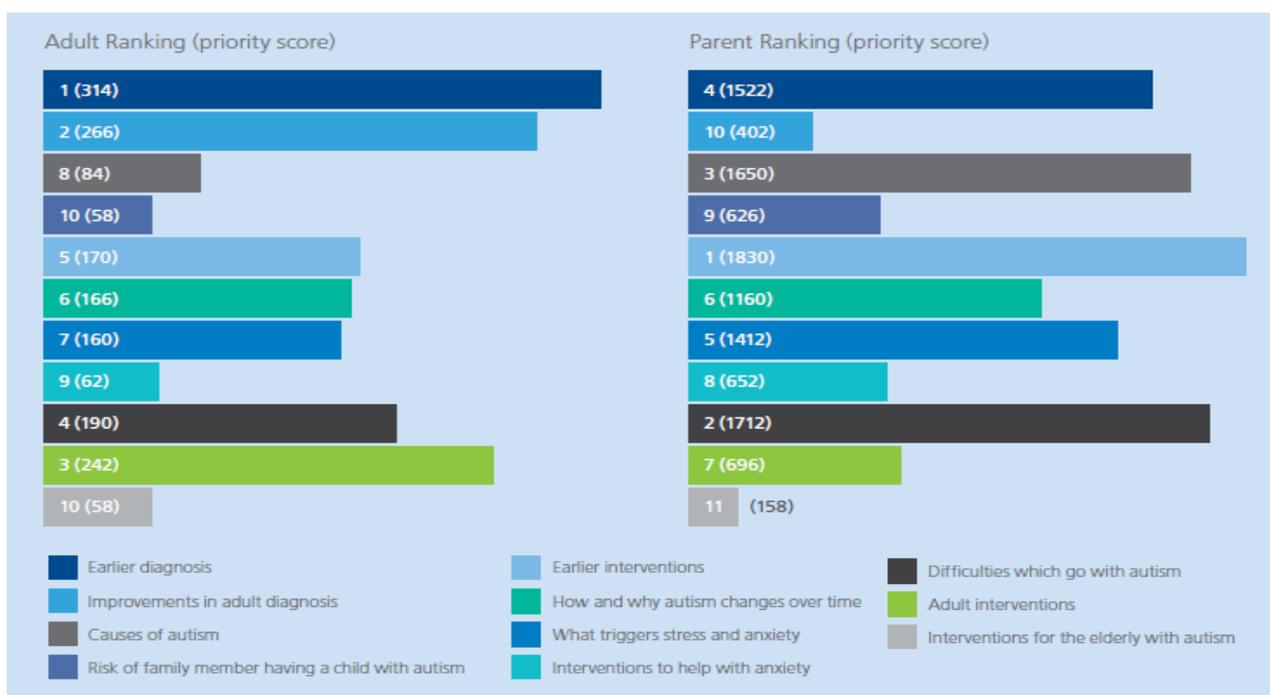
Attitudes to scientific research

82% of parents and 57% of adults agreed that more medical research would positively affect their lives

34% of parents and 27% of adults in the survey have tried interventions not scientifically proven

Research priorities

Parents were asked to choose their top 5 priorities from a set of 11 possible medical research questions and number these 1 – 5 (1 being the top priority) The table below shows the research priorities for adults and parents.



Studies recruiting families from ASD-UK

ASD+ - In the Spring 2013 newsletter we told you about the project that Dr Beena Koshy would be doing, extending the work already done about emotional and behavioural problems in children with ASD. ASD+ aims to identify the impact of these problems on families of children with ASD, and families' experiences of the services available to support them.

ASD-UK families have been contacted about ASD+ and almost 400 families are now taking part. A further 250 families are also taking part from the regional ASD database in North East England (Daslⁿe). ASD+ is the biggest UK study so far about children with ASD and behavioural and emotional difficulties, and will help us understand more about these problems

Seeing the world differently — *Dr Liz Pellicano, University of London*. This project is interested in the way that children with autism 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 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.

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 do better if information is presented by a computer, rather than 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.

Autism and Technology – gathering parent wisdom on using technology with children with autism in the home - *Dr Sue Fletcher-Watson, University of Edinburgh*. People with autism often use a lot of technology in their leisure time, and may develop important skills by working and learning in this way. However, there are some specific reasons to be cautious about the use of technology, including the risk of avoiding other more varied experiences. This study aims to find out more about how children with autism use technology in the home, alone or with their parents, and to use that information to begin to provide evidence-based guidelines for parents. The goal is to gather the views of experienced parents in order to then provide information to people who are less experienced with technology.

If you would like more information about any of these projects, please contact us

Joining ASD-UK

If you have not yet had a chance to complete your consent form & questionnaires so you can take part in ASD-UK, please contact us if you need another pack, or join online at www.asd-uk.com and click on the 'register with asd-uk' tab on the home page

If you would prefer not to take part, please let us know and we will remove your details from our list of families who have contacted us about taking part. If you would like to take part in the future, please do contact us. We would like to hear from you.

Contact us

ASD-UK, Institute of Neuroscience
Henry Wellcome Building
Newcastle University
Framlington Place
Newcastle upon Tyne, NE2 4HH.

Tel. 0191 2825965

Email: asd-uk@ncl.ac.uk

Future newsletters

We will send the next ASD-UK newsletter by email for those for whom we have an email address. If you would prefer a paper copy, please let us know and we will be very happy to send you one.

The ASD-UK team



From left, back row – Sarah Nolan is the administrator for ASD-UK at Newcastle University. She works on 2 other child health research projects, including a large study looking at the transition of young people with complex health needs.

Richard Hardy is a computer officer at Newcastle University. He acts in an IT and database support role for the ASD-UK project. He developed the database and the online registration system for ASD-UK.

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

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.

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

Front row, from left – Anna Hodgson is a psychology graduate and Research Assistant at Newcastle University and works with ASD-UK one day a week. Anna also works on two research projects investigating therapeutic interventions for children with ASD.

Denise Brett joins the team as a co-ordinator in March 2014. Denise is a Research Assistant at Newcastle University where she has worked on a research study assessing a parent group intervention to manage repetitive behaviours in ASD. She previously worked as a tutor teaching children and adolescents with ASD.

Padmini Ramesh (not in the photograph) is a research volunteer with ASD-UK. Padmini previously worked in a children's research unit as a data manager and has experience working on a number of different projects.

If you have 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

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|--------------------|--------------------|
| Child's name..... | |
| Parent's name..... | |
| Address | |
| | |
| Phone..... | Email address..... |