

## Welcome to the Autism Spectrum Cohort Newsletter!

This newsletter is for adults on the autism spectrum, and relatives of adults who are involved in the autism spectrum cohort, as well as for all NHS Trusts and organisations supporting the research. We use the newsletter to let you know about our progress with recruitment, and keep you up to date with some of the findings.

The Adult Autism Spectrum Cohort—UK (ASC-UK) is a national research cohort of and for adults on the autism spectrum and relatives of adults on the autism spectrum across the UK. The study is the first of its kind and collects information on topics such as health, education, support, and employment. We hope that this might lead to improvements in services offered to the autism community. Participants are informed at regular intervals about the progress of the study.

Adults on the autism spectrum and relatives are working as part of the research team.

**A big thank you to everyone who is supporting this research!**

## Some information about the people joining ASC-UK

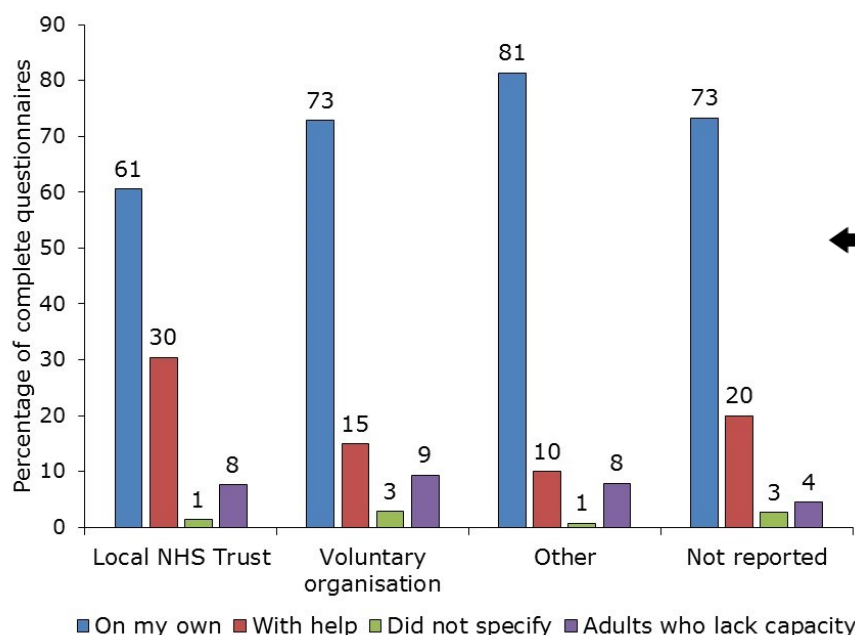
By March 2017, **1009 adults on the autism spectrum** and **354 relatives/carers** had given consent to join the cohorts.

### Adults on the autism spectrum

- 530 males, 455 females, and 24 people reported 'other gender'/did not report it
- 61% registered online and 39% completed paper forms
- 76 people (8%) lacked the capacity to consent for themselves

### Relatives of adults on the autism spectrum

- 52 males, 300 females, 2 relatives did not want to report their gender
- 53% registered online and 47% completed paper forms (consent from close relative/carer)



This graph indicates recruitment source from 921 autistic adults and whether they received support completing the questionnaire or not

## Research supported by ASC-UK: Uncertain Futures

Anxiety related to uncertainty about the future is a very real and significant concern for many individuals on the autism spectrum and their families. Many parents and carers will have increased concerns about what the future will hold for the individual on the autism spectrum they support or care for, once they die or are no longer able to provide the level of support previously given. The aims of this research are to find out more about the nature of the worries adults on the autism spectrum and their family members might have about the future in order to identify priorities for future research and inform service provision.

### How was the research done?

Four Focus Groups were conducted with 23 adults on the autism spectrum and an Online Survey was completed by 120 family members of adults on the autism spectrum. The focus groups included discussions about worries and concerns regarding the future. But also what might be helpful in order to help them prepare for the future. Some of the results are below:

### What might help autistic adults to be better prepared for the future?

Adults on the autism spectrum stated that:

- APPROPRIATE SUPPORT that was autism specific and individualised was most important in helping them to manage their worries about the future including support from family, friends and professionals.
- A clear supported structure to help with problem solving in relation to future concerns and challenges would be very helpful. This would include breaking issues down into manageable steps and tackling challenges step-by-step.
- Participation in therapy had been extremely helpful and suggested that ongoing access to therapy to deal specifically with future concerns may be useful.
- Having an outlet for concerns such as writing things down or confiding in supportive others would be helpful in alleviating future related anxiety.

### What concerns do relatives have?

- 77% of family members worried weekly that the needs of their relative on the autism spectrum will not be met in the future.
- 72% of family members worried weekly whether their relative on the autism spectrum would be happy in the future.
- 58% of family members worried weekly about who would care for their relative on the autism spectrum in the future, when they were no longer able to support them.
- Relatives self-reported moderate levels of worry (47%) and anxiety (37%), mild levels of depression (23%) and stress (21%) and high levels of intolerance of uncertainty (28%).
- Family members expressed the importance of appropriate, tailored support to be in place for their relative in the future. This included practical support in terms of housing, employment and finances but also emotional support.

**More information about these studies can be found here:**

**<http://researchautism.net/publicfiles/pdf/uncertain-futures-executive-summary.pdf>**

## Other studies related to ASC-UK

**WHOQoL:** This study is exploring 'Quality of Life' for autistic people. We are consulting on some new questions that will be added to the World Health Organisation Quality of Life Questionnaire. So far 355 ASC-UK participants have agreed to help.



**ADEPT:** This study is looking at whether it is possible to adapt an existing psychological therapy, called Guided Self-Help based on Cognitive Behaviour Therapy (CBT), to better meet the needs of autistic people in the North East and around Bristol who experience low mood and also report differences in social communication.

## 'About me' by Stacy Reed

Stacy Reed has joined ASC-UK and has given us her permission to share her experiences.

"My name is Stacy. I'm 33 and I've recently been diagnosed with autism spectrum disorder. I'm classed as having Asperger's which is high functioning autism. It is similar to autism but I don't have any learning difficulties. In fact, I've always been ahead academically!!! I always knew I was different but back in the 80s and 90s, autism wasn't as well known. It wasn't until my son was being assessed for autism that I realised we were very similar and asked to be assessed myself. 8 months later, I had my diagnosis and 19 days later my son got his.

Living with autism is very difficult. I don't like change, I like routine and I suffer from anxiety. Going somewhere new and meeting new people can make me ill! As a female on the spectrum, I hide this well though. I've become a good actress!!! Nobody ever guesses I have autism. Social situations are really difficult for me, even in places and with people I know well. I need to plan ahead and know what's going to happen. I struggle to maintain friendships, I only really have a couple of friends who are very patient with me!! I can't deal with being in a relationship, I've tried dating but if things become serious, I end things!

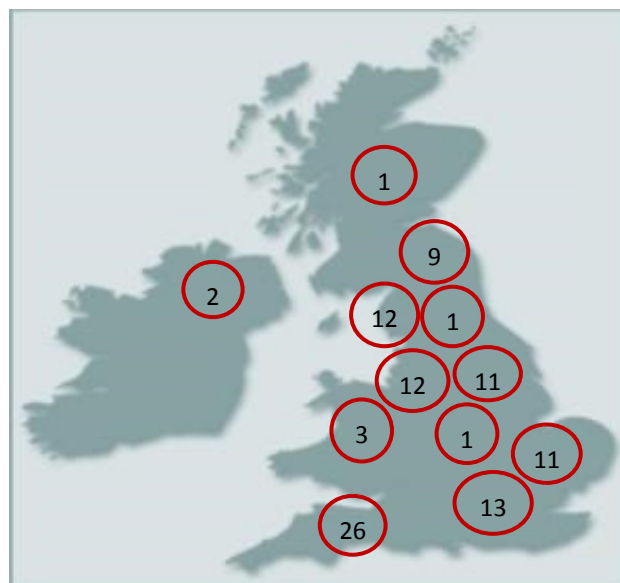
But having autism also has its upsides. Because there's just me and my autistic son, we live in a world of routine and planning and it just works well for us! I also believe that being autistic makes me good at my job. I work in admin at the council and I have 'systems' that make my work very organised. I also have an amazing memory. My colleagues find me useful as I can describe a case to me and I can tell them who it's for. I've found my diagnosis really helpful as I now have understanding from family, friends and colleagues for my quirky behaviour. They previously used to get frustrated with me!!

I think the things I've achieved in my life show that autism shouldn't hold you back!! I have a degree in computing, I have a good job working full time, I own a house, bring up my son on my own and can drive a car (although I did have to take 11 tests due to my anxiety)."

## Trusts and Organisations working with us

**51 NHS Trusts** and **over 100 Voluntary organisations** are now **working with us** to recruit adults on the autism spectrum, and relatives of adults. This number is increasing all the time. We are pleased to be working with so many groups!

The map shows the number of NHS Trusts and voluntary organisations currently working with us in different regions across the UK. The number of sites and organisations across the UK will continue to increase over the coming months.



A list of NHS Trusts and organisations working with us can be found on our website:

**<http://research.ncl.ac.uk/adultautismspectrum>**

If your organisation would like to work with us, please contact  
**[adultautismspectrum@ncl.ac.uk](mailto:adultautismspectrum@ncl.ac.uk)** or **0191 282 1380 / 5965 / 5966**

## Continuing Professional Development event

We are pleased to announce that we will be holding **our first CPD event** for professionals who are supporting recruitment to ASC-UK. This will take place on **5<sup>th</sup> and 6<sup>th</sup> June 2017** at **Newcastle University**. Please save the date! The draft programme has been sent out and registration is now open.

## Progress with recruitment and plans for 2017

During 2017, we continue to recruit both autistic adults and relatives of autistic adults.  
**Do you know anyone who might be interested in taking part?**  
**If you do, please let them know about this research.**

People can sign up directly online or by completing paper forms, see  
**<http://research.ncl.ac.uk/adultautismspectrum>**

We are recruiting 3 groups of people:

- Adults on the autism spectrum of all ages and abilities (confirmed diagnosis not required)
- Relatives or carers who can respond for people on the autism spectrum who cannot take part themselves
- Relatives give information about themselves and their own lives

## The ASC-UK team



### Back row, from left

Jahnese Hamilton (Clinical Studies Officer)  
Dr Tom Berney (Researcher)  
Deborah Garland (National Autistic Society Autism Resource Centre Manager in NE)  
Dr Alex Petrou (Research Associate)  
Dr Jeremy Parr (Lead for ASC-UK)  
Prof Helen McConachie (Co-Lead)

### Front row, from left

Dr Faye Buckingham (Programme Administrator)  
Richard Hardy (IT and database support)  
Prof Ann Le Couteur (Co-Lead)

### Not present


Cos Michael, Chris Mitchell & The Goth (Autistic researchers)  
Joan Mackintosh (Research Associate)


## Contact ASC-UK

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**Tel: 0191 282 1380 / 5965 / 5966**

**Email: [adultautismspectrum@ncl.ac.uk](mailto:adultautismspectrum@ncl.ac.uk)**

 Adult Autism Spectrum Cohort-UK

 @uk\_asc #ascuk

**Website: <http://research.ncl.ac.uk/adultautismspectrum>**