

As mentioned in our latest newsletter, here is a summary of recent research findings relevant to the everyday lives of autistic people.

## **National Anxiety Survey and Personalised Anxiety Treatment – Autism Trial**

A summary of this programme of research was outlined in the Winter 2020 newsletter and is still available to view on the website [by clicking here](#). It is very encouraging to know that our research has led to important findings about autistic people's experiences of anxiety and about the treatments and services that they receive. We have published findings in peer reviewed journals and presented at national and international conferences. We continue to analyse and share these important findings and raise awareness about the need to ensure that autistic people have access to anxiety assessments and treatments that are both accessible and effective.

### **Anxiety Survey**

Over 550 autistic people completed our anxiety survey as well as relatives and parents of autistic children. People who took part told us that anxiety had a significant impact on their daily life.

- Our self-report anxiety questionnaire was the first designed specifically to measure anxiety experienced by autistic adults. This measure is free to download (over 550 downloads so far), has been translated into 4 different languages, and is being used in several research and healthcare settings. The anxiety questionnaire can be downloaded [by clicking here](#)
- We are preparing to publish more findings from the survey about autistic people's experiences of anxiety.

### **Personalised Anxiety Treatment – Autism (PAT-A) Trial**

PAT-A is a novel anxiety therapy designed to be personalised to meet the individual needs of autistic people. 34 autistic adults took part in our first small-scale trial of this therapy. The findings ([click here](#)) showed that PAT-A is acceptable to autistic people and can be delivered in the NHS.

Some of the preliminary findings about the effectiveness of PAT-A in treating anxiety were difficult to interpret due to the impact of the pandemic. However, many of the participants who received the treatment told us that PAT-A led to real life, positive changes in their anxiety. One participant told us:

*"I have had therapy for many years, and this was by far the best therapy I have had...it has helped me so much in such a short space of time. I have grown so much and learnt so much about myself.... Everything is good now, my outlook on everything is different. I have made massive changes to my life..."*

We are now discussing with NHS clinicians about whether they'd like to provide PAT-A treatment and considering the next steps in our research.

## **Treating phobias and situation specific anxiety using an immersive Virtual Reality (VR) environment**

The current recommended treatments for phobia and situation specific anxiety may not be accessible or effective for many autistic people. In this context, we developed a new therapy that is designed to be delivered in an immersive VR environment. Following successful trials of this intervention with autistic children, we tested this intervention with autistic adults.

Eight autistic adults with situation specific anxiety took part in the study. They each had one session with a therapist to learn anxiety management techniques followed by 4 treatment sessions in the VR environment. We learned that this treatment was acceptable to the autistic people who took part, and most participants reported positive changes to their anxiety. [Click here to see the VR study.](#)

Following this study, Newcastle University and Cumbria Northumberland Tyne and Wear NHS Foundation Trust set up a company called XRTherapeutics (<https://xrtherapeutics.co.uk/>) to deliver treatment in partnership with NHS Trusts and other organisations. XRTherapeutics are measuring how successful the treatment is when part of a clinical service and have adapted the anxiety treatment for people with learning disabilities.

We will soon be recruiting to another study that aims to find out about the impact and cost of experiencing situation specific anxiety or phobia. We hope that this information will help us to work towards making the VR intervention more readily available in the NHS.

## **Reasonable adjustments to healthcare**

Our study about adjustments to make healthcare more accessible to autistic people showed that adjustments are very important but too rarely available. We have shared these findings with NHS management and local NHS teams, and we hope that they can contribute to the reduction of barriers to healthcare for autistic people. [Click here to see the reasonable adjustments study](#)

**If you are interested in finding out more about any of the above studies – please contact Dr Sam Brice [Anxiety.Autism@ncl.ac.uk](mailto:Anxiety.Autism@ncl.ac.uk)**

## **Developing and testing an adapted treatment for depression**

Depression is common for autistic people and impacts on daily life. The effectiveness of current treatment options is uncertain. We were part a UK-wide team which developed an adapted treatment for depression designed to meet the needs of autistic people.

70 autistic adults with depression took part in an initial research trial. The finding showed that autistic people were willing to engage in the research and the treatment. Most people told us that they found the treatment helpful. This treatment is now being tested in a larger study that will show whether or not the treatment is effective for autistic people. [Click here to see the adapted treatment for depression study.](#)

## **Understanding the lived experiences of autistic adults**

Our cohort questionnaire was completed by most people when they joined the main cohort study – we have data about the lives of 2129 autistic people, and from 811 relatives. The data continue to be analysed – and results will be published in 2023/24. We are focusing first on health and mental health, and in the future will be able to consider topics such as support requested and received; education and employment-all priorities identified by the autism community.

In our qualitative research (interviews) 29 autistic adults and a separate sample of 18 relatives were interviewed about their health, relationships, employment & education, quality of life and everyday experiences. Some of the themes to emerge included the impact (both positive and less positive) of receiving an autism diagnosis, supportive and non-supportive social contacts, the invisibility of autistic people's needs and autistic people's health.

These qualitative studies highlight how important it is that we all continue to work together towards a greater public understanding of autism in adulthood. The studies emphasise the crucial importance of improving the availability of and access to appropriate health and social care services for autistic people. The findings from the autistic adult study can be found [by clicking here](#). A paper describing relative's experiences should be published later in 2023 and will then be put on our website.

## **Autistic people's Quality of Life**

We have published several research studies that have aimed to understand autistic people's quality of life (QoL).

370 autistic adults took part in a study to investigate key factors that may influence autistic adults' QoL. The findings showed that QoL was lower for autistic people than population averages. The things that were linked to higher QoL were: 1) being employed, 2) receiving support and 3) being in a relationship. Having a mental health condition was associated with lower QoL. [You can view this paper by clicking here.](#)

Another study recruited older autistic people and found that both anxiety and depression were both linked to lower QoL for older autistic people. This highlights the importance of autistic people having access to appropriate mental health care. [You can view this paper by clicking here.](#)

As part of this work, we developed a questionnaire to measure autistic people's QoL. This is free to download from our website ([by following this link](#)) and has been downloaded 620 times in the last 12 months. The measure is being used in international research and has been translated into 3 other languages.

## **Improving the health of older autistic people and health checks for autistic adults**

Our physical health research focused on access to services and how to improve this. We found that barriers to service access include healthcare professionals who did not have good knowledge about autism and difficulties communicating with healthcare professionals; ways to improve services included making adjustments to make healthcare more accessible to autistic people and having staff who could help autistic people 'navigate' the healthcare system. Our papers relating to access to healthcare services can be seen by clicking [here](#) and [here](#).

We were then funded by Autistica to co-design a health check for autistic adults that can be used in primary care (General Practice). This paper can be seen by clicking [here](#). The health check materials are being used by NHS England, and we are now evaluating whether or not the health check improves the health of autistic people in a Randomised Controlled Trial (recruitment via GP practices in NE England). The Health Checks for Autistic Adults website can be accessed at <https://research.ncl.ac.uk/autismhealthchecks/>.

## **Autism Clinical Interview for Adults (ACIA)**

We have previously told you about our work to develop a set of diagnostic interviews: the Autism Clinical Interview for Adults (ACIA). Our research paper can be found here: [Click here to see the ACIA research paper](#). Since our last newsletter, we have designed and rolled out a training programme to enable clinical professionals to use this set of interviews.

ACIA training started in 2022 and more than 700 multidisciplinary team (MDT) clinicians and practitioners from the UK and internationally have attended and completed the training. We have also contracted with colleagues internationally to complete translation of the ACIA so they can deliver training in other countries.

The training is online, and delegates receive the ACIA documents in hard copy and as PDF versions for printing and use in their service – reducing costs for the services. Clinicians from a range of clinical backgrounds including psychologists, psychiatrists, nurses, and occupational therapists have been trained. They come from a wide range of settings including NHS autism assessment and diagnosis services, mental health, learning disability, eating disorders services, HMPS prison services and private clinical settings across a range of countries including the UK, Ireland, Portugal, Australia, the United States, Canada, Sweden and Brazil.

Next steps:

- (i) A new document near completion will enable summarizing ACIA scores at the end of the interviews
- (ii) Work with the Newcastle University software engineering team is helping us create an electronic version of the ACIA documents that could be stored with clinical records
- (iii) Revisions are being made to the ACIA informed by consultation and feedback from training attendees

For those people involved in autism spectrum diagnostic assessments of people age 16 years and over, [here is a link to available ACIA training courses](#).

Our national surveys with autistic people, relatives and professionals led to new recommendations about service provision for diagnostic and post diagnostic services - and has been cited in national guidance regarding clinical services.

**For more information, please contact Dr Sarah Wigham at [ACIAtraining@newcastle.ac.uk](mailto:ACIAtraining@newcastle.ac.uk)**

We hope that you have enjoyed reading this Research Update. We would like to contact you with more updates about our findings in the future. If you would prefer not to receive any more research updates, then please let us know by contacting us at: [adultautismspectrum@ncl.ac.uk](mailto:adultautismspectrum@ncl.ac.uk).

Thank you once again for being part of the  
**Adult Autism Spectrum Cohorts (ASC-UK)**