



*Welcome to our first
newsletter!*

*This first issue will bring
you news of our progress so
far since the start of the
project in January 2016.*

What is MHAutism? Mental Health in Autism (MHAutism) is a research project exploring the unique challenges adults with Autism Spectrum Conditions (ASC) face in relation to mental health problems, self-injury, and thoughts about ending life. We are a team of researchers, led by [Dr Sarah Cassidy](#), that want to understand why adults with ASC experience these difficulties so we can lobby for better support to improve the quality of life for those affected.

What we know so far? Approximately 1% of people have an ASC, and a growing majority of those are now adults. [Recent research](#) has shown that:

- 66% of autistic people have considered suicide in their lifetime.
- Adults with ASC are 9 times more likely to die by suicide than the general population.
- Approximately 30% of adults with ASC have depression, a significant risk factor for suicide.

Why is this research important?

Services need to provide adults with ASC access to appropriate diagnosis, support and treatment. However, there is a lack of research into adults with ASC and their mental health. This means that service providers do not understand how problems such as depression and suicidality manifest in adults with ASC. Therefore, services cannot effectively provide access to appropriate support and treatment for these difficulties. This has led to many adults with ASC slipping through the net.

How will MHAutism make a difference? There is little research and currently no valid tool to assess depression or suicide risk in adults with ASC. MHAutism has three aims:

1. To develop new tools to enable service providers to effectively assess depression and suicide risk in adults with ASC.
2. To determine how many adults with ASC experience these difficulties in the UK.
3. To raise awareness of mental health problems, self-injury and thoughts of ending life in ASC and to lobby for better support.





MHAutism Research News

Progress so far:

We have been carrying out a systematic search of the scientific evidence to identify the best tools to assess depression and suicide risk in adults with ASC.

We searched thousands of articles. However, **no studies** have ever used a valid tool to assess suicide risk in those with ASC. We did find a small number of studies that had used depression measures developed for the general population with people with ASC. However, none of these tools have been validated for this group.

Because there are no tools, which have been developed to assess depression or suicide risk in those with ASC, we plan to adapt the best measures currently available for this group. We are currently assessing the quality of the measures we have found, to make sure that we choose the best measures to adapt for people with ASC.

Next steps:

We will be recruiting adults with an ASC diagnosis, without learning disability, to feedback on the depression and suicide risk measures selected from our review. We want to ask people with ASC how they interpret the questions, get feedback on the appropriateness of questions, and find out whether any important questions are missing. This will ensure that any changes to the measures are appropriate for adults with ASC.

We need your help!

We have created an **online survey** in partnership with a group of people with ASC. The survey is the first of its kind and will help us understand how problems such as depression and suicidality manifest in adults with and without ASC. We are looking for adults **with and without** a diagnosis of an ASC to complete the survey. The findings will help us understand what needs to change in relation to supporting people with ASC who experience these difficulties. If you would like to help please follow this link to complete our survey https://coventrypsychology.qualtrics.com/SE/?SID=SV_7R5ZdETBU3pJDU1 Please help us spread the word about this important research by sending it to everyone you know!



MHAutism Research Champions:

MHAutism is looking for people with ASC who have experienced mental health difficulties, and family members who support a person with ASC, to share their stories.

Our wonderful [MHAutism Research Champions](#) have recently recorded videos talking about what they would like their GP to know to help them access the right support and treatment from specialist services.



You can watch the videos [here](#) and read about Eilish's experiences [here](#).

A big thank you to all our MHAutism champions for helping us get this message out! Please contact us if you would like to become a MHAutism champion: mhautism@hls.coventry.ac.uk.

Other related news:

In May 2016 the MHAutism team organised a new **Special Interest Group (SIG)** at the International Meeting for Autism Research, in Baltimore, USA. The SIG brought together for the first time over 40 researchers, clinicians and members of the autism community, to discuss the next steps for suicide in autism research.

The SIG identified three priority areas for future research: 1) Risk/Protective Factors; 2) Measurement/Assessment; and 3) Intervention/Prevention. It was agreed that there is a growing body of research evidence showing that suicide thoughts and behaviours are common in people with ASC in clinics or hospitals. However there is no research exploring how common this is in the wider ASC population, *why* this is the case, and *what* can be done to prevent suicide. We will reapply to run a second Suicide in Autism SIG meeting at IMFAR in San Francisco in May 2017 to continue this work.

In June our **mortality review** began. This is a research study being conducted by researchers from MHAutism at Coventry University, and the Autism Research Centre, University of Cambridge. The study aims to identify how many people with ASC die by suicide in the UK. The MHAutism team are currently analysing the first wave of data. We plan to use the results from this review to work with service providers to prevent suicide in people with ASC.

Kathy Cook is a **MHAutism PhD student**, working to understand why adults with ASC may be at more risk of mental health problems and suicide than those without a diagnosis of ASC. This research will help us design ways to better recognise when someone with ASC is at risk of suicide, and develop better support to reduce suicide risk in these people.

Help needed!! Kathy is currently looking for adults (aged 18-60), both with and without a diagnosis of Autism Spectrum Condition (ASC) to complete an anonymous online survey. This should take no more than an hour of your time. This work is important because there is a lack of research helping us understand the way adults with ASC experience suicidal thoughts and behaviours. If you are able to help with this much needed research or would like more information please email Kathy: cookk6@uni.coventry.ac.uk.

Save the date!

We will hold our first **MHAutism Stakeholder Event** on the **27th January 2017!**

This will be a free half-day event at Coventry University bringing together researchers, clinicians, adults with ASC, and charities to discuss the implications of our research for them, their practice, and policy. The event will provide an opportunity for delegates to engage in discussions that will help shape the projects research questions, methods and translation of results into practice. Help us make a difference by registering your interest in attending by contacting: MHAutism@hls.coventry.ac.uk

Contact us!

If you would like to know more about the MHAutism project and keep up to date with our news and events please visit our [website](#) or contact us on mhautism.hls@coventry.ac.uk



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