

Natspec

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specialist further
education

AUTISTICA

Building brighter futures through autism research

Towards evidence-based practice: latest autism research findings

Dr James Cusack, director of science, Autistica

Who we are

The national charity for autism research aiming for a world where all autistic people live a long, healthy, happy life

Autistic people and families at the centre of decision-making

We fund studies across the spectrum and across the lifespan

Priorities include mental health, early death, language and employment

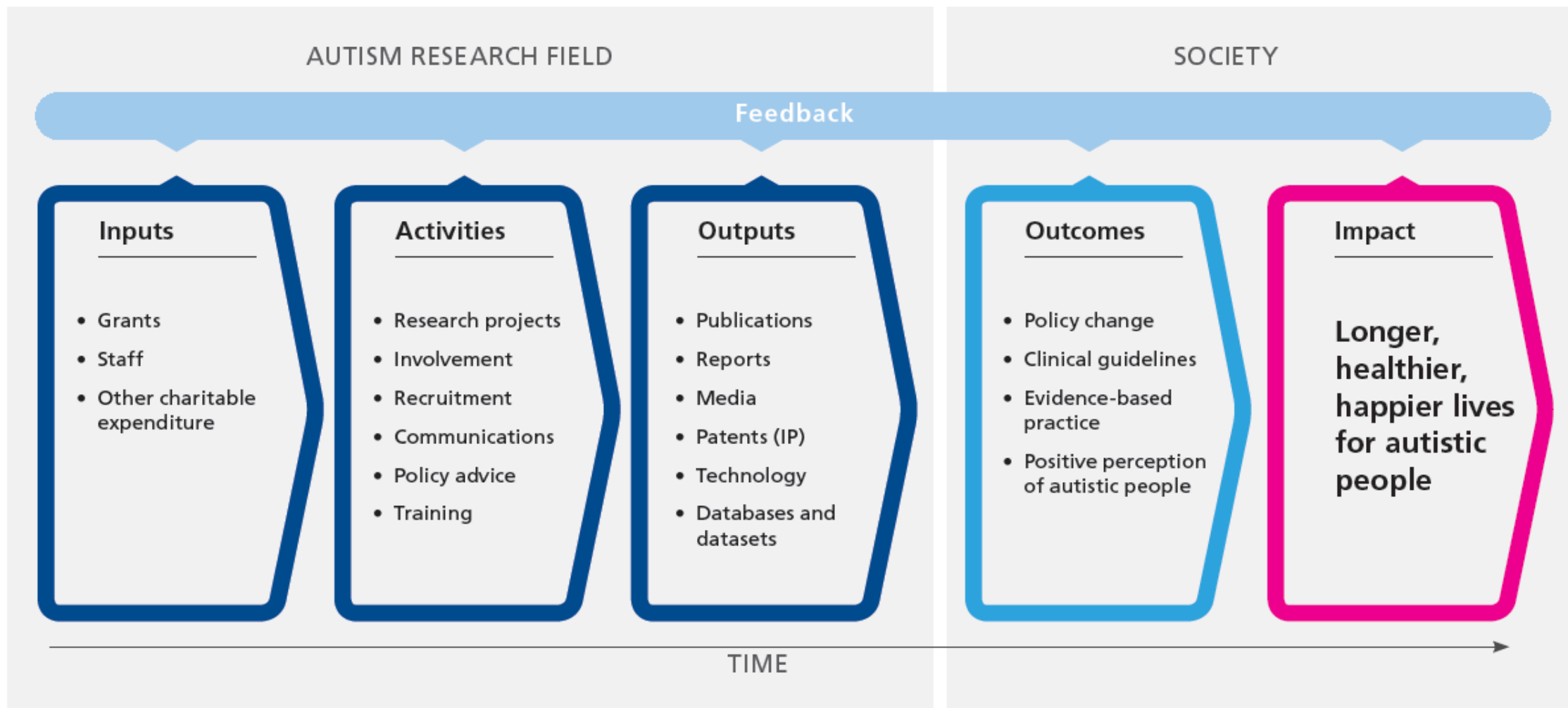
#UnderstandMore



Could citizen science help us to
#UnderstandMore?

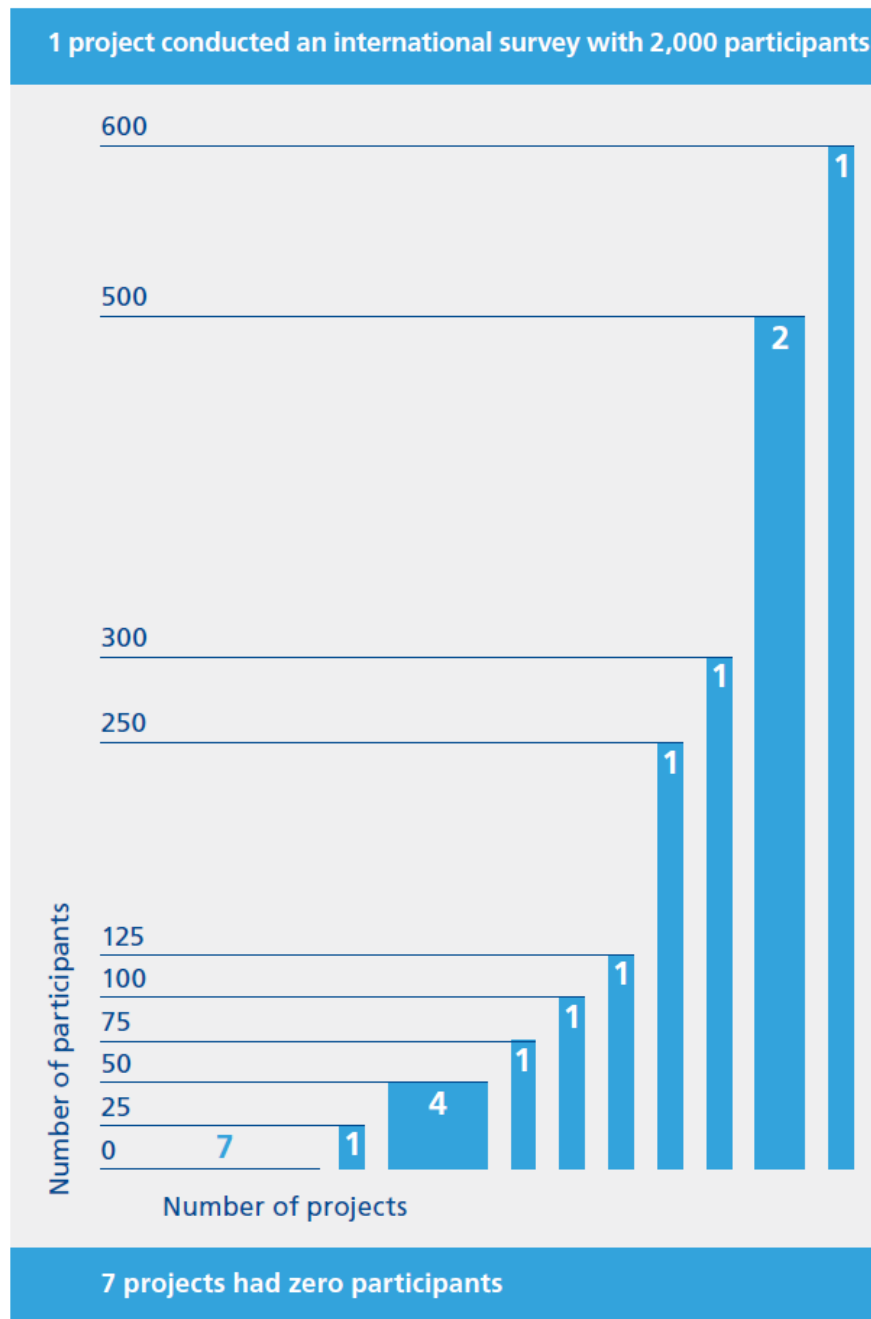


How does research make a difference?



Who has been taking part in autism research in the UK?

- Small samples
- Children



- Older adults (50+ years)
- Adolescents (14-17 years)
- Adults (18+ years)
- Children (0-13 years)

44% of UK autism research funding was spent on animal studies

3 studies recruited people with a learning disability

2 included minimally verbal people

How research can change the weather



Autism is strongly genetic but varies greatly



There is an environmental link



Diagnosed based on behaviour



Language and cognitive ability at age 5 are the best predictors of later life outcomes



Autistic people die younger



More likely to be under employed

Top 10 questions for research



- 1 Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?
- 2 Which interventions are effective in the development and communication/language skills in autism?
- 3 What are the most effective ways to support/provide social care for autistic adults?
- 4 Which interventions reduce anxiety in autistic people?
- 5 Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?
- 6 How can parents and family members be supported/educated to care for and better understand and autistic relative?
- 7 How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
- 8 How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
- 9 How can sensory processing in autism be better understood?
- 10 How should service delivery for autistic people be improved and adapted in order to meet their needs?

Latest findings

Childhood trauma and bullying

*Leading researchers: Professor Francesca Happé and Dr Freya Rumball, King's College London | Dr Dheeraj Rai, University of Bristol
| Dr Sarah Griffiths, University of Cambridge*

The research

- Research is finding that autistic people are more likely to experience physical, sexual or emotional trauma during their childhood.
- Research is beginning to suggest that (as with the neurotypical population) autistic people's traumatic childhood experiences are associated with the development of long term mental health problems such as depression and potentially their increased risk of dying by suicide.
- Trauma was one of the priority research topics identified during Autistica's collaborative, cross-sector workshop on mental health.

Implications for learning providers

- Some of the autistic children and young people you are supporting may experience childhood trauma.
- More research is needed into what types of experiences are especially traumatic for autistic people and what interventions can help autistic people with issues like PTSD.

Latest findings

Anxiety

Leading researchers: Professor Emily Simonoff, King's College London | Dr Jacqui Rodgers, University of Newcastle | Dr Teresa Tavassoli, University of Reading

The research

- Anxiety disorders are the most common mental health problem autistic people face. 4 in 10 autistic CYP have an anxiety disorder. Currently most autistic people continue to struggle with these and other mental health problems into adulthood.
- Autistica and King's College London have developed Molehill Mountain, a free smartphone app to help young autistic people understand and manage their anxiety, based on adapted CBT techniques. There is increasing evidence that mental health interventions for anxiety such as CBT need adapting to work for autistic people.
- The University of Newcastle is running a feasibility trial on an intervention to help autistic CYP cope with uncertainty in everyday situations.

Implications for learning providers

- Consider whether your autistic CYP have problems with anxiety. Emerging research could help us intervene more effectively to prevent autistic CYP from struggling with anxiety and related mental health problems into adulthood.

Latest findings

Anorexia

Leading researcher: Dr Will Mandy, University College London; Prof Kate Tchanturia, KCL

The research

- Autistic women and girls account for approximately a quarter of all women with anorexia.
- Amongst people with anorexia, autistic people have been found to benefit the least from existing interventions and care pathways and have the worst outcomes, with particularly low rates of recovery and levels of functioning.
- Researchers are exploring how anorexia differs for autistic people and what implications that has for interventions and service design.

Implications for learning providers

- Anorexia has the worst outcomes of any mental health problems. Amongst those affected, autistic women and girls have particularly poor outcomes.
- Be alert to signs of disordered eating, including autism-specific signs like obsession with precise calorie targets or sensory issues around food.

Latest findings

Suicide

Leading researchers: Dr Sarah Cassidy, Nottingham University, Dr Jacqui Rodgers, Newcastle University

The research

- A significant proportion of people who die by suicide are autistic (c.11%). Autistic people are also likely to account for a disproportionate number of those hospitalised after attempts.
- Between a third and two thirds of autistic adults without LD report having considered or attempted to end their own life. One study found that this was also true for 14% of CYP on the autism spectrum, compared to just 0.5% of their non-autistic peers.
- Autistic people may consider and approach suicide differently to non-autistic people. Research is currently looking into the risk factors for suicide amongst autistic people.

Implications for learning providers

- Keep abreast of the emerging evidence around suicide in the autistic community.
- Be aware that frontline support services (e.g. Samaritans) may not be suitable for autistic people in crisis and that assessment tools for suicidality may not accurately account for autistic people's risk of dying.

Latest findings

Anxiety and depression amongst people who speak few or no words

Leading researcher: Professor Chris Oliver, University of Birmingham

The research

- Many autistic people with a learning disability have untreated mental health problems which can present as distressed behaviour. Different mental health issues are hard to tell apart in people with complex needs.
- We're developing a short assessment tool to help professionals more reliably identify anxiety and depression amongst autistic people who speak few or no words.

Implications for learning providers

- This research could help HCPs identify issues that underlie behaviour that challenges.
- If adopted quickly and effectively it could reduce the use of restraint/sedation and significantly improve the QoL of autistic people in inpatient care.

Latest findings

Epilepsy

The research

- Epilepsy is the leading cause of death amongst autistic people with a learning disability. On average, half of people with a learning disability do not live to see their 40th birthday. The LeDeR review has found epilepsy is the third largest cause of death of all people with learning disability.
- Between 20% and 40% of autistic people have epilepsies (and vice versa). Autistic people's epilepsies appear more likely to be resistant to treatment. Some autistic people experience epileptic seizures very regularly, requiring frequent visits to emergency services and intensive levels of monitoring.

Implications for learning providers

- A lot more research is needed to improve outcomes for autistic CYP with epilepsy.
- Autistica brought together autistic people, families, clinicians and world leading academics to identify the most promising areas for autism and epilepsy research. The 13 top priorities include investigating whether the use of anti-psychotics at a young age is associated with the onset of epilepsy amongst autistic teenagers and young adults.

Latest findings

Employment

The research

- Autistic people are much more likely than neurotypical people to be unemployed, under-employed or employed in unsuitable roles.
- There are very few high quality studies into the best ways to support autistic people into employment, retain and develop them and make workplaces autism-friendly.
- We have launched DARE (Discover Autism Research and Employment), a joint initiative between Autistica and University College London, to fill this gap:
 - Support companies to set up autism employment schemes or optimise their own schemes
 - Gather data on autistic people's experiences in those firms
 - Publish high quality evidence on what works to drive a cycle of improvement

Implications for learning providers

- DARE can work with firms of any size in any sector and we are seeking partners, both from the corporate sector and providers of support services
- Our first publications will come out this year, looking at disclosing an autism diagnosis at work

Research has told us a lot already, but we have only really just got started.

Groups and areas are neglected but we can tackle that through strategic action.

Need to work more collaboratively to bring research and evidence closer to real life by involving autistic people, families and professionals.

We need to become better at personalisation and understanding individual needs. There is no “one size fits all” approach and research needs to adapt to this.

Research and evidence are key for many people if we are to ensure that all autistic people can live a long, healthy, happy life

Conclusions



“ Research is the only way to get the services we and future generations need. If we don't research, nothing will change.

Malcolm, autistic adult and parent

DISCOVER



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