

Autism and Epilepsy: Laying out the evidence Snapshot



Introduction

We aim to drastically reduce the unacceptable inequalities that autistic people with epilepsy face - within a generation.

People who are autistic and have epilepsy face some of the starkest inequalities in the world. We know that worldwide approximately 8.4 million people have both conditions. On average, they have poorer quality of life, poor health and can die early. We've known this for years, but a lack of evidence-based strategic action has blocked progress.

Rates of co-occurring epilepsy in autistic people are much higher than in the general population. Knowledge of factors contributing to the co-occurrence of both conditions can enable health, educational, mental health and neurodisability services to more effectively identify and support autistic people with epilepsy as well as their families.

Despite sharing some common mechanisms, autism and epilepsy remain virtually unstudied in combination.

Autistica has led a partnership with Epilepsy Research UK and Young Epilepsy to fund research to summarise the evidence focusing on co-occurring autism and epilepsy, outlining the scientific evidence and scale of the issue in human, social and economic terms.

This document aims to provide the much-needed evidence for further research investment and will assist health, care and educational services in providing better support. It will also enable people affected by epilepsy and autism to further understand their conditions. The project was undertaken between September 2020 and February 2021 and explored three key themes:

- 1. Risk factors of co-occurring epilepsy in autistic people**
- 2. Living with co-occurring autism and epilepsy**
- 3. Economic analysis of the costs of co-occurring autism and epilepsy**



Mark Devlin
CEO Young Epilepsy



Dr James Cusack
CEO Autistica



Maxine Smeaton
CEO Epilepsy Research UK

Key Facts

What is autism?

Autism affects the way people perceive and interact with the world around them. Autism is a lifelong developmental condition associated with sensory sensitivities and social communication differences.

Autism presents differently across individuals. Some people are able to learn, live and work independently, while many have learning differences or co-occurring health conditions that require specialist support.

About 1 in 100 people are autistic. The prevalence of epilepsy in autistic people is higher than in non-autistic people. Co-occurring epilepsy contributes to decreased quality of life and increased risk of mortality among autistic people.

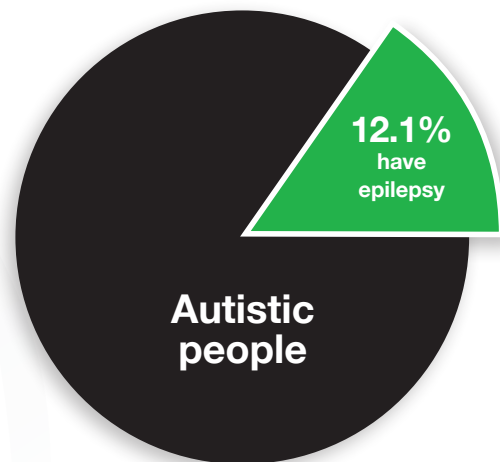
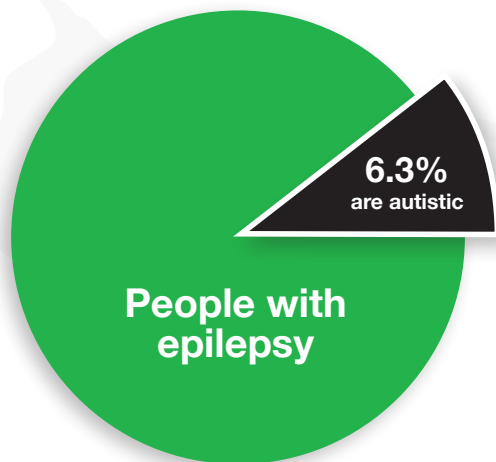
What is epilepsy?

Epilepsy - one of the most common serious neurological conditions – is a brain disorder characterised by seizures that are brought on by excessive electrical activity. There are over 40 different types of epilepsy, and no two people's experiences of the condition are the same. Epilepsy can affect anyone, at any age and from any walk of life.

Around 1 in 103 people have an epilepsy diagnosis in the UK and, shockingly, there are 21 epilepsy-related deaths every week. Epilepsy often co-occurs with other conditions, such as autism and learning disabilities, which can severely affect quality of life.

Co-occurrence of epilepsy and autism

The prevalence of epilepsy in autistic people is higher than in people without autism. A previous review found a 12.1% prevalence of epilepsy in autistic people (Lukmanji et al, 2019). Equally, people with epilepsy have a higher prevalence of autism than people without epilepsy with a previous review finding a prevalence of autism in epilepsy of 6.3% (Strasser et al, 2018). Co-occurring epilepsy contributes to decreased quality of life and increased risk of mortality among autistic people.



S Lukmanji, SA Manji, S Kadhim, KM Sauro, EC Wirrell, CS Kwo, N Jetté (2019) **The co-occurrence of epilepsy and autism: A systematic review.** *Epilepsy and Behavior*. 98(Pt A):238-248.

L Strasser, M Downes, J Kung, JH Cross, M De Haan (2018) **Prevalence and risk factors for autism spectrum disorder in epilepsy: A systematic review and meta-analysis.** *Developmental Medicine and Child Neurology*. 60(1):19-29.

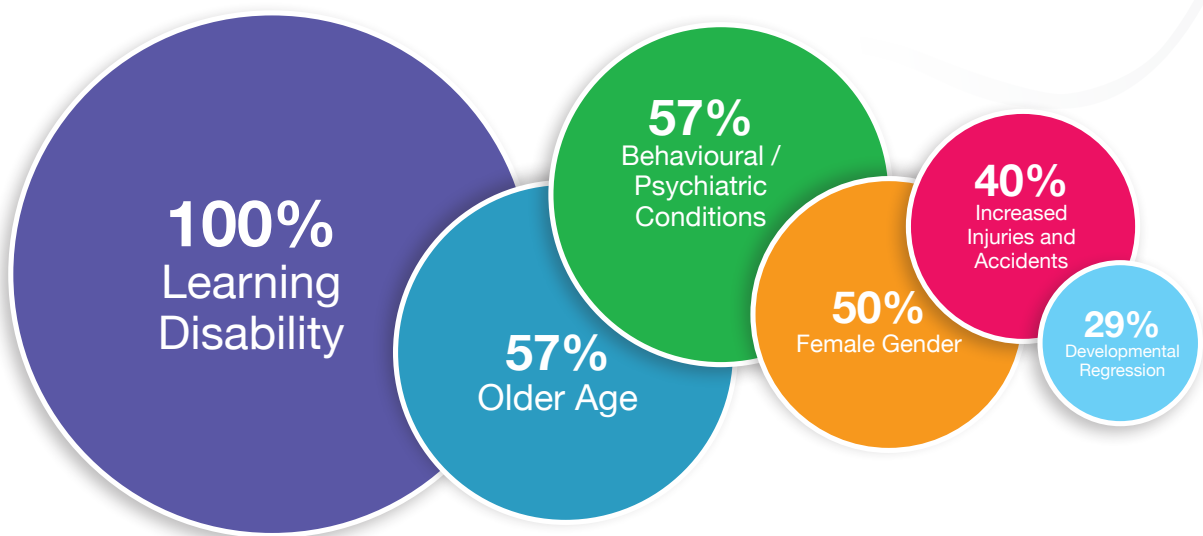
Key Theme 1

Risk factors of co-occurring epilepsy in autistic people

Fifty-one papers representing 452,268 autistic people were included in a systematic literature review to explore the risk factors associated with having both epilepsy and autism. A systematic literature review is a type of review that examines all relevant, published research studies and summarises them to answer a research question.

A range of factors were found to be associated with epilepsy in autistic people in some but not all studies. The factor most often associated with the occurrence of epilepsy in autistic people was learning difficulties or the presence of a learning disability. Autistic people who have a learning disability or learning difficulties thus have a greater chance of also having epilepsy compared with autistic people without learning difficulties.

The risk factors of co-occurring epilepsy in autistic people ranked by the percentage of papers which considered them and found them to be significant



Not every paper which looked into possible risk factors of co-occurring epilepsy in autistic people considered all of these factors but these were the most commonly considered.

The presence of a learning disability, or learning difficulties, was the only factor which was found to be a significant risk factor in every single study which considered it.

The other significant risk factors for co-occurring epilepsy in autistic people, for example older age and behavioural conditions, were found in some studies which considered them, but not in others. This means the evidence for them being an important risk factor for co-occurring epilepsy in autistic people is much weaker than it is for a learning disability or learning difficulty.

Key Theme 2

Living with co-occurring autism and epilepsy

Our search for research describing the lived experiences of autistic people who have epilepsy uncovered no previous studies, meaning this document is the first of its kind.

Alongside this review, a Patient and Public Involvement (PPI) group was formed to identify key issues with regards to living with co-occurring autism and epilepsy. The group consisted of three autistic people with epilepsy and four parents of autistic children who have epilepsy. The PPI group met digitally on three occasions and also contributed their thoughts individually.

Through our PPI meetings and email correspondence, we identified 18 key themes and 60 subthemes. This process is known as thematic analysis and is a method of identifying, analysing and interpreting patterns of meaning within data.

1 **Lack of support during assessment and after epilepsy diagnosis**
"Nobody has explained what epilepsy is to me"

2 **Lack of understanding of autism-epilepsy comorbidity**
"When the evidence is so clear these conditions go hand in hand, how can those departments not talk to one another"

3 **Lack of integration of care**
"Need for professionals knowledgeable about both conditions"

4 **Failure to identify autism and subsequent lack of support after diagnosis**
"Its her medication not autism" (professionals said)

5 **Assessment and investigations for epilepsy often difficult for autistic people**
"Because she didn't have an autism diagnosis at the time she was perceived as just being difficult"

6 **Experiences at school often negative**
"They don't understand epilepsy and they definitely don't understand autism"

7 **Other comorbid health issues**
"I am depressed - no you are not ...you have autism"

8 **Potential difficulties with epilepsy medication including potential side effects and adherence**
"I don't know how 23 years of medication has affected my brain"

9 **Impact on siblings' wellbeing**
"She (sibling) was always on guard for me."

10 **Impact on parental wellbeing**
"Our friends fell away very quickly"

11 **Perceived understanding in the wider family of autism and epilepsy**
"For their grandmother, there is no autism. They're just ill behaved"

12 **Autistic person's perception of impact on their family**
"I think it affects all of my family. I've definitely felt guilty over the years that it's not my fault, but I feel it"

13 **Economic impact on person with autism-epilepsy**
"Very hard to get a job if you mention epilepsy - autism is a little better"

14 **Economic impact on parents and family**
"I'm essentially a 1950s housewife"

15 **Impact of behaviour that challenges**
"Public misinterpret behaviour especially when child does not look physically different"

16 **Learning and communication difficulties**
"She does a good job of masking how little she understands"

17 **Epilepsy/autism has greatest impact**
"The focus shifts depending on whether seizures are active or not"

18 **Sleep**
"When I fall asleep it's at that time when I start to have seizures... so it takes me a long time to get to sleep and it's just like an ever-ending circle"

Key Theme 3

Economic analysis of the costs of co-occurring autism and epilepsy

There is a lack of economic evidence for the cost of epilepsy in autistic people. Only three papers all based in a high-income country (USA or Canada) were published within the last decade and appropriate for inclusion for this review.

Across different contexts, each study examined only costs or resource use, but none considered health outcomes. This means that no relevant economic evaluations of specific support/treatment targeted at autistic people who have epilepsy were found.

Although evidence suggests that autistic people with epilepsy are likely to have greater healthcare needs, and therefore higher costs, it is difficult to comment on what drives differences in resource use, based on the evidence reported.

Conclusion

Given the high co-occurrence of autism and epilepsy there is increasing interest in their possible shared biological causes. Understanding why autistic people have an increased risk for epilepsy at the biological level may allow for the development of treatments which can treat both seizures and lead to improvements in the quality of life of autistic people.



The prevalence of co-occurring epilepsy in autistic people is higher than in non-autistic people. The factor most consistently associated with this co-occurrence is the presence of a learning disability or learning difficulties.



There is no published data on the lived experience of people with both conditions. The experts by lived experience, the Patient and Public Involvement (PPI) group, highlighted a range of needs, including specific aspects, that people both conditions have. These specific aspects include difficulties for autistic people with respect to epilepsy related investigations and hospital visits, a lack of integrated health care, limited knowledge of autism among epilepsy professionals and potential impact of epilepsy medicines on perception of autism symptoms and subsequent manifestation of symptoms.

There are few previous studies which focus on the economic impact of having both conditions, although it would appear that having both conditions increases economic costs. Additionally, analysis of responses from the PPI group suggest a potentially very significant broad economic impact of having both conditions.



Recommendations for support & future research



Ways to improve support

- ✓ Improve awareness of the frequent co-occurrence in national guidelines and support organisations
- ✓ Make hospital visits more autism friendly
- ✓ Improve awareness of autism among epilepsy professionals
- ✓ Screen people with epilepsy for autism and other neurodevelopmental conditions, as well as mental health conditions
- ✓ Ensure that autistic people who have epilepsy have access to evidence-based therapies for co-occurring conditions



Future research recommendations

- ✓ Qualitative research with autistic people who have epilepsy and their families
- ✓ Key relevant economic interventions for this population remain unclear and need to be identified
- ✓ Further research is needed on long-term non-healthcare costs and outcomes
- ✓ Research is also needed on the impact that being autistic and having epilepsy has on job/employment prospects

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The research team was led by Dr Colin Reilly, Educational Psychologist and Honorary Researcher at The UCL Great Ormond Street Institute of Child Health.



autistica

Autistica is the UK's national autism research charity. We focus on giving autistic people the opportunity to live long, happy, healthy lives. We do this by funding research, shaping policy and working with autistic people to understand their needs.

info@autistica.org.uk



Epilepsy Research UK is the only charity exclusively dedicated to driving and enabling life changing, life saving research into epilepsy. Our pioneering clinical research discovers ways to advance the medical care and management of people living with epilepsy and our lab-based scientific projects investigate causes and methods for improved diagnosis, treatment and prevention.

info@eruk.org.uk



Young Epilepsy is the children and young people's epilepsy charity. We exist to create a society where children and young people with epilepsy are enabled to thrive and fulfill their potential. A society in which their voices are respected and their ambitions realised.

info@youngepilepsy.org.uk

