

Make Things Work: Epilepsy Discrimination in the Workplace

Summary

Between July and September 2023, Epilepsy Action carried out two surveys, the aim of which was to determine the extent of discrimination in the workplace for people with epilepsy. The surveys focused on two key groups:

- a) People with epilepsy, to gather their experiences
- b) Employers, to understand their attitudes towards people with epilepsy

Key findings from the surveys:

- 42% of employers admitted that they would be inclined not to hire someone with epilepsy to save their company potential challenges, even though they know this is discrimination
- Almost two thirds of respondents with epilepsy (60%) say they have experience unequal treatment or discrimination at work because of their condition
- Two in five (40%) say their employer has refused to provide reasonable adjustments
- Over a third (36%) have had their colleagues, manager or employer make derogatory comments about their epilepsy
- One in three (33%) have been bullied because of their condition, either by their employer, manager or their colleagues
- 28% have been subjected to disciplinaries for having seizures

The findings of the survey highlight unacceptable levels of discrimination faced by people with epilepsy in the workplace. It is clear that current repercussions for employers who discriminate against people with epilepsy are not sufficient to stop this illegal behaviour from occurring.

Research from the [Institute of Economic Studies \(IES\)](#) (Francis et al., n.d.) identified that employers tend to 'stigmatise' epilepsy and, by association, people with the condition, making them reluctant to employ people with epilepsy or support them to progress their career.

Experiencing discrimination can have a negative impact on an individual's future employment opportunities. The research from the IES found that people were deterred from being open about epilepsy because they had previously encountered employer discrimination.

As well as being discriminated against in the workplace, people with epilepsy can also face discrimination when looking for work. Many people with epilepsy suspect they have been discriminated against during job applications when they have informed the potential employer that they have epilepsy.

Background

We know that people with disabilities still struggle to [find and stay in work](#).

Despite the Government committing to [improving the number of disabled people in work](#) the disability employment gap – the difference between the employment rates of disabled and non-disabled people – has consistently remained at around [30% since 2010](#) (House of Commons Work and Pensions Committee, 2017).

This means that disabled people are more than twice as likely as non-disabled people to be out of work.

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We know that some people with epilepsy will not be able to work due to the severity of their condition. However, for many others there are few jobs that their epilepsy would prevent them from doing.

However, people with epilepsy can struggle to find employment more than many other disabled people. People with epilepsy have one of the lowest rates of employment among disabled people; Only 43% of people who identified epilepsy as their “main” health condition are in employment, according to figures from the [Office for National Statistics](#) (*Disability and Employment - Office for National Statistics, 2021*).

[Research by the Trade Union Congress \(TUC\)](#) has also highlighted that people with epilepsy in work are paid on average 11.8% less than non-disabled workers (Trade Union Congress, 2019). This means that not only are people with epilepsy less likely to have a paid job, but when they do, they earn less than their non-disabled peers.

The above demonstrates that too few people with epilepsy are in work, and when they are, they are all too often **paid less, bullied and discriminated against**.

Methodology

Epilepsy Action gathered survey data to better understand the current employment environment in the UK for people with epilepsy. Two separate surveys were created and circulated to different audiences. The first survey asked people with epilepsy who lived in the UK for their experiences with employment. The second asked employers (managers or HR professionals) operating in the UK for their attitudes towards employing people with epilepsy.

People with epilepsy

A survey of 15 questions was circulated by Epilepsy Action to its members, service users and followers. It was shared on social media (X/Twitter, Facebook, Instagram, LinkedIn), the Epilepsy Action website, in the Epilepsy Today magazine, and through email newsletters. The questions were

targeted at people with epilepsy who were currently employed or had been employed at an earlier time in their life.

Survey responses were collected from 18 July to 28 August 2023. The survey was created and hosted using Typeform.

The questions asked people with epilepsy about:

- Demographic data including age group and location
- Seizure frequency
- Employment status
- Financial circumstances, receipt of benefits (e.g. Universal Credit), and home ownership status
- Experiences of workplace discrimination
- Use of the Access to Work scheme

Analysis was performed in Microsoft Excel version 2309 and R 4.2.2.

Employers

Using an external survey provider, eight specific questions were circulated to 500 randomly selected employers and managers and 500 employees. Survey responses were collected from 22 August to 29 August 2023.

The questions asked about:

- Their own attitude towards and understanding of epilepsy
- Their organisation's attitude towards and understanding of epilepsy
- Knowledge and training related to epilepsy
- Knowledge of reasonable adjustments and the Disability Confident scheme
- If relevant, specific instances of discrimination against people with epilepsy

Analysis was performed in Microsoft Excel version 2309 and R 4.2.2.

Results

People with epilepsy

This survey received 1,403 responses.

Demographics

Region	% of respondents
Midlands	15.8%
North East	5.6%
North West	13%
Northern Ireland	3.7%
Scotland	5.3%
South East	32.1%
South West	12%
Wales	4.5%
Yorkshire	8%

Region	In Full-time Employment	Have experienced discrimination	Have been made redundant	Have been bullied by employer/colleagues
South East	46%	57%	16%	17%
South West	35%	63%	19%	24%
North East	40%	65%	23%	21%
North West	41%	67%	14%	24%
Midlands	37%	55%	14%	18%
Yorkshire	43%	69%	13%	26%
Scotland	27%	53%	13%	11%
Wales	37%	61%	13%	17%
Northern Ireland	26%	53%	6%	20%

There was little significant regional variation in relation to people's experiences of discrimination. However there were fairly clear differences in the levels of full-time employment between the different regions, with the rate of employment in the South East and Yorkshire being significantly higher than in Scotland and Northern Ireland.

Age

Age	% of respondents
16-20	3%
21-30	17.1%
31-40	20.9%
41-50	22.7%
51-60	23.9%
61-65	6.1%
65+	5.1%
Prefer not to say	1.2%

Age range	In Full-time Employment	Have experienced discrimination	Have been made redundant	Have been bullied by employer/colleagues
16-20	17%	50%	5%	12%
21-30	54%	63%	14%	18%
31-40	48%	69%	15%	25%
41-50	45%	66%	15%	21%
51-60	31%	50%	17%	15%
61-65	26%	58%	19%	20%
Over 65	7%	38%	14%	10%

Those over 65 years of age reported experiencing less discrimination than younger people.

Results

- Almost two thirds (60%) say they have experienced unequal treatment or discrimination at work because of their condition
- 9% of people have been demoted
- 25% made redundant
- Two in five (40%) say their employer has refused to provide reasonable adjustments
- Over a third (36%) have had their colleagues or employer made derogatory comments about their epilepsy
- One in three (33%) have been bullied because of their condition, either by their employer or their colleagues
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Employers

Hiring and team dynamics:

- Almost two in five respondents (37%) would be reluctant to hire someone with epilepsy
- 42% said they would be inclined not to hire someone with epilepsy to save their company potential challenges, despite being aware that this is discrimination
- Almost one in six (14%) believed employers are allowed to decide not to hire a candidate because of their epilepsy
- Over two fifths (42%) believed an employee with epilepsy could be a liability for their company
- Almost two in five (37%) also believed having an employee with epilepsy could affect their team's productivity because of the unpredictable nature of the condition
- Over two fifths (44%) thought people with epilepsy would struggle with a demanding job such as being a team manager or leader

Training, reasonable adjustments and costs:

- A quarter of respondents had no understanding about the reasonable adjustments a person with epilepsy would need in the workplace – 25% considered themselves 'not at all knowledgeable'
- The majority (62%) of respondents said they would know what to do if one of their employees had a seizure at work, however 43% had never received epilepsy or seizure first aid training
- Almost two in five (37%) thought employers and managers do not receive enough information on how to support employees with epilepsy
- 43% also said that in the current economic climate, they thought employers would be more likely to make people with epilepsy redundant before other employees due to the higher costs of reasonable adjustments
- 38% thought the cost of reasonable adjustments to have a person with epilepsy in their team could outweigh the benefits of their work
- Just 14% of respondents had signed up and completed at least one level of the Disability Confident scheme

Attitudes, discrimination and company culture:

- 32% of respondents had said or done something they now regret when it comes to people with epilepsy

- Over nine in 10 (92%) had at least one wrong assumption about people with epilepsy in the workplace, when presented with a mixed selection of true and false statements
- Almost half (49%) thought an employee with epilepsy might hesitate to report incidents of bullying or discrimination at their company for fear of repercussions. Just 13% thought they might hesitate, but not for reasons related to their disability
- Almost a third (32%) were aware of epilepsy being used against an employee when evaluating their performance at their current company. Of these, 13% could recollect a specific case in which this happened
- 40% were aware of cases where an employee's epilepsy was used as a reason not to give them additional responsibilities or promotions at their current company. Of these, almost a fifth (18%) said they have directly witnessed or been informed of such a case

Discussion

From these findings, it is concerning to see that so many people with epilepsy have been refused reasonable adjustments in the workplace. The Equality Act 2010 obliges UK employers to make 'reasonable adjustments' such as changes to the workplace and working practices to enable people with disabilities to access work.

While employers can refuse to make reasonable adjustments if they believe the proposed changes would be too costly or impractical ([EHRC](#)), for many people with epilepsy reasonable adjustments are relatively inexpensive and unintrusive. They can include options such as flexible working, and a place to recover after a seizure.

In addition, only 12% of people with epilepsy had applied for help through the Access to Work scheme. [Access to Work](#) can provide support to people with a physical or mental health condition or disability to help them get or stay in work. This support can include funding for reasonable adjustments, or support such as taxi fares to work or a support worker if you cannot use public transport.

Raising awareness of and implementing the Access to Work scheme is a key factor, and one which employers have a duty to raise and support employees in accessing.

In addition, the scheme should be further improved to ensure that people with epilepsy get the support they need to find and stay in a job.

In response, Epilepsy Action have launched a petition calling for the government to strengthen employment law and ensure that employers are properly punished for discriminating against disabled people.

It is evident that current employment law – and the punishments employers face – are failing people with epilepsy and not tackling the discrimination they face in the workplace.

Currently employment tribunal payments are made up of loss of earnings and costs for missed opportunities. While in theory disability discrimination compensation awards are uncapped, in practice the average award in the UK is just over £13,500. This is not enough of a deterrent to stop discrimination against people with epilepsy in the workplace.

Key recommendations

For the government:

- Make Access to Work support available during the search for employment to help people find work, and ensure that support is in place from employment commencing
- Ensure that the Access to Work scheme have clear timescales to hold the employer to making required adjustments
- Introduce minimum fines for any employer found guilty of discriminating against a person with a disability. The minimum fines should be a percentage of the employer's annual turnover
- The proceeds of these fines should be given to the victims of discrimination to provide more meaningful compensation than the meagre awards currently available

For employers:

- Use Epilepsy Action's [employment toolkit](#) designed to help support employees with epilepsy in the workplace
- Undertake [epilepsy-specific training](#) to better understand the condition
- Offer personalised and specifically designed employment support for people with epilepsy, including a personalised toolkit for employees and employers to promote positive disclosure and active self-management

References

Disability and employment—Office for National Statistics. (n.d.). Retrieved 18 December 2020, from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/datasets/disabilityandemployment>

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