Disability Act 2005 – A Short Guide for the ME Community

Please see our short guide for people with ME, family members and carers which we put together for anyone interested in completing and sending a submission.

The Disability Act 2005 has 7 Parts.

Below is a simple explanation of what each part does, part of what is missing, and some of the main changes MEAI recommends.

You do not need to read it all at once.

Part 1 – General rules and definition of disability

What is this Part about?

Part 1 contains some of the basic rules of the Disability Act.

Importantly, it includes the Act's general definition of disability.

What is missing for people with ME?

The definition does not adequately reflect disabilities that are:

- fluctuating or episodic;
- invisible;
- cognitive;
- energy-limiting.

A person with ME may be able to do something once or on a better day but be unable to do it reliably, repeatedly or sustainably.

Activity can also cause delayed deterioration.

What does MEAI recommend?

MEAI recommends a modern, rights-based definition of disability.

It should clearly recognise fluctuating, episodic, invisible and energy-limiting disabilities such as ME.

Disability should be judged by its real impact on a person's life and participation, rather than what they appear able to do at one particular moment.

Part 2 – Assessment of Need, Service Statements and Redress

What is this Part about?

Part 2 deals with assessing disability-related needs.

It includes:

- Assessment of Need;
- Service Statements;
- complaints and appeals.

What is missing for people with ME?

Assessments may not properly recognise fluctuating or invisible disability.

A short assessment on a relatively good day may give a very misleading picture of someone's actual ability.

There can also be long delays between needing an assessment, receiving one and actually receiving support.

The current Part 2 definition of “substantial restriction” may also fail to capture some of the main limitations experienced in ME, including stamina, exertion intolerance and cognitive dysfunction.

What does MEAI recommend?

Assessments should consider a person's functioning over time, including post-exertional deterioration and the delayed effects of activity.

Assessors should understand ME and fluctuating disability.

Assessments should identify actual need, regardless of whether a service is currently available.

Service Statements should clearly state what support will be provided, by whom and when.

Complaints and appeals should be accessible and provide timely and effective remedies.

Part 3 – Access to Buildings and Services

What is this Part about?

Part 3 is about access to:

- public buildings;
- public services;
- public information;
- heritage sites.

It also provides for accessibility plans and complaints.

What is missing for people with ME?

Accessibility is often thought about mainly as physical access to a building.

For someone with ME, a building may be wheelchair accessible, but the service may still be inaccessible.

Barriers can include:

- travelling;
- walking or standing;
- waiting;
- noise or bright lighting;
- long appointments;
- cognitive demands;
- lengthy forms;
- repeated appointments;
- having to attend in person.

These barriers can be especially serious for people who are housebound or bedbound.

What does MEAI recommend?

Accessibility should include physical, sensory, cognitive, communication and energy-related barriers.

Services should provide appropriate flexibility.

This could include remote or telephone access, home-based services where needed, flexible appointments, rest opportunities, reduced waiting and avoiding unnecessary travel.

Public information should also be clear and cognitively accessible.

People should not have to make repeated complaints before accessibility barriers are addressed.

Part 4 – Genetic Testing

What is this Part about?

Part 4 protects people in relation to genetic testing and genetic information.

It includes important protections concerning consent, privacy and the use of genetic information.

What is missing?

Genetic and genomic science has developed enormously since 2005.

The law needs to remain strong enough to protect people as technology and the ways genetic information can be obtained and used continue to develop.

What does MEAI recommend?

Strong protections against genetic discrimination should be retained and updated.

Genetic information should not be used unfairly in areas such as employment, insurance, pensions or mortgages.

A person should also not be denied disability rights or support because there is no genetic test or genetic explanation for their disability.

Disability support should be based on the person's actual needs and functional limitations.

Part 5 – Employment in the Public Service

What is this Part about?

Part 5 aims to increase the employment of disabled people in the public service.

It includes an employment target and monitoring of public bodies.

What is missing for people with ME?

Simply counting how many disabled people are employed does not tell us whether they are genuinely included.

People with ME may be able to work but need flexibility because their capacity can fluctuate.

Rigid requirements around commuting, attendance, working hours, meetings and workload can make employment impossible even when the person could do the job with appropriate accommodation.

What does MEAI recommend?

The employment target should be retained, but success should also be measured by whether disabled people can:

enter, remain in and progress in employment.

Reasonable accommodation should be strengthened.

For someone with ME this might include:

- remote or hybrid working;
- flexible hours;
- rest breaks;
- reduced commuting;
- flexible meetings;
- pacing of workload;
- reduced unnecessary travel.
- Physical presence should not automatically be treated as evidence of productivity or commitment.

Part 6 – Universal Design

What is this Part about?

Part 6 provides for the Centre for Excellence in Universal Design.

Universal Design means designing environments, services, products and systems so that as many people as possible can use them.

What is missing for people with ME?

Universal Design can still be understood too narrowly.

Something can be technically accessible but still be impossible for a person with ME to use.

For example, a service may require too much:

- energy;
- walking or standing;
- waiting;
- concentration;
- form-filling;
- sensory tolerance;
- travel.

What does MEAI recommend?

Universal Design should explicitly include energy and exertion as accessibility issues.

It should consider the person's whole journey through a service.

Digital services should be simple and cognitively accessible, with alternatives where digital access creates barriers.

Disabled people, including people with fluctuating and energy-limiting disabilities, should be involved in designing and testing services.

Universal Design should remove barriers wherever possible, but it should not replace the right to individual reasonable accommodation.

Part 7 – Miscellaneous, Enforcement and Other Matters

What is this Part about?

Part 7 contains several different provisions.

These include provisions connected with accessible broadcasting and offences under the Act.

What is missing?

Having rights written in law is not enough if people cannot enforce them.

Complaints and enforcement systems can themselves be exhausting and inaccessible.

For somebody with ME, lengthy forms, correspondence, meetings, travel and repeated appeals can worsen their health.

What does MEAI recommend?

There should be clear, accessible and effective ways to enforce disability rights.

People should not have to repeatedly fight to obtain rights that the law already gives them.

Complaints and redress should be simple and accessible.

Enforcement should not depend entirely on an individual disabled person having the health, energy, knowledge or money to pursue a case.

Penalties and enforcement powers should also be reviewed to make sure they are effective.

The main message from MEAI

Across the whole Disability Act, MEAI is asking for one fundamental change:

Disability law must recognise how disability actually affects a person's life.

For people with ME, this means recognising:

- fluctuating disability;
- invisible disability;
- energy limitation;
- cognitive and sensory difficulties;
- post-exertional deterioration;
- Severe, Very Severe and Profound ME;
- people who are housebound or bedbound.

A person's ability should not be judged simply by what they can do once, on a good day, or by worsening their health.

Disability rights should lead to real access to assessment, support, reasonable accommodation, independent living and participation.

People with ME should not have to sacrifice their health in order to access their rights.