
You don't look disabled: supporting members with invisible impairments
Advice from the TUC

"You don't look disabled": supporting members with invisible impairments

Why is guidance needed?

Popular misconceptions of disability and the consequences

Of the millions of disabled people living in Britain today, only a very small percentage use wheelchairs, or assistance dogs, or are otherwise identified by visible evidence of impairment. But everywhere, from supermarket car parks to public transport to workplaces, people believe that "real" disability can be seen and that anyone who is not visibly impaired is not really disabled. Time and again the words "you don't look disabled" are used to show disbelief – and at the same time, to challenge an individual's right to "reasonable adjustment", often associated with a view that the disabled person is wrongly gaining an unfair advantage.

One consequence is that many people who are entitled to legal protection against discrimination and to "reasonable adjustments" are discouraged from coming forward to seek such adjustments from the employer. Often, it can be disabled people themselves who do not recognise that a condition they have, that means they need support or adjustments to enable them to function the same as their colleagues, may count as a disability in the law. Sometimes, especially with mental health conditions, those affected are afraid that the stigma associated with mental health means they would lose their job and have great difficulty finding another. Sadly, all too often this is still the case, but unions can – and often do - make a major difference.

Even among those aware that disabled people are protected against discrimination and that disability covers far more people than those with visible impairments, there are many who misunderstand the fundamental principle of disability discrimination law that disabled people may need to be treated *more favourably* in order to overcome the disadvantages they already face and to arrive at an equal outcome.

The consequences of the widespread stereotyping of disabled people and common misunderstanding of the law are serious. They mean that disabled people have to

confront yet another barrier to their participation in society, including at work, if they have to explain every single time that they are in fact disabled, and that they are entitled to the adjustments required to enable their participation. They may be deterred from asserting their rights, and attempt to conceal the effects of an impairment in order to "fit in". Sometimes this will cause serious consequences for their own health as failure to act promptly may make a mental health crisis (for example) much worse.

Meanwhile, at a national level, government messages reinforced by sections of the popular press that people claiming benefits are defrauding decent hard-working taxpayers reinforce another sadly popular stereotype, that there are two types of disabled people: those who "deserve" to be supported in helpless dependence (through charity, rather than the support that would enable them live independently), or like injured war veterans; but everyone else is a fraud. This accusation is more likely to be thrown at anyone who is disabled but does not show visible evidence of it, leaving them even more exposed to the risk of abuse or worse.

Trade unions reject these stereotypes as both false and oppressive.

The role of trade unions

Trade unions have an important role to play at several levels:

- Supporting members with "invisible impairments" in the workplace to secure their entitlement to adjustments and to enable them to work in the same, safe, environment as their non-disabled colleagues. As the case studies presented here confirm, this can be a difficult and sometimes lengthy process requiring close consultation with the member and the collection of evidence;
- Ensuring that members who have invisible impairments are aware that they may be protected against discrimination and may be entitled to adjustments to compensate for the barriers that make their full participation more difficult. This will require a continuing campaign of awareness and education and will be achieved most easily by persuading employers to work collaboratively to demonstrate in practice that they are "disability-friendly";
- Persuading employers of the necessity of ensuring that managers are trained to understand and to respond correctly when a worker presents with an invisible impairment;
- Educating fellow trade unionists and other workers away from the misleading stereotypes too often found in the popular press so that the widespread demonisation of disabled people is more effectively challenged.

A precautionary note: the language of disability and the social and medical models

The TUC has for many years supported the Social Model of disability which is the reverse of the medicalised approach contained in UK law. The social model sees the disability not in the "defect" of the individual, but in the barriers put up by

society that interact with the individual's impairment to deny them access or participation. The social model is also used in the United Nations Convention on the Rights of Persons with Disabilities, which has been ratified by the UK government, but which has not led to a change in the definition of disability contained in UK law. TUC guidance is therefore obliged to use the language of the medical model because this reflects what is found in the law.

Who is "disabled" in law?

The Equality Act 2010

The relevant law is the Equality Act 2010 which absorbed the definitions first set out in the Disability Discrimination Act 1995 and its subsequent improvements. By law, people are defined as disabled (and therefore entitled to protection against discrimination, and – critically – to have the right to "reasonable adjustments" by the employer or service provider) whether their impairments are "physical", or "mental". The deciding factor is whether the impairment has "a substantial adverse impact" on their ability to carry out "normal" day to day activities and whether it is long-lasting (i.e. will last a year or more, although fluctuating conditions are also covered "if likely to recur"). Some conditions are explicitly included: chronic conditions such as diabetes and asthma, progressive conditions such as rheumatoid arthritis or Motor Neurone Disease. Anyone with cancer, multiple sclerosis or HIV is covered from diagnosis. The law also explicitly covers mental impairments such as autistic spectrum disorders, dyslexia and dyspraxia, depression, "personality disorders", schizophrenia, bipolar affective disorders and obsessive compulsive disorders.

These definitions cover millions of people. The problem is that too many employers have only a vague grasp of equality law and share popular misconceptions of "disability", and therefore do not understand what they are required to do when faced with workers who are not visibly impaired but who are entitled to the protection of the law. The problems that then arise relate to the right to demand a "reasonable adjustment", with the additional obstacle of demonstrating to managers and fellow workers that this may lead to the disabled member receiving more favourable treatment in the interests of achieving equality of outcome. It also often extends beyond this to dealing with attempts by managers to use company procedures on capability or attendance to get rid of the disabled worker rather than adjust the procedure, as the law may require. Union representatives therefore need to be alert both to how to support members who need adjustments to do their job, and to prevent the misuse of employer policies that should be adjusted as well.

Problems for union representatives

The problem for union representatives when faced by managers either ignorant of the law, or determined to test it to the limit in order to get rid of a worker who

they may feel is insufficiently productive, or too expensive to support, is that every case is unique and that identifying that the member is covered by the protection of the Equality Act may only be the starting point in negotiations. It is, however, the critical first step to a successful defence of a member's employment. For this, as some of these case studies confirm, it will be necessary to obtain clear medical evidence or an Occupational Health (OH) report that confirms that the member is disabled in terms of the Equality Act. An employer who then ignores this evidence will be vulnerable to legal action for discrimination but in some cases (including an example here) the member will have become so stressed as to be unable to contemplate the prospect of a tribunal hearing.

Some case studies

The TUC has gathered some case studies from unions of examples of members with "invisible impairments" across a range of conditions, how they were treated and how the union intervened to resolve the situation.

A key message that emerges is that a reasonable adjustment is usually able to make it possible for the disabled worker to continue in employment and to deliver their role, but that where management resort to disciplinary procedures based on other company policies such as attendance or sickness it often makes the situation much worse.

The studies have been anonymised and edited but the words used are all from the original submission. Some of the cases reveal the cross-cutting real-life consequences for the member of management (in)action, and the readiness of managers to resort to disciplinary action; others concern the difficulties created by lack of comprehension by colleagues rather than management. All present real challenges for trade unions.

The studies are presented under the general headings of (1) management failing to recognise issues or misusing absence procedures; (2) two cases of illegal behaviour by management taken to Employment Tribunal; (3) one example of misuse of performance management; (4) bullying and harassment; and (5) colleagues' negative or unhelpful attitudes.

1. Management failure to recognise issues or misusing absence procedures:

Autistic member

"I've worked for a railway company for 17 years... recently I was diagnosed as being on the autistic spectrum... I told my employer and asked for a discussion on reasonable adjustments. I know I can do the job but there are few measures that would help me organise myself and fit in better and/or protect me from punitive action if I make (non-safety critical) mistakes that others might not, e.g. losing stuff!

It took them over six months for OH even to reply. The reply was that because I can do my job there is no point having the appointment! Funnily enough when someone goes off sick they are sent to OH within days... eventually, after I kept pursuing the issue, I got the appointment and have had some adjustments recommended."

Member has diabetes and stress

"Member A has diabetes and is susceptible to work-related stress. He was bullied by a manager (leading to) lengthy periods of absence. Member was in breach of a disciplinary warning regarding his attendance.

(The union rep advised an OH appointment which found that A was disabled both for diabetes and work-related stress and that the absences should be regarded as "injury at work". This was accepted. A grievance against the bullying manager was upheld).

Mr A was therefore moved to a new role as a reasonable adjustment, and was permitted to work from home."

Member has dyslexia and stress

"Member has dyslexia and dyspraxia. OH recommendations for adjustments were not applied; member went off with work-related stress and was placed under disciplinary investigation. Managers asserted the absences were not disability-related. Member went onto half pay then no pay. Union rep made robust representations leading to the dropping of the disciplinary matter. The rep applied for disability leave. This application was refused but a grievance was raised as a form of appeal and an ET1 [originating claim to an Employment Tribunal] lodged and immediately stayed to facilitate negotiation. Disability leave was granted to cover the absence and the member was given over £20,000 to compensate for the loss of pay."

Member has GAD and depression

"I have Generalised Anxiety Disorder (GAD) and depression which affect me every day. Colleagues have said or done:

- Kissed her teeth and said "I need a good talking to"
- When I mention depression in conversation with others, cough as if to say "yeah right!"
- Said I was "milking it"
- Talked about my situation amongst themselves. When I tell management about it they just say it's hard to prove, and occupational health has not been helpful either."

Member has invisible impairment

"I've had a problem in the workplace with having absences and managers questioning my absences because they don't understand my disability and they look at me to say you're not disabled... after having a year off sick I was invited to a meeting [and] told they would have to let me go..."

Member has ME (also known as Chronic Fatigue Syndrome)

"Member has ME.. Management and HR did not believe she was disabled, but this was confirmed by an OH report. Member is a lawyer... ME made it difficult to appear in court and travel. Extensive, regular rest breaks and working from home were recommended. The employer failed to apply these recommended reasonable adjustments. Member went off sick, employer sought to proceed under absence management policy.

The union representative suggested a transfer to a role which involved working from home. This was declined and a grievance was lodged. With ET hearing looming, employer allowed member to transfer to an office and home-based role. Attendance record has improved dramatically".

Member with mental health issues

"I have a member with long term depression, she can manage the condition fine for months, however there are times when it becomes unmanageable and she is off work. in an attendance meeting her manager told her she was not supporting her attendance and she 'should snap out of it'.... I was able to get a support plan put in place ... however when I followed up the plan a few weeks later I found nothing had changed ... her manager said 'the members seems OK now so they did not see any point continuing with the support plan'."

Failure to adjust work

"Despite my employer knowing about my disability, as I use voice recognition software, I feel this is not taken into account in relations to allocation of work and there is lack of understanding that using VRS means it takes longer to deal with emails etc...."

Mental health issues

"I have a department where we have a high incidence of stress and depression – this department has had an issue for at least three years – it took us months [with a member] to get to a place where [the member] felt he could usefully contribute to the team. He approached me a year later to raise the issue as due to him having been a sufferer he could see the visible signs in his colleagues – I raised this with the HR department however nothing was done."

2. Illegal discrimination by management

Worker with Asperger syndrome and learning disability

"AB worked as a golf club green keeper and had no problems for 13 years. A new boss made him wear highly visible clothing, banned him from using a motorised vehicle, gave him an unfair amount of heavy work, violently knocked a rake out of his hands, pushed him and swore at him, gave him a verbal warning and ridiculed him by giving him a child's game as his staff Christmas present. AB resigned and took a claim for constructive dismissal and disability discrimination."

(This case was won and AB was awarded £78,000).

Worker has Asperger syndrome and dyslexia

"AD worked as a hotel chef. His boss paid him less than half the minimum wage and did not pay him for working extra hours. The boss threatened to sack him for 'taking too much off the end of a cucumber', and threw frozen bread rolls around the kitchen'. AD resigned and took a claim for unfair dismissal, disability discrimination and breach of minimum wage law to Employment Tribunal".

(This case was won and AD was awarded £40,000).

3. Performance management

Member has epilepsy and depression

"I suffer from epilepsy ... there was a period when the drugs caused side effects which impacted on my short to medium term memory.. my duties were compromised and my performance suffered ... my appraisals were pretty damning and I was denied pay increases.. the fact that the epilepsy might have been a factor was either ignored or more likely didn't occur to my line manager. Things got worse, I received a formal warning and when I explained about my epilepsy I was put under pressure to take retirement on medical grounds. I started to suffer from depression. I called in the union representative. I now have a different job which I do well".

4. Bullying and harassment

Invisible condition

"My disability is chronic endometriosis.... (the) Head Teacher bullied me even if I attended a hospital appointment. I resigned as I had depression and PTSD by then and wasn't well enough to go to grievance. My pain cannot be seen and because I look OK as far as he was concerned my time off when I physically could not drive to work or stand was an inconvenience that he could not manage."

Autistic member

"Member called a representative for advice after being threatened and intimidated by other members of staff on two occasions, including a meeting with line manager. ... it wasn't until several emails later that the member revealed she is autistic. The line manager was aware but the meeting did not go well [and] the member still felt threatened and distressed. ... she informed her rep that she sometimes had some difficulty in communicating when she became stressed. [On advice of rep] she disclosed the disability to HR who made an OH referral. Meanwhile at an informal meeting and using the TUC "Autism in the Workplace" a number of reasonable adjustments were agreed."

5. Colleagues' negative or unhelpful attitudes

"You look well"

"As well as an ongoing battle with depression I had a brain tumour and brain surgery. I get quite sick of being told how well I look when I'm barely managing to stay vertical... My speech has been slightly affected and I find it hard to find and say words when I get stressed, like in meetings.... I'll tell people that I need a moment of silence to write things down but they will carry on talking and I will forget what I am writing. I also can't separate out lots of noise so if people are talking or there's a lot of background noise – like in an open plan office – I can find it very difficult to concentrate on my work or make out the conversation I'm meant to be taking part in."

Use of parking space (1)

"For six years since having a hidden disability people look at me in disabled parking space and give me dirty looks to say you're not disabled. I have some good days and some bad depending on how my condition is reacting with my body"

Use of parking space (2)

"The comment "you don't look disabled", the snide remark and the disgusted looks happen all too often. I have a blue badge which allows me to access my place of business and I park outside the building – normal access arrangements require all staff to park in the staff car park and then walk onto site, which is quite a long walk. My mobility problem is due to having been diagnosed with osteoarthritis in both knees. (Following weight loss and cortisone injections) I now walk a little faster, I get the snide remark "don't you think you should be walking onto site now." I find these comments really rude and put them down to certain individuals being jealous that I am allowed access with my vehicle to the site and they cannot."

Use of parking space (3)

"For a while I wasn't able to walk very far and had a blue badge, as such I was allowed to use the disabled parking close to the front door. However I wasn't using a walking stick or a wheelchair or any other "visible" sign of disability, I would frequently get funny looks and glares from other members of staff walking past .. I felt very self-conscious and uncomfortable."

Using the lift – member has asthma

"I have asthma and colleagues ... often make fun of me when I have to take the lift just to go up one floor."

Using the lift – member has invisible condition

"I suffer with VPM (similar to Ménière's disease) and there are days when I'm unable to climb the stairs particularly if I'm carrying something – I used to work on the first floor and have very often taken the brunt of comments around 'oh you're not really taking the lift to the first floor – in one case it came from the director of HR – I also suffer from osteoarthritis in my hips."

The right to work from home

"I have a hidden disability. A colleague asked why I was allowed to work from home and he wasn't. I explained it was because I have a rare medical condition requiring medical appointments, physiotherapy and need to work flexibly around appointments. He then said "but you don't look ill".

Conclusions

Twenty years after the Disability Discrimination Act and five years after the Equality Act widespread ignorance of the law is a cause of much continued discrimination against disabled people at work. When this is combined with popular stereotypes of disability which routinely take the form of not accepting that someone whose impairment cannot be seen can be disabled, the task confronting trade unionists in educating both employers and fellow workers is challenging.

The case studies cited here suggest that more often than not, when union representatives are well equipped with the facts and the law, they are successful in negotiating reasonable adjustments.

There are three clear steps required of the trade union representative in making representations to the employer:

- Understand the law. The first conclusion is the importance of union representatives having an understanding of the range of conditions that is protected by the Equality Act so that they will be aware when there is an issue, and that there is legal protection available to support the claim for adjustments.
- Understand what adjustments could help. The second step is to understand what adjustments will be effective in removing the disadvantage faced by the member. In every case it will be essential to discuss this with the member concerned. Every case will have unique aspects, an approach based on preconceptions about particular conditions will likely be useless in identifying the specific adjustments needed. It is clear from a number of these case studies that these may be adjustments to absence or sickness procedures. Separate advice on sickness absence and disability is available from the TUC.
- Gather evidence. If the employer is refusing to accept that the member is disabled, the third step will probably be to obtain medical evidence. This may be needed in support of the case that the member is disabled in the first place, or it may be needed to support the case for particular adjustments being effective. A joint reference to the employer's Occupational Health consultant may be the best route but to be more sure of an outcome that does truly reflect the reality, it will be best if the rep asks to accompany the member to the meeting (with the member's consent).

In the cases cited here, the stereotypical version of disability applying only to wheelchair users or blind people is frequently the root of the problem. It will therefore be helpful for the employer to be invited to provide training for all managers and supervisors on disability law and who is protected by the definition as well as on the duty to provide reasonable adjustments. In this the understanding of more favourable treatment to achieve equal outcomes will be vital in getting decision makers genuinely to grasp what the law requires.

Beyond the challenge of representing individual disabled members with hidden impairments, it is evident that the union representative may also have to take on the challenge of educating others that there are a wide range of conditions that fall within the legal definition of disability if fellow workers are to be won to support their disabled colleagues rather than contribute to their discomfort or

isolation. The support of fellow workers can make a great deal of difference in any workplace.

This briefing and the attached fact sheet may help in this process.

Further reading

"Disability and Work – a trade union guide to the law and good practice". Revised edition 2011. Available free from TUC publications.

"Representing and supporting members with mental health problems at work", by Michelle Valentine, available from TUC publications.

Guidance and Codes of Practice on the Equality Act 2010 are available from the Equality and Human Rights Commission, www.equalityhumanrights.com.

For the latest criteria for use of the Access to Work scheme go to www.gov.uk/access-to-work.

"You don't look disabled"



Invisible impairments

A fact sheet for workers and trade union representatives

1. Who is "disabled"?

In law, you are "disabled" if you have significant difficulty in doing everyday tasks and the problem is long-lasting. A "disabled person" is protected against unfavourable treatment and is entitled to reasonable adjustments. If you have depression, and if it lasts or recurs, you may be legally "disabled". But someone who is off work with a headache and recovers in a few days is not.

Everyone recognises that someone who always uses a wheelchair to get around, or who is blind and uses an assistance dog is a disabled person. But many more people are disabled than those who can be identified by sight alone.

The legal definition of disability includes millions of people who don't look different on the outside. Some of the conditions that many people have that make it difficult for them to carry out ordinary day to day activities without adjustments are:

- Mental health conditions – depression, schizophrenia, bipolar affective disorder, obsessive compulsive disorders and personality disorders;
- Conditions such as dyslexia, dyspraxia, autism and epilepsy;
- Progressive conditions such as rheumatoid arthritis or Motor Neurone Disease
- Chronic conditions such as diabetes and asthma
- People with cancer, Multiple Sclerosis or HIV are automatically counted as disabled from the time of diagnosis.

... and these are just some of the conditions that are normally invisible but that count as disability under the law (where the consequences of the impairment are alleviated by treatment, this is ignored for the purposes of the definition).

2. What the law requires of employers

- The Equality Act 2010 says that it is illegal to treat someone who is disabled less favourably because of their condition. This protection covers everything in employment: such as recruitment, promotion, access to staff benefits and pension schemes, redundancy and grievance and disciplinary procedures.
- The Equality Act also protects people against less favourable treatment because of their race, their gender, whether they are LGB or T, what they believe or their age. What is different about disabled people is that the law also requires employers (and providers of services) to make reasonable adjustments. A "reasonable adjustment" is something that will overcome the barrier someone with a disability may have in doing their job.
- For someone with limited mobility this may involve putting in a ramp or a lift. For

people with invisible impairments this can involve a wide range of adjustments that will be unique to each person. Adjustments may cover working hours, modifications to equipment, changes in job responsibilities, training ... what matters is that they achieve the result of enabling the disabled worker to carry out their job. They also have to be "reasonable" for the employer to do.

Many disabled people – visibly disabled or otherwise – require no adjustments to do their job and the *average* cost of adjustments is tiny. But whether yours is or not, no one should be put off asking for their legal rights by fear of the price tag.

3. How to get your adjustments

If you have an "invisible disability" and you are facing additional difficulties in doing your job, you are advised to follow these steps:

- Talk in confidence to your union rep. Explain any problems you have in carrying out your duties and discuss what adjustments could be made to remove these problems. Sometimes, you may already be involved in other company procedures such as attendance, sickness absence or capability. If your disability is the reason for this, this is essential information because these procedures are also subject to adjustment to take account of disability.
- The union rep will need to arrange a meeting with managers and this will mean you have to disclose your condition to the employer. Employers only have to make adjustments if they know about the disability. What is most important is that any adjustment that is agreed with managers is actually fit for purpose.
- It may be useful to refer the employer to the existence of the Access to Work scheme that offers financial support for the employment of disabled people (www.gov.uk/access-to-work).
- Sometimes it may be necessary to get medical evidence, if your manager does not accept that you are disabled. This may also include a referral to Occupational Health. With this evidence, it is usually enough to get them to make the appropriate adjustments.
- If your employer still refuses to make the adjustments, you have the right to take a case to an Employment Tribunal. You are required first to go through all the internal company procedures (grievance, and appeal if necessary). Because a fee now has to be paid before going to tribunal, make sure you discuss everything thoroughly with the union at each stage. Don't miss the three month time limit on submitting a claim.