

SCOPE

= Equality for disabled people

Let's talk

Improving conversations about disability at work



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Leigh Day

Leigh Day and Scope

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Leigh Day is a specialist human rights and employment law firm committed to achieving justice for all.

Leigh Day has partnered with Scope since 2014 to support disabled people to have the same opportunities as everyone else.

At Scope, we have a long-standing interest in disabled people's experiences of employment. Through a range of research, policy and campaigns activity, we work to tackle the barriers disabled people who want to work face in entering and sustaining employment.

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Summary of recommendations

Recommendations for employers

Employers should consider:

- Making it clear to all staff through different communication channels that support and adjustments are available, setting out examples of what this could involve.
- Embedding flexible and remote working practices across the organisation.
- Creating opportunities for disabled employees in more senior roles to share their experiences through formal or informal initiatives.
- Developing opportunities for peer-to-peer support among disabled colleagues, such as a staff network or one-to-one mentoring.
- Ensuring line managers have access to information and resources to support conversations about disability and requests for support.
- Equipping line managers to effectively challenge negative comments or behaviour towards disabled people at work.
- Exploring ways they can invest in and foster peer support among disabled employees.
- Using disability equality training to drive a shift in workplace culture around disability.
- Confronting negative comments and encourage all colleagues to contribute to developing an inclusive working environment. Resources such as Scope's tips on How to End the Awkward could play a part in this.

Recommendations for employers

When gathering information, HR leads within organisations should consider:

- During recruitment, ensure that any data collected is not shared with recruiting managers. This should be made clear to candidates.
- Using different approaches, for example face-to-face meetings alongside anonymous staff surveys.
- Develop a more comprehensive approach to exploring progress as an inclusive employer through measuring the experiences of existing staff, looking at levels of engagement, retention and progression.
- Be clear why you are gathering the information to help encourage individuals to engage with the process.
- Provide individuals with the flexibility to use the language they prefer to talk about their impairment or condition.
- Support individuals to set out what, if anything, they want to happen as a result of sharing information.

Once information has been received, HR leads should consider:

- Acknowledge the information has been shared. Where information is shared anonymously, consider how tools such as online signposting could be used to acknowledge receipt.
- Outline the next steps once an employee has shared information, including where appropriate, timings for follow-up activity.
- Signpost to available support once somebody has shared information
- Explore ways of developing processes for gathering information and sharing this at line manager handover.
- Gathering information is not a one-off process, as people's support needs and personal circumstances may change over time.

Recommendations for government

- The Department for Work and Pensions (DWP) should work with employers and disabled people to develop best practice guidance for line managers in supporting disabled employees.
- The Government should expand the remit of the Equality and Human Rights Commission (EHRC) to allow it to challenge discriminatory working practices on behalf of disabled people.
- Online recruitment agencies should explore tools they could develop to support disabled candidates to learn about the working practices within different employers, for example reviews from disabled employees.
- The DWP should develop a hub of information and resources for working disabled people on things such as employment rights and in-work support.
- The DWP should invest in the Access to Work programme and encourage employers to arrange assessments to facilitate conversations about support needs at work.
- The DWP should embed information about rights at work into employment support programmes provided by DWP and Jobcentres.\

Recommendations for other organisations

- Both organisations which develop information and guidance for disabled people and those which develop guidance around employment should consider their role in providing more targeted resources for working disabled people.

Ideas for disabled people to consider

Remember that:

- You are not legally required to talk about your impairment or condition with anyone at work, either as a candidate or employee.
- However, doing so could be the starting point of a conversation about getting changes to the way you work, or additional support to do your role.
- How you feel about sharing information might change over time. You can tell different people in different ways and at different stages.

If you feel unsure, take some time to find out more about your rights at work:

- Using online resources such as Scope's website.
- If you would like professional advice or support, think about contacting Scope's helpline, or services such as the Advisory, Conciliation and Arbitration Service (ACAS) which can provide information and guidance to prevent or resolve problems at work.
- You may find it helpful to speak to people who have already spoken about their impairment or condition at work.
- There may be information provided by your employer about supporting staff who are disabled or have health conditions. It could be beneficial to look at this before sharing information.

Have your conversation your way:

- Sharing information about your condition through equality forms is usually anonymous and can help an organisation to understand its own progress in employing disabled people. As sharing in this way may not lead to your manager or other staff being told about it, you may feel more comfortable with it. However, you may also want to think about having a conversation with your manager.
- If you want people you work with to know about some aspects of your condition, think about who you want to tell and what you want them to know about.
- Think about how you will feel most comfortable sharing information. For example, you may want to have a face-to-face conversation or may prefer to share it in writing, or a combination of these with different parts of your organisation.

Sharing doesn't have to be a one-off:

- Feel free to share the information that you want to in a way that works best for you. For example, this could involve sharing more information with some people than others, or it could involve sharing information with the same person gradually in stages.
- It's ok to share information in some ways and not others. For example, some people like to identify as disabled through forms, and others may choose not to.

Think about what you want to happen and set your expectations:

- If you are talking to your line manager about your impairment or condition, think about whether there is anything specific you want them to do and try to make that clear as you share the information. For example, if you would like to talk about working in a different way, or request additional support to do your job, try to be as clear as you can about this.
- Think about boundaries and expectations you want to set. Do you want the person you have talked with to keep your conversation private? Or would you like them to share any of the things you've talked about with other people that you work with?

Introduction

This research explores the opportunities and barriers working disabled people come across in having conversations about disability at work. It demonstrates that gaps between policies and practice are preventing businesses from supporting their disabled staff to thrive at work. Finally, it sets out practical ideas businesses can put in place to drive the organisational changes needed.

Many disabled people face barriers in entering work and progressing through their careers. The difference between the employment rates of disabled people and non-disabled people is 31 percentage points,¹ and has stubbornly remained at this level for over a decade.

The Government has committed to supporting one million more disabled people in to work by 2030² There is a clear impetus on employers and government to better understand the experiences of working disabled people, and equipped with this insight, create workplaces where disabled people can thrive at work.

We spend a large part of our lives at work. Not feeling able to talk about disability or to start a conversation about support at work will have lasting impacts on individuals, businesses and the economy more widely.

Why sharing matters

Sharing information about disability with an employer will vary from one individual to another. It's important to recognise that some disabled people will have more choice over if, when and with whom they share information than others. However, this research has found that even among people who have a visible impairment, conversations about this and any support needs can have a significant impact on experiences at work.

For some disabled people, talking about disability at work means they can start conversations about their support needs and how these may change over time. In other cases, conversations between disabled colleagues can help create an environment where more people feel comfortable sharing information about their own impairment or condition at work.

1 Scope analysis of ONS (August 2017) Labour Market Statistics, table A08

2 Employment and Disabled People, House of Commons, Parliament. (9 October 2017)
<http://hansard.parliament.uk/Commons/2017-10-09/debates/23EFABB2-579A-462F-8E84-DC8ED16A4FE6/EmploymentAndDisabledPeople#contribution-BA7E9C4A-4D15-4DEF-8B2D-190A181CA4F5>

By establishing an environment where disabled staff feel able to start conversations about disability, employers will be better placed to support their staff to reach their potential. Sharing information also allows employers to gather information about the experiences of disabled staff and helps them to develop a picture of how effectively they are recruiting, retaining and developing a diverse workforce.

There are tangible economic gains to be reached from getting this right. Disabled people are falling out of the labour market at a staggering rate – for every 100 disabled people who move in to work, 114 leave.³ By taking some of the practical steps proposed within this report, employers could prevent this talent and expertise going to waste.

More widely, previous Scope research has shown that making sure all disabled people who want to work are supported to enter and stay in employment will have significant economic impacts in terms of increasing GDP and gains to the Exchequer.⁴

Methodology

The qualitative evidence described in this report is based on analysis of in-depth interviews with disabled people about their experiences of talking about disability at work which took place over July and August 2017. Some participants had shared information about their impairment or condition with their employer, some had shared limited information and others had not shared any information with their employer at all. The topic guides for interviews were informed by a literature review and supplemented with two surveys, one with 306 working disabled people and another with a 1004 disabled people which has been weighted to provide nationally representative sample data.

³ Analysis of the Labour Force Survey Two-Quarter Longitudinal dataset shows that between October 2016 and March 2017, 123,000 disabled people moved out of work. This represents 5 per cent of the total number of disabled people who had been in employment in January-March 2016. During the same period 108,000 disabled people moved into work, which represents 3 per cent of the total number of disabled who were out of work in October-December 2016.

⁴ Scope worked with Landman Economics to explore the impact of an increase in the disability employment rate from 2014 to 2030 using a micro simulation household level model based on the Family Resources Survey. For more information, refer to Scope (2015) Enabling work: disabled people, employment and the UK economy



Emily's story

Emily, (age 33), has Ehlers-Danlos syndrome. She is a junior doctor currently working in a GP practice.

"I'm a junior doctor and I'm on the training track where you change role every four months. I'm currently in a GP practice but previously I've been in various hospitals. The change every four months is stressful and very challenging, because it's new people who don't know you, don't know why you're in a wheelchair, and are desperate to ask.

Normally the training is two years, but I'm doing it part-time. Every four months I must resubmit my claim to work part-time – the criteria are strict and it's so much extra admin.

There isn't a clear system of who pays for Access to Work. It can be difficult to establish who is responsible when I change department - and sometimes hospital – every four months. At the back of my mind, I worry that my part-time status and condition will affect my job opportunities at the next training stage.

I use a wheelchair at work quite a lot, and the rest of the time I wear knee braces with hinges. It's about being proactive and saying, 'I need this so that I can do this job well'.

I and a friend run a support group for people at university with a health condition. Our advice generally is that if your impairment or condition might become apparent in your role, it's better to be upfront about it - put it in a positive way and ask for what you need. I do get more tired, but I've also really learned to prioritise my time, and I've got lots of insight from being a patient myself. My patients really like that, because they know I've been in their shoes.

I've always taken the approach that if you tell people about your impairment or condition, you can set them up for how they think about it. It's about finding what it has given you in terms of life skills."

1. Barriers to sharing information

This section explores the barriers disabled people may face to sharing information which include both external factors and are influenced by employer practices, as well as individual factors.

It is also important to recognise, particularly for disabled people who do not have an immediate need for a workplace adjustment, that sharing information can initially seem quite exposing, and may offer very little in terms of benefit. Talking about disability at work is seen as a gamble, where taking the step to differentiate from non-disabled colleagues is often more difficult and can carry more risk than not doing so.

Risks to employment opportunities

Our research found that nearly half of disabled people (48 per cent) have worried about telling employers about their impairment or condition.⁵

This experience was a central theme among interview participants who avoided or delayed sharing information about their impairment or condition. In particular, several participants expressed concern that sharing information about their impairment or condition could limit their opportunities at work.

“ You have to think about how it is going to be perceived by them. In 90 per cent of cases it will be negative, because if they have a stack of applicants and you are the only one that is disabled why would they pick you? **Mark** ”

“ It’s always a question on the form. Are you taking antidepressants? And to me that means that they’ll put a red cross by you and think ‘uh-oh this person’s not going to last very long. **Rachel** ”

For some participants, this concern was based on previous experiences where they perceived they hadn’t been hired because they had referred to their impairment or condition during recruitment. This was supported by our survey, which found 15 per cent of respondents felt they had been turned down for a job because of their impairment or condition.⁶

Other participants felt concerned by the approach their employer had taken to requesting information, which had fostered a sense of distrust.

⁵ Source: Scope polling of 1004 disabled adults 25–31 July 2017

⁶ Source: Scope polling of 306 working disabled people in the UK 31 May–8 June 2017

For instance, a small number of participants questioned why they were being asked to provide information about their medical history, as well as medication they were taking.

Being advised against sharing information

Many participants had been given professional advice to either completely avoid sharing information about their impairment or condition, or to limit the extent to which they talked about their experiences and support needs at work. For some participants, professionals providing back-to-work support encouraged people to avoid sharing information about their impairment or condition when applying for new jobs.

“ When I was out of work I was told all along the line not to make a big thing about your disability when you go for the interviews **Margaret** ”

Other participants had been encouraged to modify their behaviour and the way they managed their support needs so as to draw attention away from their impairment or condition.

“ I had one experience with Occupational Health... [The Occupational Health Worker] was very keen to dissuade me from using a wheelchair. He was like ‘we can change this role and we can tell them that you just have to be on one ward and you can’t attend meetings and then you won’t have to use the wheelchair.’ And I was like, ‘but then I wouldn’t be doing the job’. The way he was about it made me think that he thought it was weird that I was using one. **Emily** ”

Experiences like these simply emphasise to disabled people that sharing information brings risks to employment opportunities.

Attitudes towards disability

There was a strong perception among interviewees that negative attitudes towards disability are prevalent in public life. This was consistently presented as a blocker to sharing information at work.

Some participants anticipated that they may receive a negative response if they shared information with their employer, such as pity, negative comments or difficulty accessing support.

“ What worries me about telling people is they will suddenly want to feel sorry for you. **Amy** ”

Participants highlighted impairments and conditions that carry particular stigma. Among these, mental health conditions were seen as risky to talk about, with participants concerned that misconceptions could cause their skills and capabilities to be underestimated, or to requests for support or adjustments not being taken seriously.

For instance, when asked why she wanted to work part-time, Gladys* said:

“ I would say ‘I am unwell and getting medical treatment’. Some of it is not actually medical treatment in a hospital or doctor’s surgery. And that is the thing that you tend not to do because doing something for your mental health also might mean going for a walk. Well, if you say ‘I can’t come to work because I’ve got to go to the allotment’, who’s going to take that seriously? ”

Some described their concern that sharing information could draw unnecessary or unwanted attention. Several participants referred to wanting to ‘just get on with the job’ or avoid causing a fuss.

In addition, some participants expressed gratitude when their employer didn’t respond negatively, while others expressed cynicism regarding corporate motivations in gathering disability information.

Not identifying as disabled

Some participants decided not to share information about an impairment or condition at work because they did not consider themselves to be disabled.

“ I think people think people are disabled when they’re in a wheelchair. Or a visible thing. A mental thing is not a disability to a lot of people. And it’s difficult for me to say I’m disabled. **Rachel** ”

The approach taken by many employers to requesting information about their staff is to ask a yes or no question, usually referring to ‘disability’. Several participants who have a long-term impairment or condition did not use this opportunity to share information at work because they did not feel the question being asked was relevant to them.

Adjusting to a transition

A small number of participants described their perspective on their own impairments or conditions changing over time. Factors such as receiving a new diagnosis or changes in support needs meant some participants needed time and space to come to terms with the transition they were experiencing before they could feel in a position to start sharing information about disability at work.

Not needing support or adjustments

Some participants felt there was no motivation to share information because they did not need any adjustments or support.

However, other participants reported a range of positive motivations and outcomes to sharing information. This suggests that disabled people who view sharing information as a transaction which leads towards arranging support, may be missing out on some of the other positive outcomes that may come with talking about their impairment or condition, regardless of their support needs.

A second challenge is that disabled people may not be aware of the support or adjustments that could be arranged. A Scope survey found that only 49 per cent of disabled people were aware of their rights at work.⁷ In addition, our findings indicate that there is often a view that workplace adjustments often relate to adaptations to premises or assistive technology, rather than to other things such as an adjustment to working hours.

“ Well I always tick no. If it says ‘Do you consider yourself to have a disability?’ I say no...because I think I can carry out the job without any need for... help. It’s just that it affects me when I get home... there is just the odd occasion when I might need that flexibility and have a day off and maybe work a different day or catch up at some other time. **Rachel** ”

The role of line managers

For several participants, their decision to talk about their impairment or condition at work hinged on how they believed their line manager would respond.

For participants who had experienced several changes of line manager while working with the same employer, this presented a barrier to sharing information.

⁷ Source: Scope polling of 306 working disabled people in the UK 31 May – 8 June 2017

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I was new to full-time employment and in that two years... I had eight changes of manager... that was what was most frustrating for me, because you never had any continuity. I think that is important for any new graduate and I suppose it is for me even more important because... 'oh god I've got to go through explaining this, oh I just won't bother as they'll be gone again soon' ... I think I told one of them because they were going to stay around for a bit longer but then they got moved. And I'm not sure I actually bothered telling the rest. It just didn't seem worth it. **Emma**

”

A growing understanding of this issue has led some large UK employers to introduce a mechanism of sharing this information through a document, termed a 'disability passport'. This is passed on as line managers handover to their successors. However, these are only effective when line managers adopt the process and take it seriously.

Sharing information also presented a challenge for participants who did not have a single consistent manager, and so reported to more than one person. For one participant, having no clear line management structure made sharing information about her impairment or condition particularly difficult.



Jon's story

Jon, (age 40), has MS. He is a senior test engineer for a medical device company.

“When I worked in a factory based environment I didn't feel comfortable walking around the company with a limp, due to my MS. I perceived that people were talking about my problems, or sneering about my limitations, often disguised as banter. It felt like they were looking at me funny, and I didn't want that.

After not being able to work for a few years, as I had several relapses, I went back into employment as a contractor to make myself more employable, this time in more of an office-based environment. One of the firms I worked with took me on permanently, which gave me huge confidence. Yes, I have MS, but I showed them I could still be productive, and my employer had confidence in me.

When I first started work, I considered not telling my employer about my condition. I thought no one is going to want to employ a disabled person with a degenerative condition – that they'd always consider a non-disabled person first.

I've got to tell employers about my condition now because it's more visible and they ask you on HR forms. I can fight my own battle and explain my situation and needs, but I will always be slightly concerned about somebody else's pre-judgement of my capabilities.

Even though I am disabled, I am still very productive, and I still have a useful set of skills and experiences to offer.

My advice to other disabled people would be: once you are employed, if it feels right to talk to people, then do. Tell your work colleagues, and definitely talk to HR and your line manager who should support you. You have nothing to hide, it is who you are, people are nicer than you think and you can add real value to a company.”

2. What leads to sharing information at work?

This section explores the circumstances which contributed towards people talking about disability at work. These included both external and personal factors.

Sharing driven by external factors

Some participants started to talk about their impairment or condition in response to questions raised by their employer. In particular, questions regarding gaps in employment history or requesting information on sickness absence taken have led to conversations about disability.

Employers facilitating conversations about disability

Being encouraged to talk about disability at work can be a positive experience. One participant found that an internal campaign with short films featuring disabled employees at different levels of her company made 'a massive difference' in how she felt about talking about her condition at work.

Several participants said they would prefer that employers initiated the conversation - that they 'asked rather than waiting to be told'.

“ If they make the first move as an employer you're going to feel a little more at ease and comfortable in regards to going to them if you have a problem. **Jacqueline** ”

“ Because my manager shared with me she was a type 1 diabetic I felt comfortable sharing information with her and I think that is the basics of building a relationship. **Amy** ”

Inappropriate approaches to gathering information

On the other hand, several participants reported being asked inappropriate questions about their impairment or condition. This included detailed questions on medical history and on medication being taken.

For other participants, the behaviour and comments of their colleagues presented an external driver to a conversation about disability.

“ I felt like I had to [talk about it] because I was being stared at all the time. **Darren** ”

Here, disability is seen as something to be found out, and disabled employees are expected to justify themselves or their support needs. Personal questions, however well intentioned, at times appeared to cross social boundaries and become invasive.

“ Often people would make comments about my cough, because that is the only thing that is noticeable. I was quite open about it if someone asked... They are asking questions because they are interested and wanted to understand but what they actually meant was ‘how do you get it?’ **Amy** ”

Sharing led by the individual

By contrast, many participants initiated sharing information about their impairment or condition. A strong theme among participant experiences was the importance of having ownership over the way that information about their impairment or conditions was shared.

“ I thought it best to be open with it, have an opportunity to explain it on my terms without there being some sort of crisis, you know being called into the office, ‘why are you having trouble?’ I’ve explained it on my terms, warned them what the possible implications might be for the future and put my case as best I can, rather than being defensive about it. **Mark** ”

“ I always find I am ok in telling my story but if someone asks me how I feel about it that is different. **Hayley** ”

Choosing what to talk about and when

Several participants limited the information they shared about their impairment or condition, choosing to avoid sharing some elements. This was particularly relevant for people with multiple impairments or conditions.

“ Why do I share one and not the other one? I don't know I suppose, this is a personal perception, different conditions are viewed differently and...I feel I would be judged differently if I declared one or the other. **Emma** ”

Some participants chose to share information at interview stage, considering this to be less risky than sharing through an application.

Several found interviews to be an opportunity to highlight skills or perspectives they had developed as a result of living with their impairment or condition.

“ Once it gets to an interview, bring it up then, you can explain the situation then and they can see how you are in person and rather than just throw the application in the bin, they can see you are fit for work and you can argue your case in person. **Mark** ”

For a small number of participants, sharing information at the interview stage was a means of gauging an employer's attitudes and working practices, with their reaction offering an indication of attitudes within an organisation.

“ You have to get a feel for the employer. It is better to find out if an employer is going to be an abusive employer before you start. **Mark** ”

Others shared information after an extended period working with their employer. Several participants described changing the information they shared or the language they used in communicating with different people about their impairment or condition at work, for example sharing in a different way with wider colleagues compared to HR.

“ I did with the teaching assistants that I worked with. Some of them. But I didn't ever with senior management. I would just say I needed to have set days because of the children. And in a roundabout way that is because of my illness. **Rachel** ”

Requesting support

Many participants were motivated to talk about their impairment or condition at work because they wanted to request support. This included both formal arrangements involving applications to Access to Work, and more ad-hoc and informal conversations with peers as well as line managers.

Some participants who had not told their employer about their impairment were motivated to do so by a change in their support needs at work

“

I only shared it when I had to go in for treatment. **Amy**

”

For other participants, this was a case of pre-empting that support needs may change over time, so that both they and their employer would be ready to adapt their approach if needed.

Challenging perceptions about disability

For some participants, recognition of the negative public attitudes towards disabled people set out in section one of this report had proven a driver to start conversations about disability at work.

In some cases, this involved challenging myths or stereotypes about working disabled people.

“

The other ladies that worked with me were saying to me ‘What is wrong with you?’ Then they would ask me ‘how do you get here in the mornings? Do you have a lift?’ and I would say ‘No, I drive a car’, ‘Ooh, ooh!’ they were quite surprised. **Margaret**

”

In other cases, this was rooted in recognition that there is a lack of awareness and high levels of stigma associated with certain impairments and conditions, and that starting conversations could help to improve understanding.



Jacqueline's story

Jacqueline, (age 43), has cerebral palsy as well as other conditions. She is an account manager for a consultancy firm.

"I'm an account manager for a consultancy firm. We look after accounts for companies to help increase their revenue.

Back when I started working, I didn't see my cerebral palsy as a disability. That wasn't the word I was thinking. My mum used to say to me 'Oh you just have a bad leg, that's it'. The word disability was just never used in our house.

I never shared, ever, on an application form. I'd just never done it. My view was, if I put I have a disability – there's no chance I'll get the job, they'll pre-judge me.

I've just told my current employer that I've got cerebral palsy, and how it affects me. I've had to tell them now because I've got doctors, hospital appointments and therapy etc. They were shocked, as it's not something I broadcast at all.

Because I'm not used to talking about cerebral palsy, I was worried what the reaction would be. When I told them, they were very understanding. If I have to pop off to the doctors they're absolutely fine, which is what you want your employer to be.

If I apply for a job again I'll put 'yes'. I think it's me getting wiser and accepting the truth. If they don't want me because I am disabled then that's up to them.

People are much more open about disability, and it's not something that is sort of taboo, unlike the 80's and 90's. When I was younger, there were lots of strange and unkind comments.

If they make the first move as an employer you feel more comfortable going to them if you have a problem. They can't support you with anything if they're not aware."

3. Outcomes of sharing information at work

Negative outcomes: when sharing information doesn't go well

While sharing information can lead to positive outcomes, it can also be a negative experience. In the extreme, this can involve discrimination and unfair treatment. Feeling pressurised to share information about an impairment or condition, or to discuss personal matters, drives unbalanced workplace dynamics between disabled people and their colleagues and managers.

Ineffective responses

Several participants who had shared information through an indirect route, such as through forms at recruitment stage, reported that there had been no reaction from their employer. For a small number of participants, this fostered a sense of uncertainty because they weren't sure who information had been shared with as they started work.

Other participants described feeling they hadn't been listened to, or that their manager came across as disinterested when they shared information about support needs at work. A small number of participants had made requests for support or adjustments which were either not acknowledged or were rejected.

In a similar vein, some participants expressed frustration that information had not been shared in the way that they had expected. This included information being passed on to other colleagues without first securing an individual's consent, whilst others wanted information to have been shared more widely than it was:

“ I think I would have found it useful maybe if the manager had shared information to my colleagues instead of them asking me. It would have put things into a better context for colleagues. **Shelley*** ”

Being treated differently unnecessarily

For a small number of participants, telling their employer they were disabled led to being singled out in ways that they felt were inappropriate. This included taking a different approach to managing redundancy and drawing attention to employees' impairments or conditions, for example requiring an individual to unnecessarily follow a different fire evacuation procedure.

Another outcome of talking about an impairment or condition at work is that it may become more difficult to ask for support in other areas of work. One participant described feeling that if she raised concerns regarding her workload with her line manager, they would respond differently than they would to a non-disabled employee:



I think for non-disabled people it's much easier for them to go to the manager and say there's an awful lot of work I think we need more people because we can't keep up with things. I think as someone with a disability you're really frightened that they will focus in on you and think it's because you're disabled as to why you can't keep the pace. **Shelley***



Discrimination, unfair treatment and negative comments

Several participants believed they had experienced unfair treatment at work as a result of telling their manager and colleagues that they are disabled. This included feeling that opportunities for progression had been passed over, or several cases of negative comments and abusive language being directed towards participants by colleagues. Some participants pointed to a perception that information about support available is deliberately withheld from disabled staff.

Shaping career decisions

Several participants had taken significant career decisions based on their experiences of talking about disability with an employer. This included moving from an industry with a pervasive 'lad culture' to one where name calling was seen as less likely, choosing not to share information in subsequent roles and moving into self-employment to avoid conversations about disability at work altogether.

Positive outcomes – when sharing works

Among participants in this research, positive outcomes following conversations about disability took many different forms.

Several participants talked positively about their experience of sharing information at the interview stage. Participants valued interview panels which acknowledged that information had been shared, but focused their questions on skills and expertise rather than support needs.

For some, there was a tangible result of sharing information, such as arranging a change to working hours. Within this group, some were pleased that their employer had actively encouraged them to arrange adjustments or support at work.

“ It was part of my one to one and I said ‘This is what I want to talk about, I’m going to tell you about me. I’m going to tell you how it impacts me.’ I went into more detail than I probably ever have done and she said ‘Thank you, that’s brilliant. Thank you for sharing with me, I just need you to tell me whatever you need from me’. She was really good about it. **Amy** ”

Even where no formal adjustments or support were required, many participants valued that their line managers often ‘checked-in’ with them and provided reassurance. This included asking about how colleagues had responded when information was shared, or showing interest in an employee’s wellbeing.

“ My line manager says to me things like “I know you’ve had a few issues with your back and your bladder, how’s it going?” So they’re aware of it, they are considering what I’ve told them and asking the question. It shows that they actually care as an employer. Before, I didn’t have that. **Jacqueline** ”

There was a reoccurring theme among interviews that talking about disability was an opportunity for individuals to be themselves at work and develop supportive relationships with disabled colleagues. Our research found that for some participants, this was a means of sharing advice and information, whilst for others, it represented a way to combat potential feelings of isolation at work. More widely, there was a shared feeling that conversations about disability could help motivate others to share information as a result.

“ They [my disabled colleagues] tend to be more open because they’ve seen me be more open. I set up the staff network and they joined straight away. **Darren** ”



Emma's story

Emma is based in the south of England, and works for a bank.

"I've had medical conditions since birth and I've acquired more along the way. There's always the dilemma 'How much do you share? What impact will it have on my working life?'

I share a description of my symptoms, rather than giving the medical name. I say, 'In practical terms, my condition means I have some limited movement and increased fatigue'. That makes it easier for the employer to understand my condition and support needs, rather than thinking 'Is that person in a wheelchair? Are they this, that and the other?'

The bank is a good place to work. The culture has changed over the past few years. People regularly work from home, whether for health reasons or other reasons. That change has come down from above and has been to my benefit.

By supporting disabled staff, the bank is rewarded too. People don't mind putting that bit extra in when needed, because they know they can manage their work-life balance.

At one point I was off work for 6 months, during which time I was diagnosed with Crohn's disease and had eyesight complications. I had a phased return to work, and going back to a job I knew made it a lot easier. My employer has been far more supportive than I thought they were going to be.

The have recently introduced the reasonable adjustments passport, so when an employee changes jobs, or if their manager changes, they don't have to go through the process of explaining the adjustments they need every time. They have a document which the individual can discuss with the relevant people.

Through mentoring a disabled colleague – I have been able to support and guide her when needed. I also helped set up a voluntary buddy scheme for disabled staff. Everyone brings different skills and knowledge to the table."

3. What needs to change?

This section identifies key areas where Scope feels change is needed based on this research, and sets out opportunities for employers and Government to explore in driving change forward.

This report has shown that disabled people's experiences of talking about an impairment or condition at work can vary widely.

While there are opportunities available to some disabled people who share information, it is clear this is not always the case. Some disabled people may feel pressurised to share information they do not want to or with colleagues they would rather aren't aware of it. Some people may feel obliged to talk about disability before they feel ready to do so.

More than this, it seems employers often aren't equipped to receive or respond to information disabled people share.

As a result, talking about disability at work is perceived by some people as a high-stakes gamble. Here, we explore what employers and Government can do to reduce the risk disabled people perceive they face when sharing information.

Employers should establish an environment where people feel they can be themselves at work

It is crucial that employers recognise the level of risk that disabled people associate with talking about disability at work. Alongside and ahead of any operational changes to the way information is gathered, senior leaders should consider how they can cultivate an inclusive working environment for disabled employees within their organisation.

Working practices such as flexible working and remote working can be effective in supporting disabled people to thrive in their roles, regardless of whether they feel ready to have a conversation about disability and individual support needs.

Considering the emphasis that participants placed on the importance of hearing from other disabled colleagues and peer support, employers should consider how they can foster opportunities around this. For large employers, this could involve supporting disabled people in different parts of the organisation, and particularly senior roles, to talk about their experiences at work through internal communications.

Recommendations for employers

Employers should consider:

- Making it clear to all staff through different communication channels that support and adjustments are available, setting out examples of what this could involve.
- Embedding flexible and remote working practices across the organisation.
- Creating opportunities for disabled employees in more senior roles to share their experiences through formal or informal initiatives.
- Developing opportunities for peer-to-peer support among disabled colleagues, such as a staff network or one-to-one mentoring.

Employers should develop line managers who are ready to respond when information is shared

Throughout this research, the role of line managers has emerged as a crucial factor in both blocking or enabling conversations around disability at work. In several cases, participants did not feel their line managers were equipped to respond appropriately and effectively when information was shared. In others, the absence of consistent support or a clear line management structure had proved blockers to conversations about disability.

On the other hand, where experiences of sharing information had been more positive, participants often attributed this to the way their line manager had fostered a trusting professional relationship and had reacted to information about disability when it was shared.

To develop truly inclusive workplaces, employers should shift their thinking beyond policies and procedures which comply with legal duties, to fostering a work culture where disabled people feel comfortable and able to access support to do their job.

Depending on the size, structure and ways of working of an organisation, this may involve developing an agreed approach to managing information sharing and arranging adjustments, or disability equality training.

Recommendations for employers

Employers should consider:

- Ensuring line managers have access to information and resources to support conversations about disability and requests for support.
- Equipping line managers to effectively challenge negative comments or behaviour towards disabled people at work.

Employers should explore different routes to gathering information

Our research has shown that preferences around approaches to gathering information also vary widely. Given that most employers rely on a single means of gathering information - often which is paper-based, indirect, prescriptive and formal - they may be unintentionally preventing disabled people from sharing information at work.

While ensuring that clear routes are carved out for employees to share information and request support at work, it is also important to recognise that for some disabled people, informal conversations with colleagues may be preferred over formal processes for capturing information.

Recommendations for employers

When gathering information, HR leads within organisations should consider:

- During recruitment, ensure that any data collected is not shared with recruiting managers. This should be made clear to candidates.
- Using different approaches, for example face-to-face meetings alongside anonymous staff surveys.
- Developing a more comprehensive approach to exploring progress as an inclusive employer through measuring the experiences of existing staff, looking at levels of engagement, retention and progression.
- Being clear why you are gathering the information, to help encourage individuals to engage with the process.
- Providing individuals with the flexibility to use the language they prefer to talk about their impairment or condition.
- Supporting individuals to set out what, if anything, they want to happen as a result of sharing information.

Recommendations for employers

Once information has been received, HR leads should consider:

- Acknowledging the information has been shared. Where information is shared anonymously, consider how tools such as online signposting could be used to acknowledge receipt.
- Outlining the next steps once an employee has shared information, including where appropriate, timings for follow-up activity.
- Signposting to available support once somebody has shared information.
- Exploring ways of developing processes for gathering information and sharing this at line manager handover.
- That gathering information is not a one-off process, as people's support needs and personal circumstances may change over time.

Recognise the importance of peer support and role models

Conversations with disabled colleagues played an important role for a large group of participants within this research, and in some cases had proven a catalyst for sharing information about disability more widely. Employers should explore what role they can take in recognising this and in fostering opportunities for disabled staff to offer peer support to others, particularly individuals who are considering whether to share information with their employer. This might include investing in schemes such as a staff network or one to one mentoring, as well as exploring opportunities for disabled staff to share their stories through internal communication channels.

Recommendations for employers

- Employers should explore ways they can invest in and foster peer support among disabled employees.

Confront and tackle negative attitudes about disability

Just as colleagues can prove a vital source of support for working disabled people, in some cases they can also create an isolating environment. For many participants within this research, invasive personal questions, negative comments and assumptions from colleagues proved commonplace. While in some cases, these instances spurred individuals to start conversations about disability in order to disprove stereotypes, in other cases they led to individuals perceiving that sharing information, or sharing more information than they already had, would be met with negative reactions. Corporate initiatives to foster greater trust between disabled employees and their employer could be undermined without a concerted effort to put a stop to this.

Recommendations for employers

Employers should consider:

- Using disability equality training to drive a shift in workplace culture around disability.
- Confronting negative comments and encourage all colleagues to contribute to developing an inclusive working environment. Resources such as Scope's tips on How to End the Awkward could play a part in this.

The role of Government

Ensuring employers make the right changes

The Government has made clear its ambition to drive best practice among employers in this area. Our research indicates there is a gap between policy and practice, with line managers with responsibility for supporting disabled employees unclear on how to deliver this in practice.

Where the current approach to tackling poor practice among employers places the burden of responsibility on individuals, several participants felt there was a need for greater scrutiny of employers in this area, and for employers to be challenged to improve their working practices.

A range of suggestions were raised, such as an independent authority actively monitoring employer practices, as well as tools to increase the transparency of organisational working practices for disabled people considering applying for new roles.

Holding employers to account against their obligations to disabled people falls within the remit of the Equality and Human Rights Commission (EHRC).

The findings of this research suggest there is a strong case to be made to support an expanded role for the EHRC in this area, considering a strengthened role to challenge poor workplace practices.

Recommendations for Government

- The DWP should work with employers and disabled people to develop best practice guidance for line managers in supporting disabled employees.
- The Government should expand the remit of the EHRC to allow it to challenge discriminatory working practices on behalf of disabled people.
- Online recruitment agencies should explore tools they could develop to support disabled candidates to learn about the working practices within different employers, for example reviews from disabled employees.

Meeting gaps in support

Awareness of rights at work and of employer responsibilities was mixed among participants. Several felt there was a gap in current information and guidance around employment relations which could support disabled people to make informed decisions about how and with whom they share information about their impairment or condition.

Recommendations for Government

- The Department of Work and Pensions (DWP) should develop a hub of information and resources for working disabled people on things such as employment rights and in-work support.
- The DWP should invest in the Access to Work programme and encourage employers to arrange assessments to facilitate conversations about support needs at work.
- The DWP should embed information about rights at work into employment support programmes provided by DWP and Jobcentres.

The role of other organisations

Disabled people may come into contact with a range of organisations outside of their employer which they trust to provide up to date information and guidance in different aspects of their lives. These include charities, advice services, trades unions and Disabled People's Organisations.

Recommendation for other organisations

- Both organisations which develop information and guidance for disabled people and those which develop guidance around employment should consider their role in providing more targeted resources for working disabled people.

Ideas for disabled people to consider

This research has found that talking about disability at work can have lots of positive results, from getting support to carry out your role to connecting with colleagues with shared lived experiences.

“ By sharing information with other people with similar and slightly overlapping situations themselves you get your mind broadened, you look outwards and you get to see the bigger picture of the world and also you can share information on dealing with it to some degree. **Mark** ”

The experiences of participants involved in this research have shown that there is no ‘best way’ to approach deciding whether to share information. Below is a series of ideas you may want to think about when working out what will work best for you based on the experiences of people who took part in this project:

Remember that:

- You are not legally required to talk about your impairment or condition with anyone at work, either as a candidate or employee.
- However, doing so could be the starting point of a conversation about getting changes to the way you work, or additional support to do your role.
- How you feel about sharing information might change over time. You can tell different people in different ways and at different stages.

If you feel unsure, take some time to find out more about your rights at work:

- Using online resources such as Scope’s website.
- If you might find it helpful to get professional advice or support, think about contacting Scope’s helpline, or services such as ACAS which can provide information and guidance to prevent or resolve problems at work.
- You may find it helpful to speak to people who have already spoken about their impairment or condition at work.
- There may be information provided by your employer about supporting staff who are disabled or have health conditions. You might find it helpful to look at this before sharing information.

Have your conversation your way

- Sharing information about your condition through equality forms is usually anonymous and can help an organisation to understand its own progress in employing disabled people. As sharing in this way may not lead to your manager or other staff being told about it, you may feel more comfortable with it. However, you may also want to think about having a conversation with your manager.
- If you feel you may want people you work with to know about some aspects of your condition, think about who you want to tell and what you want them to know about.
- Think about how you will feel most comfortable sharing information. For example, you may want to have a face-to-face conversation or may prefer to share it in writing, or a combination of these with different parts of your organisation.

Sharing doesn't have to be a one-off

- Feel free to share the information that you want to in a way that works best for you. For example, that may involve sharing more information with some people than others, or it may involve sharing information with the same person gradually in stages.
- It's ok to share information in some ways and not others. For example, some people may choose to identify as disabled through forms, and others may choose not to.

Think about what you want to happen and set your expectations

- If you are talking to your line manager about your impairment or condition, think about whether there is anything specific you want them to do and try to make that clear as you share the information. For example, if you would like to talk about working in a different way, or request additional support to do your job, try to be as clear as you can about this.
- Think about boundaries and expectations you want to set. Do you want the person you have talked with to keep your conversation private? Or would you like them to share any of the things you've talked about with other people that you work with?

We're Scope, the disability equality charity. We won't stop until we achieve a society where all disabled people enjoy equality and fairness. At home. At school. At work. In our communities.

We provide practical advice and emotional support to disabled people and their families whenever they need it most.

We use our collective power to change attitudes and end injustice. And we campaign relentlessly to create a fairer society.

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