

Work and Pensions Committee

Oral evidence: Disability employment, HC 591

Wednesday 15 May 2024

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Members present: Sir Stephen Timms (Chair); Debbie Abrahams; Siobhan Baillie; Neil Coyle; Marsha De Cordova; David Linden; Nigel Mills; Selaine Saxby; Sir Desmond Swayne.

Questions 71 - 135

Witnesses

I: Becca Stacey, Senior Research Officer, Money and Mental Health Policy Institute; Ruth Wakeman, Director of Services, Advocacy and Evidence, Crohn's and Colitis UK; Ceri Smith, Head of Policy and Evidence, MS Society; and Russell Fleming, Head of Communications, ME Association.

II: Georgia Harper, Policy Manager, Autistica; Alison Thwaite, WorkFit Employment Development Manager, Down's Syndrome Association; and Evan John, Policy and Public Affairs Adviser, Sense.

Written evidence from witnesses:

[Money and Mental Health Policy Institute DYE00012](#)

[Crohn's and Colitis UK DYE0019](#)

[MS Society DYE0020](#)

[Autistica DYE0015](#)

[Down's Syndrome Association DYE0051](#)

[Sense DYE0022](#)



Examination of witnesses

Witnesses: Becca Stacey, Ruth Wakeman, Ceri Smith and Russell Fleming.

Q71 **Chair:** Welcome, everybody, to this evidence session of the Work and Pensions Select Committee in our inquiry on disability employment. We are very grateful to the four witnesses joining us for our first panel, three here in person and one joining us remotely. Let me ask each of you briefly to tell us who you are, starting with Ceri Smith.

Ceri Smith: Good morning, everyone. I am Ceri Smith. I am head of policy and evidence at the MS Society.

Becca Stacey: Good morning. My name is Becca Stacey. I am a senior research officer at the Money and Mental Health Policy Institute. We work to break the vicious cycle that exists between having a mental health problem and struggling financially.

Ruth Wakeman: Good morning. I am Ruth Wakeman. I am director of services, advocacy and evidence at Crohn's and Colitis UK.

Russell Fleming: Good morning. I am Russell Fleming, head of communications at the ME Association. We support people with ME/CFS, long covid and post-viral fatigue syndrome.

Q72 **Chair:** Thank you all very much for being with us. I will put the first question to you. Can each of you outline the main barriers to work for the people you support and whether those have changed over the last few years? I will start with Ceri Smith.

Ceri Smith: Multiple sclerosis is a progressive neurological condition that affects around 150,000 people across the UK. They tend to be diagnosed in their 20s, 30s and 40s, so it is a condition that starts to affect people at the peak of their career and throughout the rest of their working lives.

One of the key issues that people with MS face is that in the earlier stages of the condition it very often fluctuates, so the majority of people who are diagnosed with MS are diagnosed with what is known as relapsing remitting MS. They experience periods of neurological activity, or relapses, that will cause all sorts of symptoms, including fatigue, issues with eyesight and movement, and a wide range of other symptoms, followed by periods of remission where they may feel better. That unpredictability can vary week by week, month by month or even day by day. That can cause all sorts of issues for people with MS.

As the condition progresses, people tend to experience what we call accumulating disability, so they will have more mobility problems. Many people as they progress with MS may need to use walking aids or wheelchairs, and experience difficulties with things such as typing at work or other mobility problems, as well as exacerbation of the symptoms I have already mentioned.



People need a wide range of support measures to be able to work. It could be access to flexible working. It could be access to reasonable adjustments in the workplace to allow someone to physically access a space. The problem that people with MS encounter is that there is still quite a lack of understanding about what “reasonable” means when it comes to reasonable adjustments among employers. There is still a fear that adjustments will require lots of money, and there is a fear, particularly at the point of employing people with MS, of what the employer’s response will be when adjustments need to be put in place. Around half of people with MS are in employment, and a lot of people would prefer to stay in employment for longer, but the main barrier is not having the right adjustments put in place by their employer. That support to enable them to stay in work for as long as possible seems to be the main issue that we encounter.

Chair: Have things changed much?

Ceri Smith: Unfortunately, we have not seen any marked change.

Becca Stacey: Unfortunately, despite advances having been made in addressing stigma relating to mental health problems, the mental health employment gap still stands at 28 percentage points, as of 2023. So 51% of people with a current mental health problem are in work, compared to 79% of people without a current mental health problem.

There are several reasons driving barriers to work for people with mental health conditions. Some people, because of the nature and severity of their condition, are not in a position where work is appropriate, but there are many people with a mental health condition who would like to work and who face barriers such as a lack of effective support to access work that is personalised, bespoke and understands the barriers they face as a result of their condition. Biased recruitment practices are, unfortunately, all too often something we hear about—for example, people having difficulties explaining gaps in their CV, which might be as a result of periods out of work due to poor mental health.

When it comes to being in the workplace, discrimination is still an issue we hear about from members of our research community, which is a network of 5,000 people with lived experience of having a mental health problem. We know that one in five people with a mental health problem have experienced discrimination in the workplace.

There is also a lack of action from employers to make workplaces accessible and supportive to people with mental health conditions. Going to Ceri’s point about reasonable adjustments, we know that, where people with mental health problems have requested a reasonable adjustment, two thirds of those either have not been met or have only partially been met. There is still a big way to go in terms of employers making the adaptations needed to make work accessible.



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The final point is that half of us in our life are going to experience a mental health problem. The failure to address the challenges that people with mental health problems face in order to work is essentially a failure to address the challenges that tens of millions of us are going to face in the future, which will continue to have an impact through low employment rates and low tax revenues and, most importantly, on the financial and mental health of individuals.

Ruth Wakeman: Crohn's and colitis affects around 500,000 people in the UK, or around one in 123. The reason this inquiry is of particular interest is that many people are diagnosed before they are 30, so you are looking at people throughout their working lives.

Crohn's and colitis is a relapsing remitting condition. It has a serious impact on people's lives. Symptoms include frequent and urgent diarrhoea—we are talking about 20 times a day—sometimes with blood. There is also pain and fatigue. Many people will also require surgery, and sometimes repeated surgery, at some point in their lives. We are talking about major surgery, with part of the bowel removed and people needing a stoma, either temporarily or permanently. You can see that the conditions have a really serious impact on people's lives. Some 68% of people with Crohn's and colitis have told us that it has affected their career and their working life.

The system does not work for relapsing remitting, invisible conditions, and there is a complete lack of understanding and awareness. Somebody may look young and healthy, but that does not mean that they are not severely affected. Employers need to make sure that people have the practical adjustments that they need, which might be priority for flexible working requests, access to toilets or seating near toilets, and they need to recognise that people may be well for periods but then may also be seriously ill. There needs to be much more support for employers, to enable them to keep people with long-term conditions in work throughout their working life, and much more education and awareness-raising for employers.

We hear stories of people who need simple things, such as being able to sit near the disabled toilet in their office, which is perhaps always used by somebody getting changed because they are cycling or running. However, the employer does not support them or recognise that they have a serious condition and that they may need to access that toilet urgently throughout the day. The current system is very focused around equipment and more visible disabilities, whereas we need to think about serious long-term conditions.

I would just add that the language needs to be more inclusive as well. Many people with Crohn's and colitis will not identify as disabled, even though many of them will meet the legal definition for having a disability. So it is also about thinking about long-term serious conditions and how we can support people with those conditions to stay in work.



Russell Fleming: What we need first is good healthcare to be put in place for people with ME/CFS and long covid, because that is the best chance of improving life quality in the absence of any effective treatment—we do not have any effective treatment at the moment—and before further welfare reforms are considered.

There have been two key developments in the last couple of years. The first was that the National Institute for Health and Care Excellence produced a new NICE guideline on ME/CFS, which was welcomed by clinicians working in the field and by patients. The challenge ahead of us is to ensure that the guideline's recommendations are implemented effectively across the UK. We need specialist services in place, so that the newly diagnosed and patients who have had the illness for a while can be referred to good specialist services that can help them learn how to effectively live with the condition and manage it, and that can, when a person feels able to return to work, provide that liaison between healthcare and employers, which is another key recommendation in the NICE guideline.

The second key development is that we have been working with the Department of Health and Social Care since May 2022 on a delivery plan, which will prioritise implementation of the guideline's recommendations and improve training for ME/CFS for medical professionals. It will also examine—the DWP has been part of this development—employment opportunities, which we as a charity would like to be involved with. We are considering an employment campaign next year to raise awareness with employers and trade unions of ME/CFS and long covid, of long-term conditions and about how they can work better with potential employees.

Unfortunately, there is limited research available in our field, but based on the latest evidence on ME/CFS and data from the Office for National Statistics on long covid, we estimate that there are around 770,000 people with ME/CFS and long covid in the UK today. These people's ability to initiate or complete normal everyday activities is extremely limited, limited a lot, or limited to some extent.

It needs to be recognised that ME/CFS and long covid can greatly affect a person's ability to complete normal, everyday activities and that these medical conditions affect a person's cognitive and physical function—for example, their ability to communicate, to think clearly, to process and retain information, to access energy on demand, and to mobilise normally. People can also be extremely sensitive to external stimuli such as light and noise, and they need to rest more often than normal. The impact of the conditions on a person's mental health should also not be underestimated.

These things need to be taken into account whenever somebody feels able to return to work. They are chronic and fluctuating medical conditions, and I do not think that fluctuating conditions are discussed



enough or truly appreciated. I echo what was said about multiple sclerosis in this respect.

People are very motivated to return to work; I have not come across a single person who is not. Often, people will try to return to work before they are able to return to work, so you will have this stop-start. When people are physically able to return to work, we need to find them jobs that they can achieve, that they can stay in and that are sustainable. At the moment, there do not seem to be those opportunities. I know we will come on to talk about work capability assessment and so on, and perhaps we will talk again about remote working opportunities.

Q73 Chair: Can I follow up on a quick point with Becca? We will keep it quick because we are a bit under the cosh on time this morning. As you know, the Prime Minister and the Secretary of State have both warned recently about the dangers of medicalising the everyday challenges and worries of life. What is your response to those concerns?

Becca Stacey: We have been really concerned about those claims, mainly because they are very misguided. We have seen a very real and genuine rise in the number of people dealing with genuine mental health problems—in some instances, very severe and debilitating mental health problems. This is not people medicalising everyday stresses and worries; these are people dealing with quite intense mental health problems.

At Money and Mental Health, we are not entirely surprised about that rise in mental health problems, because there has been an increase in known financial drivers of poor mental health. We have come off the back of a pandemic, where people's finances have been stretched. We have then gone into a cost of living crisis, where over half of UK adults have felt stressed, unable to cope or anxious because of the rise in the cost of living. For some people that effect has been a lot more severe, and one in six people have had suicidal thoughts or feelings as a result of the cost of living crisis. That is then combined with the fact that we still have inadequately low levels of social security support. For us, the real question is around how you address those financial drivers of poor mental health, instead of scapegoating the people impacted by it.

The final point is that, alongside those financial drivers, it has been increasingly difficult for people to access mental health support. As of 2021, there are 8 million people who have a mental health condition who are not in touch with the services they need. There are long wait times and difficulties getting the right level of support. All of those are the true issues that the Government should be looking to address, not the people who are suffering due to a lack of action on those factors.

Q74 Sir Desmond Swayne: The Government policy is informed by the disability employment statistics. Those rely on self-assessment by those who have disabilities. Is that a problem? Does it matter? If it does, how could it be changed without disproportionate cost and bureaucracy?



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Ruth Wakeman: Yes, it is a problem, because, as I mentioned in my introductory words, many people with long-term serious conditions such as Crohn's and colitis will not identify themselves as disabled, so they are completely missing from those statistics. We need to think about how we capture accurate statistics on people who are unable to work or to work fully in a full-time role. We need to think about different ways of addressing that issue—for example, by thinking more flexibly about things like partial sick leave, supporting people to stay in work, having priority for flexible working requests and making those adjustments that people may need with long-term conditions.

There does seem to be more of an all-or-nothing approach, and we need to think about how we support people throughout their working lives to stay in employment. Those needs, particularly for someone with Crohn's and colitis, will change throughout their lifetime. So how can we flexibly support and empower employers to keep people in work for longer?

Becca Stacey: For us at Money and Mental Health, it is about creating workplaces that are supportive and that encourage people to share their mental health condition and to disclose. Among our research community, only 29% of people will disclose to a prospective employer about their mental health condition, mainly for fear of the discrimination they could face on the back of that—for example, different treatment at work or being passed up for opportunities for progression or promotion.

We would be reluctant to see a focus on diagnosis-based recognition of mental health problems. There are plenty of people who do have a diagnosis and who know exactly what reasonable adjustments and flexible working they might need on the back of that, but there are also people who do not have a diagnosis but who still face very real challenges with their mental health that affect them in the workplace. It is about equipping line managers and teams more generally with the training to be able to create a workplace where conversations about mental health are encouraged and people feel able to share these things, in the knowledge that, when they do make that disclosure, support, adjustments and flexible working can be put in place on the back of it.

Ceri Smith: MS is in an interesting position, in that under the Equality Act anyone with an MS diagnosis is automatically considered disabled. One of the issues that people experience is very similar to what Becca has just described for people with mental health conditions: there is a real concern among a lot of people, particularly where their symptoms are less visible, about what will happen if they disclose that they have MS and what the perception of them will be as an employee.

There is definitely a lack of awareness about MS as a condition—I think Russell mentioned similar issues around ME/CFS as a condition. There is definitely an issue about how well equipped employers are to have those conversations where they have identified potential issues but where the



person may be reticent to talk about their diagnosis or what they are experiencing.

For us, it is a twofold issue. There is an issue around how comfortable people feel to disclose themselves as disabled in official statistical releases, but it is much more about what the on-the-ground experience is for people with their employers and about their employers proactively identifying where support could be put in place.

Russell Fleming: I would like to stress again that it is highlighted in the NICE guideline that ME/CFS, ME or chronic fatigue syndrome, in particular, have suffered a lot from stigma in the past. I was diagnosed 24 years ago, with the yuppy flu banner still flying around social media—well, not social media at the time, but the media. Since the NICE guideline was published, we have been able to mark a line in the sand, but it is still awkward describing this illness; it is still difficult coming forward to say you have this illness. We are still faced with GPs, unfortunately, and social care professionals who do not get it, do not believe in it, do not validate a person's experiences and do not give the correct diagnosis.

As I say, I am desperately hoping that, now that the NICE guideline has been published, and with the Department of Health and Social Care bringing about this delivery plan, we can see some fundamental changes. But, yes, I would certainly imagine there are a lot of people who have the symptoms but not a diagnosis, who do not get picked up by any official statistics, and who do not get the benefits they are perhaps entitled to. Around stigma, ME is a very good example, unfortunately.

Q75 **Selaine Saxby:** Good morning. Some of the barriers, such as local transport networks and access to NHS treatment, will vary across the country—for example, I represent a very rural community—or in more deprived areas. Do you think we pay enough attention to this point?

Becca Stacey: We did a piece of research a couple of years ago looking at how experiences of money and mental health vary across the UK. Time and again, what came up was poor access to regular and affordable public transport, which is so interlinked with people's ability to access local labour markets. Again, we found that only 42% of our research community agreed that they had access to regular and affordable transport, with huge variations between urban and rural areas. It is something that absolutely needs to be taken into consideration, especially given the fact that people with mental health problems are more likely to be on lower incomes and, therefore, to face further barriers to accessing transport when it is prohibitively expensive.

Q76 **Selaine Saxby:** I am aware that there are issues with bus pass times. Even if you have access to transport, the blue badge is available only after 9.30 am. Is that an issue you have also come across?



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Ceri Smith: It is not something that comes up a huge amount, but it does add an extra layer of complexity and what a lot of people with MS describe as disability bureaucracy. So you have to be keenly aware of how you can utilise things like a disability railcard or a bus pass to be able to travel.

Ruth Wakeman: For people with Crohn's and colitis, accessing those passes and blue badges in the first place is incredibly challenging. Many people with Crohn's and colitis are turned down for a blue badge. There is no recognition of the fact that many people will have incontinence or urgency and will need to be able to park quickly so that they can access a toilet straightaway. The system does not work for those conditions.

Thinking about the rural versus urban and the different variations, it is around transport links, the huge variation in waiting lists and access to specialist care. You may be living in an area where there is no specialist Crohn's and colitis care, and waiting times for tests and investigations, such as colonoscopy, vary hugely across the country. We hear from people who wait for over a year for a colonoscopy and who then wait another year to see a gastroenterologist before they can start treatment. That is very different in different parts of the country. While people are not on treatment, their condition has worse outcomes, but they are also not able to return to work.

Ceri Smith: On the health side of things, that is definitely something that we see in neurology. There are huge variations in the number of neurologists available per capita in different parts of the country, and there are entire areas, particularly rural areas, where there is not even a single neurologist to support people living there.

The other thing we have seen since the pandemic is a huge shift in the availability of NHS-provided physio, which is a huge support mechanism for people with MS in particular to remain mobile and be able to work.

Selaine Saxby: Russell, I can see you nodding along. Is there anything you would like to add?

Russell Fleming: I echo the fact that applying for a disabled bus pass or for a disability blue badge is just another thing that a disabled and sick person has to try to go through, and the local authorities just do not make it easy now.

In terms of healthcare, there are some good examples. I live in Cornwall, and we have a ME/CFS specialist service and a long covid clinic. Although they are attached to the Truro hospital, they offer local clinics around the county—it is a very big, rural county, as you are perhaps aware—which makes accessing the clinics easier. They also offer remote access, so patients who cannot leave their homes or their beds, or their carers, can get in touch with clinicians and attend various appointments.



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This is a postcode lottery, of course. We do not have the same standard of provision everywhere. Particularly in Wales, Northern Ireland and Scotland, you do not get anything. Another thing we are hoping for from the NICE guideline is that there will be some standardisation of available care and support for people throughout the country.

Q77 Selaine Saxby: There is a current campaign to allow blue badge holders to use e-scooters and other such electrical vehicles on the road. Do you support this campaign?

Russell Fleming: I do not think the people we represent would be capable of using those things. I do not think it would be relevant.

Ruth Wakeman: I cannot comment on that campaign, but we would support anything that is going to enable people with invisible disabilities to get out and about and that recognises their unique needs. That would be very variable depending on the condition.

Q78 Selaine Saxby: The Government have said that the rise of remote working will make it easier for some disabled people to work. Do you think this is right, and are there enough of these jobs to make a difference to the disability employment rate?

Becca Stacey: From our perspective, there are many benefits with remote working. It can be a great way to enable someone to manage their mental health condition alongside work. Where there has been a lack of understanding is around the availability of work from home roles. People with mental health problems are over-represented in low-paid work. As of, I think, the second quarter of 2023, only 8% of people in low-paid roles were primarily working from home. So this expectation that these jobs are available is pretty detached from the reality.

The other point is that while some of us might be able to better manage our mental health if working from home, there are many instances where the challenges we face in a workplace still persist. There is still the expectation that you engage socially via calls, video calls and emails, which can still present challenges with social anxiety, emotional self-regulation, following conversations and other symptoms related to having a mental health condition—for example, low levels of energy and motivation, and difficulties keeping up with tasks, deadlines and time management. All those still exist, whether you are in an office or working from home. Again, I think there is a lack of understanding about how a mental health problem can affect you and the fact that the environment does not necessarily alleviate those challenges for everyone.

Ceri Smith: For certain groups of people with MS, it has been a benefit to have more normalisation of working from home. It allows them to manage symptoms like fatigue and any continence symptoms they might have if they can work from home and not have to manage a commute. However, I want to echo what Becca said, which is that that has to be supported by an inclusive working arrangement. People may still



encounter barriers, just by the nature of the work they do. Perhaps there are other adjustments that need to be put in place to support people with MS to continue to work effectively.

There is also a lack of data about how different groups of people are able to work from home effectively. There has perhaps been an over-generalisation that this is something available to the whole workforce, when we actually encounter quite a few people with MS who were perhaps working in retail roles and who have to leave the workplace much sooner because the ability to work from home simply is not available.

Ruth Wakeman: Remote working does have benefits for some people with Crohn's and colitis. We heard from people during the pandemic that they were suddenly able to manage their symptoms and their fatigue, that the problems of toilet access were less, and that they were doing reduced commuting. But many people with Crohn's work as teachers or nurses, or in supermarkets or transport, so we need to recognise that remote working is not the answer for everyone.

It is also important that people are not forced into working from home. The answer is to have supportive employers and inclusive workplaces, so that people have the same opportunities to work in careers and progress as people who do not have long-term serious conditions.

Russell Fleming: I would not be working today if I had not been offered the opportunity to work remotely from home. I never expected to end my career working with a charity. I was working in private banking; that was my career. I was an investment manager before I got ME. The charity offered me a role, and I started volunteering, just doing a few hours a week. I slowly built it up as my symptoms allowed. I went part time, and then I went full time about four or five years ago. I could not do that without being able to work from home. I have a lot of support around me to enable me to work from home. It is not easy. I need to work flexibly. I will start work in the early hours of the morning if I have had a particularly bad night, or if I have had a seizure and I have come round. Sometimes, just being able to get into work helps me to clear my mind.

It is not for everybody, and we need to consider everybody's abilities, but it is perhaps a useful stepping stone. I am just not convinced that all employers have accepted remote working. I think the Government thinks there is a lot of opportunity out there, but we just cannot find any evidence to support that. That is why we responded as we did to the work capability assessment consultation. It is great to think that we can use technology in this way, and it can enable disabled people to work who are able to work, but I do not think it is going to be for everybody and for every employer.

Q79 **Chair:** Russell, you have worked full time at home for some time. Were you doing that before the pandemic, or was it the pandemic changes that made that possible?



Russell Fleming: Yes, I was doing it before the pandemic. The ME Association is a charity, and we employ disabled people with ME and long covid, as well as healthy people. We have always offered this remote working opportunity; it helps. My team all have ME and we all work flexible working arrangements around each other. We make it work and we are better for it.

Q80 **David Linden:** Let us say we are in a situation where good work has been done to try to get more people with a disability into the workplace. I want to turn the questioning now to what we do in terms of retention to ensure we are supporting disabled people in work. Ms Wakeman, you gave a very good example earlier about how somebody with Crohn's and colitis who is working at a desk would need to be positioned closer to a disabled toilet, and about how that disabled toilet might also be used as a facility for folk to change out of their Lycra, if they cycle to work. Can I ask some of the other panel members to give us a few more examples of areas where employers could make reasonable adjustments that are perhaps not happening now? We will start with Ms Smith and work along.

Ceri Smith: I think I already mentioned that there is, broadly speaking, a twofold response. One is where people need physical adjustments in the workplace—for example, making sure that people have access to a height-adjustable desk if they are using a wheelchair, or to speech-to-text software if they are unable to type any more, because dexterity can be affected as a result of progressive MS. As I mentioned, people with MS also often also experience continence issues, so being close to a toilet, and having access to a properly allocated accessible toilet, is very important.

There is also a need for an understanding of flexible work arrangements as an adjustment—for example, the ability for people to use compressed hours, or having a good flexible working policy in place to allow people to manage their work time more effectively, and that particularly works for people in office-based jobs. At the MS Society, for example, we have a very flexible working policy, which can allow people to manage their symptoms. If they wake up one day dealing with fatigue issues, they can then manage that, and then work a slightly longer day on a day when they are feeling slightly better. The issue comes back to there not being enough flexibility with enough employers, which is something that people struggle with.

Q81 **David Linden:** Is that just a culture issue?

Ceri Smith: It depends on the workplace, the type of work and the expectations around it. If you work somewhere that has an expectation around shift work, you cannot necessarily work flexibly, in the way that someone working in an office-based job may be able to.

The other thing goes back to the point around stigma and people's fears around disclosing their impairments. Particularly for people who are newly diagnosed with MS, who may be younger, there is a worry around



coming to terms with their diagnosis and the effects of treatment—that is something I have not yet mentioned. People with MS, particularly relapsing remitting MS, will be mainly on what we call disease-modifying therapies, some of which can have quite large side effects. Particularly if people are on infusions, either on a four-weekly or a six-monthly basis, that can require them to take time off around the time they have their treatment. People do not necessarily understand that they may be able to take disability leave or sickness absence without that affecting their employment record. We do hear of people using things like annual leave to be able to manage those periods, which we do not think is particularly fair or appropriate.

It goes back to that point that there is a lot more understanding around physical access and accessibility and going through an occupational health assessment, for example, to put in place physical things like an ergonomic desk arrangement, but there is less understanding around flexible working arrangements and how people can manage a fluctuating and progressive condition.

Becca Stacey: For people with mental health problems, reasonable adjustments can range, as Ceri mentioned, from flexing hours—enabling people to take more regular breaks or to take time off if they need to attend mental health appointments—to the workplace itself and the work from home adjustment. There is also the ability to create quieter spaces within an office, so that there are less sensory demands on people who might struggle in noisier and busier parts of an office. When people are going through periods of poor mental health, there is also the ability to adjust workload—for example, reducing some of the tasks people are expected to do or some of the more high-stress tasks, such as customer or client-facing roles.

The point to make with reasonable adjustments is that a lot of the time when we speak to people, they are not aware of what adjustments could be made; that in itself is a barrier to them making that request, because they are not sure what their employer could put in place. What we would love to see is employers being proactive, identifying what adjustments they could make and communicating those throughout the recruitment process and to existing staff, so that people feel empowered and able to put in those requests and know what could be available to them.

David Linden: Okay. I know that I cited Crohn's and colitis, but I will go back to Mr Fleming before I come to you, Ms Wakeman.

Russell Fleming: I echo completely what has been said. It is difficult as a person with this condition to know what you can expect an employer to do without that employer feeling you are not going to make a very good employee. There is a feeling that you do not want to be too demanding of the new employer, because that then diminishes your attractiveness as an employee. I do think there needs to be more understanding and awareness around the reasonable adjustments that could be put in place.



To again echo what has been said, there is a lot already being done on physical disabilities that are recognisable—somebody in a wheelchair, for example. But a lot more work needs to be done for so-called hidden or invisible disabilities—adjustments such as flexi hours, and being able to take breaks when you need them to rest. We have talked about remote working opportunities.

There is also a bit of a disconnect, I think, in terms of the size of the employer. When we have discussions around this topic, we seem to be talking about quite large employers, and usually office-based work. I do not think it necessarily translates well across to other forms of employment. I think, again, that that needs looking at.

Q82 David Linden: We touched on people self-disclosing to their line manager. I was in a situation where a member of my staff in the last couple of years got a diagnosis of ADHD, and that was disclosed to me as line manager. We made sure we got things like noise-cancelling headphones to support that individual in the workplace. What more can be done to address that challenge when you have to self-disclose to your line manager? What can we do to try to encourage more of that? Does anyone have anything they want to add?

Ceri Smith: One of the things we encounter is where there is openness right from the off, when someone is looking to work for an employer. One of the concerns that people raise quite frequently about living with MS and looking for a new job, or being diagnosed with MS when they are working somewhere, is about that openness and up-frontness about the culture of acceptance of disability in the workplace. Where places have clear policies around support for disabled colleagues, or there is a disability network that can provide peer support, advice and guidance, that makes a big difference. Where you have things written down in policy, that will make a big difference to the level of trust.

That being said, even with that, particularly if it is a new diagnosis, people will struggle sometimes to come to terms with a new diagnosis. A lot of this then comes down to the empathy and support from the line manager, to try to unpick where problems may be identified. Employers do have a duty, where they could reasonably deduce that someone is disabled, to try to provide that support. Part of that does need to involve having those conversations where someone is clearly struggling, or perhaps could do with a bit more support, to try to get them to open up, and to build that trust so that they can talk through what support they require, without necessarily needing to disclose what the exact diagnosis is. It is about taking much more of a social model approach to supporting people in work, rather than a diagnosis approach.

Ruth Wakeman: For Crohn's and colitis, it is one in 123, so everyone will know someone with Crohn's and colitis, but you may not know that you know someone with Crohn's and colitis. People do not talk about it. Poo is the last taboo. It is quite a big step for somebody to talk to their employer about a bowel condition and explain that they may have



incontinence and that they need to run to the toilet frequently throughout the day. It is a big step for someone to disclose that, so many people will not disclose or do not want to disclose.

Even when people do disclose, the level of understanding and awareness from the general public, and so from employers as well, means that they do not realise that these are serious conditions; they think, "Oh, it's a bit of a tummy ache or a bit of diarrhoea." People have a real battle to get across what they do need in the workplace. So we need much more general awareness-raising around serious conditions. Scotland did a great awareness-raising campaign for Crohn's and colitis, and it would be great to see something like that across the rest of the UK. We need much more awareness, education, and support for employers, so that even when someone does disclose, they know how to react, what to do, and what those conditions may mean.

Q83 David Linden: The last question I am going to ask each of you is, what more can the Government do to encourage employers to employ more disabled people? Also, on the introduction of mandatory disability workforce reporting for large employers, am I right in thinking it is anything from 250 employees upwards? Do you support the mandatory workforce reporting? We will start with Mr Fleming and work our way back.

Russell Fleming: I do not know anything about the mandatory reporting. What was the first question?

David Linden: What more can be done to encourage employers to employ people with a disability?

Russell Fleming: I think we need to look at the skills available to potential employers. People do have their lives devastated by ME and long covid. They are often dragged out of hard-fought careers. They can be quite highly skilled. It can affect anyone. We need to raise employers' awareness of the potential benefits of employing highly motivated people with disabilities, particularly ME and long covid, who possess strong skills.

As an employer, we found that employing people with these conditions has brought huge benefit to the charity. I know we are a charity, but their expertise and skills, applied in a different way, have been amazing. Some people do return to jobs related to their former careers, in a different capacity. I think education and teaching tends to be a big catchment area. A lot could be done to raise awareness. We hear from former teachers trying to return to roles, only to find that schools are not accommodating and flexible enough. There needs to be more understanding on both sides to try to find accommodations. Job sharing is a good option, as well as other possibilities.

As has been said about Crohn's, we need more general raising of awareness and to meet employers to learn more from them what their problems are. Maybe we can help employers as well.



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Ruth Wakeman: With mandatory reporting, the devil is in the detail. What difference is it going to make? How will disability be defined? How will employers then respond to the mandatory reporting being measured? I think there is a lot more to think about and understand around mandatory reporting. As I have mentioned, we need to think about long-term serious conditions wider than disability, so it is about changing the conversation.

In terms of what the Government can do, the system does not work for people with these long-term relapsing remitting conditions. The language needs to be far more inclusive, and there needs to be a lot more support for employers, including education and awareness-raising.

It is good for everyone if people with long-term serious conditions can work, so we need to support employers to keep people in work. That includes people who may need periods of time in hospital or time off for medical appointments. They may have periods where they are very unwell. We need to support employers to keep those people on, so that when they are well, they can work. So it is about being much more flexible about different ways of supporting people with long-term conditions.

Becca Stacey: From Money and Mental Health's perspective, in terms of what the Government can do to support more employers to employ people with mental health conditions, there are a couple of things that we have not touched on. Access to Work is a fantastic scheme but, as we know, the backlog for people getting a decision on their Access to Work claim is huge. I think that, as of December 2023, around 25,000 people were waiting.

Neil Coyle: It is 36,000 now.

Becca Stacey: Okay. Thank you.

David Linden: I do not want to steal too much of Mr Mills's thunder, because I think he is going to come on to this shortly.

Becca Stacey: Putting resource and personnel into addressing that backlog is key.

The other key thing we want to see is a shift from a right to request flexible working to a right to flexible working. Quite often, what we see is individuals not feeling that their flexible working requests will be honoured, or wondering whether that could result in them being treated less favourably or being passed up for opportunities within the workplace. People face barriers to making those requests, so if there was a shift whereby this was a right that employees had, people would hopefully feel that this was something they were able to do and should be putting forward.



Something else we want to see, to encourage employers to start acting more on reasonable adjustment requests, is reporting for larger employers—people with over 250 employees. They should start publishing the amount of reasonable adjustment requests they receive and their responses to those, to create a bit of an incentive for employers to make adjustments that can make work more accessible.

On the disability reporting point, we echo what has been said. There are other measures that should be looked into. The mental health income gap is a significant issue. There are other measures that it would also be useful to report on. The main point is the purpose of this. If there are no repercussions for employers who are not taking steps to employ more people with mental health conditions, other disabilities and health conditions, there is very little effect from having this mandatory reporting in place.

Ceri Smith: I wanted to point out a drawback with mandatory reporting. Given the issues we have talked about in terms of people feeling reluctant to disclose their impairment or condition at work, if they are working for an employer where they feel that a disclosure could be used against them in some way, you may end up with an under-reporting of disability data. I echo very much what has been said; we would be much keener to see strengthening around transparency of reasonable adjustment requests and how many of those are granted.

In terms of what the Government can do, one of the things that people with MS bring to the MS Society quite regularly is the concern around business reasons being given for turning down a reasonable adjustment request but no detail being provided.

David Linden: It costs too much for a height-adjustable desk.

Ceri Smith: Exactly. It might be as simple as cost, but without much more detail. We would like to see a strengthening of the Equality Act duty around detailed response, and timely response, to someone who has made a reasonable adjustment request. Ideally, it should be done within a couple of weeks, with people being told, “Okay, this will cost too much” or, “We think we will need to go down an Access to Work route to justify the expense of doing this.” At the moment, it is very inconsistent what requests will be granted, and in what way.

David Linden: Thank you all so much for your evidence. I appreciate that.

Chair: We are going to need to speed bit, given we are getting a little bit behind.

Q84 **Nigel Mills:** Can I follow up on one thing? When you say there should be more support for employers when they have an employee who is off for a long period with sickness, what do you think that support should be?



Ruth Wakeman: It is about more flexibility with the sickness pay and about supporting employers. A good, supportive employer will recognise that someone may be off for a few weeks, or even a few months, but then they will be back in the workplace, able to do their job, maybe for years, maybe for the rest of their working life. At the moment, the systems are not there to support employers to keep somebody in work—I am thinking particularly about smaller employers. Currently, the system just does not work to provide that level of support.

Q85 **Nigel Mills:** Are you suggesting that the employer should be able to reclaim sick pay or something?

Russell Fleming: Like the furlough arrangement during the pandemic. The other thing, if you have one of these conditions and you incur a relapse, is that you could be on statutory sick pay, reduced pay. The employer also has a gap in their staff. I think there should be more help on both sides. When you have a long-term condition, it should be expected almost that there are going to be periods when you are just not capable of turning up for work. From an employer's perspective, we had furloughing, and employers could claim the compensation for staff who were off.

Q86 **Nigel Mills:** Becca, can I ask about the right to be entitled to flexible working? How can we draft that? Presumably, if I am a bus driver and I request to work from home, that is not going to work all that well. How do you craft a requirement that could reasonably be enforced on employers when you probably have quite a lot of jobs where you cannot have that flexibility?

Becca Stacey: That is why it is important to go back to the point that employers themselves are proactive about what adjustments could be put in place, given the context of the working environment they are situated within. Only one in six people with a mental health condition has put forward reasonable adjustment requests, and the real barrier is around fear of that not being granted. Yes, there will be some workplaces where different adjustments are going to be more acceptable, so the more employers can communicate what they could do and the more that they encourage people to put forward those requests—therefore addressing some of the stigma and the concerns about subsequent discrimination that individuals face—the better. If you encourage employers to report on that, it creates an environment that shows people that these adjustments—some can be very small but can still have a very big impact on the accessibility of a workplace—can be put in place.

Q87 **Nigel Mills:** It almost becomes a right not to refuse unreasonably—that is the sort of language.

Can we switch back to Access to Work? In general, our feedback is that it is a brilliant scheme but no one knows about it, that it is a bit slow and that it is a bit of a nightmare if you change jobs and have to go through it again. Is that your experience? Have you sensed anything improving



recently?

Ceri Smith: From an MS Society perspective, I do not think we have seen much improvement. Where it works, it is brilliant and it does have a transformative effect on many people's ability to work. Obviously, it does allow for more expensive adjustments to be made or for things like taxis to and from work to be paid for, which allows the disabled person to afford to travel to and from work, when they may not be able to otherwise.

That being said, if you move jobs—and, I am pretty sure, even if you move house—it is very difficult to port it over. If someone wants to move to a new employer, they cannot even give an indicative award to that employer; they have to be offered the job and to have taken up the employment before they can reapply to Access to Work. We definitely support the idea of passporting or indicative awards that could allow people to more easily transfer their Access to Work award.

Russell Fleming: I wanted to raise a point. I have obviously told our community that I was coming here today, and I have had loads of comments on social media to raise points. One of the strongest points was that, although it says it does not, people are still worried that if they apply for a grant from Access to Work, it will prompt a benefits review, and that puts people off applying for Access to Work. I wanted to raise that point.

Q88 **Nigel Mills:** Are any of you familiar with the health adjustment passports that I think have been introduced or trialled recently? Do any of you have feedback on those?

Ceri Smith: We do not have any feedback. We are supportive of them, but we do not yet have any feedback on how they are working in practice.

Chair: We have been told that Access to Work applications have been digitised. I think this has been announced this week. It would be interesting if anyone has any experience of how that goes in practice.

Q89 **Marsha De Cordova:** Thank you all for being here today. I am going to talk about disability employment and the Disability Confident scheme. First off, we know that the disability employment gap has not really changed for a very long time, and the Disability Confident scheme was, I think, introduced around eight years ago. What is your view of the impact of that scheme in its current format in terms of helping to alleviate the disability employment rate?

Becca Stacey: It is similar to what other witnesses in previous panels have mentioned: pretty ineffective. For us—again, this is similar to the reporting point—if there is not a degree of accountability for firms or employers who are not putting in place actions associated with what should be done under that commitment, we sometimes see very few real-life changes being made in the workplace. That is the issue. As long as



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there are no repercussions for people who are not upholding their actions under the commitment, there is going to be a limit to how effective it can be, which is what we have sadly seen all too often.

Q90 Marsha De Cordova: Would that be the case for everyone on the panel? It is very much a tick box and there is no accountability.

Russell Fleming: I think it is a great idea, and it helps when some disabled people are applying for jobs to see that the employer is Disability Confident. I just do not think it has been promoted enough or, as has been said, monitored effectively. I think more could be done.

Ceri Smith: I think there is a particular problem with the committed level; employers can sign up and do not have to provide any evidence they are doing what they are saying they are doing. It is only really when you get to leader that there is any of that accountability. Where it is being applied, it is good. As I have mentioned, there is a fear about moving to a different employer and how accepting they will be. Having that badge is a good thing, and having some accreditation system is positive, but I would echo what has been said particularly about that level 1, committed employer. It is largely just a badge on a website.

Q91 Marsha De Cordova: It is not helping to reduce or close the disability employment gap. As we have highlighted, you can be at level 1 or 2 and not employ a single disabled person but be a Disability Confident employer.

Russell Fleming: It should be a great opportunity. You could go to all Disability Confident employers and you could get them involved in what we have all been talking about this morning. That should be our target area, in a way. Unfortunately, it is no more than a badge on a website, as has been said.

Q92 Marsha De Cordova: Do you think there should be a scheme that employers can get accreditation for that would really demonstrate that they are a Disability Confident employer?

Russell Fleming: Definitely. It should involve people within the company who are disabled, who can vouch for what that company is doing to support disabled people.

Ruth Wakeman: Again, it is about the language. This is about disabilities. What about long-term serious conditions and employers being able to show that they support people with long-term serious conditions, thinking about support plans and so on? There are good employers out there. Quite often it comes down to a good, supportive line manager. A whole company will not necessarily be supportive. It may have the right policies in place, but we hear from people with Crohn's and colitis that the line manager is key. Having a good, supportive line manager makes the difference. There are good employers, but they do not necessarily carry the Disability Confident badge.



Q93 **Marsha De Cordova:** Moving on to the work capability assessment, will the Government's proposed changes to the WCA have an impact on the number of disabled people who will engage in work?

Becca Stacey: From Money and Mental Health's perspective, no. I think we will see it becoming increasingly hard for people with mental health problems to get the extra support they need. These people are not in a position to engage in work preparation or to engage in the workplace yet.

The removal of the LCWRA risk regulation is really concerning for us, because the activities and descriptors of the WCA routinely fail to capture mental health problems, in particular. That vital protection ensured that this group still got the additional financial support they needed, but also protection from conditionality. You are just creating a less secure financial base for someone, which is not at all conducive to someone, at some point in the future, if they would like to or it is appropriate, engaging in work.

The final point we would make—I know there have been lots of announcements around the benefits space recently—is that it would be hugely concerning if there was that shift to replacing the WCA with PIP and having work coaches take more of a role in deciding someone's conditionality and level of support, given the mental health knowledge gap we know exists among work coaches.

Ceri Smith: We are hugely concerned about the proposed changes to the WCA, and particularly the removal of the mobilising descriptor. By the time someone with MS needs to apply for universal credit or ESA because they are no longer able to work, they are usually experiencing quite high levels of impairment. The greater availability of flexible working or home working does not compensate for removing that descriptor; we do not think that that is an appropriate or proportionate response to the changes in the workplace post pandemic.

We are concerned about the long-term impact of putting more conditionality on people who are very unwell and living with a progressive condition from which they will not recover. By the time they reach that stage with MS, they will have been living with the condition for a number of years—probably decades—and will have acquired quite a lot of nerve damage. Nothing will return them to being able to work in the way they previously did. All that will happen is that they will be made poorer and placed under greater stress.

Ruth Wakeman: Every time there are announcements like this, it causes incredible fear, panic and anxiety, which can actually make many conditions worse. We are really concerned about the proposed changes. Already, assessors do not understand Crohn's and colitis. They see a young person in front of them who looks healthy, and they assess them based on subjective views. Any changes like this are really concerning to us, because there is not the level of understanding and awareness.



Some of the descriptors just do not work. The toilet descriptors do not work. It is not about whether someone with Crohn's or colitis can get themselves on or off a toilet; it is the fact that they go to the toilet 20 times a day and may be getting up in the night six or 10 times. So the descriptors do not work either for conditions like Crohn's and colitis.

Q94 Marsha De Cordova: Jobcentres have work coaches and disability employment advisers. Is the quality of the specialist support they provide adequate? What needs to be done to upskill their capacity to deliver better for disabled people?

Becca Stacey: As I mentioned, we see a big mental health knowledge gap among work coaches. The mental health, behaviour and relationships training given to frontline DWP staff assists them with understanding how having a mental health problem can affect people. A recent FOI that we did, though, showed that only 62% of DWP staff have received that training. DWP's own figures showed that, as of February this year, over 20,000 DWP frontline staff were yet to receive this training.

The way that plays out is really damaging to a lot of the people we routinely engage with. We have heard of instances where people are pushed into conditionality commitments that are completely inappropriate for them and that exacerbate their poor mental health. We have heard of people being pushed into roles that are not suitable for them and their mental health condition or being encouraged to engage in generic, non-personalised, non-bespoke work preparation, because there is that gap in understanding among work coaches. We want to see high-quality mental health training provided to them.

But the key point is that the wider culture within the DWP is around making sure that people get into work as fast as possible. That initial movement into work is the key thing, as opposed to whether it is good, high-quality work or you have retention, and so on. You can have that knowledge among work coaches, but unless they are empowered to use it and to work in an environment where personalised, less coercive support is actively encouraged as the way of operating, the effectiveness of that training will be limited.

Marsha De Cordova: Does anyone else want to come in on that?

Chair: If not, that is fine because we are up against the clock.

Siobhan Baillie: Chair, can I ask a quick question to Russell?

Chair: Briefly, yes.

Q95 Siobhan Baillie: In Stroud, in Gloucestershire, we have a really effective and constructive ME group. When the new NICE guideline came through, they got in touch with me and I spoke to the ICB. I was going to write to all GPs, but the ICB said, "Don't do that. They are busy. We will do it." We know increasingly that the interaction between the NHS and the work coaches in DWP is vital for getting the right approach for individuals. Is



any assessment going on to understand whether GP practices all over the country have adopted the NICE guideline? How do we monitor that? I know how pressured GPs are. It is not because they do not care, but they have a lot coming across their desks.

Russell Fleming: I don't think it is not monitored, unfortunately. The implementation of the NICE guideline, or even recognition of the NICE guideline, is not monitored. We hear from people who have been to their GP, and the GP does not even acknowledge that there is a NICE guideline on ME, which suggests that they have not even bothered to look at the computer to find it.

As I said, I hope that the delivery plan from the Department of Health will help to demonstrate that the NHS needs to look at it, and these initiatives that are coming out will cascade down throughout the NHS. As a charity, we are keenly focused on, and putting more resources into, local efforts to drive change from the bottom up. Hopefully, we can look forward to a future of better healthcare.

Q96 **Neil Coyle:** Can I ask a quick follow-up to some of the points made about the crucial need to support employers and line managers, in particular? Ruth, you touched on line managers. Who should provide that more tailored support to employers and line managers? Would you like to see DWP do that? Personally, I would have reservations. Should employers' organisations like the FSB do it? Or is there a place for rebuilding what the Disability Rights Commission's practice development team used to do? Who should provide that support? I assume you will suggest that this should be free support to employers to support their businesses and to support the retention of disabled people in work.

Ruth Wakeman: The Government cannot relinquish all responsibility for training and educating employers and line managers, but I would ask them to work with us in the voluntary sector. Many of us have schemes, educational materials and support for employers. Much more could be done, working with us as patient charities, to support employers and line managers. But the Government definitely have a role as well in making sure that people are aware, informed, supported and educated.

Neil Coyle: It would be Government funded but involve working with others. Sorry, Russell, you want to come in?

Russell Fleming: There is also a role from a healthcare perspective. I am sorry to keep bashing on about the NICE guideline, but one key recommendation is that while healthcare professionals deliver specialist support services, they get to know the patient and the patient's abilities. Some of those patients will be in a position to return to work. The NICE guideline says—

Neil Coyle: I am talking about in-work support, rather than returning to work.

Russell Fleming: All right. I beg your pardon.



Q97 Neil Coyle: I am talking specifically about support for people who are already in work. Does anyone have any other thoughts now? If not, please feel free to feed in after, because we are running out of time.

Turning, then, to out-of-work support and its importance to the people you serve and represent, what opinions do the panel have about universal support and WorkWell? Are they going well?

Becca Stacey: It is early days still. Universal support and WorkWell have many positive aspects. For example, we are happy to see the expansion of IPS through the IPS and primary care scheme. We look forward to seeing how that is rolled out.

Another positive is that there is an understanding of trying to take a more holistic approach to some of the barriers people face to work—for example, by trying to link people up with mental health support, if that is a barrier, or with debt advice, if that is another reason why someone struggles to access support.

What I would say, though, is that those schemes as they stand are still quite small-scale. We have seen continuing threats to more specialist disability employment support, like the Work and Health programme, which, thankfully, is now being extended to 2026, but there has been an ongoing narrative around the threat to its existence. We saw the wind-down of the intensive personalised employment support at the end of last year.

More generally, we would be especially concerned about the fact that WorkWell is being used to trial some of those more concerning points that have come under the back to work programme. For example, the reform of the fit note being trialled through WorkWell is especially concerning for us. We do not believe that you can go from having mental health or clinical professionals deciding whether someone is fit for work to having non-clinical members of staff having that say.

Overarchingly, they come under this back to work plan that, on the one hand, provides support and personalised assistance into work but that, on the other hand, very much bangs the drum of sanctions and withdrawing assistance from people. As long as you try to dress support up in more punitive measures, there is a very big contradiction there. We are really concerned about that, given the known mental health and financial impact of sanctions.

Q98 Neil Coyle: Are you involved in the pilot with—

Becca Stacey: No, we have just been watching.

Neil Coyle: Not even as part of a stakeholder engagement exercise by DWP? They are not talking to you about how the pilots are working?

Becca Stacey: On universal support and WorkWell, no. Money and Mental Health have not been engaged in those conversations.



Neil Coyle: Who is DWP talking to?

Becca Stacey: I am not sure.

Q99 **Neil Coyle:** That is fascinating. We will have to come back to that. Are there any other views on universal support or WorkWell?

Ceri Smith: The key thing for us is the scale of both programmes. Universal support is probably less relevant for people with MS because, as I have already described, by the time they are out of work, they probably would not qualify for that. The WorkWell pilot had 59,000 people. The criteria could capture people with MS but they are much more likely to skew towards people with mental health conditions and musculoskeletal conditions. That is one of the main problems. To echo what Becca said, there is also a lack of trust among a lot of disabled people about what actually underpins both programmes.

Q100 **Neil Coyle:** There are issues around the scale and reach so far. Is there an imbalance between the timetable and reach of the support programmes that are meant to help disabled people into work and the drawing back of other help? We have already seen the abolition of DLA, and now there is PIP. Is there an imbalance in how DWP withdraws support before delivering things? We have already talked about Access to Work and promises that have been committed to for many years—for more than a decade.

Ceri Smith: The perception among people with MS at the moment is that it is very punitive. The changes to the work capability assessment were followed by a Green Paper on PIP, which has some damaging proposals. People have called us saying that they are literally sick with fear about the proposals. The problem is the narrative about being quite hard on people who are out of work and tackling out-of-work benefit bills, but it needs to be said that PIP is not an out-of-work benefit.

The issue, which we raised with the previous disability Minister when the WCA consultation was live, is that huge numbers of people would be collateral damage in these proposals, which do nothing to address the issues that Becca has already identified around the increase in people who are out of work or struggling at work due to mental health conditions. We would advocate much more for support to keep people healthy, to prevent people from becoming unwell and to keep people in work for longer, as a measure to tackle the economic problems we face.

Q101 **Neil Coyle:** Any other thoughts about making sure that the commitments to support people in work are delivered before further cuts are made?

Ruth Wakeman: That is really important. Sanctions do not work. Most people with long-term conditions want to work. They are keen to get back to work or stay in work.

Some of the language and terminology has been really damaging. People with Crohn's and colitis report to us regularly that they get abuse from



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members of the public for using disabled toilets. What we have seen helps to foster this sense that people with disabilities or long-term conditions are making it up and that they do not suffer conditions that impact their lives severely.

All the talk of sanctions has been hugely damaging. People call our helpline. As soon as there is an announcement, we get a spike in calls from people feeling suicidal, people who have managed to get support feeling they will lose it and people who have been trying to get support feeling there is literally no hope for them.

Q102 **Neil Coyle:** Do you tell people who call your helpline who are very worried that legislation to deliver on this has not yet appeared and that there is little time to get it through, despite the lack of an agenda from the Government at the moment?

Ceri Smith: Yes. We have made the point to the Secretary of State. That is true, but a disabled person hearing about this in the press does not necessarily know the difference between a Green Paper or legislation and what will happen next week.

Chair: Thank you very much. Becca, a moment ago you said something in passing that I did not know, which is that the Work and Health programme has been extended to 2026. We have checked, and that has been announced. I had missed that. Thank you for giving us that welcome news.

We are grateful to you all. Thank you very much for helping us this morning. That concludes our first panel. Thank you, Russell, as well, for being with us remotely.

Examination of witnesses

Witnesses: Georgia Harper, Alison Thwaite and Evan John.

Q103 **Chair:** Welcome to our second panel this morning in our inquiry on disability employment. I am grateful to you all for being with us. Can I ask each of you to tell us briefly who you are, starting with Alison Thwaite?

Alison Thwaite: Good morning. My name is Alison Thwaite. I am the employment development manager for the Down's Syndrome Association's WorkFit programme.

Georgia Harper: Hello. I am Georgia Harper, and I am the policy manager at Autistica, the UK's leading autism research and campaigning charity.

Evan John: Hi. I am Evan John. I am policy and public affairs adviser at Sense, a national disability charity that supports the UK's 1.6 million people with complex disabilities.



Q104 **Chair:** Thank you all very much for joining us. The first question I will put to you is the same one I put to the previous panel: what are the main barriers to work for the people you support, and have things changed much for better or worse in the last few years? We will start with Alison Thwaite.

Alison Thwaite: We support people who have Down's syndrome to live full and rewarding lives. Just under 40,000 people in the UK have Down's syndrome. Only 4.8% of people with learning disabilities are in employment. We are passionate about supporting people with Down's syndrome to fulfil their potential and their career ambitions.

One main barrier for people with Down's syndrome is a lack of high-quality work experience in education. We are looking for education providers to set a presumption of employment for people who have Down's syndrome. We want people to have access to high-quality opportunities. We want them to be prepared for that transition into adulthood and to be prepared to join the workforce. That is one key barrier.

Employers can have a lack of flexibility. The previous panel talked about reasonable adjustments, which are so essential. The perception is often that reasonable adjustments will be challenging, expensive and difficult to implement. We spend a lot of time working with employers in the WorkFit programme and helping them to understand that reasonable adjustments can often be simple and straightforward. We support them to implement whatever they need to do in the workplace.

The recruitment process tends to be technology-driven with a lot of employers. The big employers, in particular, want efficient, effective recruitment programmes to bring their talent in, which often does not work for people with learning disabilities. We focus on a person-centred approach when we develop opportunities with employers. We want them to strip back all these assessment days, telephone interviews and things, which do not work for people who have learning disabilities.

We also wonder about the lack of understanding that we see around the Equality Act 2010. Sadly, some employers still contact us who want to develop an opportunity but then say, "How much should I pay somebody who has Down's syndrome?" We say, "Well, you pay them the going rate for the job that they do, as you would with anybody else in the organisation." There is certainly an education piece there around helping employers understand the value and the contribution that somebody with a learning disability can bring to the organisation.

A lot of that is around perception. Sometimes employers see a person with a learning disability as a risk rather than an asset to their business. We want to change those perceptions, if we can.

Q105 **Chair:** Are employers more open to this than they were five or 10 years ago?



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Alison Thwaite: Absolutely, yes. In the last three or four years, we have seen a huge increase in the number of employers who come to us.

We provide a lot of support to employers. We hold their hands from day one, carving a role, giving them resources and training them. Then our support is ongoing for as long as that person is with that organisation. It could be 12 months or 12 years. Whatever it is, we pledge our ongoing support.

In the 2021-22 financial year, we saw a fourfold increase in the number of employers coming to us to say that they want to work with us. It is very positive, yes.

Georgia Harper: Prevalence statistics vary, but we think the UK has about 1 million autistic people. The employment stats, unfortunately, are pretty dire across the board. The latest Government statistics we have show that three in 10 autistic people are in work, which is the worst employment rate for all disability groups. Even at graduate level, gaps persist. Just four in 10 autistic graduates find full-time work within 15 months, compared to six in 10 non-disabled graduates. Again, the statistics on whether that is a permanent contract and whether the role is at the person's qualification level are quite dire.

In terms of main barriers, some are wider issues. In general, getting even a diagnosis is difficult. At the end of December 2023, 172,000 people were on the waiting list, which is about the population of Oxford. Years-long waiting lists are not uncommon. For those who do get a diagnosis, it is often the norm to be sent away with a leaflet or a website. The result is barriers to education, which has a knock-on effect, with quite high rates of mental health conditions. As you have just heard, that has knock-on effects for employment.

In terms of the career pathway, work readiness is not necessarily thought about. Too often, autistic young people are assumed to be incapable or not to need support. As you can see, even at graduate level, among autistic people who can access education, they are not necessarily able to access employment in its current form. Lack of accessibility of transport and housing for people who might struggle with sensory overload can limit their options, particularly if flexible working is not there.

We supported Sir Robert Buckland's review of autism employment, which was published in February. Lack of confidence was a very big thing, both for autistic people because of the past negative experiences they had faced, but also for employers. Again, there is this assumption that reasonable adjustments are complicated and so on.

Application questions are often unclear. Job descriptions are often unclear; they might automatically include things like "team player", which could put off an autistic person, even when that is not necessary for the role. As Alison was saying, forms can be inaccessible. About a third of



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autistic people have a learning disability, so some of the same barriers apply.

Psychometric tests and the increasingly automated screening processes that large employers use often screen out things that are not phrased in a correct way, because autistic people are not necessarily directly told about them.

Job interviews are often more a test of adherence to social norms and verbal competence under pressure than ability to do the role. Questions often have hidden meanings. Our research has found that autistic people rate their experiences of interviews as significantly less positive than non-autistic people.

Then, as we will come on to, getting into the work, they have difficulties with the sensory environment, with discrimination and with those unclear social expectations. Often the onus is on the autistic person to identify and ask for adjustments.

Evan John: As I said, we support the 1.6 million people with complex disabilities in the UK. We define complex disabilities as two or more conditions like blindness; hearing loss or hearing impairment, or being deaf; learning disabilities; or autism. If someone has two or more of those, they have a complex disability.

It is a broad category, but people with complex disabilities often face high barriers to work. Our research has found that 82% of people with complex disabilities are unemployed, compared to 23% of non-disabled people. Only 13% of people with complex disabilities are in full-time employment.

Importantly, while this inquiry is about disability employment, not every person with complex disabilities will be able to work in the future. In the long term, that might be an aspiration, but not now. Or it might never be an aspiration for them, but that is okay, and we should not demonise people who cannot work.

The barriers that people face start early. Our education system often does not have high aspirations for disabled people, particularly people with complex disabilities. That means that they do not get the right specialist career support, so they do not necessarily know what opportunities are out there or what support is available for them. That has an impact when they start looking for work.

Society's attitudes to disability are another big barrier, as are unfair recruiting practices, as Georgia mentioned, and a lack of suitable job opportunities. When people get into work, there is also a failure to provide them with the support they need. We found that 44% of employees with complex disabilities have been bullied or harassed in the workplace, and one in 10 people with complex disabilities in work have



told us their employers are not willing to make reasonable adjustments. Clearly, that is a requirement under the Equality Act.

Another issue is that people with complex disabilities do not get the specialist support when they look for work. Our research has found that half of job seekers with complex disabilities say they do not have the support and equipment they need to look for work. Over half of job seekers with complex disabilities say they do not feel supported by their work coach, and 46% say they do not feel supported by their disability employment adviser. This is not surprising, given that there is limited coverage of disability in the training for work coaches.

Finally, jobcentres do not even have the assistive technology that lots of disabled people need in order to use computers. For example, somebody who is blind may need a screen reader to read and fill in job applications online. As things stand, a non-disabled person can walk into a jobcentre and use a computer onsite to apply for a job. Somebody who uses assistive technology cannot do that. That is why Sense is calling for every jobcentre in the country to be equipped with assistive technology, which would cost around £5 million.

Q106 Sir Desmond Swayne: I asked the last panel if it was a problem that the employment disability statistics, which inform Government policy, rely on self-declaration, and they thought it was. My question to you, unless you disagree with them, is what can we do about it? Is there a solution that is not intrusive, bureaucratic and at disproportionate cost? In any order, but do not all speak at once.

Alison Thwaite: Down's syndrome is a diagnosed condition. Somebody does not go to a job interview and not declare the fact that they have Down's syndrome. We support that process. We have a person-centred approach, where we talk to an employer on an individual level. Imagine a big hotel chain. We talk to the hotel manager, and the work officer builds a relationship with them. We talk then about a candidate who we know well, who we have spent a bit of time with and who we have vocationally profiled. The approach is very person-centred and one to one. Of course, we disclose that we want to develop an opportunity for someone who has Down's syndrome. It is a very open process; nothing has to be disclosed, because we have already disclosed it and, with the permission of the candidate, we have also disclosed any additional health conditions or preferences they may have. That is the position with the DSA. I will hand over now.

Georgia Harper: We are certainly grateful that, in recent years, autism has been included in the labour force survey and in the annual population survey. That has given us statistics we have not really had and has highlighted some of the worst gaps among all disability groups. So I definitely understand the importance of data.

However, I agree with the previous panel about potential issues of undercounting. You mentioned the issue of people, for understandable



reasons, choosing not to disclose, which will always be the case. Our research has found that about one in 10 autistic people who are in work do not disclose to anybody at work, and only about a third are fully open to everybody in their organisation—

Sir Desmond Swayne: But what is the answer? Is there one?

Georgia Harper: Honestly, some people will always choose not to disclose. I mentioned the assessment crisis, and getting more people diagnosed would go some way towards addressing this. Otherwise, it may just be about having that awareness that any statistics we collect are likely to be an undercount.

Evan John: Yes, like Alison was saying, a lot of the people we support have diagnoses, so self-identification is not much of an issue for us. We would not necessarily have a strong opinion about it.

Q107 **Selaine Saxby:** Good morning. Some barriers, such as the transport network and access to NHS treatment, vary across the country—for example, in rural communities like my own or in more deprived areas. Do we pay enough attention to this point?

Alison Thwaite: Travel, training and transport to work are certainly a factor for some of the people we work with. Access to Work is a great resource, and we are a huge fan of it in terms of people accessing support to get taxis to and from work—certainly for the group we work with. So, yes, we would welcome anything to enhance services in rural areas.

Georgia Harper: Yes, I am inclined to agree with you that it often gets overlooked. Certainly, assessment waiting times are a huge postcode lottery. We are in the process of obtaining replies to freedom of information requests, which so far show that the median waiting time for children ranges from three to five months up to four and a half years, and for adults from just under six months to up to five years. So there is real variation there.

On some of the other barriers, I know we will come on to remote working a bit later, but that can be difficult for autistic people, particularly in sectors that are concentrated in London and other big cities, where housing is limited and living in close quarters with strangers is often expected. That, again, can limit your options.

Evan John: One important thing to mention here is the role of social care in supporting work. We found that one quarter of people with complex disabilities who receive social care need it to go to work, to volunteer or to take part in education or training. That includes informal support, but also formal support from social care services.

As things stand, social care is under huge pressure. If you are in work and you draw on social care, you need consistency; you need to know that the person will arrive at the right time so that you can get to work



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on time. But if there is a staffing crisis, that often does not happen. Last year, we found that over the previous 12 months one third of people with complex disabilities who used social care had experienced staff shortages and a quarter had experienced cuts to services. It is quite possible that that has an impact on somebody's ability to work.

Q108 **Selaine Saxby:** There is currently a campaign to allow blue badge holders to use e-scooters and other such electric vehicles on roads. Do you support this campaign?

Alison Thwaite: It is probably less relevant for the cohort of people that I work with, so I will let the others answer.

Georgia Harper: Again, I am not familiar with the detail of it. Certainly, we know that, again, autistic people often struggle to access blue badge support in the first place, autism being a hidden disability. But I am not familiar with the detail of the policy.

Evan John: Same. It is not something we have worked on.

Q109 **Selaine Saxby:** The Government says the rise in remote working will make it easier for some disabled people to work. Do you agree, and are there enough of these jobs to make a difference to the disability employment rate?

Alison Thwaite: For people who have Down's syndrome, remote working is not usually an option. They need to be in a workplace with workplace buddies, and that is a scheme that we support. They need that interaction regularly; they need somebody there doing their training in person, face to face, and somebody there as a workplace buddy supporting them and helping them to grow in confidence and to be more comfortable at work.

We have a small number of people who do some assembly work at home and a young man who does accessibility testing on websites for people who have learning disabilities. But, generally, working from home is not an option for somebody who has Down's syndrome.

Georgia Harper: For the people we support, remote working has been a bit of a mixed bag. It is a game changer for a lot of autistic people, and particularly those who struggle with busy, noisy, open-plan offices. But it really is not suitable for everyone or, as the previous panel said, for all sectors.

Some of the advantages include, again, being able to control your sensory environment, being able to avoid a potentially inaccessible commute, being able to avoid distractions, and being able to avoid having to mask autistic traits all day. However, it is hard to find fully remote jobs these days. Some employers are willing to make adjustments, but even then jobs are often still advertised as in a location. People have very different definitions even of the words "flexible" and "hybrid". Autistic people will tend to take things literally. If a job is advertised in a way that



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is inaccessible to them, they are more likely to think, “It is not for me,” rather than doing what is perhaps expected but not necessarily made explicit, which is asking and negotiating.

Remote working is not a magic wand. There is still a lot of social interaction; even video calls are still social and can still present challenges. Remote working does not remove other challenges that the person might face—for example, anxiety around uncertainty. Some, as Alison said, find remote working and online communication platforms difficult, particularly those who have learning disabilities or those who speak few or no words. As the previous panel said, remote working is also not feasible in a lot of sectors. Bus drivers cannot work from home. That is also true of many entry-level jobs—things like retail and hospitality, which are how many people, not just disabled people, get their foot in the door. We also need to work to ensure that those sectors are accessible so that disabled people have a chance to get their foot in the door.

Evan John: Yes, I agree with everything the panel has said so far. Some of the discussion around flexible working and remote working has perhaps oversimplified the barriers faced by people with complex disabilities. Disabled people themselves would not recognise the characterisation that we have seen a transformed world of work.

Working from home is not a panacea. It does not address any of the barriers lots of people face, such as negative attitudes; that will not be changed by somebody working from home. It is true that, for some people with complex disabilities, the growth in working from home has been a game changer, but disabled people are varied and they have different needs. Working from home is not the answer to loads of people’s problems.

The Institute for Fiscal Studies have concluded that it is not clear that disabled people have particularly benefited from a shift to home working. The ONS has found that disabled employees are only marginally more likely to work exclusively from home. Half of disabled employees say that they cannot work from home and they have to physically go into a workplace.

So remote working is not the answer. We should definitely encourage it, but it is not the answer. We definitely want to avoid employers abdicating their responsibility to make workplaces accessible. If the default is that disabled people work from home, that is a problem on two counts. First, loneliness and difficulty building relationships are a huge problem for disabled people. Going into the workplace has much wider benefits than simply doing a job; it allows people to build relationships with other people, and disabled people should have the opportunity to do that as well.

Secondly, employers have a responsibility to make their workplaces accessible to disabled people. We would worry if employers, rather than



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installing a lift, were telling disabled people, “You can work from home.” It should always be a choice for disabled people.

Chair: Thank you very much. I will change the order slightly here and bring in Debbie Abrahams. Debbie has to leave a bit early.

Q110 Debbie Abrahams: Can I ask a question that flips this on its head a little bit? The focus of our inquiry has been around what the social security system can do and what individuals can do to make themselves more employable. But based on what you have said, what do we need to do to enable employers to be more supportive? Do we need to encourage a cultural change? What would that look like? Do you talk with any of the employment organisations like the Federation of Small Businesses or the CBI, for the larger organisations, to proactively look at how to change employers’ attitudes towards disabled people?

Alison Thwaite: We have had contact with different organisations like that. We tend to get a positive initial response, but then not everybody follows up with that.

At the DSA, we look for employers who are committed to doing this because they understand that a diverse workforce is a strong workforce. It is really important that we get that message across. I know we will come on to the mandatory reporting, but we do not want to work with employers who do these things because they feel that they should. We want to work with employers who are genuinely interested in welcoming a diverse range of people into their workforce.

In the past we have networked with different business organisations, but we now tend to focus more on employers. We have a strong network of employers, and word of mouth has been a huge thing. They have talked about having an experience with WorkFit that has gone incredibly well. That has spread throughout the organisation. If they are a national organisation, other branches want to get involved. They say, “We want to do this. We have seen this success story.”

For us, it is a lot of word of mouth, sharing our success stories on social media and letting people see what we can do. We provide an awful lot of support to employers. It is all free of charge. Everything is funded through the Down’s Syndrome Association as a charity.

That is more powerful to us, to be honest, than going through the business networks. Yes, we can raise awareness, but we work with a fabulous group of employers who do that on our behalf and nominate us for awards and various different things.

Georgia Harper: First, we recently supported Sir Robert Buckland’s autism employment review. I would signpost that for a series of recommendations for employers and the Government.

Beyond that, we need a culture change and particularly—we talked about this a lot in the review—universal design. Rather than waiting for



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somebody to come forward with a diagnosis, we need think about what we can do in general for all employees to make work more accessible to all. Of course, we will always need individual adjustments, and I know we will come on to that later. That can include changes to the sensory environment and considering alternative recruitment methods.

Looking more widely, the Government have a real opportunity to lead by example. We are a research charity, but we would like to see more pilots of best practice and to have the Government working with employers of all sizes. We have had some good initial conversations with the Recruitment & Employment Confederation and Adecco on the recruitment side.

Echoing the previous panel, work coaches do not necessarily have a good understanding of autism and neurodiversity. We would like to see more training in that area.

Again, picking up on something that Alison said earlier, sometimes there is a lack of clarity in the autistic community on autistic people's position on the Equality Act 2010, because not all autistic people identify as disabled. We would love to see more guidance in that area.

Evan John: I said before that 44% of employees with complex disabilities experience bullying and harassment in the workplace. Clearly, there is a problem with attitudes towards people with complex disabilities. Employers need to do more to make sure that workplaces are inclusive of disabled people.

Also, not all employers are willing to make reasonable adjustments. Some 12% of employees with complex disabilities say that their employer has not been willing to make reasonable adjustments.

It is also worth talking about progression, as well as retention. Sometimes the perception is that you get a disabled person into a job, and then they are happy to be there and they stay. Actually, disabled people have aspirations, they have training and they want to contribute to a workplace. Our research has found that half of people with complex disabilities in work have taken on less challenging jobs because their needs have not been met as a disabled person. Clearly, employers need to do more to recognise what people with complex disabilities bring to the workplace and how they can progress in that career.

Finally, on the point about working with employers, this is something that Sense does a lot at a local level. For example, we have employment services in Birmingham and Loughborough. Today we have a pan-disability jobs fair, which people from across the country are visiting to speak with employers about jobs.

Q111 **Debbie Abrahams:** Fantastic. In terms of the out-of-work employment support that members of your organisations access, how is that going? Could I ask you for brief answers?



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Alison Thwaite: Do you mean things like support from Jobcentre Plus?

Debbie Abrahams: Yes, the Work and Health programme and that sort of thing.

Alison Thwaite: I can keep that brief. The cohort of people we work with do not tend to access the Work and Health programme, WorkWell or anything like that. I am not aware of anybody in the group of people we work with who has had a job opportunity through Jobcentre Plus.

We did develop a work opportunity in a jobcentre. Somebody went in and did an admin role for three months. She did well but, unfortunately, there was not a vacancy at the end of that.

So our candidates have not had a lot of exposure to Jobcentre Plus and they have not had any outcomes that I could share with you.

Georgia Harper: The National Autistic Society recently piloted their autism accreditation framework, working with DWP, in a limited number of jobcentres. The Government intended to roll that out, but we are still waiting for an update. So, yes, we welcome news on that side.

On wider support, what we heard in the Buckland review was a bit of a mixed bag, particularly around the understanding of autism from work coaches and that sort of thing.

Evan John: It varies. Some people have had a positive experience of disability employment advisers and work coaches, but that is not universal. As I said earlier, over half of jobseekers with complex disabilities do not feel supported by their work coaches. That is a big problem if you are trying to support those people into work. Similarly, 46% of employees with complex disabilities do not feel supported by their disability employment advisers. Clearly, if they are meant to be the specialists, that is a huge problem.

One reason is that training does not cover things like disability equality for work coaches. I have the training guide here for work coaches and disability employment advisers, but topic guide does not mention disability for work coaches. A lot of the focus is on complex needs, which of course is great, but someone supporting somebody who has complex disability needs to understand the barriers they face. We have been working with the DWP on this, but from what we can see there is not enough training for work coaches.

Alison Thwaite: A number of jobcentres have reached out to us and asked us to do training for them, which we are happy to provide. We are working with them. Signposting a lot of those DEAs to specialist providers like the Down's Syndrome Association is a good way to go, because we probably cannot expect them to have that breadth of knowledge about all the different disabilities out there. We are very happy to provide that service.



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Q112 **David Linden:** I will be very brief. First, how many disability employment advisers have a disability? Do we know that?

Evan John: We did a parliamentary question on this a while back. I cannot remember off the top of my head, but it was about in line with the population. We were quite surprised.

Q113 **David Linden:** Interesting. In terms of my main question, we have done some good work on getting people with disabilities into work. How do we sustain that? One thing we have spoken about is reasonable adjustments. What reasonable adjustments help the groups that you represent today—people who have Down’s syndrome, who are autistic or who have a sensory impairment? How willing are employers to make those adjustments now? Evan, you mentioned earlier that 12% had refused them. Can you give the Committee a bit of a flavour of reasonable adjustments that we expect employers to make for somebody? We will start with Down’s syndrome.

Alison Thwaite: The main one is flexibility. We encourage them to be flexible around shift patterns and break times and to consider how somebody will travel to work. We help them with job carving; we might look at all the different entry-level jobs in a particular team or area, and we might help them to carve a role. We would take elements from different job descriptions and bring them together in a new job description.

We would look at the number of hours that somebody can work. The majority of people who have Down’s syndrome would not initially be able to work 16-plus hours, so we might start with one shift of four hours and then over time increase it to two shifts, three shifts or whatever somebody is comfortable to do. As that person becomes more confident in the workplace, we can increase in line with that.

It is about employers being open to suggestions. They are often open to our ideas about reasonable adjustments. If somebody has limited verbal skills, they might need some communication tools or communication cards. Do we want to do a checklist or a timetable for them? There are so many different reasonable adjustments that are simple and straightforward. We can provide employers with all those templates and the information, work with them to create those things and work with their designated WorkFit officer. It is really about just being open and flexible.

We would have employers do a site tour rather than a formal interview. People with learning disabilities feel pressured and do not respond well to formal interview processes. We have somebody come in, have a wander around and look at the different jobs onsite. People relax and have a casual chat. Mum and dad will usually come along, as well as a WorkFit officer.



It is about getting employers to think differently and, more importantly, to see that person as an individual. Everything that we do is person-centred; it is about that employer talking to that individual, making a connection and understanding their needs. That employer can then think, “How am I going to get the best out of this person? Everybody has skills, talents and abilities. How am I going to get those skills from this person and make them an asset in my organisation?”

Q114 David Linden: Ms Harper, can you talk about reasonable adjustments that we would expect employers to make for autistic people?

Georgia Harper: For autistic people, it varies quite a lot. Before I forget, let me say that, in our research around disclosure, the most common time for autistic people to disclose that they are autistic to their employers is after they have started the job. Again, I emphasise the point about making the recruitment process, in particular, accessible without waiting for someone to come forward.

On reasonable adjustments, again, flexibility is a huge one. Others include providing or allowing the person to use sensory aids like noise-cancelling headphones or stim toys; having a fixed desk if the organisation usually revolves around hot-desking; having instructions provided in writing; giving meeting agendas in advance; and perhaps giving interview questions in advance for recruitment—I saw the other week that John Lewis have announced that they are doing that, which is welcome.

Often it is about things that are not complicated or costly. Despite this, though, many people are denied adjustments. There is still a bit of a stigma around requesting adjustments. In the survey we did, around one third of autistic employees did not request adjustments but would have found them useful. As I mentioned, there is often confusion around the Equality Act, and autistic employees might not be sure that they count—for want of a better word—and that they are allowed to ask for adjustments. People fear repercussions. Sometimes the pathway for asking for adjustments is unclear. Sometimes there is a lot of worry about a perceived detrimental impact on others.

Of the autistic employees who requested adjustments, over a quarter were refused and more than one in 10 told us the adjustment was poorly implemented—that is, it was something they had to keep fighting for it. As the previous panel mentioned, sometimes this relies on individual line managers and, when they move on, the fight has to start all over again.

Q115 David Linden: Mr John, do you want to add anything in terms of sensory impairment?

Evan John: I agree with everything the panel has said so far. One thing to bear in mind is that external factors will often constrain whether somebody can make reasonable adjustments. I am thinking particularly of Access to Work. The best employer in the world can want to put



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everything in place for their employee, but the Access to Work backlog is at about 25,000, which means that some people have job offers withdrawn. We will get on to that later, but it is also a matter of whether employers can make these adjustments.

Q116 David Linden: I will do a quick question, and I want just a yes or no answer, because I know we are up for time and I do not want to upset the Chairman. Do you support the introduction of mandatory disability workforce reporting for large employers?

Alison Thwaite: No.

Georgia Harper: In theory, yes. We have seen how disclosure is difficult.

Evan John: Yes, we are in favour of anything that improves transparency and helps to hold companies to account, but we do not have a strong position on whether it should be mandatory.

Q117 Nigel Mills: We have just got to Access to Work, so perhaps you can tell us your thoughts on how well it is working and what should be changed.

Alison Thwaite: We find Access to Work incredibly helpful. The majority of our candidates use it for taxi costs to get to and from work. A lot of people who have Down's syndrome may not travel independently, or they may need time to learn a bus route or a train route. Having that taxi service initially is hugely beneficial.

We do not use job coaches at WorkFit. We ask employers to designate two or three workplace buddies in their team to support the person. Initially, employers are a little bit daunted by that, but then we reassure them that we provide the training. Few people using WorkFit apply for job coaches, so I could not comment on that.

Generally, we are huge fans of the concept of Access to Work. The online portal makes a big difference to the speed of processing applications because, as we all know, there is a bit of a backlog. It is positive that that has been changed.

In terms of having to reapply every three years, somebody with a Down's syndrome diagnosis will not change. It would be helpful if we could possibly remove the need for them to reapply.

Georgia Harper: In terms of the people we have spoken to, I would say, very much echoing the previous panel, that Access to Work is generally viewed positively when it works, but not enough people know about—awareness is poor. The initial set-up is often quite difficult and is not necessarily accessible and, as we have heard, there are long delays.

The recent announcement of enhanced Access to Work packages and, in particular, access to mental health support through Access to Work is particularly welcome. Autism is not a mental health condition, but eight



out of 10 autistic people experience mental health conditions, so that could be particularly beneficial for our group. Mental health support is often quite patchy for autistic people, and sometimes traditional approaches need to be adapted. It will be interesting to see how those changes can be made once we get the detail on that.

Evan John: I agree with everything the panel has said so far. Unsurprisingly, we think that Access to Work is a brilliant scheme. It is a real enabler of work for a lot of people with complex disabilities, but not enough people know about it. Our research has found that half of job seekers with complex disabilities do not know about Access to Work, which is quite a big problem.

Recently, Access to Work has been digitalised. That is quite new. I was speaking yesterday to my colleague who is deafblind. He was saying that that has completely transformed his experience. It used to be the case that his application form and claim forms were all paper, which meant that his supporter had to do everything for him—copy receipts and sign things—because he was not able to do that, as somebody who is blind. Now he can do it completely independently over the computer. It has made a huge difference to him.

Q118 **Nigel Mills:** Do you have any experience of the new health adjustment passports? Have they made a difference, or have you not seen them yet?

Georgia Harper: We do not have a lot of experience with those, no.

Evan John: No, we do not have much experience, but anything that helps people get reasonable adjustments is positive.

Q119 **Marsha De Cordova:** Good morning, everyone. What impact has the Disability Confident scheme had on disability employment rates?

Alison Thwaite: My understanding from recent research is that it has not had much of an impact, sadly. It is a great concept and a great scheme, and a lot more could be done with it. It perhaps needs a little bit more bite and a little bit more accountability. It is generally welcomed, and it is a great idea, but it needs a little bit more depth.

Georgia Harper: Yes, I agree. It is fair to say that Disability Confident was viewed less positively by the stakeholders we spoke to through the Buckland review—autistic people and employers alike. It is often seen as a bit of a tick-box exercise that does not necessarily translate into the practical changes that the scheme intends. As Alison has said, it does not necessarily translate into employment of disabled people.

The Buckland review recommended increasing the rigour of the assessment and developmental work needed to achieve those higher levels, which we support. I understand that the Disability Confident scheme more widely was under review, and I look forward to seeing any updates that come out of that.



Evan John: Yes, we agree. We hear a lot from disabled people that it is seen as a tick-box exercise that does not often have any meaningful impact for disabled people. As the panel has said, there is a lot of self-assessment in the current scheme, so employers can say a lot about what they have done for Disability Confident, without actually employing disabled people or providing evidence of those changes. We favour making the whole process more robust and making sure that any review is not just focused on employers but is informed by the experiences of disabled people and disabled employees.

Q120 **Marsha De Cordova:** To overcome that, would you see independent evaluation as a better approach than self-assessment?

Evan John: Yes, that would definitely make a difference. At the moment, it is at level 3. Another level 3 organisation carries out the audit process, rather than—

Marsha De Cordova: So independent, then?

Evan John: Yes. We would agree with that.

Georgia Harper: On the neurodiversity front, Autistica are currently in the process of launching our neurodiversity employers index, which aims to provide a framework for assessing and becoming more accessible to neurodivergent employees or would-be employees. That is currently open for employers to sign up to and will launch in the summer.

Alison Thwaite: For employers as well, we talk about diversity inclusion a lot. We should talk about diversity equity, inclusion and belonging. We need to expand all that and help employees to understand those concepts.

Q121 **Siobhan Baillie:** I am after opinions about the programmes that were announced this year or last year about universal support and WorkWell. What are your experiences and your opinions from your involvement?

Evan John: We have not had much experience of it, but we support anything that means that disabled people get more support to find work. I have already highlighted how a lot of work coaches do not have the skills they need to support disabled people. While we support work coaches having more time with disabled people, if the training does not change, it will not have the impact it could have.

Georgia Harper: Likewise, I do not have a lot of direct experience with this. Autistica are a research charity. We do not directly provide services, which is why some of my more practical experience is limited.

Universal support was announced by the time the Buckland review was being written up. There is a recommendation in there to ensure that that meets the needs of autistic people, perhaps including supported employment.



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In general—and I know we will potentially come on to some of the benefits changes in a minute—the Government unfortunately have a bit of a habit of framing punitive measures as support. That creates distrust and makes it quite difficult to encourage people to apply for the support that is there. That was mentioned on the previous panel, regarding Access to Work. That is a more general point.

Q122 **Siobhan Baillie:** Alison, I suppose it is wraparound support with universal support.

Alison Thwaite: Yes. What tends to happen is that our members have been through Jobcentre Plus and various Government schemes and Departments, and they come to us. Ideally, they get a permanent paid job with us. Of the people who get jobs through us, 92% stay in work, so our retention rates are really good. The people we work with get to us and then do not tend to look for anything else, because, ideally, we have found them the job that they want.

Q123 **Siobhan Baillie:** For Down's syndrome specifically, do third sector organisations make more of a difference than jobcentres or DWP?

Alison Thwaite: The fact that we are a specialist provider makes a huge difference. We place people in the private sector. We have just gone up to 80% in the private sector. Some 80% of our jobs are with private sector employers. Our retention rate is at 92%, which we are very proud of.

People have tried lots of different things, maybe been a little bit disappointed with the provision in education, maybe been a little bit disappointed with Jobcentre Plus, and have come to a specialist provider like us. We understand the condition of Down's syndrome. We understand how people learn and how they communicate effectively. We are able to address the apprehensions, and concerns perhaps, of an employer and to give them the training and all the information they need. We bring those two parties together, with a lot of ongoing support. We find that a very effective model.

Q124 **Neil Coyle:** Hopefully, you heard the earlier panel outline their concerns about the fear that has been created for many people by the proposed changes to the work capability assessment. What impact will those changes have on the number of disabled people engaging in work?

Alison Thwaite: We know that benefits and assessments are worrying for the people we work with and their families. We know that a lot of the things that they have are hard won. They have been through lots of battles.

In our view, having the PIP assessment and not having the work capability assessment is the way to go, if that was a possibility and that could happen. The PIP assessment is thorough, and the families are comfortable with it and used to it. Our preference would be just to have a PIP assessment.



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Georgia Harper: From our side, as was mentioned by the previous panel, there is a mismatch between the assessment descriptors and what in practice is required of somebody to do the jobs that are available. Often, there is a focus on punitive measures for people who are, through no fault of their own, shut out of the workforce. Most autistic people do want to work.

The situation is worrying for a lot of the people we support and for a group that struggles particularly with uncertainty. The nature of a lot of policy reforms in general is big headlines in the press, with details coming a lot later. As the previous panel said, people are not necessarily aware that this is not legislation yet and that the process takes a long time. That drawn-out anxiety is particularly difficult for autistic people.

Again, it is not an area we work a lot on. My concerns are more about the narrative it feeds and how that ties into wider attitudes around disabled people and autistic people not trying hard enough, with the knock-on effects that has in other areas, including when seeking reasonable adjustments at work.

Evan John: First, we tentatively support the proposal to ultimately get rid of WCA, because the WCA causes stress and anxiety for lots of people.

We are concerned about the proposal to make it harder to go into the LCWRA category, because that would, of course, lead to fewer people getting that extra support, which is about £300 extra a month. The main impact of that will be fewer people receiving that extra support, rather than necessarily being pushed into work.

Q125 **Neil Coyle:** If I could turn to support and jobcentres, you have each made a point already about this. Alison, you mentioned some training that you gave to a disability employment adviser at one jobcentre.

Alison Thwaite: It was to a team of people there. I contacted them to talk about WorkFit and to ask whether they would be interested in developing an opportunity with our support. I outlined all the support we could offer, and they said, "Yes, we are absolutely open to doing that." We developed a 12-week part-time admin role for a local woman. She went in and did the job successfully. Unfortunately, they could not offer anything longer term.

Q126 **Neil Coyle:** Not on that occasion. I think the 92% statistic is strong. Did the jobcentre pay you for providing that training?

Alison Thwaite: No, everything we provide is free of charge, both to our candidates and to employers. We are funded through the Down's Syndrome Association.

Neil Coyle: You are not commissioned to do it?

Alison Thwaite: We are not. We get no Government support.



Q127 **Neil Coyle:** Is something missing here? Georgia, you also mentioned training for jobcentre disability employment advisers. Is there not a requirement on jobcentres to make sure they are accessible? Evan, you made the point about assistive technology as well. Are jobcentres not particularly good at being accessible to disabled people, if you have to supplement with additional training and support?

Georgia Harper: A lot of the issues around jobcentre accessibility are similar to those that we see in public spaces generally—schools, healthcare providers and so on. There are baseline requirements to be accessible in terms of the Equality Act and so on, but the needs of autistic people are not necessarily what people think of when they think about disability access. There is a bit of an education piece there, which I know that some jobcentres have been doing, and I would welcome it being rolled out. But, yes, there is a bit of a gap between what, theoretically, is required universally and what works in practice for the groups represented on the panel here.

Q128 **Neil Coyle:** Is the question not a bit beyond this? On one level, it might be understandable if jobcentres just reflected every other workplace, but on another it is unacceptable because of the higher proportion of disabled people who are meant to be supported in those specific sites.

Georgia Harper: When I say it is reflective of the wider world, I mean it is a problem everywhere. I do not mean it is okay.

Q129 **Neil Coyle:** I understand. Evan, on assistive technology, did you say it is £500 per jobcentre?

Evan John: It is £5 million for all jobcentres in the country. That includes screen readers, which help people who are blind or visually impaired to access computers. It includes headphones and refreshable Braille displays, which some blind people use to read computers as well. Some money would be left over to allocate to each jobcentre to spend on local needs.

Q130 **Neil Coyle:** If jobcentres are not accessible for disabled people and they are not able to support disabled people in what they do routinely, why has none of your organisations sought a challenge under the Equality Act?

Alison Thwaite: From our point of view, we provide this service, we get people into work and we circumvent the Jobcentre Plus because we—

Neil Coyle: If people can find you.

Alison Thwaite: Yes. We have quite a strong membership. More than 20,000 people are members of the DSA; a lot of what we do is word of mouth, and that is families. Maybe a young person gets a job through us and talks to their local Down's syndrome support group.

Q131 **Neil Coyle:** Is there a risk that the Department for Work and Pensions is failing in meeting its legal obligations to ensure its premises and staff are



accessible to the people they are meant to support into work?

Evan John: Yes. Some jobcentres are fine, and some work coaches are great, but overall it is simply not good enough. We have shared some horror stories of people missing appointments because they are blind and they stand waiting for somebody to tell them where to go, or somebody points them in the right direction without noticing that they are carrying a cane and are blind and cannot see the directions. We have clear examples of that. I mentioned that about 50% of people do not feel trusted by their work coach, which is a clear example of how jobcentres are not working for disabled people. Yes, charities like us and the Down's Syndrome Association often pick up the pieces when the jobcentres do not do what they should.

Q132 **Neil Coyle:** Does the Department need to get its own house in order and to make sure that the support is in place through the schemes that have been touched on, like Access to Work and some of the newer programmes, like Universal Support and the IPS scheme, before the Government bring forward further cuts for disabled people?

Evan John: Definitely, there needs to be more emphasis on what the Government can do to support disabled people. Currently, the emphasis is often on disabled people themselves, rather than on the barriers they face and on employers and what the Government provide.

Alison Thwaite: I think employers have an appetite to embrace that and recruit more diverse people, but the barriers are still there.

Georgia Harper: That very much chimes with what we hear. A lot of employers want to do more and to do the right thing, but they do not know how or they do not want to be the first to put their head above the parapet. Yes, the appetite is there, but more support is needed.

Q133 **Chair:** Alison, is it your normal experience that a person with Down's syndrome can be placed in a job with WorkFit?

Alison Thwaite: Yes, absolutely. We believe everybody can work if they want to work, if they are motivated to work and if they have the right position.

Q134 **Chair:** At the moment, we have a 30% employment rate or less?

Alison Thwaite: For people who have learning disabilities, the percentage is 4.8% in paid work. Our figures are much higher. We have had considerable success with WorkFit. We are working towards our 1,000th job opportunity. For learning disabilities overall, it is only 4.8%, which is dreadfully low.

Q135 **Chair:** Of the people who come to you, what proportion do you get into a job?

Alison Thwaite: The vast majority when we can work with them. We have a waiting list of people who want to work with us. We work across



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England and Wales, and we are only a small team. The DSA is not a huge charity by any means. We rely on funding allocated to WorkFit, but we have a lot of other major projects in the DSA on health, education and all those things. We could do a lot more if we were Government funded, for example. We are very proud of that 92% retention rate.

Chair: Yes, quite rightly. That was very interesting. Our time is up. Thank you very much indeed to all three of you for coming to talk to us.