**Government must rewrite its National Disability Strategy, court is told**

The government could be forced to rewrite its National Disability Strategy, if four disabled campaigners are successful in their bid to persuade the high court that the document is unlawful.

Yesterday (Wednesday), their legal team attempted to persuade the court, through a judicial review, that work and pensions secretary Therese Coffey failed to carry out a lawful consultation before publishing the [cross-government strategy](https://www.gov.uk/government/publications/national-disability-strategy) in July.

The high court heard that the four claimants – Miriam Binder, Jean Eveleigh,Paulley and a fourth campaigner – had expressed “anger, frustration and disappointment” over Coffey’s claim that she did not have a legal duty to consult with disabled people on the strategy before publishing it, and that she had chosen not to do so.

They believe that the UK Disability Survey, which the government carried out in January and February this year, was intended to be a consultation on the national strategy but that it was an unlawful one.

They have also highlighted the failure to consult disabled people’s organisations (DPOs) on the strategy, which they say was “conspicuously unfair”, and they argue that the way the survey was carried out breached the government’s public sector equality duty under the Equality Act.

They believe that the process of engagement with disabled people and their organisations in developing the strategy was “grossly inadequate”, the court was told.

Now they want the court to order the government to devise a new, lawful consultation process in conjunction with disabled people and disabled people’s organisations (DPO) and then produce a revised national strategy.

When the strategy was published in July, [outraged DPOs described it](https://www.disabilitynewsservice.com/national-disability-strategy-outrage-over-rehashed-strategy-that-is-not-fit-for-purpose/) as “tokenistic” and “rehashed” and said it was “not fit for purpose”, not developed in co-production with DPOs, and failed to tackle the growing poverty, exclusion and discrimination disabled people face.

In his written evidence to the court, one of the four, Doug Paulley, said the survey was “flawed in both form and content”, while the multiple-choice format of most of the survey “was deeply frustrating” and “did not provide any opportunity to describe the specific barriers I faced in my life, or to provide suggestions as to how these barriers could be reduced or eliminated”.

His legal team showed how the government had referred to the survey as a consultation on “multiple occasions”, including describing it as an “open consultation” and referring to it in a blog as “part of our ongoing consultation”.

Sarah Hannett QC, representing Coffey, admitted that there was “perhaps some unfortunate language referring to consultation”.

But she argued that the survey was only an “information gathering exercise”, designed to gather data about the lives of disabled people, and not a consultation on the proposed national strategy.

She suggested that the strategy was “best described as a framework” and was “never intended” to include every disability-related policy or legislative proposal that the government will take forward.

Hannett described the National Disability Strategy as “a bucket” in which the government had dropped “a mixture” of “some firm policy commitments”, some proposals that would be tested, and other potential policies that would be put out to consultation.

She suggested that it had not been appropriate to carry out an overall consultation on such a wide-ranging strategy containing so many proposals, and that consultations would be carried out on some of the individual proposals “in due course”.

But Steve Broach, the barrister for the four disabled claimants, who are also represented by [Bindmans solicitors](https://www.bindmans.com/), said the survey had taken place “in the context of a concrete commitment to publish a strategy and with the express purpose” of obtaining views about what should be in it.

He said it was an “unsustainable” argument for the government to suggest that the survey “was anything other than a consultation” and he said it was “inconceivable” that the government would publish a national strategy about any minority group without carrying out a proper consultation on it.

He added: “It is crystal clear that this was a consultation, not merely a gathering of information.”

He added later: “It is not a mere information-gathering exercise. Its purpose was to check whether what was proposed by the strategy was right.

“All of the survey is about what should be in the strategy.”

Broach told the court that the four claimants were “particularly aggrieved” that most of the survey had been in a multiple-choice format, so restricting how they could respond.

He also pointed out that there had been no way for people with learning difficulties and others who wanted to respond to the easy read version of the survey to send their response to the government.

Broach told the court that “nothing about us without us” was a “vital principle for the disabled people’s movement”, and the government had failed to follow that principle.

He also said that many disabled people were in a “disadvantaged” position and so were not able to make their views known directly, and so the government’s failure to consult formally with DPOs – which could have responded on their behalf – was “conspicuously unfair”.

Hannett said that the government did gather views from some DPOs through a wider engagement exercise, which included round-table events.

The judge, Mr Justice Griffiths, said he would deliver his judgment at a future date.

**4 November 2021**

**Multiple access failures at COP26 ‘send shocking message’ to disabled people**

Disabled campaigners have raised serious concerns about the UK government’s multiple failures to ensure the accessibility of the COP26 climate change conference in Glasgow.

The first concerns came after high-profile complaints made by the Israeli energy minister, Karine Elharrar, a wheelchair-user, [who was unable to access the conference venue at all](https://www.theguardian.com/environment/2021/nov/02/wheelchair-using-minister-denied-entry-to-cop26-venue) on Monday and had to return to her hotel.

She told journalists that the vehicle she had arrived in was not allowed inside the compound, despite her delegation apparently informing organisers of her access needs in advance of the conference.

The shuttle bus she was offered instead was not wheelchair-accessible, she said.

A government apology for the “confusion” was made directly to Elharrar by prime minister Boris Johnson the following day.

But Disability News Service (DNS) has learned of a series of other access concerns that have since been raised, including an apparent failure to provide British Sign Language (BSL) interpreters and captions for COP26 broadcasts.

It has also heard from Jason Boberg, of the [SustainedAbility Disability and Climate Network](https://www.sustainedability.org/), who said he had been unable to enter the conference on Tuesday morning because the accessibility entrance had been closed.

He said this was “extremely unfortunate” and had caused injuries to some of his colleagues.

Boberg was forced to wait until the afternoon when the line reopened so he could enter the venue “which meant for the morning of the first day I was unable to access COP”, although he said it had been working well since then.

He said this showed the need for the UK government to “really understand the need for full participation” of disabled people, as described in the UN’s Convention on the Rights of Persons with Disabilities.

He said SustainedAbility had been in discussions with the COP26 team since the beginning of the year and had repeatedly made clear its concerns about accessibility issues with the venue.

Boberg said they had “made the point that a disabled person that has experience within the COPs over multiple years needs to be on the ground here assessing the accessibility requirements, as accessibility Is extremely difficult to get right at the COP”.

He said: “We are hoping these unfortunate circumstances shed light on the need for disability representation and accessibility.

“How are we supposed to get our rights included if we can’t get into the venue?”

He said SustainedAbility had been working for the last four COP conferences to include the needs and rights of disabled people into the approved conference text during negotiations.

He said: “The accessibility situation for many disabled people is no surprise, but the exclusion of a disabled minister particularly highlights the exclusion of disabled people in the climate change negotiations.

“It’s a physical illustration of why it is so important to have disability rights in the text to make sure civil society and disabled people can fully participate in the negotiations.

“We know that disabled people are left behind in climate disasters, floods and fires, and now we are left out of the conference that is supposedly meant to address that.

“This is an international disaster for disability rights.”

[Inclusion Scotland](https://inclusionscotland.org/), which will be taking part in an official COP26 event tomorrow, said it was “appalled” at what had happened to Karine Elharrar.

And it said it had seen no evidence of BSL interpretation or captions at the conference.

It said the venue was a “large, well-used events campus” with buildings that were “generally accessible for wheelchair-users”, and entrances which are wheelchair-accessible.

But it said that the way the event had been set up meant that Elharrar could not access the conference.

Heather Fisken, Inclusion Scotland’s head of policy and research, told DNS: “This episode sends out shocking message which says that disabled people are not expected to be at decision-making tables.

“That’s nonsense. Even the United Nations [Convention on the Rights of Persons with Disabilities](https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf) (PDF) recognises our right to participate in public life and decisions about us should not be taken without us.

“It is never enough to say that a building is accessible; you have to prepare for and manage the event, and make sure even temporary staff know what to do to ensure access.”

[Lynn Stewart-Taylor](https://twitter.com/jerseysnail), who has led the #WhereIsTheInterpreter campaign, aimed at highlighting the UK government’s failure to provide a BSL interpreter at its televised pandemic briefings, said she was appalled at the failure to provide an interpreter or subtitles for the televised speeches of world leaders from the COP26 conference.

She said this had left her feeling frustrated and panicked at not being able to understand what world leaders were saying about the climate crisis.

She told DNS that Deaf people had yet again been treated unfairly, adding: “It’s another day feeling empty, forgotten, feeling we are not worthy of knowing this vital information.”

The mounting concerns come just three months after the UK government published its much-criticised [National Disability Strategy](https://www.gov.uk/government/publications/national-disability-strategy), which Johnson said at the time was about “our ability to acknowledge and appreciate the contribution that disabled people make to our national life, and to listen and respond to their needs”.

[Dzaier Neil](https://twitter.com/dzaierneil), national convenor of the Green Party’s disability group, and co-equality and diversity officer on its national executive, said there was a “huge” level of concern about the access failings at COP26, particularly as disabled people in many parts of the world were experiencing the worst impacts of the climate disaster.

She said: “Disabled people in terms of climate change are the hardest hit.”

But despite this, she said, disability was “low in the pecking order” of the UK government.

She said the access failures were “highlighting again how this government is absolutely going out to silence disabled people”.

She pointed to the admission by the prime minister’s office [in April](https://www.disabilitynewsservice.com/prime-minister-ignored-accessibility-of-media-briefing-room-no-10-admits/) that it had made no attempt to ensure that a new £2.6 million Downing Street media briefing room would be accessible to disabled people.

Neil said: “The government have made it very, very clear that they want to ensure that disabled people do not have a voice.”

Kamran Mallick, chief executive of [Disability Rights UK](https://www.disabilityrightsuk.org/), said: “A lack of accessibility has nothing to do with ‘confusion’ and everything to do with a lack of the social model of disability being at the heart of government strategy to assure that not only can the 20 per cent of the UK population be able to access everything they need to, but that international ambassadors are also afforded this most basic of human rights.”

He said the government was “out of excuses”, 26 years after the Disability Discrimination Act and 11 years after the Equality Act became law.

The UN Climate Change press office did not respond to a request to comment on the access concerns, including about the apparent lack of subtitles and BSL interpreters on its webcasts.

A spokesperson for the UK government’s COP26 team said on Tuesday: “This was a genuine mistake and we have apologised to Minister Elharrar – we look forward to her attendance at COP26 today.

“We remain committed to an inclusive event accessible to all and the venue was designed to facilitate that.”

The government has claimed that the COP26 permanent structures were “fully wheelchair accessible” and that the venue holds “gold level accessibility status”, although it has not been able to explain what that is, while it claims the temporary structures were found to be “fully compliant” after an accessibility audit.

The government also said there were two fully accessible shuttle routes, and that COP26 has an accessibility support desk.

But the government spokesperson had failed by noon today (Thursday) to explain why Karine Elharrar was unable to use the shuttle service if it was “fully wheelchair accessible”, to explain what “gold level” accessibility is, to comment on the apparent lack of BSL interpreters and subtitles at the conference, or to comment on the further concerns about the accessible entrance.

**4 November 2021**

**Judge highly critical of DWP’s flawed IT systems that helped cause claimant’s distress**

A judge has been highly critical of flawed IT systems that prevent the Department for Work and Pensions (DWP) and one of its contractors from sharing vital information about disabled benefit claimants.

District Judge Lacey told Bournemouth County Court on Friday that it was “very poor indeed” that DWP and Maximus were unable to exchange information about claimants’ past requests to have their benefit assessments carried out at home rather than in an assessment centre.

He was hearing a case brought by Angela Bennetton, a former teacher, who was claiming that Maximus and DWP had discriminated against her by initially telling her in 2018 that she would have to attend an assessment centre for her work capability assessment (WCA).

Bennetton, a wheelchair-user with post-traumatic stress disorder and agoraphobia, who represented herself in court, had requested a home assessment.

But Maximus told her in December 2018 that she would have to visit an assessment centre for her WCA or lose her employment and support allowance (ESA).

It later emerged that her GP had mistakenly ticked a box on an ESA form stating that she would be able to attend an assessment centre.

But it was not until late January 2019 that Maximus told her that it had made a mistake and she did not need a face-to-face assessment.

She was eventually reassessed based solely on paperwork and found eligible to stay in the ESA support group, for those disabled claimants not expected to carry out any work-related activity.

The judge ruled on Friday that DWP and Maximus did have a system in place that allowed reasonable adjustments to be made for claimants who needed them, and that a reasonable adjustment had not initially been made for Bennetton due to error.

He said this was not a breach of the Equality Act and he was satisfied that “systems and action exist that do go far enough to avoid disadvantage that may be suffered” by a disabled benefit claimant.

He added: “I must find that both policy and procedures are in place to make reasonable adjustments and they were made in this case, apart from the mistakes by the GP and [a Maximus healthcare professional].”

But he said these mistakes were not enough to lead to “a finding that the whole process is discriminatory”, although the mistake by the healthcare professional was “unfortunate and should not have happened”.

He said it was a “wholly unsatisfactory situation which has been caused by the mistakes both by the GP and the original [Maximus] healthcare professional”, exacerbated by the time taken by DWP and Maximus to tell Bennetton that she no longer needed an assessment.

But he said that the flawed systems of Maximus and DWP and the “careless” actions of the GP and the healthcare professional do “not equate to indirect discrimination in this instance”.

He told Bennetton that he had to rule that Maximus and DWP had not breached the Equality Act, but he added: “Legally, I have not found in your favour.

“Morally, I completely understand your frustrations.”

The judge repeatedly praised Bennetton on Friday for the “impressive” way she had represented herself through the legal process.

She is now taking advice on a possible appeal.

She had told the court previously that the seven weeks during which she believed she would lose her ESA had caused her anxiety, stress and insomnia.

She was attempting to claim damages for this mental distress.

Bennetton had told the court that she believed there had been indirect discrimination because of the repeated requirement every time she was reassessed to obtain medical proof that she needed a home visit.

She told Disability News Service after the hearing: “The whole assessment system for ESA and personal independence payment (PIP) is undoubtedly seriously flawed, and I’m saying that despite getting a maximum award every time.

“Every assessment I’ve had, when I’ve seen the report I’ve initially thought it was for someone else.

“Even when the assessors know they’re being recorded they don’t seem to care whether or not what they write down is accurate.”

She added: “The only people who are profiting from this are the assessment contractors – DWP are undoubtedly paying a fortune for unreliable and often entirely unnecessary assessments and there seriously can’t be any question that claimants are being damaged by the process.

“I’m an ex-CAB [Citizen’s Advice Bureau] advisor and now provide advice on a couple of online forums and I’ve yet to come across a single person who, having gone through the assessment process once, is not at least apprehensive about doing it again.”

Bennetton said the assessment system was “particularly discriminatory” because it relies on claimants “being able to complete the very lengthy forms themselves or get help”.

She said: “I don’t know what the waits for appointments for advice agencies are like now, but when I was doing face-to-face advice, I’d need at least two two-hour slots for a disability living allowance form and I’d be fully booked for at least six weeks ahead.

“By the time the forms arrive, claimants often only have three weeks to fill them in and get them back to DWP, which alone severely discriminates against anyone who needs help.”

She has had two previous “identical” complaints upheld by the Independent Case Examiner (ICE), with one of them even appearing in the ICE annual report for 2018.

[The annual report](https://www.gov.uk/government/publications/dwp-complaints-annual-report-by-the-independent-case-examiner-2017-to-2018/annual-report-2017-to-2018#contracted-provision) described how the assessment provider Atos refused her request for a home assessment of her eligibility for PIP, even though she provided medical evidence.

Instead, Atos arranged an appointment at an assessment centre nearly 40 miles from her home.

When a complaint was lodged, a home assessment was arranged, only to be cancelled at short notice without telling her.

Her complaint was upheld, and Atos was ordered to apologise and pay her £150.

Her other successful ICE complaint was also against Atos.

A DWP spokesperson said: “We welcome the judgment in this case.

“Work capability assessments held in assessment centres are the most appropriate in terms of health and safety, providing a suitable environment to conduct a comprehensive review.

“However, if a person is unable to attend an assessment centre they can be offered a home visit.”

DWP said that all healthcare professionals who carry out assessments on behalf of the department are highly trained and registered, and that if someone cannot attend an assessment centre due to evidence of a health condition that prevents them travelling there, or for practical reasons, they can be offered a home visit.

Maximus had failed to comment by noon today (Thursday).

**4 November 2021**

**Purple Tuesday defends itself from ‘purplewashing’ accusation**

The founder of a high-profile access campaign has denied that it provides powerful corporations with an opportunity to parade their supposed commitment to disability equality without having to prove they are implementing the public promises they make.

This week saw the fourth annual Purple Tuesday, an event devised and run by the organisation [Purple](https://wearepurple.org.uk/), led by its disabled chief executive Mike Adams.

The aim of Purple Tuesday is to “improve the disabled customer experience by engaging with organisations across all sectors and all sizes to make commitments to change their practice for disabled customers and their families”.

Adams said: “What we want is disabled people first and foremost to be seen as customers and have a quality experience.”

Purple was originally a community interest company, [which replaced the former Essex Coalition of Disabled People](https://www.disabilitynewsservice.com/jobs-focus-and-dropping-user-led-status-could-usher-in-new-purple-reign-says-adams/), but since 2018 it has been part of a limited company that aims to operate at a profit.

Adams defended Purple Tuesday from the suggestion that it allows businesses to secure positive publicity by pledging their commitment to disability equality without having to prove in subsequent years that they have implemented the promises they make.

These long-term commitments have been made since the first Purple Tuesday event in 2018, but Adams admitted there had been no attempt to check on whether they have been kept.

But he added: “The evidence we have got is that organisations have made commitments, they have implemented those commitments.

“What we don’t do is follow up with every organisation and say ‘show us the evidence of what you have done’… [but] we know that commitments that have been made in previous years have been followed through and added to.

“We are a catalyst for change. I would claim that Purple Tuesday as a brand has galvanised people to take action.

“If you’re asking for a bit of paper that sets it out line by line, then we haven’t got that.

“We work hugely hard 365 days a year to make sure that people who sign up to Purple Tuesday deliver on their commitments and come on the journey with us, but we are not auditors.”

He told Disability News Service: “It’s not a greenwash, it’s not a purplewash, it’s not a whitewash.

“We actually believe that Purple Tuesday is making a significant difference in the lives of disabled customers.”

The event is set to make Purple an estimated £100,000 in revenue from partner organisations that have signed up as sponsors, with “sector sponsors” with more than 250 employees – such as high street retailer Boots, insurance giant Zurich and auction website eBay – paying £9,000 plus VAT to be associated with Purple Tuesday.

Asked if this suggested that Purple Tuesday was more about making money for Purple than anything else, Adams said: “That’s a fair question to ask.

“I would say like most organisations you need to generate revenue to make it bigger and better and that is exactly what we are doing.

“Our utter commitment is to make the lives of disabled customers better and better and better.

“We need to make it bigger and bigger to have as much impact as we can.

“I am not concerned that actually we are raising revenue in order to do that, and the money is going back in to make this bigger and bigger.”

He said that more than 5,000 organisations signed up to Purple Tuesday this year, making more than 7,000 commitments to improve the experience for their disabled customers.

Purple Tuesday has previously been criticised for its close links to the government, and [particularly the Department for Work and Pensions](https://www.disabilitynewsservice.com/dwps-links-with-accessible-shopping-day-lead-to-boycott-call/).

This year, the minister for disabled people, Chloe Smith, was due to attend an event alongside business leaders who have sponsored Purple Tuesday, and carry out associated media interviews, but she pulled out just hours after concerns began to be raised internationally about access at the COP26 international climate change conference in Glasgow (*see separate story*), which her government is hosting.

Adams said Purple Tuesday had been told she had pulled out because of a “diary change”.

He said the access problems at COP26 were a “stark reminder about how far we have still got to go and why we do what we do”.

But he repeatedly declined to criticise the government directly, even though it produced a National Disability Strategy this summer that highlighted the “countless instances of unfairness that plague daily life” for disabled people, and then hosted a global climate change conference that itself has been plagued with access failings.

Asked about the government’s failure, Adams said it was “a stark reminder about how far we have still got to go and why we do what we do”.

But he declined to criticise its actions, saying only that he did not know the full details, although he said his message to the government was that “we have got to be doubly determined to make sure that when we think about accessibility and inclusion we think about all issues for all individuals with all impairments and we have got to double down and we have got to go faster”.

Asked again about the government’s apparent hypocrisy, Adams said: “I’m here to talk to you about Purple Tuesday.”

Asked if was concerned about whether Purple Tuesday would be seen as lacking in credibility if he refused to criticise the government for its COP26 access failures, he insisted he had already answered the question.

He said: “I have said to you every time that [if] access isn’t as it should be [it] is disappointing and which is why we are driving Purple Tuesday as hard and as fast into every sector.”

Asked again about the government’s apparent hypocrisy, he ended the interview without warning.

**4 November 2021**

**Autistic campaigners’ anger over Spectrum 10K protest lock-out and ‘scare tactics’**

Autistic campaigners protested for hours outside the research centre at the centre of a £3 million study that they believe could be used for the purposes of eugenics.

They were forced to protest outside the entrance, beside a main road, after managers locked the main gate.

Protesters who spoke outside the main gates warned that the Spectrum 10K study “could potentially be used to eradicate us” and was treating autistic people like “lab rats”.

There was also anger among many of the activists after Professor Sir Simon Baron-Cohen, who is heading the research, warned them in advance that police officers and police dogs would be present during the protest.

He had told one of the organisers that the University of Cambridge and NHS, which have offices in the building where his research centre is based “have had to take advice from the police to protect their property, staff and patients in the event that a protester decides to do something unlawful”.

Emma Dalmayne, chief executive of the autistic-led group [Autistic Inclusive Meets](https://autisticinclusivemeets.org/), who helped organise the action, said the warning that police would attend had been a “deliberate scare tactic”.

“He was hoping, I believe, to put people off protesting.”

Baron-Cohen later apologised to her for “providing inaccurate information” and “any distress this has caused” after he admitted that there were “no plans for police, or police dogs” to be present and that he had “misunderstood the situation”.

Dalmayne, who is hoping to meet Baron-Cohen later this month, said she was “sadly not surprised” that they had been locked out – with a “brand new chain” – because “they lock us out of everything”.

Protesters were forced to use the facilities of a local golf club that allowed them to use their facilities and accessible toilet.

The efforts of autistic campaigners – particularly those from the #StopSpectrum10K campaign – had already persuaded Baron-Cohen’s team to pause work on the high-profile study, which was aiming to collect DNA samples from 10,000 autistic people across the UK.

The Spectrum 10K project would be the largest study of autism in the UK, and the researchers say they want to examine how biological and environmental factors impact on the wellbeing of autistic people.

[They say the project](https://spectrum10k.org/about-spectrum-10k/) will “not look for a cure for autism and does not aim to eradicate autism”, but campaigners say there are “enormous” concerns about the research and its undertones of eugenics, and have warned autistic people not to take part.

The study is led by researchers at Baron-Cohen’s Autism Research Centre (ARC) at the University of Cambridge, the Wellcome Sanger Institute, based near Cambridge, and the University of California Los Angeles.

[One of those who spoke](https://www.youtube.com/watch?v=ErdHaHDZFzs&t=3s) at the protest was Priscilla Eyles, who told fellow protesters: “They try to pretend… this is something that’s going to help us, and it’s just the absolute opposite of that, it’s like doublespeak, it’s like Orwellian doublespeak.

“We are not lab rats, we’re human beings.”

She added: “How is this going to help people who are going through mental health crisis because no-one will give them a job, or because they think they’re being disruptive at school? How is this going to help?

“They’ve locked the gate, they don’t even want to speak to us and yet [they claim] they’re friends to autistic people. How?”

Dalmayne said: “To all the parents that think you’re helping, you will have been told that you’re helping your child but actually when you’re asked for your child’s DNA ask if that money could not be better spent on support, on EHCPs (education health and care plans).”

She pointed to the locked gate and said: “We’ve got all of these people out here, all autistic, no-one’s here to speak to us.

“Literally, they’ve locked us out completely. And that’s how it is in reality, we are locked out of any research or anything about us and it shouldn’t be like that, there should be nothing about us without us.”

Another speaker, Lizzie, said: “I just want to appeal to any of the parents out there who think Spectrum 10K is going to help their children.

“What we need is that three million invested in CAMHS, in support services, and in things to help people that are already alive – autistics and future autistic children that are going to be born – to support their needs and to help us communicate effectively, get the mental health support we need, and the access to services, so that they don’t have to go through the trauma that so many autistic people have already gone through.

“This study is not going to do that. Giving your child’s DNA is not going to do that.”

Nicky Vere-Compton warned that the research could eventually be used to encourage parents to abort unborn babies that had a genetic link to autism.

She said: “We have already seen what happened when they found a DNA link for Down’s.

“They used that as an opportunity to have conversations with the parents of unborn Down’s babies, saying, ‘Would you like to abort your child?’

“And as a consequence, less Down’s babies are being born now.

“If they find the DNA link for autism, which they won’t, because I don’t believe it exists, but if I’m wrong and they do, what will happen is that every doctor will be speaking to the parent of an unborn autistic and saying, ‘Would you like to abort your baby?’

“The level of ignorance about the autistic neurotype means that more parents than not will say, ‘Oh no, I don’t want an autistic child’ and there will be less of us being born.

“There is no argument that this is not eugenics.”

Cos Michael, who held a placard saying, ‘embrace don’t erase’, said: “Whenever the government want to know about autism, whenever they are developing policy, whenever there’s a big international conference, Simon Baron-Cohen is the go-to expert, he is the keynote speaker who everybody who is not autistic goes to.

“If he is at their conference, if he is round their policy-making table, they are satisfied they have ticked the box.

“As an autistic person, I just want everybody there to know that when they employ Simon Baron-Cohen, he does not speak for us.

“He has never asked us what our priorities are, he has never asked us about how to improve our welfare and our lives. He is not for us.”

A statement read out on behalf of the London Autism Group Charity said that it supports only “ethical” research that is not linked to eugenics and which respects and is led by autistic people, and which will improve the lives of autistic people.

The statement added: “Therefore, we stand alongside our autistic allies and fully support the campaign to boycott Spectrum 10K, which fails in this regard. We call for its permanent cancellation.”

David Gray-Hammond, who read out the statement, added: “On a personal note, I think most of us were lost for words when we saw this research come out… it’s yet another attack on the autistic community.

“Yet again, people are trying to find out what causes autism, rather than actually support the ones that are already here.

“Because we are here, we are human beings, we exist and we deserve support, and instead £3 million is being poured into research which could potentially be used to eradicate us.

“We have a right to exist.”

Dalmayne told Disability News Service (DNS) afterwards that the protest showed the researchers that “autistic people are not going to be ignored”.

She said: “Shutting a gate and putting a padlock on it is not going to shut us out of the discussion.

“We will be part of it whether they like it or not.

“It’s going to affect future generations of autistics for ever, the outcome of this research.

“It would be negligent of us not to stand up and say something.”

Baron-Cohen agreed that he had mistakenly told Dalmayne that police and security dogs would be present when she had asked if they would be, and when he realised this was wrong “contacted the campaign group as soon as possible to inform them and to apologise for any distress this may have cause”.

He told DNS: “My first email to the protest leader was in no way intended to discourage autistic people from attending the protest, or to cause them any distress.

“My team and I support the right of anyone to hold a peaceful protest.”

He said: “The Autism Research Centre team shares a private building and site with other clinical and research teams… and access is by appointment only, subject to visiting restrictions during the pandemic.

“We only occupy part of the building, which is unable to host a large group of protestors.

“The site is not open to the public and was closed on Friday to maintain safety and security.

“The campaign group did not ask permission to visit the site and organised the protest without involving us in their arrangements or requesting a meeting first.

“We are pleased to now be in touch with the campaign group leaders and have offered them a meeting to discuss their concerns.”

He said he had phoned the golf club across the road “to make them aware that this peaceful protest was happening and to ask if they could let the protesters use their café and toilets.

“The manager of the golf club was happy to agree. I immediately emailed this information to the leader of the protest to explain they could use the golf club café and toilets, and to shelter if it rained.

“I gather that golf club staff brought the protestors free drinks and refreshments, which I think was a lovely gesture of local community support for autistic people and their families, and we are very grateful to the golf club.”\*

He said the Spectrum 10K project “aims to understand the genetic and environmental factors that contribute to autism and the health conditions experienced by autistic people”, and that his team “acknowledge that more work still needs to be done to address concerns expressed by some members of the autism community, including this protest group”.

He said that “both eugenics and the development of a prenatal test for autism run counter to our values and that this is not why the research is being done” and that the research was “being done purely to deepen our understanding of the genetic causes of autism and of the genetic links between autism and health conditions (such as epilepsy and gastrointestinal pain) that are more common in autism”.

He added: “But given the history of eugenics in the field of disabilities, we take the protestors’ concerns very seriously and want to address them meaningfully.

“This is why we have launched a wider consultation with the autism community, to listen, better understand, and discuss their concerns.

“The consultation is expected to run well into 2022.

“Our research team has been discussing this project with an advisory group, made up of autistic people and their families, for two-and-a-half years, and we have paused the study to expand on this dialogue with a much larger group of autistic people and their families as part of the consultation.

“After the consultation we will continue to include an expanded autism community advisory panel in the research.

“We are looking forward to meeting with the campaign team in a few weeks’ time, to discuss the project with them, alongside the consultation we are co-designing with autistic people and their families.

“An organised meeting will give us an opportunity to listen to their concerns, and to share and respect different viewpoints in a constructive way.”

He added: “I hope that we can work together via the consultation process to make changes to our study to improve it and put in place any additional safeguarding required.

“We also look forward to clarifying misunderstandings about the aims of the study and explaining that our team would never want to do research that could cause harm to autistic people.”

*\*Dalmayne said: “As lovely as the golf club were, we paid for our coffee and muffins, [but] they were kind enough to donate some water.”*

**4 November 2021**

**Fight for justice goes on, after Capita agrees Philippa Day compensation**

The sister of a disabled woman whose death was caused by flaws in the benefits system has pledged to fight for a public inquiry into other such deaths, after a government contractor agreed to pay “substantial” compensation for its failings.

Both Capita and the Department for Work and Pensions (DWP) were closely linked to the death of Philippa Day by evidence that emerged at an inquest into her death in January.

Assistant coroner Gordon Clow highlighted 28 separate “problems” with the administration of the personal independence payment (PIP) system that helped cause the death of the 27-year-old, from Nottingham.

It took Clow more than two hours [to read out his conclusions and findings](https://www.disabilitynewsservice.com/philippa-day-flawed-pip-system-led-to-young-mums-death-says-coroner/), after a nine-day inquest that uncovered multiple failings by both DWP and Capita in the 11 months that led up to Philippa Day’s death in October 2019.

He had concluded that flaws in the benefits system were “the predominant factor and the only acute factor” that led to her taking her own life.

And he issued what is known as a [prevention of future deaths (PFD) report](https://www.judiciary.uk/publications/philippa-day/), which calls for action from organisations linked to a death to prevent further such tragedies.

That report was addressed to both DWP and Capita, which carries out PIP assessments on its behalf.

Now Capita has agreed to compensate Philippa Day’s family for its failings, a sum likely to be in six figures.

The compensation from Capita will be used to support Philippa’s six-year-old son.

The terms of the settlement include an agreement to withdraw the family’s legal claims against DWP.

Capita will also meet the family to discuss the changes it has made since her death.

Imogen Day, who is herself disabled, promised her sister that she would fight for justice for her if she died because of her PIP claim.

She told Disability News Service that she would continue that fight, despite the settlement.

She said: “It’s not justice, but it is a measure of accountability, a measure of financial accountability, for the mistakes that were made and the trauma we suffered as a result.

“It is one chapter closed but we have still got more to do.

“Now the settlement is out of the way I can speak far more freely.”

She added: “In 2019, my sister was stolen from me.

“What followed was a difficult inquest full of inappropriate tactics and attempts to conceal wrongdoing.

“The DWP has broken the public’s trust that there is social security that is kind and well-balanced.

“In the years since, I am aware that changes have been implemented at both DWP and Capita, changes that should help prevent another tragic loss.”

But she said there still needed to be accountability for the deaths of many other disabled benefit claimants that have been linked to the actions of DWP and its contractors.

She said: “I will continue to campaign for a full public inquiry into benefit deaths.”

She had earlier said in a public statement: “Our family have always maintained that my sister’s treatment by the Capita, on behalf of the DWP, directly impacted her mental state and in the end is the reason for her death.

“Capita’s wall of bureaucracy, with no consideration for Philippa’s mental state, exacerbated her despair at her debt and poverty.

“She was met with cold, uncaring call operators who would not listen to her cries for help.

“However, we welcome the opportunity to meet with Capita to discuss improvements to their service.

“This settlement will in some measure provide for Philippa’s family and a materially stable upbringing for Philippa’s son, but he has lost his mother, and there is nothing Capita can do to put right the wrong that contributed to Philippa’s death.”

Merry Varney, a partner at solicitors [Leigh Day](https://www.leighday.co.uk/), who has represented the family, said: “Capita has shown acceptance of their failures and a willingness to ensure their mistakes are not repeated.”

But she said there were still “too many examples” of DWP “acting inhumanely to those receiving benefits and a continued resistance by the DWP to transparent investigations into benefit-related deaths”.

She added: “Until the DWP changes its attitude, people like Philippa and her family remain at risk of gross human rights violations, and ‘benefit related deaths’ are just another example of preventable deaths of people with disabilities occurring without any proper investigation or scrutiny.”

Capita had refused by noon today (Thursday) to confirm that it had settled the case.

But a Capita spokesperson said in a statement: “We are very sorry for the mistakes we made in processing Philippa’s personal independence payment claim and the additional stress this caused her.

“In partnership with the DWP, we have considered and reviewed the coroner’s report and we are implementing all the recommendations that are relevant to us.

“Following this incident, we have strengthened our processes and we are working to continuously improve and deliver a professional, efficient and kind service for every PIP applicant we assess.”

A DWP spokesperson said: “Our condolences remain with the Day family.”

**4 November 2021**

**Justice for Jodey fight continues with fresh request for appeal**

The mother of a disabled woman who took her own life after her benefits were wrongly stopped is to make a second attempt to secure permission to appeal against a high court ruling.

Joy Dove is fighting to secure a second inquest into the death of her daughter, Jodey Whiting, because she believes that the first inquest in May 2017 – which lasted just 37 minutes – was not a “thorough investigation” into the role played by the Department for Work and Pensions (DWP).

But the high court refused in September to quash the result of the first inquest and to order a second one, arguing that new evidence that had come to light since May 2017 did not require a second inquest.

Last month, the high court refused Dove permission to appeal that decision.

Now she has lodged a fresh application for permission to appeal with the Court of Appeal.

In rejecting her case in September, Mrs Justice Farbey argued that DWP’s failings had been “shocking” and that the decision to remove Jodey Whiting’s employment and support allowance (ESA) “should not have happened”.

But she said that DWP’s errors “amounted to individual failings attributable to mistakes or bad judgment” and were not “systemic or structural in nature”.

Despite that conclusion, scores of deaths have been linked to DWP’s systemic failings, including its refusal to act on reports by coroners [following inquests in 2010 and 2014](https://www.disabilitynewsservice.com/dwp-the-case-for-the-prosecution/) and a report in March 2014 by the Mental Welfare Commission for Scotland.

Secret reviews obtained by Disability News Service have shown that DWP civil servants repeatedly warned – between 2012 and 2014 – that policies on the work capability assessment were putting the lives of “vulnerable” claimants at risk.

In 2017, DWP admitted failing to keep track of whether it had implemented 10 recommendations on improving the safety of “vulnerable” disabled people that had been made in these secret reviews.

Jodey Whiting took her own life in February 2017, 15 days after she had her ESA wrongly stopped for missing a work capability assessment.

She had been a long-time claimant of incapacity benefit, and then ESA, and DWP and its assessors had previously noted the severity of her mental distress, and the risk that would be posed if she was found fit for work.

They were also aware of her long history of suicidal ideation.

At the time of the assessment, she was unable to leave her house because she had pneumonia, had been in hospital, and had found out that she had a cyst on her brain.

Dove, who has been fighting since 2017 for justice for her daughter, said: “My fight continues to have a fresh inquest that will examine the role of the DWP in Jodey’s death.

“It seems to me that there were obvious failings in the way the DWP treated Jodey, which were proved and documented by the Independent Case Examiner, and it is ridiculous that this has not been fully and publicly investigated.

“How can lessons be learned, and future tragedies prevented, if no one examines this properly?”

Her solicitor, Merry Varney, of [Leigh Day](https://www.leighday.co.uk/), said it was “disappointing” that the high court had rejected the application for a second inquest.

She said: “The possible link between the DWP making repeated errors in the handling of Jodey’s welfare benefits claim shortly before her death, which left her without income, housing benefit and council tax benefit, and her death has never been publicly investigated.”

A DWP spokesperson said: “This is an incredibly tragic case and our condolences remain with Ms Whiting’s family.

“We cannot comment on active legal proceedings.”

**4 November 2021**

**Police hate crime failure ‘alarming’, say disabled campaigners**

“Alarming” official figures show how police forces are repeatedly letting disabled people down by failing to investigate disability hate crime properly, leading campaigners warned this week.

They spoke out after [Disability News Service (DNS) revealed](https://www.disabilitynewsservice.com/disability-hate-crime-prosecutions-plummet-but-police-stay-silent/) how figures showed that prosecutions of disability hate crime have plunged by nearly half in just two years (from 579 to just 292), even though offences recorded by police forces are rising sharply.

The fall appears to have been caused by a drastic drop in the number of disability hate crime suspects referred to prosecutors by the police for a charging decision.

Crown Prosecution Service (CPS) figures show this has fallen from 924 in 2014-15 to 367 in 2018-19, to 320 in 2019-20, and to just 298 in 2020-21, across the whole of England and Wales.

Anne Novis, a member and former chair of the Metropolitan police’s disability independent advisory group, former chair of [Inclusion London](https://www.inclusionlondon.org.uk/) and a long-time campaigner on disability hate crime, said disabled people were seeing “the same lack of action” on disability hate crime that they experienced from the police in the 1990s and early 2000s.

This only changed because of years of pressure from disabled campaigners like Novis, Stephen Brookes and Ruth Bashall, and [allies like journalist Katharine Quarmby](https://www.disabilitynewsservice.com/ehrc-harassment-inquiry-activists-welcome-report-but-say-rights-approach-is-crucial/).

Novis said: “We shouldn’t as a community have to keep saying to the police, ‘You’re not allowing us to access justice,’ and yet that’s what we keep having to do.

“They keep letting us down.”

She said she believed that many cases were not being investigated by experienced officers after being flagged as disability hate crimes, which meant there was no evidence to be passed to CPS for a potential prosecution.

Novis said that disabled people’s organisations and disabled activists had “worked really hard” to make the police more aware of the hate crime disabled people were experiencing, “but it’s just not happening”.

Louise Holden, Inclusion London’s hate crime partnership project manager, said the figures were “really concerning”.

[Inclusion London](https://www.inclusionlondon.org.uk/) is the lead organisation in the London Deaf and Disabled People Organisations Hate Crime Partnership, which has 24 members, and has been working with CPS to examine why prosecutions have been plummeting.

Holden said the partnership had been hearing of “disturbing cases where police officers are dismissing disabled victims’ experiences and downgrading cases to anti-social behaviour incidents, not investigating or gathering evidence and closing cases and generally providing an extremely poor response”.

She said: “This will be included in the report I am putting together to present to the London Assembly police and crime sub-committee later this year, as we also feel that the police are not listening to us and we need to go to the London Assembly to demand they hold the Met police to account and take action.

“All this points to disabled victims not getting the justice or support they deserve, and we are doing all we can to raise this issue and demand change.”

[Sue Groves](https://twitter.com/SUEG46), the disabled chair of Medway independent police advisory group and an independent critical incident advisor to Kent police, said the figures were “alarming”.

She said she welcomed the increased reporting of disability hate crime to police but said the drop in referrals to CPS was “something that I have been concerned about for a while now”.

She said Kent police and the regional CPS had agreed to carry out a review “to establish whether there are areas for further learning or where processes in place need to be amended”.

She added: “The police and CPS have a lot of work to do nationally but this is a start.

“Other forces could do the same as a starting point at the very least, as well as acknowledge the problem.”

Yesterday, the National Police Chiefs’ Council (NPCC) finally responded in depth to the concerns, two years after DNS first tried to question its press office about the falling number of police referrals to CPS.

Deputy chief constable Mark Hamilton, NPCC’s hate crime lead, said: “We are currently undertaking a national audit into hate crime, and are also planning to carry out a specific thematic audit on disability hate crime reports.

“We are already working closely with our criminal justice partners to understand the reasons behind a reduction in the percentage of crimes that go to court, including where victims withdraw from the justice process.”

He said: “Hate crimes against disabled people are a particular shocking form of crime, motivated as they are by the perpetrator’s hostility to a victim’s disability.

“Aside from any physical injuries, we know that victims of disability hate crime are often intensely traumatised by these incidents.”

He claimed that police forces “will always pursue action against perpetrators where there is evidence to do so”.

And he said: “Unfortunately, sometimes the evidence is scarce and there are no witnesses to the crime.

“Particularly in recent years, it may be the case that a suspect cannot be identified because of anonymity online, and a charge cannot be brought.

“Additionally, in some cases, for example where a perpetrator is young, a caution may be considered more appropriate than prosecution.”

He encouraged anyone who thinks they may have experienced any hate crime to report it to the police\*, as soon as possible after an offence has been committed.

*\*Victims can report a hate crime by dialling 101 (999 in an emergency) or through the True Vision website:*[*www.report-it.org.uk*](https://gbr01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fwww.report-it.org.uk%2F&data=04%7C01%7Cchristian.bace%40npcc.police.uk%7Cb8515927c0b44b92260908d99eb520ee%7C1333559a439a4a0abdc0a46cd38882d7%7C0%7C0%7C637715323047240717%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C1000&sdata=OHuT7QNlRP66ZzpqD84H00U%2Fyoiwr8bwZ0Kxt2d%2FUrM%3D&reserved=0)*.*

**4 November 2021**

**DWP appears to confirm that spending review came up almost empty on disability**

The government appears to have confirmed that ministers have secured new funding in just two areas – education and employment – to support the implementation of their new National Disability Strategy.

[Last week](https://www.disabilitynewsservice.com/spending-review-and-budget-come-up-nearly-empty-on-disability-strategy-funding/), Disability News Service (DNS) reported that Treasury documents suggested ministers in only two departments, the Department for Education (DfE) and the Department for Work and Pensions (DWP), had secured new funding as part of the budget and spending review.

This was despite the prime minister, Boris Johnson, [saying in August](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006098/National-Disability-Strategy_web-accesible-pdf.pdf) (PDF) that the strategy would be a “down payment” on the promise to “build back better and fairer, for all our disabled people”.

[Analysis of the strategy](https://www.disabilitynewsservice.com/government-reveals-national-disability-strategy-offers-just-28p-per-person-in-new-funds/) by DNS showed it was accompanied by only £3.95 million in new funding, or just 28p for every disabled person in the UK.

Last week’s spending review, which sets departmental budgets up to 2024-25, suggested the Treasury had agreed new funding to provide 30,000 new school places for disabled children and those with special educational needs (SEN), both to build new segregated free special schools and improve the accessibility of existing school buildings.

The only other new disability-related funding appears to be an extra £156 million over the next three years to provide employment support for disabled people, which will focus on providing more DWP work coaches.

After being asked by DNS for details of new disability-focused bids that were successful in the spending review (SR), a DWP spokesperson said: “To support disabled people into work, the government at this SR is providing specialised disability employment support worth over £1.1 billion over the next three years, including an additional £156 million over the SR period for health and disability support with a focus on additional work coaches.

“This is alongside the Work and Health Programme which will continue to provide personal support to disabled people to find jobs that match their employment and health needs, and the Access to Work scheme which will continue to help cover the costs of workplace adaptations, special equipment and travel.”

But when asked three times to confirm that the school funding and the £156 million were the only new bits of disability-focused spending, a DWP spokesperson refused to clarify the government’s position.

DNS had also approached the Treasury and the government’s Disability Unit for clarity, but the questions were answered by DWP.

When [challenged by MPs in September](https://www.disabilitynewsservice.com/government-reveals-national-disability-strategy-offers-just-28p-per-person-in-new-funds/) about the lack of new funding, the then minister for disabled people, Justin Tomlinson – later sacked in a ministerial reshuffle – had suggested that new funding was likely to be announced soon.

He said that a “huge amount” of the work of the government’s Disability Unit in the following few weeks would be to provide evidence for individual government departments that would “strengthen the likelihood” of disability-focused funding bids being successful in the spending review.

But the spending review and budget outcome suggests that government departments other than DfE and DWP failed to put in any disability-related bids to the Treasury, that the Disability Unit did not provide them with the necessary evidence, or that the Treasury had rejected their bids.

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**News provided by John Pring at** [www.disabilitynewsservice.com](http://www.disabilitynewsservice.com)