**Activists set for ‘David and Goliath’ fight to defeat assisted suicide court bid**

A group of disabled activists – led by a crossbench peer – are to intervene in a legal case for the first time next week, in a bid to persuade three high court judges not to weaken the law to allow assisted suicide.

[Not Dead Yet UK (NDY UK)](http://notdeadyetuk.org/), a campaign group of disabled people opposed to a change in the law on assisted suicide, has been granted the right to intervene in the high-profile judicial review being taken by Noel Conway, who is terminally-ill.

Conway is taking a case against the Ministry of Justice, and wants the court to find that the Suicide Act – which makes it illegal to assist someone to take their own life – is incompatible with articles eight (on the right to a private and family life) and 14 (which prohibits discrimination) of the [European Convention on Human Rights](http://www.echr.coe.int/Documents/Convention_ENG.pdf).

NDY UK, led by its founder, the disabled peer Baroness [Jane] Campbell, had just 10 days to put together its legal submission to the high court, after being granted permission to intervene in the case, but even then was only allowed to submit 20 pages of legal arguments.

It is now hoping the three high court judges hearing the case will also allow NDY UK to submit a witness statement from Baroness Campbell herself, and permit NDY UK’s barrister, Catherine Casserley, [of Cloisters chambers](http://www.cloisters.com/barristers/catherine-casserley), to respond to the arguments of Conway’s legal team in court.

If NDY UK wins the right to be heard orally in court, it could even risk bankruptcy if Conway wins his case and the judges make an order that the campaign group should pay some of his lawyers’ costs.

Baroness Campbell and her members were only able to secure their status as interveners in the case because their two lawyers, Casserley and solicitor Chris Fry, [of Fry Law](http://www.frylaw.co.uk/), offered to work pro bono.

Although they are on the same side as the Ministry of Justice, which is also fighting a change in the law, they are facing a well-funded team from solicitors Irwin Mitchell, backed by the substantial financial resources of the campaign group Dignity in Dying, formerly known as the Voluntary Euthanasia Society.

Baroness Campbell told Disability News Service: “This is David and Goliath.

“It always tends to be those organisations not run and controlled by disabled people that get the cash. That does stick in the throat a bit.

“Whether you agree with assisted suicide, you should have a balanced opportunity to hear both views and I fear the [judges are] in jeopardy of not hearing all the views which [they need] to hear in order to make a good judgement.”

It is the first time NDY UK has intervened in a legal case on assisted suicide in the 12 years since it was founded by Baroness Campbell.

Their case has relied on disabled activists from NDY UK, the pro bono work of Fry and Casserley, and support from its sister organisation in the USA, [Not Dead Yet](http://notdeadyet.org/), and its president and founder, Diane Coleman, as well as law students from both the University of Sheffield and Sheffield Hallam University.

Conway argues that the current law prevents him exercising his right to choice and control over his death.

He said earlier this year: “I know I am going to die anyway, but how and when should be up to me.

“To have the option of an assisted death in this country would provide me with great reassurance and comfort.

“It would allow me to decide when I am ready to go, rather than be forced into a premature death by travelling abroad or be left at the mercy of a cruel illness.”

But Baroness Campbell, who plans to attend court for the first day of the judicial review on Monday (17 July), said the prospect of a change in the law was “terrifying”, which was why she and fellow activists had decided that NDY UK must intervene in the court case.

In the witness statement – which may not be accepted by the court – Baroness Campbell says that any ruling in favour of Conway would “impact negatively on the lives of other terminally ill and disabled people”.

She says it would “damage beyond repair the way in which society views the elderly, sick and disabled to the point where the Equality Act itself and the protection which it provides becomes fundamentally defective”.

She adds: “I (and the hundreds of disabled and terminally ill members of NDY UK), want people to understand that it is perfectly possible to have a fulfilling and enjoyable life whilst living with a substantial, progressive condition.”

She hopes to tell the court that continuing cuts to health and care services would mean that disabled and terminally-ill people “may become more inclined towards considering desperate options such as assisted suicide”, if it was legalised.

The writer and activist Penny Pepper, another NDY UK member, who is quoted in Baroness Campbell’s witness statement, says: “The massive publicity machine working for those who promote assisted suicide drowns out the ‘small voices’ of disabled people who want support to live, not die.”

Another member, Felicity Wright, warns that legalisation would destroy the doctor-patient relationship, and that doctors are “amongst the very last people I would trust to have a balanced opinion about the quality of my life”.

Baroness Campbell, whose own impairment, spinal muscular atrophy, leaves her in a similar physical situation to Conway, who has motor neurone disease, says she identifies with and understands his fears of the possible death he might face due to an eventual “physical shutdown”.

But she says that “parliament has concluded that legalisation would be ‘a dangerous and inappropriate way to tackle end of life fears’”\*.

She adds: “In every country where assisted suicide has been made legal, original safeguards have been watered down, allowing the parameters to widen and include people that were outside of the original legislation.

“There is no reason that this would not happen in the UK, and frankly I predict it will.”

Fry, who worked with fellow discrimination law expert Casserley on another high-profile disability rights case, [which saw their client Doug Paulley](https://www.disabilitynewsservice.com/we-must-keep-banging-the-drum-says-bus-campaigner-after-five-year-fight-for-justice/) win a ground-breaking legal victory that protected the rights of wheelchair-users to travel on buses, said he felt an “overwhelming sense of responsibility” about the case.

He said he had been involved in other high-profile cases which have changed the law – including Paulley’s – but “this is the one that carries for me the greatest sense of personal responsibility because ultimately the issues being decided in this case will affect almost everybody in today’s society”.

He said a change in the law would have a “multi-layered impact across the whole of society” and would undermine the Equality Act, which is “founded on the concept that we should do more to empower people and to give an effective right to life and a right to an engaged, fulfilling and accessible and inclusive life.

“If you suddenly start saying it’s about the right to die and start unravelling it all, you’re unravelling a quarter of a century of positive equality legislation and case law.

“This, for me, is probably the biggest case I will be involved in in my career, because of the significant responsibility that comes with trying to ensure the voices of disabled people are heard as part of this judicial process.”

He said there was a “serious threat” that Conway could win, as Dignity in Dying and its lawyers had spent a “significant amount of time and money” in preparing their case since the last attempts to change the law, on behalf of Tony Nicklinson and two other disabled men, [ended in failure at the Supreme Court three years ago](https://www.disabilitynewsservice.com/supreme-courts-assisted-suicide-ruling-is-just-prelude-to-big-debate/).

Fry said: “This poses a real threat that the law will be changed. If we lose this case and subsequently it gets as far as the Supreme Court and the Supreme Court decides that assisted dying should be legal, that’s it.”

In her legal submission to the court on behalf of NDY UK, Casserley warns that the court is being asked to create “a climate in which a disabled person is seen as a burden and the option of a course which involves termination of life becomes routine”.

She asks the court to consider not only Conway’s rights, but those of the other disabled and terminally ill people “who will be potentially affected adversely by the Court’s decision and the message that this conveys to them”.

She adds: “NDYUK has significant concerns that if society indicates that as a disabled or terminally ill person assisted dying is an option open to them there is a risk of application of internal pressure derived from a value system which views disability negatively.”

*\**[*Nearly two years ago*](https://www.disabilitynewsservice.com/elation-relief-and-dread-as-mps-throw-out-assisted-suicide-bill/)*, the latest attempt to change the law in parliament was heavily defeated, with MPs voting 330 to 118 against a private members’ bill put forward by Labour MP Rob Marris that would have legalised assisted suicide for people said to have up to six months to live.*

**13 July 2017**

**Government’s UN response ‘exposes failings on disability convention’**

The government has ignored key evidence that demonstrates widespread breaches of the UN disability convention, according to disabled people’s grassroots groups and organisations that are working together to expose its failings.

They spoke out after the government [submitted its response](https://www.gov.uk/government/publications/disabled-peoples-rights-information-for-the-uks-first-periodic-review/list-of-issues-in-relation-to-the-initial-report-of-the-united-kingdom-of-great-britain-and-northern-ireland-government-response) to concerns raised earlier this year by a UN committee, which described where it had questions about whether the UK may have failed in its obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The UK government’s 168-paragraph response to the “list of issues” produced by the UN’s committee on the rights of persons with disabilities (CRPD) is the latest step in a process that will see it examined in public in Geneva next month on how it has implemented the convention.

But disabled activists and campaigners who have been working to highlight the UK’s breaches of the convention said this week that the government’s defence of its position was “poor quality” and lacking in evidence.

Ellen Clifford, a spokeswoman for the [Reclaiming Our Futures Alliance](http://www.rofa.org.uk/) (ROFA) – a national anti-cuts network of user-led organisations – said the government had claimed in its response that its policies were having a positive impact on disabled people, without providing any evidence for those claims.

She said the government had claimed that the Care Act 2014 was “helping to overturn traditional approaches to disability in health and social care by placing greater power in the hands of service users, including disabled people”, when there was substantial evidence to show that the act was not being implemented.

There is no mention in the government’s response of the Department for Work and Pensions’ (DWP) [own evaluation of the closure of the Independent Living Fund](https://www.disabilitynewsservice.com/dwp-report-confirms-fears-over-impact-of-ilf-closure/), in which it had found that some former recipients had experienced a loss of support, a greater reliance on unpaid care and a negative impact on their physical and mental health after it closed.

[Only last week](https://www.disabilitynewsservice.com/years-of-austerity-have-left-personal-assistance-in-very-fragile-state/), Disability News Service reported how leading figures in the disability movement had described how the concept of disabled people using personal assistants had been severely damaged by years of austerity and government policies that have “degraded” the support mechanisms designed to enable independent living.

Clifford pointed also to the second paragraph of the response, where the government claimed that it “embraces the social model of disability”.

She said there was substantial evidence to show the government was instead influenced by [the discredited biopsychosocial model of disability](https://www.disabilitynewsservice.com/biopsychosocial-basis-for-benefit-cuts-is-cavalier-unevidenced-and-misleading/) in its welfare reforms, by the psychiatric model in mental health services, and by the medical model in the use of assessment and treatment units for people with learning difficulties, all of which had caused harm to disabled people and led to breaches of the convention.

Clifford said the government’s response overall was “just a list of policies” and “doesn’t deal with any of the substantive issues” raised by the UN in its list of issues.

She said: “It just doesn’t present a picture of the experiences of Deaf and disabled people in the UK in 2017.”

Dr Rosalind Tyler-Greig, human rights policy and engagement officer for [Inclusion Scotland](http://inclusionscotland.org/), said the government’s response “once again demonstrates its refusal to engage with many of the most important issues affecting the lives of disabled people”.

She pointed to “telling” omissions, including the government stating that it spent nearly £17 billion on personal independence payment (PIP) and disability living allowance (DLA) in 2015-16, compared to £11 billion in 2006-07, but ignoring new figures – [reported last week by Disability News Service](https://www.disabilitynewsservice.com/pip-reassessments-cause-more-than-half-dla-claimants-to-lose-motability-rights/) – that showed more than half of those previously eligible for the higher mobility rate of DLA had lost that eligibility after being reassessed for PIP.

And where the government states that legal aid “continues to provide access to justice for people in the most serious cases”, Tyler-Greig said that many disabled people with housing, employment or social security concerns “now find themselves priced out of justice” because of the UK government’s legal aid reforms.

She added: “The government claims to have embraced the social model of disability.

“However, this statement is merely a case of lip service and there is little evidence to support it.”

In Scotland, she said, there had been progress in dealing with the impact of austerity, with the Scottish government promising “a different and non-discriminatory approach to social security”.

But she said the delivery of social care “remains a significant concern in Scotland, and there is little in the state response to address this.

“Inclusion Scotland is working with a range of partners to ensure that this UN process provides the appropriate levers to drive progress for disabled people in Scotland as well as in the UK.”

There is also anger about the government’s continued failure – repeated in its response to the list of issues – to address the recommendations made by the UN committee following a separate inquiry into breaches of the convention.

That inquiry – taken under article six of the convention’s optional protocol – found last year that the UK government [was guilty of “grave” and “systematic” breaches](https://www.disabilitynewsservice.com/un-confirms-that-uk-governments-treaty-violations-were-both-grave-and-systematic/) of three specific articles of the human rights treaty.

Most of those breaches – under articles 19 (independent living), article 27 (work and employment) and article 28 (adequate standard of living and social protection) of the convention – were caused by policies introduced by Conservative DWP ministers between 2010 and 2015.

The government said last November that the inquiry report presented an “inaccurate” picture of life for disabled people in the UK, and dismissed all 11 of its recommendations.

And in this month’s response to the list of issues, it says only that it “maintains [the position of its response](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f17%2fR.3&Lang=en)” to the article six inquiry and planned to “further showcase [its] commitment to progressing the rights and lived experience of disabled people” through the examination of its overall record on implementing the convention.

[Disabled People Against Cuts](https://dpac.uk.net/) (DPAC), which played a key part in persuading the UN to carry out the article six investigation, is to meet with the UN committee next month in Geneva to discuss progress in following up the results of the inquiry, which is a separate but parallel process to the routine examination.

DPAC has already told the committee that it believes “rights are regressing even further” since the publication of the inquiry report, including through further cuts to social care, concerns about [DWP’s new health and work conversation](https://www.disabilitynewsservice.com/boycott-call-after-dwp-wrongly-claims-dpos-helped-devise-punitive-work-scheme/), and the “utter disaster of universal credit”.

Linda Burnip, a DPAC co-founder, said: “The message is very much that this isn’t over yet, and I will be speaking about the UN inquiry in the European parliament in September to MEPs and hammering home how shamefully the Tories have behaved.”

ROFA and other organisations [that visited Geneva in March](https://www.disabilitynewsservice.com/dpos-join-forces-to-brief-un-on-how-uk-has-breached-disability-convention/) to give evidence to the committee about the UK’s breaches of the convention – including Inclusion Scotland, Disability Wales and Disability Rights UK – are now working on a joint response to the government’s response, and have until the end of this month to submit it to the committee.

**13 July 2017**

**Inclusion London set to test social model job support, after £775k grant**

A pan-London disabled people’s organisation (DPO) has been given the chance to test “exciting” and “important” approaches to supporting young disabled people into work that reflect the social model of disability, after securing more than £750,000 in funding.

Inclusion London has been awarded £775,000 over five years by the [City Bridge Trust](https://www.citybridgetrust.org.uk/about-us/), which funds charities on behalf of the City of London Corporation, as part of a new £3.3 million Bridge To Work fund set up to support more young disabled people into employment.

Inclusion London said the grant will allow it to “test and pilot and evaluate” models of employment support that reflect the ethos and values of DPOs and the social model of disability, in contrast with the unsuccessful approaches of large government contractors that have previously secured funding through the Work Programme and Work Choice.

Tracey Lazard, chief executive of [Inclusion London](https://www.inclusionlondon.org.uk/), said there was frustration that DPOs had not previously been funded for such work.

She said: “You have a whole set of practices around mainstream employment support that just aren’t working and all the evidence shows that the success rates are so tiny... whichever way you look at it, the current approaches are not delivering.”

She pointed to the “perverse incentives” for employment support providers not to work with disabled people perceived as being harder to find jobs, and the “non-social model understanding about what the barriers in the workplace really are”.

She added: “That’s what was [really frustrating in the government’s [work, health and disability] green paper](https://www.disabilitynewsservice.com/g4s-maximus-and-a4e-all-set-to-win-contracts-under-work-and-health-programme/), apart from [all the really devious stuff](https://www.disabilitynewsservice.com/devastating-unethical-cruel-disabled-people-react-to-green-paper/), was just that it’s kind of going to be business as usual in terms of delivery models but with a lot less money, and that’s just not going to work.

“It’s shocking but it’s not surprising.”

She said DPOs had been excluded from the big government employment support contracts, although most of them would not want to bid for such contracts anyway because of the “whole range of mandatory and devious practices” they impose on out-of-work benefit claimants, such as the use of sanctioning disabled people’s benefits.

Lazard said: “It is pretty shocking that there’s not any evidence of any real commitment to look again at models of employment support, because they are not working.

“So this is an opportunity and City Bridge Trust are a great funder and they understand that this is strategic, long term structural work which is why I think there is five years of funding.”

Inclusion London will work closely with [Action on Disability](https://actionondisability.org.uk/about-us/) (AoD), a user-led organisation based in Hammersmith and Fulham, and plans to develop some of the “innovative” work AoD has been doing to support disabled people into work.

One of the models they will be developing is an AoD internship scheme, which has worked with people with learning difficulties who were previously “trapped in the revolving door of classroom based support” and has seen as many as 70 per cent of those taking part securing jobs.

The aim is to identify job vacancies that a large employer is finding difficult to fill, find a young disabled person from a local college to fill those positions, and then provide “really quite high levels of ‘in situ’ job support”, using college and Access to Work funding.

Action on Disability has been focusing its work on young people with learning difficulties, so one of Inclusion London’s aims is to expand that to other groups.

Inclusion London will now aim to recruit five other London DPOs to work with this and other employment support models, providing those user-led organisations with the support they need to build their own capacity.

Another support model will be to target small and medium-sized employers along a local high street, again providing high levels of support when the young person is in post.

Inclusion London will also be trialling different ways that young disabled people can approach job-seeking, including direct approaches to a potential employer, even targeting the chief executive.

There is also funding through the grant to train other DPOs in skills and approaches and tips that they can pass on to their members and service-users, and to work with public sector employers such as the NHS to open up their job opportunities to young disabled people.

Through the five years, Inclusion London hopes to build evidence of what approaches work and share those conclusions with other organisations and the government.

The Bridge To Work programme aims to use learning from the projects it is funding – including Inclusion London’s – to “better inform government and other funders” in how to support more disabled people into work.

Other disability organisations awarded grants from the fund are Action for Kids (£250,000), the National Autistic Society (£199,000), Muscular Dystrophy UK (£276,000), Mencap (£350,000) and Whizz-Kidz (£384,000).

In addition to the funding for the six organisations, there is a separate pot of more than £500,000 to support paid work experience and internships for young disabled Londoners in charities and the private sector, focusing on small and medium-sized enterprises.

Jack McLellan, who has benefited from Muscular Dystrophy UK’s Moving Up programme, which has previously received funding from the trust and will now see that support continued for another five years, said: “I was so disheartened when I first tried to find work after university that I needed a real boost to my confidence and skills to get on the right track.

“The Moving Up programme helped me gain experience, try out new roles and get that crucial break of a first job.

“I hope this new support means lots more young people are given the same chance to show their worth.”

Alison Gowman, who chairs the City Bridge Trust committee, said: “We are certain this new programme will really transform lives of young disabled people.

“The charities we are funding will give employers the support, skills and resources they need to increase opportunities for disabled people.

“The programme has a wider mission and is looking to influence policy in this area and make real long-term change for the disabled community.”

**13 July 2017**

**Osborne shares ‘discriminatory’ cartoon ‘that breaches his own code of conduct’**

London’s evening paper, and its editor, former Tory chancellor George Osborne, have been accused of showing a “deep disrespect” for disabled people after publishing a “disgusting” cartoon that compared being a wheelchair-user with being powerless and incompetent.

The London Evening Standard cartoon showed the prime minister, Theresa May, approaching the “lame duck access” entrance to the G20 summit, which had a wheelchair ramp.

Anger at the cartoon on social media was heightened by it being shared on the social media platform Twitter by the newspaper’s editor, George Osborne, who was chancellor for more than six years from 2010 and responsible for implementing [significant cuts to disabled people’s benefits and services](https://www.disabilitynewsservice.com/anger-grows-over-governments-plans-for-dla/).

After disabled people on social media described the cartoon as “deeply offensive”, the cartoonist, Christian Adams, said on Twitter that he “meant no offence on that level” and had been making “a political point”.

But Chris Stapleton, a wheelchair-user who lives in London and is a regular Standard reader, told Disability News Service (DNS) that he was “disgusted” by the cartoon.

He said: “A ‘lame duck’ means someone who is powerless, feeble, incompetent and ineffectual, so the association offered to the reader is: powerless, feeble, incompetent and ineffectual = user of a ramp as an alternative to stairs.

“This association is inseparable from the insulting idea that ‘wheelchair user = powerless, feeble, incompetent and ineffectual’.

“Wheelchair users are nothing of the sort. The fact that we use wheels to get around does not turn us into lame ducks.

“Would the cartoonist have dared to use, for example, a racist joke to convey his political point?

“Society is gradually getting the message that picking on, mocking and laughing at black people, gay people, Jewish people, Muslims, and many other minorities is absolutely not acceptable.

“But, as this cartoon clearly shows, there is still a feeling that picking on, mocking and laughing at disabled people is fine. This has got to stop now! It is emphatically not fine.”

Disability activist Alice Kirby was also appalled by the cartoon.

She said: “I’m utterly disgusted that this cartoon was published.

“Not only does it imply disabled people are weak and impotent, it aims to insult Theresa May by likening her to a disabled person.

“Furthermore it’s a clear breach of the Evening Standard’s [own code of conduct](http://www.standard.co.uk/incoming/code-of-conduct-complaints-7467885.html), which prohibits both discrimination and pejorative references to disabled people, something I’d have thought George Osborne would have been aware of, given his position.”

Labour politician Pam Thomas, a member of Liverpool City Council and herself a wheelchair-user, told DNS: “The cartoon itself and George Osborne retweeting it, show a deep disrespect toward disabled people.

“This level of disrespect is so much a part of our culture that they probably haven’t even realised how it can contribute to an environment where disabled people are excluded, viewed as not equal citizens and targeted for hate crime.”

She said that the progress towards equality made under the last Labour government was “swept aside as if [it] had never happened” after 2010, while Osborne was chancellor, and with it “went financial life support for disabled people, funding for our organisations and academic research into disablist practices.

“So in some ways we shouldn’t be surprised that Osborne is clueless about how disabled people have to fight every single day against exclusion and discrimination.”

Doug Wills, the Standard’s managing editor, said in a statement: “We are sorry if the cartoon has upset some readers.

“It was certainly not the aim of our cartoonist for his drawing to be interpreted this way.”

But he refused to say if Osborne and the newspaper understood why the cartoon was so offensive to disabled people.

**13 July 2017**

**Project aims for inclusion and a collective voice for ‘spoonies’**

Disabled activists behind a pioneering new project are aiming to build the first organisation that will give people with chronic illness the chance to have their voices heard outside their own “social media bubble”.

The Chronic Illness Inclusion Project [plans to recruit people with chronic illness](http://centreforwelfarereform.us14.list-manage.com/subscribe?u=7c70c97c9339ab0c59ade90c4&id=7303002384), develop a manifesto for social change, and ask how the internet and social media can provide them with new possibilities for “participation, organisation and action”.

The aim is to “forge a collective voice” for the online chronic illness community, and find a place for them under the umbrella of the wider disability movement.

Catherine Hale, the project’s manager and lead researcher, said they planned to build on the work of groups such as [The Broken of Britain](http://thebrokenofbritain.blogspot.co.uk/), [Spartacus Network](https://spartacusnetwork.wordpress.com/) and [#MEAction](http://www.meaction.net/), and the community of [“spoonie”](http://www.shapingourlives.org.uk/resources/shared-resources/on-spoons-and-spoonies) activists who have developed an online “badge of identity” through social media.

Despite the growth of this community, Hale said that those who identify as spoonies or as people with chronic illness were still “largely invisible to the ‘real world’ because social media often acts as an echo chamber.

“The challenge is to move beyond the echo chamber and have our voice heard.”

As she says [in a blog for Shaping Our Lives](http://www.shapingourlives.org.uk/resources/shared-resources/on-spoons-and-spoonies): “The trouble is no one outside of our social media bubble knows who we are.

“We’re doubly invisible. We mostly can’t go out into the world to tell people about our lives. And when we do go out into the world our impairment is generally hidden.”

She believes the project is the first attempt to “consciously bring the issue of chronic illness to the fore, the first attempt to forge a collective voice that cuts across diagnostic labels, and work out where we fit within the disabled people’s movement.

“It’s very exciting because I know there’s great interest out there in doing this. It’s daunting because, well, we’re all ill and organising anything poses huge challenges.”

She said she hoped the project would help to build a new movement that would have a place “under the broader umbrella of the disability movement”, which she said has so far not recognised or involved such groups as well as it could.

She said: “To me, ‘chronic illness’ is not an alternative or competing framework to ‘disability’ and the social model of disability.

“It is simply a form of impairment, like neurodiversity or visual impairment, that needs better recognition within the disability movement as well as wider society.”

Among the aims is for those participating in the project to develop a manifesto for social change, which might present policy priorities for government, on issues such as welfare reform, employment or healthcare, or highlight issues that need to be addressed by families and communities, such as addressing social stereotypes and disablism.

The lack of understanding of the challenges faced by those with chronic illness is stark, says Hale.

She said: “The public can understand someone needing to work part time to manage a health condition.

“The public has no understanding of the lives of people who could work just five hours a week from their bed, if such a job existed; or people who can’t ‘work’ at all but who actually work incredibly hard just to keep themselves alive.

“I want these lives to matter equally.”

Although she says the hashtag #ChronicIllness on social media usually refers to “health conditions where stamina problems/fatigue and/or pain are associated with systemic impairment”, she wants anyone with a long-term health condition to [sign up to their mailing list](http://centreforwelfarereform.us14.list-manage.com/subscribe?u=7c70c97c9339ab0c59ade90c4&id=7303002384) to find out about the project.

They will set up an online forum for up to 20 of those who sign up, for detailed discussion of the experience of chronic illness and the barriers they face to social participation.

They will also survey the broader base of supporters, as part of a process among all those taking part that will lead to the co-production of a “manifesto for social change”.

The three-year project will receive £40,000 lottery funding through the pioneering user-led DRILL ([Disability Research into Independent Living and Learning](http://www.drilluk.org.uk/)) programme, and is led by Hale, who has had ME for nearly 30 years and previously worked as a policy researcher for the Spartacus Network, [Inclusion London](https://www.inclusionlondon.org.uk/), [Action for ME](https://www.actionforme.org.uk/) and [Mind](https://www.mind.org.uk/).

She will be working with [co-investigator Jenny Lyus](http://inclusionproject.org.uk/about-us/jenny-lyus-biography/), herself a disability rights and ME activist.

[The project](http://inclusionproject.org.uk/about-us/) is also supported by an expert committee of people – including the artist-activist Liz Crow and the researcher and activist Dr Sarah Campbell – whose lives have been severely affected by chronic illness, and supported by the [Centre for Welfare Reform](http://www.centreforwelfarereform.org/).

**13 July 2017**

**Labour silent on access for disabled MP excluded from debates**

The Labour party has refused to say if it will take any action to support a newly-elected disabled MP who has been prevented from taking part in some House of Commons debates because of access barriers.

Disability News Service (DNS) reported last week how Labour’s Jared O’Mara had been unable to attend a couple of debates in the Commons chamber because there were no seats free and he cannot stand for longer than five or 10 minutes.

O’Mara, who was elected for the first time in Sheffield Hallam last month, [told DNS last week](https://www.disabilitynewsservice.com/disabled-mp-forced-to-miss-commons-debates-because-he-has-nowhere-to-sit/): “There has been a couple of times where I have not been able to get a seat and so I have not been able to attend.

“The thing is with the Commons chamber, it is 650 MPs but there’s not 650 seats, so for busy events… there’s not enough seats for everybody. It’s ridiculous in this day and age.”

The story caused outrage among many on social media, with Twitter and Facebook users branding it “shocking”, “grotesque”, “ridiculous”, “appalling” and a “disgrace”, while another said the Commons was “not a seat of #democracy unless everybody can sit in it”.

Another said: “The thought of a disabled MP with nowhere to sit during a Commons debate takes my breath away.”

But one disabled person, who said he previously worked in parliament, was critical of O’Mara.

He said on Twitter that the MP could obtain a “prayer card” from a member of Commons staff, which he could use to reserve a seat for the remainder of that day if the chamber was likely to be busy.

When asked what steps it was taking to ensure that O’Mara was able to take part in the work of parliament whenever he needed to, a Labour spokesman said in a statement: “Parliamentary authorities should take the concerns of Members of Parliament with disabilities seriously and make every effort to ensure they are able to carry out their jobs effectively.”

Asked whether this meant it was taking no action to support O’Mara to address this access issue, the party had failed to reply by noon today (Thursday).

The House of Commons refused to comment last week on the issue of seating in the chamber.

It said instead that it “aims to provide a positive, inclusive working environment where people are valued for the skills and experience they bring to work, whilst being representative of the society they serve”, which means “making parliament more accessible, diverse and free from discrimination and meeting the requirements of the Equality Act 2010”.

**13 July 2017**

**DPAC set for week of protests over social care, Atos and access to transport**

Disabled activists are set to lobby MPs this week on the urgency of the social care crisis, as part of a week of action that will take place across the country, including a protest outside the Olympic Stadium.

The highlight of [the week of action](https://dpac.uk.net/2017/07/2017-dpac-week-action-summerofdiscontent-notonemoreday-cutskill/) planned by Disabled People Against Cuts (DPAC) is likely to be the parliamentary lobby, on Wednesday (19 July), in which campaigners will try to persuade MPs to address the funding crisis which has seen many working-age disabled people experience cuts to their social care packages.

This year’s general election campaign saw politicians, and the mainstream media, focus on the social care needs of older people, and almost completely ignore working-age disabled people.

A DPAC spokesperson said: “Theresa May has promised a consultation on social care later in the year but disabled people battling cuts to essential daily support need concrete action now.”

The lobby will take place as MPs take part in the last prime minister’s questions before parliament’s summer recess.

But DPAC’s week of action will also see a renewed attempt to highlight the damage caused to disabled people by the actions of the Department for Work and Pensions contractor Atos.

The week will begin tomorrow (Friday) with a protest on the Olympic Park, in east London, with DPAC organising its own “opening ceremony” as the World Para Athletics Championships begin.

It plans to make sure those attending the athletics event know that Atos is an international partner of the International Paralympic Committee, and will be providing IT services at the championships, while DPAC will also be “drawing awareness to the issues that disabled people are experiencing”.

The week of action will end on Friday 21 July with a protest outside the Atos headquarters in Triton Square, London.

Previous protests in Triton Square have focused on the company’s government contract to carry out work capability assessments, a process that researchers, activists [and the Equality and Human Rights Commission](https://www.disabilitynewsservice.com/disability-rights-have-regressed-in-nine-areas-says-ehrc/) have concluded has caused significant harm and distress to many of those being assessed, and has also been linked to the deaths of many disabled claimants.

Atos itself was viewed as being responsible for many of those failings.

But although Atos quit the WCA contract in 2014, it is now developing a similar reputation for the way it carries out another assessment contract, this time for the government’s new personal independence payment (PIP) benefit.

[A major DNS investigation](https://www.disabilitynewsservice.com/election-forces-mps-to-abandon-pip-inquiry-but-evidence-backs-up-dishonesty-claims/) has uncovered scores of cases in which claimants have described how Atos assessors – and those from the government’s other PIP assessment contractor, Capita – have produced dishonest reports after carrying out face-to-face assessments.

Ellen Clifford, a member of DPAC’s national steering group, said: “Atos have had it easy. The way they have been treating people has been with continued utter contempt, so we need to focus back on them.

“We haven’t been back to Atos HQ for a while so we thought it was time we went back.”

[A national day of action](https://dpac.uk.net/2017/07/dpac-local-actions-july-18th/), on Tuesday (18 July), will see local DPAC groups organise their own actions on issue that are important to them, with many protests likely to focus on cuts to social care, Atos and its PIP assessments, and disabled people’s right to access public transport.

There will also be a national action outside the Department for Transport’s offices in London, on Thursday (20 July), to highlight how increasing moves towards “driver only operated trains”, and the removal of both guards from trains and rail staff from stations, threaten disabled people’s freedom to travel.

Those taking part will be delivering [a petition](https://www.change.org/p/department-for-transport-disabled-people-demand-guards-on-trains) to the government, which will demand that every train has a “safety critical” guard.

Clifford said DPAC was likely to focus its efforts over the next year on “trying to get the Tories out” and help to “finish them off”.

She said: “That is it explicitly, because they are very weak at the moment.

“Across the anti-austerity movement and the trade union movement there is a push now following the election result to finish them off, and so next week is part of that.”

**13 July 2017**

**Purple boss raises concerns over Disability Confident accreditation**

New concerns have been raised about the government’s Disability Confident employment campaign, after a leading disabled social entrepreneur said that some businesses could be finding it easier than intended to secure the highest level of accreditation.

Mike Adams, chief executive of [the social enterprise Purple](https://wearepurple.org.uk/), said he was concerned that some organisations providing Disability Confident accreditation might not be as strict on potential “leaders” – the highest of the three Disability Confident levels – as they should be when carrying out the validation process.

Disability Confident has previously been heavily-criticised, with critics arguing that it is easy for employers to sign up to the scheme, but still continue to discriminate against disabled people.

The Department for Work and Pensions (DWP) [has itself been validated as a Disability Confident leader](https://www.disabilitynewsservice.com/dwp-declared-a-leading-disability-confident-employer-despite-un-rights-violations/), despite being found guilty of “grave and systematic violations” of the UN disability convention, and a Civil Service survey showing that more than 1,400 disabled DWP civil servants had claimed they had faced discrimination in the workplace.

Purple offers a strict, detailed accreditation process for employers that want to be approved as Disability Confident “leaders”, but Adams fears that other organisations offering accreditation are making the validation process far easier.

He said he believed there was a “quality assurance issue” over how validation is carried out, and that the government had not been clear enough about which organisations can carry out this process.

Adams said that Disability Confident would only work if the organisations carrying out the level three validations were as thorough in their demands as Purple is.

The organisations carrying out the validation might not even be accredited themselves as a Disability Confident “leader”.

Adams said: “The issue is, it is not in the public domain who did the validation.

“If Disability Confident is going to be the driver that the government want, then it has got to set out its real credentials around what it is and how people get it.

“We have had people come to us and go, ‘Your template is a bigger hurdle than the template DWP use and you’re charging us. We could go somewhere else and get it for free and the hurdle’s not so big.’

“And we go, ‘Well, don’t come to Purple then.’ We’ve done that on a number of occasions.”

Adams said he still believed that the government had “missed a trick” by not insisting that organisations should also be accredited on how “disability confident” they are in the relations with their disabled customers, and not just on their disability recruitment and employment policies and procedures.

He is still pushing the government on this issue.

But he does still believe that Disability Confident is a useful way of having “different conversations with businesses”.

Only last week, one of the organisations that Purple has validated as a Disability Confident “leader” said that it was about to appoint its first disabled employee as a result of being “inspired” by the training they had received from Purple.

He said: “On some levels you can say Disability Confident is just a bit of paper, but what we are starting to see is real changes, real impact on the ground.

“In the organisations that we have a relationship with, we are starting to get traction.

“If you come to Purple and we take you through Disability Confident, we scrutinise everything that gets said and we ask challenging questions, and we expect them to have an action plan.”

A DWP spokesman said: “We frequently hear from employers, disabled representative groups, and disabled people themselves that Disability Confident is a big step forward from what went before.

“It is much more comprehensive, assessing a wide range of practices and procedures that employers need to follow to successfully recruit, retain and develop disabled people, and coupling that with advice, guidance, case studies and more so employers can get better.

“Disability Confident has always been seen as a journey. Employers can progress up through the levels, but even if they reach DC Leader stage we encourage them to continue to develop and improve their practices.

“And the scheme itself will continue to develop to ensure it keeps up to date with best practice and continues to be respected and valued.”

He added: “Mike Adams was part of the original task group that developed the Disability Confident scheme and keeps in touch with the department about further possibilities for developing the scheme.

“He has raised these and other points with us and we will work with him and other experts to consider them and see where it makes sense to incorporate them.”

Adams was speaking as Purple launched a new campaign to encourage retail and hospitality businesses to provide disability awareness training to their in-store staff, and to sign up to Disability Confident.

[Help Me Spend My Money](https://helpmespendmymoney.com/home/) has been backed by the shopping centre owner intu, Marks and Spencer and the Institute of Directors.

It calls on businesses to sign up to Purple’s charter, which commits them to provide disability awareness training to instore staff, provide an accessible website, provide key customer information in large print, Braille, and easy read formats, and sign up to Disability Confident.

And it points out that – [according to the Extra Costs Commission](https://www.scope.org.uk/Scope/media/Interim-report/Extra-Costs-Commission-Final-Report.pdf) set up by Scope – three quarters of disabled people have left a shop or deserted a business because of poor disability awareness or understanding.

Adams said that that research was backed up by the disabled people and their families that he spoke to in the day he spent at intu Lakeside shopping centre when launching the campaign last week.

They described how retail staff would often “swerve down the aisle to avoid having to meet a disabled customer” because of a fear of “saying something that is unintentionally offensive or wrong”.

He said: “What we have been saying is that can be rectified through your customer service training that you should be having anyway.”

Adams said that organisations that sign up to the charter “absolutely have to do something”, rather than just express support for its principles.

He said that “investing in disability confidence isn’t just about social responsibility, there’s also a big commercial opportunity to be had if you get it right”.

[Almost exactly a year ago](https://www.disabilitynewsservice.com/jobs-focus-and-dropping-user-led-status-could-usher-in-new-purple-reign-says-adams/), Adams announced that the disabled people’s organisation (DPO) he ran, ecdp, was ending its commitment to being a user-led charity in a bid to become a national player in the employment support market, and was relaunching as Purple, a community interest company.

A year on, Adams says he has no regrets about extending the services the organisation offers away from a focus solely on providing services to disabled people and towards also finding disabled people permanent jobs and supporting businesses to become Disability Confident.

Despite that change in focus, Purple – which no longer calls itself a DPO, although three-quarters of its board are still disabled people – has secured disability-related contracts worth more than £650,000 in the last two months, including direct payments support contracts in both Essex and Cambridgeshire, and it is hoping to secure another direct payments support contract in the north of England.

Adams said: “Our absolute commitment to the legacy services, of what ecdp stands for, absolutely remains, as we build the offer to business as well.”

**13 July 2017**

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