**‘Shocking’ case of disabled woman trapped in care home that wants to evict her**

A young disabled woman has been unable to leave a residential home for nearly three weeks because its managers are trying to evict her for complaining about her care, and for her attempts to enjoy a proper social life.

Lakhvinder Kaur, who has spinal muscular atrophy, says she has been “fighting non-stop” for seven years to secure a proper care package that will keep her safe, and allow her to live in her own home, manage her own support, and enjoy the typical social life of a young woman in her 20s.

Instead, she has had to move from one inappropriate care home and supported living setting to another since she turned 21.

Her current care home has raised objections to her organising birthday parties, and occasionally inviting friends over for late-night drinks.

It has also objected to the 28-year-old’s demands that she be supported by female staff who are properly trained to assist with her personal care needs.

Because she has nowhere else to go, and fears moving to another care home that she believes is unsafe for her – which her council insists is suitable – Kaur is refusing to leave the building.

Managers at the home say they will change the security code on the entrance if she leaves the building, and have already tried twice – unsuccessfully – to persuade the police to evict her.

The care home’s threat – and her lack of a support package – means she is unable to attend the funeral of her cousin, who died last week in Wales.

She has also now been told that staff will only provide her with reheated frozen food – which puts her health at risk – until she leaves.

Kaur says the forced move to a second care home would put her social life, her job – and her life – at risk.

She is being supported by the disabled women’s collective [Sisters of Frida](http://www.sisofrida.org/) and two of its co-founders, Michelle Daley and Eleanor Lisney.

They say her “shocking” story “raises serious questions about not just the quality and services of many care homes across the country – particularly for people who are scared to speak out about their conditions – but about how their customers are respected and valued”.

All she wants, she says, is to live in her own home with her own tenancy, with a package of direct payments that reflects her significant support needs and allows her to employ and manage her own well-trained support staff.

But she is now being forced to move to yet another care home, one she believes is so inaccessible that it puts her safety at risk, and even though its managers have said they do not believe they can meet her high support needs.

In a complaint she has lodged with Newham council, she says: “As an Asian disabled woman, being forced to live in a care home or supported living dehumanises me and disconnects me from my community and the everyday life of society, and hinders any aspirations and life chance opportunities I may have.

“This is my cry for help – I refuse to move from one care home to another care home.”

She currently receives just three-and-a-half hours of support a day, and another one-and-a-half hours at night, which means she only has enough support while at work for care home staff to take her there, support her to use the toilet just once, and then bring her home again at the end of her shift.

She was even told by her social worker that instead of receiving the support she needs to use the toilet, she should use incontinence pads or have a catheter fitted, even though she does not have a problem with incontinence.

The care home where she currently lives wants to evict her because it cannot cope with her demand that the staff who provide her care must be appropriately trained, which involves learning the strict, step-by-step routines that are needed to keep her healthy and safe.

Managers at the home have also said they cannot cope with her attempts at enjoying a social life.

They complained that she organised a birthday barbecue last year, which took place in the building’s car park and was attended by friends and fellow residents.

They also complained that she invited 20 friends to her flat for a late-night party, and that she has had friends visit her after her “curfew”.

Kaur said: “They have given me a ‘curfew’ of midnight, but I work, my friends work and sometimes we finish at 11pm.

“It has happened three times while I have been here that my visitors have left at 4am.

“I am 28 years old, not 12. I feel like I have lost out on my 20s.”

She fears the council’s failure to provide her with the support package she needs will make it impossible to continue with her customer service job in the hotel industry.

Her boss – who she says has been very understanding – has placed her on annual leave while she tries to secure a reasonable support package and an accessible place to live.

The care home that the council want her to move to is even further from her friends and family, and she says it is unsafe and inaccessible.

The bathroom is too small for the equipment she uses, and has no step-free shower, and the system to call for assistance is inaccessible to her, so she will be unable to call to be turned in bed at night, which must be done to prevent fluid draining into her lungs and causing potentially fatal chest infections.

There is also no specialist bed, which she needs to support herself, and she would be unable to operate the locking system on the door to her room.

Even the main entrance to the home would be inaccessible to her without assistance.

Daley and Lisney told DNS that, as a young disabled Asian woman, the discrimination she is facing “crosses many equality strands”, and violates both article six (on disabled women) and article 19 (on independent living) [of the UN Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html).

They said they believed that her experience was “not a one-off” and “reinforces what we already know, that when residents speak up about poor and unfair services they are highly likely to be evicted.

“It’s easy to evict a care home resident because they have no tenancy agreement. They are basically living under a hotel service.

“The reality is that a care home owner does not want complaining customers.”

They questioned why she was not being offered the opportunity “to live in her own home and have her own care package, which she has control of”.

They added: “The worrying thing here is the local authority appears to be not taking its responsibilities seriously.

“Their recommendation is to refer Laki to another care home, which Laki believes will put her health and safety at risk.

“Laki is a young disabled Asian woman who has particular concerns, based on her needs and identity, which must be taken seriously and should not be ignored.

“One of the things which led to her eviction was that she requested female staff, and for them to be trained in assisting with her personal care needs.

“By doing so she has been labelled as problematic – this is shocking!”

They said they feared the situation she is facing increases the risk of harm to her health and well-being, and could lead to her losing her job.

They said: “She is in fear that if she leaves the care home she will not be able to regain access because the key code will be changed.

“She has been told to present herself as homeless, but how can she do this when her care package is locked into the care home and she fears that she will have no-one to assist with her personal care needs?

“This is a horrible story which we would not be expecting to read about in the UK.

“Newham is a flagship borough for its work on inclusion and in this case we are disappointed that it has seriously let down one of its residents.”

A spokeswoman for the care home said in a statement: “Providing residents with the most appropriate package of care is core to the ethos of our business.

“In this case the needs of one service user need to be balanced with the safe and efficient operation of the home for all other users.

“We have been working closely with the local authority which has found alternative accommodation with the necessary support that better suit the service user’s needs.”

A Newham council spokeswoman said: “We have been working closely with Ms Kaur to ensure the care and support she receives meets her needs.

“She has an allocated social worker who has been supporting her to review all her options.

“We know she wants to live independently and this is something we are actively exploring.

“She has highly complex care needs and finding a solution to enable her to live independently in the community is not easy.

“We are investigating whether direct payments could assist with this and will update Ms Kaur once we have completed all our assessments.

“The current accommodation we have found for her is an interim measure until there is a long-term plan in place.

“A full assessment has been completed on the interim accommodation sourced for her and was found by the provider to be suitable for her needs. We will carry out an additional review of this accommodation.”

But Kaur said: “I am totally devastated by the way my case is being treated.

“I am being placed out of borough and being forced to live in a care home with people three times my age, placing me at risk of losing my job and forcing me to compromise my health, safety and well-being.”

**9 November 2017**

**University apologises after asking social model critic to deliver first ‘Finkelstein lecture’**

A university has been forced to remove the name of a pioneer of the disabled people’s movement from an annual series of lectures, after it invited a leading critic of his work to deliver the first talk.

The University of Leeds decided to launch the Finkelstein Lecture Series on Equality and Social Justice in memory of Vic Finkelstein, the disabled academic and anti-apartheid campaigner [who died six years ago](https://www.disabilitynewsservice.com/movement-mourns-father-of-social-model/) and whose ground-breaking work laid the basis for what became known as the “social model of disability”.

But the decision to launch the series – [which “celebrates scholars working at the intersection of academia and activism”](http://webcache.googleusercontent.com/search?q=cache:dGHB1z4wnQgJ:www.sociology.leeds.ac.uk/events/2017/the-finkelstein-lecture-series-on-equality-and-social-justice-professor-tom-shakespeare+&cd=2&hl=en&ct=clnk&gl=uk) – and invite Professor Tom Shakespeare to deliver the first lecture, was made without any consultation with Finkelstein’s family or his closest academic colleagues.

The university decided to use Finkelstein’s name in recognition of his contribution to its School of Sociology and Social Policy between 1994 and 2008 as a visiting senior research fellow.

But it has now removed his name from the event after four of the academics he worked with most closely, themselves all key figures in the field – Professors Mike Oliver, Colin Barnes, Len Barton and John Swain\* – wrote to the university’s vice-chancellor to ask him to “urgently” reconsider the plans.

They said in the letter last week: “We have worked closely with [Vic Finkelstein], individually and collectively… and a central tenet that has guided his own work throughout this time has been ‘nothing about us without us’.

“This planned series totally ignores this and we can say with certainty that Mr Finkelstein would not have consented to these plans.”

Although the lecture was set to go ahead this evening (Thursday), all references to Vic Finkelstein [have now been removed from the event](https://www.eventbrite.co.uk/e/equality-and-social-justice-lecture-series-professor-tom-shakespeare-tickets-37937847122).

The lecture was being co-hosted by the university’s Centre for Disability Studies, but it stressed that it had no involvement in launching the event or in inviting Shakespeare to deliver the lecture.

Oliver was the first academic to be appointed as a professor of disability studies and it was he who described Finkelstein’s redefinition of the fundamental principles of disability as “the social model of disability”.

He worked with Finkelstein for more than 30 years on various projects, and the three other professors had all worked with or for Finkelstein for more than 20 years before his death in 2011.

Oliver told Disability News Service (DNS) yesterday (Wednesday) that the choice of Shakespeare to deliver the first lecture was “wholly inappropriate” because he had been so critical of Finkelstein’s work, including in his book Disability Rights And Wrongs.

He said Shakespeare had once said in a lecture that the social model “should be thrown out of the window”, and then pointed outside.

Disability Rights And Wrongs was, he said, “an attack on Vic’s work and my work, saying the social model is wrong and it’s time we got rid of it”.

He also said that Finkelstein had “no time” for the kind of “qualitative” research that Shakespeare was planning to talk about in his lecture.

Oliver is close to Finkelstein’s family and he said they had confirmed that there had been no discussion with them about the lecture series.

He also pointed out that the university had previously rejected a request by Colin Barnes – another key figure in the movement – for Finkelstein to be awarded an honorary doctorate.

Oliver said he and his three fellow academics had heard nothing from the university’s vice-chancellor since their letter, but saw last Friday that Finkelstein’s name had been removed from publicity about the lecture.

He said: “I am annoyed that they [used his name] and that they have not even bothered to reply to our letter, which is pretty tatty.

“All the four of us professors know is that Vic’s name is no longer on the website.”

When contacted by DNS, Shakespeare stressed that the lecture would go ahead, without Finkelstein’s name attached to it.

But he said that he would be talking about disabled people in southern Africa, which is where Finkelstein was born and raised, and that he would discuss psychology, which Finkelstein had studied.

He said: “I had no intention of disrespecting his memory or work. This feels like another attempt to close down debate. Are we really ‘no platforming’ people we disagree with?”

He added: “Talk to Leeds Uni about their choice of speaker, not me.

“Vic was a highly original thinker. He and I had very positive conversations together. I never ‘attacked’ his work, I debated it.

“In a world with many huge issues for disabled people, this is a non-story.

“The research on which I am reporting gives voice to over 100 disabled African people. That seems an appropriate way of marking Vic’s memory [he was born and raised in South Africa and was imprisoned for anti-apartheid activities, before coming to Britain in 1968 as a refugee].

“As you know, the lecture is now going ahead but not in honour of Vic. So they got their way. End of story. No further comment.”

A University of Leeds spokesman said: “We recognise the sensitivities involved and regret any upset caused.

“We removed references to Mr Finkelstein from the event after being made aware of the unhappiness of his family and former colleagues.

“The new Equality and Social Justice Lecture Series organised by the School of Sociology and Social Policy reflects the university’s commitment to celebrating and promoting debate.

“We would like to clarify that the Centre for Disability Studies was not involved in the choice of speaker for the event or the original decision to associate it with Mr Finkelstein’s name.”

*\*Mike Oliver is Emeritus Professor of Disability Studies at the University of Greenwich; Colin Barnes is Emeritus Professor of Disability Studies at the University of Leeds; Len Barton is Emeritus Professor of Inclusive Education at University College London’s Institute of Education; and John Swain is Emeritus Professor of Disability Studies and Inclusion at the University of Northumbria*

**9 November 2017**

**Disabled people ‘will go into government alongside Labour’, says McDonnell**

Disabled people and their organisations will “determine” and “implement” the disability policies of the next Labour government, the shadow chancellor has promised a national conference.

John McDonnell told the National Disabled People’s Summit that disabled people would “go into government just as much as we do when that election comes”.

He said: “You can also rest assured that when we go into government, whenever this government falls, it will be you that will be determining our policies, it will be you that will be involved in implementing them, because we believe that principle for disabled people of ‘nothing about us without us’.”

McDonnell [made a similar pledge last year](https://www.disabilitynewsservice.com/mcdonnell-promises-dpac-a-seat-at-the-heart-of-government/), when he promised that organisations like [Disabled People Against Cuts (DPAC)](https://dpac.uk.net/) would be “at the heart of government, sitting alongside ministers and others, advising them on how to implement… policies”.

Up to 200 Deaf and disabled people attended the summit, which brought together disabled people’s organisations (DPOs), grassroots campaigns, individual activists and unions to “pool their knowledge and experience”, coordinate the fight against austerity and “reinvigorate” the disabled people’s movement.

The conference, at the headquarters of the National Education Union in central London, was funded by unions, and co-organised by the [Reclaiming Our Futures Alliance](http://www.rofa.org.uk/).

McDonnell, whose speech was delivered through a video recording, also called on disabled people and others to continue to mobilise and demonstrate, and take direct action in protest at the government’s austerity cuts “whenever we possibly can”.

He said the government was “absolutely brutal” and had “made a specific decision that they would target disabled people for their cuts”.

He said: “They thought that disabled people were vulnerable and therefore would not fight back. We have got to show them that we are not going to take any more.”

McDonnell also paid tribute to those disabled people who had “thrown themselves into the campaign against austerity”, including DPAC and the TUC’s disabled workers’ committee.

He told the conference that it was vital to “explain in every aspect of life what this government has done to disabled people” and “expose all that is going on, all the reports, make sure they are published and publicised, make sure the research that we do is out there so that no-one should ever really say they don’t know what is happening to disabled people”.

Bob Williams-Findlay, a former chair of the British Council of Disabled People, told the conference that disabled people’s oppression “revolves around our relations with the rest of society”.

He said: “In simple terms, we want to be included in structures, systems, and practice which are managed by powers that have no desire whatsoever, unless pushed, to accommodate us, as this would threaten the status quo.

“Our movement is confronted by a huge contradiction: we want to end our oppression by entering a society created in ways that reject us at every turn.”

Williams-Findlay said this meant that the Disability Discrimination Act had to be viewed not as a victory for disabled people but as “a political defeat, because it wouldn’t deliver on our demands”.

He said the resistance struggle needed to focus not only on protesting against the cuts and reforms brought in through the period of austerity, but also on the necessity to challenge the nature of capitalist society itself.

And he said the disabled people’s movement needed to be far more radical in its approach.

He said the movement needed to be reminded that its roots were “in an emancipation struggle, and while organising, educating and campaigning are essential to this, our ultimate goal has to be social change.

“Personally, I would go further and say it requires a complete transformation of society.”

Ellen Clifford, a member of DPAC’s national steering group, told the summit that Deaf and disabled people’s work in the lead-up to this autumn’s report by the UN’s committee on the rights of persons with disabilities had shown that they should “not be underestimated”.

She said the report the committee produced on the UK’s progress in implementing the convention had shamed the government and showed “how effective Deaf and disabled people can be when we work together”.

She said Deaf and disabled people, and their organisations, had worked “extremely hard” to provide a “united message” to the UN committee.

This work – and ensuring that Deaf and disabled people’s messages were not “watered down by people with other agendas” – meant the committee members were able to “see behind the smoke and mirrors that the government representatives were spinning”, with their repeated attempts to portray themselves as “world leaders in disability”.

Clifford said: “The outcome was a damning report and public statement from the UN disability committee that never in its history has it been so worried about a country as they were about the UK today.”

She told the conference that after seven years of austerity, the government’s cuts were “biting harder than ever”, and that it was “difficult not to drown in the level of unmet need that is increasingly swamping our communities”.

Clifford said: “Deaf and disabled people’s organisations are overwhelmed by demand for support that they are not funded to provide and with nowhere to signpost people because the support services that people need just don’t exist anymore.”

She said the rollout of the government’s new universal credit benefit system was “causing even more devastation”, and social care was “being cut to the bone, leaving individuals trapped at home without access to toilet, food or water for hours on end”.

Clifford said the government had tried to “divide and rule” disabled people by “scapegoating” benefit claimants and targeting different impairment groups through cuts to Access to Work, but the campaign by [StopChanges2AtW](https://stopchanges2atw.com/) had brought together Deaf and disabled people and BSL interpreters and shown that “we haven’t let ourselves be divided”.

She also paid tribute to some of the “inspirational activists” who have died in the past year, including [Debbie Jolly](https://www.disabilitynewsservice.com/debbie-jolly-a-force-for-good-and-a-passionate-social-model-advocate/), [Sophie Partridge](https://www.disabilitynewsservice.com/sophie-partridge-friends-mourn-activist-and-performer-of-wit-wisdom-and-kindness/), [Robert Dellar](https://www.disabilitynewsservice.com/activists-mourn-robert-dellar-co-founder-of-mad-pride-and-a-tenacious-force-for-good/) and [Eleanor Firman](http://www.sisofrida.org/in-memory-of-eleanor-firman/).

And she said that one of the best ways to honour them was to “step up and escalate our campaigning”.

Although there had been an “unprecedented input” from Deaf and disabled campaigners into Labour’s 2017 election manifesto, she said, “the fact is we can’t wait until 2022 for a Labour government to be elected because there is simply too much at stake here and now, and now is the time we need to up the pressure while the Tories are as weak as they are”.

She said there was a need to “build alliances” and “bring more people into political activity because it is through collective organisation that we will win”.

But Clifford said that there was “no quick fix to the issues we face”, and that Deaf and disabled people’s oppression was “intrinsically linked to capitalism”.

And she said the only way to achieve an inclusive society “where each person is valued for their individual worth, rather than their ability to produce profit”, was to “take down” capitalism.

**9 November 2017**

**Council faces legal action after slashing woman’s post-ILF care without telling her**

A local authority is facing legal action after a “deeply concerning” decision to slash a disabled woman’s care package before it had completed an assessment of her care needs.

Hounslow council appears to have ignored its obligations under the Care Act by removing more than half of her support without even telling her what it had done.

Jane\* is a former recipient of support from the [Independent Living Fund (ILF)](https://www.disabilitynewsservice.com/dwp-report-confirms-fears-over-impact-of-ilf-closure/), which closed in June 2015. ILF had been helping Jane and nearly 17,000 other disabled people with high support needs to live independently at the time it closed.

Local authorities in England have been receiving funding from central government to cover the support previously provided under ILF, but that money is not ring-fenced and so councils have no obligation to spend it on former ILF-recipients, or even on adult social care.

Jane only found out that her support had been cut last month when her bank told her that the money Hounslow council had been paying her every month to match the support she previously received from ILF had not been paid in for the last two months.

The council’s decision meant her support package had effectively been cut from 12 hours a day to just five, despite – she says – the council recognising that she needs and has 24-hour support and has needed this for years.

The 84 hours of paid care she previously received – which has been topped up with unpaid care provided mainly by her personal assistants (PAs), which mean she is supported almost 24 hours a day – has enabled her to participate in her local community, chair three disability organisations, and even attend Glastonbury Festival to deliver a talk about disability rights.

Jane said: “It is just a complete nightmare. The way they have treated me is inhumane, disrespectful and unlawful and it has exacerbated my depression and anxiety enormously.

“It has left me feeling even more desperate, worthless, hopeless and suicidal and I keep getting panic attacks and feeling nauseous and struggling to breathe.

“I am and feel responsible to my PAs as their employer. No-one should have to work not knowing if their employer will be able to pay them at the end of the month.

“If I cannot afford to pay them they will need to find alternative employment, leaving me with even less care, as they currently do many extra unpaid hours for me, over and above their paid hours, as I need someone with me 24 hours a day, but I am only funded for 12 hours a day.

“With the council stopping the ILF element of my care, that’s effectively cutting my care support to just five hours a day.

“I was virtually housebound before I received ILF funding for the additional care I needed, and I cannot bear the thought of losing my independence and the choice and control over my day-to-day life that my carers support me to have.

“Cutting my care will leave me housebound once again, unable to contribute to or to be a part of the world around me.”

Hounslow council told Jane that it believed it no longer needed to fund any of the hours previously funded by ILF because of a court of appeal decision [in the case of another former ILF-user, Luke Davey](https://www.disabilitynewsservice.com/failed-legal-bid-shows-un-was-right-to-call-for-a-right-to-independent-living/), from Oxfordshire.

The court of appeal ruled in September that Oxfordshire County Council had been legally entitled to cut Davey’s support package from £1,651 a week to just £950, following the ILF closure.

Davey’s lawyers had argued unsuccessfully that the council had breached its duty under the Care Act 2014 to meet his assessed needs, and would breach its duty to ensure his “wellbeing”.

But in Jane’s case, Hounslow council had not even completed a proper assessment of her needs, and appears to have simply decided that – because of the Davey ruling – it no longer needed to fund support previously provided by ILF.

It previously assessed her needs in October 2015, but her lawyer says the assessment was fundamentally flawed and after he threatened the council with a judicial review, it agreed to reassess her. That reassessment has still not been completed.

Jane’s solicitor, Mitchell Woolf, from lawyers [Scott-Moncrieff](https://www.scomo.com/), said he believed the council’s actions were a clear breach of the Care Act.

He said: “What they have done is to stop the ILF element of her care package without any notice.

“They have cut her care package without having completed a lawful assessment since ILF closed and the Care Act came into force in 2015. I think this is deeply concerning.”

He is also concerned that, using the Davey case as its justification, the council may have taken a similar step with other former ILF-users in the borough\*.

This week, following the warning from Scott-Moncrieff, the council appears to have backed down – at least temporarily – and has reinstated the 84 hours per week funding, pending the completion of Jane’s assessment.

Cllr Kamaljit Kaur, Hounslow council’s cabinet member for adult social care, said: “Hounslow council carried out two legal assessments of resident [Jane] in June 2015 and November 2015.

“[She] was assessed as not requiring the additional [ILF] payments… in order to meet her care needs.

“The council is carrying out a third assessment and has agreed to re-instate [Jane’s] payments for September and October 2017 while this current assessment is carried out and until this is completed.

“[Jane] was informed of the situation by the council’s legal team in a letter, which was sent to her lawyers.

“The council is not aware of any other residents in the same or a similar situation.

“The health and wellbeing of all our residents in the borough is our priority.

“Despite difficult challenges that we continue to face because of severe cuts to the social care budget, we aim to ensure that our services meet the needs of those who need it most.”

*\*Any former ILF-user in Hounslow who has been treated in a similar way to Jane can contact Svetlana Kotova at Inclusion London by emailing:* [*Svetlana.Kotova@inclusionlondon.org.uk*](mailto:Svetlana.Kotova@inclusionlondon.org.uk)

**9 November 2017**

**Summit hears calls on direct action, assessment boycotts and hate crime**

A new handbook on direct action, a national day of action on inclusive education, and a call for healthcare professionals to boycott disability benefit assessments were among campaign ideas suggested by disabled activists at a national conference.

The National Disabled People’s Summit saw up to 200 Deaf and disabled activists discussing ways to coordinate the fight against austerity and “reinvigorate” the disabled people’s movement.

Sean McGovern, co-chair of the TUC’s disabled workers’ committee, who chaired the event, said disabled people had not “passively” accepted the attack on their rights and services over the last nine years.

He told the conference that the aim of the event was to bring together Deaf and disabled people from the trade union movement, Deaf and disabled people’s organisations, and grassroots campaigns to “find ways to better pool our knowledge and experiences” and organise joint campaigning.

He said: “We are trying to get together to build our resources together… and hopefully stop fighting battles separately.”

A key part of the event saw disabled people take part in workshops aimed at producing ideas for future campaigning across areas such as accessible transport, inclusive education, independent living and social security.

Other workshops discussed how to develop those campaigns, for example through direct action and protests, trade union organising, and using the law and media.

The conference, at the headquarters of the National Education Union in central London, was funded by unions, and co-organised by the [Reclaiming Our Futures Alliance](http://www.rofa.org.uk/).

Among the ideas suggested were the need for a national strategy and set of principles describing the aims of the disabled people’s movement, and for a new handbook for direct action protests, which would take leads from the activists’ handbook developed by the Disabled People’s Direct Action Network (DAN) and the activist toolkit used by the US disabled people’s grassroots group ADAPT.

The conference heard that there was a need to “spread protest and direct action everywhere”.

Other workshops suggested the need for a national education service that is “inclusive from the top to the bottom”, and called for a national day of action that highlights both the “good things that are happening” in inclusive education and the “threats” it is facing.

On independent living, fears were raised about the reinstitutionalisation of disabled people, particularly concerns about the number of people with learning difficulties being forced into long-stay private hospitals.

There were also calls for a legal right to independent living through a free national independent living service, paid for from general taxation, and for “real choice and control, where disabled people are in control and not professionals or social workers”.

On accessible transport, ideas for campaigns included a focus on the importance of disabled passengers being able to “turn up and go”, which the summit heard was “gradually being phased out” by train companies.

On mental health, there was a call for recognition that all people “contribute to society even if not contributing to profit”, for an emphasis on the “social causes of mental distress”, and for unions “to be able to represent people both working and not working and recognise us all as members of the working class”.

Among the campaign ideas on social security was a challenge to nurses and doctors who are members of the Royal College of Nursing and the British Medical Association, and who carry out disability benefit assessments, to “down tools and not take part” in such testing for ethical reasons.

There were also objections to Labour’s “pause and fix” policy position on universal credit, with activists demanding instead that the line on the government’s new working-age benefits system should be to “stop and scrap” it.

On disability hate crime, there were calls for more to be done to challenge and report such offences and to pursue them with the authorities “because we need charges, convictions and sentencing in order to make people confident to go down this path”.

There was also a call to “find allies in the police, Crown Prosecution Service and local authorities and elsewhere and work with them”, and to develop allies and alliances across different equality strands and build on their past successes, for example in combatting race hate crime.

Other workshops produced calls for international solidarity with disabled migrants and refugees and disabled people facing starvation in other countries; and the need for better training for union representatives, so they can provide improved support for disabled employees.

There was a recognition that cuts to jobs and services mean people are “having to work harder and faster in much more difficult conditions”; a call for regular disability arts protests; and for attention to be paid to the barriers faced by disabled people who are “intersectional”, such as black disabled women, or gay disabled men.

And there was a call for a new hub where disabled people and their organisations could share information and resources, for example on benefit assessments and appeals, as a way of taking action to “increase our knowledge of our rights, but equally importantly how we use that knowledge in our lives”, such as in day-to-day communication with social workers or service-providers or in “big strategic legal action cases”.

Ideas that came out of the workshops will now be collated and worked into a report to be published in the next few months.

**9 November 2017**

**‘Years of council neglect’ have left campaigner’s home ‘too dangerous for firefighters’**

A disabled campaigner is accusing his council of years of neglect and discrimination, after its failure to provide him with a support package left his home so full of rubbish that firefighters said it was too dangerous to enter.

Mark White says he was told by Cornwall Fire and Rescue Service in September that it will not allow any of its firefighters into his home for safety reasons.

He is terrified that he will not be able to escape if the bags of rubbish stacked around his home catch fire.

He lives in a three-bedroom terraced house which he said was supposed to be “temporary, emergency accommodation”, but he cannot leave the house because he would need an electric wheelchair or scooter and cannot get one into the building.

White, from Hayle, Cornwall, [has spent years advocating for other disabled people](https://www.disabilitynewsservice.com/jailed-conman-who-targeted-disabled-people-defrauded-hundreds/) in Cornwall, and across the country, and believes he is being punished for that work by his local authority, which he accuses of being “incompetent”, “intransigent” and “abusive”.

Cornwall County Council insists that White has been unwilling to “engage” with its services, and that it is trying, alongside other agencies, to persuade him to do so.

White told Disability News Service (DNS) that he has been asking the council to assess his needs for four years, but that it refuses to provide him with the necessary forms in an accessible format.

He has several impairments, including diabetes and mobility and sight impairments, and has asked the council to provide him with the assessment forms on a CD or a USB stick.

But he says the council has refused to do so, and instead sent him a 150-page document in a huge font (72 point) and demanded that he read it with a magnifying glass, something he would be unable to do because of the size of the stack of paper.

He says the council even refuses to send him the form in normal 12-point print so that he can scan and view it with the electronic equipment he has had installed, which magnifies text to a size he can read comfortably.

He also says that he is unable to pick his post off the floor, and so cannot respond to the council’s letters, has no money or food because his benefits have been stopped since March, and has had no access to a bath or shower for more than three years.

He said: “It seems that Cornwall council hate those who advocate for disabled people and seek to punish them in any way they can.

“I’m now so desperate I have nothing to lose and no shame left.”

White believes the way he has been treated by the council amounts to serious criminal neglect, and he has accused it of disability hate crime, lodging a complaint with the police through the anti-hate crime organisation [Stop Hate UK](https://www.stophateuk.org/).

A spokeswoman for the council, which also runs the county’s fire and rescue service, said in a statement: “The council and its partners take their responsibilities very seriously.

“Where a person has complex needs and is not willing to engage with services that have been offered, a multi-disciplinary group, which includes social workers, housing officers, representatives from the fire service, the police, health professionals and voluntary organisations will work together and with the resident to try and offer alternatives and solutions.

“In this case, many services are involved in attempting to engage with him and have been for some time.”

She said the council had “tried to engage in undertaking an assessment and support plan but have been unable to do so despite numerous attempts”, and was “happy to discuss with him other forms of technology”.

She said: “With regard to the property itself, it has been adapted for the needs of the resident and the structural element of the property and internal fire safety detection system meet requirements, however we continue to work with the resident to ensure his safety and security at the property.”

When asked about concerns raised by the fire and rescue service, she said later that “services continue to try to work with him to address issues with the property”.

She also said that the council was “unaware of any history of his work as an advocate.

“As we have said, many professionals continue to try and engage with him in challenging circumstances.”

A spokesman for Devon and Cornwall Police said: “Police received a complaint from Stop Hate UK on behalf of Mr White, and enquiries were made into this matter.

“Mr White has been informed that this does not appear to be a criminal matter.

“His complaints in relation to a number of public bodies and their perceived withdrawal of services needs to be raised directly with them, through their appropriate complaint channels.”

White insisted that he had not been contacted by the police since he lodged the complaint through Stop Hate UK.

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**Concern over government’s four-year delay on PIP ‘safety’**

Campaigners have asked why it took the government four years – and a tribunal judgement – to ensure that eligibility for a disability benefit takes proper account of whether a disabled person can carry out certain activities safely.

Penny Mordaunt, the minister for disabled people, [told MPs this week](http://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2017-11-02/HCWS218/) that as many as 10,000 disabled people could end up receiving higher rates of personal independence payment (PIP) as a result of changes made to government guidance.

Those changes reflect a benefits tribunal decision in March that found that Department for Work and Pensions (DWP) guidance was wrongly reflecting the intention of the legislation that led to PIP’s introduction in 2013.

By 2022-23, an estimated 10,000 claimants are now likely to be receiving between £70 and £90 more per week, Mordaunt said.

The new version of DWP’s PIP guidance affects how DWP decides whether a claimant can carry out an activity safely, and if they need supervision to do so.

Mordaunt said the changes would most affect claimants with conditions that affect consciousness, particularly epilepsy.

She said DWP would now examine all existing PIP cases and “identify anyone who may be entitled to more”, and then write to those affected, backdating payments to the date of the change in case law.

Mordaunt also announced that DWP had made a number of changes to “add clarity” to guidance on how claimants with sensory impairments are assessed for PIP.

Disability Rights UK (DR UK) [has now written to Mordaunt](https://www.disabilityrightsuk.org/news/2017/november/dr-uk-writes-dwp-minister-raise-concerns-about-new-pip-descriptor-activity) to welcome the decision not to dispute the tribunal decision, and to recognise its implications, and to trawl through PIP claims to see how many should be increased.

But Kamran Mallick, DR UK’s chief executive, also asked Mordaunt for details of the changes her department had made and how DWP will carry out the trawl of PIP claims, and to say whether disabled people who have been refused PIP or have lost eligibility for the benefit will also have their claims reviewed.

He also asked if DWP will be asking claimants to submit evidence to show they cannot carry out an activity safely, and how far back any increase in PIP awards will be backdated.

Ken Butler, DR UK’s welfare rights adviser, said: “DWP action aimed at ensuring disabled people are receiving their correct PIP entitlement must be welcomed.

“But it is disgraceful that after four years of PIP being in operation it has taken a legal judgment for the DWP to properly assess disabled people’s safety.”

He said DWP had refused, when designing PIP, to allow it to be paid to disabled people who need “constant supervision” to avoid placing themselves in substantial danger, as had been allowed under the benefit it is replacing for working-age claimants, disability living allowance.

Butler said this meant that many disabled people, many of whom have epilepsy, had not moved successfully from DLA to PIP, or had been awarded a lower rate of benefit.

He said it was now “essential” that DWP confirms “how it will ensure that all current PIP claimants will properly have their PIP uprated” and “that it will consider if claims from those previously refused PIP had their claims wrongly decided”.

Other social security experts called for DWP’s decision to benefit not just claimants with epilepsy, but also those with impairments such as learning difficulties, dementia, heart conditions or mental distress.

[The Benefits and Work advice website](https://www.benefitsandwork.co.uk/news/3686-dwp-starts-search-for-pip-claimants-entitled-to-more) mirrored many of the concerns raised in DR UK’s letter and said it had taken DWP “a shameful seven months to update their guidance” after the tribunal ruling.

Benefits and Work said it feared that many claimants who should now be entitled to PIP would still miss out from DWP’s trawl of claimants, particularly those who previously received no award at all.

It warned that “few claimants would trust the DWP to identify all those who should receive a higher award and [so] it would definitely be worth getting advice if you believe your case should be looked at again, especially as the DWP seem to be focussing almost exclusively on claimants with epilepsy”.

Philip Lee, chief executive of the charity [Epilepsy Action](https://www.epilepsy.org.uk/), said: “We are delighted to see the government is starting to recognise the complex needs of people with epilepsy.

“Many people with the condition could have a seizure at any time, often without warning.

“The daily risk to people’s safety needs to be taken into account.

“We know the current system is not working and is failing people with epilepsy. They are more likely to be refused PIP than those with any other health condition.”

But Epilepsy Action said there were “still a lot of questions to be answered about how these changes are going to work in reality” and there was “still more to be done to improve the PIP system to make sure people who need this extra support receive it”.

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**PA employers will not be exempt from further HMRC action on minimum wage**

Disabled people who employ personal assistants (PAs) will not be exempt from a new government scheme designed to ensure that sleep-in care workers receive the minimum wage back pay they are due, HM Revenue and Customs (HMRC) has confirmed.

Disability News Service (DNS) has been told by HMRC that some individual employers of PAs are still being investigated over their failure to pay the full national minimum wage (NMW) to PAs who had worked overnight “sleep-ins”.

And HMRC has made it clear that any arrears owed by disabled employers of PAs will eventually have to be paid.

But it is not clear whether those arrears will be the responsibility of local authorities who funded direct payments that paid for PAs, or if individual disabled employers will have to meet that liability themselves.

Other disabled employers of PAs may have funded that support themselves.

The government announced this week that it was launching [a new “compliance scheme”](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/656564/Final_Draft_Announcement_Text_updated_for_final.pdf), which will give social care employers up to a year to identify how much they owe to staff who have been incorrectly paid below the legal minimum wage for sleep-in shifts.

At the end of this period, employers who have identified arrears will have up to three months to pay workers what they are owed.

Those who decide not to opt in to the scheme will be “subject to the full HMRC investigative process”, which could lead to financial penalties, public naming and shaming, and prosecution.

The government had previously waived further penalties for sleep-in shifts underpayment that took place before 26 July 2017, and temporarily suspended enforcement action between 26 July and 1 November 2017.

[That action in July](https://www.disabilitynewsservice.com/pa-employers-are-facing-probes-into-sleep-in-minimum-wage-back-pay/) followed a high-profile tribunal ruling involving the disability charity Mencap, which found in April that many care workers should have been paid at least the minimum wage for the hours when spent on an overnight shift.

An HMRC spokesman told DNS this week that his department was not able to say how many individual PA employers were being investigated for non-payment of sleep-in NMW arrears.

But he said: “The government is aware that individuals who have used their own money, or direct payments, to fund sleep-in shifts could be personally liable for NMW arrears.

“These individuals are themselves extremely vulnerable, and the government is committed to doing all it can to prevent them from suffering financial difficulties as a result of this issue.

“However, the law states that all employers must pay NMW for sleep-in shifts, and this includes cases where an individual becomes an employer.

“The government is working with local authorities to develop solutions that enable these arrears to be paid to workers without causing financial hardship for individuals.

“Personal budget holders who have NMW arrears will be eligible for the social care compliance scheme as part of the government’s efforts to make sure that vulnerable individuals receive the support they require.”

But he added: “The Care Act sets out a number of duties on a local authority to ensure a personal budget adequately reflects personal needs.”

Asked whether this meant that HMRC believed it could be the responsibility of local authorities to meet the arrears faced by PA employers who receive direct payments, he said the government had “engaged local authorities to ensure personal budget allocations take into account the rules on NMW and when time spent asleep is working time for NMW purposes.

“The government will work with local authorities to provide appropriate support on a case by case basis and intends to carefully monitor any additional local authority spending as a result of supporting individuals and the effect on local authority finances.”

But he had not been able to clarify by noon today (Thursday) whether HMRC believed local authorities who funded direct payments could now be responsible for meeting the sleep-in shift NMW arrears of individual PA employers.

Meanwhile, Sue Bott, deputy chief executive of Disability Rights UK, [has warned](https://www.disabilityrightsuk.org/news/2017/november/govt-creates-care-worker-sleep-pay-compliance-scheme) that some disabled people are now having to cut back on their day-time support in order to be able to pay NMW rates during the night.

She said: “Although employers will have longer to deal with any underpayment of sleep-ins, the government announcement fails to get to the heart of the problem.

“Of course, PAs and other social care staff should be paid the proper rate for the job, but a direct payment must be sufficient to cover the costs.

“Unfortunately, what we are seeing is that people are having to reduce the support they have in the day to pay for support at night.

“The hole in social care funding just gets deeper every day with disabled people and older people having to pay the price through lack of essential support.”

Cllr Izzi Seccombe, chair of the Local Government Association’s community wellbeing board, said: “The fact that employers won’t have to settle any back-payment for sleep-in costs until March 2019 is helpful and buys some much-needed time to further understand the size and potential impact of the historic liability.

“But this announcement does not end the uncertainty for providers, care workers, the people they care for and their families, and those who pay for their own care or employ a personal assistant through a personal budget.

“It was misleading government guidance in the past which caused the confusion over whether national minimum/living wage should apply for sleep-in shifts.

“Now the government has clarified the position, it needs to provide genuinely new funding to deal with back-payment.”

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