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Disability benefits suspended

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shared.dataunit@bbc.co.uk

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What's the story?

Thousands of disabled people have had their benefits stopped during extended hospital stays under a rule which charities say penalises the most vulnerable.

It comes after a court case was withdrawn which had been set to challenge the lawfulness of the so-called "hospitalisation rule" through an application for judicial review.

Under this rule, a person's entitlement to the disability benefit Personal Independence Payment (PIP) is suspended if they have received care in a hospital or a similar institution for 28 days or more.

Affected families said they were needed to help care for their disabled relatives in hospital which led to extra expenses during this time.

The government says when somebody is in receipt of long-term NHS in-patient care, it does not pay benefits to stop the taxpayer from paying double.

What critics have said

Critics say the so-called hospitalisation rule particularly affects people with profound and multiple learning disabilities (PMLD) who are more likely to have lengthy hospital stays.

They say that a disability does not stop when a person enters hospital, and the costs incurred by family members - often the known carers for the person claiming benefits - are often higher during this time.

Charities also said the way the rule was applied to people detained under the Mental Health Act meant they could not benefit from the independence to aid their treatment, to which they were entitled.

Learning disability charity Mencap's head of policy, Dan Scorer, said people with PMLD were "more likely to fall foul of the 28-day rule".

The loss of financial support could have a detrimental impact on the ability of family members and carers to continue their support, he said.

Though the judicial review case had been withdrawn, Mr Scorer said Mencap would continue to work with affected people to "challenge its fairness".

Campaigners seeking to overturn the "hospitalisation rule" also point to the case of Cameron Mathieson.

Cameron was five years old when his Disability Living Allowance, the benefit Personal Independence Payment is replacing, was stopped after he spent more than 12 weeks in Alder Hey Hospital, Liverpool.

Cameron Mathieson's family fought and won a four-and-a-half-year legal battle which went to the Supreme Court.

Judges agreed the Department for Work and Pensions (DWP) had been "grossly unfair" when it stopped his payments.

Cameron, from Warrington, Cheshire, died in 2012 after he had cystic fibrosis and Duchenne muscular dystrophy, among other conditions.

What the government said in response

The Department for Work and Pensions (DWP) said this "long-standing rule" was "to avoid double provision from public funds".

It said it had not found any evidence suggesting people with PMLD were disproportionately impacted.

The department maintained that because of rising numbers of people receiving PIP, suspensions "still formed a very small proportion of the overall PIP caseload".

A spokesperson said the DWP was "committed to ensuring that disabled people get all the support to which they were entitled".

What we have provided:

We have provided figures for the total number of people whose PIP payments were suspended due to spending 28 days or more in a hospital or similar institution for each local authority for the quarter from 1 February to 30 April for each of the past three years - 2020, 2021 and 2022 - so we were comparing the same point in time. For a sense of proportion we have also provided the total PIP claims for each local authority for each of the past three financial years.

As the Secretary of State for Work and Pensions was originally named as the defendant in the application for Judicial Review, we sourced figures from The Department for Work and Pensions (DWP) only and they cover Great Britain.

The suspensions data were obtained through a request to the DWP under the Freedom of Information Act (FOI). The total claims data are the DWP's figures too and they were obtained from the DWP's online Stat-Xplore tool.

For each year and local authority, we have provided the ratio of total suspensions due to hospitalisation, to total PIP claims to give a sense of proportion.

For each year and local authority, we have also calculated which was the primary disabling condition for people claiming PIP which had the highest number of suspensions due to hospitalisation.

In some cases, several groups had the same number (because the DWP rounded its figures on suspensions) so in those instances, the conditions are in a list separated by commas. The number of suspensions for those groups is contained in the corresponding "Max" column for that year.

Notes on the suspensions data from the DWP's FOI response

The figures include PIP claims where the suspension reason was recorded as "Hospitalisation/Certain Other Accommodation" or "Hospitalisation / Other Accommodation Ongoing Enquiry" on the PIP Computer System. As well as hospitals, this also includes accommodation such as care or nursing homes, hospices, residential colleges, sheltered housing and respite care.

The DWP FOI response said to please note that the data provided reflected the position on suspensions as recorded on the PIP analytical data system as at 3 May 2022. This is subject to future revision as the Department receives more information about a claimant's situation.

The data are based on primary disabling condition as recorded on the PIP Computer System at the time the claim was originally cleared. Claimants may often have multiple disabling conditions upon which the decision is based but only the primary condition is shown in these statistics.

These figures include claims made under normal rules and special rules for terminally-ill claimants and include PIP new claims and Disability Living Allowance (DLA) to PIP reassessment claims.

Figures on suspensions less than 5 were redacted by the DWP and replaced with "#", to ensure that no data were released which could risk the identification of individuals in the statistics. Figures of 5 or greater are rounded to the nearest 10, after all calculations. Therefore, totals may not exactly equal the sum of individual values.

Our findings:

The total number of PIP suspensions under the hospitalisation rule has increased from 30,860 at the end of April 2020, to 45,850 at the end of April 2022.

The highest numbers of suspensions were for groups of people with mental health conditions listed as their primary disabling condition e.g. "Schizophrenia" had the most in each of these three years followed by "Learning disability - Other / type not known".

INTERVIEW QUOTES:

Carolin Ott (she/her), the solicitor at law firm Leigh Day which represented Cameron Mitchell in the [now-withdrawn] application for judicial review, said:

"Our client's case was withdrawn due to a change in his personal circumstances. However, that change in circumstances did not alter the underlying issues put forward in our client's case that the hospitalisation rule is unlawful, in particular on the basis of its impact on social and dignity related needs, and access to an adapted mobility vehicle."

Dan Scorer (he/him), head of policy at Mencap, the learning disability charity, said:

Why was Mencap supporting the original application for permission for judicial review – how does the hospitalisation rule affect people with PMLD/severe learning disabilities in particular please?

Mencap was supporting the legal case because we do not believe it is right that extra costs disability benefits are withdrawn from disabled people, with some of the highest support needs, after they have spent 28 days in hospital.

This is because the financial support the benefits provide, is still needed to support the person and their family members/carers throughout the hospital admission.

We understand that the current [legal] claim has been withdrawn, but we remain committed to working with people impacted by the policy to challenge its fairness.

While the NHS is taking steps to support family carers and acknowledge the important role they play in contributing to successfully managing hospital stays for their loved ones with a learning disability, the benefits system has this arbitrary 28-day cliff edge after which support is stopped.

People with profound and multiple learning disabilities have a profound learning disability and several co-existing disabilities (sensory, physical and mental) and are likely to be using or developing skills that generally appear at a very early stage of development. This group of people are more likely to need lengthy hospital admissions due to their often-complex health needs and due to the complexity of the barriers they face in communicating their needs, rely heavily on family members and carers, who know them well, to advocate for them and support them in the hospital environment and to tolerate medical interventions.

This group are therefore more likely to fall foul of the 28-day rule, yet the loss of financial support can have a detrimental impact on the ability of family members and carers to support the person at a key time, throughout a lengthy hospital admission.

How is this linked to your Treat Me Well campaign please?

The Treat Me Well campaign has focussed on key aspects of healthcare that need to be improved for people with a learning disability. It has focussed on reasonable adjustments - extra time, accessible communication and also the importance of working with people with a learning disability and their families and carers.

Where a person has communication needs, or lacks capacity to make decisions about their care, the role of family members and carers is central to supporting and advocating for a person whilst they are in hospital. We do not want the benefits system to work against family members being able to provide this vital support and believe the withdrawal of DLA/PIP after 28 days in hospital fails to reflect the extra costs that family members will sustain, and the vital support family members play as partners in care. We believe that the benefits system, like the health system, should make reasonable adjustments based on people's support needs.

What does Mencap think to the DWP's reasoning for the "hospital rule" as articulated in the unsuccessful Mandatory Reconsideration decision given to Cameron Mitchell and Nicola Clulow (https://www.leighday.co.uk/latest-updates/news/2021-news/cameron-mitchell-launches-court-challenge-to-loss-of-personal-independence-benefit-payments-after-28-days-in-hospital/)? "The rationale behind the cessation of benefit payments when a claimant has an extended stay in hospital is because the individual's needs are met by the state (the NHS) financially during this period. Continuing benefit payments while also supporting an individual in hospital would mean that the state would double pay for the individual's needs during this period…"

We do not agree with the DWP's claim that when an individual is in hospital that all their needs are met. Hospital staff understandably do not know a person when they are admitted and will struggle to understand, for example, how a person who is non-verbal communicates and presents. Staff are also working in a highly-pressured environment, often with vacancies on their team, and so cannot provide the level of 1:1 care that can be needed where a person with significant additional needs is staying in hospital. It is for this reason that families make such a vital contribution, knowing the person well,

being able to interpret their behaviour and communication and advocate for them, as well as meet sensory and other needs. Families maintaining this level of support costs money, yet the benefits system cuts off that financial support after 28 days.

In the attached tables you will see the DWP supplied these data on suspensions broken down by the claimants' primary disabling conditions. Which of these would Mencap describe as PMLD/severe learning disabilities?

PMLD is not recorded, so people with PMLD will be scattered across different primary

diagnosis. Most may be within the learning disability group, which at 4,980 is

one of the biggest groups.

Which of these conditions are frequently experienced in conjunction by people with PMLD/severe learning disabilities?

We would highlight the groups below as all being relevant in terms of identifying where

people with a learning disability and complex needs may be found.

Learning disability (4,980)

Specific Learning Disorder (500)

Autism (1,780)

Cerebral Palsy (420)

Down syndrome (820)

What does Mencap think about the apparent rise in these figures of PIP suspensions year-on-year due to the "hospitalisation rule"? Was that something of which you were aware before this press inquiry through anecdotal accounts?

Through advances in medicine and care, many people born with complex needs are able to survive into adulthood and indeed into older age. This hugely significant and welcome progress means that government policies and public services need to adapt to cater for the needs of people and their families. Through our work with partner organisations such as PMLD Link, we have been aware of increasing numbers of families struggling to support their adult children with complex needs during lengthy hospital admissions and losing access to benefits after 28 days.

Leigh Day puts forward the argument that the current "hospitalisation rule" regarding PIP is very similar to the "unfairness" which the Supreme Court found previously in stopping the legacy benefit Disability Living Allowance payments to the late Cameron Mathieson after he spent more than 12 weeks in Alder Hey

Hospital, Liverpool: https://www.bbc.co.uk/news/uk-england-33442942. Does Mencap subscribe to that view too?

Yes, we believe that there are strong similarities in the cases and that the level of support from family members and carers required by children and adults with learning disabilities and complex needs can be similar.

Jonathan Beebee (he/him), Royal College of Nursing professional lead for learning disability nursing, said:

“People with Profound and Multiple Learning Disabilities often have complex unique communication needs. They often rely on close relations with people who know them well to understand and interpret what they are expressing.

“These communication needs cannot be replaced by hospital staff when they are admitted to hospital, and their carers cannot stop caring. If they do their needs will likely be neglected.

“Poor understanding of the needs of people with learning disabilities has been highlighted in reports such as Learning Disability Mortality Reviews. It has also been recognised by the need for mandatory training in learning disabilities and autism coming into place for all staff across health and social care.

“Whilst this will undoubtedly improve outcomes for people with learning disabilities it will not replace the specialist knowledge that those providing direct care build up over time or fill the gap of the shortage of Learning Disability Nurses in the NHS.”

Asked why an individual might be unable to access care from learning disability nurses due to workforce shortages:

“We know that approximately 1/3 of acute hospitals do not have access to a learning disability liaison nurse because they do not have those roles.”

“A shortage of learning disability nurses is affecting the availability of this expertise for people with learning disabilities.”

“Family members are often unable to work due to complex 24/7 care needs. Whilst some of this can be met by hospital staff when someone is admitted, people with profound and multiple learning disabilities need to have people they can trust, that they

have built strong rapport with, who can pick up on the subtlest of behaviours that a person may use to communicate their needs".

Craig Mathieson's family won its legal bid to challenge limits on payments of Disability Living Allowance – the benefit PIP replaced - to severely-disabled children in hospital, after the experience of his late son. Cameron, from Warrington, Cheshire, died in 2012 after he had cystic fibrosis and Duchenne muscular dystrophy, among other conditions. Craig Mathieson (he/him) said:

I was not aware of the year on year rises in hospitalisations, but neither am I surprised, as those in receipt of PIP at the highest rate are also the most vulnerable. That they would be hospitalised in greater numbers during the pandemic (either through contracting COVID, or because of a deterioration in their care resulting from the loss of carers due to COVID, or a combination of related factors) seems to me a logical thing to expect and plan for.

I wholeheartedly supported this application for Judicial Review because the argument is unassailable in my view. During Cameron's case the Government argued that the rule was fair because "all of a disabled persons needs are met in an NHS hospital." This was the justification given by Ann Widdecombe to Parliament in 1991 for the 84 and 28 day rules. However during Cameron's case at the Supreme Court, the government entered into evidence, and then hastily withdrew, a statement from the Chief Policy Advisor to the DWP, in which she admitted that the department had known in 1990 that the close involvement and participation of parents and carers was essential in order to meet the needs of children in general and disabled children in particular. In fact the Government had been well aware of this fact since the publication of The Platt Report in 1955, which it had commissioned. The government voided its own knowingly false argument by that statement and by repealing the 84 Day Rule for anyone under 18 in SI 2016/556. (I am surprised that the Courts had continued to entertain an argument already proven false in near-identical circumstances.)

What does this then say about those over the age of 18, who by virtue of their disabilities, are as vulnerable and dependent as children, but who are cared for in hospitals with greater patient to nurse ratios than in any children's hospital? The answer is clear and unarguable in my submission. Their needs cannot now, nor ever have been met free of charge in an NHS hospital. However dedicated or professional the nurses are, there is a yawning chasm between what their best efforts can achieve and what their young and disabled patients require, particularly now as resource and staff shortages are increased deliberately.

It may interest you to know that in Cameron's case we argued that the legislation was irrational and disproportionate under the rules for Judicial Review, as well as relying upon Article 14, Article 1 Protocol 1, and Article 8, although the last was not addressed directly by the court, which had already found breaches under all the previous statutes and rules submitted.

As for the data, I am not a statistician, but it does not surprise me that those with the most debilitating conditions, and the greatest need for help with the hugely expensive business of being disabled in this country, would also be those most likely to be hospitalised for extended periods. The figures seem to me to illustrate that the principle at play is to give these people umbrellas, only to take them away as soon as it starts to rain.

What I believe would be far more informative than my opinion would be for the department to tell us what analysis they have carried out on this data, and what their conclusions are. After all they surely would not go to the time and trouble of collecting raw data for no purpose?

Ken Butler (he/him), welfare rights and policy adviser for the charity Disability Rights UK, said:

DR UK was aware of this legal challenge but we have not had direct contact from Leigh Day solicitors about it.

It may be that other organisations, such as Carers UK, are more directly involved.

DR UK was, however, very supportive of Cameron Mitchell's case.

His case is very similar to that of Cameron Mathieson, a five-year-old boy whose family successfully challenged in the Supreme Court the 84-day hospital rule for children's disability living allowance at the Supreme Court, which ruled in Mathieson [2015] UKSC 47 that the rule breached Cameron Mathiesen's human rights.

In that case the government's aim in suspending DLA after 84 days was to avoid overlapping provision to meet disability-related needs.

However, a range of evidence was presented to the court demonstrating that in fact the disability-related needs of children in hospital are far from being entirely met by the NHS.

The case resulted in June 2016 of the introduction of regulations removing the 84-day and 28 day payment limits for disability DLA and PIP for hospital in-patients who are under eighteen on the day they enter hospital.

The DWP was again claiming that the hospital rule is based on the principle that the needs of the claimant are being met by the NHS. So, to continue to pay these benefits after 28 days, in order to support the additional costs of having a disability, would amount to double provision of funding from the public purse.

However, this blanket rule simply does not reflect the reality of the situation in Cameron's case.

The DWP claims that the hospital rule is based on the principle that the needs of the claimant are being met by the National Health Service (NHS).

So, to continue to pay these benefits after 28 days, in order to support the additional costs of having a disability, would amount to double provision of funding from the public purse.

This position is disingenuous as it simply does not reflect the reality of Cameron's situation.

While he was in hospital, his mother and father were in daily attendance and, as his full-time carers, were on call at the request of NHS staff.

When his condition stabilised they took him on daily trips outdoors, and provided essential care such as suctioning his chest, looking after his stoma bag, and checking for hard-to-detect signs of distress and pain.

The hospital staff depended on his parents to communicate for him and identify and treat his complicated seizures as otherwise, he could deteriorate very quickly.

Cameron's care needs were not and cannot be met by the NHS alone without the input of his parents, his known carers, and those care needs did not suddenly cease to exist after he has spent 28 days in hospital.

For those disabled people whose care needs cannot similarly be met in hospital without the input of a known carer, the 28-day rule must be revoked.

Instead, where care to a disabled person is needed and provided from 28 days in hospital that cannot be provided by the NHS then PIP should continue.

In addition, any carers allowance should in turn remain.

The PIP suspension statistics you cite mean that the hospital rule is likely to be impacting on more disabled people who need additional care.

However, I'm not aware of any research that has considered the impact of the hospital rule in a similar way to the following
-https://contact.org.uk/wp-content/uploads/2021/03/dla_takeaway_2013_final.pdf

Alex Kennedy (he/him), head of campaigns from the charity Rethink Mental Illness, said:

"It's troubling that a significant proportion of people impacted by the hospitalisation rule are severely affected by mental illness. Changes in benefit arrangements can trigger significant stress and worry at a time when people should be supported to focus on improving their health, and this policy risks exacerbating the pressures people are under during this cost of living crisis. It's vital that the DWP communicates clearly to anyone impacted by this rule. This includes carers, who may still need their allowance while their loved one is in hospital.

"The sudden rise in people affected by the hospitalisation rule is a cause for a concern and the DWP must explain why this has increased so significantly. Further efforts must also be made to increase access to Mental Health Crisis Breathing Space when people are in hospital detained under the Mental Health Act. This scheme can't replace lost benefits, but it can help take the pressure off people's finances, offering legal protection from creditors for credit cards, utility bills, mortgage, or rent arrears while someone is receiving treatment. Crucially, when people leave hospital, PIP must be swiftly reinstated to help them transition back to independent living, especially as the cost of living crisis escalates."

Rheian Davies (she/her), head of the legal unit at the mental health charity Mind, said:

Q: Have we done any research on the "hospitalisation rule"/formed a position on it before?

Q: If we do believe it should change, why and what changes would we endorse?

"At Mind, we believe the basis for the 'hospitalisation rule' should not be the length of the stay, but instead the needs of the patient, and whether they continue to have care needs while in hospital."

Q: Were Mind aware of this [now withdrawn] application for judicial review and did Mind support the application?

"Mind was aware of the judicial review on the hospitalisation rule brought by Leigh Day, and we supported the application.

"The way the 'hospitalisation rule' is currently being applied is manifestly unfair, so we believe it's only a matter of time until it will be brought before the courts for judicial review."

Q: What impact specifically could the suspension of PIP benefits have for the individual and for their known carers/family members?

Q: Are there any cohorts of people who are more acutely affected by the hospitalisation rule, in Mind's experience – what impact could it have for someone who has been sectioned for example?

"People with mental health problems tend to be hospitalised for longer than those with physical health problems, and those hospitalised under certain sections of the Mental Health Act (detained against their will) can be there for several months or even years. Given people with mental health problems are more likely to be hospitalised for more than 28 days, there's a greater chance they will be affected by the 'hospitalisation rule' and have their Personal Independent Payment (PIP) stopped as a result.

"However, just because someone is hospitalised does not mean their additional financial needs are eliminated, nor that they will spend all of their day-to-day life in the hospital. For example, Section 17 of the Mental Health Act provides for people sectioned to have a leave of absence from the hospital where they are being treated. However, without the financial support from PIP, it can be incredibly difficult for those sectioned to afford the

support they require, such as for transport, and hospitals are not always able to replicate this support.

“Another group particularly affected by the hospitalisation rule are those in long term placements in community hospitals, which are stand-alone units with limited beds with clinically trained staff on hand. These facilities are considered ‘hospitals’ under the hospitalisation rule, despite the fact they are set up to allow someone to live there as independently as possible and patients can have their own bedsits or even front doors and come and leave as they please. Because of this, even though the people living in these facilities may want to go out into the community, they are denied the PIP support to help with this that they’d be entitled to if they lived at home or even another type of residential facility providing mental health care.

“The hospitalisation rule has an impact on those people who support the person claiming PIP too, such as their family and carers. Families may find a portion of relied upon household income has suddenly vanished, while costs of supporting their family member in hospital may still remain. Carers and others who are employed to help the person claiming PIP may suddenly find that their services can no longer be funded from the benefit, and needing to find other employment, which can then have a further impact on the person in hospital as they will need to make new care arrangements when they leave.”

Q: What does Mind think to the DWP’s reasoning for the “hospital rule” as articulated in the unsuccessful Mandatory Reconsideration decision given to Cameron Mitchell and Nicola Clulow (www.leighday.co.uk/latest-updates/news/2021-news/cameron-mitchell-launches-court-challenge-to-loss-of-personal-independence-benefit-payments-after-28-days-in-hospital) “The rationale behind the cessation of benefit payments when a claimant has an extended stay in hospital is because the individual’s needs are met by the state (the NHS) financially during this period. Continuing benefit payments while also supporting an individual in hospital would mean that the state would double pay for the individual’s needs during this period…”?

Q: Leigh Day puts forward the argument that the current “hospitalisation rule” regarding PIP is very similar to the “unfairness” which the Supreme Court found previously in stopping the legacy benefit Disability Living Allowance payments to the late Cameron Mathieson after he spent more than 12 weeks in Alder Hey Hospital, Liverpool: https://www.bbc.co.uk/news/uk-england-33442942. Does Mind agree with that view too?

“The Department for Work and Pensions’ (DWP) reasoning for the ‘hospitalisation rule’ is outdated. This has been apparent since the Supreme Court found against the DWP in

the 2015 case of the late Cameron Mathieson, which looked at the award of Disability Living Allowance (DLA) to children. In this case, the position of the organisations challenging the DWP was that the rule should not be based on length of hospital stay, but instead on how much financial support they require for needs to be met while in hospital.

“The Supreme Court in *Mathieson* seemed to agree with this position, specifically where children are concerned, stating that it is hard to disagree with the Citizens Advice Bureau’s reference to ‘the country’s most vulnerable people.’ The Court also said they agreed with Leigh Day about the ‘unfairness’ of the hospitalisation rule in this case, highlighting that ‘the grant of DLA (for children) is linked to the existence of disability-related needs. It is plainly legitimate to make its continuation or withdrawal conditional upon the continuation of the same needs (whether in hospital or not).’

“Mind believes that the approach taken in *Mathieson* should apply not only to children losing Disability Living Allowance under the ‘hospitalisation rule’ but also to those losing Personal Independence Payment.”

A Department for Work and Pensions (DWP) spokesperson said:

“We are committed to ensuring that disabled people get all the support to which they are entitled. It is a long-standing rule that payment of extra costs benefits, such as Personal Independence Payment, is suspended after the first 28 days in a hospital or similar institution, to avoid double provision from public funds.

“While the number of hospitalisation suspensions has gone up so has the number of PIP awards; suspensions still form a very small proportion of the overall PIP caseload.”

Background to editors from the DWP:

- Where someone has a “leave of absence” from hospital e.g. at weekends they can be paid a daily rate of PIP at the rate(s) they were receiving prior to admission.

- The 2015 Supreme Court judgment was specific to Cameron Mathieson’s case and children generally and took into account modern hospital practice for children.

- We have not found any evidence to suggest that people with PMLD are disproportionately impacted by the rule –each person with PMLD can have very different levels of need – it is a broad spectrum.

- The issues that Rethink raise are not what PIP (or any other extra costs disability benefit) is intended to contribute to. PIP helps towards the disability-related extra costs faced by people with long-term health conditions or disabilities.

BBC dataset:

https://docs.google.com/spreadsheets/d/1zR4GxlqNb7pHvqF6OAMWbBp5zSJ7_fP8Rk0UPtL6DI0/edit?usp=sharing