



**Stop the DLA Takeaway:** fairness for families when their child is in hospital

## Contact a Family and The Children's Trust, Tadworth are calling for the scrapping of the rules whereby:

- a child under the age of 16 who is eligible for DLA stops receiving payments once they have spent 84 days (which may be linked rather than consecutive)<sup>1</sup> in hospital or another medical setting. This would require changes to regulations 8, 10(2), 12A and 12B(1)(b) of the Social Security (Disability Living Allowance) Regulations 1991.
- a child under the age of 16 who first becomes eligible for DLA whilst in hospital or another medical setting is not able to start receiving payments until they have been discharged home. This would require changes to regulations 10(3) and 12B(2) of the 1991 Regulations.

### Introduction

Some of the UK's most severely disabled and sick children and their families are being denied financial assistance at a time when they need it most.

Contact a Family and The Children's Trust, Tadworth want the rules scrapped which limit payment of Disability Living Allowance (DLA) when a child (aged 0 to 15) is in hospital or another medical setting.

DLA is paid to meet the additional costs of being disabled and has a care component for people who need extra care and attention, and a mobility component for people who have problems walking or getting around.

Families use their child's DLA to meet the additional costs of raising a disabled child – care, travel, transport, heating, disability aids and equipment and childcare.

A child's DLA is suspended after 84 days in hospital, but this is linked rather than consecutive. Unless hospital stays are separated by 28 days at home, the stays will be added together. For a child who has complex health needs and is frequently in and out of hospital, this can soon add up. If a child's DLA is suspended, the parents' Carer's Allowance must stop, even if that parent continues to provide a substantial amount of care to their child whilst in hospital or another medical setting. This can affect other benefits they may receive.

A child who is in hospital or another medical setting when they become eligible for DLA cannot receive payments until they are discharged home, which in turn prevents parents from receiving Carer's Allowance.

*"I was definitely not in a position to work as my daughter needed emotional support from me and not just medical care. She would often be ill and improve when I arrived, so I felt when she became very ill that I should be there to reduce her anxiety. This important support is often overlooked."*

This can be financially devastating at a particularly difficult time. It is thought that families whose children have complex health needs are less likely to be in work and more likely to be reliant on benefits, hence they are more vulnerable to financial difficulties.

We think the rules should be scrapped because:

- Research shows that there are **extra costs** for a family when their child is in hospital or another medical setting including loss of earnings, travel, parking, childcare for siblings and meals away from home.
- The **level of care** provided by parents remains the same or increases when their child is hospitalised, with many families at their child's bedside 24/7.

We estimate that there are up to 500 reported cases of children and their families affected by this rule each year and the cost to the Government to scrap the rules would be only between £2.5 million and £3.1 million per year. Furthermore, part of this amount would be offset by savings made in reducing the administrative costs of stopping and restarting families' payments.<sup>2</sup> For a very small outlay in Government budget terms, it would make a huge difference to some of the most vulnerable UK families.

The Government has shown its commitment to widespread reform of the benefits system in its '21st Century Welfare' White Paper.<sup>3</sup> It represents a clear opportunity to overhaul the DLA regulations that are causing such difficulties to families when they are in most need of stability and support. Such a move would help the coalition Government to achieve its stated aim of "protecting the most vulnerable".

*"My son spent months in hospital and I stayed with him because he's non-verbal and I do all his care. If I'm not there, then his medications and his catheter are not done on time. I tell the doctors and nurses what my son cannot say for himself, there is no way I would ever leave him. I struggled to pay for day to day living and got into terrible debt as the DLA was stopped."*

## Financial burden on families

When a child stays in a hospital or other medical setting, their parent(s) will naturally want to spend as much time as possible supporting them.

Health professionals recognise that the presence of a parent is important for the child's wellbeing and can help their recovery.

Parents are often experts in their child's care and are sometimes required to continue carrying out the same if not increased levels of care.

Research shows that there are extra costs for a family when their child is in hospital or another medical setting<sup>4</sup>:

- loss of earnings
- travel for family members
- parking costs
- meals at hospital
- childcare for siblings.

**“My daughter was in hospital and it was costing us a great deal to be with her 24/7. The impact on the family was that it made it very difficult with much less income and we had to rely on savings and the family to help.”**

A parent's loss of earnings can be catastrophic for families. When a child is hospitalised, parents may be unable to work for prolonged periods, with no clear idea of when their child will be discharged. Employers may be flexible or exercise some compassion in giving leave of absence which is often unpaid, but some parents lose their jobs in this situation.

**“My son is in hospital and has had his benefits suspended. We are finding this extremely difficult financially as travelling to and from the hospital to visit and attend meetings is costly and the nature of his challenging behaviour means we are continuously replacing clothing.”**

There can be high childcare costs for siblings left at home. Many families are torn apart, with the main carer staying at hospital, leaving other children to be cared for by a partner or family member if they're lucky or costly childcare providers if they're not.

It is well documented that hospital car parking charges are costly for people frequently using hospitals. Patient's Association figures show that the average charge per hour for hospital car parks in England in 2008/9 was £1.09.

## Level of care

The law as it stands suggests that families are getting some form of respite when their child is in a hospital or other medical setting. It suggests that a parent's responsibilities and costs are reduced. This could not be further from the truth.

Parents are more driven to look after their child when they are unwell. If a parent has faced the possibility of losing a child, it makes them determined to protect and watch over them to prevent the unimaginable happening. Many parents stay with their children 24/7 and continue to provide the same if not increased levels of personal care to their unwell child.

Children can become very anxious when separated from their parents in an unfamiliar place and the presence of a parent can provide vital emotional support and motivation.

**“My son was in hospital and I continued to look after him when he was seriously ill. I was carrying out complex nursing tasks like changing his tracheostomy, administering oxygen, as well as feeding, dressing, playing and when he was able, ensuring his education continued. However his DLA stopped and my Carer's Allowance stopped, despite me spending a longer time than usual caring for him.”**



## Forced into a corner

A child's DLA is suspended after 84 days in hospital, but this is linked rather than consecutive. Unless hospital stays are separated by 28 days at home, the stays will be added together. For a child who has complex health needs and is frequently in and out of hospital, this can soon add up.

“(It was) bad enough being in hospital, but the added stress of dealing with money was an extra I did not need. I think the rule is wrong. If a family has to be with their child in hospital (DLA payment) should not be stopped.”

The rules undoubtedly put extra pressure on families at a time when stress levels are already very high.

It is the parents' responsibility to inform the Department of Work and Pensions (DWP) when their child is admitted to hospital, so that the authorities can calculate when a child's DLA should be suspended. It is also the parents' responsibility to inform the DWP when their child is leaving hospital, otherwise reinstatement of DLA can be delayed.

With many families pushed to their financial limits by the suspension of payments, it is not surprising that we have heard of families taking the risk of not informing the authorities.

If parents are found out, at best it will be seen as an overpayment and the family will have to pay back a lump sum or an amount will be deducted from their benefits payments until it is all paid back. And at worst the family could be prosecuted for benefit fraud.

While we would always advise families to make the proper declarations to the authorities in order that they do not falsely claim benefits, we are concerned that parents in such a dire emotional and financial situation are being put in this predicament.

“I didn't ask to become a benefit fraud, I just can't afford not to be.”

## Recognising the costs

Many families receiving DLA will also receive the disability element of Child Tax Credit and this payment continues whether a child is living at home or staying in hospital for any length of time. The implication is that while the Government understands families with disabled children should be helped to meet their additional costs, it believes these costs are smaller when a child is in hospital. However we know that the loss of earnings and costs for a family are greater when their child is in hospital.

“I slept on the floor of my daughter's hospital room and did most of her care and was penalised further by them taking away our financial help. My health deteriorated a lot after this episode.”

## Footnotes

<sup>1</sup> The suspension of a child's DLA payments after 84 days in hospital is linked rather than consecutive, meaning that unless hospital stays are separated by 28 days at home, the stays will be added together. For a child who has complex health needs and is frequently in and out of hospital, this can soon add up.

<sup>2</sup> Using figures from the Department of Work and Pensions we looked at the number of children aged 0-15 who were entitled to DLA and those that were in payment over a period of three years. The difference between the two figures is the number of children who have been hospitalised and so lose both the care and mobility components. An average of 285 were affected at any time in the quarterly snapshot. We have estimated that there will be a proportion of new cases and a proportion of recurring cases within a year, so estimate the number of families affected to be between 400 and 500. To calculate the cost to the Government to amend the regulations we used the highest possible DLA payment figure – high rate care and high rate mobility = £121.25 per week. It is unlikely that all children will be on the highest rate, but this gives us a maximum cost to Government. £121.25 x 400 or 500 gives total cost as £2.5 million to £3.1 million.

<sup>3</sup> 21st Century Welfare is a consultation from the Department of Work and Pensions, which seeks views to inform their thinking on reforms to the benefits and Tax Credits system, including the idea of a single integrated Universal Credit. <http://www.dwp.gov.uk/consultations/2010/21st-century-welfare/>

<sup>4</sup> Bliss research in 2007 showed that having a sick or premature baby costs parents an extra £189 per week on average during the time their baby stays in hospital. <http://www.bliss.org.uk/page.asp?section=00010001000900020011&search=costs+of+prem+baby>

## What families say

*“Despite having an increase in costs and the amount of care and time your child requires, the Government removes any financial help. It makes a desperate situation dire.”*

*“I am a mum of three children. My son has had a variety of complex and life threatening medical complications since he was little and his life has been peppered by hospital stays, some short, some rolling into months. This has meant his DLA and my Carer’s Allowance have been suspended a good few times.*

*“My son’s stays in hospital have undeniably had a hugely negative emotional and financial impact for us all.*

*“The costs are astronomical, not only are there the costs that I incur (extortionate hospital food or microwave meals) but there is also the daily train tickets for my two*

*other children to come and see us and childcare both day and night so they can be looked after while I stay in hospital.*

*“Parenting my son has turned me into part doctor, nurse, physiotherapist, occupational therapist, play therapist and dietician. None of my roles stop when my son is unwell enough to need to stay in hospital. In fact the reality is precisely the opposite.*

*“Despite having an increase in costs and the amount of care and time your child requires, the Government removes any financial help. It makes a desperate situation dire.*

*“At present we are in hospital. We have been here for five weeks already with no end in sight. I’m sleep deprived from doing his round the clock care and emotional from having to force my two other children home sobbing without me once again. I have £20 left in my bank account having just paid last month’s childcare costs, and I have no idea how I’m going to pay for this month’s, let alone the next meal or train ticket that is required.*

*“So am I going to let the Government know my child is in hospital this time? No, I just can’t afford to. I didn’t ask to become a benefit fraud, I just can’t afford not to be.”*

*“It’s been a really distressing time for the whole family and worries about money only added to the stress.”*

*“Our 13-year-old son Jamie was struck down out of the blue by a brain haemorrhage last year. He was rushed to hospital for emergency surgery and spent three weeks in a coma. Thankfully he pulled through and went straight from hospital to The Children’s Trust where he spent nine months on a brain injury rehabilitation programme, learning to regain some of the skills he had lost. He was discharged home three weeks ago. It’s been a really distressing time for the whole family and worries about money only added to the stress.*

*“My wife and I were determined that one of us would be by Jamie’s side throughout his ordeal but we also had to look after his younger sister at home. It meant we just couldn’t*

*work. My wife had to give up work completely and I had to take a considerable amount of time off.*

*“On top of being unable to work, there were extra costs while Jamie was away. It was a two-hour trip from home to Tadworth, so the travel costs soon mounted up. We had to buy Jamie new shoes and lots of new clothes – mostly cotton to keep him as comfortable as possible in his wheelchair. There were also just the costs of keeping ourselves going while we stayed with Jamie – you end up spending a lot more on food than you would at home.*

*“Jamie has been left with mobility needs and difficulties with his memory and communication, so even after all*

*the great progress he made at The Children’s Trust my wife will still need to remain off work to look after him now he’s been discharged home. We’ve started receiving Disability Living Allowance and it will certainly be a great help. But life would have been more bearable over these past months if we’d been able to claim it before he came home.*

*“It was such a worrying and stressful time we could have done without the additional money worries – it just heaped the pressure on us as a family when what we really needed was support.”*

## Conclusion

The DLA regulations are penalising vulnerable families at the most distressing times of their lives. Some families report that they are forced to break the law and become "benefit frauds" because they simply cannot afford to be truthful when their child is admitted to hospital.

Contact a Family and The Children's Trust understand that these are financially challenging times, but estimate the cost to scrap these rules to be no more than £3.1 million.

It is the Government's intention to simplify the welfare system, make it fairer and ensure those who most need it are getting financial assistance. Scrapping these DLA rules for children aged 0 to 15 would ensure that the welfare system was simpler, fairer and was working for the most vulnerable children and families when they need it most.

## How to support the campaign

Visit [www.cafamily.org.uk/dlatakeaway](http://www.cafamily.org.uk/dlatakeaway) or [www.thechildrenstrust.org.uk/dlatakeaway](http://www.thechildrenstrust.org.uk/dlatakeaway)

This briefing paper is being submitted to the Department of Work and Pensions' '21st Century Welfare' consultation, which proposes significant reforms to the UK's benefits system.

If you agree that the Disability Living Allowance regulations need to be changed, you can back our campaign by writing to or e-mailing the DWP consultation yourself.

You can support our campaign by going to either [www.cafamily.org.uk/dlatakeaway](http://www.cafamily.org.uk/dlatakeaway) or [www.thechildrenstrust.org.uk/dlatakeaway](http://www.thechildrenstrust.org.uk/dlatakeaway)

[www.thechildrenstrust.org.uk/dlatakeaway](http://www.thechildrenstrust.org.uk/dlatakeaway) and following the instructions to send an automatically-generated email to the Government. It will take just 30 seconds of your time but the more support we receive, the more chance we will have of making a real difference to these families.

Please note that the deadline to e-mail your support to the DWP consultation is 1st October 2010. However you can continue to support the campaign after this date by visiting the same websites and registering your support.

**The Children's Trust, Tadworth** is a national charity providing care, education, therapy and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury. We run the UK's largest rehabilitation centre for children who have suffered a serious brain injury as a result of a tragic accident or serious illness.

**Contact a Family** provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspect of raising a disabled child including help with benefits, tax credits and other sources of financial help.



[www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)  
Charity registration number 288018

**contact a family**  
for families with disabled children

Helpline: 0808 808 3555  
[www.cafamily.org.uk](http://www.cafamily.org.uk)  
Charity registration number 284912  
Charity registered in Scotland No. SC039169