



Stop the DLA Takeaway Survey Report:

fairness for families when their child
is in hospital

Summary

"When my son is in hospital I still have to pay the mortgage, pay the bills, put food in the fridge at home and pay for ready meals to heat up at hospital or very expensive hospital food. I also have to pay for someone to look after my other two children day and night. That's before the train tickets and extra accommodation so my other children can visit me and their brother in hospital. The mobile phone bills as they sob down the phone to me also have to be paid. Imagine that kind of outgoing for a week, how about a month...how about 8 months? Then imagine that expense after someone took a whole chunk of the income you rely on away."

Parent of a 6 year old boy who spent 8 months in hospital last year.

Summary

Contact a Family and The Children's Trust, Tadworth are calling on the government to abolish the rule which suspends Disability Living Allowance (DLA) when a child spends longer than 84 days in hospital.ⁱ

The government argues that DLA is no longer needed when a child spends substantial periods in hospital because a patient's needs are fully met free of charge.

However a survey conducted by Contact a Family and The Children's Trust with families whose children spend long periods in hospital provides evidence for the first time that this is not the case. Our survey found that:

- Almost all carers (99%) provide more (68%) or the same (31%) level of care when their child is in hospital compared to when their child is at home.
- 93% have increased costs relating to their child's disability when they are staying in hospital.

The removal of DLA from a child in hospital adds to the immense stress that they and their family are under. It can be financially devastating for parent carers who are continuing to provide substantial

care to their child at a particularly difficult time.

Before Contact a Family and The Children's Trust's survey, there do not appear to have been any attempt to build a national picture of whether families' costs and care levels increase or decrease when their child is in hospital. This particular DLA rule was introduced over 20 years ago. As such we believe it is now outdated and needs to be revised, particularly as more children with complex health needs are surviving and living longer.ⁱⁱ

The government has made a commitment to help the most severely disabled and those most in need. The children that are affected by this rule are among the most disabled and sick in the country. And yet financial assistance is denied to them when they need it most.

Contact a Family and The Children's Trust estimate that there are up to 500 reported cases of children affected by this rule each year in the UKⁱⁱⁱ. The cost to the government to abolish it would be between £2.7 million and £3.4 million per year.^{vi} We understand that the government is having to make tough decisions about expenditure. However this would be a simple targeted change with a relatively small cost, that could make an enormous difference to the lives of the UK's most disabled and sick children.

"Hospitalisation is a period of extreme stress where the normal money saving activities of frugal housekeeping are, of necessity, placed to one side as the family strives to aid the recovery of our disabled child. We also suffer from a loss of income over such periods as we have to prioritise staying with our daughter in hospital, whose extreme personal care needs cannot be consistently met by nursing staff. The loss of DLA under these circumstances could put our finances in a perilous state and have a negative impact on Nina's recovery."

Parent quote

Contact a Family and The Children's Trust, Tadworth would like to thank all the parent carers who completed our survey and shared their personal, often distressing experiences with us.

About the survey

"Following the removal of my son's DLA which led to the loss of our carer's benefits, we were unable to pay our mortgage payments. We were extremely emotionally and physically exhausted due to our caring role anyway and living with the fact we could lose our son. It was the most painful, long term experience and on top of this we really struggled financially. The prospect of losing our family home during this time was overwhelming."

Parent of a 14 year old boy whose DLA was suspended after spending over 84 days in hospital.

About the survey

This report is based on an online survey carried out between 17 October and 30 November 2012. It was made up of open and closed questions. We asked families whose children spend significant periods of time in hospital to take part in the research and fill in the short survey. This briefing provides a summary of the quantitative and qualitative results.

About the respondents

Our survey was completed by 104 families across all four nations of the UK.

Age of children

- 44 have a disabled child aged 0-5.
- 28 have a disabled child aged 6-10.
- 32 have a disabled child aged 11-16.
- One family's child has sadly died. He had spent eight months in hospital when he was three years old.

Disabilities and conditions

The families' children have a range of complex health conditions and disabilities.

Several respondents are parent carers of premature babies who are now living with complex health needs. The most common health conditions listed by respondents include: cerebral palsy, epilepsy, chronic lung disease, severe respiratory and feeding issues, duchenne muscular dystrophy, spina bifida, acquired brain injury, brain tumour, acute liver failure, acute myeloid leukaemia and kidney disease.

Hospital stays

In the last year 18 children spent over 61 days in hospital. Several children spent more than 100 days in hospital and three children were in hospital for the entire year.

In the last five years 49 children out of the 108 families who responded had had at least one hospital stay lasting more than 61 days.

Several children had spent more than 100 days in hospital, with one child in for more than 200 days and two for 240 days. Three children had been in hospital for an entire year.

"Parents/carers do not see a hospital stay as a chance to relinquish care of their child and therefore shouldn't be forced into poverty by an outdated benefits system. We were very lucky not to fall foul of the DLA rule but it was close on a number of occasions and I dread to think what sort of a financial position we would be in had DLA and Carers Allowance been stopped. I cannot imagine how many families are living in poverty because their child has an ongoing medical condition and it is a situation that has got to change."

A parent

Key findings

"Having a loved one poorly in hospital is emotional and harrowing and stress levels are very high. The thought of having my son's DLA removed is terrifying. The money pays for all the extra things he needs while in hospital. It's awful to think the government wants to penalise my son for being seriously ill."

A parent

Key findings

- Almost all carers (99%) provide more (68%) or the same (31%) level of care when their disabled child is in hospital when compared to when their child is at home.
- 93% have increased costs relating to their child's disability when their child is in hospital.
- 15% have experienced their child's DLA being suspended because they were in hospital for 84 days or more.
- 47% have been at high risk of having their child's DLA being suspended because of prolonged stays in hospital (more than 61 days).

DLA suspension

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.

Our survey suggests that 15% of families whose children spend long periods in hospital have experienced their child's DLA being suspended. In addition, we have previously heard from other families who have taken the risk of not reporting their child's hospital stay because they cannot afford to live without this financial support. It is the parents' responsibility to inform the Department for 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. With many families pushed to their financial limits by being in hospital, it is perhaps not surprising that some families take this risk.

Almost half of families (47%) whose children spend long periods in hospital, have been in danger of their child's DLA being suspended. The comments left by families taking part in the survey show that the 84-day rule, and the approaching threat of losing DLA, undoubtedly put extra pressure on them at an already stressful time.



Level of care

"When my child is well, he is at school for 6 hours during the day. When he is in hospital I am expected to be there covering all his waking hours as the staff do not have the time to give my child one on one care. Whilst in hospital I take care of all Jack's needs including peg feeding, water boluses, changing pads, clothes, washing, giving meds. The nurses will help with hoisting and changing but often you have to wait until they are available. A few years ago, I was also having to stay in the hospital by my son's bedside overnight as well as do the day shift because his seizures were so frequent. At one point I did this for 6 weeks straight."

A parent

Without a parent's input a disabled child's needs are not fully met in hospital

Our survey shows that most of the children affected by this rule are likely to have severe disabilities and/or complex health needs. Most will need round the clock care that even the most well equipped hospital cannot provide. Many of the children cannot communicate verbally, are seriously unwell and some are facing painful treatment.

The majority (68%) of families responding to the survey say they provide more care when their child is in hospital compared to when they are at home.

Families who completed the survey described their wide ranging caring duties while in hospital. This includes personal care such as feeding, changing nappies and pads, bathing, dressing, taking their child to the toilet and turning their child every few hours because they are unable to change position in bed. In addition they help communicate with hospital staff on behalf of their child and provide education, stimulation and reassurance.

In some cases parent carers provide medical care such as administering feeds and medications, changing nasogastric tubes, physiotherapy exercises and monitoring oxygen levels. Often they stay with their child 24/7, sleeping by their hospital bedside.

"He's often ill with chest infections and requires constant suctioning. I never leave his side when he is in hospital especially through the night when I often don't sleep at all. My son needs turning and monitoring throughout the night as he cannot do anything for himself. Hospitals are down to skeletal staff at night and cannot give him the one-to-one he needs."

A parent

What the professionals say

In addition to our survey, we asked hospital clinicians about their experience of the level of care provided by parent carers when their child is in hospital:

"When a severely disabled child comes onto the ward their parents absolutely need to be there with them. These children might be completely dependent on others to stay comfortable and happy in hospital, so someone needs to be by their side for much of the day, dealing with practical things but also just talking to them and keeping them reassured and entertained. The nursing staff in a hospital simply can't provide that level of care."

Senior paediatric hospital clinician

"I've been working for a number of years in paediatrics and in that time I've seen an increase in the level of complexity amongst the most severely disabled children that come into hospital. Children can now survive with much more complex needs than would have been possible 20 years ago, and these children need more time and care than the ward staff are able to give. We need mums and dads to be there to pick up the extra care that's required."

Senior paediatric hospital clinician

Increased costs

"For at least one of us to stay with him in hospital I had to give up work entirely and my husband had to only take time off at points of crisis in our son's condition. Plus we continue to have all the normal costs associated with running a family home. We had to borrow a minimum of £10,000 against our mortgage to help cover the extra costs of our son being in and out of hospital for the first two years of his life, we also changed to interest only on our mortgage to help reduce our outgoings (we are still not back on repayment terms) and family lent us small amounts of money where they could to help cover the costs."

A parent

Higher not lower costs for parents when their child is in hospital

Families who completed the survey describe the substantial extra costs associated with their child's disability that they incur when in hospital. These include:

- transport and car parking costs
- buying food from expensive hospital canteens
- phone costs
- costs of toys, internet access and other entertainment to keep children occupied on hospital wards.

On top of this, many also experience loss of earnings because they need to take substantial time off work and additional childcare costs for their other children.

Families with disabled children are already at greater risk of living in poverty than those without disabled children. Contact a Family's *Counting the Costs 2012* report shows that for families with disabled children not in work due to their caring responsibilities a quarter are going without food and a third without heating. For those in jobs, one

in seven families with disabled children is missing meals and one in six cannot afford to heat their home.

Removing DLA from a child when in hospital can also lead to parents losing their Carer's Allowance and in some cases other benefits, including Income Support. Together with the extra costs incurred, this can prove financially devastating for families with severely disabled children who are often in and out of hospital. 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.

Under the government's plans for the new Universal Credit, a parent will stop receiving payments for a child if they are expected to be temporarily absent from home for 6 months or more. This will include where a child is absent because they are in hospital. It is not yet clear whether a short return home (e.g. over a weekend) within that 6 months will start a new separate period of absence thus allowing payments to continue or whether payments would still stop because the overall absence exceeds 6 months.

"When my child is in hospital there is added costs of travelling to and from the hospital (approx 30 miles each way) with laundry/fresh clothing. This usually requires both my husband and I to take turns sitting with our child during hospital stays which means both of us having to take unpaid time off work. There is also the cost of eating out of the hospital canteen and hospital car park charges."

A parent



Conclusion

"The costs of providing his living accommodation obviously stay the same whether he is at home or not (we can't rent out his downstairs bedroom and level access bathroom!). We cannot just stop paying the carers we have booked for a weekly respite session of a couple of hours without giving them notice and then risk losing them if they rebook their hours. We have the increased costs of travelling to and from the hospital and the parking charges and the additional costs of finding other methods of meeting the needs of the rest of the family while we are providing round the clock care and supervision for our son."

A parent

Please stop denying financial help when it is needed most

The DLA 84-day rule around hospital admissions means that a very small group of severely disabled children and their parent carers are being denied financial help when they need it most.

We believe that this rule needs to be urgently changed to keep up with changing times. Many more children are surviving with severe and complex health needs due to advances in medical care. Their parents care for them lovingly and diligently at home and our survey shows that they continue to do so when they are hospitalised. Even the most fully equipped and well staffed hospitals cannot provide the one to one care that these children need.

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

In addition to providing this high level of care, families experience extra or increased costs and other financial pressures at a particularly challenging time. Some have to contemplate losing their jobs and homes. It is not right that the benefits system fails them at this time.

Our evidence proves that the government's argument that a patient's needs are fully met free of charge whilst they are in hospital is not true for this group of children in today's health system.

We urge the government to review and change this DLA rule to show that they are committed to helping the most severely disabled and the most vulnerable. This would be a simple, targeted change in the law with a relatively small cost, which would make an enormous difference to the lives of the most disabled and sick children in the UK.

References

ⁱ 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) in hospital or another medical setting. A change to this rule would require changes to regulations 8, 10(2), 12A and 12B(1)(b) of the Social Security(Disability Living Allowance) Regulations 1991.

ⁱⁱ *Rising National Prevalence of Life-Limiting Conditions in Children in England*, a study by the University of Leeds, Martin House Children's Hospice in Yorkshire, and the Children's Hospital, Cardiff.

ⁱⁱⁱ The estimate of 500 cases of children affected by this rule each year in the UK was calculated using figures from the Department of Work and Pensions. We asked the DWP for 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.

^{iv} Contact a Family and The Children's Trust calculate the cost to the Government to amend the regulations to be between £2.7 million and £3.4 million. To calculate this we used the highest possible DLA payment figure – high rate care and high rate mobility of £131.50 per week. It is unlikely that all children will be on the highest rate, but this gives us a maximum cost to Government: £131.50 x 400 = £52.6 million or £131.50 x 500 = £65.8 million.

^v Contact a Family's *Counting the Costs 2012: The financial reality for families with disabled children across the UK*

About us

Contact a Family is the only UK charity that supports all families with disabled experience, Contact a Family provides advice, information and support to over 320,000 families each year and campaigns for families to receive a better deal.

The Children's Trust, Tadworth is a national charity providing care, education and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury. Many of the children the Trust works with have just the kind of needs that can unfortunately result in long hospital stays.

contact a family
for families with disabled children

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Charity registration number 284912
Charity registered in Scotland No. SC039169

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The Children's Trust
Tadworth
For children with multiple disabilities

www.thechildrenstrust.org.uk
Charity registration number 288018