**Spending review Feb 2025 submission**

**About Contact**

[Contact](https://contact.org.uk/) is a UK charity providing advice to around 400,000 families with seriously ill and disabled children each year. We provide advice and guidance on a broad range of topics including benefit, education, health and social care support.

Contact’s family finances helpline hears from parent carers every day who struggle to access the financial support they are entitled to. Our help can boost family incomes by an average of nearly £6000 a year per call. Services like ours have never been more vital.

**About disabled children**

The UK’s 2 million disabled children should never live in poverty or be without opportunities to play and learn. Sadly, the reality is very different.  Disabled children live in some of the poorest households in the UK.

Caring for a disabled child involves many extra costs. Most families pay more for energy, food, and other costs relating to the child’s condition.  They also have costs those without disabled children don’t have, such as therapies and continence products.

As local support is eroded, rising costs of getting a diagnosis, therapies and help at school is adding to stress and family isolation.

Nearly two thirds (62%) of parent carers are forced out of the labour market due to a lack of childcare, with huge income losses, on average £21K.

This isn’t something new, but it is getting worse - especially for lone parents and for those claiming Universal Credit.

**What can be done**

Recent increases to the Carer’s Allowance working hours are welcomed. We urge the government to take the following steps to ensure disabled children have the opportunities to thrive:

1. Fix Universal Credit so disabled children are no longer adversely affected
2. Unlock £210 million of savings held in Child Trust Funds.
3. Work with energy companies to introduce discounted tariffs for families running mini hospitals at home.
4. Support parent carers to stay in pad employment but ensuring breakfast clubs and childcare options that meet the needs of disabled children.
5. Investment in support for disabled children through schools, social care and health to reduce financial burden on families.
6. Rebuild parental trust and financial resilience by offering a benefit check for every parent carer in the UK.

**Rationale**

**1.Fix Universal Credit so disabled children are no longer adversely affected**

Although the Contact Helpline has fielded enquiries about Universal Credit (UC) for several years, the past 18 months has seen a huge increase in demand for advice on UC issues.

This is partly as a result of the large numbers of households moving onto UC via managed migration, but also due to a number of specific issues that have emerged for families with disabled children already on UC.

**Not just an increase in demand but also in complexity**

It is not just the large numbers of parent’s now on UC that makes it such a pressing issue for our advisers, but also the increased complexity of the enquiries we are dealing with. As a relatively new benefit there is little caselaw on how the UC rules should be correctly applied – this means more ambiguity in how it is being administered, with more families seeking advice about whether decisions are correct.

**Universal Credit and transitional protection**

Families with a disabled child are often at greater risk of being worse off under UC than other households - chiefly because additional UC amounts for disabled children are often lower than under the legacy benefits they are replacing. Given this it comes as no surprise that we are seeing a huge demand for advice about the system of transitional protection designed to ensure that UC claimants are not left worse off when migrating.

The policy of transitional protection throws up a whole series of issues that parents need detailed advice about. This isn’t limited to questions from parents currently going through managed migration and seeking advice about the timing of a UC claim to maximise transitional protection. Increasingly we are being contacted by parents who have already migrated but who are seeking advice about how their transitional element will be impacted by subsequent changes in their circumstances.

Unfortunately, many families appear unaware that the transitional element that they currently receive is not fixed amount but is eroded by changes of circumstances and can even ended altogether – for example due to a sustained drop in earnings. We are braced for a large increase in enquiries of this nature, particularly following the annual uprating in benefit payments in April 2025 which will inevitably result in decreases in the transitional element for families on UC.

**No transitional protection for some families**

Not all families who are worse off on UC are transitionally protected. We have come across two specific groups who face major losses in income but who are not transitionally protected upon migrating to UC. This is because the calculation used in working out the amount of transitional protection due, ‘assumes’ that the family will receive payments for that child even though no such payments will be made in practice[[1]](#footnote-1).

**Families with a disabled child who is looked after in a residential setting.**

Under tax credits, families with a disabled child who is looked after in residential care solely for disability reasons can continue to receive payments for that child. Unfortunately, there is no equivalent rule under UC. No UC payments are made for any child who is looked after by their local authority regardless of whether they are disabled or not. These families commonly face of losses of more than £800 pm. To mitigate this, the UC Managed Migration Stakeholder Engagement Team has implemented a policy of postponing until Feb 2025, the migration of any cases involving looked after children that Contact’s FFT bring to their attention.

**Families with a young person aged 16-19 who is temporarily out of non-advanced education.**

Tax credits rules allow payments to continue for a 16-19 year during a ‘temporary interruption in education’ e.g. while they are temporarily unable to continue in education due to ill-health or the failure of an educational placement to meet their special educational needs but who are expected to return to non-advanced education in the near future.

However, there is no equivalent provision under UC. In this scenario a family migrating onto UC will cease to receive any payments for that young person, and will not eligible for transitional protection to make up for the loss in income that results.

**Other common UC issues**

The demand for advice regarding UC is not limited to those families under-going managed migration. Other very common UC enquiries that our helpline deals with include:

**Problems for young disabled people claiming Universal Credit while still in non-advanced education.**

We speak to large numbers of families facing a huge drop in income, when their son or daughter reaches the September after their 19th birthday. At this age a young person ceases to be treated as a dependent child and as a result their parent stops receiving any UC payments for them as part of their family. This applies even if that young disabled person remains – as many disabled young people do - in full-time non advanced education.

This creates a situation where the parent stops getting UC payments for that young person, while the young person is often refused UC for themselves because they are someone who is ‘receiving education’[[2]](#footnote-2). With no access to maintenance grants or loans in non-advanced education, families in this scenario face a loss in income of up to £821 per month, despite facing all the same on-going costs in supporting their disabled child.

It's sometimes possible for a young person to receive UC despite being in non-advanced education. However, the rules are extremely complex and rely on UC staff exercising their discretion in switching off work conditions while that young person is awaiting the outcome of a detailed work capability assessment. Not all staff agree to use their discretion in this way and as a result large numbers of families continue to approach Contact for advice on challenging decisions refusing UC to a 19 or 20 year old in education.

**Systemic problems with the underpayment of additional Universal Credit amounts for disabled children and carers**.

It is very common for Contact to speak to families who are missing out on additional UC amounts for their disabled child or for themselves as carers. However, even with this is identified and the correct higher payments put in place, a problem often emerges where families are often wrongly refused backdating of these additional payments.

It’s true that backdating of UC payments is normally restricted where there has been a delay in the department being informed of a change of circumstances. However, there is an exception to this general rule where the change of circumstances is the award of a disability benefit such as Disability Living Allowance or Personal Independence Payment. Both the legislation[[3]](#footnote-3) and the department’s own guidance[[4]](#footnote-4) make clear that in this particular scenario, additional UC payments should be backdated in line with the date that the disability benefit commenced – regardless of any delay in the department being notified.

Unfortunately, many decision makers seem unaware of this exception, resulting in families routinely being told that these additional payments will not be backdated unless they can show special reasons for late notification. This issue has become so prevalent that we have developed a series of templates for parents to use in setting out the correct rules and guidance in their UC journal.

**Work conditionality and parents each providing full-time care to a severely disabled child**

A carer on UC who provides at least 35 hours a week care to a disabled child on certain rates of Disability Living Allowance or Personal Independence Payment is normally exempt from having to look for work or meet any other work-related conditions as a condition of their UC claim.

However, a problem emerges where two parents each provide full time care to the same disabled child. In that scenario only one parent is automatically exempt from meeting work related conditions as a carer. This leaves the other parent at risk of being asked to look for work or training on top of the 35 hrs + care they already provide - with the threat of sanctions if they fail to comply.

In fact, UC staff have a discretionary power[[5]](#footnote-5) exempt that second full-time carer from any job seeking requirements, but many staff either appear unaware of this, or reluctant to use that power unless specifically referenced by the claimant. We regularly assist couples caring for the same severely disabled child to argue that these discretionary powers should be used in their individual cases.

Our helpline advises families on all aspects of Universal Credit and the wider benefits system. However, it is our expertise in the areas mentioned above, specific to families with disabled children and young people that means our service is unique. Other more generic benefits advice services will often lack the experience to advise parents fully in these more specialist areas.

Furthermore by offering detailed one to one advice by way of pre-booked telephone appointments we are able to provide detailed, high quality advice that is accessible to families whose caring responsibilities will often prevent them accessing face to face support at a busy advice centre.

**2. Unlock Child Trust Funds for 80,000 disabled young people who lack mental capacity. This would release £210 million of savings which could be spent on vital disability equipment.**

Many disabled young people who lack mental capacity are unable to access savings in their Child Trust Funds/Junior ISA. This has left families facing an overly onerous court process to access their child’s savings.

We see first-hand, on a daily basis, the battle that families face already. To ask them to fill in over 90 pages of legal paperwork, 13 court documents and pay a range of fees is a step too far for many and is risking the savings in these accounts remaining locked away forever.

This is yet another example of the unnecessary extra hurdles faced by disabled young people that non -disabled do not face.

It is important to emphasise that no one is denying the need to protect vulnerable individuals. But what we must not do is use that as an excuse for a system that isn’t working.

There are several solutions.

* Extend the DWP Appointee Scheme to include CTFs and JISAs. Parents are already entrusted to manage their child’s benefits through this scheme, with amounts often far exceeding that held in their child’s CTF/JISA.
* Government backed industry process. Some finance firms like One Family and Foresters UK have been using an industry-developed process to help parents to access a CTF account in exceptional circumstances. This simple process asks for proof that the parent is already managing benefit payments for their child as a DWP approved Appointee. Most parents supporting a disabled child will be registered under the DWP Appointee scheme and will be managing benefit payments for them, which will have a higher ongoing value than the average CTF account. It is estimated that around 2,700 disabled young people have successfully been able to enjoy their savings using the finance industry process, which most firms are operating at their own risk.

If the government supported the industry initiative and extended the authority of the DWP Appointee scheme, this issue could be efficiently resolved. In May 2021, the Scottish government took action to simplify access to CTF accounts, by allowing parents to use a Scottish scheme known as ‘Access to Funds’

**3. Work with energy companies to introduce discounted tariffs for families running mini hospitals at home.**

Many families Contact supports use electrical medical equipment such as oxygen concentrators, ventilators, ceiling hoists and feeding pumps to keep their children alive and healthy. As energy prices soar, more and more families are struggling to pay their energy bills and asking us for advice on what help is available.

Taran, single dad to Skye who has complex medical needs after being born four months premature told [Channel 4 News](https://www.channel4.com/news/disabled-children-suffering-as-energy-costs-stop-use-of-vital-equipment):

*“The extra costs of her ventilation and other medical equipment leaves me unable to afford to keep her warm and therefore healthy. Choosing between breathing or freezing isn’t a choice any parent of a seriously ill child should be made to do*”

Contact’s Out of Energy[[6]](#footnote-6) research as featured on the BBC and Channel 4 News found families with seriously ill and disabled children are paying almost double that of an average UK household on their energy bills.

On average they pay £1,596 extra a year to run essential medical equipment such as hoists, ventilators, oxygen and feeding pumps (this before heating costing and other household appliances).

Since April 2022, more than a third (39%) of surveyed families have been forced to cut back on using life-saving medical equipment – and 40% say this is making their child’s condition worse.

Local NHS grants for equipment

The NHS Service Specification states that local NHS Trusts can reimburse running costs of certain equipment such as oxygen concentrator and home dialysis machines used at home. But reimbursement (sometimes called a medical grants) is inconsistent across the country and many patients receive none or very little financial support to pay for the additional energy costs of running medical equipment at home. Information and awareness of grants and local reimbursement schemes is also poor among families, disabled people, advice charities and NHS providers themselves.

Our Out of Energy research found only 3% of surveyed families had received help from local NHS trusts or councils towards the costs of running lifesaving medical equipment. Those that had managed to get a medical grant, usually after a long battle, said not all equipment is included, and grants rarely cover true running costs.

Therefore, we are calling on the Government to create a national energy assistance payment to replace or supplement the inconsistent access to local NHS medical grants and reimbursement schemes.

The energy assistance payment could be administered by DWP to households in receipt of DLA or PIP. There is a similar payment in Scotland for disabled children in the winter.

1. **Support parent carers to stay in paid employment but ensuring breakfast clubs and childcare options that meet the needs of disabled children.**

Research has found that just over half (51%) of parents are unable to work and just under half (45%) of parents have to work fewer hours than they would like to due to lack of available childcare7. Our research about holiday clubs, during non-term time, found that a third (34%) of parents don’t work because of a lack of holiday clubs. Over a third of families report that holiday club providers cannot meet their child’s needs. One in five parents who are in paid employment have to reduce their hours over the school holiday period8 . Therefore, reducing their options when it comes to the type of employment or career they want to do.

We welcome plans to offer all primary school children access to breakfast clubs but will they benefit disabled children equally?

They must have access to specialist support staff, so that every child can access a breakfast provision.  Reasonable adjustments must be made to support disabled children in using their regular council provided school transport. Where this is not possible other appropriate transport should be offered.

More funding is required for local authorities and providers to improve the quality and number of childcare places for all disabled children.  We urge the government to look at new ways of increasing holiday childcare for disabled children such encouraging special schools to open up their purpose-built facilities that are largely left empty during school holidays.

1. **Investment in support for disabled children through schools, social care and health to reduce financial burden on families.**

[Research](https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/10/The-gap-widens-final-report-October-2021.pdf) by Scope and the Disabled Children’s Partnership in 2021 found that the funding gap for disabled children’s health and social care had continued to increase to £2.1 billion – an increase of over £500 million since our last calculation in 2016/17.

Addressing this funding gap, which has likely increased further in the past three years would not only improve the lives of countless families but would generate net positive gains for public finances. With sustained investment:

* + Tax revenues would substantially increase as more disabled children, their siblings, and parent carers would be able to enter employment.
  + Long-term health and social care costs would also reduce as early intervention improves, and health problems are identified earlier.

Below, we attach a table outlining some of the long-term benefits to the taxpayer of a proper invested health and social care service for disabled children and their families.

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Addressing the gap would support disabled children and their families to get services and support that are not currently being delivered consistently across local areas, such as respite care, therapies, rehabilitation support, provision of medicines and in-home support. When accessible, these services make a significant difference to disabled children and their families and can be complimentary to a wide variety of medical procedures. It is essential that the new Government takes these services into consideration when funding an NHS fit for the future.

Apart from the types of gains set out above that are capable of being readily quantified and monetised, there are other types of potential benefits associated with levels of support for disabled children’s health and social care services that have not been included in the quantified analysis. These could include the following:

* The potential for public expenditure savings linked to levels of marital breakdown, linked to stress and pressures on mental health.
* The potential for expenditure savings linked to reduced levels of need for social housing improve opportunities for these children to achieve their full potential and thrive.
* Societal welfare gains linked to a potential increase in levels of volunteering undertaken by parents of disabled children.

Alongside this, our analysis shows that targeted investment to address gaps in service delivery would create the potential for net positive gains for public finances in the medium and longer term.

* Provision of these services enables a significant proportion of parents of disabled children to participate in employment.
* Investment in current health and social services in many individual cases averts the need for more expensive treatments, therapies, and interventions later in life.
* Investment in health and social care services increases the chances of a greater proportion of disabled children to participate in education and eventually to gain qualifications and skills that are relevant to the needs of the future labour market.

1. **Rebuild parental trust and financial resilience by offering a benefit check for every parent carer in the UK.**

Contact offers highly specialist advice. It’s not uncommon for families we come to us after been given incorrect information from local welfare advice services or job centres. We can increase household income on average by £6000 per year per call.

Our ambition is that every family with disabled child has access to a specialist benefit check so they can get everything they are enabled too.

Our Counting the Costs research shows two thirds find the benefits systems difficult to claim everything they are entitled too for their disabled child, and more than half don't trust the benefit system.

Contact’s research also found that the benefit system feels like a minefield for most and many don’t trust it either. Contact is uniquely placed to help families get the financial support they are entitled to, making the process of claiming less stressful

Despite the positive impact and the increases in the numbers of Disability Living Allowance (DLA) claimants (and awards) in recent years too many families are missing out on DLA and much more need to be done to challenge the misconceptions about DLA eligibility.

Experiences commonly reported by families on DLA, which if tackled could improve trust and the experience of the benefits system:

* DLA Helpline answer times: Lots of complaints from parents about the amount of time they were on hold when phoning the DLA Helpline (and the fact that many ended up being cut off before they managed to get through). Average around 45 mins.
* DLA processing times: Haven’t been able to track down any official data on how long it is taking for DLA decisions to be made but anecdotally parents are reporting waiting 5-6 months for a decision. We used to tell parents it would take around 8 weeks! May be worth asking for confirmation of average waiting times at the meeting.
* Poor data sharing between DLA Unit and Universal Credit is seeing many families missing out on disabled child addition. We regularly speak to parents who are missing out on this element or who are seeking backdating of this addition because there was a lengthy delay in UC finding out that DLA was in payment to a child. This appears to be a widespread problem – hence the development of our backdating template letters.

In addition the following changes to the DLA rules would significantly improve parental trust:

**Allowing some severely disabled children under the age of 3 to qualify for higher rate mobility** – for example younger disabled children who require to be accompanied by bulky medical equipment or who may require medical attention at very short notice (the current blue badge rules for under 3s would be a useful starting point).

**Amending the higher rate mobility severe mental impairment (SMI) tests**. These are unnecessarily complex. For example, one of the tests is that a child must be on higher rate care component. Why should a child need to have night-time care needs in order to qualify for higher rate mobility? This test seems to serve no logical purpose other than simply to restrict the numbers of children who would otherwise be eligible.

**Allowing DLA claimants the option of waiting until 18 to claim PIP similar to what currently happens in Scotland**

Scrapping the three month backwards qualifying condition i.e. that a child must have had needs for three months before DLA payments can start. Surely there is an argument that so long as it is clear that their condition is likely to be long term (and bearing in mind that there is also a forwards qualifying period whereby a claimant must show their needs are expected to last at least 6 months to be paid DLA) then DLA payments should start immediately – as the current backwards qualifying test leaves families in a situation where they will be incurring disability related costs without any financial support towards these for at least 3 months – and also stuck in a situation they face an initial 3 months where they cannot be treated as carers under the benefits system as this is reliant on establishing DLA entitlement first.

For more information on this submission please email [una. summerson@contact.org.uk](mailto:una.%20summerson@contact.org.uk)

1. regulation 54(2)(a) of the Universal Credit (Transitional Provisions) 2014 [↑](#footnote-ref-1)
2. Regulation 12 of the UC Regulations 2013 [↑](#footnote-ref-2)
3. Schedule 1, paragraph 31(2) of The Universal Credit, Personal Independence Payment, Jobseeker’s Allowance and Employment and Support Allowance (Decisions and Appeals) Regulations 2013 [↑](#footnote-ref-3)
4. Advice for Decision Making staff guide, para A4361 [↑](#footnote-ref-4)
5. Regulation 89(1)(b) Universal Credit Regulations 2013 [↑](#footnote-ref-5)
6. [Out of Energy (Contact 2022)](https://contact.org.uk/help-for-families/campaigns-and-research/out-of-energy/) [↑](#footnote-ref-6)