

Helping families navigate Welfare Reform

An independent evaluation of the
Contact helpline's
welfare rights project

Executive summary

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“Getting the decision overturned was so important. It was the difference between my son being able to come home at weekends or having to stay in care. It meant I had money to pay for food and clothing and to cover all the petrol costs in picking him up and taking him home. ... a fantastic service that makes such a difference, not just financially but also emotionally.”

This is the executive summary of the report of the independent evaluation of the Contact helpline’s welfare rights project, covering the period June 2016 to June 2018. This project is funded by the Big Lottery until May 2019.

The financial, caring and other stresses of looking after a disabled child are well documented. Poverty further aggravates the stresses of getting a diagnosis, providing care, dealing with health needs and securing suitable education, housing and health services and planning for the future.

Disabled children, young people and their families commonly do not get their full entitlement to welfare benefits. This is often attributed to the public’s difficulties in understanding the benefits system, as well as its inherent complexities, administration and regular overhauls.

This independent process and outcome evaluation investigated how parents and carers who used the Contact helpline’s welfare rights project viewed the service and the process of getting advice from them and what, if any, financial and other outcomes were experienced as a result.

A mixed methods approach was adopted. Methods included secondary analysis of Contact’s quantitative and qualitative data on advice calls, caller demographics, query subjects, advice given and financial and other outcomes. In addition, the evaluator conducted qualitative depth interviews with twenty families who had used the project; and convened a group discussion with Contact about emerging findings.

“Really impressive service. Wasn’t able to get advice elsewhere”

Who sought advice:

Over the two years of this evaluation, the Contact helpline received 11,931 enquiries about benefits and finances, accounting for nearly half of all calls to its helpline. Most of these were handled by Contact general helpline advisers who received training and specialist support from the welfare rights team.

The welfare rights team, which is the subject of this evaluation, provided 1,346 in-depth, one-to-one advice sessions by telephone to approximately 1,175 families. Some required several calls and long-term input due to the complexity of their issues.

Most of the parents/ carers advised by the team were female (86%). Nearly one half (48%) were lone parents and just over one fifth (22%) described themselves as disabled.

In addition, the team produced guides about benefits, website articles, podcasts and e-bulletins. Podcasts proved increasingly popular over this period.

Benefit topics

The most common benefit topics were: Disability Living Allowance (DLA) and Personal Independence Payment (PIP), especially challenging wrong decisions; “better-off” calculations around starting or stopping work or varying hours; young people’s own benefit entitlement and preparations for independence; Universal Credit and Carer’s Allowance. Calls around Universal Credit increased over this period and some unexpected anomalies emerged, especially around young people’s entitlement. Many calls involved the complex interrelationship of several benefits, and advising on how these impact on each other, as well as changing needs and situations and disabled children growing older and potentially becoming entitled to claim some benefits in their own right.

Outcomes

The main outcomes found were significant financial gains, indirect material improvements, and positive psychological, emotional and social changes.

“I was really struggling financially. So, it has lifted a lot of financial pressure from my family.”

Financial gains

Recording financial outcomes relies on being able to follow up the families to find out what happened to their claim, review or appeal. Unsurprisingly not everyone is contactable. In respect of these two years, 224 families were followed-up, just under one-fifth of those advised.

Seven in ten (71%) of these 224 families reported income increases ranging from about £10 to over £300 per week; and in over half of these cases (57%) the weekly increase ranged from £50 to £150 per week.

The average increase was £100 per week, or £5,200 per annum.

In addition to following-up a sample of families, Contact estimates how much each family should gain if all the benefit advice given is followed. This is done at the end of the first call with the project, and then adjusted based on the follow-up sample.

Over this period, Contact estimated that just under half (48% or 564 families) of the 1,175 families who received advice from the welfare rights project got an increase in income, averaging £103 per week.

It was estimated that over the two years of this project **an additional £3million was secured for these families annually.**

Additionally, many callers received backdated awards of entitlement in respect of periods when they had been wrongly refused or underpaid. Accurate data on such payments is harder to collate for various reasons. However figures gathered from ten families, whose arrears payments ranged from £450 to £10,000, suggest that the sums can be significant. With advice from the welfare rights team families also successfully challenged alleged benefit ‘overpayments’, which often amounted to thousands of pounds.

“The advice was really clear and so accurate. I would have had no idea that my Housing Benefit award didn’t include my youngest child if I hadn’t spoken to Contact. The Housing Benefit letters made no sense to me and I couldn’t understand how they calculated my rebate.”

Case vignette

Jenny lives with her partner and two teenage children (aged 19 and 16). Both young people are severely disabled. Her partner works full-time and Jenny gets Carer's Allowance in respect of her eldest who gets Personal Independence Payment (PIP) and who had finished school a year previously. Child Benefit and Tax Credit additions had stopped at that point.

The Contact welfare rights team advised Jenny to help her 19 year-old make their own claim for Universal Credit, on the grounds of incapacity to work and to request a Council Tax Reduction and discount. As well as making a PIP claim for the 16 year-old, the family were advised to help them start their own claim for Universal Credit too, although establishing entitlement while in education was complicated and relied in turn on a "credits only" claim for Employment and Support Allowance.

By the time of the follow-up call the 19-year old had been successful in their own claim for Universal Credit; the 16 year-old's PIP claim had been successful, but their Universal Credit claim was delayed by the wait for a medical assessment.

Indirect material gains

Families reported being more able to:

- afford elementary items and manage basic household costs
- reduce or avoid debt
- meet some of the extra costs associated with their child's disability, typically travel, clothing, footwear and furniture, and
- cover a few modest 'extras', such as family outings and better food.

Often relatively modest changes were felt to make a huge difference to the family's financial stress.

"Before [we] weren't able to do anything, or get them anything extra or go out at all. Even buying things like school shoes was difficult, going out at all, even food shopping was difficult... Now able to pay bills, clearing debt, eating better, able to afford buying school uniform & shoes for the children."

"Before...we were running up debts and completely at a loss as to how we would manage... we were not managing financially with all the extra costs of coming back and forth to hospital and the lost income from taking time away from [work]."

Other non-financial outcomes

Respondents to Contact's follow up survey and the parents interviewed for this evaluation reported a wide range of positive psychological and social changes resulting from getting advice from the welfare rights project. These included:

- reduced stress
- feeling more able to deal with stress
- being more informed, knowledgeable and confident to deal with benefit issues in the future
- undertaking more social activities

- reduced social isolation and getting out and about more as a family.

Prior to getting this advice, the evaluation interviewees recounted feeling intensely distressed, confused and often despairing. As well as losing money, getting into debt and not being able to afford everyday items or the costs arising from their child's disability, they described being extremely anxious about being able to cope in either the immediate or long-term.

"Generally, it has taken the pressure off, as I was very, very, stressed, which made me depressed as well. And that has benefitted the children as I am not just lying in bed feeling hopeless, worried and stressed."

Social isolation

This is a major risk of both disability and low income: over 90% of respondents reported feeling less isolated as a result of the project's advice. As well as feeling reassured that Contact's advisers understood their situation and were at hand; having more scope to get out and about as a family and, in some cases, pursuing training or employment all served to reduce isolation.

"Allowed us to get out as a family much more and we can do things with my son and are not so isolated."

"It was so stressful when my husband left. The advice given was so clear and detailed it immediately made me more confident and made me think that I could go on."

Understanding the benefits system

Families said they understood the benefits system more, including Universal Credit and other changes, their options regarding work, how to pursue any future claims, and the need to report circumstantial changes in time to avoid over or underpayments. Alongside feeling more confident to navigate the system themselves, they were immensely reassured to know that Contact's helpline was at hand when needed.

'There are times in the past when my benefits were stopped out of the blue and I couldn't get them to talk to me or explain what was happening. Contact made sure that my payments were sorted out and all the correct amounts paid. I was really stressed and the help I got made such a difference not only to me but also to my son who was really worried too.'

"It gave me the confidence to challenge the refusal of my son's PIP. I would have given up without your help."

Young disabled people

Clarifying disabled young people's individual entitlements and their choices from age 16 helped to reduce parents' anxieties about how they would cope financially in the future; as well as supporting disabled young people's independence in very practical and holistic ways. This type of expertise was said to be distinctly rare and lacking elsewhere.

"It's been a great help because it's such a quagmire out there. To know they have a little bit of financial security... they're very unlikely to be ever able to work ... Taken that

pressure off, knowing there's something out there available to them. Took the stress off."

How these outcomes were achieved

Those interviewed had no doubt that all the positive changes experienced were directly attributable to the advice from Contact's welfare rights project. Many had previously unsuccessfully sought benefits advice elsewhere. Accurate advice had proved very difficult if not impossible to find. They said that without Contact's help they would have continued as before, unaware of their full entitlement, struggling to cope, and might have taken on more debt, in turn becoming even more isolated and stressed.

"If not for getting benefit advice I would still be losing out by £54 each week: The discrepancy would have just carried on."

Views on processes

"Very clear. Understood completely - made it easy to understand Made it very clear what my options were. And it was correct."

The depth qualitative interviews probed parents' and carers' views on talking to an adviser about such sensitive and often complicated issues. They were also asked how they came to know about Contact, how they had found the process of getting through to the welfare rights team and any attempts to get advice on these matters elsewhere.

Overall interviewees were happy using the telephone for this type of advice. In fact having a disabled child often made using the telephone easier as it avoided the multiple access and caring problems, associated with travelling to and getting into an advice office and perhaps queuing for hours.

Most reported finding out about Contact quite randomly, commonly by a generic internet search, or being told by other parents with disabled children. Interviewees felt that the name of the organisation did not make it immediately clear what services were on offer. Indeed, even those parents who had previously used Contact's other services, had not realised that they offered benefits expertise as well.

Interviewees had typically tried to find advice elsewhere before reaching Contact, and reported a range of barriers. Often benefits advice was unavailable either locally or from the many professionals working with their children. Advisers in other agencies, or Jobcentres, were said to lack knowledge or experience on benefits for families with disabled children, or on disabled young people's entitlement; local advice services often had long waiting times and / or were inaccessible; and online calculators were too basic and generalist. Worse still, many had previously received inaccurate advice elsewhere. Luckily this group at least had persevered and eventually got accurate advice from Contact.

The welfare rights team had also noted a significant reduction in the availability of local advice services, and how this had had a direct impact on the project's work. As a result, they had to do more for each family, whereas in the past they might have referred on to a local service to complete a claim form or write an appeal letter.

The welfare rights team were highly praised for their comprehensive, specialist knowledge and expertise; their warm, empathetic, responsive and understanding approach; how quickly they got to grips with and understood the issues; and the clarity, detail, practicality and precision of their advice.

“very helpful and brilliant service, took time to listen, that meant so much to me.”

In conclusion

The welfare rights project was highly effective, especially considering the magnitude and complexity of the benefit changes over this period. Families clearly gained financially, socially and psychologically from the advice received. This small team managed to provide expert advice nationally, on often niche issues, to a high standard, in an empathetic, sensitive, caring and calm manner; and ensured that the advice was practical so that families knew the next steps to take. They also helped families prepare for future changes.

By all accounts this specialism and precision around benefit matters for families with disabled children and young people is otherwise unavailable, locally or from the many professionals families encounter.

Such expertise is essential to help families, already under great financial strain, to rectify erroneous decisions, receive their full legal entitlement and be better able to financially manage and provide care for their disabled children.

“Without them I would have been left with nothing. They were my life-line. I owe them so much.”

About the Contact helpline’s welfare rights team

Contact is a UK charity which supports families with disabled children. Contact provides advice, information and support through a telephone helpline, social media and its website, as well as through workshops and face-to-face support in a number of UK areas. The Contact helpline deals with any concern or question raised by parents and carers and responds to approximately 12,000 individual enquiries a year.

The helpline team can offer a call back appointment with the welfare rights team if a benefits enquiry is complex, unusual or likely to involve repeated calls or ongoing advice. Contact’s welfare rights team seeks to maximise families’ incomes where possible and demystify the benefits system, so that parents are better informed about how changes in circumstances will impact on their benefit income.

As well as providing one-to-one advice mainly by telephone, the team also produces a series of podcasts and writes a suite of benefit guides, factsheets and the benefit content for Contact’s website and social media channels.

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