

# Helping families navigate Welfare Reform

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

Berni Graham  
Research & Evaluation  
October 2018

## 1. Contents

1. Executive summary .....	2
2. Introduction .....	7
2.1 Financial circumstances and poverty in families with disabled children in the UK .....	7
2.2 Ongoing benefit changes .....	8
2.3 About the Contact helpline’s welfare rights team.....	9
2.4 How this report is structured .....	10
3. The independent evaluation.....	10
3.1 Evaluation aims .....	10
3.2 The key evaluation questions were: .....	11
3.3 Evaluation methods .....	11
3.3.1 Primary data collection for the independent evaluation.....	11
3.3.2 Advice and support to Contact on internal data collection methods and tools.....	12
3.3.3 Analysis of Contact’s data .....	13
4. Key Findings .....	14
4.1 Who sought advice from the Contact helpline welfare rights project .....	14
4.2 Advice topics .....	15
4.3 Other outputs provided by the welfare rights team .....	16
4.4 Outcomes achieved by the project.....	17
4.4.1 Financial outcomes .....	17
4.4.2 Other material gains .....	20
4.4.3 Other, non-financial outcomes reported.....	24
4.4.4 Attribution: how much were the changes reported due to Contact’s input? .....	30
4.5 Views on processes and getting benefit advice from the project .....	32
4.5.1 Getting through to a welfare rights adviser.....	32
4.5.2 Views on using the telephone for welfare benefits advice.....	33
4.5.3 How interviewees had found out about the Contact helpline welfare rights project..	34
4.5.4 Views on the welfare rights advisers’ understanding, knowledge and approach .....	35
4.6 Availability and experiences of using other local advice services.....	39
5. Conclusion.....	43
Key recommendations and learning points .....	45
6. Appendices.....	47
6.1 Summary of planned Universal Credit full implementation to 2023.....	47
6.2 Data collection methods used in this evaluation.....	48
6.3 Qualitative interviews for the independent evaluation .....	48
6.4 Project targets agreed with Big Lottery .....	53

## 1. Executive summary

This is a report of the independent evaluation of the Contact helpline's welfare rights project, covering the period June 2016 to June 2018. This project was funded by the Big Lottery.

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 and dealing with health needs, 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 process and outcome evaluation investigated how parents and carers who used the Contact helpline's welfare rights project viewed 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 independent evaluator conducted qualitative depth interviews with twenty families who had used the project; and convened a group discussion with Contact about emerging findings.

### *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 receive training and specialist support from their colleagues in the welfare rights team.

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

Most of those 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.

## *Outcomes*

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

### *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 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.

### *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.

### *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.

### **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.

### **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.

### **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.

### **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.

### *Views on processes*

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.

## 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.**

### *Acknowledgements*

This evaluation benefited greatly from the efficient and timely assistance from Contact's Monitoring and Evaluation Manager and the project staff in supplying data; helping the evaluator create a sampling framework and recruiting families to interview; and commenting on drafts of this report. But most of all I'd like to thank the individuals who agreed to be interviewed and gave their time, experiences and views to the evaluation. Their details are kept anonymous for obvious reasons.

## 2. Introduction

### 2.1 Financial circumstances and poverty in families with disabled children in the UK

Having a child who is disabled is known to add its own set of demands on parents and carers. As well as extra caring duties and dependency, which may persist for longer than for non-disabled children, disability increases the likelihood of poverty. For example, using the Household Below Average Income statistics 2013/14, Tinsen et al (2016)<sup>1</sup> calculated that:

- over a quarter (28%) of people in poverty are disabled
- this includes 2.6 million working-age adults, 940,000 pensioners and 310,000 children
- 20% of people in poverty are not disabled but live with someone who is
- thus together, almost half (48%) of people in poverty are in a household where someone is disabled, and
- poverty rates among disabled people have risen over recent years.

The report attributes higher risks of poverty to lower rates of employment, low skill levels and low pay for those in work; and the higher living costs as a result of disability. The authors state that:

*“The social security system plays an important role in supporting those unable to work, whether temporarily or over a longer time period, as well as mitigating some of the extra costs of disability”*  
(p6)

A survey by Contact in 2014<sup>2</sup> found that:

- over a third of parents with disabled children had gone without food because of financial pressures and that low income had affected their own health, and
- in one-fifth of cases the health of their disabled child.

A review of evidence funded by the Economic and Social Research Council (ESRC) by Heslop (2013)<sup>3</sup> found that the evidence on the direct link between having a disabled child in the house and income was not always linear, but that families with a disabled child experienced disadvantages across a wide range of social economic indicators, including:

- lower income
- higher costs of living
- higher levels of debt, and
- lower availability of suitable childcare (to facilitate working).

---

<sup>1</sup> Tinsen, A., Aldridge, H., Born, T., and Hughes, C., (2016) Disability and Poverty, London, New Policy Institute.

<sup>2</sup> Contact (2014) Counting The Costs Survey.

[https://contact.org.uk/media/805120/counting\\_the\\_costs\\_2014\\_uk\\_report.pdf](https://contact.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf)

<sup>3</sup> Heslop, P., Disabled People and Their Relationship with Poverty, Poverty & Social Exclusion UK, Working paper seris 23 <http://www.poverty.ac.uk/sites/default/files/attachments/WP%20Methods%20No%2023%20-%20Disabled%20People%20%28Heslop%202013%29.pdf>



Moreover, these issues have proved tenacious over time. An earlier report (Langerman and Worrell 2005<sup>4</sup>) noted the limitations on employment from being a carer, mostly due to the challenges of juggling two roles. Only 16% of mothers with disabled children are in paid employment, compared to 61% of mothers whose children are not disabled. Statistics compiled by Leeds University for the Every Disabled Child Matters campaign (2007) noted that:

- 93% of families with a disabled child experienced financial difficulties
- one in five reported not being able to afford enough food, school outings or new clothes for their children, and that
- these families were much more likely to get into debt<sup>5</sup>.

Dobson, Middleton & Beardsworth (2001) found that:

- it costs twice as much for families to bring up a child with a disability as a non-disabled child
- families with a disabled child spent about one-fifth of their income on a disabled child, but felt that this was less than what their child required<sup>6</sup>.

A review by Surrey University (2014) found that advice on welfare benefits can play a critical role in easing the financial pressures that families with a disabled child tend to face. As well as impacting on household finances, families may also benefit from:

- improvements in health, physical or emotional wellbeing
- confidence and self-esteem, which in turn sometimes supports people to move back to education or employment<sup>7</sup>.

## 2.2 Ongoing benefit changes

The UK welfare benefits system is notoriously complicated, a situation aggravated by continuous restructuring and changes<sup>8</sup>. The Welfare Reform Act 2012 introduced the benefit cap, Personal Independence Payment (PIP) and Universal Credit, amongst other changes, with the stated aim of ‘simplifying’ the system. However, fears were expressed that these changes would add further layers of complication and restrictions in entitlement and result in confusion, under-claiming, reduced entitlements and people being worse off.

The cumulative impact of these welfare reforms have been noted to be much more negative for families containing at least one disabled person, particularly a disabled child, and have a double

---

<sup>4</sup> Langerman, C., and Worrell, E., (2005) Ordinary Lives, Disabled Children and Their Families, London New Philanthropy Capital

<sup>5</sup> Disabled Children and Poverty a briefing paper by the EDCM campaign 2017 <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/every-child-disabled-children-and-child-poverty.pdf>

<sup>6</sup> Dobson, B., Middleton, S., Beardsworth, A., (1998) the impact of childhood disability on Family life. York Joseph Rowntree Trust, <https://www.jrf.org.uk/report/impact-childhood-disability-family-life>

<sup>7</sup> Cookson, G., Mold, F., (2014) Social Welfare Advice Services – A Review, University of Surrey,

<sup>8</sup> <https://fullfact.org/economy/changing-face-welfare/>

impact on low income families<sup>9</sup>. The changes which have impacted most include those to Tax Credits; replacement of Disability Living Allowance (DLA) by PIP; cuts in Employment Support Allowance for some young disabled people; and the introduction of Universal Credit. More details about all of these can be found on the Contact website at <https://contact.org.uk/advice-and-support/benefits-financial-help/>

By far the biggest development has been the drive to replace six existing means-tested benefits with Universal Credit. Although initially much delayed, from 2016 Universal Credit was increasingly rolled-out to Jobcentres. By the end of 2018 it is expected to apply to all new claimants in England. Over 2019-2023 existing means-tested benefit claims will be stopped and people are expected to lodge new claims for Universal Credit. Some existing claimants will get transitional protection. Many will not.

Although the gradual phasing in of Universal Credit enabled it to be amended somewhat in response to emergent problems, this also added immense complexity, as two means tested benefit systems operated in parallel, in the early implementation areas. Over 2017-18, Contact saw increasing numbers of enquiries about Universal Credit, including parents seeking to remain on their existing benefits and wanting to put off claiming it for as long as possible. Families of disabled children rightly feared being made worse off under the new benefit, as the reduction in the payments for a disabled child can equal £1,750 per year in comparison to the previous Tax Credits system.<sup>10</sup> Moreover, as documented in the media, Universal Credit roll-out has been beset by administrative problems, including issues with the online claiming system, inaccurate awards and delays in initial payments.

### 2.3 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 has three teams: general; education; and the welfare rights team, on which this evaluation is focussed. The welfare rights team comprises 2.5 staff. Contact operates a triage model. Parents initially call the general helpline, who deal with issues like entitlement rules. The helpline team can offer a call back appointment with the welfare rights advisers if a benefits enquiry is complex, unusual or likely to involve repeated calls or ongoing advice. Contact's records show that benefit advice accounts for half of all enquiries to its helpline and on-line services, and totalled 11,931

---

<sup>9</sup> Reed, H., Portes, J., (2014) Cumulative Impact Assessment: A Research Report by Landman Economics and the National Institute of Economic and Social Research (NIESR) for the Equality and Human Rights Commission EHRC Research report 94, <https://www.equalityhumanrights.com/en/publication-download/research-report-94-cumulative-impact-assessment>

<sup>10</sup> This is because the lower rate of the child disability addition is set at £29.10 per week. Given that the equivalent additional payment under Tax Credits is £62.86 per week, this represents a cut of £33.76 per week or just over £1,750 per year

for the two-year period of this evaluation, June 2016 – 18. The proportion requiring benefits advice has increased over recent years (from 46% of all helpline enquiries in 2015/16 to 51% in 2017/18). 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.

## 2.4 How this report is structured

- Section 3 summarises the evaluation's aims, key questions and methods.
- Section 4 provides the key findings on outcomes and processes.
- Section 5 provides conclusions and discusses the implications of the findings, including emerging recommendations and learning points for Contact to take forward.

All findings are based on the rigorous analysis of the qualitative and quantitative data. Quotes and case vignettes are used to help exemplify the issues and show how these complex matters apply in real life. Robust data analysis is more than collating good quotes however. But the examples used help remind us of the real life issues involved and are often more eloquent than dry research writing.

## 3. The independent evaluation

In 2016 an independent evaluation was commissioned to evaluate the work done by the Contact welfare rights project under the Big Lottery funding. The evaluation had a dual role: to carry out an independent evaluation of the project's work over 2016-18; and to advise Contact on its existing data collection and analysis for the welfare rights team and recommend any improvements.

### 3.1 Evaluation aims

- Gather views and experiences directly from users to explore the process of using the Contact helpline welfare rights team and to inform any recommendations on how this could be improved.
- Collect primary qualitative data from callers on the quality of the advice given, and any difference the advice made to them and their families.
- Combine qualitative and quantitative data to assess effectiveness.

- Collaborate closely with Contact to develop a suitable and proportionate evaluation framework, methods and tools for the project, to ensure it collects robust and usable data systematically and efficiently, and
- Provide recommendations and learning points arising from the findings to inform Contact's future work.

### 3.2 The key evaluation questions were:

- How do families experience the process of using the Contact helpline's welfare rights project?
- How many families were assisted and in what way?
- What material and other outcomes have been experienced by families?
- How well do parents understand: a) their current entitlements; b) how their benefits might be affected by changes in their own circumstances, and c) how upcoming changes to the benefits system will impact on them.
- What learning points and recommendations emerge?

### 3.3 Evaluation methods

To meet the evaluation aims and address the key questions, a mixed methodology was adapted. The key methods were:

- a) primary qualitative data collection
- b) advice and support to Contact on internal data collection methods and tools
- c) secondary analysis of quantitative and qualitative data collected by Contact, and
- d) a group interview with Contact's welfare rights team and Monitoring and Evaluation Manager to review the findings and any key learning points.

#### 3.3.1 *Primary data collection for the independent evaluation*

The independent evaluator gathered views and experiences directly from families who had used the welfare rights team. Qualitative interviews were deemed the most appropriate way to get reliable and robust data to answer the evaluation questions and fill the gaps in knowledge, not covered by other methods. Qualitative investigation also offered the opportunity to get a richer analysis and deeper understanding of issues which matter to families, individual circumstances, views and nuances. Moreover, as many of the topic areas are private and potentially distressing, they require careful and individualised exploration. Sensitive topics include disability, health, income, benefits, debt and caring responsibilities. Other methods, such as surveys or group discussions do not provide the same facility to examine these issues in depth or from the point of view of those researched. Conducting the interviews by telephone was the most accessible option. It helped ensure that the sampling could reflect the national geographic spread of callers, obviate any need to travel and be timed to suit interviewees.

The interview topic guide was produced in close collaboration with Contact to ensure it covered priority issues and that questions were worded appropriately. Initial interviews served as pilots, but few changes were needed. A copy of the topic guide is in Appendix 1.

The qualitative interviews were digitally recorded with consent and then transcribed and entered into Framework<sup>11</sup>, along with qualitative data gathered by Contact in its surveys. All the qualitative data were analysed using the Framework approach. Framework is a rigorous and systematic way to organise, condense and summarise data from different sources and facilitates analysis by theme and sub-theme and comparison between groups. It is also relatively flexible, which enables unanticipated but significant themes to be added if and as they emerge. The evaluation questions and emerging issues created the themes and sub-themes.

### *About those interviewed*

Twenty people who had received advice from the project were interviewed over 2016-18. The sampling process ensured a geographical spread across England. Sampling reflected the range of people who had been helped by the welfare rights team, in terms of family composition, circumstances and welfare rights subjects raised.

All 20 were parents of disabled children and young people and in one case the adoptive parents. Most (18) were mothers; and 13 were lone parents. These characteristics are broadly reflective of the composition of all callers to the project. The children and young people in this sample had a range of physical, mental and cognitive conditions. In many cases there was more than one disabled child in the family and four of the parents were also disabled. Across this sample, callers sought help about a range of topics, most commonly: entitlement to Disability Living Allowance (DLA), challenging DLA decisions and the transition onto Personal Independent Payment, and also Universal Credit, Tax Credits, Housing Benefit, Child Benefit, Carer's Allowance, better-off in work calculations, hospital admission and what would happen to their own and their children's benefit entitlement as their child matured and left school and / or home.

### **3.3.2** *Advice and support to Contact on internal data collection methods and tools*

Contact collects detailed data about its welfare rights project to help assess how well it meets targets around demographics, advice issues and other criteria. There are two main data collection points:

- At the time of the first call with the welfare rights team, a **point of service survey** is done. In addition to noting the reasons for the call, benefits received, the advice given and estimating their correct financial entitlement, advisers try to collect as much demographic data as possible (including gender, geographic location and ethnicity) and ask callers' views on the advice given and their previous attempts to find advice elsewhere.

---

<sup>11</sup> Ritchie, J and Spencer, L, (1994), *Qualitative Data Analysis for Applied Policy Research*, in *Analysing Qualitative Data*, edited by Alan Bryman and Robert G. Burgess) pp. 173 – 194, Taylor and Francis Books Ltd.

- Contact conducts a **follow-up survey** roughly four months later. As well as providing any further advice needed, the adviser uses this call to find out what transpired, for example what happened to the benefit claim or appeal, so that a reliable assessment can be made of any financial impact from the advice given. Details are gathered about benefit outcomes and open questions also aim to explore non-financial matters, such as any changes to confidence in dealing with benefit issues, or getting out and about more.

Over the two years, June 2016 to June 2018, the welfare rights team provided 1,346 call back appointments, giving expert in-depth advice to an estimated 1,175 individual parents and carers. Over half ( $n=774$ ) also answered questions for the point of service survey, albeit not necessarily each and every question. Fewer people replied to the follow-up call and survey ( $n=224$ ) four months later.

This is to be expected, given the circumstances. Initial advice call backs can last an hour or more. Many respondents had limited time or energy to answer an additional suite of questions for the point of service survey, because of caring priorities, work and other stresses and demands, not least their current financial crisis. The follow-up call was only targeted at those who were expected to see a financial change, or had a complicated benefit issue which warranted follow-up; families were often not contactable; and the welfare rights team had to balance the time required to collect follow-up data with other priorities.

Before the evaluation began, this data was collected using different instruments and entered into at least two different databases. This made it difficult to connect and track cases and inputs, or link these with outcomes or examine attribution over time. Using different methods was also quite time consuming. The merits and potential suitability of alternatives, including using a single identifier were explored with Contact. In the end it was decided to enter all financial, survey and demographic data collected by the advisers into a single Excel database and link all data sets using a single identifier per caller. This made it much easier to view the initial advice needs, demographics, number of contacts, the advice provided each time and any reported financial or other outcomes.

### 3.3.3 *Analysis of Contact's data*

To help protect confidentiality, Contact conducted the primary analysis of all the monitoring and the quantitative data collected in their own surveys, which are explained under 3.3.2 above. The evaluator conducted primary analysis of the anonymised qualitative data.

## 4. Key Findings

This section sets out:

- the statistics around the families who sought advice and some demographic details (4.1)
- the most common advice queries (4.2)
- financial and other outcomes experienced (4.3), and
- how people found the process of using the project (4.4).

### 4.1 Who sought advice from the Contact helpline welfare rights project

Table 1 below shows the total numbers who received benefits advice from Contact's helpline over 2016-18. Most of the 11,931 queries were handled by Contact's general helpline. Of these, the welfare rights team provided further in-depth advice on 1,346 occasions to an estimated 1,175<sup>12</sup> unique callers in the form of a pre-arranged telephone call back appointment. Some families required more than one appointment.

*Table 1: Numbers of enquiries regarding benefits and finances answered by Contact's helpline and welfare rights project over 2016-18*

Period	Total of all forms of advice given by the welfare rights team (by telephone, email and social media)	Number of call back in-depth telephone appointments by the welfare rights team	Total enquiries answered by the Contact helpline regarding benefits and finances
Year 1 2016-17	1,075	597	6,286
Year 2 2017-18	1,326	749	5,645
Totals	2,401	1346	11,931

At the end of the call with the welfare rights adviser, demographic details were gathered in relation to 774 of the 1,175 callers (about 66%). Table 2 summarises these details. As not everyone answered every question the counts and bases for individual items vary.

---

<sup>12</sup> All the calls received by the welfare rights team are logged on Contact's CRM database. Where possible they are linked to a caller's existing contact record (if they are already known to the organisation), or a new record is created. This makes it possible to estimate unique callers as well as the total number of calls. It is nonetheless treated as an estimate as sometimes discrepancies arise, for example if names are spelt slightly differently, or two discrete calls are not easy to match up.

Table 2: Demographic details of callers, collated in Contact's point of service survey<sup>13</sup>

Details reported by callers at the first call and collated by Contact		
Gender (n=719)	86% were female	14% were male
Family composition (n=711)	52% lived as a member of a couple	48% were lone parents
Parents with a disability (n=705)	22% of parents said they were disabled	
Age (n=717)	96% were aged 25 to 64	3% were aged 24 or under
Ethnicity (n=686)	<ul style="list-style-type: none"> <li>• 74% described themselves as White British, Irish or other White</li> <li>• 11% as Asian;</li> <li>• 9% as Black African or African Caribbean;</li> <li>• 3% as having a mixed ethnic background; and</li> <li>• 3% other</li> </ul>	

#### Case vignette

Kirsty is a lone parent with a teenage child who is disabled. Kirsty had to give up work as her employer would not let her alter her hours to fit around the caring required for her child. Kirsty felt that it was only feasible for her to work about 4 to 5 hours a day to fit around school hours, at minimum wage levels. She had tried to claim Universal Credit but had been refused on the basis that she had given up work voluntarily and without good reason.

Given her caring responsibilities Contact's welfare rights adviser was able to help Kirsty challenge the refusal of Universal Credit. She was also advised to claim Personal Independent Payment (PIP) for her child and Carer's Allowance for herself. Kirsty was awarded all three of these benefits including arrears for the periods in question. She subsequently got another job, but her Universal Credit and PIP continued.

## 4.2 Advice topics

Parents often needed help to navigate the system. Enquiries handled by the project related to a wide range of benefits and income maximisation and frequently one call concerned more than one topic. Hence the percentages for each topic do not add up to 100%.

- The most frequent issue was Disability Living Allowance (DLA), accounting for 25% of call back appointments. As simple DLA queries such as eligibility are answered by Contact's general helpline, the welfare rights team covered more complex problems, such as challenging decisions, and the interaction of DLA with other benefits. In addition, over the first two years of this project, the team noted a marked deterioration in the quality of decision making and

<sup>13</sup> These details were collected through the point of service survey at the end of the first call



corresponding increase in the number of requests for help to challenge erroneous DLA decisions.

- Nearly one in five (19%) of calls related to working hours or work status. These involved doing numerous calculations, trying to figure out whether families would be better or worse off and any other implications of taking on a job, or increasing working hours, or reducing them, in order to provide more care for their disabled child, and / or deal with a current crisis.
- 18% related to young people (16+) and their potential independent benefit entitlement and choices as they got older; how this would impact on the household income; benefits when in or out of education; and entitlement if and when they moved into independent living.
- 8% were about Universal Credit. However, this increased over time and in the first half of 2018 Universal Credit was the third most frequent topic. Entitlement for young people in education was particularly complicated and proved more problematic than anticipated.
- 8% related to Carer's Allowance.
- Successful legal challenges resulted in a number of relevant case law developments for families with disabled children in this period. These included changes to Personal Independence Payment (PIP), DLA mobility component for children and young people with mental health problems and / or autistic spectrum disorders; and the decision that the DLA or PIP personal care entitlement can continue when a child is in hospital for extensive periods.
- Other frequent topics included: Housing Benefit, the "bedroom tax", benefits on coming from abroad, Income Support and Council Tax.

Sometimes associated issues, such as getting an Education, Health and Care Plan, or a more definitive medical diagnosis for a child were raised, along with other forms of support such as the Blue Badge disabled parking scheme, or applying for a Disabled Facilities Grant for housing adaptations.

#### 4.3 Other outputs provided by the welfare rights team

As well as the telephone advice, the Contact welfare rights advisers produced a number of other outputs to assist families to navigate the benefits systems. Over 2016-18 these included:

- Published four new benefit guides: Disability Living Allowance (DLA) when in hospital; benefits changes; Universal Credit; and mortgage interest changes for people on benefits.
- Revisions to over eight existing guides and factsheets, including: DLA, Personal Independence Payment (PIP), Universal Credit and Carer's Allowance.
- Over 13,400 printed versions of these guides were disseminated and a further 2,644 were downloaded from Contact's website.
- 74 articles on benefits issues and regular content updates for Contact's website.
- Eight benefit e-bulletins, covering new case law and other benefit updates were written and disseminated to individual parents and local and national support groups.
- Two articles for Contact's national magazine.
- Six new podcasts on a range of benefit issues, including changes to mortgage interest support; Council Tax discounts; moving onto PIP at 16; and Universal Credit. Podcasts were accessed 4,771 times over 2017-18. This was reported to be a marked increase and for the first time exceeded the number of factsheet downloads.

#### *Case vignette*

Dawn had recently separated from her husband. Her child, aged 6, had learning disabilities. Dawn had made a claim for Universal Credit. But she did not feel able to meet the (Universal Credit) requirement to look for and take on work because of her child's care needs as well as the impact of the recent separation and distress. The Contact welfare rights team advised her to claim Disability Living Allowance (DLA) in respect of her child, for its own sake and in order to claim Carer's Allowance and in turn to get the Universal Credit work requirement waived; and while awaiting the DLA decision to ask Universal Credit to reduce the number of hours she would be required to work. She was successful in each of these and everything worked out as the Contact adviser had predicted.

## 4.4 Outcomes achieved by the project

Clearly those calling the welfare rights team primarily wanted assistance with finances. In addition, Contact hoped that callers would benefit in other indirect financial and non-monetary ways. This section assesses both financial and non-financial outcomes reported during the evaluation depth interviews and Contact's surveys.

In summary, the average financial gain was £100 per week for those followed up by Contact. These financial gains enabled families to pay for the additional costs associated with their child's disability, as well as managing debt and other household expenses. Additionally, non-financial outcomes such as reduced stress, improved confidence and reduced isolation were reported. The families interviewed were certain that these improvements were all directly attributable to Contact's welfare rights team. The following sub-sections cover the financial and non-financial outcomes reported.

### 4.4.1 *Financial outcomes*

During the initial call back appointment the welfare rights team record details of all benefits in payment at that time, along with earnings and other income and provide advice on what the family could be claiming, as well as how to do so. Advisers keep a record of both current amounts received and record estimates of the weekly and annual amounts which should be paid for that family - if all claims, reviews and appeals prove successful.

Contact's telephone follow-up survey, conducted about four months after the initial advice call, collects details about what actually transpired. By the end of July 2018, 224 parent carers (19% of the total estimated -1175) who had received in-depth advice from the project over 2016-18 had responded to the follow-up survey. This relatively low response rate was considered to have numerous causes, not least:

- the project did not try to call those where no financial gain had been expected
- difficulties getting people to answer calls or arranging a mutually agreeable time
- it is not a priority for families; not everyone who got advice consented to be followed up
- it often takes longer than four months for benefit problems to get resolved, more so when there are appeals, and last but not least

- this exercise can be very time consuming and conflicts with pressures of providing advice.

As a consequence, this data should be seen as live, as it will change and possibly increase as more results are gathered.

### *Recorded financial gains*

Table 3 illustrates the actual increases in income received by the 224 families followed-up.

*Table 3: Reported and estimated financial gains over 2016 -18*

All amounts are averages	Year 1		Year 2		Average over 2 years	
	Weekly	Annually	Weekly	Annually	Weekly	Annually
<b>Reported actual increase per family followed-up (n=224)</b>	£102	£5,314	£99	£5,147	£100	£5,219

- Seven in ten (71%) or 159 of the 224 families followed-up reported that their income had increased as a result of the project's specialist advice.
- Individual increases ranged from about £10 per week to over £300 per week; and over half (57%) reported a financial gain of between £50 and £150 per week.
- On average over these two years, these families saw an increase in income of £100 per week.

### *Estimated financial gains for all those advised by the welfare rights team*

As it was only possible to collate precise details on monetary outcomes for around one fifth of families using the welfare rights service, in order to estimate total financial gains we examined the estimates calculated by the Contact project, and explored how well these estimates compared with the data on sums actually received.

At the point of the first call, the welfare rights team estimated that around 68% of those getting a call back could expect a financial gain. Other families were not expected to see any gains, for example if they did not meet all the criteria for a specific benefit, or they had simply wanted to know their options regarding work, or hospital admissions, but no immediate action was necessary.

The team estimated that about two-thirds of callers (68%) would see a financial gain (based on the details of their case). This group were prioritised to get a follow-up call. Seven in ten of those followed up reported that they had indeed seen an increase in income. If this rate was applied to all callers, it implies that 48% of unique callers would see a financial gain.<sup>14</sup> This equates to 564 out of the 1175 unique families getting an increase in income as a result of the project's advice.

Contact used the data gathered in the follow-up calls to revise their estimates. A comparison of the initial estimates, recorded at the end of the first call, and the actual gains for families followed-up (Table 3), found that the estimated gain was on average 21% higher than the actual gain achieved. Although there might be many reasonable reasons for this, such as people not wanting to pursue

<sup>14</sup> As mentioned above, the welfare rights team mainly follows up callers who could reasonably be expected to see a financial gain, to check whether this has materialised, and to check if they need any further advice.

every action required and all new claims at the same time, or benefit appeals or reconsiderations taking a long time, Contact decided to adjust its estimates downwards for all the 1175 callers to match this data.

Table 4 shows Contact’s revised estimated average income increases for all those advised by the project, adjusted by this factor. Despite the revisions, the sums involved are still substantial:

- On average weekly gains were estimated at £96 for Year 1; £109 in Year 2; and £103 overall.
- This equates to over £1million in Year 1; nearly £2million in Year 2; and over £3million in total.<sup>15</sup>

*Table 4: estimated gains across all those advised by the welfare rights team*

All amounts are averages	Year 1		Year 2		Average over 2 years	
	Weekly	Annually	Weekly	Annually	Weekly	Annually
Contact’s estimated average increase across callers for whom a financial gain was expected	£96	£4,992	£109	£5,668	£103	£5,356
Contact’s estimates of the total increased annual entitlement of all those advised and for whom an increase can reasonably be expected. <sup>16</sup>	£1,053,000		£ 1,970,000		Total over 2 years: £3,023,000	

Those interviewed for this evaluation generally reported increases in benefit income. The follow-up calls and evaluation interviews found that the variance between the original estimates and what transpired were normally caused by:

- people not pursuing all aspects of the advice, for example deciding to defer one benefit claim, as they could only deal with so many challenges at a time, not least because of concomitant caring pressures.
- delays in getting benefit issues sorted. For many evaluation interviewees benefit problems had taken several months to be rectified and some were still outstanding.

*“It gave me the confidence to challenge the refusal of my son’s PIP. I would have given up without your help.”*

<sup>15</sup> The increase in total financial gains between year 1 and year 2 is mostly accounted for by additional staffing thus allowing for higher call back volumes in year 2.

<sup>16</sup> Figures are rounded to nearest £1000 to avoid spurious accuracy

*‘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.’*

*“Gave me the confidence to apply for benefits that I have been scared to apply for therefore increasing my income.”*

#### *Case vignette*

Kerry is a single parent with two disabled children. She was advised to apply for Disability Living Allowance for each, Carer’s Allowance for herself and the associated increases to Child Tax Credit and Income Support. The family’s benefit income increased from £190 per week to £480, (a difference of £290). They described the change as; *“Life changing for me financially...this has changed my life.”*

However, even where any increase was modest or not possible, interviewees and respondents nonetheless reported feeling more informed about how entitlement was calculated and more aware of their options in the future.

#### *Backdated benefits*

Most families who saw a financial gain also received some backdating of the new or increased benefit entitlement, for example from the date of initial claim or the wrongful decision. The welfare rights team was not able to collect this information routinely in all cases, as getting accurate figures and dates is too difficult unless parents had the official notification or award letter in front of them. Most struggled to remember precisely how much arrears they had been paid. However, some parents did remember or had the right documentation to hand, usually then the sums involved had been considerable. For example, for 10 particular families, arrears ranged between £450 and £10,000 with an average of £5,400. In one case a family had seen an (incorrect) overpayment of over £2000 removed, on top of backdated arrears of £4,000 and getting increased weekly benefit payments.

This is not representative, but suggests that if all arrears were recorded and added to financial gains the estimated increase in money generated for all callers would be larger than the figures given in Table 4 above.

#### **4.4.2** *Other material gains*

The follow-up survey and independent evaluation probed what, if any, other material differences had transpired from sorting out benefit problems. Overall the most common improvements reported were that the increased income had:

- helped them afford more elementary items and manage basic household costs
- reduced or avoided debt
- helped pay for some of the extra costs associated with a child’s disability

- made it possible to afford a few modest ‘extras’, such as family outings
- clarified the considerations to make decisions about work, and
- promoted young people’s independence.

### **Paying household bills**

Primarily, the additional money went on paying normal household bills and eased day-to-day financial worries. Interviewees commented extensively about feeling more in control of their budgets and income, and being able to predict and plan more. In many cases, the arrears paid helped clear debts. Additional weekly income helped avoid further debt and sometimes reduced the need to use relatively small savings put aside for future contingencies.

*“Helped bring stability into their lives... made a huge difference.”*

*“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.”*

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

### **Meeting extra costs**

The extra money also helped meet the additional costs associated with their children’s conditions, as well as relief from perpetual anxiety about affording, or denying, such things. Everyday items such as clothing, footwear, bedding and household furniture were often worn out quicker than usual, especially if a child or young person had behavioural issues or incontinence. Behavioural issues also led to damaged furniture, furnishings and other household goods. In one case a child needed expensive custom-built shoes, and these had to be replaced every four weeks. Travel costs were also said to be more expensive for different reasons, not least the need to attend multiple medical appointments. Moreover, qualifying for certain benefits brought adults or young people entitlement to free prescriptions which indirectly reduced some health-related costs.

*“Advice made a big difference. We were really struggling when [benefit] was cut. We needed that money to pay for clothes and for activities for my disabled son.”*

*“It has been a massive help. I felt as a failure as a father as I wasn’t able to afford the things that my child needed or wanted. It was a massive struggle before.”*

*“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.”*

Being prescribed a special diet was common and cost more, such as those requiring high levels of protein and / or fat. Specialist equipment was often needed, but could be prohibitively expensive.

*"[child's] special diet is very demanding... very high fat and protein ... Prescribed by Great Ormond Street ... a long waiting list to get onto this. So very expensive. Benefits makes it easier to afford."*

*"I can buy a lot more sensory equipment and not have to worry about how I will afford the things."*

Interviewees often had to pay hospital parking charges, travelling and overnight accommodation, for example to see specialists and / or if their child had a spell in residential care and / or in hospital. Sometimes the additional money was spent on seeing specialists to get a more detailed diagnosis, or physiotherapy.

*"I could pay for extra therapy privately that has made such a difference to her posture, balance etc."*

The ability to work was frequently limited by caring responsibilities, more-so in times of crises, or when a child was in hospital. Additional benefit income or the resolution of benefit problems alleviated this.

*"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]."*

### **Affording the extras**

The ability to afford a few extras was widely remarked upon and these in turn signified a sense of an improved quality of life and "normality". Although apparently modest on the face of it, the items mentioned were nonetheless critical to the families concerned. They included being able to afford better quality food; fares or petrol for days out; a cup of coffee; or the occasional ice-cream.

*"Means we can go out more, for leisure, as a family with the children ... can go out and about more. We've visited some historic places, done day trips, which we could not do before."*

*"We've gone to the zoo. I've been able to buy him toys, some Pokémon cards... Our quality of life has improved a bit... It was a bit of extra money I hadn't banked on. It has made a big difference. Been buying better quality food... more healthy food."*

*"Now I take him out once a month - that's new since got the money ... We might go to the seaside and have an ice-cream - it all adds up for a day out somewhere. Can now afford a few snacks. Think that has helped my son a bit. He is happier."*

The scope to leave the house and get out and about more, even if just to window shop and afford the price of a coffee was repeatedly raised and possibly indicates a reduction in social isolation. Knock-on entitlement to indirect benefits and concessions from getting certain benefits also helped, such as public transport concessions.

*"Good to be able to get out and about more. Live in cramped house"*

*“Able to walk around the shops, go up town and have a coffee. ... Can get out of these four walls, especially in the winter...afford a coffee ...little things make the difference, not massive things. Not stuck in four walls doing nothing. I don't have to worry about the cost of a coffee”*

### **Complex decisions around work**

Many parents struggled with decisions about work and hours of work. The demands of caring, including attending frequent appointments and having to respond to emergencies, frequently curtailed how much parents could pursue employment. At the same time there is great pressure within the benefit system to get claimants into jobs.

But whether or not a family is likely to be better off through employment relies on numerous variables, not least hours, pay levels, the availability and costs of suitable child-care and benefit entitlement (in work and out). Families needed to know how these complex calculations applied in their individual cases and how much Tax Credits or Universal Credit would help. Those already in employment wanted to explore how any increase or decrease in hours (to accommodate care duties) would impact on their family income.

#### *Case vignette*

Hannah is a lone parent with two children aged 9 and 5, one of whom gets Disability Living Allowance at the highest rate. When her youngest child started school, Hannah looked for work. She saw a part-time job at minimum wage and tried several on-line benefit calculators but got different results each time. This made her anxious and uncertain about what was the right thing to do. She phoned Contact to get clarification. Hannah had assumed that her earnings would be too high to retain Carer's Allowance. However, she was advised that if she paid a small amount of her wages into a pension scheme, this would enable her to keep Carer's Allowance. Despite losses to her other benefits, her new earnings and Working Tax Credit entitlement would then make her £70 per week better off overall.

*“The system is so complex that I felt overwhelmed in trying to work out whether I could afford to give up work or not. There is no way that I would be in a position to make this decision without the advice [Contact] has given me. I was unable to sleep worrying about what I would be expected to do if I started to claim Universal Credit. It is such a relief to find out that both me and my husband would be exempt from having to sign on and look for work.”*

Only precise and individualised advice, necessitating multiple complicated calculations of different scenarios, could answer these questions. As mentioned earlier, families did not find the online calculators as exact or personalised as necessary. In some cases, the project's advice enabled families to take on extra hours. In others it enabled them to reduce their hours of work or to remain full-time carers for the time being at least.

*“Let me know whether I could afford to increase my hours.”*

*“Has enabled me to care for my son and reduce my working hours.”*

*“I did not have to increase my work hours and have more time for children's appointments.”*



#### Case vignette

Roxanne is a single parent with two children, one of whom is disabled. She got Income Support, Housing Benefit and Disability Living Allowance at the middle care rate. Once her youngest turned five, Roxanne had been under pressure to get a job. She found a job earning about £43 per week, for six hours work per week, which she thought would fit in with her children's school hours and needs.

The Jobcentre advised her that she would be financially better off by taking this job and claiming Universal Credit, as it has a better earnings disregard than Income Support. A friend cautioned that this might not be the full picture and advised her to get advice from Contact. A speedy call back appointment with the welfare rights team was organised. The adviser spotted that she would lose roughly £40 per week if she moved onto Universal Credit at this stage, as Universal Credit pays less in respect of some disabled children. In addition, she would have to find the money to pay for childcare during school holidays and the extra travel costs to get to and from work. At the time new Universal Credit claimants also had to wait from four to six weeks to get their first Universal Credit payment.

She was previously largely unaware of Universal Credit. Although Contact had advised that she would eventually have to move onto it, she felt more prepared and planned to save for the future loss of income.

#### 4.4.3 *Other, non-financial outcomes reported*

Numerous non-financial gains were reported, not least psychological and emotional help. The analysis found that these partly resulted from the benefits advice and the resolution of the relevant benefit problem. However, it was also evident that the advice process itself had its own discrete valuable impact, including being treated with respect and empathy and gaining a greater understanding of the system. These findings were echoed in Contact's own surveys.

The psychological, emotional and social benefits recounted included:

- reduced stress
- feeling more informed, knowledgeable and confident to deal with benefit issues, and
- more social activity and getting out and about more as a family.

#### *Reduced Stress*

Both Contact's point of service and follow-up surveys found self-reported reductions in stress attributed to the advice received from the welfare rights team, as reflected in the rates below.

Table 5: reported reduction in stress by families

90%	of respondents reported feeling more able to deal with stress, in the follow-up survey. This exceeded the target of 50% which was set by Contact.	n= 203/224 <sup>17</sup>
82%	reported feeling generally more confident in the point of service survey	N= 635/773
73%	said they felt better able to deal with stress, in the point of service survey.	n= 560/772

The evaluation interviewees reported feeling extremely distressed, confused and often despairing prior to seeking advice from Contact. As well as losing money, getting into debt and not being able to afford everyday costs, let alone the additional costs arising from their child’s disability, they described being very anxious about coping in the immediate and long-term. One had got a referral for emotional counselling to help deal with this stress and their associated suicidal thoughts. The decisions made and incomprehensible letters and calculations sent by, for example, the Tax Credit Office often added to this stress:

*“Very reassuring ... would probably have killed myself ... the adviser gave me peace of mind.”*

*“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.”*

*“Would have sunk completely otherwise.”*

As well as being directly helpful with that immediate issue, sorting out the benefits and clarifying ongoing entitlement had helped families budget and feel more in control of their household finances.

*“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.”*

For these parents, the financial stress caused by their benefits being wrongly stopped or underpaid came on top of the pressure of caring for disabled children and the regular associated crises, such as illness, deterioration, hospital admissions, ad-hoc expenses and the need to take time off work.

*‘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.’*

---

<sup>17</sup> The figures give the numbers who gave the response reported (number on the top of /). The number underneath the line is the total of those who answered this particular question in each survey, and / or for whom it was relevant

### Young disabled people's benefits

Clarifying a young disabled person's individual benefit entitlement from age 16 reduced parents' anxieties about how they would cope financially in the immediate and longer-term. Interviewees praised and welcomed the advisers' expertise on transition and in setting out the benefit choices available to families, and how these varied according to whether the young person stayed in education or not, moved into independent living and / or desired to claim benefit for themselves as opposed to continuing to be "dependent" in benefit terms. As well as the advice itself, the knowledge that such advice was available mitigated anxieties about how their disabled children would cope in the future.

*"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."*

### Planning for the future

Sometimes this also helped plan for and promote the young people's independence. For instance it sometimes helped the young people get practice for the future and living independently from their families and managing their own money. For instance, advice about the potential to claim Working Tax Credit encouraged one young person to take on a low paid job, an important first step on the ladder of employment. Other families were advised that their child could make a claim for Employment Support Allowance in their own right. As well as increasing the household income, the parents were then able to support them to set up a bank account and budget their own week-to-week expenditure.

#### *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. They advised that this would be better than the alternative option which was to temporarily reclaim Child Benefit up to the 20<sup>th</sup> birthday. 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.

### *Case vignette*

Sam has six children and suffers from anxiety and depression. The two eldest aged 17 and 21 have long term health conditions. Contact advised that each of the young people could claim Employment and Support Allowance (ESA) in their own right; that the 17 year-old could also claim Personal Independence Payment (PIP); and that if PIP was awarded Sam was entitled to Carer's Allowance.

As Sam was struggling financially and had multiple debts they were also directed to a local advice service for money advice. The 17 year-old's claims were successful and so they were awarded ESA (£125 pw) and PIP (£55.65pw). As a result, Sam got Carer's Allowance which led to a further increase in his income of £34.95pw.

### *Feeling more informed, knowledgeable and confident to deal with benefit issues*

The data provided in Table 6 shows that those advised by the welfare rights team felt it had helped them feel much more informed and more confident about dealing with benefit issues in the future. The positive feedback exceeds the original targets set on all fronts. The statistical analysis of the surveys conducted by Contact shows very strong endorsement for the welfare rights project.

The evaluation interviews echoed this. Interviewees reported an improved understanding of the benefits system, alongside knowing that the Contact helpline's welfare rights team was there when needed, helped people feel much more confident about dealing with benefit problems into the future. As well as the advice on the precise benefits and amounts they were entitled to, the advisers had passed on skills in navigating the processes involved, such as what arguments and terms to use and how the different parts of the system were interlinked. Interviewees understood that more difficulties would inevitably emerge over the long-term, not least as their children and young people grew older, and started to transition and live and claim more independently.

**Table 6: Feedback from the point of service (PoS) and follow-up (FuS) surveys**

<b>%</b>	<b>Indicator</b>	<b>No. responding / surveyed</b>
<b>99%</b>	felt better informed about their rights to benefits. (PoS: Target 90%)	<i>n</i> = 764/774 <sup>18</sup>
<b>99%</b>	felt they had a better understanding of how any changes in personal circumstances affected their benefit entitlement and financial situation. (PoS: Target 80%)	<i>n</i> =413/419
<b>98%</b>	of those affected by the new welfare reforms had a better understanding of how these changes affected them in benefit terms. (PoS: Target 80%)	<i>n</i> =247/252
<b>95%</b>	of those identified as missing out on benefits described themselves as more confident about applying for benefits or grants in the future. (PoS: Target 80%)	<i>n</i> = 431/452

<sup>18</sup> The figures give the numbers who gave the response reported (number on the top)/ and the total the number who answered this particular question in each survey, and for whom it was relevant.

*“Good to know all the things, otherwise would not know your benefit and what you are supposed to do or not to do.”*

*“Given me confidence ... before that did not know what things were.”*

*“Relief that others understand what is going on, not alone ... can cry on their shoulders.”*

*“Better idea where to go for advice. Now saving for when things go wrong. Empowering, given me control and knowledge where to go if I need advice.”*

Simply knowing that Contact’s welfare rights advisers were there *“at the other end of phone or email”* provided immense reassurance and helped parents feel less isolated. The experience of getting sound advice, being treated with respect and having the reassurance that there was a place to go for support and accurate advice proved highly significant.

*“The advice and reassurance from Contact has made me feel better as I know where to get advice and information. Knowing there is that support there at end of the line is very reassuring.”*

*“Took away a lot of the stress. I felt very alone before. Now someone was helping me and they were knowledgeable and so I was able to trust them.”*

*“Helps me understand what my rights are and how to cope with benefits. I wouldn’t have had the confidence to go to appeal without that support.”*

*“I feel much more empowered. It gives me the strength to fight for my daughter’s rights.”*

### *More social activity, reduced isolation and getting out and about more as a family*

Social isolation is a major risk from being disabled and / or having disabled children, not least because of caring and accessibility issues. Poverty can also trigger isolation as it can be more expensive to participate in society. The evaluation interviewees described that they previously had not been able to get out much as a family, mainly because of the cost. Contact’s point of service and follow-up survey queried their sense of isolation and asked if they got out and about more as a family as result of the advice received. The responses shown in Table 7 below indicate that the advice and increased income had an effect on families’ sense of isolation and scope to participate in more activities.

*Table 7: Reduced isolation reported in Contact's surveys*

<b>%</b>	<b>Indicator</b>	<b>Numbers responding / surveyed<sup>19</sup></b>
<b>96%</b>	Reported feeling less isolated (follow-up survey)	<i>n</i> =203/211
<b>79%</b>	Stated they felt less isolated (point of service)	<i>n</i> = 606/771
<b>67%</b>	Said they were playing a more active role in the community, going out more and trying more local groups and networks (follow-up survey)	<i>n</i> =144/216

It is accepted that 'isolation' has no universally accepted interpretation, and respondents and interviewees expressed this in their own terms. Moreover, it is a complex issue for advisers to probe at the end of a lengthy advice session. The Contact surveys relied on self-identification and measurement, whereas the in-depth evaluation interviews explored this type of topic and its nuances and circumstantial details more. Two strands of how people perceived isolation and its reduction emerged from the qualitative analysis. One was the comforting sense that there was someone out there, namely the Contact helpline and welfare rights team, who could support them when needed; the other was the increased scope to get out and about more and take part in life outside the house and participate in activities perceived as 'normal'.

*"Fantastic to have Contact there for support and advice as prior to this was very isolated."*

Interviewees said that increased income helped them and their children get out of the house more often and feel more part of their local area. This meant being able to use their local shops and cafes, but also enabling the children (whether disabled or not), to participate in more social, local and school activities which were otherwise inaccessible because of cost.

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

*"My children can do things that we couldn't afford to do before - like go out on school trips or take part in local clubs and activities."*

For some parents the advice they received from the welfare rights adviser was a major factor in encouraging them to move in new directions such as entering education, training or employment. Parents who started work reported gains in the realms of self-esteem, confidence and social interaction.

---

<sup>19</sup> The figures give the numbers who gave the response reported (number on the top)/ and the total the number who answered this particular question in each survey, and / or for whom it was relevant.

#### 4.4.4 Attribution: how much were the changes reported due to Contact's input?

Contact's follow-up survey asked callers how important the advice from Contact had been in helping them achieve any changes in benefits<sup>20</sup>. All but one person who answered this question (99%; n=167) reported that Contact's welfare rights advice had been 'very important' to achieving those outcomes. That one other person felt that Contact had been 'somewhat important'. This endorsement was echoed in the evaluation: interviewees were of no doubt that it was the advice and support from Contact which had brought about any changes. Moreover, the difficulties interviewees reported in accessing expert advice locally, further augments the likelihood that the changes can be attributed to the Contact project.

*"I feel much more confident in challenging the Housing Benefit Office, having someone behind me to help me out and to explain things in detail. I think I would just have given up if you hadn't been there."*

If not for Contact helpline's welfare rights project, they said they would have continued as before:

- not realising they were being underpaid or that they were not receiving their proper entitlement
- not challenging the incorrect decisions in question, or known that they could do so, and
- that they may have followed other, wrong, advice, for example to take a course of action which would make them worse off' or
- not claimed the right benefit, or
- switched to Universal Credit too early, or too late.

Filling in many of the forms to claim certain benefits was described as too 'daunting' without support. Living on less than they were entitled to, not being able to afford basic items and getting into (more) debt were described as the alternative prospects before families talked to Contact. This included taking out loans to buy clothes for their children. Overall, they felt they would still be highly stressed, 'struggling' and 'not know where else to go' and the advice had provided 'peace of mind'.

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

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

*"I had no idea that my Housing Benefit award was wrong until I spoke to [adviser]. I was at risk of losing my home and facing eviction. Because of all the information Contact sent, I was able to convince my council to stop treating my son as non-dependent. I am sure I wouldn't have been able to do that if they hadn't sent me the regulations."*

---

<sup>20</sup> The question posed was: "If you experienced a positive change, how important was Contact's advice in achieving that change?"

Evaluation interviewees had been largely unaware of Universal Credit, prior to talking to Contact, or had previously received incorrect information, or had experienced mistakes in the calculation of their entitlement. Contact had proved instrumental in getting these sorted.

*“There was such a lot of bad press about Universal Credit I would never have known that I could be better off claiming it unless I had spoken to you.”*

*‘There is no way I would have been able to even try and claim Universal Credit unless [Adviser] had been there to explain what I should do and to warn me that I would need to insist on a medical assessment.’*

### *Where families will go for advice in the future*

As stated previously, for many the Contact helpline welfare rights project had become their preferred, and sometimes only, port of call if benefit problems arose, mainly because of the welfare rights team’s depth and range of expertise and pragmatic advice, but also because this advice was provided very clearly and empathetically and had proved correct. This is endorsed by the findings from the point of service survey (Table 8 below):

**Table 8: Where families will go for advice – from point of service survey**

<b>82%</b>	Reported feeling better informed about how to get the support they needed	n=626/767
<b>99.6%</b>	Said they would recommend Contact’s advice services to others	n= 767/770

Becoming more knowledgeable about the benefits system, had also made people more aware of the pitfalls of getting misleading information.

*“It’s a really important service and over the years I have used it on many occasions where I just couldn’t get clear advice about what was the right thing to do ... I’ve had advice about Housing Benefit errors, advice about moving into work, and dealing with the transition from child to adult benefits for my children. The advice has always been really clear and most importantly accurate! The help has allowed me to fight to make sure my family was getting everything they were entitled to.”*

*“Wrong advice can be dangerous - don’t need advice all the time, but when you do it needs to be accurate.”*

*“I cannot imagine what my family would do without [Contact’s] advice.”*

The current programme of welfare reforms will be fully implemented over the next few years (details in Appendix 6.1). Families will continue to need advice on avoiding pitfalls and ensuring their correct entitlement is paid timeously.



## 4.5 Views on processes and getting benefit advice from the project

Contact's helpline operates with three sub-teams: the general team, the education team and the welfare rights team, the focus of this evaluation. The welfare rights team employs 2.5 staff and reached its full staffing complement in year 2 of the project. When a parent calls the free helpline number, they first have the option to speak to the general team or the education team. Advisers on the general line assess the nature of the enquiry. Over a half of the enquiries dealt with by the general team relate to benefits and money matters, and this team provides initial advice, information and local signposting, which in most cases is enough. However, where a query seems more complex, or urgent or likely to require long-term input, the general adviser arranges a time for a call back appointment, with consent, by a member of the welfare rights team. This team also trains and support the general helpline staff. This triage system had been developed and honed over a period of time and was ready to take on this specialist project from the start without the need for much set-up time.

Similarly, enquiries made through social media and email are also initially assessed by the generalist advisers and either answered by the generalist adviser, with guidance from the welfare rights team, or referred on to the welfare rights team for their attention. The helpline advisers ask some key information and enter this into Contact's central database, which is used by the welfare rights team when they call the person back for their appointment.

This evaluation was interested in exploring how people found this two-step process; and how they felt about discussing often private and complicated disability, family and financial matters over the telephone, not least as such issues are normally considered quite confidential and sensitive.

### 4.5.1 *Getting through to a welfare rights adviser*

Across the 20 qualitative interviewees, the time it had taken to first speak to the welfare rights team ranged from immediately to a week. For most it took a few days. One woman who had stressed the urgency of her query, was called back within 30 minutes. She needed to give a decision that day about a job she had been offered, and was rightly worried that it might make her worse off financially. It turned out she would have been substantially worse off because of the interaction with benefits and the costs of travel and childcare. Overall, those interviewed did not mind waiting because of the advice quality. In other words, any wait was counterbalanced by the soundness and reassurance of the advice.

*"I don't mind waiting as the advisers are very experienced, and know what they're talking about."*

*"The quality of the advice makes it worth it. The first people are also good. They explain why there is a delay and how long to expect to wait and why it is best to speak to someone with more experience."*

In addition, the time lapse gave callers the opportunity to get all their papers and details of key dates, decisions and precise amounts in order in **preparation** for the advice discussion, as advised in their initial call. This helped get the most out of the conversation with the project.

*“Helps to get everything ready.”*

*“Not a panic thing... gave me chance to get everything together.”*

The advisers’ **reliability** was highly praised, in that they were said to always call back at the appointed time. This helped establish trust with the service, and was valued by interviewees. Often, one call was not enough. If issues were complex or if changes occurred over time numerous calls were required. Furthermore, some interviewees said that they got back in touch with the welfare rights advisers, and could do so easily, for example using direct line numbers or emailing individual advisers to request a call back when anything else arose. In other words, the system was found to be highly responsive to individual needs and some case work developed over time.

*“It is a really good service - the best I have used. I keep coming back to get advice every time there is a change and it is great to be able to speak to someone who knows my case already.”*

One downside, reported by the welfare rights team was that sometimes families were unable to keep to appointments made and so required numerous calls.

#### **4.5.2 Views on using the telephone for welfare benefits advice**

The evaluation explored feelings around using the telephone to discuss the personal, and often private and complicated matters involved, such as disability, health, personal care needs, money, family circumstances and emotions. Views divided into:

- those who would normally prefer to talk to someone face-to-face, but nonetheless found using the Contact helpline welfare rights service easy and effective, and
- people who preferred using the telephone.

A face-to-face situation was said to make it easier and quicker to establish trust and rapport with someone and to be better suited to the topics under discussion. Discussing various financial permutations, especially those needed in better-off calculations, was said to be tricky over the phone: a face-to-face appointment would enable them to observe how sums were being done, step-by-step.

Conversely, using the telephone was said to bring many advantages:

- The call did not interfere much with caring responsibilities or impinge as much into their busy lives as would visiting an office somewhere for advice.
- It minimised disruption. There was no need to arrange care for the children and the call could carry on while they attended to caring or household duties.
- Disabled parents said that using the telephone was better as they could agree a time that suited them and working hours. The extended opening hours were welcomed on this front.
- Travel and physical access problems were removed. One interviewee said they would otherwise have to get two disabled children in wheelchairs into an office in another town.
- The advisers were said to make the information accessible, which overcame many of the problems which would have otherwise occurred.

- Interviewees understood that this was a national service and that providing a quality service in each locality would not be feasible, and
- Some found a phone call less stressful than seeing an adviser in person.

*“Great service, suits me being on telephone as a busy working mum and carer.”*

On the whole, people said they did not mind how the advice was delivered, as long as it was available and accurate. Possibly interviewees’ positive experience of the Contact advice, inclined them to be more positive about the mode of advice.

*“They were very helpful from the get-go and made it very easy.”*

#### **4.5.3** *How interviewees had found out about the Contact helpline welfare rights project*

The evaluation was interested in how people came to know of Contact’s welfare rights project, as this can inform further promotional work. Those interviewed had come across the helpline in diverse ways. A few had attended events or talks given by Contact, or had previously used some of its other services. Most had never heard of Contact before, let alone its welfare rights advice. They found it through random internet searches, recommendations or referrals from other agencies, or from friends who also had disabled children, and one person found it listed on a local authority website. Some were referred by professionals and other agencies. All felt that the Contact helpline should be advertised more and that the organisation’s name did not make internet searching easy or explain what services were on offer. Note two-thirds of these interviews were undertaken prior to the organisation’s change of name from ‘Contact a Family’ to ‘Contact’. But similar points were made across all interviews.

#### *Call context*

All the interviewees recounted feeling extremely stressed and anxious prior to seeking advice from Contact. Commonly they were struggling with a new diagnosis or the effort of getting one; as well as emergencies; low income; conflicting or no advice; multiple hospital and other appointments with professionals; and considering whether to give up work because of caring responsibilities or take on a new job because of pressure from the Jobcentre. All of this was being juggled with the day-to-day pressures of caring for a disabled child or young person.

*“It was a time of absolute desperation, because of not having a diagnosis as well as having to give up work.”*

*“Confusion: did not understand special needs; knew nothing about benefits; very slowly gathering info about SEND [Special Educational Needs and Disability]. Felt really anxious and scared.”*

*“Everything was in the air... Always financially struggling. I needed somebody who knew what they were talking about.”*

*“I was feeling completely blank ... in desperation.”*

#### *Case vignette*

Martin is in low paid work. Both he and his partner have health problems and their child, aged 18, has severe learning disabilities, needs a lot of care and support and gets Disability Living Allowance. Martin describes life as very stressful. The parents get Tax Credits, Carer's Allowance, Child Benefit and Council tax support. They were concerned about everyone's benefit entitlement when the young person turned 19, and if they went into further education, or supported accommodation. Although they '*shopped around*' for advice and had previously used MENCAP and a local carers organisation, they felt that this was a very complicated benefit question which required greater expertise. Some parents at their child's special school recommended the Contact helpline.

They got through on the first phone call and got a telephone appointment with the welfare rights team for the next day, which gave them time to get all the details ready. Normally Martin does not like using the phone because of his own health problems, but he said talking to the Contact welfare rights adviser felt easy and relaxed. They found that the adviser understood the issues raised instantly and was nice to talk to. The advice was clear and easy to follow. This covered various living, education and benefit permutations for them all, including advice about the young person claiming Personal Independence Payment, postponing a transfer to Universal Credit, or the young person's separate claim for Employment and Support Allowance, for as long as possible, to delay becoming worse off, financially. As a result, Martin felt quite clear about the various options, but also that they could ring Contact's helpline again whenever they needed to.

#### **4.5.4** *Views on the welfare rights advisers' understanding, knowledge and approach*

Numerous aspects were praised in the evaluation interviews and in Contact's surveys, not least the advisers' ability to quickly grasp the issues, no matter how complex, the depth and breadth of the advisers' experience and expertise, the specificity and thoroughness of the advice given and how pleasant each adviser had made the experience.

*"Understood it better than I did."*

*"Their knowledge about everything was top rate. Spoke to one other adviser as well and she too was wonderful. Understood what might be going on for me, as much as the benefit rules ... very gentle and kind."*

*"... seem to know more about [Tax Credits] than the Tax Credit Office."*

#### *Speed of getting to grips with issue*

Interviewees were really impressed with how quickly and thoroughly the advisers understood the issues they called about, more so given the incomprehension, lack of knowledge and errors they had encountered elsewhere.

*“Understood immediately.”*

*“Knew straight away what it was about - much better than anyone’s else, more than Tax Credit office... they just did not understand what I was saying.”*

*“They were brilliant. Wow... Because it was so complicated.”*

### *Depth and breadth of expertise*

More than anything, interviewees were really impressed with the breadth and depth of the advisers’ expertise and practical experience, especially its accuracy, expertise and specificity to their individual situations.

*“Wonderful, absolutely wonderful.”*

*“Gave me the best advice ever... Hard to know this kind of thing when so busy with disabled children.”*

### *Comprehensive assessment of needs*

Not only did they provide pertinent and detailed advice about the topics people had initially sought help on, the advisers also identified other issues, such as:

- other entitlements, or knock-on consequences and available options
- discussed better-off considerations
- discussed actions to avoid
- advised on tangential matters, such as education, or getting a definitive diagnosis
- provided advice around Universal Credit and other forthcoming changes, and how these might impact on their family members, and
- recommended the best course of action to take.

*“Fantastic. Exceptionally useful and knowledgeable. I was not aware of, did not realise that DLA existed.”*

*“Beyond expectations and they advised on other matters ... lots of things we would not have had a clue on ... had never even heard of Child Tax Credit, let alone looking into.”*

### *Clarity, detail and accuracy of the advice given*

The detail, precision, depth and clarity of the advice and “*first class knowledge of the advisers*” was highly rated. The qualitative data from interviews and Contact’s surveys indicate that the information provided was precise, accurate, individually modulated and conveyed clearly in appropriate, user-friendly, ways. As well as explaining entitlement and how the rules applied to their individual circumstances, the advisers detailed what steps callers had to take in order, as well as what to say and expect at each juncture.

Additional information was often sent to callers, such as print-outs of the detailed criteria. Sometimes the advisers gave people the exact wording to use when talking or writing to the relevant benefits departments. Whether relayed by phone or sent in writing, this helped ensure claimants used the correct terminology and phrasing and any precise legal references required. Often the team drafted the letter for the family to send on to the relevant office.

*“[Advisers] told me what to write in my review letter, basically gave me the words over the phone and I wrote them down.”*

*‘Spot on: [Adviser] sent very detailed notes on who to talk to and what to say and what number to ring. If I did not have that information, I would have been absolutely lost... crystal clear.’*

*“[Adviser] wrote a letter for me which I brought down to the Housing Benefit and that sorted it immediately.”*

What is striking is that callers understood even highly complicated issues and calculations by the end of the call; that advisers spent as long as necessary with each person to ensure this; and that they often called people another time to help ensure the information had been understood and / or to provide advice on subsequent steps.

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

*“Very easy to follow”*

The advisers regularly prepared families on what glitches to expect, either around a certain rule, or with that benefit’s administration. Even when everything eventually worked out exactly as predicted, the inefficiencies encountered with say the Jobcentre came as a surprise to families. In one case, a claimant had to return six times with different pieces of information and proofs to help resolve a Universal Credit issue. Interviewees appreciated how the Contact adviser had prepared them for this, and that they were there for back-up if needed.

*‘told exactly how to do things and what would happen. Everything was good.’*

*“Put my mind at ease.”*

Interviewees’ views on accuracy are echoed by the quantitative findings on financial outcomes, covered above, which proved fairly accurate. Most deviations were accounted for by people not pursuing all aspects of a claim at that time and / or the issues still awaiting final resolution, such as an outstanding appeal hearing.

### *Case vignette*

Charlotte is a lone parent with three children under 18, one of whom is disabled. She also has her own health problem and works part-time. She came across Contact when doing an internet search about disability and benefits, following the refusal of her child's Personal Independence Payment (PIP), on transition from Disability Living Allowance. She also faced an overpayment of other benefits, which she felt had not been her fault. Charlotte was very distressed and confused, which aggravated her own health. She did not know where to turn and although she had tried a local advice service, had not found the advice sufficiently detailed.

Charlotte emailed Contact. She got an appointment to speak to the welfare rights team within a few days. Although she normally prefers face-to-face or email, she found talking to the adviser by telephone worked well. She said they were very knowledgeable and understood her situation immediately. Over eight months she had about five phone calls with the welfare rights team. They took her through each issue step by step, explaining what she had to do and what arguments to use.

The advice covered how to argue against recovery of the overpayment; points to make in an appeal about her child's PIP; and to claim PIP in her own right which in turn would lead to increased Housing Benefit and Tax Credits. At the time of the evaluation interview, she had successfully claimed those three benefits for herself, had overturned the overpayment and so had eliminated debt on that front, and was awaiting an appeal hearing for her child's PIP.

### *Welfare rights advisers' approach*

As well as their level of expertise, interviewees praised the welfare rights advisers' general approach and said that the advisers established trust and rapport, were very responsive, "compassionate", empathetic and "calm" and helped them feel relaxed quickly. Providing the advice clearly and in an unrushed manner was both appreciated and made it more usable.

*"Very positive experience ... they could not have made it any easier."*

*"Adviser was brilliant. It was like speaking to a sympathetic friend... Not patronising. Just absolutely brilliant."*

*"Poured my heart out to her. Understood the issues a lot more than I did. ...Always very nice in emails and on the phone."*

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

The word cloud below picked out the most common terms used to describe views gathered in response to the point of service survey question which asked if they had any other comments about the service.

absolutely **accurate**  
**always** amazing appreciate  
 best **better** brilliant calm clarify **clear**  
 clearly concise **confident** delighted detail **detailed** easy efficient  
 excellent explained extra extremely **fantastic** friendly glad  
 good grateful **great** happy help  
**helpful** impressed information informative  
 informed knowing knowledge knowledgeable listen nice **options**  
 patient pleased precise professional prompt **questions** quickly relief rights  
**service** stressed supportive sure system thank time  
 understanding understood  
 useful worried

#### 4.6 [Availability and experiences of using other local advice services](#)

It was important to find out where the Contact helpline welfare rights service fits in the grand scheme of benefits advice provision across the country. Some areas have local advice services, such as law centres, Citizens Advice and local authority welfare rights services, and nationally many large disability and carers' organisations offer benefits advice, although welfare rights advice has always been sparse and has reduced more over recent years especially as a result of public sector cuts. This issue was queried both in the point of service survey and by the independent evaluation. Findings concurred, in that most had not been able to find advice elsewhere; and even where they had they were generally unhappy with the advice services found.

Many described going from pillar to post looking for advice, which is much harder to do when caring for disabled children.



*“Didn’t know where to go for help.”*

*“I had real trouble finding the information I needed about my son’s benefits. So very glad I found you.”*

*“I felt demented. I was sure Tax Credits were wrong, but I could not get good advice.”*

Despite long-term and intensive contact with hospitals, health professionals, social workers and other agencies, a surprising number of interviewees had never previously received any advice around benefits, nor any recommendations to get benefit advice from these professionals, and were largely unaware of what existed. Professionals and statutory agencies often did not recognise that families with disabled children may be entitled to discrete benefits or possibly presumed that the correct benefits were being claimed. Either way, these families said they had not received encouragement to seek advice on these matters. Equally it was clear that families did not perceive these professionals as knowing much about this subject.

*“I don’t think social services are the right people to ask: they ask me about benefits ... I fought a hard war with social services to get [Direct Payments] ... They don’t easily give out money. No point asking them for advice.”*

Those who had sought advice previously had predominantly used local Citizen’s Advice; government departments, such as Jobcentres and Tax Credit Offices; online calculators; carers, disability and children’s organisations; and local council welfare rights units. Their experiences were variable but on the whole unsatisfactory. That said, there is clearly going to be some bias in the sample of callers using the Contact helpline: in that people satisfied or getting adequate advice from another agency would not have needed to use Contact.

*“Tried a lot. None useful. You go all the way down there and they say “oh we can’t help you”. That’s very difficult when you have children with special needs. That’s really bad, really bad service... They could have told me that on the phone. You haven’t got time to do all this dragging about.”*

Stated challenges included getting timely advice, inaccessibility and long wait periods for appointments. In some examples waiting times were two months and / or people were expected to queue for hours. Reliability was another complaint, in that people reported that agencies often failed to phone them back when promised.

*“I used [named advice service] in the past, but they were not much help... Basically sat there for a couple of hours and then told would have to come back a month later for an appointment.”*

*“Couldn’t answer my question when I asked, and said I would need to speak to a specialist adviser. They said they could organise this but that there would be a wait of several weeks.”*

Those who had reported getting advice elsewhere reporting being disappointed with the lack of expertise. Most of the other agencies these families had tried could only provide very generalist advice and lacked specialist knowledge around benefits for disabled children and young people or their families.

*“Tried local advice services - no good. No point. They don't have much knowledge or expertise. We see [named local children's disability charity] for other issues. You can't get into our local Citizens Advice and they only seem to deal with debt in any case.”*

People feared, and indeed many had direct experience of, getting inaccurate, misleading or totally erroneous advice. Because the benefits system seemed so complicated, daunting, confusing “a minefield”, and the gravity of the issues involved, interviewees felt that this topic needed particular expertise: “need to know their stuff”. Again, this sample is probably biased to some extent and there is no way of knowing what proportion of people using other services were dissatisfied.

*“I tried the local council. They did not understand how DLA could impact on Housing Benefit... We tried [a local advice service] when [child] was younger to claim DLA. I waited from 9am to 2pm. The woman was nice but had never filled in a DLA form before. So, no better than me doing it.”*

*“Did not have a clue.”*

*“They were useless.”*

Several examples of incorrect advice from other advice services were given, including deterring people from pursuing certain benefits or from challenging wrong decisions.

*...[they] were absolutely useless. They said ‘there is nothing you can do. You will lose everything if she doesn't continue in education. You're stuck.’*

*“The [local advice service] accepted the overpayment decision without question: they treated it as a debt query and simply offered to help me set up a repayment plan.”*

Currently many online calculators can help people compare the financial side of taking on certain jobs, or compare in-work to out-of-work income. However, these were often reported to be too generalist and their results not detailed enough and unable to accommodate the nuances of entitlements and situations relevant to families with disabled children.

It became evident in the analysis of the open responses in Contact's surveys and in the evaluation interviews that some families had grown to rely totally on Contact for benefit advice and used the welfare rights team several times. They said they trusted them absolutely and returned to them because of absolute confidence in their expertise. Some had the advisers' direct numbers and email addresses.

*“I always come to Contact if I have any benefits questions. I have used them many times, and the advice has always been really accurate.”*

*“It is a huge support. I have relied on Contact's advice several times and it has always been really clear and helpful. It means that I have the knowledge to make decisions about what is best for myself and my son and not feel paralysed by not knowing what is the right course of action.”*

*“Only knowledgeable people in the universe.”*

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

From the welfare rights team’s point of view, the reduction in local advice services meant that they often had to provide more practical help to parents, for example drafting letters on their behalf to pursue a mandatory reconsideration or appeal, or writing more detailed emails explaining the benefit options and necessary action points in writing. To an extent this may indicate an unintended move towards case work, was time consuming and may impact on overall numbers. In the past they were more able to refer families to local advice agencies for this type of help.

#### *Case vignette*

Yvonne’s child was admitted to hospital temporarily but ended up having to stay for over a year. The child got Disability Living Allowance (DLA) and the parents received Carer’s Allowance and Tax Credits. The Tax Credits Office sought repayment of an overpayment of over £2,000, arguing the family were not entitled to a disability element for their child while they were in hospital. They found this amount daunting and impossible to repay as both parents were on low earnings and had lots of additional costs associated with their child’s disability and hospitalisation (including long-distance travel). Yvonne felt sure the decision was wrong and queried it. Nonetheless numerous calls to the Tax Credit Office to check the calculations proved fruitless; their normally helpful social worker said they knew nothing about benefits; and the local Citizen Advice said the decision could not be challenged and suggested setting up a repayment plan.

Eventually she found Contact through a random internet search. When she rang the helpline she found they understood instantly what she was talking about. It took several telephone conversations to cover all the different strands involved in her case.

Ultimately the welfare rights adviser confirmed that no overpayment was due because the child’s continuous underlying entitlement to DLA (although payment was suspended) meant that the additional Tax Credits element had been correctly paid. Yvonne was advised what to say in a letter to the Tax Credit Office and the matter was then rectified very quickly.

## 5. Conclusion

Overall this relatively small project was found to provide a much-needed service for families with disabled children, and advice which they could not find elsewhere. It is hard to see how these families would have otherwise experienced the substantial financial and other gains recorded. Moreover, beyond the increase in income and the knock-on material and psychological and social impact, these families greatly appreciated how well the advisers understood their queries, no matter how complex, as well as the accuracy of the advice. They got immense reassurance that this expertise was available. Returning to the key evaluation questions:

- *How do families experience the process of using the Contact welfare rights project?*

Families found Contact's project accessible and easy to use. Even those who would have preferred to see an adviser in a face-to-face setting said that the advisers had made the process pleasant and enjoyable. The legal and practical expertise, finding advisers who grasped their situation quickly and could provide a wealth of useful information on complicated topics put callers at ease, and resulted in significant increases in weekly income.

Interviewees valued the way the advice was given and praised the advisers' warmth, understanding and sensitivity. They reported feeling **respected, valued** and **understood**. While the quality, depth and accuracy of the advice was key, that it was delivered in such a personable, sensitive and highly individualised manner was another bonus. Many of these parents had tried and failed to get advice elsewhere. The Contact helpline's welfare rights team made a huge difference to them, in being able to provide this expert specialism around benefits for disabled children and their families.

- *How many families were assisted and what material and other outcomes have been experienced by families?*

Approximately 1,175 families received in depth advice from this project. The amount of under-claimed and underpaid benefits which families successfully secured through advice from this project was striking. An estimated 564 families, or just under half (48%) of those families getting in-depth advice from the welfare rights team were estimated to have received an average increase of £103 per week, excluding sums paid in arrears, or cancelled overpayments. Those families who did not see any financial improvement, nonetheless had their benefits checked and verified and may have received useful advice about, for example, working hours, or options regarding Universal Credit.

It was evident that the benefits claimed were essential to cover day to day living costs; reduce debt; and help meet the, often substantial, additional expense of having a disabled child. In addition, it was found to enable a certain amount of normalcy to families' stressed and stretched lives. Parents got out and about more and felt able to afford a few relative 'luxuries', like an ice-cream or cup of coffee.

- *How well do parents understand: 1. their current entitlements; 2. how their benefits might be affected by changes in their own circumstances, and 3. how changes to the benefits system will impact on them.*

The findings of this evaluation provide no indication that the welfare system was getting less complicated or confusing, nor any simpler to access or more accurate. There are no signs that the numbers needing this type or depth of support will diminish. Continual changes and implementation of new benefits and rules on top of the existing ones only aggravates the confusion. Disabled people and their families continue to be amongst the poorest in our society and the causes do not seem to be changing either. In addition, there will always be families new to both children's disability and social security who will need assistance.

As evident from these findings, trying to navigate the complex welfare rights field for disabled children and young people and their carers on top of caring responsibilities, work and other pressures is not easy and sometimes defeats people. As well as poverty, debt, under-claiming and confusion, high levels of stress and distress were reported by interviewees and survey respondents. These factors alone underpin the need for timely, quality, accurate information and advice to help people know what they are entitled to and assistance to establish their entitlement.

The context of a diminishing field of local advice services, may be putting additional pressure on Contact and other national agencies. Moreover, even where a service exists, it may operate long waiting times for appointments; may be inaccessible for families with disabled children if they operate a queuing system, or the premises are not disability-friendly. In any case they may not have the necessary expertise about how benefits rules apply to families with disabled children in different situations.

### *Implications for the future*

There is every indication that advice needs will continue or increase. Children will continue to be diagnosed with conditions and there is no evidence to indicate that the circumstances and needs of disabled children and their families will reduce. The data demonstrates an acute need for specialist advice as disabled children mature and move through education, and into early adulthood, work and living separately from their families. This often involves a complex set of considerations and systems for the young person and family to balance, on top of multiple benefit computations. The interviews found that this is a highly stressful period for families. Being able to rely on solid advice was said to help reduce the stress.

*"It's great knowing that there is someone there to help who genuinely wants to ensure I get everything I am entitled to. It makes me feel that you are on my side."*

The Contact welfare rights team had predicted many of the issues raised by parents and carers around the 2012 Welfare Reform Act, including poor or incorrect information about Universal Credit and additional barriers for young disabled adults in education claiming Universal Credit. The slower than expected implementation of Universal Credit which has led to a lengthier operation of two, parallel, means-tested systems further aggravated problems and understanding amongst families.

For families with disabled children there is little reason to assume that the problems evidenced to date will abate while Universal Credit is fully implemented over the next five years (2019 to 2023). Examples of hardship are likely to continue and new issues may arise. For example, a Department of

Work and Pensions (DWP) report in June 2018<sup>21</sup> found that over four in ten people needed help to make an online claim. The National Audit Office (2018)<sup>22</sup> reported that many claimants have experienced difficulties and hardship and is doubtful if it can ever provide value for money for public spending. The next stages of implementation are summarised in the Appendix.

All the evidence points to the need to continue providing highly individualised and expert advice around Universal Credit. For example, families may need detailed advice about:

- whether transitional payments have been correctly calculated
- the sorts of changes in circumstances which would end transitional protection and trigger a new (reduced) claim
- how to minimise delays
- the job-seeking rules, and
- entitlements for those affected by the policy limiting payments to the first two children.

This advice project has shown the difference which can be made in providing accurate and specialist advice to families with disabled children. However, needs may change and poverty may affect different groups of disabled people but shows no signs of abating.

## Key recommendations and learning points

All the families surveyed and interviewed were extremely happy with the service received, even when they may have had previous apprehensions about using a telephone advice service. Nonetheless some suggestions for improvements, mainly in relation to profile and processes, emerged.

### *Recommendations made by interviewees*

- Continue to provide this excellent service.
- Advertise the welfare rights service more specifically and maximise the likelihood of quickly finding Contact and its welfare rights advice through internet searches.
- Make it more transparent that the Contact helpline provides expert benefits help.
- Target professionals and services working with disabled children and carers, not least disability agencies, health workers, social care, SEND staff and social workers.
- Employ more staff on the helpline both to speed up getting through to a specialist welfare rights adviser and to deal with increased calls on Universal Credit, Disability Living Allowance and young people's transition.
- Consider if direct access to the specialist welfare rights advisers would be possible and useful sometimes, in other words without going through the general helpline first.

*“Just keep being there.”*

---

<sup>21</sup>[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/714843/universal-credit-full-service-claimant-survey-summary.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/714843/universal-credit-full-service-claimant-survey-summary.pdf)

<sup>22</sup><https://www.nao.org.uk/report/rolling-out-universal-credit/>

*“I did not know about you, service could be better advertised.”*

#### *Additional recommendations arising from the data analysis*

- This is a highly expert, complicated and focused advice area which families need: it is highly unlikely that many generalist advisers would ever get enough experience to be able to give reliable advice to the required breadth and depth for this demographic and the topics involved.
- The specialism of this advice service and level of expertise needs to be valued. It has proved unique and essential to families, cemented its proficiency and developed a good reputation.
- The need for detailed, clear and unbiased advice is likely to increase, with Universal Credit and other changes on the horizon. Meanwhile the advice landscape, especially the availability of other and more local advice, and specialist advice in this field is unlikely to improve.
- The “managed migration” and potential for transitional protection will require detailed advice for families with disabled children, given the level of potential losses.
- Internally, the evaluation points to a few process changes which might be worthwhile. While collating data on profiles, needs, and outcomes is essential, and in this instance has demonstrated the demand and worthwhileness of this advice, it may be possible to simplify the two surveys and reduce the time advisers need to spend on these, and gather some data in other ways. Piloting different methods might help determine how to best balance these two needs.
- Likewise, any ‘new’ information delivery methods should continue to be trialled and followed up, building on the popularity of podcasts.
- Future advice needs are only somewhat predictable and a service needs some in-built flexibility to respond to the key topics as these emerge. For example, this project predicted more queries around mortgage interest payments than transpired, whereas more needs emerged around Disability Living Allowance, Universal Credit, and young people’s transition.

*“It really made all the difference for us. Sometimes it feels as though we have an uphill battle just to get any help, but having someone in our corner who understands the system and has the patience to help us is such a blessing.”*

## 6. Appendices

### 6.1 Summary of planned Universal Credit full implementation to 2023<sup>23</sup>

From July 2019 a programme of “managed migration” to Universal Credit will commence. This has two main strands:

- 1) “Managed Migration” The DWP will invite 2.09 million existing means-tested benefit claimants to claim Universal Credit. At capacity, an estimated 69,000 households per month are expected to be affected.

However individual families will not be automatically transferred onto Universal Credit. Instead their current benefits will be stopped and they will need to initiate a claim for Universal Credit. In the past claiming Universal Credit has proved a struggle for claimants. Under “managed migration”, families moving onto Universal Credit will get transitional protection to ensure they are no worse off at the point of transfer. However, the proposed formula for calculating this is complex.

- 2) “Natural migration” In addition, a further 3.71 million households are expected to move onto Universal Credit as a result of a change in their circumstances, necessitating a Universal Credit claim. They will not get any transitional protection regardless of any loss of income.

Families, especially those with a disabled child are at a high risk of being worse off:

- the amount paid in respect of most disabled children, is less than half of current entitlement. This equates to a cut over £1750 per year for one disabled child; as an amount is paid for each disabled child families with more than one disabled child will face even greater drops in income;
- no payments will be made in respect of a disabled child in residential accommodation who has “looked after” status;
- reduced entitlement for disabled parents, which make up roughly 20% of parents using Contact’s project.
- some parents will be subject to job seeking conditions for the first time. For example, couples both caring full-time for a disabled child; and parents awaiting a DLA decision.
- this is likely to result in more parents getting benefit sanctions.
- from early 2019 no additional child element will be made in respect of a third or subsequent child born after 6<sup>th</sup> April 2017. This two child limit will also be applied to some new claimants whose third or subsequent child was born before that date.

---

<sup>23</sup> Correct at the time of publication, October 2018



## 6.2 Data collection methods used in this evaluation

The data in this report comes from four main sources

- a) Contact's point of service survey, conducted at the end of an advice call
- b) A follow-up survey conducted about four months later; and
- c) Qualitative interviews carried out by the independent researcher
- d) A group interview with members of Contact's welfare rights team and the Monitoring and Evaluation Manager to review the findings and consider the key learning points.

The response rates to both Contact's surveys are affected by numerous factors. For example:

- while these topics are interesting to Contact and help monitor and evaluate the service, this is not a priority for the families calling. They had called because of a benefit problem, often urgent and these monitoring data might seem relatively unimportant;
- advisers also have to prioritise the advice aspects over this type of data collection;
- parents often have to end a call suddenly (for example, most commonly to address the needs of their children);
- calls taking much longer than scheduled and advisers may have another appointment booked);
- parents can be distressed: asking monitoring or evaluation questions would be insensitive;
- this data is quite sensitive, eg ethnicity, money, religion, and so on;
- in planning follow-up calls Contact prioritises those cases where there is a clear outcome to measure such as financial gains, correcting decisions made in error or helping parents plan for a change in employment status. It is less critical to call back parents who merely sought a benefits check or clarification around particular benefit rules;
- despite over-sampling, only a small percentage of those parents who originally agreed to being followed up actually return calls when contacted them four months later;
- the time taken to phone people repeatedly and to get families in has to be balanced with the main priorities of the job – that is, advising people.

## 6.3 Qualitative interviews for the independent evaluation

20 interviews were conducted with parents and carers who had used Contact's welfare rights project.

To protect confidentiality and ensure informed consent a number of stages were used. During Contact's four-month follow-up call, families were asked if they would be willing to be included in the sample for these interviews. A large sample was collated from those who initially consented and basic details about each case was supplied anonymously to the researcher. This included the subject of their query and advice given, but no personal details such as names or area to protect confidentiality.

From this sampling frame, a long short-list of potential interviewees was selected on the basis of the type of benefit query, demographics and geography. Contact then provided names and telephone numbers to the researcher, who rang those on the long list to provide more information about the

evaluation, check if they were still willing to be included and if so to agree an interview time. Some were not available despite many attempts and others had changed their mind, or were too busy. In the end 20 people were interviewed. The tables below provide a breakdown by gender, family composition and geography.

#### *Gender*

Female	Male
18	2

#### *Family composition*

Lone parents	Couples
13	7

#### *Sample callers' geographical*

London	West Midlands & East Midlands	East & South East	Yorkshire & Humberside	North East	North west	Southwest
5	3	3	3	2	2	2

#### **Child's disability**

There was extensive co-morbidity, in other words many children and young people had more than one diagnosis and some children had no diagnosis yet. The main conditions reported for this sample were learning disabilities; behavioural problems, including Attention Deficit Hyperactivity Disorder (ADHD); mental health issues, including anxiety, Post Traumatic Stress Disorder (PTSD), self-harm and suicide attempts; epilepsy; and cerebral palsy.

## Qualitative interview topic guide

### **Background, setting the scene**

- About them and their family: Number of children. Age and situation of disabled child/ children. Is the interviewee the main carer?

### **Advice**

- Thinking back to the time of your advice phone call with Contact (CAF), can you remember what was going on at the time? Prompts, eg how you felt? Were you worried about something? ..... (ie what prompted the call and level of stress at the time)
- Had you ever spoken to Contact before (that date)? If so, was it about benefits, welfare advice, grants, or something else?
- Can you remember how you first heard of Contact? How did you know about Contact?
- Have you ever tried to get advice on issues like this (benefits, money, grants, work) near you? Is there anywhere/ any service near you that gives advice?  
- As appropriate according to answer: can you remember what happened when you tried to get advice/ got advice locally/ elsewhere?

- Probe any views on quality of local / other professionals' advice?

- If they had used/ tried to use other advice services: How would you compare Contact (CAF)'s Benefits Advice service and the advice from any other advice service you used, or tried to use (Probe quality, specialism; understanding/ grasp of their situation; detailed knowledge of systems and options; quality of advice, clarity of advice/ what they could do next; anything else....)

### About the advice call, etc, with CONTACT

#### About processes:

- How easy was it for you to get through to speak to Contact (CAF) the first time?
- Was that the first time you'd rung about this query?
- I understand the advisers ring you back at an agreed time: were you happy with that? (probe any time lapse, but only interested if due to Contact, not to their own availability)
- In general, how do you feel about using the telephone for advice like this? Do you feel there are any advantages/ disadvantages? How **accessible** is using the telephone service for YOU?
- How easy was it to talk about these issues with the adviser?
- Were you aware that you can contact them again if anything changes/ any other issues come up for you/ your family?
- If they had tried to call subsequently: how easy was it to get to speak to someone who knew about your case / knew you'd called before, and were able to follow-up on that?
- Is there anything Contact could have done differently to make getting advice easier/ make the call easier for you?

#### About the advice given:

*(Check they can remember their query and what was discussed – basic reminder)*

- Do you feel the adviser understood your questions/ what you were asking?
- Did the adviser give you any advice on what to do next about this/ these issues?
- How easy was it for you to do this? Were you able to do this?

#### ➔ **If did follow advice given— skip to Qx below**

##### ➔ **If didn't follow advice given:**

- Was there a particular reason why you weren't able to do what the adviser suggested? (probe: time, stress of caring, confidence, understanding of issues, understanding of advice accessibility, literacy, change of circumstances, need for someone to do it with/for them, forgot/ never got round to it ....)
- Do you think you will at some stage (soon- ish)?
- If yes, when, why (ie why now and not previous?)
- If not ever, is there any reason why?
- Would it help/ would you like Contact to contact you to talk about this, help you with the next stage / a particular barrier) – if so get permission to pass this back to CONTACT

- Then skip to Further Information questions

➔ **If did follow advice given**

- Check outcome of advice – did they get that benefit, what happened with appeal?
- How long did it take to get sorted (may be multiple benefits/ issues and strands – probe each)
- How easy/ difficult was it to do this?
- Was the advice you received appropriate/ accurate?
- If they got advice about subsequent steps to take: eg how much did it help you deal with the next stages/ what happened next?  
**OR** (*some will have been advised to revert to the WR advisers*): was it clear to you when you were expected to get back in touch with [the Contact adviser]?
- If there was a financial gain / other positive outcome– how long do you think you missed out on this benefit(s)? /other gain/ for example, how long had x situation been going on for?

**Any impact**

- Has this (advice/ claim/ grant/ challenge...) made any difference to you?
- Has it made any difference to the child/ young person in question?
- Any difference to anyone else in the family/ family as a whole? (as appropriate)

**Probe impact**

- Direct and indirect financial – for example, able to afford anything different? Let them expand & explain and then probe with sub-questions below:
- Any impact on (any) debt/ overpayments.....?
- Do you have more money to pay for things your child needs?
- Is there any difference in how much you worry about managing financially?
- Has it made any difference to how you feel about managing and controlling family finances?
- Has it made any difference to where you might now go for advice/ support if anything else crops up?
- Are you/ the CYP/ your family doing anything differently as a result of this advice/ action taken following the advice?
- Has it helped in any way to do more yourself/ CYP/ as a family? If so what kind of things (looking for community engagement, participation in activities inside and outside home)
- Has it made any different to how you feel? (Has there been any change in stress levels –if stress etc previously mentioned), any change in how you feel about the future?
- Do you feel any different about dealing with benefit issues yourself, for example, in the future?
- Does it make any difference to you knowing there is an advice service you can talk to?
- Did speaking to Contact help you in any other ways?
- Can you think back to before you got the advice, what would be happening now if you had not contacted Contact?
- Did the advice you received help you to prepare for a drop in your family's income? (for example, if child turning 20, residential school, reducing work, impact of welfare reforms...)

If **work/ changing working hours** was a point in the advice:

- how the change has affected them if at all
- As relevant: did the advice help you to make a decision about work/ working hours? E.G to start/ stop / stay in work? or changing their working hours .....

Probe more if **hospital/ residential school** situations

### Further information

Sometimes the advisers send people written information or suggest downloads from websites

- Did you talk about getting any extra information/ things to read?
- Did [Adviser] send you anything, eg an email, or a written information, or ideas/ links about where to get more information? for example, links to a website?
- If you remember: how did you find the information sent (probe: was it useful; written clearly for you? how much did you use it? How helpful was it overall?)
- Do you think you needed / would you have liked any/ more written information? If so, about what? What difference would it have made?

### Feelings about the future

- Have you any particular concerns about your child/ children getting older?  
Probe for example, school, turning 16+, using adult services, ...?
- Are you aware of the **different benefit changes** going on – for example, UC.
- Were you aware of them before you spoke to Contact/ M/D?
- How do you feel about these changes? How do you think they will affect you? / Do you know how they might affect you?
- Do you think people in your situation are likely to need advice about these changes?
- Do you feel that having a disabled child makes any difference to the amount or type of advice people need?

### Last but not least:

- Do you think you would you use Contact's helpline again if another issue / benefit problem or question came up? (probe reasons either way)
- Would you recommend Contact to other parents / carers in your situation?  
If yes, why? If not, why not?
- Have you any recommendation for how the Contact benefit advice service could be made any better for people in your situation?

### That's all my questions

- Is there anything else you'd like to add / that I've forgotten to cover?
- Thank you again for your time. It's been really interesting and useful
- Remind re anonymity and confidentiality and what happens next.

## 6.4 Project targets agreed with Big Lottery

<b>Outcome 1:</b> Families are better informed about welfare benefits and have a better understanding of how changes will impact them	90% of families surveyed after contact with our service will report that they feel better informed about their rights to benefits
	80% of parents facing a change in personal circumstances will report having a better understanding of how this affects their financial situation.
	80% of parents directly affected by welfare reforms will report a better understanding of how these benefit changes will affect them
<b>Outcome 2:</b> Families are better-off, with their income having increased as a result of our advice	80% of families identified as missing out, will report being more confident about applying for benefits and grants
	50% of families contacted in follow-up surveys will report that they have received an increase in their income as a result of our advice
<b>Outcome 3:</b> Due to families' improved financial situation, they are better able to actively participate in their local community	50% of families contacted in follow-up surveys will report that they feel less isolated
	40% of families contacted in follow-up surveys will report they are able to play a more active role in their local community
	50% of families contacted in follow-up surveys will report that they feel better able to deal with stress