

Qualitative research into families' experiences and behaviours in the Childcare Affordability Pilots (CAP09): Disabled Children's Pilot

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Glossary

BACS	Bankers' Automated Clearing Services (a system for the electronic processing of financial transactions)
CA	Carer's Allowance
CCE	Childcare Element of Working Tax Credit
CTB	Council Tax Benefit
CTC	Child Tax Credit
CAP09	Childcare Affordability Pilots 2009
DfE	Department for Education (formerly known as the Department for Children, Schools and Families)
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
HB	Housing Benefit
Formal care	Childcare provided by an Ofsted registered nursery, childminder, breakfast or after-school club or other provider. Support for this kind of care can be claimed for through the CCE.
HMRC	Her Majesty's Revenue and Customs
IS	Income Support
OFSTED	Office for Standards in Education, Children's Services and Skills
Informal care	Childcare which is not eligible for support through the CCE.
TCO	Tax Credits Office
WTC	Working Tax Credit

Summary of findings

Background

- (i) The primary aim of this research was to understand the extent to which affordability was the main barrier to parents of disabled children in using formal childcare in order to take up employment. The Disabled Children's Pilot, one of three Childcare Affordability Pilots launched by HMRC and DfE in 2009, offered parents of disabled children living in London the opportunity to claim up to 80% of their childcare costs (subject to tapering) if they went into work for at least 16 hours per week, paid up to a higher level than is normal within tax credits.
- (ii) To assess the impact of this, a Control group of parents in Birmingham and the West Midlands and Greater Manchester were also informed of the standard offer of help available to them through the tax credits system. In total, 9,713 families were informed of the Pilot offer and 9,713 were informed of the Control offer. Of these, 16 families took up the Pilot, while only six families took up the Control.
- (iii) Between October 2010 and January 2011, Ipsos MORI conducted 50 face-to-face depth interviews with Pilot and Control group parents of disabled children who were eligible for help with their childcare costs through the Childcare Element (CCE). Parents were split into three research groups of customers as defined by their behaviour in response to the offer. Those termed *Not Interested*, either called or were called by the DfE Contractor helpline and said they did not want to register an interest. Those termed *Interested*; either called or were called by the DfE Contractor helpline and registered their interest in the offer but were subsequently unable to find work and/or childcare. Those termed *Take-up*, registered an interest in the offer with the DfE Contractor helpline and subsequently found work and childcare. This group were then transferred to a dedicated team within the Tax Credits Office in order to make their claim for the WTC and CCE. Given the limited sample available for the Take-up groups, the findings for these participants are based on a very small number of interviews compared to the 100% Costs and Actual Costs Pilot research. This had an impact on the breadth and level of detail of the findings for these groups.
- (iv) In addition to the primary aim of the research, these interviews sought to understand the barriers and enablers that existed for parents when considering returning to work and taking up childcare, parents' experiences of work and childcare and their perceptions of dealing with the DfE Contractor helpline and the Tax Credits Office when making their claim for the CCE.
- (v) Overall, we found that the cost of childcare was not felt to be the most significant barrier to work for participants; the nature of the Pilot offer did not seem to have a considerable impact on their decision to move into work. However, for some it was felt that the window of opportunity to join the pilot was too small for parents of disabled children to overcome the numerous barriers they faced in finding suitable work and childcare. For those who took up the offer, it was felt that it was a case of good timing as they were either already about to start work or were planning to. These issues are discussed in more detail below, and throughout the remainder of this report.

Participant Profiles

- (vi) There were a number of distinctive characteristics of the three research groups, the most striking being the high prevalence of lone parents in all of them, which reflected the Pilot sample. Experiences of a relationship breakdown were very common, frequently said to be a direct result of the couple trying to cope with caring for a disabled child. These difficult circumstances were then often compounded by mental health problems for the mother, such as depression after the diagnosis of the child's disability.
- (vii) Therefore, the extent to which the participant felt 'work ready' was vital which, in turn, made the timing of the offer extremely important. Participants needed to be in the emotional and practical position of being able to find the right job and suitable childcare before the window of opportunity provided by the Pilot offer closed.

Practical and attitudinal barriers and enablers to taking up work and childcare

- (viii) A number of attitudinal barriers prevented parents of disabled children using childcare and finding employment. These were particularly prevalent in the *Not Interested* group and were the most significant determinant of how participants responded to the offer. Traditional views about the mother's place being in the home to care for the children were fairly common, and were exacerbated by a high proportion of participants feeling that they were the expert in their children's disability which made them doubt whether a formal childcare provider could provide the same quality of care. As such, there was a common belief that combining work and childcare in a family with a disabled child was not feasible, a view reinforced by the perception that, especially for those with few skills, work did not pay.
- (ix) Aside from attitudinal factors, there were some practical issues which prevented participants from moving into employment. Of these, the most significant was participants' ability to find suitable childcare. Participants spoke of how they lacked confidence in formal childcare providers, that there was limited supply of suitable childcare due to their child's specific needs and that any childcare available would be too expensive as they were typically asked to pay higher rates. That said though, while cost was a barrier, it did not deter those determined to take up the offer.
- (x) Finding suitable work was also challenging, particularly given the economic climate at the time of the research. Their difficulties here were reinforced by the fact that these participants were demanding jobseekers; they wanted flexible or part-time hours, the ability to leave at short notice if their child was unwell and for their employer to be located close enough to their child's school and childcare provider so they could get to them quickly if needed. However, many lacked both a recent employment history and confidence which narrowed their employment opportunities.
- (xi) There were, however, factors which enabled the take up of work and childcare and, of these, the most important was that the participant felt ready to work; a mindset most frequently exhibited by those in the *Take-up* and *Interested* groups. These participants tended to emphasise the non-financial benefits to working such as the

chance to socialise, improving their self-confidence, setting a positive example to their children and using work as a form of respite.

- (xii) In practical terms, flexibility was the key factor in being able to use childcare and take up work. Having access to a childcare provider with the right skills, attitude and who was willing to be flexible both in terms of the care which the disabled child needed and the parent's childcare needs made using childcare more viable. Similarly, finding a job with flexible working hours and either having an employer who understood the caring responsibilities the parent had, or being self-employed made it easier for parents to work around childcare.

Experiences of taking up work and childcare

- (xiii) When taking up childcare, most participants in the *Take-up* group reported that they had been asked to pay more than the standard rate for childcare because of the level of attention their child needed, or the specialist skills the provider needed in order to offer suitable care. However, participants understood this reasoning and were happy to pay more if necessary as finding the right provider was felt to be more important than cost.
- (xiv) In the *Take-up* group, both informal and formal channels were used to help them find work. A large proportion of those with low skills levels took jobs in care as they felt this work made the most of their skills developed as a carer at home, and allowed them to choose their working hours. Those who had stronger employment histories with professional skills tended to use their personal contacts to find employment and often registered as self-employed in order to control their working hours. Similarly, a few participants used their links with charities or local organisations to undertake paid work for groups for families with disabled children.
- (xv) The *Take-up* group had fairly high awareness of both WTC and CCE, largely because a high number of them had made claims previously. The majority of the *Take-up* group said that they had already either been looking for work or were planning to look for work when they received the offer so were already thinking about making a CCE claim. Pilot participants that this applied to reported that the additional money being offered made them feel that taking up work and childcare would be more worthwhile financially and so they intensified their job search. Only a small number, who had been out of work for a number of years or who had never worked lacked awareness of both WTC and CCE but, on receipt of the offer letter, reported being surprised by, what they considered to be, the generous level of help available to them.
- (xvi) Responses to the offer letter varied enormously, and reactions were largely influenced by participants' attitudes towards using childcare or working. To illustrate, those in the *Not Interested* group, who had traditional views about being a mother, or felt that their job was caring for their child, frequently reported having a defensive reaction to the offer letter; they felt that the government was trying to force them back to work and didn't understand their responsibilities at home. This demonstrates further that the key driver for employment and childcare take-up was attitudinal.
- (xvii) Alongside this, the offer's window of opportunity was another common reason that parents gave for not registering an interest in it or taking it up. These participants

were often studying, or had a disabled child who, they felt, was too young or too unwell to be put into childcare. Additionally, even parents who originally registered an interest felt that the number of hours they would be required to work in order to be eligible for the offer was a barrier to them taking it up.

Communication with HMRC

- (xviii) Participants in all groups were generally positive about the communications they had with the DfE Contractor helpline about the offer regardless of whether or not they took it up. Although a small number were critical about the level of information supplied in the offer letter stating that there was not enough detail, almost all were happy with the information and encouragement provided by DfE Contractor helpline advisors. Similarly, the *Take-up* group were generally happy with the service when they were transferred to the dedicated Tax Credit Office (TCO) helpline for the Pilot. However, a small number in both the Control and Pilot groups felt that the service provided by the TCO helpline was too variable in terms of the quality and consistency of the information they were given.
- (xix) However, while being sent a separate cheque for the CCE helped some to budget more effectively and increased transparency about what they were receiving, we can infer from this research that a letter outlining these details did not have the same effect given that Pilot participants did not spontaneously mention correspondence of this nature that they were sent by TCO on a monthly basis. Additionally, a high proportion of *Take-up* participants questioned whether the childcare provider should be paid directly to prevent error and fraud in the system.

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1 CHAPTER 1: INTRODUCTION AND BACKGROUND

CHAPTER SUMMARY BOX

- (i) The Childcare Element (CCE) is designed to offer working parents financial support for the payment of childcare costs. **Subject to a range of eligibility criteria, working families could claim 80% of their total childcare costs via this system, at the time of the Pilot. However, this has now been reduced to 70%.** In recognition that some parents of disabled children may face higher childcare costs, in 2009 the government introduced the Childcare Affordability Pilot for disabled children; a way of offering working parents with disabled children extra financial support with childcare costs through the tax credits system.
- (ii) Ipsos MORI conducted **50 face-to-face depth interviews with parents of disabled children** who could be eligible for help with their childcare costs through the Childcare Element (CCE). Interviews were conducted between October 2010 and January 2011. The **key objective of the research was to test the importance of the affordability of childcare in parent's decisions to move into work and take up childcare.** It is hoped this evidence may help the government understand how it can encourage families with disabled children into sustainable employment.
- (iii) Parents from the Pilot were split into three groups of customers as defined by their behaviour in response to the offer: those termed *Not Interested* did not register an interest in the offer; *Interested* registered an interest in the offer but subsequently did not take it up; and, *Take-up*. Each group was split between and recruited on the basis of:
- **Pilot:** customers who were offered increased childcare costs limits (but maintaining support at 80% of costs) via the CCE; and
 - **Control:** customers who were offered the existing level of financial support via CCE.
- (iv) Before describing the research findings in relation to the offer, understanding the data gathered on customers' lifestyles, experiences of financial management, debt and family life is important as, in many cases; participants' circumstances underpinned their behaviours in relation to the offer.
- (v) The most distinctive characteristic of all groups interviewed was the **high prevalence of lone parents**, many of whom felt it was their responsibility to improve their family's lifestyle by returning to work. Linked to this, the emotional and physical demands of caring for a disabled child often put a **massive strain in the participants' relationships** with their partner and other non-disabled children.

- (vi) Parents in the Not Interested group seemed to have the best social networks with many saying they used family and friends for support and informal childcare. The most socially isolated families were in the Take-up group.
- (vii) Not Interested participants were more likely to have been workless for many months or in some instances years. In comparison, parents from the Interested group had strong employment histories.
- (viii) Some parents were engaged in skills training and/or further study across the range of qualification levels in order to enable them to better compete in a tightening labour market while others wanted to pursue a care related qualification to gain work in this sector.
- (ix) Due to the fact that many families were in receipt of welfare and other state benefits almost all participants reported low household incomes.
- (x) Generally, participants in the Not Interested group had less experience of formal childcare and also tended to be less trusting in the quality and availability of childcare. Underpinning this was the fact that, for many, the dual role of parent and carer for their disabled child was their key purpose in life and was regarded as being a 24-7 job.

1.1 INTRODUCTION

The Childcare Affordability Pilots 2009 (CAP09) were devised to assess the impact of providing alternative forms of childcare support to families moving into work. This report contains findings from qualitative research for one of the three Pilots which made up the

¹ Unless one member of the couple is incapacitated, is an inpatient in hospital, or is in prison (whether serving a custodial sentence or remanded in custody awaiting trial or sentence).

² An eligible form of childcare is a provider that is registered or approved. In England, the provider must be registered with Ofsted. The childcare element can be paid for any child up to the last day of the week in which falls the 1st September following that child's 15th birthday.

³ The government announced in the 2010 Spending Review that families can claim up to 70% of their childcare costs from April 2011.

Childcare Affordability Pilots (CAP09) evaluation. This element of CAP09 was conducted among workless families, or those in work for fewer than 16 hours a week, with disabled children who were either offered extra support with childcare costs if they returned to work through the payment of the Childcare Element (the Pilot offer), or were informed of the standard offer of help with childcare costs (the Control offer) which was already available through CCE and WTC. The research was undertaken by Ipsos MORI Social Research Institute on behalf of HM Revenue & Customs (HMRC) and funded by the Child Poverty Unit. In this introductory section we set out:

- The context of the research;
- The research objectives;
- The methodology used to conduct the research;
- Information on sampling and recruitment of participants;
- How the interviews were conducted and how research materials were used; and
- How the findings are presented.

1.2 RESEARCH CONTEXT AND BACKGROUND

According to research conducted by the DfE, the median weekly cost of nurseries stood at £72 and £55 for childminders in 2009. Furthermore, just under a quarter (24%) of those that regularly used formal childcare reported that they found it difficult or very difficult to meet their payments for childcare⁴.

In recognition of this, the government has sought to help low and moderate income working parents with their childcare costs. One form of help is administered via the Childcare Element (CCE). In order to be eligible for this, all adults in a family must work at least 16 hours per week, unless one partner is incapacitated, in hospital or in prison. They must also use a childcare provider which has been registered with Ofsted or approved. Subject to tapering, which withdraws the level of support as income rises; **these families could claim 80%⁵ of their total childcare costs, up to cost limits of £175 per week for one child, and £300 per week for two or more children.** Families need to calculate their average weekly costs for the year and they then receive equal payments in each period.

CAP09, part of a suite of child poverty pilots announced in the Budget 2008, **aimed to test the importance of the affordability of childcare in parents' decisions to move into work and take up childcare.** CAP09 consisted of five separate pilots, three of which involved changes being made to the current tax credits system and were delivered and evaluated by HMRC⁶. A robust research analysis of the three Pilots (100% Costs Pilot, Disabled Children's Pilot and Actual Costs Pilot) was commissioned by HMRC to

⁴ DfE, *Childcare and early years survey of parents, 2009*

⁵ At the time of publication, WTC claimants can claim up to 70% of their childcare costs within the CCE. This was reduced from 80% of childcare costs in April 2011. However for the duration of this study, the limits were up to 80% of costs. This report will therefore refer to upper limits of 80% as opposed to 70%.

⁶ The two further pilots for CAP09 were managed by the London Development Agency.

complement their in-house data analysis. **These Pilots were designed to test whether changes to both the amount and way in which tax credits were paid encouraged take-up of formal childcare and sustainable employment opportunities among parents**, and more broadly to determine if affordability was the key barrier to using childcare. This report is concerned solely with the Disabled Children's Pilot.

1.3 RESEARCH OBJECTIVES

The aim of the Disabled Children's Pilot was to **test whether increasing the childcare cost limits** (but maintaining support at 80% of costs) for families with disabled children, **increased the number of such parents entering sustainable employment and taking up formal childcare**. These higher weekly limits were £250 for one disabled child, £300 for one severely disabled child⁷ and £350 for two or more children, only one of whom needed to be disabled. These limits were subject to tapering for those on higher incomes.

The objective of these interviews was to understand the reasons why some customers chose not to, or were unable to, take part in the Disabled Children's Pilot as well as why some customers chose to take up the offer and their experiences of doing this. Specific objectives were as follows:

For families who *did not take up* the offer we sought to explore:

- Why, after receiving notification of assistance with their childcare costs, some families chose not to or were unable to move into work and childcare,
- Awareness of CCE, and what forms of help and support parents were aware they were eligible for;
- Why they were unable to find work and the extent to which, if at all, the offer caused them to increase their job search intensity; and,
- What kind of mix (formal/informal) parents are using, and their perceptions of the benefits and drawbacks of each.

For families who registered an interest in the offer, but did not move into work and/or childcare we aimed to find out:

- The reasons why they were interested in the Pilot;
- To explore the barriers which prevented them from moving into work and/or formal childcare;
- If there were any issues surrounding perceived eligibility for the offer; and,
- The reasons why they were unable to find suitable childcare, the factors that led them to believing that the childcare available to them was unsuitable and the extent to which this was a factor in them not taking up the offer.

⁷ The definitions of a 'disabled' and a 'severely' disabled child are based on the receipt of disabled child and severely disabled child elements of CTC, which is in turn largely dependent on the child qualifying for the lower or higher rate of Disability Living Allowance and the family being on a low income.

For families who did take up the offer we sought to understand;

- Customers' reasons for interest in the Pilot;
- Their views on moving into work and childcare and the importance of the extra help with childcare costs in their decision to do so;
- Their experiences and behaviours during the Pilot in terms of changes to their working status and hours, and their use of childcare;
- The triggers for moving into employment and taking up childcare which are not associated with affordability; and,
- What kind of mix of childcare (including the balance between formal and informal care) that parents are using, and their perceptions of the benefits and drawbacks of each.

An extension to this project was also commissioned by the Department for Education (DfE) to further explore the issues surrounding accessibility, availability and confidence in the provision of childcare for disabled children. The objectives and findings for the project extension are included in Annex A.

1.4 RESEARCH METHODOLOGY

Ipsos MORI conducted **50 face-to-face depth interviews with parents of disabled children** who were eligible for help with their childcare costs through the Childcare Element (CCE). These interviews were conducted with customers **who had been offered either the Pilot or the Control offer by HMRC**. The employment status of these customers were, in the case of single-parent households either out of work, or working fewer than 16 hours per week, and in the case of two-parent households, either out of work couples (or working fewer than 16 hours per week) or single earner couples (with one partner working 16 hours or more per week). Paired interviews were conducted with couples where possible though due to the **high proportion of lone parents in the sample**, our ability to do this was limited.

Participants in the **Pilot group** had been offered up to 80% of their childcare costs (as with the standard system) but with **higher limits** of £250 for a disabled child or £300 for one severely disabled child or £350 for two or more children (only one child needed to be disabled). To qualify, lone parents needed to work (for at least 16 hours per week), or increase their working hours to 16 or more per week and, in couples, both partners needed to do this.

Participants in the **Control group** had been informed of the **standard system of help** with childcare which at the time was up to 80% of the cost of childcare, with limits of £175 for one child or £300 for two or more children. The eligibility guidelines were the same as the Pilot offer.

Families selected to be part of either the Disabled Children's Pilot or Control group were sent a letter⁸ informing them of the offer between September and November 2009. **They then had until April 2010 to secure work and childcare** and take up the offer.

⁸ Although the letters related to tax credits, which are run by HMRC, the letters were sent out by the then Department for Children, Schools and Families (DCSF) which is now known as the Department for Education (DfE).

Families who joined the pilot received a letter each month from HMRC informing them of the amount which they would receive for childcare costs for that month. Families were on the pilot for up to 12 months. **The extra help with childcare costs paid to families who received the pilot offer ended on 31st March 2011.**

The **Pilot and Control groups were then subdivided** further according to their response to their offer:

- **Not Interested group:** Those who either called or were called by the DfE Contractor helpline and said they did not want to register an interest;
- **Interested group:** Those who either called or were called by the DfE Contractor helpline and registered their interest in the offer but were subsequently unable to find work and/or childcare; and
- **Take-up group:** Those who registered an interest in the offer with the DfE Contractor helpline and subsequently found work and childcare. This group were then transferred to a dedicated team within the Tax Credits Office in order to make their claim for the WTC and CCE.

A qualitative approach was adopted for the study to generate rich detail, and enable interviewers to obtain a full picture of the participants' circumstances, experiences, attitudes and feelings which meant that they were either able or unable to take up the offer. **A face-to-face approach was chosen**, as it was important that interviewers established a rapport with the participants. This helped to create an atmosphere of trust so that **sensitive issues, such as those pertaining to their child's disability and their financial circumstances**, could be addressed. In addition, face-to-face depth interviews enabled the interviewer to use stimulus materials, such as examples of letters which helped participants to recall certain experiences more clearly.

Interviews took place between October 2010 and January 2011 and were conducted in participants' homes which allowed interviews to generate additional observational data about participants and their families. For example, we were able to capture insight into the routines that parents of children with behavioural disabilities, or the adaptations that had been made in the homes of physically disabled children to help them have a degree of independence. These observations helped create a greater understanding about the extent of parents' caring responsibilities, which in turn, helped to contextualise some of their views on using childcare.

Analysis of the findings from the fieldwork was conducted throughout the fieldwork period through the collation of field notes in Excel spreadsheets and in regular analysis sessions with the interview team. In these sessions initial hypotheses were developed and discussed. Ongoing analysis of findings meant that research materials were adjusted throughout the field period to reflect emerging findings.

1.5 SAMPLING AND RECRUITMENT

The sample for all groups was provided by HMRC from Pilot and Control families' tax credit records. Participants were then **recruited by telephone** from this sample after being mailed and allowed a period in which they could opt out of the research. Participants were sampled on the basis that **they had at least one disabled child living in their household aged under 16 and that at least one parent was not working** or working fewer than 16 hours a week.

Location was also a factor for this research because of the relatively low number of families meeting the eligibility criteria; the **Pilot offer was made to everyone in London** (amounting to around 10,000 families). A random sample of families in Birmingham and the **West Midlands and Greater Manchester** areas meeting the same eligibility criteria made up the Control group.

The following table shows the number of people who received notification of the offer, and of that, the number who took-up the offer.

	Pilot (London)	Control (Birmingham, West Midlands and Greater Manchester)
Successfully mailed	9713	9713
Take up	16	6

The very **low take-up rates** for both the Pilot and Control offer, and for the Control *Interested* group meant that **quotas had to be reduced** for these groups due to the limited amount of sample available.

Only those that had engaged with the offer in some way were included in this research. This was important as recruitment and fieldwork for this project were suspended during and following the General Election in May 2010 which meant that, in some cases, participants were contacted about participating in interviews over a year after they had received their offer letter. Therefore, there were concerns as to how much those who had had no contact with the DfE Contractor helpline, or those who had been in contact with it but had not then stated whether or not they were interested in the offer would be able to recall about their views and experiences at that time. Consequently, these groups were excluded from the research and interviews were only conducted with those **who had either been in contact with the DfE Contractor helpline and said that they were not interested in the offer, or, conversely, had registered their interest in their offer or those who had taken up their offer were included in the research.**

The following table outlines the overall structure of the sample frame.

Group	Sample size provided by HMRC	Number of Interviews arranged	Number of interviews cancelled	Number of interviews completed
Not Interested Pilot	202	13	1	12
Not Interested Control	190	15	4	11
Interested Pilot	155	13	1	12
Interested Control	46	7	2	5
Take-up Pilot	16	6	1	5
Take-up Control ⁹	27	5	0	5
Total	636	59	9	50

In order to meet targets for the different groups outlined above, some **quotas around the customer's recall of the offer letter or phone call were relaxed**. This meant that in some cases participants had little or no recall of the specific points of contact with HMRC and so were unable to comment on their views and experiences of them or the details of the offer. This lack of recall was partly a factor of the length of time that had elapsed between when the original offer¹⁰ had been made to them and when the fieldwork took place. However, **all participants did recollect that an offer for help with childcare** had been made to them so this did not impact upon their being able to give their reasons for being able or unable to take up work and childcare.

Due to limited sample of available for the *Take-up* Control group, the numbers for this group was boosted with sample which included those who had received the Control offer letter and then went on to claim the CCE through the standard tax credits system and TCO helpline rather than through the dedicated TCO Pilot team¹¹. Although this meant that these participants were unable to comment on some aspects of joining the scheme through the Pilot team, their decisions to take up the CCE and their experiences of looking for and sustaining work and childcare were as relevant as those from the main Control sample. Of the five *Take-up* Control interviews, two were conducted with those who took up the CCE through the DfE Contractor helpline and the remaining three were conducted with those who received the Control offer letter but took up the CCE through the normal channels with the TCO.

As well as limited sample, recruitment for this strand was difficult with many declining to participate, or cancelling interviews once they had been arranged. Reasons given for **refusals or cancellations** of interviews were often related to the needs or health of the person's disabled child. Reports of the person's **disabled child being seriously unwell or hospitalised** were fairly common. Parents who were going through a period of frequent **hospital appointments or treatment for the disabled child** often refused to take part as they could not spare the time. It is important to note that **all parents of disabled children aged under 4 who were contacted declined to take part**, which may be attributed to a large extent to the issues discussed in section 1.8.7. Finally, some of the parents who had autistic children said that they could not allow an interviewer into their home because their **disabled child would be upset by a stranger entering their space**. We offered telephone interviews to three *Take-up* parents with issues such as the above due to the limited amount of sample available.

Although some participants interviewed had **English as a second language**, and some were unable to read English, all **participants had at least a basic level of spoken English** and were fully able to respond to questions in the interview. Those who were unable to understand English at the point of recruitment were excluded from this research.

¹⁰ Offer letters were sent by HMRC to customers between September and November 2009, parents then had until April 2010 to take-up the pilot by finding work and childcare.

¹¹ Families who were sent the CAP09 offer letter and called the Tax Credits Helpline, rather than the Pilot helpline given, were excluded from Pilot processes and the offer.

1.6 INTERVIEWS AND RESEARCH MATERIALS

When conducting the interviews, moderators used **semi-structured discussion** guides to ensure all relevant topics were covered consistently across all interviews and that all key issues were explored. **Interviews lasted between one hour and ninety minutes.** As is common practice in qualitative research all participants received a cash incentive as a thank you for their time and contribution. It was made clear to participants that this payment came from Ipsos MORI, not HMRC or DfE. Participants in the *Not Interested* and *Interested* groups received £30 (£50 for a paired interview) and participants in the *Take-up* groups received £50 (£70 for a paired interview).

Thirty of the interviews were extended by thirty minutes to cover the issues relating to the DfE extension, and participants received an additional £10 incentive for taking part. This report can be found in Annex A.

Different versions of the semi-structured discussion guides were used for take-up and non-take up groups in order to reflect the issues faced by that group. All discussion guides are included in Appendix A of this report.

1.7 PRESENTATION OF FINDINGS

It is important to note that findings in this report are not statistically representative of the views of parents of disabled children in general. Qualitative research is designed to be illustrative, detailed and exploratory and provides insight into the perceptions, feelings and behaviours of people rather than conclusions from a robust, quantifiable valid sample. As far as possible we have tried to state the strength of feeling about a particular point, but due to the small sample sizes of some sub-groups it has not always been possible to provide a precise or useful indication of the prevalence of a view. The perceptions of participants make up a considerable proportion of the evidence in this study, and it is important to remember that although such perceptions may not always be factually accurate, they represent the truth to those who relate them.

Furthermore, given the limited sample available for the *Take-up* groups, the findings for these participants are based on a very small number of interviews compared to the 100% Costs and Actual Costs Pilot research. This has not only had an impact on the breadth and detail of the findings for these groups, but also on the way they are presented. Tools such as customer journeys may have made the participants easily identifiable from the sample and so have not been used to protect the anonymity of participants.

This report is structured in five chapters, reflecting five distinct aspects of the findings:

Chapter 1: Introduction and Background – provides background and details of how the study was conducted and context for the findings by exploring the personal circumstances of the participants. Understanding this in depth is important, as it shapes and helps explain how participants responded to the offer in the way that they did.

Chapter 2: Barriers and enablers to take-up of work and childcare – examines the barriers which meant that some people were not able to take up the offer. It also looks at the enablers which led some people to taking up the offer as well as their experiences of finding and sustaining employment.

Chapter 3: Using childcare and the Childcare Element – explores knowledge and awareness of the Childcare Element as well as how childcare is used and experiences of using formal childcare.

Chapter 4: Operational experiences of the Pilot scheme – examines the reactions of different groups to the letter, their understanding of the offer and their experiences of contact with both the DfE Contractor helpline and the Tax Credits Office helpline.

Chapter 5: Conclusion – brings together the findings from the study to provide overall conclusions.

1.8 PARTICIPANT PROFILES

1.8.1 INTRODUCTION

In this section we will describe the range of personal and financial circumstances of the participants, drawing on the data gathered on customers' lifestyles, experiences of financial management, debt, and family life. Understanding this information upfront is important as, in many cases; participants' circumstances underpinned their behaviours in relation to the offer. We will cover the following main areas in this section:

- Household composition;
- Social circumstances;
- Employment and skills status;
- Financial circumstances;
- Childcare usage; and
- The impact of having a disabled child on the family.

1.8.2 HOUSEHOLD COMPOSITION

The most distinctive characteristic of all groups interviewed was the high **prevalence of lone parents**, particularly in the *Take-up* and *Interested* groups. **This factor had both a significant impact upon how participants prioritised different elements of their lives such as parenting and working**, and more generally on how they viewed themselves and their place in society.

A significant proportion of participants felt that, as lone parents, their role should be at home, caring for their children as there was no one else in the household to share household responsibilities with. Additionally, as discussed in section 2.2.3, due to a perceived lack of time and support, they felt unable to take up work and childcare. This created something of a vicious circle though; the longer participants spent looking after their family, the more isolated from the labour market and less confident they would be able to find work they became. Conversely, those in the *Take-up* group felt that, **as lone parents, it was their responsibility to set an example for their children and improve the family's lifestyle by returning to work because there was no partner in the household to do this.**

Couples, who were mostly part of the *Interested* group, tended to perceive or experience fewer barriers in returning to work. They were less likely than lone parents to view being a parent and carer as their sole role in life and were generally more ambitious than many of the lone parents interviewed. The reasons for this were that **participants with partners tended to have higher levels of skills and had work experience** they could call on. Additionally, because they could share childcare responsibilities with their partner they felt more able to take on employment.

The ages of participants ranged from 21 and 59, although **most participants were in their thirties or early forties**. Younger participants, in their twenties were all part of the *Not Interested* group, and they typically had very little or no work experience. All participants in the *Take-up* group were in their thirties or early forties, and participants in the *Interested* group tended to be the oldest; most being in their mid-forties.

The number and age of children in the household also differed between the groups and also seemed to have a bearing on parents' response to the offer. For instance, families in the *Take-up* group had between one and three children with most having one or two children overall. Conversely, families in the *Not Interested* group tended to have the most children, with a range of between one and six and an overall average of three children per family. **Having more than two children often meant that the cost of childcare was felt to be prohibitive** as discussed in detail in section 2.2.4.2.

1.8.3 SOCIAL CIRCUMSTANCES

Participants in the ***Not Interested* group seemed to have the best social networks**, and many said that they regularly used family and friends for support and informal childcare. This group also reported using more casual acquaintances such as neighbours or people from their church community as a source of informal childcare. In contrast, those in the *Interested* group were more likely to report feeling isolated than the *Not Interested* group. This was often because they had moved away from where they had grown up for the purposes of Higher Education or work which meant that they were less likely to have family and as many friends nearby. However, the **most socially isolated families were in the *Take-up* group**. A sizeable proportion of the families in this group had migrated to Britain and, while some were able to call on support from acquaintances in their community or church, this help could not always be relied upon, and often came at a cost.

Creating and maintaining friendships seemed to be a problem for all groups. For instance, many reported losing friends when they had separated from their partner while the demands of being a parent and a carer for a disabled child made maintaining or cultivating friendships difficult, especially for lone parents. Additionally, parents did not always feel included by other families at their child's school (if they attended a mainstream school) because of either perceived or real barriers to the child being able to play at a friends' house or attend a party. In cases where the child attended a Special Educational Needs (SEN) school, socialising outside of school was rare because of the high level of care and attention these children tended to require.

1.8.4 EMPLOYMENT AND SKILLS STATUS

Previous employment histories among all participants varied enormously. Most *Not Interested* participants were younger and had been in low paid work on a sporadic basis and, on having children, had either decreased their hours or stopped work altogether. However, even though they were not interested in the offer those with one child typically did not see worklessness as a permanent situation for them and planned to return to work when they felt both they and their child were ready, (see section 2.2.2 for further detail). Those with more than one child though were less likely to envisage a time when they would work again.

Those from the ***Interested* group were older and had strong employment histories**, including undertaking highly skilled work and full-time hours. However, they had taken a break from employment as they found it **difficult to simultaneously work and support their child's needs**. They intended to return to work, albeit for fewer hours, when the "time was right" and when their being in employment would not negatively affect their child.

Take-up parents were likely to have had relatively stable employment histories and were employed in range of part-and-full-time roles, from low-skilled low wage work (for

example, cleaning), to higher-skilled well paid work (such as, charity fundraising). These participants were so motivated by the need to secure employment that the nature of work itself was not important as long as it fitted around their caring responsibilities.

As with participants' employment histories, so too the **full spectrum of formal learning achievement was identified**, from those with Higher Education qualifications (typically those in the *Interested* group) through to those with no formal qualifications at all (and such participants tended to be concentrated in the *Not interested* group). A significant number of participants of all ages in the *Take-up* and *Interested* groups were involved in skills training accessed for free through Jobcentre Plus, and/or were studying for a degree, financed by a Student Loan, in order to increase their skills levels and ultimately their employment potential. Additionally, participants from all groups found that training and/or studying offered them some respite from the emotional and mental drain from caring responsibilities.

In terms of what participants were studying for, **many wanted to gain employment in care related work** to build on the skills they had developed looking after their child, and to overcome the barriers to finding work as described in section 2.2.3. Consequently, some were engaged in or had recently completed a training course in a care related qualification; these ranged from short vocational courses in Social Care to Higher Education qualifications in social work for example.

1.8.5 FINANCIAL CIRCUMSTANCES

Due to the fact that many families were in receipt of welfare and other state benefits **almost all participants reported low household incomes at the time of their interview**. The only exceptions here were two-parent households among the *Interested* and *Take-up* participants as they were more likely to have been in employment at the time of interview and so had experienced an increase in income since they had received the offer. Even so, their household still took in less than £16,000 a year.

Additionally, those households that claimed to have a higher income were still just as likely to struggle financially for two main reasons. Firstly, these households tended to have increased expenditure/cost levels, such as, taxes, leisure, and fewer public subsidies so their 'net' income still caused them financial difficulties. Secondly, there was also some evidence to suggest that some **parents on lower income levels seemed to be better financial managers** and possessed stronger budgeting skills.

Looking at sources of income, **all participants were in receipt of Disability Living Allowance** (DLA) as a result of their child's disability. Most *Not Interested* participants were also in receipt of a combination of Income Support (IS), Carer's Allowance (CA), Housing Benefit (HB), Council Tax Benefit (CTB) and Child Benefit. Awareness of the Tax Credit system and, in particular, Working Tax Credit was widespread among participants from all groups that had experience of claiming it. In spite of the fact that all participants claimed benefits, many participants said they felt highly embarrassed and uncomfortable in doing so and reported a preference for work but, due to attitudinal and practical barriers affecting employment take-up (see section 2.2.3), this was not considered viable.

Their low household incomes affected participants in a number of ways. Many parents found it hard to afford basics such as replacement clothing for growing children, while social events for adults were considered luxuries they could rarely afford. Transport costs were a real issue for almost all parents; frequent visits to hospitals and other medical or behavioral provision was a considerable drain on the family finances.

1.8.6 CHILDCARE USAGE

While there were few clear trends about participants' previous use of childcare, of those that had done this parents had typically used wrap around care (such as breakfast or after school clubs). Such care was often based around activities which the child enjoyed, such as art, and so tended to be seen as an opportunity to pursue an interest as well as providing a source of childcare. A few had previously used childminders, nurseries and playgroups for their disabled or non-disabled children when they had previously worked and reported varying degrees of satisfaction with these providers.

Generally, participants in the *Not Interested* group had less experience of formal childcare. **They were sceptical as to whether formal childcare providers would be able to provide the same standard of care that they could, and were concerned there would be a lack of providers willing to take on their disabled child.** Participants in the *Interested* group were more open to and positive about the use of formal childcare, often because of their past experiences in doing so.

Most participants in the *Take-up* group who had moved into work and were using formal childcare used childminders who were thought to provide a better quality of care for disabled children and were felt to offer more flexible hours than wrap around care or school groups. Please see sections 2.2, 2.3 and 3.3 for further information on attitudes towards, and usage of, childcare.

1.8.7 IMPACT OF HAVING A DISABLED CHILD ON THE FAMILY

Having a child born or later diagnosed with a disability, was, for most participants, the beginning of a **very difficult and complex stage which affected every aspect of their lives.** The following sections explore different aspects of how having a disabled child can affect and change a family. **These issues often directly impacted upon the extent to which participants felt ready or able to take up work and childcare.**

1.8.7.1 Types of disability

Of course, to a large extent the impact of having a disabled child depended on the type of disability that the child had. Children with severe disabilities were more likely to require constant supervision and/or specialist care, which in turn tended to mean that the impact of having a child with this type of condition had a greater impact on the parent(s) and wider family. The participants in this research had children with a range of medical, physical and behavioural disabilities.

Medical conditions varied in severity from eczema that did not require too much care to salt deficiency, which required regular medical management. In general, children with severe medical conditions required specialist care once they entered school, and parents were less likely to use formal childcare when they were young because they were entirely dependent on someone else to monitor their condition.

Similarly, the types of behavioural disabilities also varied. A large number of the children with behavioural disabilities had autism but this ranged in its severity. In turn, this affected the extent to which the having a disabled child impacted on the family; children with mild autism were more likely attend mainstream school and required less care and attention, and their parents were able to envisage a time when they would be independent adults. In contrast, children with severe autism were more likely to attend

special schools and their parents tended to reflect on how they would be carers for life, which meant having a disabled child would have a long-term impact.

However, there was less variation in disability type and severity for those with physical disabilities; almost all included in the research had severe Cerebral Palsy. These children needed constant specialised and skilled care and even those who were teenagers were still heavily dependant on this. Differences in terms of childcare and type of disability are discussed in more detail in Annex A.

1.8.7.2 Caring for a disabled child

Having a disabled child placed a higher level of worry and care demands on parents. Along with the normal demands of caring for a newborn, caring for a baby with a disability or condition which needed to be understood and managed could be overwhelming for parents. Often, **initial diagnosis was also the beginning of a long period lasting months or years of hospital appointments for further diagnosis and treatment which meant that at least one of the parents needed to make caring for the disabled child their main priority.** It is important to note here that, as discussed in section 1.5, all parents of disabled children aged under 4 who were included in the sample and were contacted declined to take part in an interview. Although a number of parents of children of all ages declined to take part in the research, we were unable to recruit any families with disabled children under school age. The reasons for this were not collected during recruitment. However; parents with older disabled children frequently described the first few years as the most difficult and that they had been unable, both emotionally and practically to give time and energy other than caring for their child.

This meant that often, families would need to completely adjust their lives to fit in the demands and needs of the disabled child which explains why, for many participants across all groups, the **role of parent and carer for their disabled child was felt to be their key purpose in life.** For many, **this was felt to be a 24-7 job which left no room for returning to work.** This view was even true of school age children particularly if their child spent extended periods in hospital or if they had severe behavioural disabilities and refused to attend school.

The majority of parents of disabled children with disabilities ranging from the very mild to severe **described themselves as the 'expert' in their child and their disability.** Because of this, they felt that no other person would be capable of caring for their child as well as they could. This was because even though children with the same disability would have similar symptoms and behaviours, the triggers and calming measures would be different for every child. This view was particularly prevalent amongst parents of children with autism and often prevented many parents from considering the use of childcare.

I'm very untrusting of other people with my children...especially when you've got a child like this 'cause you have to be. Unless you've got a specialist who is on top form with autistic children,

Lone parent, London, Not Interested, Pilot

While many participants said they believed that their child might be able to manage their own disability without their care when they were older, in many cases, parents believed or knew that they would need to **continue to provide care beyond the age of 18** and

into their child's adult life. This was felt to be the case even for some participants who had children with mild disabilities who could not envisage a time when their child would not need them.

Indeed, there were some participants who had children with severe disabilities, usually behavioural or medical, who knew that they would either need to care for their child until their own death or until they put their child into a home if they were no longer able to cope. For these participants, there tended to be concerns about how their life would change when their child left school as they believed that the level of support and respite available to them would decrease which may result in them caring for their child alone. These types of concerns often meant that a few of these participants in the *Not Interested* group **did not always consider the possibility of being able to start a career as they believed the levels of care which they may need to provide may increase rather than decrease.**

I thought (she) won't come to anything, she can't read, she can't write, she can't use her hands, she repeats all day long about the buses and I can't envisage any job or anything...we will have to find a place, a day centre, somewhere, that's scary, because am I going to be stuck at home with (her) until my old age?

Lone parent, London, Not Interested, Pilot

For more information on the barriers to taking up work and childcare please see section 2.2.

1.8.7.3 Impact on the parents

The emotional impact of having a disabled child was discussed by all participants. Almost all participants who had children diagnosed with serious disabilities at birth, such as cerebral palsy, said that the feelings they experienced when their child was diagnosed were similar to that of bereavement. Denial, anger, depression and eventual acceptance of their child's disability were all mentioned by participants.

Some of these participants said that they had grieved for the conventionally perfect child they had been expecting but did not have. These feelings were particularly acute for those who felt that they had somehow been responsible for their child being disabled. **These feelings, along with the demands on them as a parent and carer often prevented participants from even considering finding work until they felt mentally fit to do so.**

When I look back at it now, I suppose I was grieving for him in a way, and that takes time to get through.

Lone parent, West Midlands, Take-up, Control

1.8.7.4 Relationships

The emotional and physical demands of caring for a disabled child often put a **massive strain on the participants' relationships with their partner**, their disabled child and their other non-disabled children. These problems and the emotional turmoil which accompanied them often meant that participants would be completely focussed on their children and personal relationships. This, in turn, meant that work was not considered until their personal situation was more settled.

Partners:

As discussed earlier section 1.8.2, most participants in all groups were lone parents (all of whom interviewed were mothers), and this was said by many to be the result of the strain which having and caring for a disabled child put on their relationship with their partner. In cases where the couples had been advised by doctors to abort the baby because of abnormalities seen on scans during pregnancy there had been instances where the parents disagreed on the appropriate course of action to take. The subsequent birth and diagnosis of the child's disability then led to blame, anger or resentment on both sides.

They took us into this private room, advised me to abort him there and then and my husband was all for it...Yes, let's do this, let's do that and I said 'No, I can't do that'. He never really got to bond with (him) and even to today he is not over keen...it's the only way I can put it.

Lone parent, London, Not Interested, Pilot

Another reason for relationship breakdowns was that the level of care that the disabled child needed meant that **couples spent less time together**. This was especially prevalent within families which had other non-disabled children as often one partner would take responsibility for the disabled child and the other partner would take responsibility for the non-disabled children. While this division of caring responsibilities was not often openly discussed or decided but rather developed naturally, one consequence of it was that it led to the parents living two separate lives.

There were also some instances in all groups of participants **reporting that their partner had left because of the disabled child**. They often said that their partner did not seem to have any interest in the child or found the care which they needed too demanding. After a relationship breakdown, **it was common for the fathers to see very little of their disabled children**, if at all, although in many cases they would continue to spend time with their other non-disabled children. There were some cases of the father becoming the primary carer of the children after a relationship breakdown but these were rare and normally a result of the mother suffering from a physical or mental health problem which prevented her from being able to provide the care herself.

These issues frequently resulted in the mother feeling that they were the only one who cared for their disabled child and participants in these situations tended to be less trusting of childcare providers.

Other non-disabled children:

Having a disabled child in the family also affected the relationships and expectations between the parents and their other non-disabled children (who were typically older). Many participants in all groups said that, as a consequence of having to focus so much time and energy on the disabled child, they often felt that they had not given enough attention to the older children. This often meant that **they would not consider returning to work as it would be likely to mean they would have even less time for their families**.

I do worry sometimes that they've been a bit neglected, but it's just that the little one needs so much attention all the time. It's hard.

Lone Parent, West Midlands, Not Interested, Control

Even in cases where the disability was relatively mild, the disabled child still needed to be watched to a much greater extent than a non-disabled child, and this **responsibility was often shared between every member of the household**. Indeed, participants with teenage children frequently said that they regularly used them as a source of informal childcare as they were unable to be with the disabled child for 24-hours a day. For more information on the use of informal care please see section 3.3.1.

This responsibility, they felt, had made their older, non-disabled, children mature early, which was a concern for some. Furthermore, there was some evidence to suggest that the non-disabled children resented this role that they were given. For instance, there were cases of older siblings distancing themselves from the disabled child and the parent which primary provided care. In such scenarios, they tended to gravitate towards the other parent (normally the father) and sometimes chose to live with them if the couple's relationship had ended. On the other hand, however, while all recognised the caring burden on their non-disabled children, some thought such a responsibility at a young age had a positive impact on them and had made them more caring, patient and responsible than their peers. This dependency on other non-disabled children for childcare was a motivation for a few *Take-up* participants in taking up the offer of help with childcare which eased the burden on siblings.

2 CHAPTER 2: TAKING UP WORK AND CHILDCARE

CHAPTER SUMMARY

- (i) The key attitudinal barrier to taking up work and childcare seemed to be the extent to which parents *felt* ready to work. This meant that **the timing of the offer was important as participants needed to be in the emotional and practical position of being able to find the right job and suitable childcare before the window of opportunity provided by the offer closed.**
- (ii) Additional barriers to taking-up work and childcare, **both perceived and experienced**, by parents of disabled children included:
- Attitudes towards the feasibility **and viability of combining work and childcare were powerful factors which influenced behaviours.**
 - Many **Not Interested** group parents **viewed themselves as experts in catering for their child's needs** which translated into a lack of an inclination to find employment or childcare.
 - Parents across all groups felt that most **formal childcare providers lacked the skills** to cater for their child's complex needs.
 - Regarding attitudinal barriers to employment, some parents with lower skills and a lack of recent work **experience** believed **that work does not pay for families like them.**
- (iii) Aside from attitudinal factors, there were some practical issues which prevented participants from moving closer to employment:
- **Few available job opportunities** which met participants' employment needs e.g. part-time, flexible working hours, located close to childcare;
 - A **low confidence** in their ability to source suitable job vacancies; and
 - **A lack of employability and work focussed skills** (some lacked the skills to look for work).
- (iv) However, of those that wished to work, **securing suitable childcare was the greatest barrier to parents of disabled children in finding employment.** On this, parents of disabled children reported three key barriers in relation to taking up childcare:
- A lack of **confidence in the quality of local childcare** providers;
 - **A lack of suitable formal childcare**; and
 - **The cost of formal childcare.**

- (v) Even when parents felt that attitudinal and practical barriers to taking up childcare and work could be overcome, **the issue of *combining work and childcare* remained a key concern and acted as a barrier to looking for work and childcare at all.**
- (vi) Enablers for finding suitable work and childcare were, most importantly, **having the right mindset or attitude about personal work readiness.** Added to this, **parents who recognised the non-financial benefits** that can be gained from work were more motivated to find employment.
- (vii) Parents from the *Take-up* group who moved into employment used formal public/private recruitment agencies or informal channels (personal contacts or voluntary work). The types of jobs taken by those parents can broadly be split into three categories: **jobs in Care; self-employed professionals; and flexible work with charities and other family related work.** In terms of balancing work and childcare, the key factors were an ability to plan effectively, and being able to access both flexible employment and childcare.

2.1 INTRODUCTION

This chapter examines the barriers and enablers which exist for parents of disabled children in taking up work and childcare. It also explores the experiences of those who did take-up the offer. We will cover the following main areas in this chapter:

- Barriers to take-up of work and childcare;
- Enablers to take-up work and childcare; and
- Finding and sustaining work.

2.2 BARRIERS TO TAKE-UP OF WORK AND CHILCARE

2.2.1 INTRODUCTION

This section will explore the different barriers to taking-up work and childcare, including both those perceived and experienced by parents of disabled children which prevented them from taking up the offer of extra help with childcare costs. Given this focus, this section tends to concentrate on evidence provided by the *Interested* and *Not Interested* groups. Specifically, this section covers:

- Attitudinal barriers and timing of the offer;
- Employment;
- Skills;
- Childcare;
- Finances; and
- Logistics of balancing work and childcare.

2.2.2 ATTITUDINAL BARRIERS AND TIMING OF THE OFFER

The **key attitudinal barrier seemed to be the extent to which parents *felt ready to work***; most parents were not even able to consider going back into employment until the emotional impacts of having a disabled child had been resolved.

This meant that **the timing of the offer was important as participants needed to be in the emotional and practical position of being able to find the right job and suitable childcare before the window of opportunity closed**. Indeed, as discussed in section 4.2, most participants in the *Take-up* groups¹² explained that they were already looking for work and childcare options when they received the offer, and that the offer simply served as an extra motivating factor. In contrast, those who were experiencing depression or who were trying to come to terms with the diagnosis of their child's disability, tended to say they were not interested in the offer because they did not think these issues would be resolved before the offer ended. Additionally, those who were studying or whose children were experiencing a period of frequent hospital appointments, illness or problems at school frequently referred to the offer as coming at the wrong time as it was not always feasible for them to take employment at that point.

The research also shows that **attitudes towards the feasibility and viability of combining work and childcare were powerful factors which influenced behaviours**. Parents from the *Not Interested* group were more likely to mention these barriers as they held traditional values about their role as a parent. This perception is rooted in the traditional domestic/ parental role and the belief that caring for their child is their responsibility alone. Linked to this, these parents were more likely to attach a greater value in their role and believed that looking after their child was a more valuable use of their time compared to finding work.

It's so illogical [gaining employment and arranging childcare] and with autistic children, no one knows them better than their own mother or father.

Lone Parent, London, Not Interested, Pilot

In addition, many *Not Interested* parents suggested they held a dual role; full-time parent *and* carer. This attitude stemmed from the fact that these parents held an in-depth experience of their child's condition and consequently understood the necessary steps that should be taken if a medical or behavioural incident arose. As a result **these parents viewed themselves as experts for catering to their child's needs** which translated into a lack of an inclination to find employment or childcare as discussed in section 2.2.2. Linked with this, a significant number of parents, typically in the *Not Interested* group, reported a belief that **most childcare providers, particularly childminders and staff who work in breakfast and after-school clubs, lack the skills to cater to for their child's complex needs**. As a result they had little trust or confidence in the ability of certain types of childcare to provide the same standard of care as they would.

¹² Please note that due to the limited sample available for the *Take-up* groups, the findings for these participants are based on a very small number of interviews compared to that of the *Take-up* groups in the 100% Costs and Actual Costs Pilot research.

This is going to sound awful but I don't trust anybody to look after him the way I do because I know him.

Lone Parent, London, Not Interested, Pilot

I'm comfortable with leaving her with a family member while we go out, because she will know what to do if she had a seizure, but if I put her into childcare, would the childcare provider actually know about what to do if she had an epileptic fit or would they know about her condition, that would be my concern about childcare, do you know what I mean?

Couple, West Midlands, Not Interested, Control

Attitudes affecting take-up of employment and childcare were also strongly influenced by a more general sense that there was **a lack of available childcare provision that caters specifically to a disabled child's needs**. The evidence suggests that parents with fewer skills were more likely to have this belief which tended to be a result of a lack of information about available childcare or mis-information, spread through word-of-mouth about levels of disabled childcare provision that may exist in a local area.

She [childminder] wasn't really trained in regards to that [disability] and it's not like you really have much choice in that regards. Yes particularly around [east London] I don't know if there are any trained in regards to children with disability.

Lone parent, London, Not Interested, Pilot

Conversely, parents with higher skill levels and personal confidence were more likely to believe that appropriately trained provision does exist albeit to a lesser degree and would therefore tend not to rely on hearsay and, instead, used Local Authority websites as sources of information.

You need to put yourself in the right places to see what [disabled childcare provision] is out there!

Lone parents, London, Interested, Pilot

How parents of disabled children viewed employment also determined their behaviours in relation to the offer of extra help with their childcare costs. For those who saw the benefits of employment in purely financial terms, the logic of finding paid work only for a significant proportion of that income to be channelled towards childcare provision led to **a highly prevalent belief that work did not pay for them**.

You've got to better off [in work] haven't you really. You've got to think about how much in terms of travel and all the rest of it, how much everything's costing. I know there are benefits but if I was going to be worse off or just £1 better off per week I wouldn't go to the trouble [of securing employment].

Lone parent, London, Interested, Pilot

Linked in with this, some parents with lower skills and a lack of recent work experience believed they would be less able to find work that paid sufficiently well for them to sustain their current income levels. In turn, this also reinforced their belief that work does not pay for families like them. Added to this, parents believed few employment vacancies existed which would match their demands. Most parents **wanted part-time hours that allowed them to work around a child's school hours combined with a high level of flexibility** from their employer in case they were called to attend to their child's needs at short notice. This sense that there would not be anything suitable for them prevented many from even looking for work.

Finally, as discussed in section 1.8.7, the emotional impact on a parent from having a disabled child was a major barrier affecting take-up of or sustaining work and childcare. Parents among all Groups described negative emotional feelings, such as, stress, anxiety, and depression brought on by the demands of having a disabled child, to the extent that a few of them referred to having been on medication or attending counselling sessions. Before even thinking about returning to work, some participants suggested having to deal with these issues.

I've been so depressed about the whole thing it has taken me a good while to just get up and face life again so I would say in the last two or three years actually that's when I finally got myself together and I went to work.

Lone parent, London, Take-up, Pilot

While these attitudinal barriers were cited across all three groups of participants, they were expressed most keenly by those in the *Not Interested* group. Furthermore, participants **tended to report experiencing a number of these barriers at any one time**, for instance, they held views about poorly trained childminders *and* believed that there was a lack of employment vacancies which suited their demands creating a strong sense that work was not viable for them.

2.2.3 EMPLOYMENT AND SKILLS

As discussed in section 2.2.2, parents from the *Not Interested* group were more likely to suggest that securing employment was not a current priority for them given the caring demands placed on them by their disabled child. This group also had lower skills and had often been out of the labour market for a long time. As a result, these parents reported having **low confidence in their own ability to source suitable job vacancies** and, moreover, believed they would be considered an undesirable candidate for employers so were unlikely to be able to source work regardless.

To be honest, getting jobs for someone like me is very hard. I've got no education, I've got no qualifications, I can't read, I'm 47 years old. Who'd want to employ me?

Lone Parent, London, Not Interested, Pilot

Furthermore, this sense that they were unappealing applicants was coupled with the fact that **they believed they were seen as demanding jobseekers** which made taking up work harder still. The lack of flexibility with regard to the opening hours of childcare providers, as explored in section 2.2.4.1 meant that parents were not only restricted in

which providers they could use but, additionally, where they could look for work. For instance, in both the Pilot and Control areas, childcare provision was typically only available between 7.30am and 5pm on weekdays. Opening hours of childcare providers could dramatically cut down the job choices for some parents as they would only be able to work when childcare was available and they would also need to factor in time to travel to and from work so that they could drop off and pick up their child punctually. This was a concern for both parents who had access to a car and for those who relied upon public transport, however, for the latter it was felt to be a particular constraint.

As a result, most parents **wanted a job with part-time hours fitted around their child's school and childcare and that was located close to their child's school** and childcare provider in case they were asked to pick them up at short notice. This made finding suitable employment very difficult and very competitive as other parents were also hoping to find the same working hours. Given this, some felt that it was not worth them even looking for work while those that did faced very real problems in sourcing something suitable.

Everyone wants those daytime jobs, every mother, it's impossible.

Couple, London, Not Interested, Pilot

Indeed, this sense that they **needed a lot from their employer in order to make work viable** led to some pursuing freelance work so they could be on hand for their child as and when they were needed. However, even freelance work was not ideal for all (particularly those with lower skills levels) given the need for good work contacts, being able to provide a good track record in similar work in order to win contracts, prohibitively high business start-up costs and a likelihood of reduced salary especially in the short-term.

It is important to note as well while a high number of parents lacked the skills needed for work, some of these parents felt that they even **lacked the skills to look for work** because they didn't know how to locate job vacancies and go about filling in applications. In particular, this tended to apply to those parents in the *Not Interested* group who had not been employed for an extended period of time and, therefore, were unaware of the sources of help and support that are available to them in their job search. This could be due to the fact that many parents were in receipt of Income Support (IS), an inactive benefit, which meant they were rarely required to attend a Jobcentre Plus office. As a result, they missed out on the opportunity to familiarise themselves with existing employment related services.

Consequently, these parents often relied on informal contacts to identify potential work opportunities, such as part-time employment at their child's school or at a charity. When they did make formal job applications, they often did so speculatively and for jobs that they were interested in or they thought would fit around their child's needs rather than those that they were actually qualified to undertake. Because of this, these participants experienced frequent knock-backs from employers which, in turn, dented their confidence about their ability to find work at all.

Conversely, those in the *Interested* group were aware of the services provided by Jobcentre Plus and stated that they would call on them to help them find employment. The fact remains, however, that even though these parents had a better understanding of how to undertake a meaningful job search, there was still no guarantee that this would lead to employment due to the other barriers they faced in taking up work and childcare

which are discussed in section 2.2. For information on how participants looked for work, please see section 2.4.

2.2.4 CHILDCARE

Childcare was generally felt to be a significant barrier to parents of disabled children¹³ in finding employment. These issues mainly fell into three categories which are explored in this section¹⁴:

- Confidence in childcare providers;
- Availability of suitable childcare; and
- Affordability of suitable childcare.

2.2.4.1 Confidence in childcare providers

A lack of trust and low levels of confidence in the ability of local childcare providers to cater for the needs of disabled children was widespread among participants, regardless of whether or not they had previous experiences of using childcare. One of the main reasons for this lack of confidence was the anxiety parents felt about a provider's willingness or ability to understand and respond appropriately to their child's needs. As discussed in Section 2.2.2, **parents frequently referred to themselves as the expert in their child's disability.** They felt that they could foresee issues or situations which a provider may not be able to and which, in turn, could lead to their child suffering unnecessarily. These feelings were particularly prevalent amongst the *Not Interested* group who were more likely to identify themselves as the only person who could provide care for their child.

I don't trust anybody to look after him the way I do because I know him...if he has hurt himself he might not say and you need to know the signs in him. He can have some serious accidents.

Lone parent, London, Not Interested, Pilot

There was general acceptance among parents that a disabled child needs more care, attention and patience than a non-disabled child and some participants were concerned about whether a childcare provider would have the time to meet these needs due to the other charges in their care. Because of this, **the ratio of carers to children was an important factor** for parents of disabled children when considering what childcare providers might be suitable. Although school wrap around care and school activity clubs were typically felt to provide a more stimulating and enjoyable environment for children, parents were concerned that their children would receive less attention in these kinds of environments. Indeed, even though childminders care for much smaller groups of children, some parents across all groups and particularly those who had children with severe behavioural or physical disabilities felt that childcare was only viable if it was offered on a 1:1 basis.

¹³ Please note that all families included in this research had children aged between 4 and 16. All parents of disabled children aged under 4 who were contacted declined to take part

¹⁴ Issues relating to access and use of childcare for disabled children have been further explored in the DfE extension report in Annex A.

I should think if a child has a disability they should think about whether they should be having other children there as well.

Lone parent, London, Not Interested, Pilot

Linked in with this, parents expressed **fears about their child not being cared for properly or issues being dealt with inappropriately**. These anxieties were particularly felt by parents of children with autism or severe physical disabilities such as cerebral palsy. This was because they were concerned that, were there any issues, then their child would not be able to articulate them which would lead to them remaining undetected.

You don't really think about these things then, but then when you sit down and kind of take a step back, you say, "Yes, she [the childminder] did deal with it, but *how* did she [the childminder] deal with it?"

Lone parent, West Midlands, Interested, Control

The child's age was also identified as a key factor in determining whether parents felt ready to use childcare. Most parents held strong views that a child's needs would require them to fulfil a carer role for the duration of their disabled son or daughter's childhood with a few believing that this role would have to continue into adulthood, in effect, these parents viewed caring for their child as a job for life. Participants with children who were already at school were more likely to acknowledge this.

In contrast, parents of pre-school age children were less likely to discuss the long-term nature of their caring responsibilities as they were less certain on how their child would develop. Most parents across all Groups believed that a child's level of personal, physical and emotional development influenced their decision about the take-up of work and childcare. For example, parents felt that children were particularly vulnerable below the age of three and therefore needed intensive support which left little or no time for anything else.

When she was seven/eight months I noticed she wasn't developing properly, this was during my maternity leave, and I felt a great need to look after her even more than I normally would and to find out what was wrong with her. There were appointments, hospital, and doctor's appointments virtually every day for tests.

Lone parent, London, Take-up, Pilot

For participants with **teenage disabled children**, the level of *personal* care that most children with severe disabilities needed meant that parents felt that their children were becoming more vulnerable as they became older. Help with personal care was not something that most teenage non-disabled children would need and so even though their children were often cared for in this way at school, they often felt apprehensive and uncomfortable about using childcare and asking a provider to do this. This was because parents of teenage disabled children perceived a difference between this kind of help being provided by a member of staff in a SEN school and by a childminder in their own home. Also, most parents of teenage disabled children **did not think that childcare providers would be willing to undertake all the duties required** of them, such as helping the child go to the toilet or getting dressed, particularly if the childcare provider in question was motivated by anything other than a sense of vocation.

They [the provider] would have to take her to the toilet, she has periods now, you have to wash her, clean her teeth, do her hair, she's a young lady now

Lone parent, London, Not Interested, Pilot

Disability type also had an impact, as different disabilities tended to be diagnosed and require more care and attention at different periods of the child's life. **Parents felt that a disabled child required full time support at important times, in particular, at the point of condition diagnosis.** The evidence suggests that most medical conditions were identified by the time the child reached the age of three. However, parents with children who displayed the traits of a behavioural condition such as autism, Attention deficit hyperactivity disorder (ADHD) or Aspergers Syndrome were identified much later in their childhood for instance between the ages of three and six and this, in turn, affected parent's ability to take on work. Linked in with this, many parents felt that **having a disabled child brought with it a certain degree of unpredictability** in that they never knew when they were likely to need more help and support. In this sense, there was *never* a good time for these parents to find work and take up childcare.

It's difficult when you've got a child with special needs. It's very hard to be certain about things.

Lone parent, London, Interested, Pilot

2.2.4.2 Availability of suitable childcare

A lack of suitable childcare was a barrier faced by many parents in both the *Interested* and *Take-up* groups who reported that providers would often refuse to take on their child because of their disability. There were a number of reasons given by parents for this. Firstly, parents suggested that the **extra care and attention their child needed would be a drain on the resources of the provider** who, in turn, would be able to take on fewer children. Secondly, there was a sense among parents that **providers commonly misunderstood certain disabilities and were wary of them.** This was particularly mentioned by parents of autistic children who said their children were often labelled as naughty or disruptive yet they were merely displaying the behaviours which related to their condition. However, because of these misunderstandings, care was refused.

The moment you say the word Autism, that's it, they make excuses, talk about them being naughty, disruptive, problematic. But he isn't, it isn't a tantrum, it's a child not understanding, not processing what's going on, but they don't get that, or they don't want to.

Lone parent, West Midlands, Take-up, Control

Similarly, parents of **children with medical conditions** which required regular treatment and interventions, such as epilepsy, often reported being refused admittance by childcare providers. These parents tended to feel a sense of injustice about this; they believed that little training was required to manage these conditions, especially when the child in question was over the age of eight or nine and had, to some extent, learned to manage their own condition. Instead, they believed that the **provider's aversion to risk and anxiety about taking on the responsibility for a condition** which, if not handled

properly could result in serious harm or death of the child precluded them from finding a suitable place.

They just won't do it, the nursery staff just panic when they realise his condition is life-threatening; they refuse.

Couple, West Midlands, Interested, Control

We found some evidence of parents attempting to overcome this barrier. A small number of parents had, for instance, offered to organise or provide training for the provider in how to manage their child's condition for but that this had been turned down. It was thought that this was driven by two key factors; the **unwillingness to take responsibility for a potentially fatal condition as mentioned above; and, an element of cost benefit analysis** in that if the provider felt that it was unlikely that they would be required to look after *another* child with the same disability then it was not worth their while undergoing the training.

They just said it wasn't worthwhile because they hadn't had other parents ask them about it and they might never have another child with that condition.

Lone parent, West Midlands, Not Interested, Control

Even when parents found providers that were willing to care for their disabled child, some were reluctant **to place them with the provider unless they were qualified**, or at least had undergone relevant training and possessed the necessary skills, to look after the specific disability in question. These criteria served to narrow the number of providers parents of disabled children could turn to further still and so added to the impression that there was a scarcity of suitable care that catered for the needs of their children.

They do the job and they just train to be childminders and they just deal with situations the way they deal with it, like a normal situation. It's not like they are adequately trained for children's specific needs and special education needs, and they're unwilling to do more.

Lone parent, London, Not Interested, Pilot

Furthermore, there were practical barriers that parents of disabled children needed to consider, presuming they were willing to use a childcare provider and had found one which was willing to look after their child. **Opening hours of childcare providers** was, for instance, mentioned as a particular barrier and the lack of flexibility here meant that, for many, combining work and childcare was impossible for them. This was reported most often in relation to school wrap around care and school activity which tended to exercise more limited and stricter hours than childminders.

Groups have their time, that's the bad thing about them because some parents maybe can't make it by 6pm to get back to get the children, and you can't negotiate it like you can with childminders, you have to be there.

Lone parent, London, Not Interested, Pilot

2.2.4.3 Affordability of suitable childcare

While the **cost of formal childcare was considered a barrier to using childcare for disabled children, it was by no means seen as being the most important barrier.** The evidence suggested that participants who were determined to use childcare were not deterred by the cost, as long as they had confidence in the provider. Nonetheless, there were strong perceptions, particularly amongst those who had never considered looking for childcare, that it would be unaffordable for them and that they would probably be charged more as their child had a disability. Participants were not able to explain where this perception came from and were unable to guess at what childcare might actually cost, but nonetheless, they believed it would be expensive in relation to both their current income and what they thought they could potentially earn. In some cases this was enough to prevent them from looking to see if the reality was any different.

That said, parents' perceptions of the cost of childcare were often mirrored by those who had experience of looking for it, or who had used it in the past. **Childminders were said to be the most expensive kind of childcare**¹⁵ carrying an average cost of between £4 and £5 per hour for a child of primary school age. However, for a parent of a disabled child, the cost could be much greater than this. Childminders explained to parents, particularly to those with children who had behavioural and learning disabilities such as autism, that the extra care and attention their child needed meant they would have to look after one less child which, in turn negatively affected their income. As such, the cost was passed on to the parents of the disabled child and they were **often asked to pay double the standard rate of up to £10 per hour**¹⁶.

At the moment I'm with [Local Authority name] Children's Trust and that costs me £19.80 an hour.

Lone parent, London, Take-up, Pilot

When you tell them he's disabled they either say no outright or say it's double the standard rate because of his condition.

Lone parent, London, Interested, Pilot

The costs for caring for a child with a severe physical disability such as cerebral palsy were often even greater than this. Indeed, for children who needed very specialised care which required **a high level of staff training such as the ability to use defibrillators, childcare costs were reported of up to £20 per hour.** This was because the childcare provider would be a highly trained professional who would be taking on a serious responsibility, and as the care was often provided on a one-to-one basis, the cost reflected this.

It is interesting to note, however, that **those who had been asked to pay more for childcare understood the reasons for this** and, furthermore, agreed with them as they recognised the extra work that the provider was taking on by looking after their disabled

¹⁵ This is corroborated by the 2009 DfE Parents Childcare Survey, which shows that only nannies are more expensive per hour. See DfE, 2009. Childcare and early years survey of parents 2009 [online] Available at: <http://www.education.gov.uk/publications/eOrderingDownload/DFE-RR054.pdf> [Accessed 10 March 2011]

child. Additionally, **quality of care was such a key consideration for these parents that very few said that they would not use their provider of choice just because of the cost.**

It's fair enough really, it's a business and he needs more attention than other children, it's one-to-one.

Lone parent, London, Interested, Pilot

If you find the right one you use it, you'll find the money somewhere

Lone parent, West Midlands, Take-up, Control

However, as discussed in the previous section, one of the key findings to emerge from the research was that **the cost of childcare was not the primary barrier preventing parents with disabled children from taking up work and childcare.** Instead, parents' attitudes towards using formal childcare and the difficulties they faced finding a willing and able provider often formed such significant obstacles that they did not reach the stage of considering issues around cost. Where **cost did become a decisive issue, however, was in those families where there was more than one child.** This was because the Childcare Element (CCE) was capped at two or more children which meant that parents would be faced with proportionately higher levels of expense if they had more than two children¹⁷. As discussed in section 1.8.2, participants in the *Not Interested* group tended to have, on average, a greater number of children than the other groups and the associated childcare costs they would incur if they went into work, in part, explains their behaviour.

When you have four children, I'd have to get a good job to get a decent amount of money to make it worth my while.

Couple, West Midlands, Not Interested, Control

2.2.5 FINANCES

As described in section 1.8.5, most participants reported having a low level of household income mainly because most were in receipt of state benefits. **Lone parents from the *Not Interested* group were most likely to experience the lowest incomes.** This may have been because this group tended to have, on average, more children than the other groups which increased the strain on the household budget. These parents often said they had lived on a low income for most, or all of their lives, even before they had separated from their partner which meant they had **developed good budgeting skills.** They also tended to have the lowest levels of employment experience, and often had health problems of their own, which made finding suitable work difficult. With no other adult contributing to household expenditure, financial management was said to be a constant struggle causing stress and anxiety.

¹⁷ It is worth noting that this was a problem that large families with non-disabled children were also likely to face and was not specific to having disabled children.

All the stuff I have to buy him because he doesn't eat the same as we eat... My food bill is astronomical because of what I have to buy.

Lone Parent, London, Not Interested, Pilot

I get £30 a fortnight, I get £30 a week Income Support but they've made that fortnightly now which really sods me up because I depend on that money weekly not a fortnight. So, there is always one week I've got no money and I'm trying to run a car to take him to and from school, I'm trying to get household cleaning stuff, toilet rolls, kitchen rolls, dog and cat food. I mean the animals are his, because he loves it, even though it's a pain. The dog barks a lot but the dog gives him a little bit of responsibility 'cause there is a little green over there.

Lone Parent, London, Not Interested, Pilot

Though many parents struggled to cope with running a household and caring for a disabled child while on benefits most parents in the *Not Interested* group felt that finding **work would lead to a reduction in their household income** and therefore a reduced ability to meet their child's needs. In general, these parents did not have a detailed understanding of what they could potentially earn and how this would impact on their benefit entitlements. Nonetheless, they were under the impression that they could expect to earn a low wage and therefore would be financially better off not paying for childcare and receiving benefits. As a result, many parents felt work was not viable, certainly not without them undergoing extensive training so they could improve their skills and secure a well **paid career rather than just a job**.

I can only speak from my own experience but most people that have got a child with a disability unless you're in a well paid job it doesn't pay to be working. So the only way you can rise up out of that sitting and just collecting benefits and all the other stuff is by educating.

Lone parent, London, Take-up, Pilot

2.2.6 BETTER OFF-CALCULATIONS

During the interviews participants, particularly those in the *Interested* and *Take-up* groups, referred to financial calculations about whether to take up work and childcare. Financial better-off calculations involved the participant in weighing up the financial loss of some benefits with the financial gains of a salary and other benefits. These **calculations were merely guessed at or perceived by a high proportion of participants, as it was difficult for people to do this accurately themselves** because of tapering of benefits and the complexity of Tax Credits calculations which would affect their income if they took up work. For these participants, their main concern was in **losing their non-tapered benefits** such as Carer's Allowance (CA), which made work, seem unbeneficial financially especially if it was part-time and low paid. This is because they knew that if they earned £100 a week they would lose all £53.90 of their CA. For this to be worthwhile, they tended to feel that they needed to earn over £150 a week to make the loss of CA acceptable.

However, it should be noted that these participants had not always taken into account the Working Tax Credit (WTC) which they would receive by working and which may have off-set their fears about losing non-tapered benefits. **Awareness about in-work**

financial support was mixed and, in particular, there were low levels of knowledge around financial support such as WTC and Child Tax Credit (CTC) among participants in the *Not Interested* group. This, in turn, added to the barriers parents of disabled children faced when considering moving into work and taking up childcare. Linked with this, most participants from the *Not Interested* group were unaware of being able to get a better off in work calculation, which is available from Jobcentre Plus and other welfare-to-work organisations.

This lack of awareness of in-work benefits along with the issues covered in section 2.2.3 around low levels of work experience and skills and knowledge of how to look for work meant that a significant number of parents in the *Not Interested* felt they faced insurmountable barriers to returning to work.

2.2.7 PERCEIVED PROBLEMS OF BALANCING WORK AND CHILDCARE

As discussed in section 2.2, finding work and finding childcare carried problems with them for parents of disabled children. Even if both were found, **the issue of combining work and childcare remained a key concern and acted as a barrier**. The first factor to consider here was timing in that parents of disabled children had to find the right job and a suitable and qualified childcare provider *at the same time and within a limited time frame*. This often made the prospect of moving into employment and taking up childcare too daunting. However, those parents who did look for employment and childcare found that they did not encounter too many problems arranging childcare during their search for jobs and childcare providers; they tended to be able to rely on informal care or to focus on these tasks during school hours.

I would need to look at both really pretty much simultaneously really just look at them from both kind of angles 'cause both of them are equally as important as one another really. There's no point in me seeking employment if I haven't got suitable childcare.

Lone parent, London, Interested, Pilot

Participants in the *Not Interested* group in particular tended to feel that even if they found the right job and the right childcare that it would **only be a matter of time until something went wrong and they would have to leave work again**. The main reason given for this pessimism was the frequency with which their disabled child was either too unwell or upset to go to school, or was sent home from school or childcare was felt to be too high for any employer to be able to accept of an employee. This was one of the commonest reasons given by *Not Interested* participants for not taking-up the offer and returning to work. Both perceptions and experiences amongst this group were that trying to **balance work and childcare would be unmanageable**. Indeed, a significant number of participants in all three groups had, at some point in their lives, had to give up work in order to provide care for their children and this reality for them created a powerful barrier that some parents felt was too difficult to overcome.

Last week she did not go to school because she was upset, somebody bit her finger, the week before there was the half term, and the week before she refused to go to school because maybe it was building up with that child and so that's three weeks. How can you keep a job like that?

Lone parent, London, Not Interested, Pilot

I could not go into paid employment because in a matter of months I would be probably given notice to leave. If I have to go to the hospital, go there, go visit that happens very frequently, so being in a paid employment is not really an option for me.

Lone parent, London, Not Interested, Pilot

Even amongst participants who said that they were highly motivated to return to work and use childcare, there were concerns that the **sustainability of employment was a significant barrier for them as their priority would always be their children**. This not only meant that parents felt they needed to be readily available for their child if needed but also that they needed to be mentally and physically fit and able to provide the level of care required. Indeed, there was a belief that parents of disabled children **had to save more mental and physical energy for their disabled children** than non-disabled children because of the level of attention and support that they needed on a day-to-day basis. Therefore, concerns about being drained by work which would leave them too tired to properly care for their children were common concerns.

I like working but I have also to be in good shape and healthy and strong, physically and mentally for my children. There's no point in draining myself somewhere at work, [my child] refusing to go in the morning, be in a sweat, having my heart beating fast, being under stress, having a nervous breakdown and get sick and then all that leads to what? In the end the Government will be worse off if I'm unwell.

Lone parent, London, Not Interested, Pilot

2.3 ENABLERS TO TAKE-UP OF WORK AND CHILDCARE

2.3.1 INTRODUCTION

This section explores the factors which may enable parents of disabled children to overcome some of the existing barriers in finding suitable work and childcare. Consequently, this section focuses on the evidence provided by the *Take-up* groups as well as those in the *Interested and Not Interested* groups who had previous experience of work and childcare. Specifically, this section will cover:

- Attitudinal drivers and timing of the offer;
- Employment and skills needs; and
- Childcare needs.

2.3.2 ATTITUDINAL DRIVERS TO FINDING WORK AND CHILDCARE AND TIMING OF THE OFFER

Evidence from participants who had been in work suggested that **having the right mindset or attitude about personal work readiness was the most important enabler for parents of disabled children being able to find work and childcare**, or at least attempting to. The Pilot offer encouraged participants to continue their job search or to put more time and effort into it. However, the Pilot only had this impact on

participants who *already* had a positive mindset about their ability to enter employment and the impact this would have on their children. Parents from the *Interested* and *Take-up* groups described having been on a journey with their disabled child which had three key stages and which affected their priorities at each point. The stages included: learning about their child's disability; addressing their child's needs; and, coping with the impact of having a disabled child. Being able to see the value of work and contemplating finding work and childcare was only really seen as a priority once participants had completed this journey.

Work for me is very important. I've sat down too long and I think I've been in denial. I've gone through all of the stages of loss and all other stuff that comes with my daughter, some people deal with it differently, but that was my way. To be honest, actually, this journey that I'm on through getting up is actually helping me to love my daughter a lot more. I can see the beauty now whereas when you're just sitting in depression you can't see it so to me it's benefitting everybody, they're [the children] seeing me out of here [the home], the boys, it's giving them a better future, so to me it's the best thing that could have happened, I'm not prepared to give up. I will not.

Lone parent, London, Take-up, Pilot

As a result, it was felt that the **offer only really worked for those who were already either planning or seriously considering returning to work when they received it.** For those who were already determined to work, the offer was felt to have arrived at just the right time as it made employment more financially beneficial. However, all participants who took-up the offer said that they were already planning to move into work when they received the offer of extra help. Moreover, it is interesting to note that the impact of the offer on participants in the Pilot *Take-up* group did not appear to be much greater than the impact on participants in the Control *Take-up* group. Again, this seems to reinforce the finding that cost was not the most deciding factor when it came to parent's with disabled children decisions to return to work.

In terms of attitudes towards employment, *Interested* and *Take-up* parents were the most likely to value the benefits that can be gained from work and consequently employment was a social norm for many. Indeed, **the non-financial benefits that can be gained from work were a strong motivator for finding employment** with many *Take-up* parents describing how work gave them respite from their demanding home life, personal well-being and access to a greater social network.

I think that it [employment] gives you self esteem. I think that it also opens up a kind of a social kind of network because I've got quite a few barriers against me because I am a single parent and I'm bringing up a child on my own and it can be quite difficult. So I think actually there's something quite appealing about going back into work.

Lone parent, London, Interested, Pilot

It means independence, freedom, doing something for myself, a break, earning my own money, mixing with other people, being paid for what I was doing before, which is nice.

Lone parent, West Midlands, Take-up, Control

Having **future financial stability was also regarded as a key driver** for finding work, particularly as some parents suggested their child's future earning potential was limited due to the employment barriers posed by their disability. As a result, these parents felt a duty to save for their child's future in addition to their own retirement.

I've only got 20 years left really to think about and if I got a job full time now I have to try and catch up on all those things for my old age and not just my old age but looking after [child's name] in my old age and looking after his old age.

Lone parent, London, Interested, Pilot

Those with an element of self belief in their own abilities to find work were often more motivated to begin looking for suitable employment and this was reported most often among those in the *Interested* and *Take-up* groups. Of course, this confidence was often limited to having pre-existing strong skill sets such as academic and technical ability and personal skills including the ability to communicate effectively. Furthermore, **parents across all groups wanted to undertake skills training in order to develop to improve their employment opportunities** and in particular establish a freelance role, career or higher skilled profession. Most parents believed that a career would "make work worth it" by providing them with greater work flexibility and an increased household income.

So even when he's home on holidays I can try and work around him when he's in bed. It is hard because when he's in bed. I'm shattered myself but I just thought it the kind of job [freelance work] that I don't have to go in, I can be here.

Lone parent, London, Interested, Pilot

2.3.3 EMPLOYMENT AND SKILLS NEEDS

Having a positive attitude about moving into work often meant that participants were less prescriptive about their job criteria and therefore more open to accepting *any* work (as long as they could fit it around their child's needs) than participants from the *Not Interested* group. However, **some key practicalities needed to exist to enable even the more work focussed participants to find work**. Parents from the *Interested* group were more likely to foresee a time when they would be able to tackle some of the practical steps to securing work.

I'm thinking perhaps I could look for something when he's had near enough a full year at this school and see how he goes then. I'm anticipating that he will have settled in quite well at that point.

Lone parent, London, Interested, Pilot

Employer flexibility was a key issue, and public sector employers were often cited as being the most understanding and adaptable; for instance, they allowed parents to leave work at short notice if they were called to attend their child's needs. Other *Take up* parents tended to work from home or secure work with hours that were compatible with their child's daily routine. **Strong personal time management and planning skills seemed to be beneficial in securing work**. Indeed, *Interested* and *Take-up* participants said without these skills they would not be able to fit work around their child's routine.

Having **knowledge and skills to locate a suitable vacancy or source an employment opportunity also enabled employment take-up**. Low-skilled participants reported accessing job search support and information from a range of sources, such as, Jobcentre Plus, and key workers who they had contact with as a means of supporting their child's needs, with a few using recruitment agencies. Participants with higher skills and stable employment histories indicated using employment related contacts from their previous employment or undertaking independent job searches using the internet or newspapers. **Regardless of the source used, it seemed from the experiences of the Take-up group that what was important here was a systematic approach to finding work** and applying for that which was commensurate with their skills and experience.

While those with higher skills were more likely to find work, parents without any formal qualifications had, in some a significant number of cases, also been able to do so. **Take-up participants used their day-to-day experience and skills to work towards a care-related qualification or to secure a volunteering role** that had ultimately led to paid work, which is further discussed in chapter 6. This often came about as a result of seeking advice from Jobcentre Plus staff, who were reported as providing very useful advice on how parents of disabled children could use the skills they had learnt at home in a workplace.

Doing the caring job made sense; it's kind of what I was already doing for free at home anyway.

Lone parent, London, Take-up, Pilot

2.3.3.1 Childcare needs

In order to make the use of formal childcare practical for parents of disabled children a number of factors were needed. These included elements which would increase the level of confidence which parents had in formal childcare providers as well as more practical requirements which would make the use of childcare feasible.

Parents getting the reassurance they needed about the quality of care their child would receive was a factor in encouraging them to use childcare. As discussed in section 2.2.4, the level of skills and amount of training undertaken by the childcare provider was another key consideration and, certainly, those **parents who had sourced providers with relevant expertise were markedly more confident in using childcare**. Indeed, a few participants reported how they liked to be able to visit a childminder's home as they could see the inspection and training certificates displayed on the wall and this reassured them about the standard of care their child would receive. Linked in with this a few **Local Authorities were said to provide training for childminders** for some disabilities such as autism which encouraged parents that if a provider did not already possess the necessary skills, they could acquire them before they began caring for their child.

She knows her very well and so does her family and they're all the people that look after her, they've all qualified, they've all had that local authority training.

Lone parent, London, Take-up, Pilot

In order to feel confidence in using childcare, the parent wanted the provider to understand the child as well as the child's disability. Parents wanted to feel that their child would get the attention and care that they needed and this often meant **using a childminder as they believed that the ratio of adults to children would be higher**

and so, in turn, the childminder would be able to spend more time with each child. Beyond this though, parents stressed the **importance of finding the right childminder**, specifically one that displayed the right attitude in that they were enthusiastic, genuinely cared about the child and wanted to know more about their disability so they could provide the best level of care possible.

It is down to the individual child and knowing their habits and how they behave because even though they might be in like a box, you know of cerebral palsy, there's quite a big spectrum, from mild to severe and every child's different anyway so the childminder has to get to know the child, they have to want to.

Lone parent, West Midlands, Take-up, Control

Finding a flexible childcare provider was key for all parents of disabled children in taking up childcare. Firstly, in a practical sense, **parents often needed to be able to book a childcare provider at fairly short notice** and this was particularly true of those with experience of working shift patterns or in agency roles (or were hoping to gain this experience). Again, **childminders were felt to be best placed to provide this** as they worked from home rather than in a centre which exercised strict rules and opening hours. However, often, this kind of flexibility often came at a price as childminders who were willing to be flexible regularly charged evenings and weekends at a much higher rate than during weekdays.

The flexibility of time and if you're running late you don't have to rush back and break a leg to get there.

Lone parent, London, Not Interested, Pilot

Awareness of financial support and willingness to ask for support also helped parents view working and using childcare as financially viable. Awareness of the availability of funding for childcare from the Local Authority or local charity for disabled children helped to reduce the financial pressure which the parents were under if they were asked to pay higher rates. However, this kind of support was often not communicated widely to parents, which meant that awareness of it was low. Linked in with this, from both individual participants' experiences and comparisons between participants' it seemed that availability and level of support varied widely between Local Authority areas, across both the Pilot and Control group areas. Additionally, many parents felt that they needed to make requests strongly and persistently in order to receive additional help or support from their Local Authority, and this could be both time consuming and mentally exhausting for parents. Participants in the *Interested* and *Take-up* groups tended to be much more confident and motivated than the *Not Interested* group to demand help from their Local Authority or to approach a charity for support.

It is there, but you have to fight, I've fought for everything he has.

Lone parent, West Midlands, Take-up, Control

2.4 FINDING AND SUSTAINING WORK

2.4.1 INTRODUCTION

This section explores the experiences of participants in the *Take-up* group¹⁸ who moved into employment. It includes information on how they found their jobs and the types of employment they found as well as the factors and considerations which influenced whether or not they were able to sustain employment. Specifically, this section covers:

- Finding employment;
- Types of employment found;
- Balancing work and childcare; and
- Sustaining employment.

2.4.2 FINDING EMPLOYMENT

For participants in the *Take-up* group, regardless of their skills or experience, **the most important factor when seeking employment was to find work which would be flexible**. This meant that they needed to be able to control the hours they worked as well as when they worked them. This led almost the entire, albeit small, *Take-up* group to either being self-employed, having the ability to work at home with flexible hours or to take on temporary or shift agency work which they could accept or decline on a job-by-job basis.

In terms of how parents approached their job search, those in the ***Take-up* group identified two main ways of finding a suitable job**. The first was through formal channels which included Jobcentre Plus and agencies and the second was informal channels such as personal contacts, or through developing an existing non-paid link with local charities or organisations. In contrast, a large number of parents in the *Not Interested* group employed more haphazard approaches in their search for work; they tended to employ methods such as checking notice boards in shops as they passed, or the local paper when they received it or rely on word of mouth, rather than taking a structured, pro-active approach.

Participants who used formal channels tended to be those who had fairly low skills levels or work experience as they were less likely to be able to find work independently through informal networks. The role of **Jobcentre Plus was important** for these participants, even if they did not find their job through them as they were considered to be a good source of advice and information on the types of roles which participants may want to consider. It seemed common amongst all Groups that Jobcentre Plus would discuss not only previous paid employment experiences with parents but also the skills which they had developed informally as parents and carers.

Agencies were used by around half of the *Take-up* group to find employment and this was often after being advised to do so either by Jobcentre Plus staff or other contacts such as college tutors. **Agencies were felt to be a good channel of finding work** as

¹⁸ Please note that due to the limited sample available for the *Take-up* groups, the findings for these participants are based on a very small number of interviews compared to that of the *Take-up* groups in the 100% Costs and Actual Costs Pilot research.

they could offer training courses needed as well as offer work which was flexible in terms of working hours and patterns.

The help I get from the agency, otherwise I wouldn't have dreamt of doing it. I mean, that was my first help, the first support I had to work

Lone parent, London, Take-up, Pilot

Those with higher skills levels and stronger employment histories were more likely to use informal networks of existing contacts and links they had developed from previous employment or from non-paid roles with charities. Participants with a professional background tended to use personal contacts to **find work on a self-employed basis** and said that once they had decided to do this had very little trouble in finding suitable work. Others, who had worked with charities on a voluntary basis or who had received support from the organisation as a parent of a disabled child, had been offered paid work because of their talent and having proven themselves to be successful in a certain role within the charity. A small number of participants had sought work independently by advertising on appropriate sites online or found clients through word-of-mouth.

2.4.3 TYPES OF EMPLOYMENT FOUND

The types of jobs taken by participants in the *Take-up* group can broadly be split into three categories: **jobs in Care; self-employed professionals; and flexible work with charities** and other family related work. Essentially, most *Take-up* group participants moved into a type of work which not only gave them a greater sense of job satisfaction than they had previously experienced at work but which also gave them a greater level of flexibility with regard to their working hours which made balancing work and childcare easier.

2.4.3.1 Jobs in Care

For participants in the *Take-up* group who did not have a strong employment history, or had previously worked in a range of low-skilled jobs, a job in Care such as being a care assistant in an old people's home, was seen as a good option when seeking employment. This was because they already had many of the necessary skills needed which they had developed by caring for their child and were able to undertake any formal training necessary fairly quickly and easily through a local agency.

This kind of work was also appealing as it offered a higher wage than they could otherwise hope to get in industries such as retail. It also provided them with a **greater level of job satisfaction and confidence as, often for the first time, they felt skilled and valued by society in a way that they had not when in the home.** Many said that they felt happy that they could finally be paid to perform the role which they had been doing unpaid at home for many years and were proud of the recognition of being good at that role, which they felt these jobs gave them.

They said you've been a carer for so long it will be like duck to water. I felt quite proud to be honest with you. I thought well I haven't done a bad job even though I've done it all on my own. Yes, I will be good at this and to be honest with you I was bloody good at it.

Lone parent, London, Take-up, Pilot

Another benefit of taking a job in Care was that the hours were flexible. Joining an agency meant that they could choose the number of hours they worked and when they worked them. Often, these roles would require the participant to visit a client a few times a day for a couple of hours at a time. This was appealing as they could fit their work around the school day as well as the hours when any formal and informal childcare was available. Additionally, some participants said that if they needed to leave work to go and help their disabled child then the clients tended to be sympathetic and understanding about this.

It's just the most flexible job I can get at the moment, a couple of hours here and there in the day, rather than 7 hours together, it's manageable.

Lone parent, London, Take-up, Pilot

2.4.3.2 Self-employed professionals

Participants in the *Take-up* group who were more **highly skilled and had professional backgrounds tended to be able to make the return to their industry by becoming self-employed.** There were a few in the *Take-up* group who did this whose skills were in industries such as media and business. These participants had often previously worked full-time in fairly large companies but had left employment because they had been unable to balance the demands of their job as well as those placed on them by caring for a disabled child. This typically happened just after their child had been diagnosed with a disability as they either needed to make frequent trips to the doctor or hospital for diagnosis or treatment or because they felt they needed to spend more time at home with their child.

I had to leave in the end, sometimes I would be asked at 4pm to work until 11pm. I would desperately try to find someone to care for him at short notice, and that kind of thing wasn't good for him.

Lone parent, West Midlands, Take-up, Control

These issues prevented these participants from returning to a full-time permanent job within a company and so they **made the decision to become self-employed in order to achieve more flexibility.** These participants' jobs varied from taxi driver to music producer, however, it was the flexibility these jobs offered which meant they could decide which jobs to take on to fit around family life that was the one of the most appealing factors. In several cases, being self-employed meant they could also spend either some or all of their time working from home which ensured that they were close to their children if they were needed and that they could have flexibility around when they worked. Commonly, these participants would work both during the school day and for up to two hours afterwards while their child was in childcare, and then they would also work again once their child was asleep. **Having the option to work in the evenings relieved some of the stress** and pressure on parents if they had to make frequent trips to the school, childcare provider or hospital.

2.4.3.3 Flexible work with charities and other family related work

Finally, some participants in the *Take-up* group, normally those who had backgrounds in office roles had decided to **move into a new industry as a result of links they had made through their role as a carer for their disabled child.** These parents, as with the professionals discussed above, tended to have always worked before leaving

employment to care for their child, and their motivation, skills and determination to help both themselves and their child learn to manage the child's disability led them to working with local charities. Often this started either through becoming affiliated with a local charity in order to achieve either funding or support for their own child or through attending support groups for parents run by local groups.

This would sometimes lead to the parent doing unpaid volunteer work for a while before being offered paid employment to work either with or on behalf of other parents of disabled children to offer them help and support. This kind of work suited these participants for a number of reasons. Firstly, as with those who took jobs as carers, they often felt that they got a **greater level of job satisfaction** by helping those who were in similar or worse situations than themselves than they did from their previous job. Secondly, doing this kind of work was often either directly, or indirectly beneficial to their own family. It gave them both the **opportunity to learn from other parents with disabled children** in terms of both the disability specifically and support systems available as well work towards improving knowledge and understanding of disabilities and the systems existing to support children and parents.

Yes I work for a charity, but I do it for selfish reasons. I help other people but I'm also helping me and my son.

Lone parent, West Midlands, Take-up, Control

As explored in section 2.3.3, flexibility of the employer was felt to be vital, and working for local charities or groups meant that the participants' employer was more understanding and flexible than they had previously experienced. These participants tended to spend most of their time working from home and working flexible hours so their job fitted around school and childcare.

2.4.4 BALANCING WORK AND CHILDCARE

The key factors in *Take-up* participants being able to balance work and childcare were the ability to plan effectively, and being able to access both flexible employment and childcare. Looking at the former point, **planning ahead was important so that participants could ensure that they had childcare secured for when they needed it and so that they could manage their workload around family life.** They also needed to plan to guarantee that they would be able to spend time with their children during the week. Sometimes participants said that they needed to execute the planning of their life with 'military precision' in order to ensure that their children were receiving the right balance of care.

It all has to be planned in advance. Everything's on my phone, synchronised to my computer, my phone's always with me. So everything's got an alarm on it to remind me.

Lone parent, West Midlands, Take-up, Control

Despite forward planning, situations with work and childcare could often arise at short notice which meant that participants needed a great deal of flexibility. The types of jobs which most participants in the *Take-up* group normally found meant that they could work flexible hours and this made balancing work and childcare easier. Although around half of parents in the *Take-up* group had a source of informal care to draw on (please see section 3.3.1 for more detail), there were occasions when they could not always arrange

this at short notice as their informal carers tended to be working or studying. This meant that for all participants there were still times when they **would need childcare at short notice** and this meant that they needed a childcare provider who understood the difficulties faced by the parent and accommodated them. This need for flexibility meant that most *Take-up* participants **used a childminder rather than school wrap around care or school activity club as the opening hours were less strict.**

She's not your average childminder because she's so flexible, I'm lucky because I can literally phone or text her you know at a day's notice and say can you have her because I've got to do this for work and she always says yes.

Lone parent, West Midlands, Take-up, Control

2.4.5 SUSTAINING EMPLOYMENT

The main reasons for participants leaving work within a few months was that they were either not regularly given enough hours by their employer to make up the 16 hours a week needed to be eligible for financial support or because they found balancing the various demands on their time too stressful. As a result, around half of those who took on jobs in Care only managed to stay in work for one to three months. While those who had continued to work for up to a year reported that they found doing so only managed because they had a network of informal care available.

This was a particular issue for the very small number of participants who were studying as well as working and had taken up the offer to get help with the childcare costs they were already paying while they studied. **For these participants, trying to balance work, studying and childcare was difficult and exhausting.** This meant that for the few parents who were doing this, a typical day could involve getting up before 6am to go and visit a client and then return home to get the children ready for the childminder to collect them and take them to school. The participants would then often need to leave straightaway for college or university and then spend a further three or four hours working after that in their Care job. Sometimes this would mean that they would either get home just in time to put the children to bed, or they would sometimes miss bedtime altogether and would have to rely on the childminder to take responsibility for this task. This was not only exhausting for these participants and affected the quality of their work in both their job and their studies, but it also meant that they were not seeing their children. The result of this was that these parents felt they had to make a decision between their job and their education as trying to sustain both was too difficult. Invariably, **the decision was to leave work and remain in education** because they believed that staying in education in order to gain skills would lead to better paid and more stable employment in the future.

It dawned on me that you go and care for others and neglect your own, that's how I started to feel, imagine, because I was going out at 7 o'clock in the morning and getting in at 7 or 8 at night.

Lone parent, London, Take-up, Pilot

However, the participants who were either self-employed or working for local charities as well as some who had worked as carers had managed to continue working for up to a year after they had taken up the offer. This was attributed not only to stable and flexible work and childcare but also the high levels of motivation and determination to work, which these participants had.

2.4.5.1 Continuous better-off calculations

Making calculations about whether to take up work and childcare initially, as discussed in section 2.2.6, and then afterwards whether to continue working, were discussed regularly by participants in the *Take-up* group. These calculations were often both literal, financial calculations and figurative, emotional calculations.

Knowledge of exact losses and gains in benefits were quite rare amongst *Take-up* participants. Although a small number said that they had asked Jobcentre Plus for assistance in making calculations, they did not always rely on this calculation as these participants were generally thinking about moving into employment with variable hours, which made accurate calculations difficult. Generally, **there was not a strong feeling amongst participants that they would necessarily be better off financially if they worked**, or at least that if they were that the amount would be enough to make a significant change to their lifestyle.

The money doesn't make sense for me to work, I'm not really better off.

Lone parent, West Midlands, Take-up, Control

Indeed, **financial gain was not believed to be the most important reason to work amongst most of the *Take-up* group**. These participants tended to focus on the perceived benefits of working discussed in section 2.3.2. The most important reason for working amongst the *Take-up* group seemed to be the opportunity to take respite from their responsibilities at home, if only for a couple of hours at a time and create a new role for themselves. The opportunities to get out of the house, meet new people and develop both soft and hard skills were all discussed by participants, as well as wanting to set an example to both their disabled and in particular their non-disabled children by working. Respite through working was a common benefit discussed by *Take-up* group participants as they felt that the emotional and physical demands of caring full-time were often harder than working, and as such, they sometimes described their job as their break.

I work for my sanity, it's like a break.

Lone parent, West Midlands, Take-up, Control

Additionally, these parents tended to feel that their **relationship with their child had often improved since they had returned to work**. This was because many of these participants had previously spent a number of months or years at home caring for their children which had required all of their time, thought and energy. While no parent in any way resented this, there was a feeling that the amount of time spent with their children was in some ways detrimental of their relationship as **the parent and child relied so heavily on each other for company, support and meaning**. Many *Take-up* group participants felt that their relationship with their disabled child had improved since they had started working as they spent more time apart and so were able to appreciate the time they spent together. It was often these factors, which kept *Take-up* participants in work rather than the financial gains, which, for most, were not believed to be high enough to be the only reason to remain in employment.

It [the parent/child relationship] has changed, the time I spend with him now is more fun, we enjoy each other more.

Lone parent, West Midlands, Take-up, Control

2.5 CONCLUSION

2.5.1 MAIN BARRIERS TO TAKING UP WORK AND CHILDCARE

There were a significant number of attitudinal and practical barriers to participants being able to take up work and childcare, however, the affordability of childcare was not one of the main barriers. In particular, participants feeling that their place was at home with their children, either because of their traditional views or because they felt they were the best person to provide care for their children was common.

There was also a high level of distrust in formal childcare, as discussed in section 2.2.4, and perceptions that they would not be able to find childcare for their child. Indeed, participants either perceived or experienced a great number of barriers to using formal childcare. These mainly related to confidence in and availability of local childcare provision for disabled children. Participants generally found it difficult to find a provider with the right skills and attitude to provide the level of care needed. Availability in terms of opening hours was also a major barrier for those who expected to work outside of normal office hours and this often made the idea of balancing work and care infeasible. Barriers to work were also significant, particularly amongst participants with low skills or experience levels who often found the process of looking for work challenging. The main barrier to work faced by most participants was not being able to find a job which would fit around childcare responsibilities or an employer who would understand the need for the participant to put their child before their job.

2.5.2 MAIN ENABLERS TO TAKING UP WORK AND CHILDCARE

A large proportion of participants in all groups felt that there were a number of personal benefits to working which made them keen to seek employment. Being able to develop new skills and meet new people as well as take some time away from the responsibilities of being a parent and carer and setting an example to their children were all believed to be positive outcomes of working. These benefits often seemed to motivate participants more than the salary available to them.

The enablers to use formal childcare were the inverse of the barriers. Finding a childcare provider with the right training and skills to care for a disabled child and who genuinely cared for the child made parents more confident in using childcare. Having a provider who was willing to be flexible in terms hours was also important, especially for parents who worked outside of office hours. Having a good relationship with the provider was key to the participant both being able to trust childcare and balance the demands of work and family life.

Employment needed to be flexible as well. Finding a job which allowed them to work from home or work flexible hours made balancing work and childcare easier. Also, either being self-employed, working for an agency or having an understanding employer reduced the levels of stress caused by having to leave work early because of an emergency with the child. Flexibility of both work and childcare was key in enabling participants to balance the demands in their life and sustain employment.

3 CHAPTER 3: USING CHILDCARE AND THE CHILDCARE ELEMENT

SUMMARY BOX

- (i) There was **fairly high awareness of both WTC and the CCE amongst the *Take-up* group**, largely driven by the fact that many had made claims for this form of in-work help and support in the past.
- (ii) Parents from the **Control Take-up group were already planning to claim WTC and the CCE** when they received the offer letter. Consequently, many said they would still have made a claim through the normal channels had they not received any communications about the offer.
- (iii) Those parents who were aware of the CCE reported that the **additional money being offered made them feel that taking up work and childcare would be more worthwhile financially**.
- (iv) There was **low awareness of WTC among those who had been out of work for a number of years** or had never worked, and migrants in particular. Almost all of these parents were unaware of the CCE.
- (v) Those **parents who managed to sustain employment tended to have a strong relationship** with their children's provider.
- (vi) For most parents the **cost of care was generally not an issue**. Where it was though, it resulted in them **having to borrow from friends and family**.

3.1 INTRODUCTION

This chapter explores the experiences of the *Take-up* group¹⁹ in using formal childcare for both their disabled and non-disabled children. It also looks at the levels of awareness, knowledge and understanding of the Childcare Element (CCE) as well as how they budget for childcare. It has been split into two main sections:

- Knowledge of WTC and the CCE; and
- Using and paying for childcare.

¹⁹ Please note that due to the limited sample available for the *Take-up* groups, the findings for these participants are based on a very small number of interviews compared to that of the *Take-up* groups in the 100% Costs and Actual Costs Pilot research.

3.2 KNOWLEDGE OF WORKING TAX CREDIT AND THE CHILDCARE ELEMENT

Knowledge of both WTC and the CCE was fairly high amongst the *Take-up* group. **Around half of the participants in this group had previously claimed WTC** and others were aware of them through either word-of-mouth or formal channels such as Jobcentre Plus or employment agencies. Awareness of WTC and the CCE was higher amongst those who had been out of work for less than three years as such participants had more recent knowledge of the help and support available to people when in work and, indeed, some had experience of claiming as well.

I used to get it when I was working so I knew it was there.

Lone parent, West Midlands, Take-up, Control

Amongst those with higher levels of awareness, **those in the Control group said that they were already planning to claim WTC and the CCE** when the letter (see Appendix B) from the Department for Education (formerly the Department for Children, Schools and Families, DCSF) was posted to them. **Consequently, the timing of the offer worked well for these participants** and almost all said that they would still have made a claim through the normal channels had they not received any communications about the offer.

Most in the Pilot group also said that they would have made a claim if they had not received the offer letter; however, they had been pleasantly surprised by the extra help that the letter told them they were entitled to. For the small number of participants who had been aware of the precise nature of help and support available via the standard offer, the **additional money being offered made them feel that taking up work and childcare would be more worthwhile** financially. This was especially true of those who were studying and using childcare when they received the offer letter as they thought that the extra help with childcare would relieve some of the financial pressure they were under at that time.

I knew about the help with childcare but to me it was like a blessing from above, the extra made a difference.

Lone parent, London, Take-up, Pilot

Those who had been out of work for a number of years or had never worked, and immigrants in particular, reported lower awareness of WTC. While some were aware that WTC existed, they **did not know what the eligibility criteria were and did not think they were applicable to them**, and most were unaware of the CCE. Therefore, for a significant number, the original offer letter was the first piece of communications they reported receiving on both WTC and the CCE and being aware of the support available made them more likely to view working and using childcare as financially viable.

3.3 USING CHILDCARE

3.3.1 BALANCING INFORMAL AND FORMAL CHILDCARE

As discussed in section 1.8.3, a high proportion of participants in all groups, and in the *Take-up* and *Not Interested* groups in particular, lacked local social networks which meant that they had little informal care to draw on. Indeed, over half of *Take-up* participants had no informal care available to them *at all* which placed an even greater **emphasis on the need for a good relationship with their childcare provider**. Additionally, the few participants in the *Take-up* group who did have family or friends nearby were often unwilling to ask them to provide childcare because they did not want to burden them given that they recognised the demands associated with looking after a disabled child. Linked in with this, **participants were unwilling to ask their parents to help** them because they worried that they were too old to cope with having to care for a disabled child which could be both physically and emotionally demanding. This meant that participants did not often use their friends and family for childcare, and if they did this was normally at night time when the formal childcare was unavailable and the child would need less attention as they would be sleeping.

My mum can't look after both of them, but when it comes to it, if she goes there at 7.00 pm or 8.00 pm in the evening she's ready to sleep, she sleeps at my mum's, my mum can cope with that okay and she enjoys seeing her at the end of the night because she's a lot calmer, she's worn herself out so everybody's happier.

Lone parent, West Midlands, Take-up, Control

A very small number of participants who did not have any family or friends nearby would sometimes use other people in the community as a source of informal paid childcare. This source tended to be used by migrants who were part of a local church community. **Participants who paid people in their social network to care for their disabled child** normally did this because they needed care late in the evenings or at weekends when they were unable to find a formal childcare provider. This informal childcare was often charged for at a much lower rate than a formal provider, typically £15 for a day at the weekend, but this could often add up for the parent if their job required them to work a few evenings and the weekend. Consequently, the cost often became difficult to manage as they could be required to spend around £50 extra per week on childcare which they received no help with.

The registered childminder is working Monday to Friday, Saturday and Sunday she says she doesn't work, she don't work Bank Holiday. All childminders are the same; they don't work Bank Holiday, they don't work Saturday and Sunday, so Saturday and Sunday I find private, I pay.

Lone parent, London, Take-up, Pilot

Using siblings of the disabled child as a form of informal care was very common and was felt to be a vital means of enabling parents to combine work and childcare. While they did not always feel happy about putting this kind of responsibility onto their children (as discussed in section 1.8.7), they often did not feel they had any other option and the **child's siblings were considered to be the best type of informal care**. This is because they would know the disabled child as well as the parent and, therefore, would understand how to talk to and care for them.

The hours are unsociable and the fact I've got the older ones I'd have to put on them, but that's the reality. I don't want to do that, but if that's what I've got to do then...

Lone parent, London, Take-up, Pilot

3.3.2 EXPERIENCES OF FORMAL CHILDCARE

The following sections detail the experiences of participants in the *Take-up* group of using formal childcare for both their disabled and non-disabled children. It has been separated into the three main areas of: confidence; availability; and cost.

3.3.3 CONFIDENCE IN CARE

Participants in the *Take-up* group faced many of the barriers to childcare discussed in section 2.2.4 and shared many of the concerns about quality of formal childcare available for disabled children as those in the *Interested and Not Interested* groups. **Finding a childcare provider who they trusted to provide high quality care for their children was an important factor in sustaining work for participants.** However, they were not able to articulate why they had managed to find a good quality provider when others in similar situations had not. Instead, these participants tended to describe themselves as being *lucky* to have their provider.

So I am lucky and I know that because of the amount of people, as I say, that I know that can't get good childcare, especially for a child with special needs.

Lone parent, West Midlands, Take-up, Control

Indeed, these participants felt that they had been fortunate to find an individual who had **the right levels of skills, enthusiasm and attitude to care for their child, which seemed to be the key points in defining quality of care.** This relationship sometimes developed so that the participant's child was accepted into the childminder's family, and this made parents feel more comfortable as this brought with it a sense that the childminder would 'go the extra mile' for their child. Having confidence in the childcare provider meant that the participant could have time to concentrate on their job and their own development while they were working, and it was felt that this benefited every member of the family.

She got pictures of the girls up in her house and every year she takes them all on a trip, she doesn't charge for that.

Lone parent, West Midlands, Take-up, Control

Building a strong relationship between the child and the childcare provider was felt to take a significant amount of time and because of this, **continuity of care was felt to be of vital importance** and, in turn, bred confidence. This was another reason for most parents preferring childminders to other types of providers as there were both perceptions and experiences of high staff turnover in playgroups and clubs. This not only meant that a new staff member would need to take time to understand the child's care needs but it could also take a significant amount of time for the child to accept the new person. Indeed, familiarity and routine were both discussed regularly by parents who said that **any change to their child's normal day-to-day routine could lead to a great deal of stress and upset for the child** and in turn, the parents. This was a

particular issue for parents who had children with behavioural or learning disabilities, for which routine and repetition were often key manifestations of the disability. This meant that parents needed to find a provider who understood the need for continuity and consistency of care, and indeed, most *Take-up* participants who had managed to sustain employment felt that they had found this quality of childcare.

However, there were some *Take-up* participants who had negative experiences of using formal childcare. These experiences tended to centre on childminders complaining to the parents about the behaviour of their child, for instance, stating that they were being naughty or were refusing to eat or get dressed. The provider's ability to use their experience and skills in being able to cope with the child when they were unwell or upset was vitally important for parents being able to sustain employment. **The need to regularly leave work to collect their child from school or childcare due to upset or illness was a major barrier to working.** Parents said they needed a childcare provider who would not call them every time the child had a tantrum or needed a little extra support, patience or attention. Also, a childminder who would be willing to collect the child from school if they had to leave early so the parent could remain at work helped parents to stay at work and reduced their anxiety.

You need one that doesn't ring you the minute he cries or is sick, that happens all the time and they need to deal with that.

Lone parent, West Midlands, Take-up, Control

This was stressful for parents because they felt that a lot of the behaviours which the providers were complaining about were related to their child's disability, particularly in the case of autistic children who could be very sensitive about food and clothing and whose behaviour could be interpreted as naughtiness by those who did not understand the disability. These kinds of issues could be detrimental to the relationship between the parent and provider and sometimes led to the parent believing that the childminder (almost all *Take-up* parents used this form of childcare), was treating their child unfairly.

She told me my son break window, so I asked my son; my son says he is not the one she said my son is lying. I said well if you know my son is lying long time ago, you are professional childminder you should have told me something you never tell me anything and now you come and tell me my son is a liar, six year old boy, so I was annoyed with her so I just changed her.

Lone parent, London, Take-up, Pilot

3.3.4 AVAILABILITY OF CHILDCARE

As mentioned throughout, finding a flexible provider was key for parents in their being able to balance work and childcare. Those who felt that they could ring the childminder at short notice or ask them to provide care out of hours in evenings and weekends spoke highly of their provider and said that this flexibility enabled them to continue working.

I've never asked for a time they haven't been able to do.

Lone parent, West Midlands, Take-up, Control

However, as discussed in section 2.2.4.1, not all participants were able to find a childcare provider who would take their children on weekends and in the evenings and

this **sometimes led them to having to rely heavily on either paid or unpaid informal care**. This was a problem as they could not claim any of the costs of this. Also, the person caring for their child would be unlikely to have the training or skills the parent would like a carer for their disabled child to have.

Location of the provider was generally not an issue for participants in this group as almost all had their own car and the provider they used was generally very close to either their house or their child's school. However, in cases where the participant's child was severely physically disabled and needed very specialist care, then the provider would very often come to the participant's home. While this meant that the disabled child was in familiar surroundings and did not need to be moved around too much, having a childminder in their home did have an impact on the parents and other non-disabled children in the family.

Participants in these situations tended to feel under scrutiny as the childminder would make notes about the house and any potential hazards as normal procedure and for legal reasons. This could place a lot of stress on the parent who would feel the need to clean the house everyday so that they would not feel embarrassed or worried about what the childminder might think or tell people. For the other non-disabled children in the house, having a stranger in their home could feel intrusive.

It's intrusive, half term, which is next week, they'll be sitting literally on my sofa all day. I won't be here but the kids, they just try to just live a normal life, feel like they're under observation 24/7.

Lone parent, London, Take-up, Pilot

3.3.5 COST OF CHILDCARE

Although the cost of formal childcare was a consideration, generally, **participants in the Take-up group felt that the cost was manageable and that they were being charged a reasonable amount for the quality of care that their children received**. That said, these participants were generally highly motivated to return to work, especially in comparison with participants in the *Not Interested* group and as such, were more open to paying for childcare, even if it was expensive. Moreover, as discussed above, participants in the *Take-up* group faced difficulties finding childcare that met their requirements in terms of availability and in terms of having confidence in the provider. These difficulties were viewed as quite formidable, and as such, when participants found suitable childcare, their predominant attitude towards costs was 'we'll find the money'.

As discussed in section 2.2.4.2, parents would often be asked to pay more, often double the amount, because of their child's disability. This was most commonly an issue for parents who had children with both mild and severe behavioural or learning disabilities because childminders seemed to view these less visible disabilities less sympathetically than they did more obvious, physical disabilities. Parents who had children with physical disabilities or medical conditions who used non-specialist childcare rarely paid more than the standard rate as the childcare provider would either refuse or accept the child based on their skills and attitude and tended not to ask for extra money. However, almost all participants in the *Take-up* group that had been asked to pay a higher rate because of their child's disability said felt that it was reasonable that the cost be passed on to them and did not complain.

They are right to charge me for two children; he needs more care, more attention and more time. To provide this they need to have fewer children, I can't expect them to lose money because of me, I can't blame them.

Lone parent, West Midlands, Take-up, Control

Other *Take-up* parents who had to pay for specialist in-home care, which was often charged at around £20 per hour, felt cost to be more of a problem. **Indeed, the costs they paid for the care could be sometimes double what their hourly wage was.** This rendered childcare as being unaffordable as, due to the limits placed on the CCE, they still had to find the remaining 20% of costs to pay the provider. To a lesser extent, this was also a problem for those who were paying for additional informal care as although they were not paying very much because they were unable to claim for any of the cost it could put additional strain on the household budget.

Despite these issues, however, there was a strong feeling that finding the right provider was most important factor and that they would do everything they could to find the money to pay for the best care.

3.3.6 BUDGETING FOR CHILDCARE

Most participants in the *Take-up* group said that while they had to manage their household budget carefully, paying for childcare tended not to be a problem, even though almost all of them were paying a higher rate for childcare because of their child's disability. For participants who were self-employed or working for local charities or groups, their income, while not high, was normally enough for them to be able to cover the 20% of childcare costs they had to pay without too many problems. **To help them cope with the costs, such participants tended to adopt strategies to avoid large variations in seasonal childcare costs.** For instance, in the school holidays they tended to either take time off during school holidays or work from home so that they did not need to use much additional childcare.

However, for participants with lower incomes, paying for childcare was more of a problem, **especially in school holidays when the costs were much higher and the participants were not able to take time off.** A small number of participants in both the Pilot and Control *Take-up* group said that they regularly got behind with their childcare payments. Although most participants reported that childminders in particular were flexible with payments and would be willing to allow a parent to be in arrears, these debts could sometimes mount up. To remedy this, a small number of participants said that they had **borrowed a significant amount from friends and family** to pay back the money they owed their childcare provider and that, in turn, this debt caused them more stress. Despite financial difficulties, these participants wanted to remain in work because they felt that they were experiencing the other non-financial benefits of working as discussed in section 2.4.5.

My income compared to my outgoings is...just in childcare alone I'm £1,000 each month owing and that's out of my own pocket even with the money I've got coming in.

Lone parent, London, Take-up, Pilot

3.4 CONCLUSION

There was fairly high awareness of both WTC and the CCE amongst the *Take-up* group, largely driven by the fact that many had made claims for this form of in-work help and support in the past. It follows, therefore, that awareness was lower amongst those who had been out of work for many years and, consequently, the offer letter was the first indication they had experienced that help was available.

Being able to balance work and childcare required both forward planning and flexibility of work and childcare. Participants who managed to sustain employment tended to have a strong relationship with their childcare provider which made them more confident about using childcare and made it easier to balance work and childcare. Skills and training of staff were also important for the parent being able to trust the quality of childcare. The cost of care was not generally an issue for most, as their determination to work and the challenges of finding suitable childcare were considered so great, that most participants were willing to pay higher costs if they found the right care. Indeed, these participants were prepared to incur the costs of paying for childcare even when aware that these were greater than those for non-disabled children. Moreover, providing these participants budgeted, they found that their modest incomes were sufficient to cover the 20% of costs. However, for the small number of participants in both the Pilot and Control *Take-up* groups, the cost of childcare was a significant issue which resulted in them having to borrow from friends and family. Having a source of informal childcare was also helpful, although limited social networks meant that many had to rely on their children for this. Others, who used people in their community, such as fellow church parishioners, were often asked to pay for this which put a greater burden on the household income as it could not be included in their CCE claim.

4 CHAPTER 4: OPERATIONAL EXPERIENCES OF THE PILOT SCHEME

SUMMARY BOX

Responses to the letter varied enormously, and reactions were largely influenced by participants' views on the feasibility and viability of taking-up employment.

- (i) Many parents were **unsure who the letter was from** or why they had received it. This was even true of those who received mail from a range of government departments.
- (ii) Parents who **believed strongly in their dual role as parent/carer** felt defensive in response to the letter, believing they were being pushed into work. Other parents from the *Not Interested* group felt it was **irrational for the government to pay a childcare provider** about the same amount they would be able to earn from working.
- (iii) The fact that the **offer was time limited was criticised** by those who needed longer to complete their studies or extra time to find and secure employment.
- (iv) The letter did encourage and **motivate some parents to increase their job search activity** and consider using formal childcare. This effect, however, was restricted to those who were already looking to return to work.
- (v) Regardless of parents' levels of awareness as to the existing levels of support available through WTC, all participants including those from both the Pilot and Control **were impressed by the level of help available** provided by the Disabled Children's Pilot. However, given that affordability was not the main barrier to taking up work and childcare the offer did not always provide the support that was needed to make the transition into at least 16 hours of work per week.
- (vi) Understanding of the offer was driven by awareness of previous experience of claiming WTC or CCE.

Although a significant number of participants reported that the extra help available made work feel more worthwhile, **the key driver for employment and childcare take-up was attitudinal**. If participants felt ready to work and if they were willing to use childcare they were more likely to seek suitable childcare. **The offer's window of opportunity was the most common reason parents gave for not registering an interest in, or taking it up**. Even parents who originally registered an interest felt that the number of hours customers were required to work in order to be eligible was a barrier to some parents taking up the offer.

- (vii) Those who had repeated **contact with the DfE Contractor helpline were positive about their experiences**. Almost all described advisors as helpful, friendly and encouraging.

- (viii) Participants in the *Take-up* group were generally happy with the payment process and understood what was expected from them. However, some wanted HMRC to pay the childcare providers directly and there were some issues about payment suspension due to a reported change in circumstances.
- (ix) However, while being sent a separate cheque for the CCE helped some to budget more effectively and increased transparency about what they were receiving, we can infer from this research that a letter outlining these details did not have the same effect

4.1 INTRODUCTION

This chapter describes the reasons why participants from all Groups reacted differently to the letter, their levels of understanding of the Disabled children's Pilot and finally assess the reasons why some participants took the decision to take up the offer.

4.2 UNDERSTANDING OF THE OFFER

4.2.1 INITIAL RESPONSES TO THE INVITATION LETTER

Before discussing detailed responses to the letter it is important to note that reactions to it were largely influenced by participants' views on employment, as discussed in section 2.2.3. By this we mean **that those more inclined to view work positively, and to see combining work and childcare as a viable option were more likely to view the letter positively.**

Though many indicated that they received mail from a range of government departments and agencies some were unsure who the letter was from or why they had received it. Few parents had heard of the Department for Children, Schools and Families (DCSF²⁰) and most did not recognise the Department's rainbow logo; indeed, for some, the branding was more reminiscent of that of a charity than the public sector, which confused them as they did not realise they were being offered a state benefit and so were less likely to take the offer seriously. A few were also confused as to why they specifically were targeted with the offer of extra financial support; some thought they may have been referred onto a special system of help by a charity, school or Local Authority.

I did think it was Social Services and I actually thought Social Services saw a need in me and recognised that there was scheme and put my name forward.

Lone parent, London, Take-up, Pilot

²⁰ This is now the Department for Education (DfE). The offer letters were sent by the then DCSF because of the way the Pilots had been set up.

Those parents with higher educational attainment were most likely to express cynicism about the offer. A small number of these participants were suspicious about the wording and presentation of the letter and would have expected a more 'professional' style of letter, though it is important to note that these attitudes did not affect propensity to take up the offer and that these participants did not acknowledge the letter was written in plain English in order to be accessible to as many recipients as possible. **Parents who primarily saw their role as a parent and carer reacted defensively to the letter** believing they were being pushed into work, regardless of what was best for their family. Similarly, other parents with low skill-sets felt it was illogical for government to pay a childcare provider about the same amount they would be able to earn from working.

I thought it was really ridiculous. As I said to you really you can't always go back to work with these children. Surely they would rather me do that than pay Joe Bloggs to do it? I don't...I don't see what they are gaining?

Lone Parent, London, Not Interested, Pilot

The time limit of the offer and the condition of needing to secure 16 hours work per week was criticised by the small, number in the Pilot group who were studying when they received the offer. These participants felt the **eligibility criteria was too rigid to allow them to complete their studies** while others felt they would need longer to find work due to their complex personal circumstances.

Additionally, quite a few participants, who were not studying, said they were work ready but felt that **16 hours was too much too soon**. There were a number of reasons for both lone parents, and couples where one partner was out of work and primarily responsible for childcare wanting to secure a lower number of working hours, especially for the first few months of returning to work. Firstly, parents were **concerned about being able to find and balance work and childcare** if they were working 16 hours a week, particularly if they had either experienced or perceived a lack of suitable jobs or childcare available in their area. Secondly, parents were **worried about how working 16 hours a week would impact their disabled child**, who was used to them being available constantly, and so would prefer to work fewer hours to begin with until family life could adjust. Thirdly, parents with children with severe disabilities were **concerned about becoming tired at the end of the working day**, which might affect their ability to give their child the attention they needed, and so would have preferred work fewer hours so that they could still make caring for their child their primary focus. Finally, for those who had been out of work for a number of years, or had limited work experience, the idea of starting work for a minimum of 16 hours a week was daunting and felt like a considerable amount of time, particularly when they considered the demands on their time for caring for their home and family.

They do offer a lot don't they really and it seemed like quite an incentive to get you back to into work but the only thing was that it was almost like full time work and I just find the idea of full time work too daunting because I've got the home to run, my child and I just think that working full time hours would be too much for me.

Lone parent, London, Interested, Pilot

However, most of the participants who related these concerns felt that **if they were able to take up employment with a lower number of hours to start with, that they would aim to increase this once they and their family had adjusted** to the new routine. Please see section 2.2.2 for more detail on this.

Linked in with this, **those parents in the *Take-up*²¹ and *Interested* groups, who were already considering work and were actively undertaking a job search became more motivated and encouraged by the letter** to the extent that they increased their job search activity, explored the possibility of working longer hours, and considered using more formal childcare. These parents were most likely to view the letter as a huge help as they had anticipated that their planned transition into work would cause them emotional and practical challenges and this offer letter provided the kind of help and support they needed to ease this journey for them.

Yeah I remember at the time thinking that, that sounds great, just what I need. That sounds just what I need and I remember ringing.

Lone parent, London, Interested, Pilot

Both parents who were and were not aware of the existing levels of support available through Working Tax Credit (WTC) could see the incentive in gaining paid work and **were impressed by the level of help available to them** via the Disabled children's Pilot. However many did not see cost as the main barrier to finding suitable childcare and so **the offer did not always provide the support that was needed** for these participants to make the transition into at least 16 hours of work per week.

Cost is not the really the problem, it's finding someone [suitable childcare provider].

Lone parent, London, Interested, Pilot

4.2.2 UNDERSTANDING THE OFFER

The evidence shows that levels of understanding about the offer were connected to awareness of the Tax Credits system more generally and, in particular, to knowledge of the CCE. **Those who had previously made WTC or CCE claims (typically in the *Interested* and *Take-up* groups) felt that they had a good understanding of the offer** when they received the letter because they were familiar with the eligibility requirements and the Tax Credits system more generally and so knew what to expect.

Furthermore, familiarity with formal communications and experience of receiving similar letters or forms was linked to the level of understanding of the offer. Most participants in all Groups spoke of their experiences of receiving letters about other benefits they received such as Disability Living Allowance (DLA), which often required completing fairly complex forms to make and manage a claim. This meant that most participants had either become comfortable in understanding these forms themselves or they had the support in place to help them do so.

²¹ Please note that due to the limited sample available for the Take-up groups, the findings for these participants are based on a very small number of interviews compared to that of the Take-up groups in the 100% Costs and Actual Costs Pilot research.

There were those, however, for whom the letter was more problematic. Those from the *Not Interested* group, who had typically been out of work for a long period of time, had the least knowledge and experience of claiming in work help and support. Because of this, they tended to be the most confused about what the offer was, and what it would mean for them. There were many reasons for this. Firstly, **those who had been out of work for many years were less aware of eligibility requirements** and the system for in-work benefits and so were less likely to understand the requirements and process than those who had previously claimed Working Tax Credit. Additionally, participants in this group were more likely to have **English as a second language, a low literacy level or dyslexia and so had a very practical barrier to being able to understand the offer letter**. Participants in both circumstances tended to seek support from either a friend or through a more formal channel such as Jobcentre Plus, college tutors or local charities to help them aid their comprehension of what was being communicated to them.

I took it [the offer letter] to my teacher at college and asked her about it and she said 'yes, if you get a job then you can have this' she told me to go to the Jobcentre because they can tell you how it all works.

Lone parent, London, Not Interested, Pilot

Furthermore, there were some precise points of confusion among those in the *Interested* group who paid more attention to the letter given they were considering acting on its message. For instance, some parents in the *Interested* group who were highly trained and had previously had professional roles felt the letter could have provided more detailed information on the eligibility criteria to claim the CCE. For instance, a few expressed confusion about whether their participation in the Pilot was affected by an upper earnings limit or if the offer was only available to low income families. These participants felt that this information should have been included in the offer letter to make basic eligibility criteria clearer.

There was also some confusion around the more basic eligibility requirements which *had* been included in the letter as a few parents were unsure about the minimum number hours that they would need to work in order to be eligible. Although these points of confusion did not effect the participant's decision of whether to take-up the offer or not; providing clearer and more detailed information on the eligibility criteria in the letter was felt to be important by these parents.

I had some questions that I wanted to ask about it [the letter]. Say for instance you're working part time, can you get childcare when you're working part time or do you have to be doing a certain amount of hours before you become eligible?

Lone parent, London, Interested, Pilot

4.2.3 JOINING THE PILOT RELATED TO THE NATURE OF OFFER

Take-up parents were motivated to join the Pilot for a number of reasons most of which were not related to the offer itself. As discussed in section 2.3, the key driver for employment and childcare take-up was attitudinal; if participants felt ready to work and if they were willing to use childcare, then they were more likely to seek suitable employment.

As further evidence of this, **almost all *Take-Up* participants indicated they had already been undertaking job searches or looking into childcare arrangements when they received the letter.** For some of these parents it can be said that the offer came at the “right time” as it gave them that “nudge” to sustain their job search or arrange childcare. A few of those on the Pilot did, however, mention that the additional support they were now entitled to was an incentive for them to work.

4.2.4 REASONS FOR NOT JOINING THE PILOT RELATED TO NATURE OF OFFER

The offer’s window of opportunity was the most common reason parents gave for not registering an interest in, or taking it up. Some *Interested* parents who lacked experience in sourcing childcare provision wanted longer to be able to investigate this so they could be reassured that they had found the best possible form of care. For other parents, they would have been involved in full-time study at the time the offer ended and were therefore unable to fit combining work and childcare with their other responsibilities within the timescales set. Linked with this, most parents understood they would still be eligible for financial support available via WTC and CCE and were therefore more inclined to wait until they found appropriate childcare or completed their studies.

So yes, it was a quite a good offer, but it was too late for me because I had decided to change career and was going to back to retrain.

Lone parent, London, Not Interested, Pilot

4.3 JOINING THE PILOT

4.3.1 INTRODUCTION

The following sections describe the views of both Control²² and Pilot *Take-up* participants and their experiences in taking up the offer, receiving payments and managing their WTC claim. They also examine *Take-up* and *Interested* participants’ views on the service they received from the DfE Contractor helpline.

4.3.2 CUSTOMER JOURNEYS

NOTE: Customer journeys detailing the specific experiences of individual participants in joining the Pilot and managing a claim for the *Take-up* group have not been included in this report, because the low take-up numbers for both the Pilot and Control offers meant that any personal circumstances included may make the participants identifiable.

4.3.3 RESPONSES TO THE DfE CONTRACTOR HELPLINE

Take-up parents tended to have the greatest recall about contact with the DfE Contractor helpline based on the fact that they had multiple calls with a helpline advisor. *Interested* parents reported having one very short conversation around eligibility criteria, but recall amongst the *Not Interested* group was low as they tended not to have had

²² Evidence from the Control groups in this section is only from the two control interviews with those who took-up the offer through the dedicated TCO helpline for Pilot and Control participants, and not those who received the control letter but took up the CCE through the standard channels with the TCO.

conversations with the DfE Contractor helpline staff beyond when they received a call from the helpline and refused the offer or when they called the helpline to decline the offer.

Of those that had had repeated contact with the DfE Contractor helpline advisors, most were positive about their experiences. Almost all **described advisors as helpful, friendly and encouraging**. Furthermore, the advisors were seen as knowledgeable and parents said that they had been able to answer their questions and, if they themselves had not had the information to hand, they sought it from a colleague that did. **This good level of service helped to reassure participants of their eligibility and served to sustain their motivation to take-up the offer.**

I think anybody that I've ever spoken to have always been very helpful and very nice and if they can't answer your question they seem that they want to ask somebody else just to make sure that they're giving you the correct information so I do think that they're pretty good.

Lone parent, London, Interested, Pilot

Yeah it [telephone call] was all clear, we just talked about the hours of work and that was what it came down to [not being able to work at least 16 hours a week] in the end.

Lone parent, London, Interested, Pilot

However, a significant proportion of parents from the *Interested* group felt that their conversations with for the DfE Contractor helpline advisors could have been more useful. **The key criticism was a lack of information about the additional services described on the letter, for example, assistance with undertaking a job search.** These parents felt that advisors could have done more to signpost them to other sources of information and support for finding work and childcare. Furthermore, some stated that the service provided by the DfE Contractor helpline was quite disjointed and that, once they had registered an interest, they felt as though they were on their own and did not know who to turn to for advice.

4.3.4 PAYMENT PROCESS

Participants in both the Pilot and Control *Take-up* groups were generally happy with the payment process. However, those who had joined the Pilot specifically said that the initial payment via a cheque was problematic for them²³. This was because trips to the bank to pay in cheques were felt to be inconvenient and time consuming, especially given the other demands on their time. This had led some participants to **leave a number of cheques to accumulate before they paid them in** to mitigate these problems. This sometimes meant that they did not have the money available when childcare payments were due which meant that they would make late payments.

²³ Families on the Pilot received the standard support as part of their main tax credit award (usually in the form of a BACS payment), and the remainder in the form of a cash cheque until the end of March 2010. This was due to operational constraints within HMRC. From April 2010, all CCE payments were made by BACs.

Although **childcare providers were reported to be relatively understanding about late payments, repeated cases of this sometimes damaged the relationship between the parent and provider.**

However, once the payment was changed to BACs²⁴, participants reported being pleased with how they received the money. They also stated that **receiving the CCE separately from their main WTC award made budgeting for childcare easier and allowed them to identify changes in the amount being paid as a consequence of a change of circumstance.** Being sent a separate cheque or receiving a separate BACs payment for the CCE helped some to budget more effectively and increased transparency about what they were receiving. However, we can infer from this research that the monthly letter sent by HMRC to each Pilot participant informing them of their monthly CCE payments did not have the same effect as they were not referred to by any participants in the *Take-up* Pilot group. A copy of this letter can be found in Appendix C.

While *Take-up* participants in both groups were generally happy with the delivery model, there were some difficulties with how their award was calculated. The first and most common problem was that participants either did not understand that the CCE averaged the costs they experienced across the year and paid them equally in four weekly instalments and that, because of this, they needed to keep money back at times when costs were lower. This lack of understanding about the estimating and averaging and estimating system meant that parents in the *Take-up* group did not understand how to ensure that they were receiving the right amount of money and, moreover, that budgeting was difficult given the general pressure they were under financially. Consequently, when their childcare costs were higher (such as in the school holidays) these participants ended up paying the additional costs themselves which increased the financial strain they were under.

You can't remember to save that extra £10 or whatever it is, most people don't manage their money like that, you have money available to you and that's what you live on.

Lone parent, West Midlands, Take-up, Control

A high proportion of participants in the ***Take-up* group said that they would prefer HMRC to pay the childcare providers directly.** There were a few reasons for this. Firstly, it would have removed the need to worry about the averaging and estimating and averaging of payments across the year and, therefore, would have lessened the financial pressure felt by parents at times when childcare costs were higher, as previously highlighted. Secondly, it would remove an extra administrative task from the participants, albeit a small one, though this was felt to be a benefit given the number of other demands that they had on their time. Although parents would still be responsible for paying 20% of childcare costs directly to the provider, they felt that if HMRC paid 80% of the costs directly, they would feel less stress about the payments as they would be responsible for managing a far smaller sum.

²⁴ Families on the Pilot received the standard support as part of their main tax credit award (usually in the form of a BACS payment), and the remainder in the form of a cash cheque until the end of March 2010. This was due to operational constraints within HMRC. From April 2010, all CCE payments were made by BACs.

More broadly, because all take-up participants only used one formal childcare provider and most tended to have fairly stable levels of childcare costs some participants felt that it was unnecessary for the payments to go to them. Additionally, a large proportion of participants perceived that making payments to childcare providers through parents opened the system to abuse as claimants may not be honest about whether they actually use childcare and how much they pay. Finally, a very small number of participants said that they had felt uncomfortable having large sums for money paid into their bank accounts which they did not consider to be part of the household income.

I don't really understand why they money needs to go through me; it would be much simpler and safer if they paid the childminder directly.

Lone parent, London, Take-up, Pilot

Finally, there were also some issues around changes in payments and **payments being temporarily stopped to adjust to a reported change in circumstances**. Some participants said that they found it unfair that the CCE was not adjusted for increases of less than £10 per week. For example, in one case, the cost of an after-school club increased from £12 to £17 per week. The participant called the Tax Credits Office (TCO) helpline to report this change but was told that they **could not report any alteration of less than £10 a week**. Although the participant was able to cover these charges they were unimpressed by this policy as their total income was so low that a weekly increase of £5.50 had a significant effect on their household budget.

But the price goes up. I called them and they said because less than £10 goes up, you have to pay yourself, because we're not going to change it for £7, something like that. They say they can't pay, they can't change it.

Lone parent, West Midlands, Take-up, Control

The final issue around payments was experienced by a small number of participants who had called the TCO helpline to inform them that their disabled child was seriously unwell or in hospital. This notification meant that payments for the CCE would be stopped until the child was well enough to return to childcare. However, for most participants in this situation, **even though their child was not in childcare, they were still responsible for paying costs**. For instance, childminders were typically booked for short periods in advance and these would still need to be paid even if the child was not using the care. This could mean that the parent would need to pay for up to a fortnight's worth of unused care. More significantly, school clubs and groups were generally booked for longer periods, such as terms or half terms and paid in instalments, and if the child was unwell for a month or two, the parent could have been responsible for paying for the entire cost of childcare over this time despite the fact that it was not being used. Parents who had been in this position, and whose CCE payments had been stopped even though they were still required to pay for childcare felt that HMRC's policy was unfair and led them to believing that the TCO did not understand how childcare payments worked or the issues faced by parents of disabled children.

Just because he's not there, you still pay for it, you pay for the place, not the usage. If he's sick it costs me, I don't think they [HMRC] understand how it works.

Lone parent, West Midlands, Take-up, Control

4.3.5 UNDERSTANDING OF RESPONSIBILITIES IN CLAIMING CCE

The following sections explore *Take-up* participants' experiences of managing their claim for the CCE and examine any issues they have had specifically relating to their understanding of their responsibilities in managing a claim and communications with HMRC.

Most participants in the *Take-up* group felt that they had a good understanding of what was needed and expected of them to manage a WTC claim and the associated CCE. They said that this knowledge came from previous experiences of claiming CCE or because the information from HMRC had been clear about what their responsibilities were. Indeed, **most participants were able to list correctly the changes of circumstance which they would need to report to the TCO and were aware that these could cause changes to the award that they received.**

However, a very small number of participants said that they found it difficult to understand their responsibilities to HMRC. This was particularly true of migrants who had English as a second language. This meant that they found it difficult to understand the conversations and written communications they had with HMRC and often needed to get someone to help them fill in forms. This help came from a variety of formal and informal sources including: Jobcentre Plus staff, local charities for disabled children, college tutors and friends.

In these cases, participants were unlikely to understand how their claim was calculated and although they knew that they were responsible for updating HMRC, they could not always say what changes needed to be reported. This, of course, increased the likelihood of these already financially vulnerable people receiving a WTC or CCE overpayment.

4.3.6 SUCCESS IN MANAGING CLAIMS

Take-up participants tended to be fairly comfortable with making their initial WTC and CCE claim and this was often attributed to their experience of claiming complicated state benefits such as Disability Living Allowance (DLA) on behalf of their disabled child. They felt that DLA forms very time consuming and difficult to complete and that, by comparison, WTC forms were relatively simple.

All participants said **that joining the Pilot, or taking up the Control offer was fairly easy and did not report any problems with the system.** However, a few had experienced issues with reporting a change of circumstances. These participants said that the TCO helpline staff had either not accurately recorded a reported change, or had not recorded it at all. This sometimes led to overpayments or payments being stopped for the CCE which caused stress, frustration and sometimes financial hardship for the participant.

However, this was not the majority view and most of those who had reported a change in circumstances described being happy with the level of service provided to them by the TCO.

It's actually pretty straightforward once you take the time to read the information, it doesn't take much time or effort.

Lone parent, West Midlands, Take-up, Control

The most significant problems that participants experienced in relation to managing their claims stemmed from those who were on the Pilot scheme and ended their WTC and CCE claim because they were leaving employment. All participants who did this said that they had contacted the TCO helpline to inform them that they were no longer working and needed to terminate a claim and believed that they had fulfilled their responsibilities to HMRC. However, while we are dealing with small sample sizes here, **all of these participants then went onto receive overpayments because they continued to be paid the CCE for between two and six months.** Participants attributed the overpayment to a mistake at the TCO as they had been informed that the termination of their claim had to be carried out by a separate team and were told by the TCO helpline staff that the information would be passed on. However, they were of the opinion that this had not happened but even in spite of this, they were satisfied by the way that HMRC resolved the issue for them and participants attributed the overpayments to the inevitable teething problems of a Pilot which they knew they were part of.

I called to say I wasn't working anymore but the payments just kept coming in. They sorted it though and said it was their mistake so I didn't have to pay it back.

Lone parent, London, Take-up, Pilot

4.3.7 COMMUNICATING WITH HMRC

Experiences reported by the *Take-up* group of contacting the TCO were varied. Most participants reported that the TCO helpline **staff were helpful, knowledgeable and efficient.** This led them to be confident that when they called to report changes, these were recorded and acted upon. Additionally, participants were happy to contact HMRC by phone and felt that this was easier and more efficient than communicating by post.

You just have to make a phone call to advise them of all the changes, they take all the information by phone, I think its quite user-friendly, rather than having to send documents through the post that get lost, you know and waiting for the Royal Mail service, I think it's a lot more efficient.

Lone parent, London, Take-up, Pilot

However, a few participants felt that the **level of service provided by the TCO helpline was variable** and that far too much depended upon the individual who happened to answer their call. Therefore, when participants had issues with managing their claim, these were almost entirely attributed to the last member of staff that they had dealt with. Concerns centred on whether some members of the TCO helpline staff had received sufficient training in WTC and how changes to their circumstances might affect their award. They also believed that they had been in contact with TCO helpline staff who had not acted on the information they had given them and so caused the participants problems with their CCE payments. These participants tended to compare the level of service they felt they received from TCO helpline staff to that of the DfE contractor helpline advisors, who they felt had been more able to answer questions or concerns. However, again, this was the minority view among those that we spoke to.

There has been quite a lot of contact, some successful, some not; it's a bit hit and miss really.

Lone parent, London, Take-up, Pilot

4.4 CONCLUSION

Participants' responses to the letter outlining the offer were closely linked with their existing attitudes towards taking up work and childcare. Those with traditional attitudes were likely to feel defensive about their rationale for not working, whereas those who were already keen to find work felt encouraged by the letter as they felt it made working more worthwhile.

As cost of childcare was not felt to be the most significant barrier to work for participants, the exact nature of the scheme did not seem to have a considerable impact on their decision to take up the offer and move into work. However, as discussed in section 4.2, or some it was felt that the window of opportunity to participate was too small for parents of disabled children to overcome the numerous barriers they faced in finding suitable work and childcare. For those who took up the offer, it was felt that it was a case of good timing as they were either already about to start work or were planning to.

Experiences of contact with both the DfE contractor helpline and the TCO helpline were generally positive amongst the *Take-up* group, and most participants said that they were satisfied with the service provided and felt that they understood what was expected of them. For the small number of participants who did experience problems, this was felt to be a result of the individual person that they dealt with perhaps having less of an understanding about their claim and the WTC system more generally. There were also some concerns about how effectively information was passed between different teams. This led some participants to feeling that successfully managing a claim depended as much on who at the TCO helpline answered their calls as it did on their own actions.

5 CHAPTER 5: CONCLUSIONS

Affordability of childcare, while being a consideration, was not felt to be the main barrier for parents of disabled children in using childcare and returning to work. Instead, the key factor was the extent to which participants felt 'work ready' as well having the information, confidence and skills required to find suitable work and childcare. The following are the different attitudes, barriers and enablers to work and childcare experienced by the different research groups.

5.1 NOT INTERESTED GROUP

Attitudinal barriers to both work and childcare seemed to be the main reason for participants in the *Not Interested* group not taking up the offer. These participants tended to be furthest from the labour market, with a high proportion having little or no work experience and few skills or qualifications. This meant that a high number of these participants believed that work did not pay for families like them as they would not be able to secure anything other than a minimum wage job.

A significant number of the *Not Interested* group described being a parent and carer to their disabled child as their job. They believed that they were of more value at home, caring for their disabled and other non-disabled children, and tended to have negative perceptions about the quality, availability and affordability of childcare in their area and so did not seriously consider the offer of extra help with childcare costs. In fact, a high number of these participants reacted defensively to the offer letter and felt that by sending it, the government had shown that it did not value them as carers and did not understand the barriers they faced. Indeed, those who had attempted to balance work and childcare previously and failed because of their child's health or care needs tended to think that work and childcare was not feasible for families with disabled children.

5.2 INTERESTED GROUP

Participants in the *Interested* group generally had more positive attitudes towards work and childcare and instead, reported facing a number of practical barriers to taking up the offer. Despite feeling 'work ready', the difficulties to finding and securing suitable work and childcare were significant. Those who had low skills levels or lacked recent work experience tended to find the process of looking for work challenging either because they were unsure of how to go about looking for work or because they felt there were no suitable jobs available.

Indeed, even those who had high skills levels and strong work experience reported difficulties in finding work because of the number of factors they needed to consider when choosing what kind of employment to go into. The need for flexible working hours which would fit around childcare greatly narrowed employment options and furthermore, participants needed to find work close to home and have an employer who allowed them to leave work at short notice if their child was unwell or upset.

Alongside this, participants faced problems in finding suitable childcare. The level of attention, understanding and care which many disabled child needed meant that finding a provider who firstly, would be willing to take a disabled child, but secondly be capable of providing good quality care at the hours it was needed was difficult. A high proportion

of participants reported being turned away by local providers or not being able to find a local provider with the right skills training and attitude to care for their disabled child.

These challenges, along with existing commitments such as studying, or issues relating to the disabled child's health or treatment often meant that the timing was not right for taking up the offer. This led to criticisms that the offer had not been available for long enough for families with complex situations who face numerous barriers to seeking work and childcare.

5.3 TAKE-UP GROUP

For those in the *Take-up* group²⁵, a determination to work and a belief in non-financial benefits to working were important motivators to finding and sustaining employment. Being able to develop new skills and meet new people as well as taking some time away from the responsibilities of being a parent and carer and setting an example to their children were all believed to be positive outcomes of working.

Almost all *Take-up* participants had found employment which allowed them to work flexible hours which made balancing work and childcare easier. Those with fewer skills had made the most of their experience as a parent and carer by taking jobs in care work for which they felt qualified and valued. Furthermore, such roles could fit around their childcare responsibilities. Those with higher skills levels used their experiences and personal contacts to either become a self-employed professional or to take jobs with understanding employers such as charities.

Although *Take-up* participants had also experienced a number of barriers to finding suitable childcare, there did not seem to be an identifiable solution to overcoming these. Confidence in the quality care seemed to be based on both the level of skills and training the provider had, as well as the provider's general attitude towards both the parent and the child and a willingness to be flexible about hours of care.

Almost all participants reported paying more than the standard rate for childcare because of their child's needs but they were understanding about this and felt that access to good quality care was more important. Although the cost of care was not generally an issue for most, for others it was a significant one which resulted in them having to borrow from friends and family. Having a source of informal childcare was also helpful, although limited social networks meant that many had to rely on their children for this. Others, who used people in their community such as fellow church parishioners, were often asked to pay for this provision which put a greater burden on the household income.

Experiences of contact with both the DfE contractor helpline and the TCO helpline were generally positive amongst the *Take-up* group, and most participants said that they were satisfied with the service provided and felt that they understood what was expected of them. For the small number of participants who did experience problems, this was felt to be a result of the individual person that they dealt with perhaps having less of an understanding about their claim and the WTC system more generally.

²⁵ Please note that due to the limited sample available for the *Take-up* groups, the findings for these participants are based on a very small number of interviews compared to that of the *Take-up* groups in the 100% Costs and Actual Costs Pilot research.

Being able to balance work and childcare required both forward planning and flexibility of both work and childcare. Participants who had managed to sustain work and childcare tended to have a strong relationship with their childcare provider. This made them feel happier and more confident about using childcare as well as making balancing work and childcare easier. They also tended to be either self-employed or worked from home which meant that they could work flexibly as well as be available if and when their child needed them. However, those who had managed to sustain work reported that they found doing so either stressful or only managed because they had a network of informal care available.

Those who had been unable to sustain work and childcare tended to attribute this to either not being able to secure at least 16 hours a week needed to make a claim or because they found balancing the various demands on their time too stressful. This was a particular issue for those who were studying as well as working who found it too difficult to balance the different demands on their time and chose to remain in education and leave the Pilot in hope of gaining qualifications which would lead to a better future for their family.

6 APPENDICES

Please see separate appendices document

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