

# 2018 Off Balance

- Parents of disabled children and paid work



# Foreword

From Sarah Jackson OBE, Chief Executive, Working Families



We hear every day from parents of disabled children struggling to find, remain and progress in paid work. But the truth is that many service providers, and parts of wider society, don't think that these parents should be playing a part in the labour market at all. When we asked in our survey what would make a difference, one parent hit the nail on the head:



*"That services, schools and everyone else don't automatically assume that if you have a disabled child, you can stay at home with them all the time and always be available."*

For all the interest and support we have seen for UK working parents in recent years, it seems that some attitudes have barely shifted in decades. There are glaring commonalities in the stories that mothers and fathers across the country shared with us.

Childcare – the essential infrastructure for working parenthood – remains in limited supply for disabled children, with patchy provision and little support if arrangements break down. Specialised care often costs more, and these expenses are passed on to parents even though there is little reflection of this in the government support provided for help with costs.

While many parents told us about the positive experiences of flexibility they have had with their employer, it's clear that too often this comes down to a discretionary arrangement with their manager. So there's no guarantee that the arrangements that parents of disabled children rely on will outlast a change of personnel.

We've talked for decades about women facing a motherhood penalty. More recently, we've been alarmed to see the emergence of a nascent 'fatherhood penalty' in the UK, with men downgrading their careers and selling their skills short because they can't get the flexibility that they need. But it is parents of disabled children who are making the steepest trade-off of all: more than three out of four parents in our survey have turned down a promotion or accepted a demotion because of their caring responsibilities.

Rather than expecting parents of disabled children to stay at home, and expecting all working parents to make career compromises, we need to change the world of work to better accommodate people's lives. The Prime Minister has called on businesses to advertise all jobs as flexible from the outset, which would be an excellent start.

For too long, parents of disabled children have found themselves in a zero-sum game between working and caring. Action is long overdue.



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# Foreword

Liz Walker, HR Director, Unum



Working Families and Unum have been collaborating since 2011. In 2013, the two organisations published a report describing the advantages of creating trust in the workplace. I am immensely proud that Unum is supporting the publication of this extremely important report.

I am encouraged that employment and related social matters such as recruitment and retention of disabled and older workers, the problems faced by carers in the employment arena, mental health in the workplace, gender pay gap, women on boards, a more diverse workforce, upskilling and increased productivity, to name a few, continue to be at the forefront of political parties, business organisations, trade unions and indeed individual companies. Much progress has been made over the last 25 years or so but clearly more needs to be done.

As the report clearly indicates, parents of disabled children are still facing significant challenges in finding, retaining and indeed progressing in the job market. Regrettably, this is a constant theme that it is mentioned to me by charities and voluntary organisations that Unum has been working closely with as part of its extensive Corporate Social Responsibility programme. It is abundantly clear that keeping parents of disabled children in work is in everyone's interest – parents, children, employers and indeed the economy. Employers who support their employees to balance working and caring will have more engaged, productive and loyal employees.

However, this is not just an issue for employers. Clearly, there is a need for services to be more flexible such as scheduling appointments around working patterns and transport at the right hours and to wherever family needs the child to be. As we continue to see a growth in personalisation and choice in public services, we need to ensure that parents of disabled children are not left behind.

This report focuses on the practical measures that are needed to enable parents of disabled children to balance paid work with their caring responsibilities. It is of paramount importance that all families are given the same opportunities to find the right balance of time and money to thrive.



*“As we continue to see a growth in personalisation and choice in public services, we need to ensure that parents of disabled children are not left behind.”*

# Executive Summary

Any parent can suddenly find themselves the parent of a disabled child, and in many cases the nature and level of disability can emerge over time.

The journey is different for each family. What is common is that parents will need to make changes in their working lives to better balance the needs of their families.

But we heard from hundreds of parents who are met with an assumption that they will give up work simply because they have a disabled child. The voices of the parents in this report tell a different story. Many parents are trying to remain and progress within their jobs, in the face of a lack of support from the services that they rely on.

It doesn't have to be this way. A more flexible labour market, sufficient childcare, and more responsive public services would prevent these parents from being locked out of the labour market. And would give employers access to a richer talent pool.

Four in ten parents in our survey who are not currently in paid work have been out of employment for more than five years – with all the consequent implications for family finances and wellbeing. But more than nine out of ten want to work. These parents are highly limited in the number and pattern of hours they can work because affordable and suitable childcare remains in short supply. The majority of those parents who turned to JobCentre Plus for help with returning to work said there was little understanding of their situation.

The government is reviewing the extension of the Right to Request Flexible Working in 2019. Coupled with the Prime Minister's October 2017 call for all jobs to be advertised as flexible, this is an opportunity to revolutionise the UK labour market and make good quality, permanent flexible jobs the norm rather than the exception. Equality law should also be strengthened so that parents of disabled children are able to secure the flexible hours that they need.

Parents of disabled children who are currently in work are paying a heavy career price. More than four out of ten parents responding to our survey are working at a lower skill level than they were before they had their child. And three quarters of parents in our survey have refrained from seeking a promotion, declined a promotion or accepted a demotion because of their caring responsibilities. Even more worryingly, some mothers and fathers told us that they have lost their job because of 'having a child like yours'.

Disability is a lifelong condition. Parents need flexibility from their employer to deal with a new diagnosis or significant

change in their child's condition. The government has committed to introduce a new Carer's Leave during this parliament. This should include a new legal entitlement to a period of 'adjustment leave' for parents of disabled children, enabling them to put new care arrangements in place without losing their job. These parents also need a statutory right to paid time off to attend their child's medical appointments.

Those parents who have flexibility in their job value this highly as a key tool in balancing work and care. But survey respondents often indicated that this flexibility has come as a result of a particular manager rather than because of a truly embedded flexible workplace culture. This means parents are left worrying that arrangements they rely on might suddenly disappear or change and that they can't change job because they would lose the flexibility that they need.

Employers should use the *Happy to talk Flexible Working* strapline and logo to recruit for more flexible and 'human-sized' jobs – thinking through the roles they recruit for and what can realistically be done in the hours allocated to them. Employers should also use carer passports so that employees can have consistent support across their workplace.

Finding the right childcare is a systemic and ongoing barrier to parents of disabled children entering and staying in paid work. Eighty-six percent of the parents we surveyed said it is difficult or impossible to find suitable childcare, 82% say it is difficult or impossible to find suitable provision that is affordable and 81% said finding childcare in the hours they need it is difficult or impossible. Grandparental care is the most frequently used informal childcare, its growth partially fuelled by rising costs of formal care. Nearly half the working parents we surveyed rely on grandparents to meet their childcare needs, and nearly a third use other family members. For these families, where cost and availability are even more acute issues, their importance is perhaps even higher. But it means they cannot access the help with costs which is only available to those using registered childcare; and have limited options when childcare arrangements break down.

Parents told us that professionals and services who are meant to support and help families often expect that a parent will be at home all the time. Almost six out of ten parents had

to take up to ten days off work in the past year to take their disabled child to a medical or therapy appointment, and four out of ten used their annual leave to cover appointments. Some parents have providers who join up appointments or hold them at schools, but this is patchy. School transport is often inflexible and with limited hours, especially for children who are beyond compulsory school age, meaning that parents have to change or leave their jobs.

Public services that support disabled children and their families should take better account of the working pattern of parents. Medical appointments should be scheduled in consultation with parents and at times that minimise time away from work. Local authorities must ensure there is sufficient childcare for disabled children in their area and ensure that their school transport provision accommodates the needs of working parents.

This report focuses on the practical measures that are needed to enable parents of disabled children to balance paid work with their caring responsibilities. But the hundreds of mothers and fathers that we heard from have thrown down a wider challenge – we need to combat and change the idea that these parents shouldn't be in paid work, or should accept limits to their career progression, simply because they have a disabled child. All families should be able to find the right balance of time and money to thrive.



# Introduction

Combining work and family life is a complex juggling act for all parents. But for parents of disabled children, the challenges are greater still.

Working Families surveyed 1250 parents of disabled children during autumn 2017 and held a focus group to explore some issues in greater detail. The majority of survey respondents and all the focus group participants were women. Our findings show that little has improved for these parents since our previous reports in 2015 and 2012. Parents - particularly mothers - of disabled children are still less likely to be in paid work than other parents, and many are working below their skills level. Our findings reveal a situation where parents of disabled children have not benefited from many of the flexible working changes that have helped other working parents in recent years – because they cannot find suitable affordable childcare, because medical appointments are scheduled at times that require taking time off work and because jobs simply aren't flexible enough to accommodate these parents' needs.

Eight percent of children in the UK are disabled<sup>1</sup>. Figures from the 2011 census show that 47% of mothers of disabled children are in paid employment<sup>2</sup>, compared with 64% of other mothers, illustrating the employment penalty that mothers of disabled children are paying because of their caring responsibilities. Data from 2017 suggests that the employment rate of all mothers is now at 73.7%<sup>3</sup>, but the Office for National Statistics (ONS) has not been able to provide a breakdown of the figures for mothers of disabled children.

The employment gap for fathers of disabled children is smaller according to the census, with 72% of fathers of disabled children in paid employment compared with 74% of other fathers. This suggests that gendered ideas about work and care are prevailing, with all of the associated costs for women of lower lifetime earnings. But as our comprehensive survey of work and family life shows<sup>4</sup>, fathers very often also pay a penalty within the workplace, stalling their careers and limiting their earning potential. Fathers with additional caring responsibilities for a disabled

child may be more affected by this than other fathers.

Our survey tells a story of families with disabled children who are missing out on the benefits that being in paid work can bring. That's bad for family incomes, damaging to parents' wellbeing, and bad for the economy which is missing out on the skills these parents possess. And it's bad for children – 40% of disabled children in the UK live in poverty<sup>5</sup>. Poorer children have worse educational outcomes and lower levels of wellbeing, and limits to opportunities which impact on their overall life chances<sup>6</sup>. Yet our research shows that relatively small changes to workplace practices and to the way that services are delivered to families of disabled children would enable many more parents to stay in good quality jobs.

The challenges that parents of disabled children face when trying to get into or stay in paid work aren't new – they have been well documented for at least the last 20 years<sup>7</sup>. Despite government initiatives during that time to improve support for working parents, those with disabled children have not felt the benefits. The government needs to act so that these parents, who already face sizeable challenges in raising a disabled child, get the support and flexibility they need to enable them to hold down a job that values their skills, and contributes to their financial and emotional wellbeing.

As the UK moves to leave the EU and politicians across all political parties consider how the UK's labour market should operate in future, it is vital that they finally develop specific policies to address the challenges that parents of disabled children face when trying to get into or stay in paid work.

<sup>1</sup> ONS, Family Resources Survey, 2016-17

<sup>2</sup> Contact, Caring More Than Most, 2017

<sup>3</sup> Families and the Labour Market, England, 2017

<sup>4</sup> Working Families, *Modern Families Index*, 2018

<sup>5</sup> Disability Rights UK, June 2013, 'Risk of major disability poverty rise'; also, Children's Society, 4 in Every 10, October 2011

<sup>6</sup> Child Poverty Action Group, Improving children's life chances, 2016

<sup>7</sup> Kagan C, Lewis S, Heaton P, Cranshaw M, (1999), Enabled or Disabled? Working Parents of Disabled Children and the Provision of Childcare, *Journal of Community and Applied Social Psychology* 9: 369-381 (research from 1998)



“

“It’s not through choice that we were put in this situation [having a disabled child]. We try our best every day to do what we can and provide for our families and have as normal a life as possible. [We just want] employers to see that, that you are trying your best. We are entitled to work, and we are entitled to have a life.”

(Focus group participant)

# 1

## Getting into work

Any parent can suddenly find themselves the parent of a disabled child. Disability is not necessarily acquired or obvious at birth and can develop at any age.

There isn't always a single moment of diagnosis – in many cases the nature and level of disability can emerge over time and the underlying cause is never known. The journey is different for each family and needs to be handled sensitively and appropriately in each case. But what is common is that families often feel knocked off balance and find themselves learning a whole new language of medication, treatment and care, and entering a world that feels totally unfamiliar and daunting.

Figures from the 2011 census show many parents of disabled children are not in paid work. Of those in our survey who were not in paid work, 40% have been out of paid work for more than five years. Ninety-three percent of our respondents who were not in paid work said they wanted to work.

### The need for flexibility

We asked these parents to rate the extent to which different factors are a barrier to returning to work. The results were stark. More than nine in ten (91%) said that finding a job with the right *pattern* of hours was a significant barrier to returning to work, with 82% citing the problem of finding a job with the right *number* of hours. Parents and carers can only progress in work if there are decent quality, permanent part-time and flexible jobs to progress into. However, fewer than 10% of jobs offering more than a £20,000 (full-time equivalent) salary are advertised with the types of flexible working options parents need<sup>8</sup>.

Employees only have the right to request flexible working after they have worked for an employer for 26 weeks. This is a major barrier to parents of disabled children getting back into the workplace as they need flexibility from the outset.



*"Finding a part-time job at the level that you want is really quite challenging. I went for an interview for a job which I knew I could do and I said, "well how about this as a job share?" They wouldn't even entertain the idea, they said this was a one-person full-time job." (Focus group participant)*

*"I am part of a job share and it's hard to find new roles that will accept this arrangement."*

### The childcare gap for disabled children

Childcare is a major issue and hugely impacts on the hours and working pattern that parents can work. Eighty-six percent of the parents who were out of work said that finding suitable childcare was a significant barrier to returning to work while 77% raised the affordability of that childcare.



*"There is a complete lack of after school clubs for additional needs children."*

*"Childcare for children with challenging behaviour would cost me £18 per hour."*

Linked to having care that works and flexible working practices, 80% of parents who were out of work said that needing to collect their child from school or another setting at short notice for medical reasons was a significant barrier to returning to work. Many gave examples of schools or care settings simply not coping with a child's complex needs (whether these are medical and/or behavioural):



*"I am the de facto safety net. I cover everyone's back and fill in all the failings. Schools assume I am available throughout the day for every minor hiccup."*

Parents highlighted how, when a child is disabled, he or she cannot always easily be collected from school by a friend or family member if other arrangements break down. The friend who might willingly offer to collect a 'typical' primary school age child might not be able to do that where special car seats and/or wheelchair access to the home are required.



*"With my other children, when I used to work before, friends used to help you out [if existing arrangements broke down], but that doesn't work when you have a child with special needs."*

*(Focus group participant)*



93%

of parents not in paid work said they want to work

## Support for finding a job isn't working

Only 15% of parents who returned to work with a new employer sought any help with managing the return, mostly turning to JobCentre Plus. Seventy-one percent of them said the support they received was unhelpful, with an apparent lack of understanding of their situation.



*"They don't have the resources to overcome the barriers I have in my way."*

*"They told me I would be worse off financially. And not to bother going back into work."*

*"They think I can work all day every day and leave my child to get on with it."*

Nearly eight in ten (79%) of the parents we surveyed who were out of work said that the frequency and timing of medical appointments for their child is a barrier to returning, with 71% saying the same about therapy appointments related to their child and 67% saying that school appointments are a barrier to returning to work.

This is symptomatic of a wider problem of public services that are not geared up to supporting parents of disabled children who work. Whether that is hospital and school appointments being scheduled at times when parents need to take time off work, equipment deliveries during the working day, or professionals whose job it is to support families assuming that one parent will stay at home (and in some cases actively dissuading parents from going back to work), parents feel they face an uphill battle to juggle the demands they face.

## What would help?

Most of the parents we surveyed who are looking for a job need one that is in school hours (70%) or term time only (56%), while 57% are looking for work that they can do from home. This is because they cannot find childcare that can meet their child's needs before and after the school day and during school holidays. And inadequate childcare leaves many parents feeling that they need to be on hand to cope with any emergencies.



*"Childcare is impossible to find. Our direct payments budget doesn't make it worthwhile for somebody to have (my child's) caring role as their main/sole employment."*

We need to move to a situation where good quality, permanent jobs routinely offer part-time and flexible working as the norm and where parents of disabled children can find good quality, affordable care that meets their child's needs. Only with this combination will these parents have the best chance of being able to get back into paid work with all the benefits that brings.

## Recommendations:

- The government is reviewing the extension of the Right to Request Flexible Working in 2019. Coupled with the Prime Minister's call for all jobs to be advertised as flexible, this is an opportunity to revolutionise the UK labour market and make flexible jobs the norm rather than the exception.
- Equality legislation should be amended, so that not only disabled people but their parents and carers have access to flexible hours as a 'reasonable adjustment' from day one in a new job, reflecting the additional challenges that these parents face, and that flexibility is essential to enabling them to remain in work. Alternatively, the law on discrimination should be extended to allow parents of disabled children to challenge inflexible hours as indirect discrimination against them, because of their association with a disabled person.
- All projects funded by the £1.5m Government Equalities Office Returners Fund should include provision for supporting parents of disabled children back into work, recognising and tackling the barriers that our research has identified.
- The ONS should routinely collect data on the employment rate of parents (including the breakdown by mother and father) of disabled children. This should be reported on by government so that the employment penalty faced by mothers and fathers of disabled children can be monitored.
- The information and signposting available to carers who visit JobCentres seeking support in finding employment should be reviewed and improved. This is something the government recently committed to in its Carers Action Plan<sup>9</sup>.

<sup>9</sup> Carers Action Plan 2018-2020, Department of Health & Social Care, 2018

# 2

## Staying in Paid Work

Fifty-three percent of the parents we surveyed who are in paid work returned to work with the same employer after having their disabled child.

In terms of ongoing caring commitments, most (57%) have subsequently taken fewer than three months off at any one time to care for their disabled child.

### A bumper 'parenthood penalty'

Our 2018 *Modern Families Index* uncovered evidence of a 'parenthood penalty' – that parents are increasingly unable to fulfil their economic potential and progress in the labour market, simply because they have become parents. This penalty is even greater for parents of disabled children. Where the *Index* found that 11% of parents (mothers and fathers) have refused a new job and one in ten have refused a promotion for family reasons, 76% of parents of disabled children in our survey (the majority of respondents were women) have refrained from seeking a promotion, declined a promotion or accepted a demotion because of their caring responsibilities. Nearly two-thirds (65%) have looked for or found a different job because of their caring responsibilities.



*"My husband and I both left well-paid jobs to find jobs that fit around our disabled child (more than half our previous wages)."*

*"I am part-time but paid professional rates for the hours I do. My husband also works part-time to cover the days I work. I work far less than I otherwise would which has financial implications and implications for my career progression."*

Employers and the wider economy are missing out on the skills and experience that parents of disabled children bring. Nearly half (45%) of the working parents of disabled children that we surveyed are working in a job that is below the skill level of the job they held before they had their child.



*"Work are very understanding and allow unpaid leave and, where possible, flexible hours, but I am a senior medical scientist with a postgraduate qualification working nine hours a week as a lunchtime assistant in a nursery. What a waste of education and experience."*

*"I enjoy working but the pay difference between what I do now and what I used to do is approximately £23,000pa. My husband has also had to change his job to fit in with school hours and his income has dropped by £9,000. We are just scraping by on minimum wage. I have, in fact, just taken a second paid, but very part-time (250 hours a year), job. The jobs we do now are way below our skill levels. Without appropriate childcare and decent pay for the work we do, life is a struggle."*

And we have heard stories of parents who say they have lost their job because of having a child with a disability, which could be considered discriminatory in law.



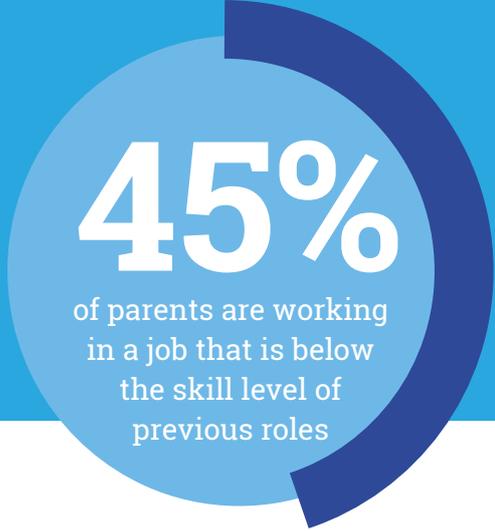
*"I was let go from a job due to 'having a child like yours'."*

*"One job gave me the opportunity to leave before they sacked me for being unavailable as my son who was 13 at the time was going to have open heart surgery and I would be off for more than a fortnight."*

*"I had to take some time off because [my son] was in hospital. My line manager phoned and said, 'well, how long are you going to be off for?' And I said, 'well, I really don't know' and that's when it was put to me that now there are voluntary redundancies coming up and now's the time to be looking at that because this really isn't working for us anymore. And it was such a kick in the teeth. I had worked with all my other children and I had given blood and sweat and tears to the job. And I was standing outside the hospital and I said, 'well, get the ball rolling then'. That was devastating, and I just thought 'well, that's it, that's all I'm worth'. Even though I'm in a job now that's lovely, it's not very mentally challenging, it doesn't give me the job satisfaction, I'm not stretched." (Focus group participant)*

### The need for flexibility

Half of the parents in work (49.5%) said they would like to move to a different working pattern. In common with those parents who are currently out of work, they are predominantly looking to work in school hours (35%), term



# 45%

of parents are working  
in a job that is below  
the skill level of  
previous roles

time only (33%) or to work fewer than five days a week (27%). This is because of the difficulties parents have in finding suitable childcare or care for their disabled child outside of school hours:



*"(childcare during school holidays and wraparound care before and after school [is the problem]. I simply don't have anyone else to look after my son."*

*"My daughter goes to a day care centre, but they don't open until 9.30am and she has to be collected by 3.30pm so I have to work day, evening, weekend and night shifts, as does my husband to ensure someone is with her at all times."*

Two-thirds have already tried to change their working pattern because of their caring responsibilities and two-thirds of those (65%) have succeeded in reaching an agreement with their employer. But parents worry about the impact that a change of working arrangement might have on their career:



*"Reducing my hours, which is what I'd like to do, would place my role at risk. I'd have to downgrade my responsibilities."*

And some have taken a step down, meaning they are working below their skills and earnings potential:



*"I now work for a family-run business and have taken a step down in some respects to get the flexibility I require."*

*"I had to step down from a previous management job because the company said I could not give 100% to the job."*

Parents talked of the need for employers to recognise that caring for a disabled child requires a long-term adjustment in working patterns (or possibly a series of long-term adjustments), not a short-term fix:



*"This isn't 'let's go back to work after maternity leave' or your child's not well, this is a long-term thing, it's not going to change. To begin with they are quite obliging, but after six, seven months it was, 'well, this isn't really working for us'."* (Focus group participant)

*"The job I have now is better. My hours are flexible and I am home-based, so I can work things around my son but before it was really difficult. Their attitude towards me having time off was that I was skiving. I was once told I couldn't go to the hospital while my son had an operation because they didn't want me to take the time off when I was legally entitled to Parental Leave."*

## The Carers Allowance cliff-edge

The earnings limit of £120 per week for those in receipt of Carer's Allowance is not tapered, meaning that anyone earning over this amount will lose all of the Allowance and other related benefits. This is a real barrier to parents in low-paid jobs increasing their hours at work:



*"I would lose my Carers Allowance if I increase my hours, but would not be better off because I wouldn't earn enough if I only increase by a couple of hours and my hourly rate is pretty low. I have a large mortgage on my adapted house and am trying to work, care and pay all my bills."*

*"I could do a few more hours or have a higher-paid job but I would be worse off financially because I'd lose my Carer's Allowance."*

Overall, parents said the biggest challenges to remaining in paid work are:

- Finding a job with the right working pattern (81%) and number of hours (77%)
- Finding suitable (81%) and affordable (72%) childcare
- The frequency and timing of medical (70%) and other (65%) appointments for their child
- Needing to be able to collect their child at short notice for medical reasons (68%).

# 2

## Staying in Paid Work

*Continued...*

These figures almost mirror those of the barriers to returning to work identified in the previous section. This means that action to tackle these problems can help parents of disabled children to both get into and stay in paid work.

### Recommendations

- Parents of children with disabilities or long-term health conditions should have a statutory right to paid time off to attend their child's medical appointments.
- For many parents, the lack of flexibility from their employer to deal with a new diagnosis or significant change in their child's condition can lead them to leave the labour market altogether, often for an extended period of time. The government has committed to introduce a system of statutory Carer's Leave. This should include a new legal entitlement to a period of paid 'adjustment leave' for parents of disabled children, enabling them to absorb the news and put care arrangements in place without losing their job.
- The government has recently committed to ensuring benefits like Carer's Allowance support employment<sup>10</sup>. Carer's Allowance should be reformed to remove the perverse incentives that keep carers working fewer hours than they would like or are able to, or at a lower wage.
- Parents of disabled children are allowed to take unpaid parental leave in days rather than weeks, yet are still required to give 21 days' notice. The notice period should be reduced to a more proportionate period.





“

Reducing my hours, which is what I'd like to do, would place my role at risk. I'd have to downgrade my responsibilities.”

# 3

# Overcoming the Barriers

How employers can make a difference

Many of the employers that we work with have long embraced the business case for flexible working: those employers who go with the grain of their employees' lives reap rewards in terms of more loyal, motivated and productive staff<sup>11</sup>. It is clear from our survey that flexibility is highly prized by parents of disabled children.

“Allowing me to work from home and to have flexible hours has meant that I can work. We need more jobs like this.”

“My employer has been fantastic allowing me to work flexibly full-time over four days and allowing me to work when it's convenient for me during those days.”

“My employer is very considerate and understanding, and has given me a lot of flexibility to balance my work and childcare arrangements. This boosts my morale and I feel more productive when I have the trust of my employer. I have seen an increase in the quality of work I do, all because of the fact that I have the flexibility. It's a two-way street.”

## Case study: Highlands and Islands Enterprise

Highlands and Islands Enterprise have a wide-ranging carers policy, which makes provision for a range of flexible working arrangements, as well as paid special leave to deal with different types of caring-related demands that parents of disabled children may have. They also have a 'carer passport' initiative so that line managers know about, and are able to better support, the carers in their teams, and carers do not need to explain their situation more than once. Support for carers is included in the induction process for new staff.

Highlands and Islands Enterprise work with a local voluntary organisation to establish peer networks for employees who are carers and bring line managers of carers together. Employees are able to take one day's paid leave a year to undertake research into, and to access, support resources for carers.

Being recognised as a winner of the Working Families' Best for Carers and Eldercare award has helped the organisation to positively promote themselves as a flexible and caring employer when recruiting.

## Case study: Centrica

Centrica has a network of over 1000 carers, run by carers, for carers. It operates a carers policy, outlining the various leave options employees with caring responsibilities can use. Centrica offers matched leave, by which employees that use annual leave for caring responsibilities are matched half that annual leave with care leave. For example if an employee needs five days off for caring responsibilities, they can take just 2.5 days of their annual leave entitlement and Centrica will match the remaining 2.5 days with care leave. This is available for up to a month's time off.

The company operates a flexible working policy, allowing employees to work from home and/or adjust their shifts, helping all employees and of benefit to those with caring responsibilities at home.

The network, in combination with the policies available (which are regularly updated), means that carers are supported in the workplace and have a good level of job security in place.

Flexible working plays a critical role in helping parents to work around their child's medical and education appointments:

“My employer is very flexible about me moving my hours around to manage my son's medical appointments and care.”

“(What works?) Being able to work flexibly so I can work at home for part of the day when I need to take my son to an appointment.”

“Very recently, I have made my employer aware of our difficulties as a family. I have been given paid leave to attend appointments.”

It also helps parents to cope with the unexpected:

“My husband's employer allows him a flexible working pattern to allow him to be at home when school transport drops our son off. I am the main breadwinner and I have an incredibly supportive

<sup>11</sup> Family Friendly Working Scotland Time to Rebalance: the results paper, 2016

employer who allows a compressed working pattern, agile working (from home) and have allowed me two long periods off (nine weeks and five weeks) with pay when my son was extremely ill. Without this support one of us would have had to give up work.”

Flexible working helps parents to work around the school day and around childcare availability:

“I returned to work last year after 13 years as a carer. I am extremely fortunate to work for a local charity who are incredibly supportive. My role is completely separate to anyone else’s so other than when I’m running a training course and absolutely have to be there, I have a huge amount of flexibility in my working hours. I work 21 hours over four days which enables me to do the school runs, and also my day off is flexible and I can change it according to my needs. I also work from home quite often, especially if I am doing extra hours. I am also disabled and my employers are really great at supporting my needs. I appreciate that I am extremely lucky to have a fairly well-paid job with a high level of support and flexibility which enables me to stay in work.”

“I told my employer I had to reduce my hours for at least a year to cover school runs and commute. They said ‘fine’ and promised to find me work within the organisation. In the event, my manager redistributed some of my work to enable me to stay in my current position.”

But survey respondents indicated that in some workplaces, this flexibility has come as a result of a particular manager rather than because of a truly embedded flexible culture. Our research with leading flexible employers found that even in forward-thinking workplaces, half view work life balance as an individual issue that needs to be worked around rather than something that can be addressed through organisational culture<sup>10</sup>.

“I am so lucky. I have a wonderful manager that has given me a term-time contract. There are no services for holiday or childcare clubs that my child can access in the school holidays.”

“My line manager has been very understanding and flexible, but I know this isn’t the organisation’s approach - just his.”

“Quite often I’ve had a manager who really gets it and then they move on. Then you get a new manager and you start all over again. Some organisations have disability passports so you don’t have to constantly keep repeating yourself. Perhaps they could have something like that in place for carers?” (Focus group participant)

Our work with leading employers also showed that whilst 96% of them provide adjustment leave or a one-off period of flexible working, 47% leave the decision on whether to allow the leave to line managers and don’t specify it in their employee policies. This means that employees working for the same organisation can have different experiences of, and access to, leave or flexibility depending on their line manager’s attitude. Access to leave and flexibility should be a matter of organisational policy rather than line manager discretion<sup>12</sup>.

“Previous manager was very focused on if the job was done, then I was doing what I should and she was happy. Current manager analyses every hour of my time to see if I am doing my hours, regardless of if I have over-achieved in the reporting period.”

“Although not officially sanctioned by my employer, my line management (who both have children with additional needs) support me taking a few hours off during the day for appointments and making the time up. Saves the stress and I don’t lose out financially.”

As a consequence, although parents are very appreciative of flexible arrangements, they worry that employers can change them at short notice. The reliance on individual line managers to support flexible working means parents of disabled children are left wondering if arrangements they rely on might suddenly disappear or change and that they might be seen as receiving ‘favours’.

<sup>12</sup> Working Families Top Employers for Working Families Benchmark Report, 2017

# 3

## Overcoming the Barriers

How employers can make a difference *continued...*

“I feel I am ‘getting away’ with things currently and that I am not pulling my weight at work. It would be helpful to have my caring responsibilities recognised and leave could be more official then. At the moment it’s hidden. I was offered a place on a course to help understand my child’s condition and how to deal with it, but it was half a day a week for six weeks and I didn’t even ask if it would be ok. I turned down the place.”

Rather than viewing flexibility as a concession to parents, employers should be considering this as simply a good way to do business. If parents make a formal request for flexible working using the right to request flexible working procedure, then they are better protected from short-notice changes to their working pattern than if relying on informal agreements.

“My employer has been incredibly supportive. They have allowed me to reduce my hours from full-time to part-time on the days that suit me. I work 16 hours a week and this is over three days a week during term time and over two days during school holidays. I am able to make up time off for appointments etc. The only issue is that my part-time arrangements have only been agreed on a temporary basis of six months so I can only hope that I will be able to continue after that point. I have no idea what I will do if I can’t.”

“(What would help?) Not having to reapply for flexibly working every 12 months and for my employer to give me my current hours on a permanent basis.”

Some parents felt that entrenched attitudes about what it means to parent a disabled child persist in keeping mothers in particular away from the labour market. Others highlighted how a good practice policy is meaningless if it isn’t available and publicised to staff in practice:

“Some employers think it’s the mother’s duty to take time off. I have time off when [my son] is ill because my husband’s employers are not understanding.” (Focus group participant)

“Where I work, they do have this period of leave for parents of disabled children, but it’s discretionary. They don’t tell anyone about it and it’s well hidden on their intranet. As parents, we set up a group and asked HR to come along and they said ‘well, we do have this policy but it’s at our discretion and we don’t want to talk about it’.” (Focus group participant)

### What would help?

The examples we have of good practice show that working arrangements can be put in place that enable parents of disabled children to work in good quality jobs. But while flexible working provision remains patchy and reliant on individual line managers, parents can get stuck in limited flexible roles, with potential long-term consequences for earnings and job satisfaction.

A more systematic approach to recruiting all jobs flexibly could make a real difference to all working parents<sup>13</sup>. Crucially, this approach prompts hiring managers to firstly think through the best way of getting the job done - to meet the needs of the business in terms of hours required, location and timing of the work, and form of contract – and the flexibility that is appropriate for the role. And secondly, to design the job in a way that matches the hours attached to it. And finally, thinking through flexibility in this way means that when an employee requests a change to their working pattern, it’s easier to assess the practicality of the proposed change.

And it can be done:

“I have flexible hours so that I can adjust my start time if we’ve had a bad night/morning. There is an inclusive culture enabling constructive conversations about how to manage home and work. I have a carer ‘passport’ where my current arrangements are communicated to my next manager who then tries to accommodate those needs, and an understanding team able to step in or deputise for me when I have to be away (and this relationship is reciprocal).”

<sup>13</sup> Working Families, *Modern Families Index*, 2018

To be successful, employers need to train their managers to manage flexible teams, and to focus on the best way of getting the job done rather than outmoded ideas about presenteeism.

“[What would help?] Better awareness among employers that not all jobs require someone to be available full-time to be able to do the job well. Not just on a policy and procedure level, where flexible working is available in theory but doesn’t happen in reality – but for line managers and colleagues to REALLY understand that people with caring commitments want to work but just need their caring commitments to be acknowledged and accepted.”

“Even if you have all these fantastic policies, it does come down to the understanding and somehow being able to educate your managers or employers about it.” (Focus group participant)

“My son had an operation and I said I needed to be out, but because it was a key period for a project I was working on, they kept calling me on the day of the operation. They were calling me about random things and I had to leave my son and go into the office and explain to them and then go back to my son. The state I was left in was beyond horrific. To think that grown adults can’t read a piece of paper. I left notes of everything that was going on.” (Focus group participant)

## Recommendations

- As accepted by the government following Matthew Taylor’s 2017 review of modern employment practices, employers should use Working Families’ *Happy to Talk Flexible Working* strapline and logo to recruit for more flexible and ‘human-sized’ jobs – thinking through the roles they recruit for and what can realistically be done in the hours allocated to them. Our evidence from employers confirms that applying flexibility on a vacancy-by-vacancy basis, specifying what is on offer, is more effective in recruiting candidates than general or blanket statements about being a flexible employer.
- Employers should use carer passports<sup>14</sup> within their workplaces to maintain consistency when line management changes or people with caring responsibilities move team and train their managers to manage flexible workers.

<sup>14</sup> [www.carerpassport.uk/employment](http://www.carerpassport.uk/employment)

“Allowing me to work from home and to have flexible hours has meant that I can work. We need more jobs like this.”



# 4

# Overcoming the Barriers

Quality, affordable childcare that meets the needs of disabled children

Finding the right childcare for a disabled child consistently emerges as a huge challenge for parents who work or wish to work. Eighty-six percent of the parents we surveyed said it is difficult or impossible to find suitable childcare. Even if it can be found, 82% say it is difficult or impossible to find suitable provision that is affordable. Eighty-one percent said finding childcare in the hours they need it is difficult or impossible. This represents a huge, systemic barrier to parents of disabled children entering and staying in paid work, and it is a barrier that often remains as the child gets older if their needs mean they are unable to be left alone for any period of time.



*"I have no issue paying for childcare fees, but paying a one-to-one wage on top of the fees means working is utterly unaffordable. It's a poverty trap."*

*"I have no help. The special school doesn't provide a breakfast or afterschool club. They expect at least one parent not to work. It's impossible to work around this and I am facing the prospect of having to resign from my job in September when my son starts at this school. I cannot find a childminder or alternative childcare to enable me to work."*

*"My daughter is at an age where she doesn't want a parent with her. She wants to be independent, but we need her to be safe. Direct payments allow her to be more independent, but we have found carers have frequent changeover – we've had four in the past four years and they can be unreliable."*

This problem is not new. Nearly 20 years ago, research reported that



*"It may be particularly problematic for working parents of disabled children to secure adequate and appropriate childcare. The need for specialist childcare continues for longer where children have impairments and the need for care can be more*

*unpredictable. (...) Where formal childcare was available, appropriate, flexible and accommodating to the needs of both the parents and the disabled child, the parents reported being able to combine working and caring roles successfully<sup>15</sup>."*

And a report of the Disabled Children's Access to Childcare (DCATCH) pilots that were held from 2008 to 2011 to test ways of reducing barriers to accessing suitable childcare for disabled children across ten local authorities found that:



*"Families described an individualised and tailored approach with [childcare] arrangements that suited working hours which could be either very specific or variable. (...) The impact on the capacity to work was the most frequently cited impact of DCATCH support with childcare mentioned by all 20 parents who were working. Of these, eight said that the childcare made the difference between working and not working at all. Most people in this situation said that they had negotiated as much leeway with employers as they could and found it hard to imagine that they would be able to find alternative jobs if the childcare ceased. (...) We were also told of examples where childcare encouraged some parents to increase working hours or apply for more senior roles with greater responsibilities (and pay).*

*"Families reported that interventions and support which cost relatively small amounts of money made a big difference – two hours a week of PA [personal assistant] time or an allowance of £200 a year to buy support for after-school activities for example. (...) Having recourse to ring-fenced and dedicated funding fostered a very 'can do' and solution-focused way of working in pilot areas."*

Local authorities are legally obliged to provide sufficient childcare for disabled children up to the age of 18 and to provide information about local services for disabled children in a Local Offer. But research has found that only 22% of local authorities have sufficient childcare for disabled children in the whole of their area<sup>16</sup>. Only one in five local authority Local Offers explain the duty on childcare providers to make 'reasonable adjustments' for children with disabilities under the Equalities Act 2010, and only half of local authorities provide

<sup>15</sup> Kagan C, Lewis S, Heaton P, Cranshaw M, (1999), Enabled or Disabled? Working Parents of Disabled Children and the Provision of Childcare, Journal of Community and Applied Social Psychology 9: 369-381

<sup>16</sup> Family and Childcare Trust, Childcare Survey, 2018

# 86%

of parents said it is difficult or impossible to find suitable childcare

information about additional inclusion support to help parents of disabled children to access childcare<sup>17</sup>. Local authorities have a statutory duty to maintain a Family Information Service that can help parents arrange childcare, but just 31% of local authorities provide details of the Family Information Service (or another brokerage service for childcare) in their Local Offer<sup>18</sup>.

Perhaps unsurprisingly then, nearly half the parents we surveyed (45%) who are in work rely on grandparents to meet their childcare needs, while nearly a third (30%) use other family members. This means they will be less likely to be able to make use of government schemes to help with the costs of childcare, which are usually only available to those using registered childcare providers.

With disabled children often needing childcare until they are older than other children, a reliance on grandparents is likely to be unsustainable as grandparents get older themselves. And as Grandparents Plus have noted, policy trends to encourage grandparents to stay in paid work until they are older mean they will be less available to help with childcare than previous generations of grandparents might have been<sup>19</sup>.

This leaves parents often struggling to cover between them school holidays, appointments and days when usual arrangements break down:

“(If I could change one thing) I would like to be able to easily access high quality, affordable childcare, just like everyone else. We have never accessed childcare since our child started school – we just do it between us as parents and have cut both our working hours and use all our annual leave (and additional unpaid leave). The quality of support is generally very poor for children with disabilities and to access the very limited ‘supported’ childcare is very difficult, involving highly intrusive and stressful assessment procedures that require families to have to fight and show themselves to be ‘failing families’ in order to access very limited amounts of childcare.”

“I went through about 20-25 nurseries. As soon as I said my child has additional needs, you should have seen their faces change. They were instantly looking to march you out of the door.”  
(Focus group participant)

Parents also told us very clearly that they need help with finding childcare quickly when usual arrangements break down. Having trusted individuals they can turn to when this happens can make a real difference to being able to stay in paid work.



“(What would help?) Having some reliable emergency childcare around so that I have more resilience – if I get delayed at work / trains fail etc. then I am totally reliant on my parents to step in. If they aren’t available to step in, then I am unable to work away from home that day.”

“(What would help?) Having one or two trusted carers who could be available at short notice to cover child illness and unexpected emergencies.”

The lack of availability of holiday clubs for children with disabilities was highlighted by many respondents. Clubs either aren’t available at all or are of poor quality that means parents do not have the confidence to leave their children there:



“A mainstream child can go to any holiday club, costing say £18 a day. There was a holiday club in [London borough] for severely disabled children, now they don’t have funding so are closing it down. They said ‘we can provide it, but it will cost you £25 an hour’. This is in [London borough], a poor borough. It’s just ridiculous. Parents are now having to give up work or get their kids into residential holiday care.” (Focus group participant)

“Holiday clubs are often run by well-meaning teenagers who just don’t have the experience. I don’t feel comfortable enough that they would be able to reassure me and calm [my son] enough for him to maybe enjoy himself. So what is provided is by people who don’t have enough training or experience.” (Focus group participant)

<sup>17</sup> Family and Childcare Trust, Childcare for all: the role of the Local Offer, 2017

<sup>18</sup> Ibid

<sup>19</sup> Grandparents Plus, Doing it all, 2011

# 4

# Overcoming the Barriers

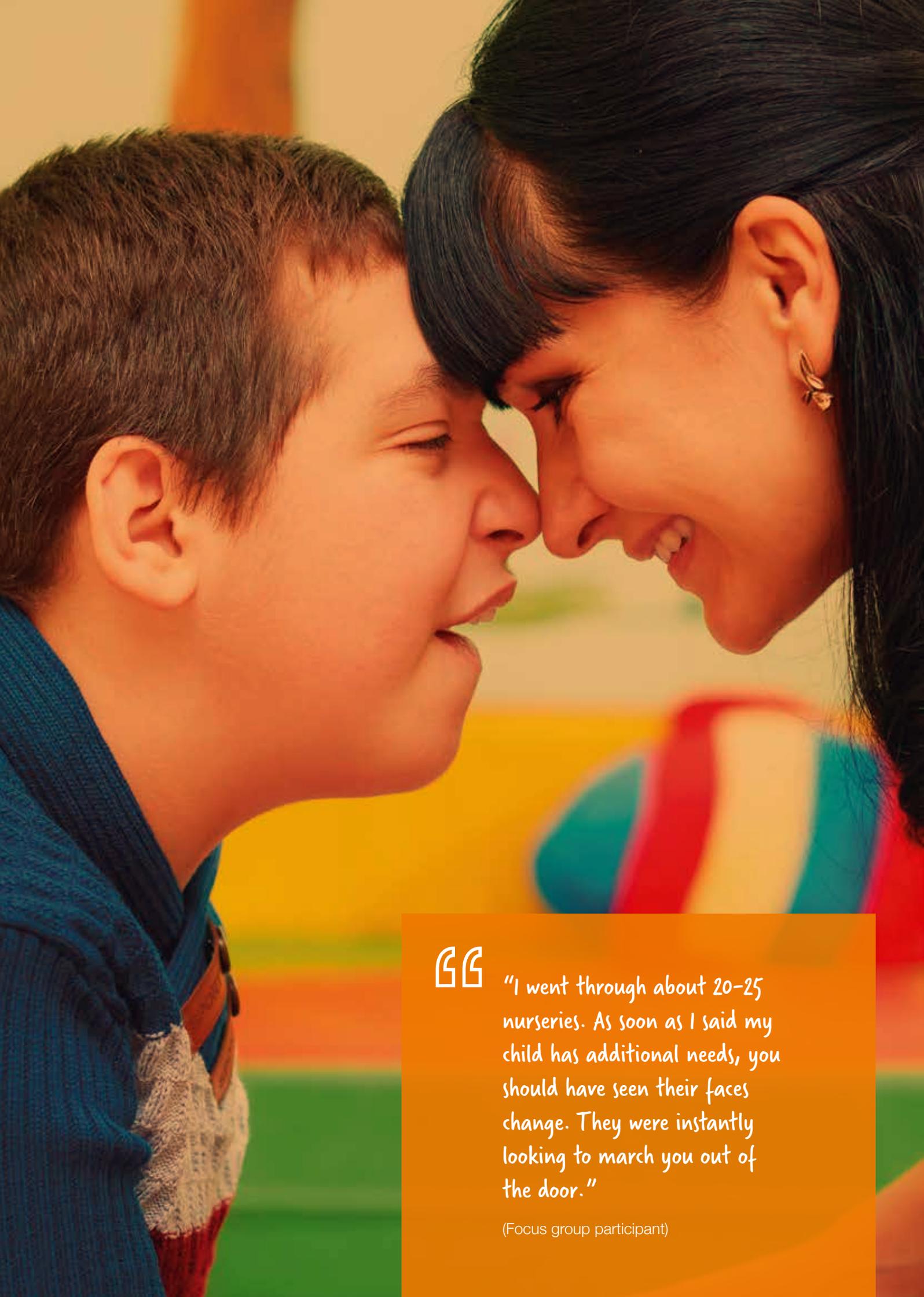
Quality, affordable childcare that meets the needs of disabled children *continued...*

## What would help

Parents of disabled children desperately need more help with accessing good quality, reliable and affordable childcare that fits around their working hours and meets their child's needs. As the DCATCH pilot demonstrated, when this help is available, it is a very cost-effective way of helping parents stay in work. This must include provision for school holiday cover, and for care before and after the school day.

## Recommendations

- As part of the 'Local Offer', local authorities should produce local childcare registers that clearly show which sorts of additional needs each provider caters for and which clearly demonstrate that there is sufficient childcare provision to meet the needs of disabled children in the area. Providers should be given appropriate incentives to provide childcare places for disabled children so that parents are not expected to pay extra costs to enable a setting to meet their child's needs. And support for childcare costs provided through the social security system should be updated to ensure that it keeps pace with the real costs of childcare.
- Local authorities should compile a local register of carers who are experienced in working with children with disabilities and special needs who parents can call on in an emergency or when usual arrangements break down. This would help bridge the gap in emergency childcare when a child has disabilities or other additional needs.
- For children with particularly complex needs, a small team of trusted emergency carers should be assigned to families by social services. Parents could turn to one of these emergency carers when normal arrangements break down, ensuring that the emergency carer has sufficient knowledge of the child to be able to step in at short notice.



“

“I went through about 20-25 nurseries. As soon as I said my child has additional needs, you should have seen their faces change. They were instantly looking to march you out of the door.”

(Focus group participant)

# 5

## Overcoming the Barriers

Public services that support parents of disabled children in work

Fifty-nine percent of parents we surveyed had to take up to ten days off work in the past year to take their disabled child to a medical or therapy appointment. Five percent had to take over 20 days off. Fifty-nine percent had made up the hours at work another time, while 42% had used annual leave to cover the appointments, eroding their own wellbeing and other opportunities for family time together. Parents often feel they have little choice but to attend appointments at the time set. Many do not feel they can influence or easily change appointment times.

“I would make it easier to arrange appointments (especially within the NHS) at a time that suited all concerned. Currently, if you try to change an appointment it might be delayed by months or in some cases over a year.”

(What would help?) Flexible working and more statutory rights about taking time off work for medical appointments and operations or hospital stays. Juggling both medical appointments and school holidays around annual leave as a single carer is impossible. It means that even as a full-time employee, I get no annual leave as it is all taken up in medical appointments before even getting to the point of addressing school holiday childcare.”

“I would use my annual leave to attend my daughter’s appointments. So when it was the summer holidays, I had no annual leave left. I didn’t know what to do. The short break provision was reserved for children who are severely autistic and non-verbal – my daughter can walk and talk so they said she was fine. In the end, I had to reduce my work days but the workload didn’t reduce. So I still worked from home and in the evenings, and when my child was at school. My pay was cut by 60% so it did affect my work and home life.” (Focus group participant)

Parents report that professionals and services who are meant to support and help families often expect that a parent will be at home all the time. Indeed, some professionals have actively discouraged parents from working:

“There is an expectation that parents of disabled children shouldn’t work and a professional suggested I look at stopping work soon.”

“For every single meeting, professionals are given the opportunity to choose and suggest dates. I am simply given the date that works for them – I am never considered.”

But there are examples of good practice too, which demonstrate that the burden of appointments can be reduced on parents. Examples include arranging meetings out of normal working hours, consolidating appointments so that children and their parents see several professionals together, reducing time out of work and school and enabling professionals to link up, and simply consulting parents about meeting or appointment times:

“School has arranged evening meetings for us. Some appointments with professionals have been combined – e.g. dietician and speech and language therapy. Some therapy appointments are at school, so we don’t need to arrange transport or care after the appointment.”

“Special school arranged for a paediatrician to visit school for children’s appointments rather than have to take child out of school. He saw several children in one visit and parents took less time off work as they didn’t have to transport children from school to hospital and back again.”

“Availability of early morning appointments, from 8am, allowing for hospital appointments before official school start time.”

“My son’s school always schedules meetings for my days off and our therapists are flexible with times.”

School transport for disabled children is another area where simple changes can deliver real benefits. An inquiry into school transport for disabled children in 2017 found that 48% of parents of disabled children (mostly mothers) could not work or had to reduce their hours because of school travel arrangements<sup>20</sup>. From our own survey we have heard examples of local authorities refusing to collect or drop off a child at anywhere other than the parental home (for example at a childminder’s), of transport not being provided for before or after school clubs and of rigidity in collection and drop-off times.

“(What would help?) For the school transport to pick up just half an hour earlier so I can get to work on time. The local authority and the taxi driver are refusing this request.”

“School had after school care which was great, but they now end it at 5pm which means you cannot work 9-5 and there is no transport.”

“The special school has stopped providing before and after school care as transport classes it as a social activity [so no transport is provided].”

“(What would help?) The taxi being able to drop my son off at childcare instead of this nonsensical home/school-only rule that the council have.”

Once a disabled child is no longer of compulsory school age, there is no requirement for local authorities to provide free home-to-school transport, even if the child was previously eligible. This means that although all 16-18-year olds are required to participate in education or training, local authorities can ask families to contribute to the cost of transport to school or college. This is having a significant impact on parents and their ability to work:

“I have to take my son to college. I had to change my job and job role significantly as the transport to and from school was cut so I was travelling 30 miles each way and he was doing breakfast and after school clubs. We are at least £8000 down on income.”

Yet there are examples of good practice where children are collected from and/or dropped off at a childminder's or grandparents' home when the parents are working:

“Our school transport treat my home address and my parents' home address interchangeably (they are only about 0.5 mile apart), so the transport will collect my daughter from and drop her off to either my home or my parents', whichever I tell them. Our driver is brilliant and really understanding that sometimes our plans change at short notice. It makes a huge difference.”

“Our transport provider has agreed to take our son to his carer one day a week and pick up from there the next morning. This was entirely at the taxi company's discretion. The local authority were unhappy about supporting this, however.”

## Recommendations

- Healthcare providers should adopt innovative approaches to consolidating appointments and offering them at times of day that minimise time out of work and school. Schools and other professionals should consult parents when meetings are scheduled and wherever possible, hold them at times that minimise the impact on parents' ability to work.
- Services which are meant to support disabled children and their families should take account of the working pattern of parents – e.g. arranging equipment deliveries in consultation with parents and offering a choice of dates and times to enable parents to fit them around work.
- When setting school transport policies, local authorities should provide flexibility to support working families – for example, collecting or dropping off from a childcare setting rather than insisting on it being the family home.



# Conclusion

All working parents can feel under strain, juggling competing demands and dealing with the unexpected. These challenges are multiplied for parents of disabled children.

Given the huge mismatch between the number of flexible jobs and the proportion of people who want or need to work flexibly, wholesale change to UK workplaces can only serve everyone's interest.

What is crucial is that the recommendations made throughout this report – around 'adjustment leave', parental leave and carer passports, for example – are accompanied by cultural change in the workplace. Otherwise, they risk being mere 'tick box' exercises that won't impact on the lived experience of parents of disabled children.

We need practical action to ensure that services better meet the needs of families with disabled children. This is about ensuring that the improvements we have seen in the availability of childcare includes all families, and that public services recognise and act on the fact that parents of disabled children want to be in paid work.

Many of the themes and findings in this report are worryingly consistent with what we found in our 2012 and 2015 reports. Change is urgently needed: it's time to act.

## About the Research

Working Families carried out an in-depth online survey between July and December 2017, generating 1250 responses from parents of disabled children either in work or wishing to work. Seventy percent of respondents were currently in paid work, and the majority of respondents (97%) were women. The survey was disseminated via our

Waving not drowning network offering employment support to parents of disabled children, and through a range of civil society organisations working with families with disabled children. We also held a focus group with parents of disabled children in July 2017 to explore key themes ahead of the survey.



## Acknowledgements

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# Annex - Summary of Rights

Rights which apply to parents and carers of disabled children

## Rights to time off work

Name of Right	Description	Terms, Conditions and Limitations	Differences for parents or carers of disabled children to non-disabled children
<b>Emergency leave for dependants</b>	Employees have the right to take unpaid time off work to deal with an unexpected event involving someone who depends on them. This includes the breakdown of normal care arrangements.	You must inform your employer as soon as possible. The request must be considered "reasonable".	Parents of disabled children have the same rights as parents of non-disabled children, although employers should take into account employee's circumstances.
<b>Parental Leave</b>	Parents of children under 18 can take unpaid parental leave if they have been with their employer at least a year. Parents can take up to a total of 18 weeks altogether for each of their children before the child is 18.	Unless you have a different agreement with your employer, you need to give 21 days' notice and can only take up to four weeks a year. There are circumstances in which your employers can postpone parental leave for up to six months.	Parents taking parental leave for a disabled child (who is entitled to DLA or PIP) can take it in blocks of a day, whereas parents of non-disabled children can be required to take it in blocks of a week.
<b>Annual Leave</b>	Employees begin accruing their entitlement to paid annual leave as soon as they start with their employer. Full-time workers are entitled to a minimum of 28 days a year, including any public holidays.	Employers can decree when you may not and when you must take your leave as long as they give you sufficient notice (twice the length of the leave).	Parents of disabled children have the same rights as parents of non-disabled children.

## The Equality Act 2010

- The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. This includes direct discrimination by association, such as treating a parent or carer less favourably because they have a disabled child (EBR Attridge LLP and another v Coleman (No 2) UKEAT/0071/09).
- The Equality Act also applies to childcare providers. They are not allowed to discriminate against disabled children and must make 'reasonable adjustments'. They are allowed to charge extra if they need to employ extra staff or limit their provision to fewer children, but they are only allowed to charge for the extra costs incurred.

## Right to request flexible working

There is no general right to work flexibly, but an employee with 26 weeks of service with the same employer has the right to make a request to work flexibly. The employer has three months to respond (although this can be extended by agreement). If the employer turns down the request, it must be for one of the permitted business reasons.

Working Families' Waving *not* drowning network provides support for parents of disabled children and carers of adults who want to combine paid work with their caring responsibilities. To find out more visit:

[www.workingfamilies.org.uk/wavingnotdrowning](http://www.workingfamilies.org.uk/wavingnotdrowning)



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