

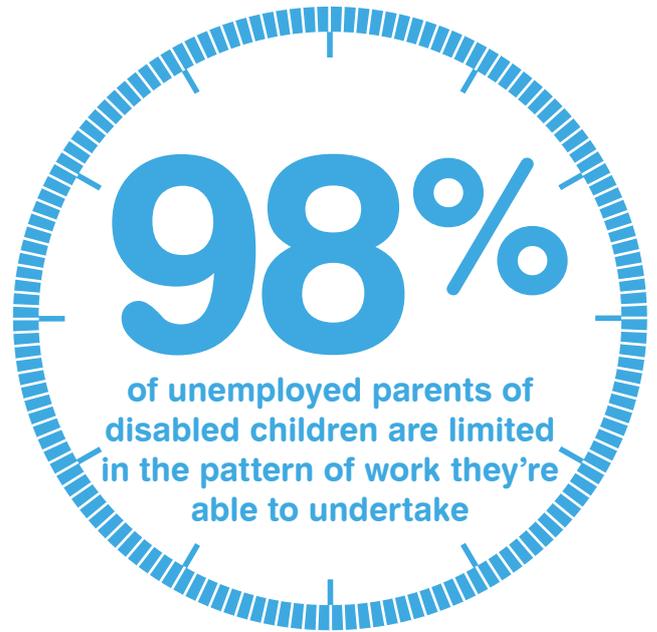
parents of disabled children and paid work

Off balance

Key Findings and Recommendations

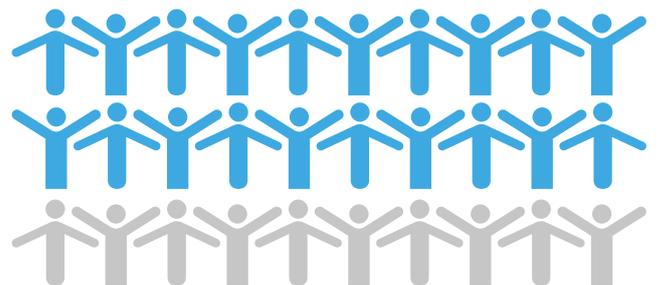
The issue of affordable childcare is rising rapidly up the political agenda, and seems set to be a key electoral battleground in the run-up to the General Election in May 2015. All three main UK parties are set to include a 'childcare offer' in their manifesto for May 2015 whilst also stressing the importance of paid work – including maternal employment – in tackling poverty and other social ills, such as mental ill-health. In short, there is broad political consensus that all those who wish to work should be able to do so.

However, none of the three UK main parties has explicitly acknowledged the especially harsh 'childcare crunch' and other major barriers to paid work faced by parents of disabled children – let alone developed specific policies aimed at lowering these barriers. This has to change.



I was forced to leave my well-paid, management level job and seek a minimum wage role, because of the lack of suitable childcare [in our area]. Our son requires 1:1 support, which our local authority would not provide [or fund]. We had to threaten legal action under the Equalities Act to get just 10 hours of 1:1 support, which are the hours I now work.

Mother of disabled 3yo.



Two-thirds of those in work have refrained from seeking promotion, declined promotion or accepted demotion in order to be able to balance work and their caring responsibilities.

To that end, Working Families has conducted a survey of some 900 parents of disabled children. Our new findings replicate those of our 2012 report Finding Flexibility and once again illustrate both the extent to which such parents value the opportunity to work – for both economic and other reasons – and the enormous challenge they face in combining their especially demanding caring responsibilities with paid work.

- For both in-work and out of work parents, the twin challenge of finding suitable, affordable childcare and finding or holding on to reasonably well-paid, part-time or otherwise flexible work, remains the biggest barrier to remaining in, or re-entering, the labour market.
- Seven out of ten parents describe finding suitable, affordable childcare as ‘very difficult’ or ‘impossible’, with only a tiny minority (six per cent) describing it as ‘quite easy’ or ‘no problem’. As many as one in two rely heavily or exclusively on ‘free’ childcare provided by family or friends. One in three of those paying for their childcare are paying more than £10 per hour.
- Nine out of ten of those currently not in work would like to return to paid work at some level. However, four out of ten have been out of work for six years or more and, for the overwhelming majority (98 per cent), their caring responsibilities would limit the pattern of work they could undertake; two-thirds say they could work school hours only.
- Under half of those in employment work 30 or more hours per week, and one-third are working fewer than 20 hours per week. Just over half have reduced or tried to reduce their work hours, and a similar proportion have changed or tried to change their work pattern.
- Two-thirds of those in work have refrained from seeking promotion, declined promotion, or accepted demotion in order to be able to balance work and their caring responsibilities.

In light of these findings, we make three key policy recommendations -

A new, statutory right to a period of ‘adjustment leave’

A ‘flexible by default’ approach to job design in the public sector

A new Minister for Disability Childcare

I would love to have paid work, to allow us to do more to help our son and for ourselves as a family, but the flexibility required just isn’t available. That is why I had to give up my job.

Mother of 3yo.

I’d love to get back into paid work. I get depression from being stuck at home. *Out of work mother of disabled 7yo.*



Nine out of ten of those currently not in work would like to return to paid work.

Becoming the parent of a disabled child

- the stormy waters of transition

If achieving even the most basic work-life compromise is a serious challenge for many working parents – and it is – then it's a challenge that parents of disabled children face in spades.

And, of course, some parents of a disabled child are also single parents. And some are themselves disabled. It's a truism that becoming the parent of a disabled child is rarely a matter of personal choice – it can happen to anyone, at any time, not just at the time of birth. One day you have a healthy toddler – and the next day he is struck down and left disabled by one of childhood's rare but vicious illnesses, such as meningitis. Or one day your teenager is knocked off her bike by a truck, and never walks again.

Such tragic, unexpected events happen, every day of every week – and their shock can hit families with tremendous force. Knocked off balance and having to learn a whole new language of medication, treatment and care, it can take time for families to make the adjustments that, in the long-run, will enable them to weather the storm that has broken over their heads.

In such circumstances, it is not unusual for parents to conclude that they should give up (or remain out of) work in order to care full-time for their child. Indeed, many parents – and especially mothers – report that health, care and education professionals clearly expect them to do so.

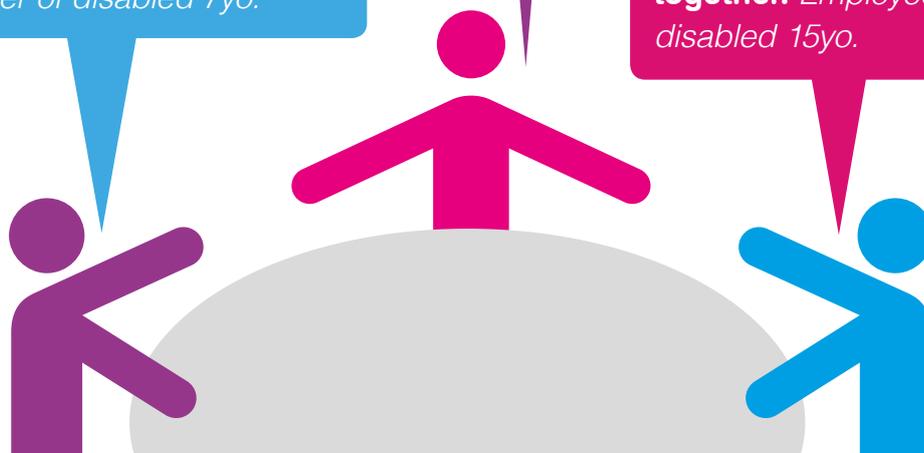
Of the parents in our survey who are currently not in work, the great majority (79 per cent) gave up work at or very soon after the time of diagnosis of their child, specifically to care for that child. And, despite the vast majority of the out of work parents expressing a strong desire to return to paid work at some level, almost four out of ten (38 per cent) had given up work more than six years ago, making their return to the labour market that much more difficult. In addition to the gap in their work history, lost or outdated skills, and lowered confidence may come into play.

I kept my job purely due to the goodwill and compassion of my employer. My husband was not so lucky and had to accept a demotion.

Employed mother of disabled 7yo.

I gave up work when my son was diagnosed, and it was around five years before I could consider going back to work, then four years of looking for a job that was flexible enough. *Mother of disabled 10yo.*

The need for my wife and I to split all our available leave to cover our caring responsibilities means that we rarely have any time-off together. *Employed father of disabled 15yo.*



While some employers do offer various forms of ‘emergency leave’ or short-term, temporary flexible working, there is no legal entitlement to a period of ‘adjustment’ or ‘crisis’ leave. Yet for some parents being able to take a period of weeks or months off work after the initial diagnosis of their child’s disability or special needs, with the security of having a job to return to, may well be sufficient to enable them to put care arrangements in place and determine a realistic, longer-term pattern of paid work for themselves. The common ‘all or nothing’ scenario results in too many parents giving up work at the point of diagnosis out of necessity, then moving inadvertently into long-term unemployment, with all of its associated economic and social costs.

Combined with a phased return to the original or a new, more flexible work pattern, this period of ‘adjustment leave’ should, where possible, be paid by employers at full or part wage replacement rates. The state should contribute at least at the same rate as statutory maternity and paternity pay to make it financially viable for all parents. However, we believe that this ‘adjustment leave’ is so badly needed that we would recommend its introduction even as an unpaid entitlement until the economy improves. It would enable parents to adjust to their new life, and put long-term care in place, whilst remaining economically active.

Figures compiled for Working Families by Oliver Wyman, the leading international management consulting firm, show that the economic impact of parents of disabled children having to leave work and remaining out of work could be up to £685million per annum. Introducing a six week period of adjustment leave paid at the statutory rate of pay could result in a potential net gain to the economy of up to £500million*.

* Assumes that all unemployed parents who expressed a desire to return to work would have remained in employment if adjustment leave was available and that those in employment but on reduced hours would all make use of adjustment leave and remain in employment.

We suggest that such a legal right to ‘adjustment leave’ could benefit not only working parents of a newly-disabled child, but anyone experiencing one of the various shocks that life deals out to many of us at some stage: a bereavement; the serious illness of a partner or child; becoming a kinship carer; or the sudden, unanticipated decline of an elderly parent.



Longer-term access to part-time or flexible work

Our survey findings confirm that, in the longer term finding reasonably well-paid, part-time or otherwise flexible work, constitutes the biggest barrier to remaining in, or re-entering, the labour market, alongside the twin challenge of finding suitable, affordable childcare.

Nearly eight out of ten (77 per cent) of out of work parents agreed or strongly agreed that finding a job with the right number of hours is a major barrier to work, and almost nine out of ten (87 per cent) agreed or strongly agreed that finding a job with the right pattern of work is a major barrier to work.

Furthermore, the overwhelming majority (98 per cent) of the out of work parents expressing a strong desire to return to work at some level said their caring responsibilities would limit the number of hours and/or the pattern of work they could undertake. Two-thirds said they would need to work fewer than 20 hours per week, and a similar proportion said they would be able to work school-hours (e.g. 9 to 3) only. Just six per cent of parents said they would be able to work 30 hours or more per week.

Despite a marked increase across the labour

market as a whole in the number and proportion of people working part-time since 2008, there clearly remains an acute shortage of quality, part-time or otherwise flexible vacancies, especially at the intermediate level. For example, of the 622 IT business analyst vacancies listed on the Department for Work and Pension's (DWP) Universal Jobsmatch website in mid-December 2014, just one was part-time. Research by Timewise in the same year found that only a quarter of job advertisements mention flexible options.¹

Working Families has previously suggested there is a role for Jobcentre Plus to bring about a step-change in employer attitudes to the advertising and filling of vacancies. To that end, we are pleased to be working with the DWP and others on promoting a strapline – “Happy to Talk Flexible Working” – that enables employers to be upfront about their flexible vacancies in job adverts.² Adding their support in November 2014, the CBI, as part of their Great Business Debate, called on employers “to encourage flexibility from the job ad onwards.”³

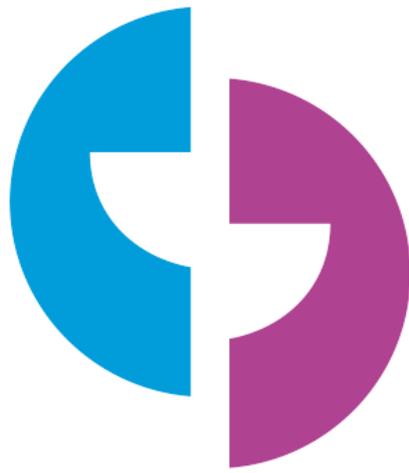
I have had to leave one job as I had to choose between a promotion to management but work full time, or leave, as they would not offer the role part-time or on a flexible basis.

Mother, now working part-time (less than 20h/pw), of disabled 14yo.

It is difficult to balance work with caring, especially with multiple hospital appointments. *Out of work mother of disabled 3yo.*

Combining work and caring is very challenging. There is never any flexibility around the timing of my son's hospital and other appointments, I just need to drop everything and be there.

Mother of disabled 2yo.



happy to talk flexible working

However, we believe the government must go much further, and adopt a 'flexible by default' approach to job design and recruitment in the public sector, so that all jobs in central and local government are advertised on a flexible basis unless there is a specific, good business reason not to.

Further research is needed but we believe that by adopting flexible working practices, public services could better meet the needs not only of their own staff but also of the parents of disabled children who report that the timing and lack of flexibility around hospital and other appointments are often the catalyst to their leaving work.

I never get a conventional one- or two-week holiday, because I have to use all of my annual leave entitlement throughout the year to cover unworked hours or time-off for meetings with social services or other health professionals.

Father of disabled 13yo.

Ministers should act and recruit business leaders as 'flexible working' champions, and should encourage private sector employers to adopt and use the Happy to Talk Flexible Working strapline.

We have so many hospital appointments, often in the middle of the day. Most of our annual leave is used for that rather than for a much-needed break.

Employed mother of disabled 3yo.

Finding suitable, good quality and affordable childcare

All working parents face childcare challenges, but these challenges increase dramatically for parents of disabled children. There are some 700,000 disabled children in the UK, and analysis by the DWP indicates that it costs up to three times as much to raise a disabled child, as it does to raise a child without special needs.⁴

Not only is there a significant lack of supply of specialist childcare capable of meeting the sometimes complex needs of disabled children, but even where such childcare is available it is often considerably more expensive than that for non-disabled children. Only 28 per cent of local authorities report there being sufficient childcare for disabled children in their area, compared to 54 per cent for non-disabled children under two, and 69 per cent for non-disabled children aged three or four.⁵ In 2011, research commissioned by the Department of Education found some parents of a disabled child paying more than £20 per hour for their childcare – more than four times the national average cost.

- Eight out of ten (81 per cent) of the out of work parents in our survey agreed or strongly agreed that finding suitable childcare for their child is a major barrier to work. And three out of four (75 per cent) agreed or strongly agreed that affordability of suitable childcare for their child is a major barrier to work.
- Similarly, the great majority of in-work parents described finding suitable and affordable childcare as ‘difficult’ or ‘impossible’.
- Almost one in three (30 per cent) of the in-work parents who pay for their childcare are paying more than £10 per hour – or more than twice the national average cost per hour.

These findings mirror not only those of our 2012 Finding Flexibility report, but also those of a recent Parliamentary Inquiry into Childcare for Disabled Children. Co-chaired by Robert Buckland MP and Pat Glass MP, the Inquiry heard “compelling evidence” from childcare providers, organisations representing parents, local authorities, and almost 1,200 parents that “childcare provision for disabled children is patchy across the country and often inadequate.”⁶

It is virtually impossible to find childcare providers who are British Sign Language (BSL) accredited. *Employed mother of disabled 13yo.*

I am completely reliant on my parents for childcare. *Employed mother of disabled 13yo.*

My mother-in-law has had to give up work to help out with childcare. *Employed mother of disabled 3yo.*

It is impossible to find specialist childcare for autistic children. *Out of work mother of disabled 17yo.*

There is simply no childcare available for disabled children in my area. *Out of work mother of disabled 11yo.*

The Inquiry's findings, published in July 2014, include:

- Adequate funding is often not available to parents to cover or help with the extra costs of 'high needs' or '1:1' support.
- Four out of ten parents who responded to the Inquiry's call for evidence said their child was not accessing the full 15 hours of the current entitlement to early education for three- and four-year-olds.
- The 'sufficiency duty' on local authorities under the Childcare Act 2006 is not compensating for the failure of the market to provide childcare for disabled children. Children with complex needs and older children are particularly missing out.
- Access to good quality, affordable childcare is important for all parents: good quality childcare has a positive impact on children's learning outcomes and enables parents to reap the economic and social benefits of paid work.

Most childcare providers are not equipped to deal with complex issues, such as epilepsy. And the burden on you is psychological, as well as financial and practical, because you worry so much that your child will not be effectively looked after. *Employed mother of disabled 14yo.*

However, as the Inquiry Committee noted,

“For families with disabled children, access to good quality childcare is particularly significant because they are far more vulnerable to poverty compared to others.

Childhood disability is frequently a ‘trigger event’ for poverty because families incur considerable additional and ongoing expenses related to their child’s disability, and they encounter significant barriers to entering or sustaining employment.”

Only one local provider offers suitable childcare for my son, but at £16 hour. This is far too expensive. *Out of work mother of disabled 1yo.*

Childcare for my disabled son is extortionately priced if you compare it with my other [non-disabled] son. This is largely due to special schools not having wrap around care such as before and after school clubs, so I have to pay for a 1:1 carer.
Employed mother of disabled 10yo.

The Inquiry Committee concluded with a blunt message to policy makers:

“Recent policy developments to improve the affordability and quality of childcare provision have to date failed to take into account the reality of childcare for disabled children. The system of financial support for families to meet childcare costs does not recognize the higher costs faced by families with disabled children. There remain significant shortfalls of knowledge, skills, and professional confidence in providing quality care and early education to disabled children.

The result is that disabled children are denied the same opportunities for positive educational and social development enjoyed by their non-disabled peers, which can help them fulfill their potential. Parents are denied the same opportunities to choose to return to work. This means families with disabled children are more likely to experience poverty, mental health problems and family breakdown.

Tackling these issues requires national leadership and recognition that access to childcare is an economic imperative for families of disabled children, and is fundamental to delivering positive outcomes for disabled children.

The first step is to recognize that disabled children cannot be an afterthought in the childcare system. Inclusion must be a basic principle that shapes policy-making, beginning with a reinvigorated programme to improve childcare for disabled children and young people.”

Working Families very much agrees. This is a complex area of policy, with no easy solutions. But we need to start working towards a system that delivers good quality, affordable childcare to all working parents when they need it, whilst at the same time protecting and enhancing the wellbeing of children.

To that end, we have suggested that, as part of a new national strategy on childcare aimed at delivering universal access to good quality, affordable childcare within ten years, the government should appoint a junior minister with specific responsibility for urgently driving up the supply of suitable, good quality, and affordable childcare for disabled children.

Conclusions and recommendations

Despite a series of welcome political initiatives and considerable public investment, our childcare system is still not fit for purpose, with demand outstripping the supply of affordable childcare. All too often, parental choice about whether or how many hours to work is severely constrained or even dictated by the local availability of affordable childcare. And, as we've seen in this report, the childcare crunch is particularly acute for parents of disabled children.

Similarly, despite great progress in both employment law and employer best practice in recent decades, negative assumptions about flexible and family-friendly working persist. Indeed, the government's latest work-life balance employer survey, published in December 2014, indicates that progress has stalled since 2007.⁷ Reduced-hours working is still heavily gendered and too often seen as a lack of commitment, with senior roles and flexible working wrongly held to be incompatible. There are key gaps in the legal framework for time off work in order to fulfill family responsibilities, especially at times of crisis such as the onset of disability of a child. And there are simply too few good quality part-time or otherwise flexible jobs, putting parents of disabled children (and also single parents) at a particular disadvantage.

In the run-up to the General Election on 7 May 2015, Working Families calls on all political parties to consider committing to:

- Establishing a new, statutory right to a period of **adjustment leave**, to enable families to weather relatively short-term life crises such as the onset of disability of a partner, parent or child, or other major change in their caring responsibilities, without having to give up work.
- Adopting a **flexible by default** approach to job design and recruitment in the public sector, so that all jobs in central and local government are advertised on a flexible basis unless there is a specific, good business reason not to. Ministers should also act and recruit business leaders as 'flexible working' champions, and should encourage private sector employers to adopt the Happy to Talk Flexible Working strapline.

- Appointing a **cabinet-level minister for childcare**. In recognition of the fact that good childcare infrastructure boosts economic activity as well as child development, this minister should be co-based in the Department for Education and the Department for Business, Innovation & Skills. He or she should lead on developing a **new national strategy on childcare**, aimed at delivering **universal access to good quality, affordable childcare** within ten years.
- Appointing a junior minister with specific responsibility for urgently driving up the national supply of suitable, good quality, and affordable **childcare for disabled children**.

happy to
talk flexible
working

About our research

Our research survey was available to complete online, and a paper version was available on request. The survey was promoted to our Waving *not* drowning network of parents of disabled children who work or wish to work, via social media, and through our partner organisations to their networks. The survey was open to any parent with one or more disabled children or young people under 25 in their family, and ran from 1 May to 31 October 2014. The survey questionnaire included open-ended and multiple-choice questions.

A total of 889 parents completed the survey questionnaire, the great majority (88 per cent) of them female; this is the same gender breakdown as in our 2012 survey. Four out of five respondents are living with their spouse/partner, and 11 per cent consider themselves disabled.

Four out of five (80 per cent) of parents are in paid employment. One-third (31 per cent) of these parents work fewer than 20 hours per week.

The great majority of the parents (87 per cent) have one disabled child and 12 per cent have two disabled children. The youngest/only disabled child is under school age for 14 per cent of the parents, of primary school age for 38 per cent of the parents, and of secondary school age for 48 per cent of parents.

Half of the parents are in receipt of Disability Living Allowance (for a child under 16), and 18 per cent are in receipt of Carer's Allowance. One in four (24 per cent) have a gross family income of £16-28,000, and very similar proportions have a gross family income of £28-40,000 (25 per cent) or £40-70,000 (27 per cent).

Endnotes

1. Timewise (2014) A flexible future for Britain?
2. Available at: http://www.workingfamilies.org.uk/admin/uploads/WF_A5-8pp_happy-to-talk-flexible%20FINAL.PDF
3. CBI (2014) "Businesses still need to do more on flexible working".
4. Department for Work & Pensions (2013) Households below average income: an analysis of the income distribution 1994/5 – 2011/12.
5. Family & Childcare Trust (2014) Annual Childcare Cost Survey.
6. Parliamentary Inquiry into Childcare for Disabled Children (2014) Levelling the playing field for families with disabled children and young people. Available at: <http://www.edcm.org.uk/childcareinquiry>
7. Department for Business, Innovation & Skills (2014) Fourth Work-Life Balance Employer Survey.

Working Families

Working Families is the UK's leading work-life organisation. The charity supports and gives a voice to working parents and carers, whilst also helping employers create workplaces which encourage work-life balance for everyone.

The Working Families legal helpline is for parents and their advisers and gives advice on employment rights for parents and benefits for families. The helpline is run by a team of solicitors and advisers and has an Advice Quality Standard Mark. The helpline is supported by the Big Lottery Fund.

Call free on **0300 012 0312**
or e-mail **advice@workingfamilies.org.uk**
www.workingfamilies.org.uk

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