

Inland Revenue  
Details of employee leaving work  
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P45  
Part 1

1 PAYE Reference  
Office number: Reference number

2 Employee's National Insurance number

3 Surname (Mr Mrs Miss Ms Other)

4 Leaving date (Week 1 or Month 1)

5 Tax Code (Continue Student Deductions(Y) Week 1 or Month 1)

7 Total tax to date

# MAKING WORK WORK

# FOR PARENTS OF DISABLED CHILDREN

## ACHIEVING A WORK/LIFE BALANCE WITH A DISABLED CHILD

A joint briefing from Scope, TreeHouse and Working Families

Time to get equal

**scope**

About cerebral palsy.  
For disabled people achieving equality.



TreeHouse

Ambitious  
about  
Autism



working families

changing the way we live and work

# Achieving a work/life balance with a disabled child

## A joint briefing from Scope, TreeHouse and Working Families

### Introduction

The Government has put employment at the heart of its strategy for ending child poverty within a generation. But for many parents of disabled children, work just isn't an option.

### The figures speak for themselves:

- 55% of families with a disabled child are living in or on the margins of poverty <sup>1</sup>
- 3% of mothers of a disabled child are in full-time employment as compared to 22% of mothers of a non-disabled child; the figures for part-time workers are 13% and 39% respectively <sup>2</sup>
- 84% of mothers of disabled children do not work, as compared to 39% of mothers with a non-disabled child <sup>3</sup>
- It costs, on average, three times as much to raise a child with a complex impairment than a non-disabled child <sup>4</sup>
- Over a quarter of parents with a disabled child are lone parents <sup>5</sup>
- Workless households have a 75% risk of poverty <sup>6</sup>

Enabling parents of disabled children to take up paid work has obvious benefits, as the Government recognises:

*“The chance to work opens up the chance to progress, to develop and to participate fully in society. We know that people in work are often healthier, and more fulfilled, than people who are not. It matters for society because the poverty linked to worklessness divides our communities and deprives too many children of a fair chance in life.” <sup>7</sup>*

But the barriers to getting and keeping paid work can often appear insurmountable for parents of

disabled children. Lack of suitable and affordable childcare, inadequate support services, non-inclusive after-school activities, inflexible working conditions, schools and nurseries that do not understand or meet their child's needs, time-consuming hospital appointments, inflexible school transport arrangements and poorly paid part-time jobs all combine to make work financially and practically impossible.

To address this disconnect between Government's ambitions for parents of disabled children and the reality of life for many parents bringing up a disabled child, Scope, TreeHouse and Working Families have put together this short briefing paper to illustrate what needs to happen to make work actually work for parents of disabled children.

Improving tax credits and benefits helps today's parents, but we argue that improvements to service provision and workplace changes will provide solutions for the long-term and allow parents of disabled children now and in the future to balance working and caring.

### Why work?

Working Families runs Waving *not* drowning – a network of 2000 parents of disabled children who work or wish to work. Parents from the Waving *not* drowning (Wnd) network see employment as a route out of poverty. They want to be economically active for their own well-being and self-esteem, for the well-being of their disabled child and their siblings, and to act as a role model for their children. Some parents see work as an opportunity to have a break from caring, and some say they need to work to enable them to cope with the pressures of caring.

It is clear that, like parents of non-disabled children, many parents of disabled children want to work but frequently inflexible or inadequate structures and services prevent them.

## **THE BARRIERS TO WORK – SUPPORT AND SERVICES**

### **Childcare**

***“A lack of high-quality, affordable and accessible child care and out of school opportunities for disabled children is still proving a major barrier for many families wanting to escape poverty by moving into work.”***<sup>8</sup>

Although for many parents caring for their child at home is a positive choice, surveys of parents with a disabled child<sup>9</sup> have found clear evidence of parents unable to work because of a lack of, or the cost of, appropriate childcare.

Parents in the Waving not drowning network cite a lack of after school and holiday care, an inability to find appropriate specialist care, and the high costs of childcare for disabled children as barriers to their employment. Even when they find appropriate care:

***“Care costs and childcare costs eat up my entire salary.”*** Wnd parent

### **Early years**

Children’s Centres remain at the centre of government’s strategy to improve outcomes for children and families with numbers expected to rise to 3,500 – one for every community – by 2010. These centres offer real opportunities to provide support and services for children in the early years. However, many centres do not cater for parents of disabled children, particularly children with complex and multiple needs. Scope’s Walton Children’s Centre in Liverpool is an example of one of the few truly inclusive children’s centres in the country and yet it has a constant battle to retain adequate funding.

If Children’s Centres, affordable childcare and extended school services were fully inclusive they

would better enable parents of disabled children to access the work, training and educational opportunities which have so far been out of reach. While such services continue to exclude disabled children, their parents will continue to be excluded too. Achieving inclusion will require a significant shift in focus so meeting the needs of disabled children and their families becomes a key success criterion for early years interventions.

## **SUPPORT SERVICES**

Many parents of disabled children, especially those with complex impairments or high levels of support need, need outside help to care for their child. Family-centred, appropriate, flexible support services that fit with the needs and routine of the family as a whole are almost non-existent and tightening eligibility criteria mean that many families get little or no support at all.

### **Direct payments**

Some families use direct payments to buy in flexible support at home, for after school and other social activities and extra support during holidays.

***“In the mornings to get both children ready for school for eight o’clock is quite a rush so that’s when I use it (direct payments). I have a lady who comes in for one hour a day in the mornings... The other thing we use it for is social activities... and it is flexible, in the school holidays she can work more if we need her.”***<sup>10</sup>

Mother of two disabled children

For many this works well but take-up is low and many local authorities do not promote direct payments despite this being a legal requirement. Much more needs to be done to support parents of disabled children to use direct payments and improve take-up so more families can benefit.

### **Bespoke services and pooled budgets**

Families with children with complex impairments need highly flexible support. To meet this need Scope designed and is currently piloting a new

service called the Scope Inclusion Team, which provides both consultative services, such as advice on equipment and best practice to schools and other organisations, and a 'hands on' service to support disabled children, young people and their families.

The Scope Inclusion Team is particularly innovative because it is designed to provide whatever combination of support is needed to include a disabled child in their family, school and community life. It can therefore cater for the flexibility and unpredictability that parents of disabled children frequently face, enabling parents to work, spend time with all their children and socialise. In short, it enables families to live the life they want.

***“Scope Inclusion turns exclusion into inclusion, by helping us all take steps back into the community. It helps keep all options open for disabled people and their families – it opens closed doors and breathes fresh air into lives stifled by circumstances.”***<sup>11</sup>

Similarly TreeHouse School staff work extensively in the home and community to ensure that the skills children learn in school are transferred to other settings and to home. They can help parents with sleep programmes and issues which can make a huge difference to family life and parents' confidence in their ability to cope.

Securing adequate funding from different budgets to meet the needs of a child with complex impairments is usually bureaucratic, time-consuming and frustrating. Many parents do not get everything they are entitled to because they cannot navigate the sea of red tape. The Scope Inclusion Team is able to negotiate pooled funding from health and social service budgets to make provision seamless and save parents precious time and effort. It's also suited to direct commissioning from clients using direct payments or individual budgets.

## EDUCATION

TreeHouse runs the Parent Support Project, which aims to support parents to constructively

campaign for better autism education in their area. Appropriate educational provision is vital both for disabled children and their families. Parents of disabled children need confidence that schools will meet their child's individual needs. Yet many schools are failing disabled children in a number of ways. Gaps in provision can mean time out of school for a disabled child. The consequence is often time off work for their parents.

## Choice

Parental choice of schools can be non-existent for parents of disabled children. Scope's research revealed that that 60% of parents had no choice at all about which school their disabled child attended.<sup>12</sup> Many parents, unhappy about the school selected for their child, resorted to taking a claim to the SENDIST Tribunal for resolution. In some cases this resulted in children being out of school whilst awaiting the Tribunal's judgement.

Lack of schools with the necessary expertise to work with children with special educational needs often leads to parents making the difficult decision to send their child away to a residential school. Though this may enable a parent to work, its impact on family life is clearly immense.

***“We tried Paul at the local school but in the end we all agreed that they just couldn't meet his needs. What social services had to offer was completely inadequate. The only solution presented to us was to send him away to a residential school. He is happy there, but we would have much preferred to have been able to keep him at home, we miss him.”***<sup>13</sup>

Other issues, such as transport provision, or the impact of having siblings at different schools often miles apart can make getting the children to school and the parent to work impossible.

## Teacher and staff training

Training for the vast majority of teachers contains no compulsory module on SEN<sup>14</sup> despite the fact that 1.53 million children are registered as having SEN.<sup>15</sup> Training is very general and teachers are not required to have any specialist training.

For example, even though one in 100 school aged children are on the autistic spectrum, there is no requirement to have specialist autism training. In schools identified as having pupils with autism, only 22% of teachers have received autism-specific training – the majority of training given is typically one to four hours. Unsurprisingly only 30% of parents of children with autism in mainstream education are satisfied with the level of understanding of autism across the school.<sup>16</sup>

Such situations present a very real obstacle to parents thinking about going back to work or trying to hold on to employment. If this situation is to change then we need schools to be more genuinely inclusive environments with not only buildings, but staff who can respond to the individual needs of disabled children and make reasonable adjustments.

At present it is too often parents who are expected to make adjustments, frequently at the expense of paid work.

### **Exclusion from school**

Disabled children are 16 times more likely to be excluded from school than non-disabled children. In 2005/06, 39 in every 10,000 pupils with statements of SEN and 43 in every 10,000 pupils with SEN without statements were permanently excluded from school. This compares with five in every 10,000 pupils with no SEN.<sup>17</sup> 27% of children with autism have been excluded from school, a quarter of whom have been excluded on more than one occasion.<sup>18</sup>

In addition to formal exclusions, many parents report 'informal' exclusions. These are not legal, but involve a school asking parents to take their child home from school. This may be because a child finds a particular lesson, or activity, or break times difficult. This is very common with children with autism since they often find unstructured social time very stressful and this impacts on their behaviour. It might also be because the school does not feel able to deal with a particular aspect of a child's personal care.

*For example, a mother of a disabled child with physical impairments was told she had to come into school to take her son to the toilet because staff would not assist him. As a result she had to go into the school three or four times a day, making holding down a job impossible.<sup>19</sup>*

### **TRANSITION SERVICES**

The Government has acknowledged that transition services – to bridge the gap between full-time education and independent living, and children's services to adult services – need to be a key consideration in the future design of services for disabled people and their families. In particular, there is a lack of skills courses and training opportunities for people with complex and multiple support needs to help them prepare for independent adult life.

The discontinuity between children's and adults' services means many young people find themselves in care homes for older people or living at home – with no access to further education, training, or work opportunities. Just at the time that other parents may be increasing their working hours as their children become independent, parents of disabled children are at risk of withdrawing from the workforce to care for their child and manage the bureaucracy of transition.

Unfortunately bespoke services for young disabled adults with high support needs like this are rare. Scope's specialist FE college in Lancaster has four applications for every place and there is no equivalent provision at all in Wales. Scope's new transition service in Cambridgeshire runs three-year courses for young adults to equip them with the knowledge, practical skills and confidence to live as independently as they can but similar services just don't exist elsewhere.

### **BARRIERS TO WORK – FLEXIBILITY IN EMPLOYMENT**

Parents who do wish to work may face limited employment opportunities. While good employers recognise the sound business reasons to offer flexible workplaces (for example, improved

productivity and recruitment and retention benefits), many parents of disabled children still encounter problems finding and keeping jobs because of their heavy caring responsibilities. A lack of flexible workplaces often means parents of disabled children have few employment choices and work in low-paid and low-skilled part-time jobs. This contributes to family poverty, and results in a loss of skills to the economy.

### **Time off to meet additional needs of a disabled child**

Having a disabled child can mean that parents who work need more time off to meet their child's needs. Time off to attend scheduled hospital and clinical appointments or to deal with unforeseen ill-health creates difficulties for parents trying to hold down a job.

Parents in receipt of Disability Living Allowance who have been working for a year, are entitled to parental leave to cover appointments. However, many find that 18 weeks of parental leave over 18 years can be insufficient and they use up their annual leave allowance as well, leaving them no time for much needed holidays. Holiday leave is a health and safety requirement and it is unjust that parents with disabled children lose out on paid leave. Parental leave is unpaid, as is emergency time off for dependants which does not cover routine appointments anyway.

***“Because of his disabilities and the number of appointments, trying to do even part-time work is difficult, as the appointments come ad hoc...”***  
Wnd parent

Health and other support services should be encouraged to offer co-ordinated appointments for disabled children far ahead, to improve parents' ability to plan time off. The Government should also consider whether more can be done to support parents who lose out on pay or holiday because of their caring responsibilities.

### **Flexible and part-time work**

Parents of disabled children do have a right to request flexible working, and this is crucial to

keeping many parents in work. However, for those considering a return to work, flexibility is needed from day one of their employment. The 26-week rule makes it difficult for parents to enter work: until they have been with an employer for 26 weeks, they can't exercise their right to request. Very few jobs are advertised on a flexible basis. For lone parents in particular, this may mean the difference between work and no work.

***“I work 16 hours a week. It's really flexible, which I need to work around hospital appointments. My child has had a lot of time off school recently for behaviour issues and staffing problems... my employer is fantastic about flexibility and I regard myself as extremely fortunate.”*** Wnd parent

### **RECOMMENDATIONS**

Employment participation and child poverty targets must take the needs of parents of disabled children into account. The Disability Rights Commission recognises that the right employment support for parents of disabled children is crucial, particularly for lone parents who otherwise may continue to occupy:

***“the lonely planet of exclusion, poverty and distance from work because of continuing failures to ensure a sound platform for their participation”.***<sup>20</sup>

We recommend improvements to support services, more inclusive schooling and greater flexibility in the workplace:

#### **Support services**

- The Government and local authorities should promote uptake of direct payments and individualised budgets and ensure there is adequate support to use them so that families can choose flexible solutions that meet their needs.
- The Government should collect, promote and disseminate flexible, best practice models of service delivery that empower parents of disabled children to live the family life they want to and remain in paid employment.

- Support services should co-ordinate and plan appointments far ahead so that parents can better plan their leave.
- The Government should recognise the additional costs of childcare for a disabled child through changes to Working Tax Credits and local authorities should commission inclusive holiday and after-school childcare for disabled children.
- The Government should commission an inclusion audit to establish how to resource Children's Centres to ensure they are inclusive and able to support all disabled children and their parents.
- Every disabled young adult should have a personalised transition plan based on their own ambitions and wishes, that outlines how they are going to move into independent adult life. Transition services, suitable housing, education and work options should be commissioned based on these plans.

## Education

- All teachers and support staff should receive comprehensive training in how to meet the needs of disabled children in school, throughout the whole of the school day, not simply during lesson time.
- The disproportionately high rates of exclusion of disabled pupils must be tackled.
- The Government should carry out research on the use of informal exclusion and put safeguards in place to reinforce current guidance and end its use.
- More must be done to reward inclusion in schools to ensure that parents have real choice about where to send their children to school.
- It is vital that, as part of OFSTED inspections, sufficient time and focus is given to SEN by inspectors who have real expertise, so that any inadequacies are properly highlighted. This should include a check on whether or not funds delegated to the school for pupils with SEN, including the amount identified in a child's

statement, are being spent appropriately on meeting children's needs.

## Employment

- The needs of parents with disabled children for greater flexibility at work should be recognised and addressed by more employers. There should be a presumption that jobs can be done flexibly, and all jobs should be advertised on a flexible basis unless there are sound business reasons why they cannot be.
- The Government should introduce the opportunity for parents seeking employment to discuss flexible working at the outset by ending the 26-week rule which limits parents' right to request this.
- The Government should consider how better to support parents who lose income and/or are deprived of holiday because they need to take time off for their child's hospital and other appointments. Paid time off would help work pay for parents at the margins of poverty.
- Finally, the Government should consider amending the discrimination laws to provide protection against discrimination in work, and in service provision, for parents of disabled children. This could be done through extending protection against discrimination to people with a caring responsibility or extending DDA protection to those 'associated with' a disabled person.

Scope, TreeHouse and Working Families  
September 2007

**Scope** is a national disability organisation whose aim is that disabled people achieve equality. We work with disabled people and their families, policy makers and professionals to advance the human and civil rights of disabled people through our Time to Get Equal campaign. We provide information, support and a range of innovative services to disabled people, particularly those with cerebral palsy, across England and Wales. To find out more, visit: [www.scope.org.uk](http://www.scope.org.uk)

**TreeHouse** is the national charity for autism education. Our vision is to transform, through education, the lives of children with autism and the lives of their families. We run TreeHouse School, which delivers high-quality education to children with autism, and work with parents, professionals and policy-makers to develop and promote best practice in autism education nationally. TreeHouse's policy and campaigns work is kindly supported by the Pears Foundation. To find out more, visit: [www.treehouse.org.uk](http://www.treehouse.org.uk)

**Working Families** is the UK's leading work-life balance organisation. It supports and gives a voice to working parents and carers, whilst also helping employers create workplaces which encourage work-life balance for everyone. Working Families runs the project 'Waving *not* drowning', for parents of disabled children who work or wish to work, which provides information and campaigns on the issues raised by parents around childcare and flexible working. To find out more, visit: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

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