

winter 2008

issue 26

the newsletter for parents of disabled children  
who work or want to work



# waving *not* drowning

...wish all our readers a very  
Happy New Year!



Working Families continues its campaigning to make combining paid work and caring for your disabled children possible. We need to be able to tell decision makers about people for whom the current rules and regulations are not working and what they need to help them. At the moment we're looking at the **'Right to Request Flexible Working'**. Have you had problems because of the rule requiring 26 weeks service with your employer before you can ask? Is your problem that your child is over six but under 18 and doesn't get Disability Living Allowance so you won't be eligible for the right to request until they are adult? We also want to hear from people entitled to take Parental or Emergency Family Leave but they can't afford to take it because it is unpaid.

If you feel you are an example of one of these people please get in touch. You are welcome to ring me just for a chat about your situation. You can email, or write if you prefer. I would also be very happy to hear from anybody else who finds that there are gaps in the legislation and the Government's efforts to promote flexible employment are not helpful in their circumstances.

Don't forget that if you want to check out your rights at work you can download Working Families' factsheets from our web site: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk), or ring our helpline on **0800 013 0313**.

Janet Mearns, **020 7017 0072** (direct line), [janet.mearns@workingfamilies.org.uk](mailto:janet.mearns@workingfamilies.org.uk), Working Families, 1-3 Berry Street, London EC1V 0AA.

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## we need your help...

of disabled children about finding work or stepping-up your work. We need to hear from you about your experiences; what helps and what doesn't help. Have you got advice or tips for other parents? We also need a small panel of people to comment on our work in progress. Have we got our priorities right? Have we left out the issues that bothered you most in your job search? We want the booklet to be based on real experience and address the barriers to work for parents of disabled children as they really are.

Please contact me if you can help, or if you have any questions. I look forward to hearing from you.

**Janet Mearns**, [janet.mearns@workingfamilies.org.uk](mailto:janet.mearns@workingfamilies.org.uk), 020 7017 0072, Working Families, 1-3 Berry Street, London EC1V 0AA

In response to requests from **Waving not drowning** network members we've managed to get funding for a booklet for parents

# our daughter goes to college now...

I was one of the founders of the **Waving not drowning** campaign in the 1990s and my daughter Eleanor is now approaching her 18th birthday. The prospect of transition to the world of adult services fills many parents of disabled children with dread - no matter how unsatisfactory your current service provision may be, there is always the worry that the future may hold something worse rather than better.

Where we live provision for young people with special needs at 16+ is in colleges of further education. We concluded early on that our nearest college was not really suitable on a number of grounds, including its physical security. We felt another college was much more suitable for our daughter, but were then faced with the problem that the local education authority would only fund transport to the nearest college. It took a year of battling with the bureaucracy before the education authority finally agreed to provide the necessary transport.

Our choice has turned out to be inspired and Eleanor enjoys her time there. It's a small sixth form college covering all abilities and the course for students with complex learning difficulties which Eleanor is following is small and friendly; she has a personalised timetable which includes all the activities she enjoys.

Hilary Simpson



For working parents the transition to college will often involve a change in care arrangements as well. Eleanor had had the same childminder - a teaching assistant at her special school - for both after-school and holiday-care from the age of five, backed up by an after-school and holiday-care scheme at the school. However, the college day and term dates were significantly different from those in the school system (the college summer holidays last for two months!) and we were therefore faced with the challenge of finding a replacement for an arrangement that had stood us in good stead for over ten years.

Local advertising for a similar arrangement did not yield any suitable responses and in the end we approached a Care Agency to provide two hours of care after Eleanor arrived home from college and full-time care in the college holidays. There are only two local agencies who are licensed to provide this type of home-based care for children, so the choice was not huge. It also seemed to us that Care Agencies were only just waking-up to the need for this type of care for working families with a disabled child.

We have ended-up using both agencies, as the first one hit a crisis after about eight months when a member of staff let them down and they were only able to offer us three days a week instead of the five that we needed. The second agency stepped into the breach and came up with a package which is still serving us reasonably well. However, agency care is very different from the "childminder" care that we had used while Eleanor was at school. Neither of the agencies could provide us with a single carer to cover all the time we needed and we have had to get used to a team of different people coming to the house (at the moment Eleanor has a team of three main carers with a couple of back-ups).

Agency care is also expensive - almost three-times as much as the reasonably generous rate we had been paying for one-to-one child-minding. This prompted us to explore the world of benefits again. Eleanor had always received the higher rate of Disability Living Allowance but we discovered that as she was now 16 and was attending a specialist college course for students with severe learning difficulties she was also eligible for Incapacity Benefit. This has boosted her income significantly. Also 16 is the age at which it becomes possible to apply to the Independent Living Fund for additional help with the costs of supporting someone to live at home, and with the help of Eleanor's social worker we have also been successful in obtaining funding from this source to help with the costs of Eleanor's after-college and college holiday care.

The transition to adult Social Care services was frustratingly slow. We like to plan ahead, but we had to wait until Eleanor was almost 17 before our first meeting with our transition social worker from adult services. Our main anxiety was whether Eleanor would continue to receive an equivalent amount of respite care, without a gap in provision. In the end our fears were unfounded, but the uncertainty was stressful. One bonus that we have found is that the adult social care system is much more receptive to contributing financially to that part of Eleanor's care which enables us to work (children's services had always resolutely refused to recognise or fund "Childcare" for Eleanor).

The last 18 months have been a time of change for Eleanor. She has had to adjust to college, to new transport and care arrangements. She now has to say goodbye to friends and staff at her current respite centre and adjust to the new environment of her "adult" respite centre. On the whole she has coped well, but we have also noticed signs of stress over this period.

The transition process won't stop there, however. Eleanor's full-time college course will finish when she is 19+ and we are already starting to think about her longer-term future and ensuring the best possible quality of life for her as she moves into her twenties - including moving away from home.

*Hilary Simpson, Local Government Officer, Oxford*

**Making work WORK** - a new publication, party conference success and a promise of an extension to the right to request.

The barriers to entering work, and the ongoing difficulties parents of disabled children face in work, were explained to Ministers and opposition parties at the Party Conferences this year. Working Families teamed up with charities Scope and Treehouse to host fringe meetings and launch a policy paper calling for improved services, support and workplace flexibility for parents of disabled children.

We were delighted to welcome Secretary of State for Children, Schools and Families, **Ed Balls MP** to our Labour fringe, along with Minister for Welfare Reform, **Caroline Flint MP**, **Danny Alexander MP**, Liberal Shadow Work and Pensions Secretary, and **Mark Harper MP**, Conservative Minister with responsibility for disability issues, joined the panels at their respective party conferences.

Each meeting heard first-hand from a parent of a disabled child about the impact of their family life on work. Cornelia Broesskamp, from our **Waving not drowning** network, spoke with candour at the Liberal Democrat fringe about the numerous roles she and other parents had to take on, and the expenditure of energy needed to ensure that their child had the same opportunities as a non-disabled child. She also highlighted the demoralising impact on parents of having to focus on what their child can't do in order to qualify for benefits or services. The charities presented their policy solutions - including more flexible employment - and the MPs were invited to respond.

Working Families' recent lobbying on the Green Paper '**In work, better off**' included writing a joint letter to the Prime Minister (with members of the Working Parents Group) saying that flexible working is essential to improving parents' employment participation rates. So we were delighted with the announcement in the Queen's Speech in November 2007 that the Government will now review how much further to extend the right to request to include parents of older children. Working Families will be submitting evidence to the review and **we need your help!**

We use many anonymous case studies from our helpline and the **Waving not drowning** network to support our lobbying work. Politicians say that the real-life stories make our arguments more powerful. So we'd like to hear from you if changes to the right to request might change your life.

If you are a parent of a disabled child who is not yet covered by the right to request - perhaps your child is not entitled to DLA - we want to hear from you. Would the right to request flexible working make employment possible for you?

If you are a parent already working part-time how did you find your current job? Did you find a flexible job or change an inflexible one? Would having a right to request from the outset have made a difference to you?

As well as wanting the proposed extension of flexible working to be as wide as possible, Working Families suggests the rule which says the right to request is only available to those who have been in work for 26 weeks should be changed. We know some parents'



Labour Party Fringe Meeting

# making work WORK

caring responsibilities make a full-time job impossible so we'd like to see the end to the 26 week rule.

Do email our policy officer:  
[Elizabeth.gardiner@workingfamilies.org.uk](mailto:Elizabeth.gardiner@workingfamilies.org.uk)  
or phone **020 7253 7243** and let us have your stories for the review by the end of January 2008. The policy paper, **Making work WORK** for parents of disabled children, will be available on our website:  
[www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)



# in brief...

## ● Carers Allowance

You can now earn up to £95 per week before you lose Carers Allowance. This is in line with increase in the minimum wage, see below:

## ● Disability Equality Duty

The Disability Equality Duty for the public sector came into force a year ago. Public bodies should have produced a Disability Equality Scheme, which has been developed with the involvement of disabled people. They should now be taking forward the Action Plans laid out in their Schemes.

## ● Sleep

Research into the incidence and impact of sleep problems in families of disabled children has found that 82 per cent had sleep problems, the effects of which included giving up or changing to part-time work. Families only made modest suggestions about what would help but 65 per cent of them had had no professional help.

## ● Jobsharing

Working Families is a partner in jobshare-uk.com, [www.jobshare-uk.com](http://www.jobshare-uk.com), the national on-line jobshare register and it is now live, providing:

- Jobs board - for part-time, job-share, interim vacancies and full-time vacancies which are open to job-sharing, with salaries over £20,000 (pro-rata)
- Case studies and best practice on job sharing and higher level part time working
- The Essential Guide to Job Sharing for registered site members
- Vacancy Posting - Employers will be able to manage their vacancies on-line and search for suitable candidates. As a government-funded project, employers are being offered free vacancy postings until April 2008.

For further information contact:

**Vivienne Duke**, Director, Jobshare-uk, [Vivienne@equalsone.co.uk](mailto:Vivienne@equalsone.co.uk) - Tel: **0113 2341811**

## ● Rights at Work

Some employees' rights have been extended but remember that while, as an employee, you can enjoy these rights if you employ anyone such as a nanny or personal assistant for your child you have to extend the rights to your employee too.

You can visit [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk) or ring Working Families' helpline on **0800 013 0313** to find out about your rights at work.

### ● Carers Can Request Flexible Working

Carers of adults (age 18 and over) now have the right to request flexible working, ie to change their hours or the way they work. The regulations do not require the sick or disabled adult to get Disability Living Allowance as is the case with children over six. The procedure is quite complicated, see website or ring the helpline.

### ● Increase in Statutory Annual Leave

Statutory Annual Leave increased from 20 to 24 days on 1 October, 2007 and will increase to 28 days on 1 April, 2009. Employers can include the eight bank holidays as part of the statutory entitlement.

### ● Employers Must Encourage Workers to Take Breaks

Under the Working Time Regulations employers must allow workers who work more than six hours to take at least a 20-minute break. The European Court of Justice has now said that employers **must encourage workers to take their breaks**, although it did not go as far as saying they must ensure breaks are taken.

### ● National Minimum Wage

An increase in the national minimum wage means that the rates are now:

Over school-leaving age and under 18	£3.40 per hour
Age 18-21	£4.60 per hour
Age 18 or over	£5.52 per hour

### ● Long Hours

The law provides protection against an average working week of more than 48 hours but long hours working is on the increase in the UK, reversing the slow but steady ten-year decline. According to a new TUC analysis more than one in eight of the workforce now work more than 48 hours each week.

## Janet Mearns reviews a new book about families of children with autism...

The photographs in *'Autism Heroes'*, a new book about families with children who have been given the label autism or Asperger's syndrome are lovely. They are high-quality black and white photographs of families which manage to radiate family warmth. The text does not live up to the standards of the pictures.

The book consists of interviews with parents of children with autism grouped into sections called **'Dignity, Hope, Opportunity and Love'**. The parents have positive things to say and the book



does serve its function of sharing experiences, but unless this is your very first encounter with a book for parents of disabled children about other parents of disabled children you will have met the sentiments before. The introductions to each section make the book repetitive and the style is syrupy. For British readers the American spelling is off-putting, the references to interventions are not familiar, and the suggested reading and details of the help-group at the end are irrelevant.

It is a book which readers can dip into and it conveys an upbeat message. The selection of parents represents a wide variety of class, ethnic and religious backgrounds and different family structures, so many will find examples they can relate to. It is pleasingly designed and produced. Perhaps it has a place on reading lists for parents and professionals, but it is not essential reading.

**'Autism Heroes: Portraits of Families Meeting the Challenge'** by Barbara Firestone, published by Jessica Kingsley, £19.99.

## Get on the list

**Waving not drowning** is available **FREE**.

Just email, ring, fax or post the form below. Please tell us if you've moved or changed email address or have just got email. If you, or someone you know, want the newsletter on tape let us know and it can be arranged.

- Please put me on the **Waving not drowning** mailing list
- I have changed address / telephone / email
- I am a parent
- I have a professional interest

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Tel (H): \_\_\_\_\_

Tel (W): \_\_\_\_\_

Tel (M): \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

Please return to:

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# unpaid time-off

How much worse off are you if you take unpaid holiday? Working Families is campaigning for **paid** time off when parents need to deal with their children's medical emergencies and the other issues that come with having a disabled child. Many parents and carers can't afford to take the Parental or Emergency Leave they are entitled to because it is unpaid. However, it is clear from our helpline calls that people aren't always sure about how much money they will lose if they take a day or a week off.

Everybody's circumstances are different. Shift patterns and term-time only working can make a difference. The following is only a general guide:

**Alex**, a lone parent, works three days a week in a local shop. She earns £9,000 a year (£173.08 a week). She takes an unpaid day off to take her daughter to a physiotherapy session. Her employer deducts £57.69 from her gross salary. She would normally pay 22 per cent tax and 11 per cent National Insurance on that £57.69 so her take-home pay is only down by £38.65. She receives Working Tax Credit. Next year she'll

report her reduced income using her P60 provided by her employer so her next year's Tax Credit will be increased by about £21.00 so, altogether, she has only lost just over £17.00 by taking the day off.

**Lesley** works full-time doing office work. She earns £20,000 a year (£384.62 a week). She takes a week's unpaid leave when her son goes into hospital. Her employer deducts £384.62 from her gross monthly salary. She would normally pay 22 per cent tax and 11 per cent National Insurance on that £384.62, so her take-home pay is only down by £257.69. She does not get Working Tax Credit because of the amount her husband is earning.

**Gladstone** works full-time for a City firm and earns £45,000 year (£865.38 a week). He takes an unpaid day-off when his son is excluded from school. His employer deducts £173.08 from his gross salary. But, because Gladstone would normally pay 40 per cent tax and 1 per cent National Insurance on that £173.08 his take-home pay is only down by £102.12.

There are 260 or 261 weekdays (Monday - Friday) a year. If you work five days a week, divide your annual salary by 260 or 261 to find out the gross deduction that your employer will make for a day's unpaid leave. The following table shows how many working days there are in a year for part-time workers:

No. of days worked each week	No. of days worked in a year
5	260 or 261
4	208 or 209
3	156 or 157
2	104 or 105
1	52 or 53

You don't pay Tax or National Insurance on money you don't earn so your take-home pay will probably not be reduced by the gross amount your employer has deducted. The following table gives an idea of the Tax and National Insurance rates employees must pay. At the moment the Tax-free personal allowance is £5,225 (£5,435 from 6 April, 2008). More than that is taxable.

April 07 - April 08 Rates		
Taxable Income (approx. per year)	Tax	National Insurance
£0 - £2,230	10%	11%
£2,231 - £34,600	22%	11%
£34,601 - £34,840	40%	11%
Over £34,840	40%	1%

If you want information on your rights to time-off see Working Families' factsheets at [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk) or ring the helpline on **0800 013 0313**.

We would very much like to hear from people who can't afford to take the Parental and Emergency Leave they're entitled to. It will help our campaign. You can phone **020 7017 0072** or email [janet.mearns@workingfamilies.org.uk](mailto:janet.mearns@workingfamilies.org.uk)



# your letters

Dear Janet

It's very hard to work full-time and deal with a special-needs child and all their demands. We are constantly exhausted and stressed. I don't think there's an easy answer. My work is very understanding, but I still feel bad about it fairly often, taking time here and there and being fairly inflexible.

*Anna Maria Williams, Office Manager, Croydon*



Dear Janet

Purely giving time-off is not enough. The additional stress of living with a disabled child means that there is a much higher requirement for support from the workplace in terms of flexible working and emotional support. Many parents of such children attend work for maintenance of sanity as much as the money. Work is also a way of maintaining 'normal' relationships with other adults outside the special needs community to avoid the possibility of becoming too special-needs focused.

*Warren Griffiths, Local Government Officer, Aldwinde. Northants.*

Dear Janet

Our son is now 13 and it has been a constant struggle to look after him, particularly in the holidays and after school but we were very fortunate to find a child-

minder who specialised in special needs. Eventually she gave up to take up full-time employment as she was a single mother who needed paid holiday, sick pay and pension. We then found a young lady from a disability scheme to look after our son. We realised that we could not carry on as we were and fought to get respite care and then went to a tribunal to get a place in a residential school. We were fortunate and we won, but had to accept the recommendation of the tribunal to put our son in a 52 week residential school. The school is brilliant as is the care element, however it is 200 miles away and so we can only visit once every three weeks. Our son has now been at the school for three years and therefore we have been able to resume paid employment, but it is a hard choice to make and one that is not to be taken lightly. There should be more support for working parents with disabled children.

*Pippa Mackinlay, Dorking*

Dear Janet

I don't think it's fair that you only get paid parental leave at the discretion of your company. I think that if you have a disabled child that needs extra care you should be entitled to at least one or two weeks paid parental leave.

*Lisa Pearson, Nursing Assistant, Tuffley, Glos.*

See [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk) or send an sae for factsheet on 'Time Off Work' for details about rights to Parental and Emergency Leave and let us know if being unable to afford to take unpaid leave has been a problem for you, see 'Unpaid Time-Off' on page 5 Ed

Dear Janet

The learning support girls at Danny's school are very helpful with daycare during the holidays. I'm just sorting out my second summer trying to work and care for Danny. It's very daunting as I'm on my own but I got through last year!

Keep up the good work.

Regards,

*Tim Ranson, Carpenter, Sudbury, Suffolk*

Dear Janet

I find that a lot of people don't know about the disabled and severely disabled child elements of Child Tax Credit which parents of children getting Disability Living

Allowance can claim. Some people are even reluctant to claim the DLA that their children are entitled to. Disabled adults can claim the disability or severe disability element of Working Tax Credit if they are working, but, oddly the definition of 'disabled' for them is not so straightforward. I would like to encourage everybody to claim their



entitlements and as soon as possible because there is a limit on how far claims can be backdated. As the mother of two disabled children and a disabled person myself I see it as empowering.

*Sarifa Patel, Outreach Worker, London E12*

See our factsheet on Benefits and Tax Credits on [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk) or ring our helpline: 0800 013 0313 for more information. Ed.

Dear Janet

It is difficult to get an employer to understand the level of involvement a child with special needs requires. Routine is supremely important.

On the whole my employer has been very supportive. My daughter has had many health issues including leukaemia and they gave me full sick pay.

*Emma-Jane Taylor, Cost Engineer, St. Bees, Cumbria*

Have your say - send your letters to:  
**Waving not drowning**, Working Families - details below!

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The views expressed are not necessarily the views of Working Families

Freephone for legal helpline and free factsheets: 0800 013 0313

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changing the way we live and work

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