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


working families
changing the way we live and work

waving *not* drowning

Eastenders baby has Down's Syndrome



Photo courtesy of the BBC

What do **Waving not drowning** readers think of the BBC's Eastenders storyline about Petal, the baby with Down's Syndrome? Clearly it is a step towards addressing the huge under-representation of people with Down's Syndrome on television, but how valid are claims that the storyline provides a "fantastic opportunity to raise awareness among thousands of people who know very little about Down's Syndrome, who may have outdated or prejudiced views"?

The Down's Syndrome Association says: "While Billy and Honey's reaction does reflect that of some real parents, all new parents react in different ways to the

news that their baby has Down's Syndrome. Many quickly bond with their baby and accept their differences. Most parents do experience feelings such as sorrow, anger or guilt, but they will of course experience these to varying degrees and for differing lengths of time. Honey's reaction is just one possible response to this news".

Is the BBC actually portraying a range of views or are they perpetuating stereotypes and negative attitudes? Perhaps most pertinent to **Waving not drowning** readers is whether the storyline continues with Honey finding childcare and returning from maternity leave to her job at the Queen Vic

without a hitch - probably not very exciting for the plot of a soap opera. Will she find that Peggy Mitchell (her employer) is sympathetic when she needs time to take Petal to her various appointments? Will Billy be able to get time off to go with her?

Considering the questions that come in on our helpline, **Waving not drowning** would like to see the BBC taking to heart the educational responsibility of a mass-audience programme and using the story to inform people about parents' rights to flexible working, parental and emergency leave and even to campaign for further rights such as paid time-off.

Draw winner

Returned annual survey questionnaires were entered in a draw. The winner of the £50 token lives in Nottinghamshire. She has been sent her prize and I have heard from her that she is looking forward to choosing something she couldn't otherwise afford. Thanks to everyone who helped by filling in a questionnaire and letting us know about yourselves and the issues that concern you.

Good news on Childcare Bill age limit

Good news for **Waving not drowning** members is the amendment to the Childcare Bill agreed in June. Originally, local authorities were to have the responsibility to ensure that there was sufficient childcare available for disabled children up to age 16 (14 for non-disabled children). The amendment, which many disability organisations campaigned for, was to extend the age limit for disabled children up to 18. **Waving not drowning** will be watching to see how this pans-out in practice. Keep us informed with your experiences.

Minimum wage goes up

From 1st October, 2006 the national minimum wage is:

- £5.35 per hour for those aged 22+
- £4.45 per hour for those aged 18-21
- £3.30 per hour for those aged 16-17

If you think you are not being paid the minimum wage, you can contact the minimum wage helpline, **08456 000678**.

Don't forget that, if you employ someone to look after your children, you must pay them at least the minimum wage, although the rules are different if your nanny lives with you or you have an au pair.

Conference for dads

Working Families will be taking part in a workshop at a national conference exploring the issues faced by fathers of children with a learning disability.

The Foundation for People with Learning Disabilities is holding the conference to present the research findings from Recognising Fathers - a project looking at the experiences of fathers of young children with learning disabilities. Delegates will explore the impact that being the father of such a child has on a man's life and how services can develop their practice to involve and engage dads. The programme will cover policy and research on fathers

and family life, and being the father of a child dependent on technology. The day will conclude with a Q&A panel, hosted by TV presenter Adrian Chiles. The conference is on Tuesday 21 November, at Mermaid House, London EC4.

Further details are available from Gillian McEwan, Foundation for People with Learning Difficulties, Sea Containers House, 20 Upper Ground, London SE1 9QB, **gmcewan@fpld.org.uk**, **020 7803 1159**, **www.learningdisabilities.org.uk**.

Education Maintenance Allowance

Education Maintenance Allowance is a government-run scheme which pays young people (aged between 16 and 19) to remain in further education, as long as they are from a household with an income of up to £30K a year. EMA encourages young people to stay in education by paying them directly up to £30 per week if they regularly attend classes and keep up-to-date with their course-work.

Key features:

- Weekly payments bands of £30, £20 and £10 per week, depending on household income
- Available for both academic and vocational study, which can include courses such as basic skills, GCSE retakes, GNVQs, NVQs, as well as AS and A2s, and LSC-funded E2E and courses that lead to an apprenticeship
- No other household benefits are affected
- Young people can still have a part-time job
- Bonus payments of £100 (worth up to £500 in total over two years) are also available to those students who have good attendance and show commitment to their course.

Young people can apply for EMA or find out more by logging on to **www.direct.gov.uk/ema** or by calling **0808 10 16219**, or by picking up an application form from their learning provider or their local Connexions centre.

Parent challenges disability law

Sharon Coleman is the mother of a disabled son and she works as a legal secretary. She is challenging the fact that the Disability Discrimination Act (DDA) prevents discrimination against disabled people themselves but not against parents and carers. She is asking the European Court of Justice to say that less favourable treatment from her employer because of her son's disability is contrary to a European Employment Directive.

If her case is successful, it will be very good news for **Waving not drowning** network members because their employers will then not be allowed to discriminate against them on grounds of their association with their disabled children.

It usually takes years for European Court cases to go through all their stages and judgement to be given, but **Waving not drowning** will keep readers posted about what may be a very welcome breakthrough.

Children with progressive conditions

It used to be that people with progressive conditions were considered "disabled" under the DDA from the time that their condition led to an impairment which had some effect on their ability to carry out normal day-to-day activities. From 5 December, 2005 anyone with progressive conditions such as cancer or arthritis is considered "disabled" from the point of diagnosis. This means that, if your child has a progressive condition, they cannot be discriminated against when you want them to access such things as childcare, leisure provision or education.

Don't forget that currently when you want to exercise your rights in the workplace as a parent of a disabled child, such as the right to Parental Leave or the right to request flexible working, the definition of "disabled" is different. For the purposes of the employment legislation, a "disabled" child is one who is entitled to Disability Living Allowance (DLA).

- For more information about the DDA, see the Disability Rights Commission's website: **www.drc-gb.org**. If you think your child is being discriminated against because they're disabled, contact the DRC helpline on **08457 622633**.

- For more information about Parental Leave and the right to request flexible working see Working Families' factsheets in the Family Zone of our website: **www.workingfamilies.org.uk** or phone Janet Mearns on **020 7253 7243**.

Updated factsheet on childcare

I have updated and re-written Working Families' factsheet on Childcare for Children with Disabilities. It has general advice about choosing childcare and information on what counts as 'registered or approved' childcare for the purposes of claiming the childcare element of Working Tax Credit.

Many people are unaware that parents of disabled children can claim the childcare element of WTC until the end of the week including 1st September following their child's 16th birthday (15th birthday for non-disabled children). Registered or approved childcare not only includes the usual childminders and out-of-school clubs, but also carers recruited from registered agencies. You can also get approval for a carer in your own home through the Sure Start Childcare Approval scheme - see www.childcareapprovalscheme.co.uk. **Waving not drowning** would be very interested to hear from anyone who has used the Sure Start Approval Scheme, about how the registration went, and also from anyone who was deterred from using the scheme because of the cost.

The factsheet also has information about childcare vouchers, direct payments and the nursery education grant.

'Childcare for Children with Disabilities' is one of Working Families' series of free factsheets on childcare and your rights at work, which are:

- Childcare options - choosing what is best for you and your child
- Childcare for Children with Disabilities
- Maternity Leave and Pay
- Fathers Rights
- Adoption
- Time off Work - Your Legal Rights
- After Maternity Leave
- Atypical Workers and Maternity Rights
- Pregnancy
- Stillbirth
- Rights During Maternity Leave
- Tax Credits and Benefits
- Debt
- What to claim for a new child
- Flexible Working
- Breaks from Work
- Working Reduced Hours
- Changes to your Contract

You can download our free factsheets from the Working Families' family zone at www.workingfamilies.org.uk or you can leave your name and address on **020 7253 7243**. Our new guide for parents trying to combine paid work and caring for disabled children - *Make it Work for You!* - can be ordered from our website or by telephone. It costs £5.50 for parents and £15.50 for others (both post free). Please contact us for discounts on bulk orders.

Janet Mearns

Every Disabled Child Matters

Working Families supports the new campaign "Every Disabled Child Matters", launched by Treasury Minister Ed Balls MP at the recent Labour Party Conference. The EDCM campaign aims to ensure rights and justice for every disabled child, making sure that the support and services are in place for families with disabled children to lead ordinary lives. The campaign organisers - Contact a Family, Mencap, Special Education Consortium and the Council for Disabled Children - are seeking 10,000 signatures of support by December 2006. To find out more, and to lend your support, visit www.edcm.org.uk.

Providing better support for families with disabled children is a key strand for consultation by the Treasury for the forthcoming Comprehensive Spending Review. In a tight spending round, the priority areas that have been identified stand a good chance of receiving new funding. Working Families has submitted information to the Treasury and joined with other members of the Treasury's "stakeholder group" to lobby for change. We have argued for more support to help parents into work, improvements to childcare and for better information services for families with disabled children.

Do keep on telling us your priorities and we'll keep you posted on our lobbying efforts.

Wnd provides "an empathetic ear" and practical advice

Thanks to all the **Waving not drowning** network members who agreed to allow Aurora to contact them. Working Families asked consultants Aurora to do an independent evaluation of the **Waving not drowning** project to see how we were doing. Aurora undertook telephone interviews and conducted an email survey of **Waving not drowning** network members. They spoke to people who read the newsletter, have phoned the helpline and people who have attended our meetings. Pleasingly, they found that a lot of you found the project relevant and informative. People had found our advice had helped them achieve the work-life balance they needed.

Aurora, the consultants who conducted the evaluation, concluded:

"It is unusual to see a project that has evolved and matured so effectively over ten years. Working Families has demonstrated that they are not afraid to self-evaluate, recognise when a service needs to change or improve and to learn from experience to develop a service that responds to need. The service provides an empathetic ear, coupled with practical and concise information. It provides a peer group network which gives a sense of belonging to a group of parents who can feel isolated. The demand for the current service outstrips the existing resources and additional funding could help to broaden the reach of the project".

One **Waving not drowning** network member interviewed by Aurora commented: "It is the only service I have found which deals with the full needs of a working parent of a disabled child - official agencies dealing with disabled children automatically assume that there is a non-working parent with the flexibility to come to inconvenient appointments".

No doubt her comment rings true for many readers!



your letters

Dear Janet

When I was working permanently, I had five weeks paid holiday and my childminder had three weeks paid holiday, so we took our summer holiday when she did! We never seemed to have enough holiday to cover appointments.

I was made redundant last year and have since gone freelance. I have been lucky with contracts so far and have been able to work short days and do school pick-up and some days I can work from home and childcare is shared between myself and my 19 year old son.

I have tried to find suitable childcare but there is a distinct lack of resources for secondary school-aged children.

Chris Franklin, IT Trainer, Hayes, Middx.

Dear Janet

One of the problems with holiday childcare for my son is it is available two days a week from 10 am to 3 pm. Whereas, for his sister, it is available 8.30 am to 1 pm or 1 pm to 6 pm, so I only have a couple of hours available for work even on those two days. I can get Crossroads carers for two more hours a week but this isn't much.

Gwenda Frosdick, Dinner Lady and Casual Gardener, Great Yarmouth

Dear Janet

I have to work the night shift which means I am at home during the day and then stay up if needed for school, hospital appointments etc. No chance of promotion. My husband works from home on reduced hours and pay.

Jo Westmore, RGN, Newport, IOW



Sarifa Patel

Photo: Lisa Cutler

Dear Janet

I feel that your charity is not well-known to a lot of parents or service providers. The **Waving not drowning** newsletter is always a good read. I could have done with support when I was struggling as a disabled parent of two disabled children, especially as I still wanted to work. I was fighting to keep my job, which I thought I was pretty good at, as it was time for myself. Carry on the good work.

Sarifa Patel, Outreach Worker, London E12

Working Families relies on voluntary donations, so please do contact us on **020 7253 7243** if you can help us.

Waving *not* drowning

Waving not drowning is a Working Families' project for parents trying to combine paid work and caring for disabled children. It provides this free newsletter and a helpline on **020 7253 7243**, as well as lobbying government and other policy-makers on a number of issues.

Working Families is the UK's leading work-life balance charity. We help and give a voice to working parents and carers, whilst also helping employers create workplaces which encourage work-life balance for all. Our vision is a society where everyone has real choices about how they balance their working and caring responsibilities.

Our free legal helpline on **0800 013 0313** gives advice on maternity and paternity leave and pay and parental leave, help to work out tax credits and benefits and support to negotiate family-friendly hours. This service is now also available via text on **07800 00 4722** and email on **edads@workingfamilies.org.uk**. There are free factsheets and an interactive guide to negotiating flexible working on our website **www.workingfamilies.org.uk**.

Send us your mobile phones!

If you have an unwanted mobile phone you can donate it to us and raise funds for Working Families. Our partner, Phonehelp, will accept phones in any condition and we receive a donation for every phone they receive on our behalf. We can provide special envelopes, or you can simply put your phone into an envelope, address it to '**Freepost Phonehelp**' and post it with a note to say you'd like your donation to go to Working Families. And that's it!

You can also raise money for Working Families just by searching the web. We are listed on **everyclick**, the search engine that helps charity. Please go to **www.everyclick.com/uk/workingfamilies** and set everyclick as your homepage, so you can search the web and help Working Families. It raises money for Working Families without costing you, or us, a penny!

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

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Contact us if you would like to receive free copies of this newsletter or would like it on tape

The views expressed are not necessarily the views of Working Families

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