

Bulletin



www.familycarers.org.uk

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Welcome to this week's Bulletin from the National Family Carer Network. You are receiving this because you are members of our organisation. If you no longer wish to subscribe, please contact info@familycarers.org.uk.

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National Family Carer Network

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NFCN is an umbrella organisation that aims to promote the voice and rights of family carers supporting a person with a LD. Its membership comprises both organisations and individuals but we cannot be responsible at any time for the views expressed by our members unless explicitly promoted by us.

National

1. An alternative guide to the new NHS in England

[The Kings Fund](#) has created a new animation which gives a whistle-stop tour of where the NHS is now – how the new organisations work and fit together – and explains that our new system is as much a product of politics and circumstance as design.

Click [here](#) to watch the short animation.

2. Caring for our future: implementing funding reform - open consultation

The Department of Health is seeking views on the practical details of how the changes to the funding system should happen and be organised locally. It is interested in hearing what you think about topics such as:

- how the capped costs system should work
- how deferred payments should be administered
- how we can help people make informed choices about their care and support

For more information, please see the consultation documents below. More details are also available on the Department of Health website [here](#).

- [Caring for our future: consultation on reforming what and how people pay for their care and support](#)
- [Caring for our future: consultation on reforming what and how people pay for their care and support \(easy read\)](#)
- [Caring for our future: consultation on reforming what and how people pay for their care and support \(leaflet\)](#)

The consultation closes on 25th October and responses can be made online [here](#), by email funding-reform@dh.gsi.gov.uk, or by post:

Caring for our future – Implementing funding reform,
Department of Health,
Area 313B, Richmond House,
79 Whitehall,
London,
SW1A 2NS

3. Advice Now guide: ‘Turned down for DLA, AA or PIP? Or think you're not getting enough?’

This guide, produced by [Advicenow](#) is for anyone who thinks the Department for Work and Pensions (DWP) have made the wrong decision about their claim for Disability Living Allowance (DLA), Attendance Allowance (AA) or Personal Independence Payment (PIP).

The guide will take you step-by-step through the whole appeal process and will be particularly helpful for you if you don't have an adviser, though it does include information on where you may still be able to get advice.

To read the guide, please click [here](#). You can also find more information and resources on the [website](#).

4. FCSS - Consultation on the Personal Independence Payment (PIP) assessment ‘Moving around’ activity

Hft's [Family Carer Support Service](#) (FCSS) is going to respond to the PIP ‘Moving around’ consultation (on the distance change of 50 metres to 20 metres to receive enhanced rate mobility component).

They have written a short briefing about the consultation for family carers who would like to share their views and have these included in the response from FCSS. The deadline for sending these to FCSS is 30th July.

For full details, please see the documents below:

[PIP Moving Around activity consultation](#)

[PIP Moving Around consultation - Appendix A - Activities](#)

5. Inside Commissioning article: ‘Five ways CCGs can improve healthcare for people with learning disabilities’

The [Confidential Inquiry into Premature Deaths of People with Learning Disabilities](#) highlighted the unacceptable situation in which people in this group die, on average, 16 years sooner than people without learning disabilities. Sue Turner's article, published recently on the Inside Commissioning website, makes five recommendations which CCGs could undertake to improve the situation.

To read the article, please visit the Inside Commissioning website [here](#).

6. Health Service Ombudsman report

A report published by the [Health Service Ombudsman](#) recently found that a London GP practice did not give Mr H, a young man with severe learning disabilities, behavioural problems and epilepsy, the medication he needed on the grounds of cost and ignored disability discrimination law in the process.

In April 2011, Mr H's mother, Ms B asked her GP practice for a repeat prescription of midazolam in liquid form to help her son's epilepsy. The GP refused her request because it was too expensive and said that he would only prescribe her son suppositories or tablets in future. Ms B advised the GP her son had only been prescribed liquid medicine from a very young age, as his learning disabilities caused him to become very distressed if he had to swallow tablets.

Furthermore, when Ms B questioned the GP's decision, he told her to "find a GP with bigger budgets who would be happy to prescribe the medications".

The investigation found service failure by the practice – and specifically that they failed to consider their obligations under disability discrimination law, and didn't follow accepted medical guidelines. GMC guidance sets out that when prescribing medicines doctors must ensure that the prescribing is appropriate and responsible and in the patient's best interests. It also states that doctors should, when appropriate, 'establish the patient's priorities, preferences and concerns' and 'discuss other treatment options with the patient'.

The Health Service Ombudsman Julie Mellor said: "This is yet another case where someone with learning disabilities has been failed. When there are failures in the care and treatment of people with learning disabilities, there are consequences in terms of their health and in too many cases, their life expectancy.

You can read the full report [here](#).

7. Guardian article: Disabled benefits claimants test: Atos reports found 'unacceptably poor'

The Department for Work and Pensions is to bring in additional providers alongside Atos Healthcare to administer the work capability assessment (WCA) for disabled benefits claimants, after a government review admitted that reports by Atos assessors were of unacceptably poor quality.

The announcement by the employment minister, Mark Hoban, follows months of criticisms of Atos which the government had so far either rejected or sought to address through fresh reviews of the scheme.

The announcement is likely to lead to new firms being brought in on a regional basis from summer 2014. Hoban said the extra firms will also help provide extra capacity to help tackle waiting times.

To read the full article on the Guardian website, please click [here](#).

8. Disability News Service article: Government’s softly-softly jobs conference sparks anger

The government has held a huge conference to set out its “non-confrontational” approach to persuading business to employ more disabled people.

The Working Together conference in London brought about 300 businesses and disabled entrepreneurs together, as the coalition launched a two-year campaign aimed at making employers more “disability confident”.

The prime minister, David Cameron, told the conference: “We need to break the myth about the complexities of employing disabled people, or to put it more simply: to give employers confidence.”

There was criticism of the government’s approach – and the conference – from some of the disabled entrepreneurs who attended.

One delegate won applause after he pointed out that it was difficult to persuade colleagues to take on disabled employees when there were “contradictory messages” coming from the government. He said the government’s benefit reforms were making disabled people “less confident and more nervous”.

To read the full article, please visit the Disability News Service website [here](#).

9. Leonard Cheshire Disability: Change100 programme

Change100 is a new internship programme run by Leonard Cheshire Disability and Vanilla, the social impact specialists. Businesses are being invited to support the programme and make a pledge to create opportunities for disabled students in their workforce. The programme is to give at least 100 disabled students 100-day work placements on a living wage.

For more information visit www.lcdisability.org/change100.

10. Making the Most of my Seating Assessment: leaflet

Postural Care has published a leaflet to help you prepare and know what to expect at a seating assessment.

To access the leaflet, please click [here](#).

You can also find more information on the Postural Care [website](#).

11. Challenging Behaviour Information Sheets

The [Challenging Behaviour Foundation](#) has developed a series of three information sheets which look at the causes of challenging behaviour, and explain how to make effective plans to reduce challenging behaviour.

The information is designed for families or professionals who support a child or adult with severe learning disabilities whose behaviour challenges.

The CBF have updated two existing information sheets, which explain how to identify the causes of challenging behaviour, and written a third sheet which shows readers how to make a Positive Behaviour Support plan.

The sheets can be downloaded from their website free of charge. Summary versions of each information sheet are also available.

Please click on the links below to access the information sheets:

- [Understanding Challenging Behaviour \(part 1\)](#)
- [Finding the Causes of Challenging Behaviour \(part 2\)](#)
- [Positive Behaviour Support Planning \(part 3\)](#)

Alternatively, email info@thecbf.org.uk or call our office on 01634 838739 to request a hard copy. Please note that hard copies are free to family carers, and cost £1 per information sheet for professionals.

12. FPLD resources: Moving on to Secondary School

The Foundation for People with Learning Disabilities (FPLD) has produced the following new resources to help support pupils in their transition from primary to secondary school in England.

- [Top tips for pupils moving on to secondary school](#) an easy-read guide that includes a checklist and poster, to give young people simple ideas of how to prepare for the move to make it less stressful.
- [Useful information for parents who have a son or daughter with special educational needs \(SEN\) moving from primary to secondary school](#)
Some practical ideas for families, to help support their child to feel more prepared and able to cope with the move to secondary school. This resource complements the Top Tips for pupils
- [Moving on - good practice in facilitating primary to secondary transitions for pupils with special educational needs \(SEN\)](#)
This guide is aimed at teachers and is divided into good practice suggestions for primary and secondary school staff. Some of the ideas are very practical and can be achieved quickly, others may take a little more planning, and there are other suggestions to consider that will require strategic or systemic change.

For more information, please visit the FPLD website [here](#) or call 020 7803 1100.

13. Down's Syndrome research project looking for more people to take part in trial

Hammersmith Medicines Research (<http://www.hmrlondon.com>) is working in partnership with psychiatrists and Imanova on a study to investigate a new treatment in people with Down's Syndrome. The project is funded by the drug company Roche.

They are conducting a clinical trial of a new medicine that they hope will improve memory and attention in people with Down's Syndrome. The trial involves taking pictures of the brain in special scanners (MRI & PET).

If you know someone with **Down's Syndrome who is aged 18 to 40** and might be interested to hear more about this study, please contact Hammersmith Medicines Research by phone or email, as follows:-

Telephone: 020 8963 4502 or 0800 783 8792. Email: recruit@hmrlondon.com.

An easy read information flyer is available [here](#) and more information can also be found on the Down's Syndrome Association website [here](#).

West Midlands

14. BILD General Practitioners Event Thursday 5th September, BILD offices, Birmingham

Family carers in the West Midlands are encouraged to tell their GPs about BILD's upcoming learning event: *What do you need to know about your patients with learning disabilities?*

This event will be helpful to GPs and Clinical Commissioning Groups wanting to improve primary health care services for patients with learning disabilities. Among the subjects the event will cover are:

- Mental health and people with learning disabilities
- Commissioning guidance
- Lessons from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities
- An example of successful commissioning

To book a place on this event please call Will Nicklin on 0121 415 6970 or email w.nicklin@bild.org.uk.

For more information please visit:

<http://www.bild.org.uk/our-services/events/gp-learning-event/>

East England

15. Free Transition Conference for Parents - Hertfordshire

Wednesday 28th August

Mymwood Life Skills Centre, Brookmans Park, Hertfordshire

[Brookdale Care](#) supports young adults with Autism and Learning Disabilities to reach their full potential through their specialist care pathways.

It is holding its first Transition Conference for parents of adolescents with Special Needs to provide some guidance and networking opportunities for families living in and around Hertfordshire

For more information, or to register, please visit the website [here](#).

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If you would like to contribute to the newsletter, please submit articles in plain English of no more than 230 words to info@familycarers.org.uk. We reserve the right to edit the articles to fit the newsletter whilst retaining the overall information. Due to the number of articles we receive we cannot guarantee inclusion of contributions.