

# Bulletin



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[www.familycarers.org.uk](http://www.familycarers.org.uk)

19<sup>th</sup> March 2012

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](mailto:info@familycarers.org.uk).

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## National

### **1. NHS Continuing Healthcare funding**

The Department of Health has set new deadlines for people who want to be considered for NHS Continuing Healthcare funding. Your local PCT should be sending out information about this. If you know someone who might want more information about this, contact the Continuing Healthcare lead person at your PCT. Here is a link to the information on the DH website:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleaqueletters/DH\\_133051](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleaqueletters/DH_133051)

## **2. Personal Independence Payment – a letter from the Office of Disability Issues**

Dear All,

I am writing to let you know that DWP have today confirmed plans to introduce Personal Independence Payment in stages so that they can learn from each stage and get the whole process right.

The Department have also announced how the Disability and Carers Service will organise itself internally to deliver the new benefit.

New claims to Personal Independence Payment

Bootle Benefits Centre will administer the first new claims from spring 2013, from areas including Merseyside, North West England, Cumbria, Cheshire and North East England. People in these locations will be the first to claim the new benefit.

This region has been chosen for a number of reasons. Primarily because Bootle handles about the right number of new claims to provide a meaningful test of Personal Independence Payment processes and IT functionality without overloading new systems.

Bootle is also a high performing unit, and has a good track record on implementing innovative ways of working.

The remaining network of benefits centres currently administering new claims for Disability Living Allowance (DLA) will start to take on new claims for PIP from summer 2013, once evidence is in place that processes are working as intended. In addition, this network will handle continuing DLA claims for children.

However the Department is currently reviewing operational structures in readiness for Personal Independence Payment and the existing regional boundaries for the benefits centres may change. We will let you know the outcome of the review.

Reassessing existing DLA claimants for Personal Independence Payment

If a person is already getting DLA they will need to make a claim for the new benefit. DWP will write to them to let them know when they can make a claim to Personal Independence Payment and how to do that.

If a person's DLA award becomes subject to change after autumn 2013, for example if they have a change in their condition, or new evidence comes to light which means that we may need to look at that their entitlement again, DWP will ask them if they want to claim Personal Independence Payment. It will not be possible to review their DLA award. If they decide not to claim PIP, their DLA award will end.

All current DLA claimants of working age will have been contacted about assessment for Personal Independence Payment by spring 2016.

Blackpool Benefits Centre (formerly known as the Disability Contact and Processing Unit) based at Warbreck House, Blackpool, will administer all reassessment activity.

DWP expect to publish a further [policy briefing document](#) on reassessment shortly.

DWP will be consulting on these arrangements and other features of Personal Independence Payment. We will also begin to draft Regulations under the powers we have in the Welfare Reform Act 2012.

ODI Communications Team

### **3. IBE Epilepsy and intellectual disability survey**

Can you take a few minutes to complete this and pass on to any families you may be in touch with?

Thanks

Janet <http://www.jan-net.co.uk/>

We have been working with Mike Glynn from the International Bureau for Epilepsy to collect some data on the needs and experiences of people who work with or care for (in both a professional and family context) people with epilepsy and intellectual disability.

We are hoping to collect data from as many different countries as possible to identify good and bad practice in the way people with epilepsy and intellectual disability are treated across the world, and to pinpoint key areas that requiring more detailed research with the eventual goal of reducing health inequalities for this group.

We have developed a short online survey that asks people to tell us in their own words about the experiences they have had in working with or caring for people with epilepsy and intellectual disability.

We have ethical approval from the Cardiff University Ethics Committee for this study.

The link to the study is here;

[https://www.surveys.cardiff.ac.uk/epilepsy\\_and\\_id\\_ibe\\_survey](https://www.surveys.cardiff.ac.uk/epilepsy_and_id_ibe_survey)

Please do not hesitate to contact me if you have any queries about the study. We would be very grateful for your help.

Many thanks

Rose

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# "HeartFelt"

*A healthy heart event for Women  
by Women*

**Come along to hear how you can improve your health**

It is well documented that there is a high prevalence of heart disease amongst black and minority ethnic communities. The British Heart Foundation and The Afiya Trust are holding an event targeting women to highlight the importance of maintaining a healthy heart and healthy lifestyle.

**Date: Wednesday 9th May 2012**

**Time: 9.30am – 3.30pm**

**Venue: Coin Street Neighbourhood Centre  
London SE1 9NH**

**Keynote Speaker: Bonnie Greer OBE - Playwright, Author and Critic**

This is a free event on a first come, first serve basis so to register please contact : [events@afiya-trust.org](mailto:events@afiya-trust.org)

**Food and refreshments will be served**

For venue details: <http://www.coinstreet.org/howtofindus/coin-street-neighbourhood-centre.html>

North West

## **5. IHAL & NDTi FREE event**

Getting better health information for people with learning disabilities and family carers - What information do we have and how can we use it?

A free all day event - April 26th 2012 at Burnley Football Club, Harry Potts Way, Burnley, Lancashire, BB10 4BX

Event aimed at:

Self-advocates and family carers, partnership board members, members of LINKs/ Health watch, commissioners, health and social care staff and others who have an interest in supporting people with learning disabilities and family carers to get better health services.

If possible, please send your completed form as an email attachment to [Pauline.white@ndti.org.uk](mailto:Pauline.white@ndti.org.uk) or send in the post to:

National Development Team for Inclusion, Montreux House, 18a James Street West, Bath, BA1 2BT.

Event flyer <http://www.choiceforum.org/docs/fcb.pdf>

Application form <http://www.choiceforum.org/docs/fccb.pdf>

## **6. Work In Progress**

Work In Progress is a 2 year lottery funded inclusive research team looking at what the barriers to work are and how supported employment projects can best support people into paid work. The launch of our findings will take place at the Eden Project on 21st June 2012. We will also be giving an account of our experience of running an inclusive research project. We think the findings of our research will be of great interest to anyone who is involved with, or has an interest in, the future of supported employment as well as a connection to the learning disability community. We very much hope you will be able to join us and look forward to meeting you. To see our flyer and booking form, go to:

[http://www.cornwallpeoplefirst.com/fun\\_events/work\\_in\\_progress\\_the\\_launch](http://www.cornwallpeoplefirst.com/fun_events/work_in_progress_the_launch)

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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.*