

Bulletin



www.familycarers.org.uk

Tel: 07747 460727

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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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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. National Family Carer Network to host the next BME Resource Guide

Reaching and Supporting Diverse Communities is a guide to meeting the needs of people with learning disabilities and family carers, from newly arrived, Black, Asian and other Minority Ethnic (BME) Communities.

Currently hosted by Hft, <http://www.hft.org.uk/Supporting-people/family-carers/Resources/BME-Resource-Guide/> the National Family Carer Network has pleasure in announcing that we will be hosting the Resource Guide from January 2013.

The National Family Carer Network anticipate that the next version will be available from March 2013. If you have any updates or information about work with supporting people with learning disabilities and family carers from diverse and BME communities, we have a form on our website [here](#), which you may complete and return to us at info@familycarers.org.uk.

If you have any queries or would like to discuss further, please do contact us at info@familycarers.org.uk or tel: 07747 460727.

2. Access to Work

The Government has announced that disabled entrepreneurs and small businesses will benefit from more support to pay for specialised equipment and other costs faced by disabled people in work under changes to the Access to Work programme.

Access to Work provides financial help towards the extra costs faced by disabled people at work, such as travel costs, specially adapted equipment and support workers.

The changes announced mean:

Businesses with up to 49 employees will no longer pay a contribution towards the extra costs faced by disabled people in work, saving them up to £2,300 per employee who uses the fund; Disabled jobseekers who want to set up their own business through the New Enterprise Allowance will now be eligible for Access to Work funding from day one of receiving Job Seekers Allowance; and Access to Work advisers will be given more flexibility in deciding which equipment is funded through the scheme, offering more choice to disabled people in work.

The Government will also implement a package of measures recommended by the Access to Work expert panel, chaired by Mike Adams from the Essex Coalition of Disabled People (ecdpp). The measures include funding the physical transfer of equipment, introducing a 'fast-track' application process where appropriate, and working with employers to find more imaginative solutions to support individuals. The panel will continue to advise DWP on further reforms to ensure the best use of funding.

Last year the programme helped 30,000 disabled people keep or get employment. Research also shows that around half (45 per cent) of Access to Work customers would be out of work if they did not receive support through the scheme.

Anyone interested in applying for this support, can search 'Access to Work' at www.gov.uk/access-to-work/ to find out details of contact centres.

3. Guardian article - Asperger's syndrome dropped from psychiatrists' handbook, the DSM

Asperger's syndrome is to be dropped from the psychiatrists' Diagnostic and Statistical Manual (DSM) of Mental Disorders, the American publication that is one of the most influential references for the profession around the world.

The term "Asperger's disorder" will not appear in the DSM-5, the latest revision of the manual, and instead its symptoms will come under the newly added "[autism](#) spectrum disorder", which is already used widely. That umbrella diagnosis will include children with severe autism, who often do not talk or interact, as well as those with milder forms.

The full article can be read [here](#).

4. Health Secretary orders review into new rating system for NHS and social care

Health Secretary Jeremy Hunt has today ordered a review of the way that information on NHS and social care services is given to patients and the public.

The study will assess the merits of an 'Ofsted-style' system of ratings for hospitals and care homes. It will look at the way in which a new ratings system could help improve standards of care across the health and social care system. In particular, it will look at how information about services can be communicated to the public and how this information can be used to drive up standards across the system.

The full article can be read [here](#).

5. Personal Health Budget report and announcement

The Personal Health Budgets evaluation report has been published, accompanied by a Ministerial announcement, which can be read here:

<http://www.personalhealthbudgets.dh.gov.uk/>

A personal health budget is an amount of money given to someone with a long term condition, to help them design a package of care support from clinicians and others.

This should mean they have more control over the nature of the treatment provided, instead of simply getting care set out by the NHS.

The Government has been piloting personal health budgets at 20 in-depth sites for the last three years. An independent evaluation report published by the personal health budgets evaluation (PHBE) team led by the University of Kent has found that people's quality of life had improved; and the amount of times people had to attend hospital decreased overall. The benefits seemed to be felt more strongly by people with the highest health needs, and costs were also lower.

As a result, personal health budgets will initially be targeted at people who are already getting NHS Continuing Healthcare (a package of continuing care provided outside hospital, arranged and funded solely by the NHS, for people with ongoing healthcare needs). The roll out will mean that by April 2014 up to 56,000 people will have the right to ask for a personal health budget.

It is also hoped that clinical commissioning groups will offer a personal health budget to more people with a long term condition who may benefit from the additional flexibility and control.

6. Pensioners fail to claim millions in benefits

An estimated 40% of people with learning disabilities are cared for by a parent over 60 years old. (Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy, 2009)

According to a survey by Just Retirement Solutions, retired people are failing to claim an average £676 in state benefits and many are not claiming at all.

Unclaimed state benefits has been an issue for many years but with average retirement income falling dramatically and pensioners feeling more and more squeezed, it's never been more important to claim everything you're entitled to. The research shows the scale of the problem, with more than half of the people contacting them for information on equity release failing to claim any or all of the benefits they are entitled to.

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

7. Shelter - Facing up to Housing Benefit changes and Housing Benefit delays

Housing benefit changes will take effect from April 2013. If the council decides you're living in a home that's too big for your needs, your housing benefit could be restricted. There will also be a limit on the total amount of benefits you can claim – £500 a week for single parents or couples with children, and £350 for individuals. If these changes affect you, now's the time to look at your options and start planning.

Visit the Shelter website [here](#) for further information, advice guides, and useful resources for Housing Benefit.

Shelter also have a number of useful resources, should you experience housing benefit delays. These can be accessed [here](#).

8. Lower use of mental health services by South Asian people with learning disabilities than white British comparison groups

The notion of double discrimination, where ethnicity and disability can form a double barrier to those seeking support, has long been recognised. Indeed, there was a clear requirement in the Valuing People strategy to identify resources to address these issues through work streams in local partnership boards.

A recent report by the Foundation for People with Learning Disabilities, '[Reaching out to Families](#)' reported on work with local groups aiming to build strong, sustainable networks to identify what factors enabled success in accessing appropriate services, and to disseminate those lessons to a wider audience.

The full article can be read [here](#).

9. Research into online support for UK-resident parents of people with Rett syndrome

Jo Belcher is a PhD student who is researching the usefulness (or otherwise!) of online support websites and email groups for UK-resident parents of people with Rett syndrome.

She would like to hear from as many parents of people with Rett syndrome living in the UK as possible - including parents who have never used or stopped using the Internet or online support.

Jo is asking parents to fill out a paper or online survey that will take between 10-15 minutes to complete (depending on your experiences of online support).

The survey is available online here: <https://www.surveymonkey.com/s/RettSyndrome> or Jo can send you a paper copy with a Freepost envelope (please contact Jo on j.belcher@surrey.ac.uk or 07583 641437).

West Midlands

10. “Managing My Money “ - Free training course for people with a learning disability and live independently

[Building Bridges Training](#) are delivering some free training after Christmas – three day accredited courses called Managing my Money. The courses are for people who live on their own and manage their own money. Please see the flier [here](#) for more information.

If you want to come but cannot make these dates or venues, please contact Buiding Bridges for future course dates:

wendy@building-bridges-training.org tel: 0121 559 9197

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