

Bulletin



National
Family Carer
Network

www.familycarers.org.uk

Tel: 07747 460727

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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. Forum for family carers of people with learning disabilities

Monday 3rd March 2.00 – 4.00pm

Royal College of Psychiatrists, 21 Prescot Street, London, E1 8BB

The [National Audit of Learning Disabilities](#) (NALD) has carried out a small study in GPs, general hospitals and mental health hospitals to see if their project team could carry out a larger study to help these services improve the care they provide to people with learning disabilities.

The team wants to organise a focus group for carers/family of people with learning disabilities to hear what they think of the findings of this study and whether they have focussed on the main issues that are important for people.

This will help them to improve the study if they were to do it again on a larger scale.

Please see the invitation [here](#) for more information.

Each participant will be paid a half day session fee of £50 plus travel expenses.

What will it involve?

All participants will be sent a short report presenting findings of the study, to read before the meeting. In the workshop, participants will be asked for their views on the findings. For example, how useful the information is and whether there is anything missing.

Who can participate?

Family/friends of people with learning disabilities who have used GPs, acute and mental health hospitals. If the person is in fulltime care and family/friends are unable to attend, paid key workers are welcome to attend. There are 10 places available and places will be allocated on a first come first served basis.

If you are interested in participating, please contact Pamela Gallagher on: 020 3701 2698 or email: pgallagher@rcpsych.ac.uk.

2. Personal Health Budgets: Brokerage, advice and advocacy

Good quality advice, advocacy and brokerage functions are a vital part of the personal health budget system. This is especially important when people do not have the capacity or confidence to manage the budget alone - without this additional support many people would be unable to take up the offer of a personal health budget.

NHS England has produced a number of useful brokerage, advice and advocacy resources on their website which can find [here](#), along with personal health budget information [here](#).

3. CQC Appoints Whistleblowing Advisor

Earlier this month, paediatrician Dr Kim Holt began a new role at CQC as a professional advisor providing advice to CQC on issues relating to whistleblowing. Dr Holt began her new role by leading a workshop with people who have experience of whistleblowing, who discussed the issues they faced and the barriers that can prevent staff from raising concerns.

The feedback will help CQC to develop its new approach to regulating health and adult social care services, which will include assessing how providers listen to and treat whistleblowers. The feedback will also give CQC a better understanding of the experiences of staff who raise concerns and the issues whistleblowers face.

To find out when and how to raise a concern, you can read their guide [here](#).

4. Counting the Cuts: report

This report, published by the [Centre for Welfare Reform](#) on behalf of the [Campaign for a Fair Society](#), summarises the impact of the UK Government's cuts programme. It demonstrates how the cuts target people in poverty and disabled people.

To read the report, please click [here](#) or visit the website [here](#).

5. Petition: Government Policy on Disability Living Allowance

Dorothy Jump, a family carer and member of the National Family Carer Network has set up a petition to stop the change to indefinite claims on Disability Living Allowance Benefit. To find out more about the campaign and to sign the petition, please click [here](#).

6. Challenging Behaviour Foundation's Family Carer's Email Network

The Challenging Behaviour Foundation (CBF) offers a free email network which is open to any family member caring for a relative with severe learning disabilities and behaviour described as challenging. Parents, siblings, grandparents and aunts and uncles are all very welcome to join.

You can use the network to ask questions, share stories and get (or give) advice to other families who might be in similar situations. The network is a confidential and supportive community, moderated by the CBF.

For more details, please see the poster [here](#). To join the email network you need to fill out a short application form which is available to download from their [website](#). Alternatively, please telephone 01634 838 739 or email network@thecbf.org.uk.

7. Confidential Enquiry DVD

The team who ran the Confidential Inquiry into premature deaths of people with learning disabilities has worked with [The Misfits Theatre Company](#) to make a DVD which presents the findings of the Confidential Inquiry through the stories of John, Bill, Karen and Emily.

You can watch the film [here](#). Alternatively, if you would like a copy of the DVD, then please email your address to: ci-team@bristol.ac.uk or phone 01173 310980.

8. Training videos on clinically related challenging behaviour

NHS Protect has launched a series of training videos to accompany the recently published guidance '**Meeting needs and reducing distress: Guidance on the prevention and management of clinically related challenging behaviour in NHS settings**'. The videos, like the guidance, have been developed by NHS Protect in collaboration with a clinically led Expert Group.

The videos focus on short scenarios involving patients and their interaction with the health service, based on common situations faced by staff. They demonstrate the importance of building staff-patient relationships and using positive engagement, compassion, empathy, communication techniques and other skills, as well as ways in which environmental elements can be incorporated to help reduce distress and meet needs.

They include interviews with experienced healthcare staff and managers in various roles speaking about personal experiences they have encountered and techniques that staff can use to prevent and manage challenging behaviour.

While the videos are designed to be incorporated in challenging behaviour awareness training, they can also be viewed independently to aid learning by staff, patients, carers, students and others.

The full set of videos can be viewed or downloaded at:
<http://www.nhsprotect.nhs.uk/reducingdistress/training-videos/>

For more information regarding the work NHS Protect and the Expert Group have undertaken on challenging behaviour, the guidance, and other resources and useful tools please visit www.nhsprotect.nhs.uk/reducingdistress/.

9. 'Putting the pieces together' guide

[Learning Disability Today](#) has recently published a guide on autism and challenging behaviour. It features positive behavioural support, living environments for people with autism, and tips for managing challenging behaviour.

To read the guide, please click [here](#).

10. Action Against Cruelty: new website resource

Action Against Cruelty is a new free resource promoting the independence and well-being of people with learning disabilities through effectively tackling loneliness, harassment and abuse. The website contains guidance, best practice information, and research.

There is also an Easy Read microsite designed for people with learning disabilities to access clear guidance on recognising and reporting cruelty, as well as identifying and promoting positive relationships and offering support to friends who might themselves be victim to crime or cruelty. There are also numerous additional accessible resources for readers to download.

You can visit the website [here](#).

11. People with learning disabilities need to be empowered to fight their cause

The Guardian has published an article about [Change's](#) campaign to see people with learning disabilities employed as experienced professionals and equal partners to help tackle learning disability-related issues.

A Guardian poll carried out in 2010 revealed widespread discrimination and misconception, with a third of Britons believing those with learning disabilities cannot live independently or take jobs.

Yet the majority of the people working in adult social care and paid to tackle these issues – though "very passionate and well-meaning" – are not learning disabled themselves. Therein lies the problem, the charity claims.

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

12. Type 2 Diabetes DVD

People with learning disabilities are 5 times more likely to develop Type 2 Diabetes. This can be because of poor health, poverty and a lack of accessible information about Type 2 Diabetes, healthy eating and exercise.

Speakup has produced a film about Type 2 Diabetes which can help people to make better health choices, eat more healthily and get more exercise in their daily life. The DVD shows people with learning disabilities talking about Type 2 Diabetes, eating healthily and exercising and gives people some good ideas about how to do this everyday and on a budget.

You can watch an online sample copy at www.diabetesdvd.org.uk. The film was produced in partnership with [Diabetes UK](#) and is available to buy for £30 including delivery. To order your copy, or to find out more, please email orders@friendlyresources.org.uk.

East England

13. Hertfordshire: Family Carers Wellbeing Groups

Hertfordshire Partnership NHS Foundation Trust has recently launched two new wellbeing groups for family carers who look after someone with a learning disability.

All meetings are free to attend and refreshments are provided. Just go along, or you can sign up for emails on the latest local and national news in learning disabilities by contacting Lucy Martensz by email: Lucy.Martensz@hpft.nhs.uk or telephone: 01438 792160.

Click [here](#) for the Hemel Hempstead group flyer

Click [here](#) for the Welwyn Garden City group flyer

Yorkshire and the Humber

14. Adult Social Care Services and Personal Budgets: short films

Barnsley Council have developed a series of short films about adult social care services, personal budgets, and living independently. It includes the story of Simon and Andrew who have learning disabilities and live in supported accommodation. Simon, Andrew and their personal assistant Mark explain how personal budgets have helped them to live independently in their own place.

You can view the films on Youtube [here](#) and find out more on the website [here](#). You can also find further information and resources on Barnsley Council's adult health, social care and wellbeing [website](#).

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