

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. National Family Carer Network news

NFCN Trustee awarded MBE

We are very happy to share with all our members the fantastic news that Carol Robinson, one of our Trustees, has been awarded the MBE in the New Year Honours "For services to children with special educational needs". Congratulations to Carol!

NFCN Membership

If you are a member organisation with information currently displayed on our [website](#), could we please ask you to take a moment to check that your details are correct and up-to-date. If you wish to make any amendments to your listing, please contact Rachel Gibson by email info@familycarers.org.uk or telephone 07747 460727.

2. Children and families bill win - amendment to include all disabled children

The children and families bill for England has been amended to include disabled children and young people within its scope. The bill, which will become law in England in 2014, will make major changes to the way children and young people with special educational needs (SEN) are supported. However around 25% of disabled children do not have special educational needs. Such children would have been excluded from the benefits which some of the new reforms will bring.

Reforms include:

- a legal duty on local authorities to work together with health services when arranging education, health and social care support for children and young people in the area with SEN
- a legal duty on local authorities to publish a 'local offer' of information about services they expect to be available in the area to support children and young people with SEN.

[Contact a Family](#) has argued along with other organisations, that the bill should include all disabled children, and welcomes these amendments which will ensure that all disabled children and young people, not just those with SEN, will benefit from some of the new reforms.

You can find more information on the Contact a Family website [here](#).

3. The Care Bill: updated factsheets

Factsheets have been updated to reflect changes to the Bill that have been made since it was published in May 2013. There are two new factsheets to reflect the provisions added to the Bill on Chief Inspectors and CQC independence (factsheet 17) and Trust Special Administration (factsheet 18).

Click [here](#) to access the updated and new factsheets on the Gov UK website.

You can also access a useful summary of clauses in the Care Bill, including whether they are new provisions, or whether they are a consolidation or modernisation of the law, on the Local Government Association website [here](#).

4. Patients with learning disabilities “invisible” in hospital, report claims

Hospital patients with learning disabilities face longer waits and mismanaged treatment due to a failure to understand them by nursing staff, a new report has claimed. The report found that the main barrier to better and safer care was a lack of effective flagging systems, leading to a failure to identify patients with learning disabilities in the first place.

There was also a lack of understanding by nursing staff about learning disability issues and a lack of clear lines of responsibility and accountability for the care of each patient with learning disabilities.

The report, ‘Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals’, published in the *Health Services and Delivery Research* journal, found one example where a patient who had problems making herself understood was accused of being drunk by hospital staff.

The study included questionnaire surveys, interviews and observation with senior hospital managers, clinical staff, patients and carers in all types of areas within hospitals in the NHS.

As a result of the findings, the report makes several recommendations, including having specialist learning disability liaison nurses and ward managers with specific responsibility to advocate on behalf of patients with learning disabilities.

It also recommended that the NHS investigate practical and effective ways of flagging patients with learning disabilities across services and within hospitals while also implementing procedures to ensure that family and other carers are involved in the care of such patients.

You can read the full Learning Disability Today article on their [website](#) and read the report and summary on the National Institute for Health Research website [here](#).

5. Plan for Life study: long-term planning in adult learning disability social care

Learning disability charity, [FitzRoy](#), has recently launched its report *Plan for Life*, which shows that lifelong planning in social care for adults with learning disabilities improves wellbeing and reduces long-term care costs.

The study based on opinion research with 100 local authorities in England, reveals the systemic pressures on local government that have led to widespread short-term planning and an increase in long-term care costs at a time when the pressure to reduce spending has never been greater.

You can read Fitzroy's report *A Plan for Life* on their website [here](#) where you will also find links to further resources and a short video explaining the key issues.

6. Limiting physical restraint: new consultation commissioned from Royal College of Nursing

The Royal College of Nursing (RCN) has been commissioned by the Department of Health to lead a consortium which will develop guidance for health professionals on reducing the need for restrictive practices in health and adult social care.

Restrictive practices refers to occasions where a patient or service user may be restrained or other physical intervention is needed.

A consultation document has now been produced, and the RCN wishes to hear from health professionals, carers, and others with experience of restrictive practices in a health care setting. The consultation will be open until 13th February 2014.

The guidance aims to provide clarity about the use of physical interventions as a last resort. It will also provide guidance for the use of positive behavioural support, an approach which when used appropriately is designed to minimise the use of restrictive interventions.

You can find full details on the RCN [website](#) and download the consultation documents, including easy read versions, [here](#).

7. Patient and Public Engagement: The Public View - Your View

Patient and public engagement (PPE) should be an integral part of delivering good healthcare. Involving the people who use healthcare services is a statutory obligation and a democratic principle. As part of their commitment to make the patient voice heard, [Patient Opinion](#) has joined forces with [People Matters Network](#) to research where the healthcare economy is on the road from good intentions to good engagement.

They want to know:

- How well does your local healthcare service engage with you?
- Do you feel consulted with, listened to and made to feel that your views can influence the type of healthcare provided within your area?
- Where do you go to make your voice heard?

If you would like to contribute to the research and share your experiences, you can take part in the survey [here](#).

South West

8. Survey - Short Breaks for Disabled Children and Young People in Hampshire

This survey has been designed by [Parent Voice](#) and [Hampshire Parent/Carer Network](#) (HPCN) to gather your views on short breaks for disabled children and young people in Hampshire.

Over the next few weeks, important decisions will be made regarding funding priorities for 2014 and beyond. In 2011, County Councillors agreed a 3 year commitment to Short Breaks funding which comes to an end in April 2014. The Short Breaks Programme was introduced in 2009 and thanks to Parent Carer feedback and the support of HPCN and Parent Voice, the programme is now supporting more than 4,000 disabled children and young people to enjoy a leisure activity with their peers and for many families this is the only support that is being received.

There is a short window of opportunity to let the decision makers know how much this programme means to families across Hampshire, and the impact it will have if budgets and services are significantly reduced.

If you are able to support this campaign, you can find more details about how to get involved on the Parent Voice [website](#). You can also complete their short survey about your Short Breaks experiences in 2013 here: <https://www.surveymonkey.com/s/shortbreaks2013>

HPCN and Parent Voice will ensure that the results are shared with Councillors before funding decisions are finalised during February.

East Midlands

9. Creative Communication Training day

Tuesday 29th April 2014 10.00am – 16.00pm

Fairplay, Alexandra Road West, Chesterfield, Derbyshire, S40 1NP

This one day Creative Communication training from [CAN Communicate](#) aims to bring to the attention of the delegates the ideas, theories and practical skills needed to use Creative Communication when working with, working for, or interacting with people with the label of PMLD.

Following the training session delegates should be able to demonstrate and apply alternative and creative methods of communication, in order to allow more effective communication with individuals.

Click [here](#) for the flyer and [here](#) to find full details of the training day, along with a booking form.

Costs:

£80 per person (£70 pre-Jan 31st) - This includes all materials, refreshments and lunch.
£65 Discounted fee (£60 pre-Jan 31st) - Student in the field of learning disability; family carer or enabler; small voluntary organisation (i.e. an organisation working in Learning Disability/Special Needs field with no more than 5 paid members of staff).

North West

10. North West Regional conference

Tuesday 25th February - Thursday 27th February 2014

Hilton Hotel, Blackpool

The 11th Annual North West Regional Conference is a three day residential event and the only conference of its kind for people with a learning disability in the North West region. It gives people with disabilities a chance to get their voices heard and raise issues which can be taken by National Representatives to Government through the National Forum.

Click [here](#) for the conference pack with more details and a booking form.

11. Autism Awareness Training - 2 free places available for NFCN members on 26th February

Wednesday 29th January 2014, 10.00am-1.00pm

Wednesday 26th February 2014, 10.00am-1.00pm

Kuumba Imani Centre, Princes Road, Liverpool, L8 1TH

This training centres on real life stories and experiences of the trainers, and is delivered by [UR Consultants](#), a social enterprise employing trainers and consultants with autistic spectrum conditions and/or learning disabilities. The day will cover:

- Introduction to the autistic spectrum
- Discuss the 'Triad of Impairment' and how this impacts on the lives of people with autism
- Learning about how people see the world differently
- Understanding of the sensory world of people with autism
- How autism impacts on interaction and communication
- Anxiety and challenging behaviour and autism
- Understanding practical strategies for working with people with autistic spectrum conditions

Costs: £30 per delegate. For more information and to book your place, contact Sarah Bird on 07854 349 613 or e-mail URConsultantsKnowsley@unitedresponse.org.uk.

We have kindly been offered two free places for the **Wednesday 26th February** session, so if you are an National Family Carer Network member and you feel this course would be beneficial for you, please contact our office on info@familycarers.org.uk or 07747 460727.

National Family Carer Network

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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.