

# Bulletin



National  
Family Carer  
Network

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

Tel: 07747 460727

31<sup>st</sup> October 2013

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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](mailto: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. NFCN Survey reminder: Promoting family-led support

Over the next two years the National Family Carer Network will be working to promote family-led support.

We want to:

- Understand more about the experiences of families that have developed their own support;
- Find out family carers views family-led support and what help they would like to consider it as an option;
- Develop practical resources that provide families with the information, advice and assistance they need when thinking about arranging support themselves.

You can help by filling in a survey telling us about your current involvement in your relative's support and your views about what might happen in the future.

Click [here](#) to take part in the survey online.

To find out more about the work, or request a paper copy of the survey, please contact Paul Swift: telephone 07740 946564 / 0117 9294365 or email: [paulswift.research@gmail.com](mailto:paulswift.research@gmail.com).

## 2. Open letter - response from the Shadow Lords Education Ministers

The National Family Carer Network joined with [Every Disabled Child Matters](#) and over 100 other signatories to draw attention to the fact that whilst the new Children and Families Bill would apply to children and young people with special educational needs, they would not benefit the whole community of disabled children and their parents.

Please read the open letter [here](#).

Every Disabled Child Matters received a response to the letter from the Labour Shadow Ministers for Education (Lords). Please click [here](#) to read. As you will see, there is much support for our concerns and there will be a continuation to work closely with Government Ministers.

### 3. Abuse allegations at Devon residential care home described as shocking by lawyer representing vulnerable adults

The lawyer representing a number of vulnerable adults allegedly abused at a care home in Devon has said that the allegations at Veilstone care home near Bideford could be one of the worst incidents of abuse towards vulnerable adults in residential care.

Alison Millar a specialist lawyer in abuse claims from law firm [Leigh Day](#) has also confirmed that one of her clients had previously been physically abused at Winterbourne View, the notorious care home near Bristol, which was exposed by an undercover BBC Panorama team.

Police confirmed yesterday that seven people have been arrested in relation to the allegations of abuse at Vielstone care home.

You can read the full article [here](#), as well as a related article [here](#).

### 4. Open consultation: Special Educational Needs (SEN) Code of Practice: 16 to 25

The Government is changing the law on special educational needs (SEN) and has written a draft Code of Practice. Now it wants to hear from young people about what they think of the areas it covers.

Click [here](#) for the Response Pack: What you need to know about SEN reforms.

Click [here](#) for the SEN code of practice consultation document.

The deadline for responses is 20<sup>th</sup> December 2013.

For more details, and to respond online, click [here](#). You can also email your responses to: [YoungPeopleSEN.CONULTATION@education.gsi.gov.uk](mailto:YoungPeopleSEN.CONULTATION@education.gsi.gov.uk)

If you would like to participate in *the Open Consultation - Draft 0 to 25 special educational needs (SEN) code of practice, draft regulations*, which closes on 9<sup>th</sup> December, you can do so [here](#).

### 5. Ordinary Residence report

[Linkage Community Trust](#) has recently published a report into the social care ordinary residence landscape in England. Ordinary residence guidance was introduced to clarify the status of people placed in residential care outside their original area and aims to establish which local authority has to fund their support. Lack of clear guidelines has left much of this matter subject to the interpretation of local authorities and health organisations and practice varies significantly up and down the country.

Click [here](#) to read the report *Location Location Location: A postcode Lottery?*

## 6. 'Ending 15-minute care': Department of Health response

The Department of Health has issued the following response to Leonard Cheshire Disability's [campaign](#) about its report 'Ending 15-minute Care':

The report and campaign have effectively highlighted the problem of poor local authority commissioning practices. The Department of Health fully agrees that it is unrealistic to think that 15 minutes is enough time to help people who are older or who have a disability to do everyday things like wash, dress and get out of bed. It is not fair on those who need support and it is not fair on care workers. The report and the accompanying online campaign have been a valuable opportunity to spread this message, and encourage local authority commissioners to change the ways they operate.

Although ministers were not able to support the amendments suggested in the report, they hope that supporters of Leonard Cheshire Disability's campaign will be content with the amendment that the House of Lords agreed, which makes it clear that local authorities must consider a person's wellbeing when arranging their care.

Authorities that commission care in ways that force people to choose between being washed and being fed would clearly be failing to meet this duty.

The department will be working over the coming months to develop statutory guidance on commissioning and market shaping, which will be a valuable opportunity to influence local practice.

To read the full statement, please visit the DH website [here](#).

To read Leonard Cheshire Disability's response: *Are we content?* on their blog, please click [here](#).

## 7. Care Bill will change lives - but the Government must go further

The Care and Support Alliance, which includes the National Family Carer Network, has published an article urging the government to ensure its vision of social care becomes a reality for everyone by re-thinking its plans for eligibility and putting in place the funding to make it happen.

To read the full article, please visit the Care and Support Alliance website [here](#).

## **8. National Co-production Advisory Group: new members wanted**

[Think Local Act Personal](#) is recruiting service users and carers for their co-production board. The National Co-Production Advisory Group (NCAG) is a group which aims to ensure that people who use services co-produce the work of the Think Local Act Personal Partnership. The group is represented on both the Think Local Act Personal Board and Partnership and has a number of subgroups which feed into this work.

Co-production involves people who use services, carers and families, providers of services, and partner organisations, being consulted, included and working together from the beginning, middle and the end of any project that affects them.

NCAG is recruiting new members to its core group. They are particularly keen to receive applications from people who have an understanding of personalisation. This rewarding and exciting opportunity requires national travel and an expectation of attending at least 12 national meetings per year. You will be fully supported to attend all meetings.

The closing date is Friday 22<sup>nd</sup> November 2013. Interviews will be held on Tuesday 3<sup>rd</sup> December 2013.

Full details, along with how to apply and related documents, are available on the website [here](#).

NFCN has queried the payment and expenses policy of TLAP for taking part in the advisory group and are pleased that TLAP have a payment policy for people who use services and family carers. Click [here](#) to read.

## **9. Save on energy bills - free resources for people with disabilities and/or autism**

[Speakup](#) has been working with The Scottish Power Energy Trust to produce some accessible information to help people with learning disabilities and/or autism think about how to save energy in the home and reduce their bills. We can all save energy in the home and the film and booklet are not only about things such as using energy saving light bulbs, but also about draught proofing, insulation, beating the cold by wearing energy efficient clothing and keeping healthy in cold weather.

To watch the film online and download the leaflet for free, click [here](#).

You can order the DVD and booklet in hard copies to use in groups sessions or where an internet connection is not possible. There is a £10 fee to cover postage, packing and duplication.

If you would like to place an order, please email [orders@friendlyresources.org.uk](mailto:orders@friendlyresources.org.uk) or ring 01709 710199.

## 10. Healthwatch England's response to A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture

The Francis report into the failings at Mid Staffordshire NHS Foundation Trust highlighted significant and serious short comings in the complaints system. This prompted the Prime Minister to launch a review of the handling of concerns and complaints in NHS hospitals. The review, entitled "Putting Patients Back in the Picture" was chaired by the Rt. Hon Ann Clwyd MP for the Cynon Valley and Professor Tricia Hart, Chief Executive, South Tees Hospitals NHS Foundation Trust.

Healthwatch England welcomes the recognition of the problems individuals face when thinking about, or trying to make a complaint. They are particularly pleased that there is a recommendation about the role of the Healthwatch network in a public facing campaign. This will be crucial to ensure that people know both how to raise a concern or complaint and secondly the standards that they should expect.

Healthwatch England is calling for new pilots so that local Healthwatch can work with providers to improve low performing complaint systems and develop good practice. This will result in co-designed practical solutions to improve local complaint systems to meet peoples' needs.

Healthwatch England also:

- Recognises the issues outlined in the report in relation to complaints advocacy services and PALS.
- Calls for consolidated advocacy services and agrees with the need to review PALS so it is clear what the service offers to patients.
- Wants to work with the Department of Health and others to design and promote standards for health and social care complaints handling alongside a consolidated PALS and complaints advocacy offer.

The recommendations in the report recognise the need for greater accountability and scrutiny. Healthwatch England believes local Healthwatch can provide challenge to assess the quality of complaints handling by local commissioners and providers but recognise this may require greater resource to be put in place.

Healthwatch England welcomes the recognition in the report that providers need to meet their existing statutory obligations and that the existing regulations need revising to bring in additional duties. Healthwatch England believe that the Regulations should be changed so that 'worried bystanders' can also register concerns or complaints and be directed to local Healthwatch.

More information on Healthwatch England and its responses can be found on the [Healthwatch England website](#).

## 11. Short film: A Good Life, too

Click [here](#) to watch a remarkable short film about Alonzo Clements who was sent away when he was young to be cared for at an institution.

You can also read more about Alonzo's story [here](#).

## 12. Learning Disability and Diabetes research project

Lorna Rouse is an MSc student at Anglia Ruskin University in Cambridge and is looking for people with mild to moderate learning disabilities to help with her research.

The research project is looking at how people with learning disabilities manage diabetes. Although this condition is far more prevalent in people with learning disabilities there is very little research on this topic. Lorna is looking for over 18 year olds with mild to moderate learning disability and diabetes, and one person who supports them to manage their diabetes (e.g. family, friends, support worker) to take part in interviews on the topic.

Please see the links below for further details:

[Diabetes Project Information](#)  
[Diabetes Project Information Easy Read](#)  
[Participant Information Sheet](#)

If you would like to find out more about the project you can contact Lorna by email at [lorna.rouse@student.anglia.ac.uk](mailto:lorna.rouse@student.anglia.ac.uk).

## South East

### 13. Creative Minds Conference 2014

**Monday 10<sup>th</sup> March 2014 10.00am until 5.00pm**  
**Brighton Dome, Church Street, Brighton, BN1 1UD**

The first Creative Minds Conference is a one day event in Brighton about quality in learning disability led arts, managed and presented by by learning disabled artists.

It will involve seeing, talking and questioning. Artists and performers from Corali Dance Company, Action Space London Events, Carousel and Rocket Artists, as well as two independent artists and performers, will be presenting short sections of the work and having conversations about quality in the work they produce with conference delegates.

For more details, please see the flyer [here](#).

Costs: £30 if you buy your ticket before 14th January 2014, after that tickets will be £40 (includes lunch & drinks). To book online, please click [here](#).

## North East

### 14. Jack and the Beanstalk: Relaxed Performance

Tuesday 14th January at 11.00am

Newcastle Theatre Royal, 100 Grey Street, Newcastle NE1 6BR

Newcastle Theatre Royal's pantomime this year is Jack and the Beanstalk, and for the first time they are going to be putting on a 'Relaxed Performance' on 14<sup>th</sup> January 2014.

The theatre wants to welcome people with an Autistic Spectrum Condition, learning disability or sensory/communication disorder, as a way to give people who otherwise might feel excluded the chance to experience a live performance.

Tickets are priced at £8.50 (carer and teacher concession are available) and are on sale now. The performance can primarily be booked through the groups department 0844 8112122, but is also available online [www.theatreroyal.co.uk](http://www.theatreroyal.co.uk) and through the box office 0844 8112121.

You can find out more about the performance on the website [here](#).

## Yorkshire and Humber

### 15. Get Creative - Free Activity Day in Calderdale

Friday 22<sup>nd</sup> November 10.00am – 3.00pm

Orangebox, Thomas Street, Halifax

[Purple Patch Arts](#) are running a fun filled day of free activity on 22<sup>nd</sup> November. There will be lots of art, dance, drama and music activities all day that will help build creativity, confidence, and positive thinking.

There is no need to book a place, just pop in to say hello and join in.

There will be free refreshments, but if you want to spend the full day there, bring a packed lunch to keep those energy levels up!

If you have any queries, you can contact Purple Patch Arts by phone on: 07590 909 071 or by email: [comms@purplepatcharts.org](mailto:comms@purplepatcharts.org).

## North West

### 16. Save Learning Disabilities Studies at the University of Manchester Campaign

The Learning Disabilities Studies course is a unique and innovative degree programme which includes learning disabled adults at the core of its work, helping to make the course real. A Partnership Steering Group of learning disabled experts by experience works alongside students and lecturers in development, teaching and research.

In August the programme was closed, ostensibly because of student numbers, yet the uniquely late recruitment patterns of the programme were not taken into account, and target figures for recruitment were changed from 22 to 25 in the spring. Inexplicably, the programme was also barred from clearing processes (open to all other undergraduate courses in the School of Education) and forbidden to continue with their usual recruitment into September. It appears that the University had made the decision to close the course before the target deadline as they do not value or wish to continue this field of study.

The quality of the programme is not in question. It has had consistently high NSS scores, in fact 100% this year, and has always done well on other student evaluations. The programme over the years has produced informed leaders and supporters who invariably go on to management positions understanding how to involve people with learning disabilities who in turn, know what it feels like to have a learning disability.

The closure announcement has been received with extreme disappointment and concern from staff, students, Steering Group members, professionals and organisations across the country, many of whom have signed an online petition asking the University to reverse its decision.

If you would like to sign the petition, you can do so [here](#).

The campaign organisers would also be most grateful if you would consider writing to Dame Nancy Rothwell, the President and Vice-Chancellor of the University of Manchester [president@manchester.ac.uk](mailto:president@manchester.ac.uk), expressing your concern at this programme's closure.

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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](mailto: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.*