

Bulletin



National
Family Carer
Network

www.familycarers.org.uk

Tel: 07747 460727

15th August 2013

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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 - Trustees wanted

The National Family Carer Network is a national charity which promotes better life chances for families that includes someone with learning disabilities. We link groups and organisations that support families of people with learning disabilities, provide information resources and workshops, and represent families at policy level.

We have a strong Board of Trustees and Advisers, the majority of whom are family carers themselves. To help us continue our development and growth of services, we are currently seeking new Trustees. If you are a family carer of someone with learning disabilities and/or have one or more of the following skills or experience, we would love to hear from you:

- Fundraising
- Financial management
- Marketing
- Public speaking.
- Law
- Local carers' centre/group experience.

The Trustees meet quarterly and all expenses are paid.

For more information please contact the Chair, Alison Giraud-Saunders, on 07721 843290. Our current Board members and information can be found on our website www.familycarers.org.uk.

We look forward to hearing from you before Wednesday 28th August 2013.

2. SCOC response to CQC consultation on 'A New Start'

The Standing Commission on Carers' response to the CQC Consultation on 'A New Start' is available to read on our website [here](#).

3. LGA and NHS England vision for £3.8 billion integrated care fund

The Local Government Association and NHS England have recently published their planning 'vision' for how the pooling of £3.8 billion of funding, announced by the Government in the June Spending Round, will ensure a transformation in integrated health and social care.

The full statement is available to read on the Local Government Association website [here](#).

4. FCSS - Free PIP workshops

Are you a family carer of an adult with a learning disability who is aged 16 or over?
Do you want to know more applying for PIP which is replacing Disability Living Allowance (DLA)?

[Hft's Family Carer Support Service](#) (FCSS) in partnership with a number of other organisations are offering free Personal Independence Payment workshops. These half-day sessions will give family carers the confidence and information they need to support their relative with their application for PIP.

Come along for practical tips and information about:

- preparing for the PIP application
- filling in forms
- how the DWP assesses and scores people
- preparing for the face to face assessment
- the new appeals process
- and more.....

The following dates are currently confirmed:

Monday 9th September - York

Tuesday 10th September - Liverpool

Wednesday 11th September - Leeds

Monday 28th October - Birmingham

Thursday 16th January 2014 - Southampton

For full details and how to book, please visit Hft's website [here](#).

If there isn't a session in your area, please revisit the website as more dates and venues will be added. You can also register your details with Hft by downloading and completing the form available on their website, and they will notify you when a local session has been arranged.

5. Centre for Crime and Justice Studies: Prison Service Journal

The [Centre for Crime and Justice Studies](#) has recently published its latest issue of Prison Service Journal which features **A brief report on the provision of services for hearing impaired, Intellectually Disabled, ADHD and autistic spectrum offenders at HMP Whatton and Doing Good Risk Assessment With Intellectually Disabled Offenders.**

To read the Prison Service Journal, please click [here](#).

6. Free Confidential Inquiry team events across England

The Confidential Inquiry into premature deaths of people with learning disabilities was funded by the Department of Health and reported its findings earlier this year. It reviewed the deaths of 247 people with learning disabilities within 5 Primary Care Trusts in the South-West of England. It also reviewed the deaths of 58 people without learning disabilities to place the findings in context.

The study reveals that the quality and effectiveness of the health and social care given to people with learning disabilities was deficient in a number of ways. Key recommendations are made which, were they individually and collectively implemented, would lessen the risk of premature death in people with learning disabilities.

The Department of Health has recently issued a formal response to the findings of the Confidential Inquiry and recognises that we all have a part to play in reducing premature deaths of people with learning disabilities.

The Confidential Inquiry team are running a series of free events across England this autumn to discuss the findings of the Confidential Inquiry and how to take forward the recommendations.

The dates and venues for these are:

- 17th September 2013, Tavistock Town Hall, Bedford Square, Tavistock, PL19 0AE
- 20th September 2013, RISC, 35 - 39 London Street, Reading, RG1 4PS
- 23rd September, Brighthelm Centre, North Road, Brighton, BN1 1YD
- 25th September, Research Park, 97 Vincent Drive, Edgbaston, Birmingham B15 2SQ
- 26th September*, Town Hall, Pinston Street, Sheffield, S1 2HH
- 27th September, East Community Complex, Peterborough, PE1 5EN
- 30th September 2013, NHS England, Newcastle Upon Tyne, NE15 8NY
- 1st October 2013, Botcherby Community Centre, Carlisle, CA1 2UE

All events (apart from in Sheffield) will take place from 10.00am – 1.00pm (9.30am for tea/coffee on arrival and sandwich lunch at 1pm).

In Sheffield the event will be from 9.30am-12.30pm

(9.00am for tea/coffee on arrival and sandwich lunch at 12.30pm)

Please book in advance to attend these meetings as places are limited.

For further information or to request a booking form please email sps-ci-events@bristol.ac.uk or call 0117 3310980.

7. Personal health budgets

On 1st August 2013, the Direct Payment in Healthcare regulations came into force across England. This means that the NHS can now lawfully offer direct payments for healthcare.

For further information please visit the NHS England website [here](#).

8. DWP stays silent on benefit cap impact on disabled people

The Department for Work and Pensions (DWP) has been criticised for failing to provide any figures showing how many disabled people have had their benefits “capped” under its sweeping new welfare regime.

DWP published research this week which showed how many people have been affected by the cap in the four trial areas of Bromley, Croydon, Enfield and Haringey, all London boroughs.

The new rules, introduced in the four boroughs in April and currently rolling out across the country, restrict the total amount of benefits that working-age households can receive to £500 per week.

Households are exempt from the cap if they include anyone claiming disability living allowance (DLA), attendance allowance, the new personal independence payment (PIP), or the support component of employment and support allowance (ESA).

But many disabled people with lower support needs are not exempt from the cap and are thought certain to have been affected.

To read the full article, please visit the Disability News Service website [here](#).

9. Legal challenge to council cap on social care packages fails

A council is set to introduce a policy that critics warn will force disabled adults into residential care, after a legal challenge against it failed.

Following a judicial review, the High Court rejected the challenge to Worcestershire Council's "maximum expenditure policy", which would set a limit on the amount the council will spend on supporting a disabled adult in the community equivalent to the cost of meeting their eligible needs in a care home.

The case was brought on behalf of D, a 17-year-old man with a moderate learning disability and epilepsy, whose mother feared that he would be forced into residential care as a result of the policy.

Lawyers for D argued that Worcestershire's consultation on the policy had been defective in so far as it failed to give respondents sufficient information about its consequences. They claimed that the consultation paper should have spelt out that people whose eligible needs were more expensive to meet in the community, rather than in residential care, would be faced with the choice of staying at home with insufficient support or moving into a care home. Instead, the council said that no one would be forced into residential care as a result of the policy alone.

To read the full article on the Community Care website, please click [here](#).

10. KIDS Playday report finds disabled children and young people still excluded from mainstream play opportunities

[KIDS](#) is a charity which works with disabled children, young people and their families. To celebrate Playday 2013, KIDS wanted to examine how inclusive play for disabled children has progressed over the past two years.

A survey of over 900 people working across play and leisure provision and disability services in England, found that although attitudes towards including disabled children and young people in mainstream activities has improved, most providers still do not have the resources or support needed to deliver good quality inclusion.

Only 47% of survey responders said that local services and playspaces were accessible to disabled children and young people.

To read the report and view the survey responses, click [here](#).

11. "Carespeak - Translating the Language of Social Care"

Following on from Mark Neary's [blog post](#) on the BBC website recently, a number of people have suggested that there should be a book written – a user's guide to the language of the social care world. Mark has compiled a list of social care phrases and is asking for readers to contribute any more that they can think of. To find out more, please visit Mark's blog [here](#).

12. Think Local Act Personal: Social Care Jargon Buster

Social care jargon can be incredibly alienating for people who use care and support services and their carers; as well as navigating the complex systems involved with social care they feel they are also expected to converse in a language they simply don't understand.

As a response the [Think Local Act Personal \(TLAP\)](#) partnership have produced a [jargon buster](#) of the 53 most commonly used social care words and phrases. A tool it hopes will save time, befuddlement and most importantly some of frustrations.

13. Easy read lung cancer leaflet

[Inspired Services](#) has created a new easy read leaflet on lung cancer which accompanies a wider NHS campaign.

Click [here](#) to download the leaflet.

14. MacIntyre Health and Wellbeing resources

[MacIntyre](#) is a national charity that provides a wide range of services for children and adults with learning disabilities and autism. Responding to the challenge posed by the changing needs of an ageing population MacIntyre set up a Dementia Special Interest Group to bring together staff from across the organisation who were supporting people who had or were at risk of developing dementia to share best practice, provide peer support and find out about what was happening across the country.

The group has created resources which they felt were missing, as well as training materials designed to facilitate a person centred approach to planning support. Some of these materials are freely available on their website, which you can find [here](#).

North West

15. Lancashire Carers Travel Guide

[East Lancashire Carers](#) have a number of booklets available on their website, including The Lancashire Carers Travel guide. It has been produced by Lancashire County Council, and features useful advice for carers who are planning to take the person they care for on holiday. It also includes links to range of organisations, companies, and hotels across the UK and beyond that can cater for various needs. To download the guide, please visit the website [here](#).

16. SeeAbility: Look Here event

Thursday 24th October 2013 10.00am until 3.00pm

The Salvation Army, Cavendish Drive, Liverpool, L9 1HQ

[SeeAbility](#) are holding a free training day for people who have a learning disability who want to learn about looking after their eyes. The day will involve:

- Learning about eye tests
- Practicing cleaning glasses
- Hearing about eye problems
- Using your other senses
- Talking about your eyes
- Doing a quiz
- Having fun!

There will be lots of breaks for drinks and you will get your lunch.

To book your place, please contact Merseyside Partners in Policymaking by email : mpip@btconnect.com or phone: 0151 287 7977.

For more information you can also contact Vikki Kendall at SeeAbility: v.kendall@seeability.org or call 07554 456330.

17. VERA: Two one-day courses for family carers

Wednesday 18th September 2013 and Wednesday 16th October 2013
St. Thomas Centre, Ardwick Green, Manchester M12 6FZ

Parents, family members, or shared-life carers are invited to attend two one-day events in Manchester, which are being offered by the [Values, Education and Research Association](#) (VERA). VERA is a small network of people whose aim is to be involved in education and training around the ideas of SRV, Personalisation and Valuing People.

Course 1: Wednesday 18th September 2013, 10.00am to 2.30pm (lunch included)

Jargon Busting - Debbie Race, VERA

- What does all the 'gobbledegook' mean?
- What are the important 'key words' you need to know?

Know Your Legal Rights - Luke Clements, Community Care Lawyer

- What are the rights of my son or daughter or the person I care for?
- How does the care assessment process work?
- How can I get the most from it?
- What are my rights as a parent?
- What am I entitled to?
- How can I challenge what Social Services or the service provider are doing?

Course 2: Wednesday 16th October 2013, 10.00am to 2.30pm (lunch included)

Imagine Something Better- Values and Action Planning

Presentations by VERA members, providing some practical ideas to try and help make things better for your family member or the person you care for.

Course cost:

£15 per day or BOTH days for £25 (includes refreshments and lunch).

Please arrive at 9.30 a.m. for registration and tea/coffee.

Some low cost subsidised places may be available.

For more details or to book a place, please email bryan.smith399@btinternet.com or ring 07856 727 258.

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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.