

# Bulletin



[www.familycarers.org.uk](http://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](mailto: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. News from the National Family Carer Network

The National Family Carer Network is continuing to develop, with an increasing membership and contributions to our weekly ebulletin. We are delighted that Molly Mattingly, Head of Learning Disabilities at the Foundation for People with Learning Disabilities and Liz Barraclough, Family Carer from Hartlepool, has joined our trustees.

Our main focus continues to be sharing information with our members and helping the voice of family carers be heard at a national level. Over the Summer we will be working hard on developing a **new website** which will allow access to more information, with better search functions and reflect the development of the network to include events and opportunities to become more involved. We know that good quality training is still vital to families and to ensure that there are opportunities for family carers to meet and discuss issues which are important to them and we are working hard to organise more events on a range of issues over the coming year.

### Events

#### **Transition event –23<sup>rd</sup> May, Birmingham**

Paul Swift, NFCN Associate will be presenting an Introduction to Safeguarding at the annual Transition event in Birmingham

#### **Know Your Rights Event – Wed 5<sup>th</sup> June, Manchester**

We recognise that lots of families have concerns around changes to benefits and cuts in LA spending. Many major changes to LA spending and Welfare benefits came into play in April 2013. We will be running an event with Mencap and Leonard Cheshire in Manchester to help families understand these changes, how they may affect families and the people you care for and peoples rights. There will also be a advice sessions available with a local solicitor.

There is also information on our website, by clicking on resources and benefits.

#### **BME Focus groups around personalisation – July, London**

We will be working with Turning Point to find out what families of adults with learning disabilities from Black and Minority Ethnic (BME) communities think about personalisation. What some of the barriers may be, what have been the experiences of families who have received direct payments or personal budgets.

#### **Launch of the Making Sure Your Relative is Safe information pack – Dates and venues TBC**

Following our stakeholder event in 2011, and the publication of the Top Tips and Essential Guides, which were funded by HFT, NFCN are delighted to be supporting the HFT Family Carer Support Service with the launch of their Resource pack and DVD which is the third resource, completing this series.

## **New Research - Family Led Support**

Successive Governments have committed themselves to increasingly personalised approaches to social care and breaking down of social care budgets to align costs with individual needs. Most importantly direct payments allow people who are eligible for community care funding to purchase support to meet their needs, an option that has now been extended to people who lack capacity to choose this option by allowing someone else, often a family carer, to manage a budget on their behalf.

We will be conducting research to determine whether family carers have been, or would consider being, involved in developing a support service, either for a relative and/or for other people with learning disabilities, what sort of involvement they would consider and the factors that would either encourage or discourage their involvement. The work will also explore family carers' satisfaction with current service provision for their relative and in their views on the potential benefits of family carer involvement in service development.

## **Collaboration and representation**

We continue as members of the Learning Disability Coalition, Care and Support Alliance, National Valuing Families Forum, Save Legal Aid and work with the Standing Commission On Carers to support the voice and needs of family carers of adults with learning disabilities.

For more information on any of the events, or work, you can visit our website [www.familycarers.org.uk](http://www.familycarers.org.uk) or contact us by email: [info@familycarers.org.uk](mailto:info@familycarers.org.uk) or call us on 07747 460727.

## **2. Launch of Information Governance Review report**

Dame Fiona Caldicott's Information Governance Review report was published recently. Dame Caldicott had been commissioned by the Secretary of State for Health to lead an independent review into the balance between sharing and protecting confidential information across the health and social care sector.

The report can be found on the DH website: <https://www.gov.uk/government/news/health-secretary-to-strengthen-patient-privacy-on-confidential-data-use>

The launch was recorded on video and can be found on the conference organiser's website: <http://www.healthcareconferencesuk.co.uk/caldicott2-information-governance-review>

You also read more on the Department of Health website: [www.caldicott2.dh.gov.uk](http://www.caldicott2.dh.gov.uk)

### 3. Consultation on Fee Remissions for the courts and tribunals

This consultation paper sets out our proposals for reform of the fee remissions system, which ensures that access to justice is maintained for those individuals on lower incomes who would otherwise have difficulty paying a fee to use court or tribunal services.

The objective of these reform proposals is to create a single system of fee remissions (waivers) for all fee paying courts and tribunals which is simple to use, more cost efficient and better targeted to those who need it the most.

The consultation is aimed at groups and individuals who have an interest in access to justice in the civil courts in England and Wales, a range of tribunals which operate in England, Wales, Scotland and Northern Ireland, the UK wide Gender Recognition Panel and the UK Supreme Court.

You can find links to further related documents via the [website](#) and you can complete an online survey to give your views [here](#).

The consultation closes on 16th May 2013.

There is also a campaign to save legal aid, which you can read about [here](#), and an e-petition, which you can sign [here](#).

### 4. Supported Backpacking Around Europe in a Month

[Go Provence](#) provides supported holidays to adults and children with learning disabilities and is looking for people who want to see more of Europe. As part of a small group of travellers, you will spend a month away, staying in hostels and mixing with people from all around the world. You can be involved with the planning of this trip as well. You can tell them what you want to see and together plot a route around Europe.

To put your name down on their list, or to find out more about this opportunity, please email [ian@goprovence.co.uk](mailto:ian@goprovence.co.uk) or telephone 00 33 4 86 56 65 61 (French land line).

Go Provence also offers supported holiday in Provence, in the South of France. They can support you from your nearest airport, or train station, down to them and back home again. Please visit their website [www.goprovence.co.uk](http://www.goprovence.co.uk) to see all the holidays provided or contact Ian on [ian@goprovence.co.uk](mailto:ian@goprovence.co.uk).

## 5. Postural Care One Day Courses 2013

[Postural Care CIC](#) have worked with leading clinicians to develop a series of one day courses for anyone with an interest in protection of body shape. The courses are accessible for self-advocates, families and personal assistants as well as for those with a professional interest in the subject.

### **Introduction to Specialist Seating 2nd July and 22nd October**

Specialist seating is a diverse subject area. It is often a technically complex and yet highly personal aspect of an individual's life. During the course of the day we will explore both the technical and personal aspects of seating provision, translate some of the jargon and spend time thinking about how to improve our advocacy skills when it comes to seating appointments. Finding a balance between what we consider to be important for us and what is important to us can be difficult. We will work together to better understand what makes a 'good' seating solution.

### **Postural Care Awareness 4th June, 6th September, 22nd November**

How and why does the body change shape? During the course of the day we will explore the causes of body shape distortion and the associated impact of changes in body shape, we will share examples of best practice and consider how families and service providers are working in partnership to move forward.

### **Introduction to the Goldsmith Indices of Body Symmetry 12th June, 10th September, 29th November**

Service providers are coming under increased pressure to demonstrate what it is they do. Measurement of Body Symmetry using the Goldsmith Indices allows both families and therapists to monitor the effectiveness of physical therapeutic intervention. During the course of the day we will have the opportunity to practice the technique, to consider how measurement can be used to support families to introduce behavioural changes as well as exploring how the data produced can demonstrate the importance of service provision.

All courses are held at The Coton Centre, Comberford Road, Tamworth, Staffordshire, B79 9AA from 9.30am to 3.00pm. Tea, coffee and lunch are provided

Cost per course £95 including VAT

Booking is essential.

To reserve your place please contact Sarah Clayton. Email: [Sarah@posturalcareskills.com](mailto:Sarah@posturalcareskills.com)  
Mobile: 07729 552626

**There are a limited number of free places on every course for family carers.**

## 6. Thinking Ahead: Improving support for people with learning disabilities and their families to plan for the future

Foundation for People with Learning Disabilities (FPLD) has launched Thinking Ahead, a campaign to highlight the anxiety felt by parents about the future when they are no longer able to support their son or daughter.

FPLD has carried out research which shows that over 80% of parents are either worried or very worried about what will happen after they die. However, there is no requirement for local authorities to support people with learning disabilities and their families to think about the future and put plans in place.

As part of the campaign, FPLD has produced a planning guide, designed with the help of people with learning disabilities and family carers, which provides a step-by-step approach to supporting people to plan effectively for the future. It covers topics such as housing and support options, building friendships and support networks, emergency planning, financial planning and talking about difficult subjects like growing older and dying. The guide is designed for families to use either independently, with other families or with support from practitioners and support workers.

The campaign report includes statistics from the Thinking Ahead research. These statistics reveal the degree of anxiety parents experience, as well as their suggestions to improve the situation. There are recommendations for policy makers, local authorities, health and social care practitioners, provider services and people in the local community.

The aim is that this new resource, together with the wider campaign, will prompt changes which can better support people with learning disabilities to put in place plans that help to secure a safe and enjoyable life. The [planning guide](#) and [campaign report](#) are available to download free of charge or can be purchased online. Further information about the planning guide is available at <http://www.learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead/>

Please help raise awareness of the Thinking Ahead campaign by sharing these resources with others. To find out how you can further help to raise awareness, please contact [press@mentalhealth.org.uk](mailto:press@mentalhealth.org.uk). In addition, if you would like to discuss how the Thinking Ahead guide could be used in your area, please email Christine Towers at [ctowers@learningdisabilities.org.uk](mailto:ctowers@learningdisabilities.org.uk).

## 7. Making Reasonable Adjustments to Diabetes Services for People with Learning Disabilities

Improving Health and Lives have published a report which brings together some of the reasonable adjustments that are being made to make diabetes services more accessible to people with learning disabilities. It includes links to resources as well as examples from practice.

You can download the report from the IHaL website [here](#).

## 8. CBF Volunteering

The CBF is a charity for people with severe learning disabilities whose behaviour challenges. They provide information and support for families and professionals.

CBF are looking for family carer volunteers, to help them support more families in England. They want to set up a network of Local Champions, who will share our information and resources in their local area, by attending events and joining networks. The CBF are also recruiting Family Link Volunteers, who will be trained to provide emotional support to other families.

Parents, brothers or sisters are all welcome – the only qualification is that you have experience of caring for a family member with severe learning disabilities whose behaviour challenges.

For more information, please click [here](#) to read the flier or visit their website <http://www.challengingbehaviour.org.uk/get-involved-with-cbf/volunteer.html>. Alternatively, please email [volunteering@thecbf.org.uk](mailto:volunteering@thecbf.org.uk), or call 01634 838739.

## South East

### 9. 'Kidz South' Free exhibition event

Thursday, 13<sup>th</sup> June 2013

Rivermead Leisure Complex, Richfield Avenue, Reading, Berkshire, RG1 8EQ

[Kidz South](#) is a free exhibition dedicated to children and young adults with disabilities and special needs, their families, carers and the professionals who support them. The event includes over [120 exhibitors](#), free seminars for parents and professionals, and a Funding Point area where you can access advice and information on alternative funding streams for equipment, respite breaks and care, and more.

The visitors' free entry ticket for this event is available to download [here](#). You can also download via the website [here](#), and find further event and venue information. Although the tickets are not compulsory they save time on registration if completed beforehand, simply hand in your completed ticket at registration on your arrival at the event. The tickets also include a full timetable of all the free CPD seminars taking place throughout the day, exhibitors list and details of the inclusive sports activities running alongside the event, and can help you plan your day.

For tickets or more information please contact the Kidz Team at Disabled Living 0161 607 8200, email [info@disabledliving.co.uk](mailto:info@disabledliving.co.uk).

# West Midlands

## 10. Guideposts Newsletter April-June 2013

[Guideposts](#)' latest newsletter features a number of events including free training for family carers, drop in sessions, support groups, and details of an Advocacy Service for Carers of Adults with Learning Disabilities.

Click [here](#) to read the newsletter or visit the [website](#) for further information.

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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.*