

# Bulletin



National  
Family Carer  
Network

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

Tel: 07747 460727

17<sup>th</sup> July 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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National Family Carer Network  
Tel: 07747 460727 • [www.familycarers.org.uk](http://www.familycarers.org.uk)

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 promotes better life chances for families that includes someone with learning disabilities. We do this by linking groups and organisations that support families of people with learning disabilities, providing information resources and workshops and representing families at policy level.

We are currently seeking family carers of an adult with learning disabilities from a wide range of backgrounds to become trustees. We are particularly interested to hear from people who have one or more of the following skills or experience:

- Fundraising
- Financial management
- Marketing
- Public speaking.

The Trustees meet quarterly and all expenses are paid.

For more information please contact the Chair, Alison Giraud-Saunders, on 07721 843290 and visit our website [www.familycarers.org.uk](http://www.familycarers.org.uk).

Please respond by Wednesday 28<sup>th</sup> August 2013.

## 2. Hft: Free Personal Independence Payment (PIP) information and practical tips sessions for family carers

Many people are understandably anxious about the upcoming assessments for people receiving Disability Living Allowance to move to the new Personal Independence Payment (PIP). Hft will be running free half-day sessions to help family carers prepare for when their relative with a learning disability will need to apply for PIP. By giving practical tips for filling in the form and information to help people through the face to face assessment, as well as looking at how people will be scored to receive the different rates, family carers will be able to support their relative with their application for PIP, armed with more information and more confidence.

Please get in touch if you would like Hft to run a free PIP session for a group of family carers in your area, or to find out more.

Contact: Family Carer Support Service, Hft on 0117 906 1751 or email [rhianon.gale@hft.org.uk](mailto:rhianon.gale@hft.org.uk).

You can also find out more by visiting the website: <http://www.hft.org.uk/current-workshops>.

### **3. DH response to the Confidential Inquiry into premature deaths and the Six Lives Progress Report**

The Department of Health have now published their response to the Confidential Inquiry into premature deaths of people with learning disabilities, and their second Six Lives Progress report.

The publications, including easy read versions, are available to download via the links below:

<https://www.gov.uk/government/publications/six-lives-department-of-health-second-progress-report>

<https://www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability>

The Principle Investigator of the Confidential Inquiry, Dr Pauline Heslop, welcomes the Department of Health's response, but suggests that given the seriousness of the issues raised by the Confidential Inquiry, more immediate actions are required which are largely missing from the Department of Health commitments. She says:

'The Department of Health and NHS England have gone some way to addressing premature deaths of people with learning disabilities. However, we cannot allow the situation to continue in which people with learning disabilities are dying from causes of death amenable to good quality healthcare. That needs tackling with some urgency, and urgency of action appears to be lacking in the Department of Health response. In particular, we are disappointed that the Department of Health has not agreed to a national mortality review body to review future deaths of people with learning disabilities – although at least it has agreed to assess the costs and benefits of this'.

Norman Lamb, the Minister of State for Care and Support at the Department of Health will be discussing the Department of Health response to the Confidential Inquiry on Monday 15<sup>th</sup> July 2013 at an All Party Parliamentary Group meeting at the House of Lords. The response will also be considered at a debate in the House of Lords on Thursday 18<sup>th</sup> July 2013.

### **4. DH response to consultation on direct payments for health care**

The government's response to its consultation on proposals to update the 'direct payments for healthcare' regulations has been published and can be read [here](#).

For further information and related documents, please visit the Gov.UK website:

<https://www.gov.uk/government/consultations/changes-to-direct-payments-for-healthcare>

## 5. Brain Bank for Autism & Related Developmental Research

Very few people know about the UK's post-mortem brain research programme, the *Brain Bank for Autism & Related Developmental Research*, which was established at Oxford University at the end of 2009, although it potentially can help us all to have a much fuller understanding of autism, epilepsy and related conditions. This research will clarify how, in these conditions, the brain develops and functions differently, leading to effective therapies to counteract their damaging effects and ideally to an accurate diagnostic test for ASD.

Two other similar initiatives, in the US and the Netherlands, have been set up. Both are working closely with the UK research programme. They are: Autism BrainNet – set up in the US in May '13 with \$7.5 million and NBB-Psy – set up in the Netherlands in Oct '12 with 3.5 million euros from the Dutch government. This level of investment, despite harsh financial constraints in Europe and the US, indicates the level of confidence there now is in this area of research. If you want to find out more, please visit [www.brainbankforautism.org.uk](http://www.brainbankforautism.org.uk)

Only post mortem research currently enables neuroscientists to understand the fine detail of the brain's structure and development. However, many professionals, across the services, have turned away from this area of research because it is carried out after death. Because many sensitive issues are involved, they have been reluctant to gain information about the research and to help to spread awareness of it. Yet those who have most to gain from it, who have an ASD or epilepsy, and their families, usually have a strongly positive interest when they do become aware of it.

Family members of those who have donated their brain for this research have been particularly positive about how much it has helped them, at a very difficult time and subsequently, to contribute to future generations in this way. Donated brain tissue is the fundamental gift on which this research entirely depends but just 22 donations have been received in the UK since the brain bank was set up.

The shortage of brain tissue is holding back the progress of the research and control tissue for comparative purposes, donated by family members and the general population, is needed as much as that donated by people with an ASD. Nonetheless, no-one is under any pressure to support research in this way. The need is for information to be given more readily, so that more people have an opportunity to form an opinion about it and to decide whether they want to make a pledge to ultimately donate their brain for research. The NHS organ donor scheme does not include the brain, so information about brain research needs to be given in other ways.

For more information, please visit the [website](#) or contact the helpline on 0800 089 0707.

## 6. Motorway Service Station Operators: Provide toilets for all disabled people - petition

Thousands of people with physical and/or learning disabilities cannot use standard disabled toilets because they cannot walk or stand. They need support from one or two carers to use the toilet or to have their incontinence pad changed.

Standard disabled toilets do not provide changing benches or hoists to lift the person on to the toilet or bench. Most are too small to accommodate more than one person. Without 'Changing Places' toilets, the person with disabilities is put at risk, and families/carers are forced to risk their own health and safety by lying their daughter, son or loved one on a toilet floor.

The Changing Places website gives further information: <http://www.changing-places.org/>

We all take it for granted that we can use the toilet at a motorway service station. However, currently there are only 2 service stations out of 100+ in the country which have Changing Places facilities. The provision of these toilets in public places would make a dramatic difference to the lives of thousands of people who desperately need these facilities.

Please sign this petition [here](#) to show service stations that in today's modern day and age everybody should be entitled to this basic human right.

## 7. Could KeyRing Be Right For You?

Recently there has been a rise in vulnerable adults who are seeking an alternative to care homes or living with parents/carers. [KeyRing](#) offers that alternative by helping Members to get their own accommodation, where they are regularly assisted by a volunteer and other KeyRing Members alongside their support worker.

KeyRing supports Members to support themselves. This is achieved by teaching them how to balance their finances, helping them to socialise with others in the community, advising them on the best course of action for their own well-being and the well-being of those around them. One advantage of KeyRing is that the KeyRing volunteer and KeyRing Members all live close to each other. This brings a sense of community, allowing members to make a positive contribution by helping one another at any time. Volunteers support Members to arrange regular meetings and events.

Another benefit of having a local KeyRing volunteer is that they can intervene early in the case of any problems. In many cases KeyRing has helped Members avoid a problem escalating into a crisis, such as homelessness. Support from KeyRing gives them skills so that they can live independently, and not rely on others. These are life long lessons that can prevent a return to more intensive support or the family home. A large benefit of supported living is that family and friends can visit unreservedly because KeyRing Members living on their own have no restrictions on family members visiting and contacting them.

Other benefits include:

- low level tenancy support,
- prompts for medication and health appointments
- safeguarding from abuse or harassment.

If you would like to find out more, please visit the website [www.keyring.org](http://www.keyring.org), email: [enquiries@keyring.org](mailto:enquiries@keyring.org) or telephone 0207 324 0750.

## London and Manchester

### 8. Rallies for Legal Aid 30<sup>th</sup> July

**London: 4.30pm–6.30pm at The Old Bailey, EC4M 7EH (nearest tube St Pauls)**

**Manchester: 5.00pm at Manchester Crown Court**

Justice Alliance is organising two rallies in London and Manchester on Tuesday 30<sup>th</sup> July to celebrate legal aid, show what legal aid has meant to people over the years, and highlight the devastating impact the cuts will have on individuals and communities.

- For details of the London rally 4.30pm–6.30pm at the Old Bailey, please click [here](#).
- For details of the Manchester rally 5pm at Manchester Crown Court, please click [here](#).

To find out more about Justice Alliance and the campaign to protect legal aid, please visit the website: <http://www.savelegalaid.co.uk/justicealliance>.

## South East

### 9. Kiss My Disco - Hove

**Wednesday 31<sup>st</sup> July 7pm to 11pm**

**The Brunswick Pub, Holland Road, Hove, BN3 1JF**

Kiss My Disco is a club night run by DJs with learning disabilities and open to all. It's all about a relaxed atmosphere, great tunes and dancing.

The next night is in Hove on 31<sup>st</sup> July and the cost is £4 on the door - PAs go free.

To find out more, please visit the Stay Up Late [website](#).

# South West

## 10. Autism Learning Needs Analysis

A participatory research group has been set up, consisting of people with autism, family members and carers and people without autism to look closer at the learning needs of private, independent, voluntary and public sector organisations in Cornwall. The purpose of this study is to find out

- what skills the workforce requires to meet the needs of people with autism in Cornwall
- what the hard to reach groups are and how to overcome this

This project is a follow on from the learning needs analysis conducted in 2012. The first part of the study involves completion of a questionnaire which can be accessed by following the link <https://www.surveymonkey.com/s/2013AutismLNA>. The group would really appreciate your input to this topic.

Your involvement in this study is invaluable and all responses will remain confidential. If you would like further information, the research team can be contacted via:

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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.*