

# Bulletin



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

Tel: 07747 460727

21<sup>st</sup> March 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. Confidential Inquiry into the premature deaths of people with learning disabilities

The National Family Carer Network welcomes the 18 recommendations of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD).

The study's shocking findings are that, on average, men and women with a learning disability die respectively 13 and 20 years earlier than the general population and that this difference is part due to the fact that the quality and effectiveness of health and social care given to people with learning disabilities was deficient in a number of ways. It is shocking that the majority (89%) of the illnesses that led to the deaths of people with learning disabilities were recognised and reported to health professionals quickly but the most common reasons for the deaths being assessed as being premature were delays or problems with diagnosis or treatment and problems with identifying needs and providing appropriate care in response to changing needs.

In particular, we ask that National Family Carer Network members do their utmost to ensure people with learning disabilities have access to the same investigations and treatments as everyone else, and that healthcare staff should acknowledge that these may need to be delivered differently to achieve the same outcome. (recommendation 7)

The report found that the lack of reasonable adjustments to facilitate healthcare of people with learning disabilities, particularly at clinic appointments and investigations was a contributory factor in a number of deaths. GP referrals commonly did not mention learning disabilities, and hospital 'flagging' systems to identify people with learning disabilities who needed reasonable adjustments were limited. Recommendation 2 is that reasonable adjustments required by individuals should be made and these should be audited annually. Families and friends can help identify that individuals have a learning disability and share what the needs of the individual may be. Sharing examples of best practice across agencies and organisations is also particularly welcome.

Family carers and close friends often advocate for people with learning disabilities but are sometimes worried about getting their voices heard or expecting too much from healthcare staff. However these results show that families have a right to be concerned about delays in treatment and should also use the Mental Capacity Act to ensure that their knowledge of the person and their needs, are recognised in decision-making.

People with learning disabilities already face many inequalities in life. We should ensure that they do not face further inequalities whilst they are poorly, leading to premature deaths.

Please click here <http://www.bris.ac.uk/cipold/> to read the finding and recommendations, including easy read reports and executive summaries.

Alison Giraud-Saunders, Chair of the National Family Carer Network was a member of CIPOLD's Advisory Group. NFCN Adviser and Hft's Family Carer Support Manager, Robina Mallett was a member of CIPOLD's Advisory Group and Overview Panel.

## 2. Important advice for families with disabled children on 'bedroom tax'

In light of the [announcement on 'bedroom tax'](#) Contact A Family's benefits adviser Derek Sinclair has some important advice for families.

"If your child's condition prevents them sharing a bedroom with a sibling, make sure that you contact your local housing benefit office to explain this. New [government guidance](#) (circular HB/CTB U2/2013) says your housing benefit award must allow for a disabled child to have their own room if their condition means they cannot share. You may be asked to provide medical evidence to confirm this. If they don't accept that your child can't share, seek advice about reviewing or appealing that decision. These new rules apply to the private sector immediately and to social housing once the bedroom tax is introduced in April.

Unfortunately the new guidance won't help where a disabled child needs an extra room for other reasons for example to store disability equipment or for an overnight carer. It may be that families in these circumstances could challenge the housing benefit rules on the basis they discriminate against disabled people. Contact a Family is seeking clarification on this point. In the meantime consider applying to your local authority for discretionary housing payments.

Whilst the new rules are great news for those families with a disabled child who is unable to share a bedroom, Contact a Family will continue to campaign for all carers and disabled people to be exempt from the bedroom tax. For further advice about these issues please contact their freephone helpline on 0808 808 3555 or email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk) ."

Contact a Family have also produced a new guide for parents on all benefits changes. Called *Personal independence payment, universal credit and other forthcoming benefit changes*, parents with a disabled child can get a free copy by calling their freephone helpline on 0808 808 3555.

## 3. Commission intervenes in Judicial Review of abolition of the Independent Living Fund

On 13<sup>th</sup> March, the [Equality and Human Rights Commission](#) intervened in a Judicial Review at the High Court into the abolition of the Independent Living Fund, a move which affects 20,000 disabled people.

The closure of the Fund, which provides money to enable disabled people to live in the community, will mean them becoming entirely dependent on local authority services. Stuart Bracking and other claimants argue they will lose their independence as a result, forcing many to live in hospitals or residential care.

They say that the decision was reached after a flawed consultation process by the Department for Work and Pensions which breached the Public Sector Equality Duty (1).

The Commission is intervening as an independent third party expert on human rights and equality law to assist the court. It will aim to clarify the point at which authorities are obliged to have due regard to eliminating discrimination, advancing equality of opportunity and fostering good relations when making plans.

It will argue that a policy which adversely affects rights protected by the United Nations Convention on the Rights of Persons with Disabilities (2), and is made without appropriate information is likely to breach the Public Sector Equality Duty.

The Fund has been closed to new applicants since June 2010. In December 2012 the government confirmed it would be permanently closed to new users and funding for existing users would only be maintained until the end of the current parliament in 2015.

The **Commission's Deputy Director , Legal, Wendy Hewitt** said:

"There are a series of cases in which the Commission has sought to clarify that the Public Sector Duty is as robust under the Equality Act 2010 as it was under previous legislation. This has been done in part by referring to standards in the UN Convention on the Rights of Persons with Disabilities.

"This case raises issues as to the point at which steps must be taken to meet the duty and to what extent authorities must consult to ensure they have enough information to assess the impact on equality."

#### **4. DWP Personal Independence Payment leaflet**

On 11<sup>th</sup> March 2013 the Department for Work and Pensions published the Personal Independence Payment leaflet which can be accessed [here](#).

#### **5. University of Glamorgan - Looking into Abuse: Research by People with Learning Disabilities**

The report of this research project was formally launched at the Senedd, Cardiff on March 6<sup>th</sup> at an event hosted by Mick Antoniw (Assembly Member). This three year participatory research study by The Unit for Development in Intellectual Disabilities has looked at what people with learning disabilities know about abuse, what they feel about abuse, how they can keep themselves safe and, if they are abused, what support they need.

The reports (including easy read versions) can be downloaded from:  
<http://udid.research.glam.ac.uk/projects>

You can also see the key messages from the project via the following link to YouTube  
[http://youtu.be/e\\_esB02z9RM](http://youtu.be/e_esB02z9RM)

## 6. Improving Health and Lives: Filling the Data Gaps

In the summer of 2011 [IHAL](#) published a review of the data collected by the NHS and the Department of Health about the health and healthcare of people with learning disabilities. That report made a number of recommendations about how the gaps could be filled. This report documents the progress by the end of the three years of the initial Learning Disabilities Observatory contract and can be read [here](#).

## 7. Improving Health and Lives - Learning Disability Partnership Boards: Reports of progress in 2010/2011

The Department of Health asked all 153 Learning Disability Partnership Boards in England to produce a report summarising their progress against Valuing People Now objectives for people with learning disabilities in 2010/2011. 118 Boards returned a report in time.

IHAL has summarised the information contained in the 118 reports to gain a national picture of the progress reported by Partnership Boards, including summaries of numerical indicators and thematic analyses of text.

The full [report](#) summarises all the numerical and textual information in the Partnership Board local reports. An [easy read summary](#) of this report is available.

## 8. “Listen to Me”: A film about people with profound and multiple learning difficulties

The aim of this film is not only to show examples of good practice but also to support the case for giving people with PMLD a say in their service provision.

<http://vimeo.com/49957264>

## 9. Fire Safety Video

A fire safety video has been made by [Innovate Trust](#) with the help of tenants who have learning disabilities. The film is being used by South Wales Fire Service, Action on Hearing Loss, First Choice Housing Association, and hopefully other Housing Associations will also want to use it.

English, Welsh, and B.S.L. versions of the film “Be Safe at Home” are on YouTube now, together with an Audio Description version.

<http://www.youtube.com/user/innovatetrust>

Any enquiries with regards to this video should be directed to Lisa Applewhite, Participation Officer at Innovate Trust on 029 20382151 [lisa.applewhite@innovate-trust.org.uk](mailto:lisa.applewhite@innovate-trust.org.uk)

## South East

### 10. Macintyre Youth Club Open Day

Thursday 28<sup>th</sup> March 2013 10.00am – 12 noon

MacIntyre Wingrave School, Leighton Road, Wingrave, Buckinghamshire,  
HP22 4PA

MacIntyre Wingrave School will be holding an open day to celebrate the launch of their new Youth Club.

The Youth Club is for young people who have severe learning difficulties and behaviour that challenges, with their families.

The open day is a chance for parents, families and professionals to view the schools facilities and meet with other parents, as well as their own Education and Health professionals.

The day takes place at MacIntyre Wingrave School on Thursday 28<sup>th</sup> March from 10am - 12pm. To book your place call the admin team on 01296 681274 or email [wingrave@macintyrecharity.org](mailto:wingrave@macintyrecharity.org), or alternatively you can book your place online by clicking [here](#)

### 11. Action for Carers Surrey: New Training/Refresher Opportunities

[Action for Carers Surrey](#) have announced some new training dates for relevant professionals, with the following free sessions being held in Surrey at various locations:

#### 1. Because Carers Count Training

This is a popular multi agency carer awareness course (half day – morning or afternoon) which forms the foundation of all other carer related courses and is for anyone involved directly or indirectly with any form of service, support or intervention to ensure good practise in working with clients and families.

#### 2. Think Carer, Think Family

These are new sessions built on new policy guidelines and legislation for developing and extending on good practises.

For further details for both courses and to book a place, please visit the Action for Carers Surrey website [here](#).

## 12. Autism & Asperger's: Strategies for Success

Saturday, 18<sup>th</sup> May 2013, 12:00 for 12:30 – 4.30pm

Thames Hall, The Kings Centre, Osney Mead, Oxford OX2 0ES

For directions, please see: <http://www.kingscentre.co.uk/content/find-us>

[Autism Oxford's](#) team of autistic trainers will talk about their success stories – what they have achieved, and strategies that helped them. They will talk about the challenges they face and how they overcome them, offering invaluable insights, ideas for solutions, inspiration, and hope to families and professionals to help children, young people and adults on the autism spectrum to succeed.

The afternoon will include a Q & A session featuring all the speakers.

For full event details and to book a place, please click [here](#).

**Booking Rates:** Professionals: £60 (£50 plus 20% VAT). ASC & Family members: £36 (£30 plus 20% VAT).

Discounts available if needed – please contact Autism Oxford on 01844 353292 or [info@autismoxford.org.uk](mailto:info@autismoxford.org.uk).

## East Midlands

### 13. Foundation for People with Learning Disabilities: Community Connecting Development Workshop

Thursday 25<sup>th</sup> April 2013 10:00am-3:30pm

Derby YMCA, The Campus for Learning and Development, 770 London Road,  
Wilmorton, Derby, DE24 8UT

The [FPLD](#) are holding a workshop to support frontline staff facilitate lasting and meaningful connections between people with learning disabilities and their communities. You can find more event information here: <http://www.choiceforum.org/docs/ccfly.pdf>

Lunch will be provided

Cost £50 per person

Offer of 3 for the price of 2.

To book a place at this event: email [kball@fpld.org.uk](mailto:kball@fpld.org.uk) or telephone : 0207 803 1144

For more information on Community Connecting please visit the FPLD website here: [www.learningdisabilities.org.uk/community-connecting](http://www.learningdisabilities.org.uk/community-connecting)

## Yorkshire and the Humber

### 14. Free ARC Conference in York: The Next Generation - Moving Staff in New Directions

23<sup>rd</sup> April 2013 from 9.45am – 3.30pm

The Gateway Centre, Front Street, Acomb, York YO24 3BN

Are we still training people just to care? The next generation of people with disabilities expect better. Once upon a time the only important thing about providing care and support was to keep people safe. It's still vitally important, but the next generation of people with disabilities expect and deserve more out of life. They expect support providers to step up a gear and offer them opportunities to acquire new skills and to participate fully in community life.

So how do we do that? Come along and find out how other providers are responding, how it feels at the sharp end of social care and how to find funding to support your new ventures. This free conference is being sponsored by Real Life Options as part of their ongoing 20th Anniversary celebrations of supporting people with learning disabilities.

[www.reallifeoptions.org](http://www.reallifeoptions.org) .

For full details of the event and speakers, please visit the ARC website [here](#). Entry is free. However, places are limited and booking is essential. To book your place email:

[bookings@arcuk.org.uk](mailto:bookings@arcuk.org.uk)

## North West

### 15. Manchester Know Your Rights events - do you have a story to share?

The National Family Carer Network is currently in discussions with Mencap and Leonard Cheshire to organise an event around cuts to Adult Social Care and Changes to Welfare Benefits in Manchester.

If you have a story that you would like to share about how the cuts have affected you personally, the services that you use or you have had to challenge a work capability assessment, we would really like to hear from you. We will not share your story without your permission. Please contact us at: t: 07747 460727 or [info@familycarers.org.uk](mailto:info@familycarers.org.uk)

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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*