

Bulletin



National
Family Carer
Network

www.familycarers.org.uk

Tel: 07747 460727

24th October 2013

Contents

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.

National

1. NHS Improving Quality: Commitment for Carers
2. Invitation to become a member of the Expert Reference Group
3. Family win legal challenge: Stop the DLA Takeaway campaign update
4. Sign up to Love Your Vote workshops!
5. Research finds new cases of autism have levelled off
6. New search engine for people with learning disabilities
7. Alcohol information for people with disabilities and/or autism
8. Stop Learning Disability Hate Crime

London

9. Fulfilling Lives – free event in Watford
10. Wild Bunch Club

North West

11. Merseyside and Cheshire Learning Disability and Autism Health Needs Assessment
12. Free Wills and Trusts Information Events in November

Yorkshire and Humber

13. Free Puppetry workshop

National Family Carer Network
Tel: 07747 460727 • 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. NHS Improving Quality: Commitment for Carers

NHS England and NHS Improving Quality are working to develop a series of 'commitments for action' that NHS England will take forward "to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment."

These will be agreed at a workshop in December, Commitment for Carers, which will bring together an invited group of carers and care representatives, healthcare professionals, commissioners, senior clinical managers, and allied health professionals.

The first step in this process is a listening exercise, to find out what carers need and want from the NHS. The exercise will look to engage with carers of every age, and from every aspect of society. In order to reach as many people as possible and ensure a streamlined mechanism to respond, the listening exercise will take place online, utilising social media, existing networks and forums, and direct email.

Over the next five weeks, NHS IQ will be asking a series of questions, and inviting carers to join the conversation, sharing thoughts, comments, and experiences. What carers say will determine the 'commitments for action' that will be taken forward in order to ensure that carers are recognised, valued and supported.

One question (or set of questions) will be asked each week:

- How can the health service help you feel recognised, valued and included when caring for someone?
- How did health staff help signpost you to relevant information and advice when you first started caring for someone, and at key stages and transition points of your caring role?
- How can health services best tailor support for you and your family particularly when caring for someone?
- How have health services or professionals helped you look after your own physical health and emotional well-being particularly in your role as a carer?

The questions will be posted on a number of websites, including The National Family Carer Network. For more details, and to see the full list of participating websites, please click [here](#).

NHS IQ will also be using Twitter to gather feedback, inviting people to join the conversation using the hashtag [#NHSThinkCarer](#). Questions will be posted each week on the NHS IQ twitter feed [@NHSIQ](#).

You can also [complete a questionnaire](#), or send your views to enquiries@nhsiq.nhs.uk.

After the workshop, NHS IQ will publish the commitments for action, and will also work to spread them throughout the health and social care system and other government departments, to ensure carer's needs and wants are prioritised at every level.

2. Invitation to become a member of the Expert Reference Group

The Department of Health (DH) is reviewing the Mental Health Act code of practice and is looking for family carers of people with learning disabilities who have experience of being sectioned under the MHA, and who would be able to provide input to the revision of the code.

This is a really important opportunity to influence the code of practice. The DH knows that people who have experience of being detained, or have had a family member or friend detained, are best placed to understand how the Code works in practice, and help them to determine how it could be improved for the individuals it is supposed to support.

For full details of the Expert Reference Group and how to apply, please click [here](#).

The deadline for nominations is 1st November 2013.

3. Family win legal challenge: Stop the DLA Takeaway campaign update

A family, whose disabled son's benefit was taken away while he was in hospital, have won the right to take their legal challenge against the secretary of state for work and pensions to the court of appeal.

Cameron Mathieson spent more than two years in Alder Hey Hospital with cystic fibrosis and muscular dystrophy. His family, from Warrington and backed by both Contact a Family and The Children's Trust, argue they acted as full-time carers until the five-year-old's death, in October 2012.

Government guidelines state disability living allowance (DLA) is not payable after the first 84 days in hospital. New research from Contact a Family and The Children's Trust shows that this rule denies families with disabled children financial help when they need it most.

Their survey of 104 families with disabled children who spend long periods in hospital shows the government's rationale is flawed with 99 per cent of those responding saying that they provide more or the same level of care when their child is in hospital, compared to when their child is at home and 93 per cent saying that their costs relating to their child's disability increased when their child is in hospital.

Both charities are calling for the '84-day rule' to be abolished and have written to the government with this new evidence. Their report highlights that most of the children affected by this rule are likely to have severe disabilities and/or complex health needs. Most will need round-the-clock care, which hospitals struggle to provide without the help of parents.

To read the full article and find out more about the campaign, please visit Contact a Family's website [here](#).

4. Sign up to Love Your Vote workshops!

[Dimensions](#), a not-for-profit provider of support for people with learning disabilities and autism, is launching its Love Your Vote campaign to increase awareness and the number of people who vote.

Working alongside the Houses of Parliament Outreach Service, the campaign will involve a series of workshops, open to the people supported by Dimensions and the wider learning disability community, to explain the parliamentary process and how to vote.

The workshops will cover all aspects of Parliament and the electoral system. They will be held across the country using easy-read materials and presentations.

The campaign also aims to inform people how to lobby their local MP about issues that affect their lives and demonstrate what impact lobbying has. The organisation is keen to educate people about voting to help them further with personalising their support and lobby MPs about what would help them in the social care sector.

For more details of the campaign, full list of workshop dates and venues, and how to book, please visit the Dimensions website [here](#).

Workshops are free and places must be booked in advance via the website or by emailing loveyourvote@dimensions-uk.org.

5. Research finds new cases of autism have levelled off

The number of newly diagnosed cases of autism has levelled off in the UK in the past decade after a five-fold surge during the 1990s, researchers have found.

The findings differ from results issued by the US Centers for Disease Control and Prevention (CDC) last year, which reported a 78% increase in the prevalence of the condition in 8-year-old children between 2004 and 2008 in the US.

Prompted by these results, which found that 1 in 88 8-year-old children in the US had been diagnosed with an autistic spectrum disorder in or before 2008, the authors wanted to find out if there were comparable rates in the UK.

Using data from the General Practice Research Database (GPRD), which contains around three million anonymised active patient records from more than 300 representative general practices in the UK – equivalent to 5% of the UK population – the researchers calculated the annual prevalence and incidence rates for autism among 8-year-olds between 2004 and 2010.

The results showed that the annual prevalence and incidence of autism did not materially change over the study period, for either boys or girls.

To read the full article, please visit the Learning Disability Today website [here](#). You can also read the full research paper on the BMJ Open website [here](#).

6. New search engine for people with learning disabilities

[Easy Read Online](#) has recently launched a 'Google' for people with learning disabilities, called 'Dobson's Choice'. It will enable people who have difficulty in reading and writing to find over 1000 websites that are interesting, relevant and accessible.

Easy Read Online has chosen websites that have good multimedia or have information that is particularly interesting to people with learning disabilities. It is free and easy to use. Just go to www.DobsonsChoice.co.uk

If you would like to give some feedback about Dobsons Choice, you can complete an easy read questionnaire [here](#). You can also help to make Dobson's Choice better by telling them about more websites for people with learning disabilities, and keep up to date with improvements by [liking their Facebook page](#) and following them on [Twitter](#).

7. Alcohol information for people with disabilities and/or autism

The [Friendly Resource Company](#) have produced a new DVD and workbook about alcohol. The resource explores units of alcohol, when and where to seek help, and gives advice about saying 'no' or 'I've had enough thank you'. This resource can be used individually to remind and support a person living alone, watched in groups to stimulate debate, or used as a learning resource together with the workbook which can be used alongside the DVD.

Click [here](#) for their leaflet, or to find out more and watch a sample of this DVD, click [here](#).

Cost:

- 1 DVD and 1 workbook £30
- 1 DVD and 10 workbooks £70
- Extra 25 workbooks £80

If you would like to order, please email orders@friendlyresources.org.uk or ring 01709 710199.

8. Stop Learning Disability Hate Crime

This is a service dedicated to supporting victims of Learning Disability Hate Crime, facilitating increased reporting of incidents, complementing existing local provisions and providing support to victims, families and professionals affected by learning disability Hate Crime.

The Stop Learning Disability Hate Crime helpline number is: 0808 802 1155 and is open 24 hours a day, every day of the year. It is free from landlines and most mobiles, and the number won't show on a phone bill.

To find out more about Report a Hate Crime and to see if they provide support where you live, please visit the website [here](#).

London

9. Fulfilling Lives - free event in Watford

Wednesday 30th October: drop in anytime between 1.00pm – 8.00pm
West Herts College, Watford Campus, Hempstead Road, WD17 3EZ

Watford Mencap and Herts CLDS are hosting a free local event in Watford for people with a learning disability (14 and over), and their families to find out about local services and activities. There will be over 50 local organisations holding stalls, and there will be the opportunity to attend several workshops and try out new activities.

To find out more, please visit the Watford Mencap website [here](#) or see the flyer [here](#).

10. Wild Bunch Club

Wednesday 30th October 2013 from 7.00pm to 11.00pm
Electrowerkz, 7 Torrens Street, London EC1V 1NQ

The Wild Bunch Club is back by popular demand for Halloween. Last year, 327 clubbers danced the night away, and this year they are aiming to beat that number.

Wild Bunch is a club night run by people with learning difficulties for everyone. Tickets cost £5 on the door. Everyone has to pay on the door including carers (carers will be given a receipt to claim back the cost from their employer).

For full details and how to get there, visit the website [here](#) and read the flyer [here](#).

North West

11. Merseyside and Cheshire Learning Disability and Autism Health Needs Assessment

This recently published assessment was produced as a collaborative project between Liverpool Public Health Observatory and Merseyside and Cheshire's Local Authorities and Clinical Commissioning Group

Liverpool Public Health Observatory was commissioned to deliver a health needs assessment for learning disabilities and autism amongst adults and children, to cover Merseyside and North Cheshire. The findings have been used to develop a set of recommendations for local commissioners.

The full report can be read [here](#) and a summary [here](#). An [Easy Read Version](#) is also available.

If you would like to know more about the Liverpool Public Health Observatory, please visit their website [here](#).

12. Free Wills and Trusts Information Events in November

Mencap has a number of upcoming free seminars for parents and carers of people with a learning disability. They will be taking place in the North West of England at the following locations:

Tuesday 5th November, 6.30pm – 8.30pm

Friends Meeting House, 6 Mount Street, Manchester, M2 5NS

Wednesday 6th November, 12.30pm – 2.30pm

Blackburn Technology Management Centre, Challenge Way, Greenbank Technology Park, Blackburn, Lancashire, BB1 5QB

Thursday 7th November, 12.30pm – 2.30pm

Knights Grange Golf Course, Barn Conference Centre, Grange Lane, Winsford, Cheshire, CW7 2UJ

A specialist local legal professional will talk at the events about how best to leave money behind to someone with a learning disability. The events are free and are a great opportunity for families and carers to get straightforward, face-to-face advice.

Mencap has planned other wills and trusts events across the country. Please visit their [website](#) to find one near you and book a place online.

If you have any questions, or would like to book a place over the telephone, please contact the team on 020 7696 6925.

Yorkshire and Humber

13. Free Puppetry workshop

Monday 28th October – Thursday 31st October 2013

Lawrence Batley Theatre, Queen Street, Queen Square, Huddersfield

[Dark Horse](#) is a national touring theatre company that also trains actors with learning disabilities. They are running a puppetry workshop at the [Lawrence Batley Theatre](#) for children and young people 11-18 years who live in Kirklees and have a learning disability.

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

To book a place, please telephone: 01484 484441 or email: info@darkhorse.co.uk.

National Family Carer Network

07747 460727

www.familycarers.org.uk

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.