

Bulletin



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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.

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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. The Care Act 2014 and our joint response to the draft regulations

The [Care Act 2014](#) received Royal Assent on 14 May, representing the most significant reform of care and support in more than 60 years.

[Click here to access a paper provides answers to questions relating to the reformed care system and how it would operate.](#)

The Government has today, 6 June 2014, published its proposals for who will and who won't get social care from 2015 under the new Care Act, introducing new national criteria for social care eligibility.

- The consultation microsite - navigate straight to the area you are interested in: <http://careandsupportregs.dh.gov.uk/>
- Department of Health press release: <https://www.gov.uk/government/news/care-act-2014-launch-of-care-and-support-consultation>
- Consultation document, draft regulations and guidance in full to download: <https://www.gov.uk/government/consultations/updating-our-care-and-support-system-draft-regulations-and-guidance>

This is the crucial decision in the Government's flagship care reforms. The aim of a national level of eligibility is to end the postcode lottery, but the proposals published today reflect the higher level of eligibility that many councils have moved to in recent years.

As members of the Care and Support Alliance we are concerned that the proposals hardwire in the status-quo of highly rationed care, rather than create a preventative system that lives up to the Government's ambitions.

Responding to the publication of the draft regulations and guidance for implementation of part 1 of the Care Act, Richard Hawkes, Chair of the Care and Support Alliance, said:

"Millions of people who struggle with day-to-day tasks face a battle to get the quality of care they need.

"The Government has hailed the Care Act as bringing in a radical new system that promotes wellbeing and integration.

"However, the Government has passed up the chance to drive through a genuinely preventative system. It has instead hardwired the year-on-year rationing that has seen people squeezed out of the system.

"Without that help people's lives fall apart. This will also place unbearable pressure on family carers.

“Sitting behind this issue is a story of chronic underfunding that has seen councils restrict who they give care to.

“There is still a chance to make a change. The Government must be bold, invest in care and create a care system that gives older and disabled people – and the families who care for them – the support they need to live well.

“If the Government gets this decision right, the passing of the Act will create a lasting legacy.”

2. Recognising the importance of physical health in mental health and learning disability - achieving parity of output

While the mental health of people with long-term physical conditions is all too often neglected. A similar situation exists for individuals with intellectual disabilities.

In 2008, the ‘Independent Inquiry into Access to Healthcare for People with Learning Disabilities’ reported that people with intellectual disabilities have higher levels of unmet need and received less effective treatment than the general population. More recent findings from the ‘Confidential Inquiry into premature deaths of people with learning disabilities’ (CIPOLD) – which investigated the deaths of 247 people with an intellectual disability across five primary care trust (PCT) areas in the south west of England between 2010 and 2012 – showed that 29 per cent experienced difficulty or delay in diagnosis, further investigation or specialist referral for an illness. In the worst cases, people with intellectual disabilities continue to suffer unnecessarily with untreated, or poorly managed, conditions.

The persistent excess morbidity and mortality in people with mental health problems, and in people with an intellectual disability, underlines the urgent need to redress the situation and make ‘parity of outcomes’ across physical health, mental health, and intellectual disability a reality. The aim of this BMA Board of Science report is to understand what needs to be done to realise this goal.

Throughout this report by the British Medical Association, mental health and intellectual disability are considered side by side. While it is recognised that intellectual disabilities are distinct from mental illness, and can occur without any other mental or physical disorder, this approach mirrors that adopted by a number of organisations, including the Disability Rights Commission (now a part of the Equality and Human Rights Commission) in their report ‘Equal Treatment’, and the Royal College of Psychiatrists (RCPsych) in their ‘Fair Deal Manifesto’.

[Click here to download the British Medical Association report](#)

3. Improving the mental health of people with learning disabilities resources:

In line with the Government's 'No health without mental health' strategy, the Foundation for People with Learning Disabilities was funded to find out about the barriers that make it difficult for people with learning disabilities to access mental health services and resources.

As part of this work they surveyed families of people with learning disabilities, people with learning disabilities, and people who work in mental health services to find out their views. As a result of this work they have written a number of reports including "Feeling Down" - report which was launched in May 2014 and an easy read guide for people with learning disabilities and their families or supporters to use to think about and help them look after their mental health. The guide includes interactive sections so that anyone using the guide can type in their information and update it when their situation changes.

[Click here to see the publications](#)

4. Update on Winterbourne View Joint Improvement Programme

Progress in moving people with learning disabilities out of Winterbourne View-style assessment and treatment units remains slow, according to new NHS figures. In fact the figures reveal a slight increase in the number of people with learning disabilities living in such units.

In December 2012, in the [government's response to the Winterbourne View scandal](#), where 11 former carers were convicted of abusing residents, it was pledged that nobody would be inappropriately placed in an assessment and treatment style unit by June 2014.

Fewer than one in 10 people with learning disabilities who were due to be moved out of hospitals in the wake of the [Winterbourne View scandal](#) will have been transferred or have a date for doing so by the deadline, 1 June 2014.

The [transfer programme](#), branded an "abject failure" by the minister responsible, has been dealt a further blow after Bill Mumford, the man drafted in to breathe new life into it became caught up in an abuse inquiry.

Bill Mumford has offered to stand down because of the police investigation into [abuse claims at the Womaston](#) residential school for children with learning disabilities run by his charity, MacIntyre, in Powys. The charity is to [close the school](#) in July. Norman Lamb, care and support minister, said that "on balance" Mumford should continue in his national role.

[Click here for Information on the Winterbourne View Joint Improvement Programme](#)

[Click here to see the article in Learning Disability Today](#)

[Click here to see the article in the Guardian](#)

[Click here to see the article in the BBC news](#)

5. Eliminating forced, coercive and otherwise involuntary sterilization

The World Health Organisation has produced a multi-agency statement to contribute to the elimination of forced, coercive and otherwise involuntary sterilization.

Sterilization without full, free and informed consent has been variously described by international, regional and national human rights bodies as an involuntary, coercive and/or forced practice, and as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination. Human rights bodies have also recognized that forced sterilization is a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.

Amongst other groups, Human rights bodies have recognized that sterilization of persons with disabilities without their consent constitutes discrimination, a form of violence and torture, or other cruel, inhuman or degrading treatment . They have called on states to prohibit such practices and adopt legislative changes clearly defining the requirements of full, free and informed consent with regard to sterilization of women with disabilities, in accordance with relevant international standards.

[Click here to see the final version of the forced sterilisation statement.](#)

6. Flexible working for carers : A guide to your rights when juggling caring and work

The right to request flexible working was first introduced in April 2003. Initially it was limited to parents caring for children under 6 years old or under 18 for disabled children. It was extended to specified carers in 2007 and to parents of all children under 17 in 2009.

The statutory procedure will be repealed in 2014. Instead, there will be a duty on employers to consider requests in a reasonable manner, which includes considering whether they can be accommodated on business grounds. The requirement to be a parent or carer will be removed. ACAS has produced a new draft Code setting out best practice. The Code will be taken into account by employment tribunals. The main remedy will still be compensation for discrimination.

This guide provides an overview of the following:

- The flexible working procedure
- Indirect sex discrimination
- Direct sex discrimination
- Discrimination against carers of disabled people

From 30 June 2014 any employee can apply irrespective of caring obligations.

[Click here to download the guide](#)

7. Children and Young People with Complex Health Needs - A one-stop booklet for families

The aim of this booklet produced by the Foundation for People with Learning Disabilities, is to offer information and routes to support of a practical nature, which they hope can improve the lives of children and young people with complex health needs.

It suggests ways in which your child can be supported to have fun, and gives details of what is available to make the home more comfortable and adapted to your child's needs as they grow up. You'll also find information on your rights and advice on how to start planning for changes and transitions in your child's life.

[Click here to download the booklet](#)

8. Dosh Banking Report and Guide

In February, Dosh published its report on access to banking for people with a learning disability. The report shares the experiences of people with a learning disability supported by Dosh and the problems they encounter when trying to set up an account and manage their money.

It focuses on problems with:

1. mental capacity (making decisions about banking)
2. proof of identity (having the right documents to show who you are)
3. accessing money (using your money in different ways like debit cards, internet banking and in the branch)
4. consistency of service and information (always getting the same good support and information when you go into a bank)

This is a practical guide that gives you tips and information on how to get the support you need in banks. It includes details of some important banking laws, as well as the Equality Act and Mental Capacity Act. It also explains what to expect when you go into a bank and how to deal with problems. Along with the guide, we have also created a short help sheet that you can print out and take with you when you go to the bank.

Find out more at: www.dosh.org/banking-report

9. Disabled Ramblers

The Disabled Ramblers exists to help mobility-challenged people get back out into the countryside. Able-bodied helpers are welcome to support members and to help with loading scooters and other jobs. They ramble in all weathers and over a variety of terrain. Their rambles are graded according to difficulty. Some are suitable for shopping buggies and power chairs whilst others need large scooters capable of traveling over rough ground.

They spend a lot of time researching routes and working with the authorities to improve access. Many of their rambles are accompanied by staff from the area. This adds to enjoyment of the ramble through their local knowledge and the extra security they can often provide. About 30 rambles are run each year across England and Wales – mostly from March to October.

Visit their website: <http://disabledramblers.co.uk/>

London

10. How do we ensure the best care for our children now and after we have passed on?

Family carers are the mainstay of support for their loved ones. Without them so many people with a learning difficulty would not receive the support and services that they so desperately need. But what happens to the learning disabled person when the family carer is no longer able to care? Can we rely upon Social Services to fulfil the role they are paid to do?

These issues will be addressed an evening seminar being held in London on 10th September 2014 where representatives of two organisations will explain the steps they have taken to ensure continuation of support and services for their loved ones when their family carers are no longer able to provide it due to incapacity or death.

[Click here for more details.](#)

[Click here to download the booking form](#)

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