

# Bulletin



www.familycarers.org.uk

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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. NHS Protect launches new guidance on challenging behaviour

New NHS guidance on how to prevent and manage challenging behaviour related to a patient's clinical condition has recently been launched. The guidance is for the use of clinical and non-clinical NHS staff and managers, and may also be of interest to patients and service users, carers and families.

Clinically related challenging behaviour by patients and service users makes it difficult for staff to deliver good care safely. It takes many forms, from mildly uncooperative to highly disruptive and potentially dangerous behaviours. Such behaviour is often related to a clinical condition or treatment and is a sign of distress and unmet needs rather than any intent to be challenging.

The guidance was developed by an expert group of leading doctors, nurses and training and security specialists, led by NHS Protect. It is supported and endorsed by a number of other leading organisations, including NHS England and the Royal College of Nursing.

It will help staff prevent and manage clinically related challenging behaviour by minimising a patient's distress, meeting their needs and delivering high quality personalised care, in an environment that is safe for staff, patients and visitors. It underscores the importance of staff employing good communication skills and being compassionate to build trust with patients and service users and better understand what leads to distress. This will ensure that appropriate care can be designed to prevent challenging behaviour.

To read the guidance: *Meeting Needs and Reducing Stress*, please click [here](#). You can also find more information and resources on the NHS Protect [website](#).

### 2. NDTi Access to Advocacy research

The [NDTi](#) has been commissioned by the [Office for Disability Issues](#) to research what needs to be done so that disabled people can have access to joined-up advocacy services to enable work, education, independence and participation in wider society.

As part of this research, NDTi wants to hear from organisations that provide advocacy services to find out more about the types of advocacy provided, gaps in provision, and examples of good practice. NDTi would be very grateful if you could help with this research by completing the following survey:

<https://www.surveymonkey.com/s/MMR76C9>

The survey should take around 15 minutes to complete and the deadline is 19<sup>th</sup> December.

### **3. National conference to review progress regarding The Confidential Inquiry into premature deaths of people with learning disabilities**

The Confidential Inquiry into premature deaths of people with learning disabilities [reported its findings](#) to the Department of Health in March 2013. A year on from this, the Department of Health will be running a national conference to review progress in taking forward the recommendations of the Inquiry.

Have you been involved in any work that is taking forward learning from the Confidential Inquiry, and would you be willing to share it at the conference? The Confidential Inquiry Team is looking for examples that are at a strategic level, as well as regional, local or 'small and specific' examples of change.

If so, please contact the team by email: [ci-team@bristol.ac.uk](mailto:ci-team@bristol.ac.uk) with a short summary of your work, and your full contact details (name, email, phone number). If you would like to discuss it with a member of the team first, please email with a contact number and they will call you back.

### **4. Finding Common Purpose**

*Finding Common Purpose* is a report resulting from the joint work between the [ADASS Learning Disability Policy Network](#) and the Care Provider Alliance (CPA) published this week. Its aim is to focus on better commissioning relationships to support people with learning disabilities. The next national steps are to progress the outcomes of this report with the Towards Excellence in Adult Social Care (TEASC) Board and with the Winterbourne View Joint Improvement Board and team to agree a way forward.

To read the report, click [here](#).

### **5. Winterbourne View improvement programme loses top two leaders**

The two heads of the government-backed programme to transform learning disability care following Winterbourne View have stepped down. Chris Bull left his part-time role leading the Winterbourne View Joint Improvement Programme (WVJIP) last month to enable the appointment of a full-time programme director. Bull had combined the role with another as local government adviser to Public Health England. Ian Winter – who had effectively been Bull's number two on the WVJIP – leaves next week when his contract comes to an end.

The programme is designed to help council and NHS commissioners achieve the government's objective of moving people with learning disabilities or autism and 'challenging behaviour' from inappropriate hospital placements back home to their communities by 1<sup>st</sup> June 2014.

To read the full Community Care article, please click [here](#) to visit their website.

## 6. Royal College of Speech & Language Therapists: 5 Good Communication standards

The Royal College of Speech and Language Therapists (RCSLT) have produced a document recommending five good practice standards around speech, language and communication. These are reasonable adjustments to communication that individuals with a learning disability and/or autism should expect in specialist hospital and residential settings.

Most people with learning disabilities have some speech, language and communication difficulties. These can be hidden or overlooked. Everyone needs to know what good communication support 'looks like' and what reasonable adjustments they can expect.

Failure to make reasonable adjustments to meet communication needs will mean people with learning disabilities will continue to be vulnerable to a range of risks. These risks include the continuing failure to design, commission, and provide best practice services, alongside continuing health inequalities faced by individuals, in contravention of legal responsibilities.

For full details of the recommendations, and to download the document: *Five Good Communication Standards*, please click [here](#).

These recommendations were discussed and endorsed by members of the Learning Disabilities Professional Senate recently. They are keen for families to use these standards to monitor effective communication by services with people who have learning disabilities.

The development of these standards was one of the pledges made as part of the Post Winterbourne View Concordat, and therefore it means communication with everyone who has a learning disability, not just those who are able to use language.

If you would like a presentation and discussion of these standards at one of your family carer meetings, or if you have other ideas for getting these standards embedded in your area, please contact your local Speech and Language Therapy service (your GP should have the details). You can also contact the project lead, Della Money, directly on [della.money@nottshc.nhs.uk](mailto:della.money@nottshc.nhs.uk).

## 7. Autism and the Criminal Justice System

[Autism West Midlands](#) have produced some guidance for professionals which provides an overview of the basics of Autism Spectrum Disorders (ASD). It also includes specific advice for different professionals, and the different situations in which they will encounter people with ASD.

Whilst aimed at professionals, family carers may also find the booklet useful. Click [here](#) to read, and [here](#) for more information on the Autism West Midlands website.

## **8. Edward Timpson addresses the AoC Learners with Learning Difficulties and Disabilities conference**

Children's Minister Edward Timpson recently addressed the Association of Colleges (AoC) about preparations for reforms to special educational needs.

You can read the speech on the Gov.UK [website](#).

## **9. Sexuality & Severe Autism: A Practical Guide for Parents, Caregivers and Health Educators**

Sexual health and sexuality can be difficult subjects for parents and caregivers to broach with autistic children, made more challenging when children are at the severe end of the autism spectrum. Some parents may even question the validity of teaching sexuality to those who are severely autistic.

This practical handbook by Kate E. Reynolds guides you through the process of teaching about sex and sexuality, answering all of the most crucial questions, including: Why is it necessary to teach this subject to my severely autistic child? When is the right time to start talking about these issues? How detailed and explicit should I be? What methods are most appropriate? It addresses male and female issues separately and covers public and private sexual behaviours, sexual abuse, cross-gender teaching and liaising with school, in addition to the more obvious areas such as physical changes and menstruation.

The handbook costs £15.99 and is available to order from Jessica Kingsley Publishers [here](#). You can also read more from the author on her blog: [Autism Agony Aunt](#).

## **10. New spending cap will include DLA, AA, PIP and ESA**

The government is to limit the total amount spent every year on social security, including key disability benefits such as employment and support allowance (ESA) and disability living allowance (DLA).

The Conservative chancellor, George Osborne, confirmed in his autumn statement that he was pushing ahead with plans for a cap on "overall welfare spending".

Osborne said the government needed to take further action to curb social security spending, on top of the £21.6 billion annual cuts already announced since 2010.

To read the full Disability News Service article, please click [here](#).

## **11. Victory for welfare campaigners as government loses appeal against benefits ruling**

The Court of Appeal has upheld a ruling which found that the process used to decide whether hundreds of thousands of people are eligible for Employment and Support Allowance (ESA) disadvantages people with mental health problems, learning disabilities and autism.

The original judgment, which was made public at an Upper Tribunal hearing in May this year, was the result of a Judicial Review brought by two anonymous claimants with mental health problems.

The Department for Work and Pensions (DWP) immediately appealed against the judgment and the Judicial Review was put on hold. Now that the DWP has lost their appeal, the Judicial Review will continue. A final judgment is expected next year unless the DWP decide to take the case to the Supreme Court.

The charities Mind, the National Autistic Society and Rethink Mental Illness intervened in the case to provide evidence based on the experiences of their members and supporters.

The case centres on how evidence is gathered for the controversial Work Capability Assessment (WCA), the process used to determine whether someone is fit for work. Under the current system, evidence from a professional such as a GP or social worker is expected to be provided by claimants themselves.

There is no obligation for the DWP to collect this evidence, even on behalf of the most vulnerable, apart from in some rare cases. Gathering evidence can be very challenging for people with mental health problems, learning disabilities or autism whose health or condition can make it hard for them to understand or navigate the complex processes involved in being assessed.

As a result, those who need support the most are frequently being assessed without this important evidence being taken into account.

You can read the full article on the Mind [website](#) and read the full judgement [here](#).

## **12. The Money Advice Service - guides to Benefit Changes 2013**

[The Money Advice Service](#) is a free, impartial, and independent service, set up by government, to help people make the most of their money. They have a number of free resources on their website about the different benefits changes which have taken place this year, and how they may affect you.

You can find these on the website [here](#).

## 13. Videos about Personal Independence Payment (PIP) for family carers

[Hft's Family Carer Support Service](#) (FCSS) has made a series of short videos about PIP.

The videos give information about:

- How people are assessed
- Completing the forms
- Going to a face to face assessment
- Decisions and appeals

You can view the PIP videos here:

PIP 1: [Rules and how people are assessed](#)

PIP 2: [How to fill out the form](#)

PIP 3: [Going to a face to face assessment](#)

PIP 4: [Your award and appeals](#)

FCSS are planning to make more videos for family carers in the future and would really appreciate feedback on which topics you would like to see covered in video format in the future. If you have any feedback or suggestions to share, please email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk).

FCSS also have a 'Guide to benefit changes' which is regularly updated. Find out how to get a copy, or download it from: [www.hft.org.uk/benefitsguide](http://www.hft.org.uk/benefitsguide). There are more events about PIP planned for 2014. Please see [www.hft.org.uk/pip](http://www.hft.org.uk/pip) for dates and locations.

## 14. Guardian article: How Atos comes under pressure to declare disabled people as fit for work

Ask Atos, the company responsible for executing the work capability assessment (WCA), or the Department for Work and Pensions, which defines how the WCA is conducted, and they will tell you that they have no targets for the number of people who pass. Yet a new report from the Centre for Welfare Reform, *How Norms Become Targets*, uses a leaked set of Atos data to suggest that the DWP is holding Atos to extremely tight tolerances on its results.

Atos and the DWP admit to the existence of "statistical norms" and that these are used to manage the performance of individual healthcare professionals carrying out the assessments. Campaigners have long claimed that these norms function as de facto targets, but were surprised by the detail of the data logged and matched against acceptable ranges. Not only are there figures for overall numbers of people awarded the points needed to qualify for the employment and support allowance (ESA), figures also exist for individual prognoses, for the points awarded, even for the word count of the summary findings. And each Atos region is expected to stray no further than 20% from the national average.

To read the full Guardian news article, please click [here](#).

## 15. NFCN Survey Reminder: Promoting family-led support

For many years family carers have designed, developed and managed support for their learning disabled relatives. Their intimate experience of what good support looks like, their energy and passion, and their lifelong commitment to their relatives means that they are often best placed to lead this process.

Family-led support comes in various shapes and sizes; it can be 'hands-on' or 'arms-length'. It includes:

- Leading planning
- Managing a relative's direct payment to pay for personal assistants
- Coordinating 'pooled funding' on behalf of several people with learning disabilities
- Setting up a service
- Working in partnership with an agency.

Changes to the way that support for people with learning disabilities is funded and purchased means that families will have an even more important role to ensuring their relatives get good quality support. However, many families never consider the option of 'doing it themselves' because they do not know what it would involve, what the benefits are, or where they could get help.

Over the next two years the National Family Carer Network will be working to promote family-led support. We want to:

- Understand more about the experiences of families that have developed their own support;
- Find out family carers views family-led support and what help they would like to consider it as an option;
- Develop practical resources that provide families with the information, advice and assistance they need when thinking about arranging support themselves.

**You can help by filling in a survey telling us about your current involvement in your relative's support and your views about what might happen in the future.**

Click [here](#) to take part in the survey online.

To find out more about the work, or request a paper copy of the survey, please contact Paul Swift: Tel **07740 946564** / **0117 9294365** or email: [paulswift.research@gmail.com](mailto:paulswift.research@gmail.com).



## London

### 16. Autism and Participation conference

Tuesday 28<sup>th</sup> January 2014

Friends House, Euston, London

[The National Autistic Society](#) is holding a one day conference delivered by people on the autism spectrum to examine aspects of autism and participation. This event is aimed at all stakeholders, including local authorities, adult services providers, clinicians and researchers, social care and education professionals and people on the autism spectrum, as well as their families and/or carers.

This conference will examine a variety of aspects of participation, including areas such as:

- working in participation with autistic people who have less verbal ability or who are non-verbal
- best practice for participation and consultation in the commissioning of services
- what is meant by inclusion in schools and colleges for autistic students
- how political representation for autistic people would be best achieved.

Costs: £45+ VAT for individuals on the autism spectrum and their parents/carers.

To find out more about the conference, and to register for a place, please visit the [NAS website](#).

### 17. Funky Moves Christmas Disco

Saturday 21<sup>st</sup> December 6.00pm – 10.30pm

Clarence Hall Bradfield Court, Hawley Road, Camden, London, NW1 8RN

[Camden People First](#) is hosting a disco extravaganza for over 18s on 21<sup>st</sup> December. The event is run by people with learning disabilities and features different DJs and prizes for best-dressed partygoer. Food and drinks will be on sale and tickets cost £5 on the door.

For more information, please see the [flyer](#) or contact Camden People First by phone on 0207 482 3539.

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