

## Updates from the CB-NSG steering group – March 2012

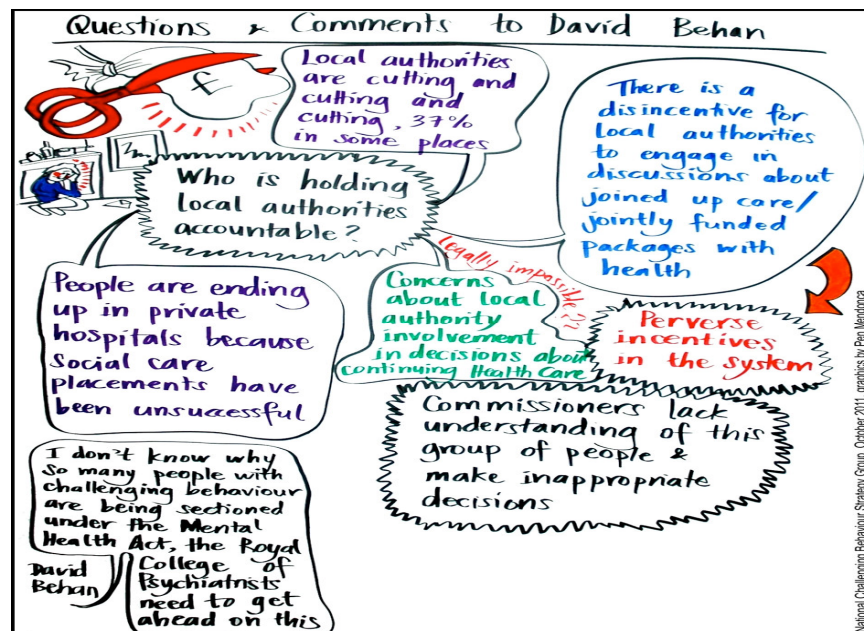
The Challenging Behaviour – National Strategy Group (CB-NSG) holds two national meetings a year. Today we are very pleased to welcome you to our first meeting in Wales.

Below is a summary of the last CB-NSG meeting held in London in October 2011 and an update from the steering group on progress.

### CB-NSG meeting - October 2011 (London)

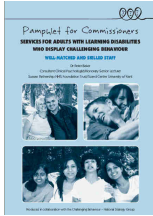
The Challenging Behaviour – National Strategy Group (CB-NSG) meeting on the 4th October 2011 focussed on the human rights of individuals with learning disabilities and challenging behaviour. It was the first chance to discuss these issues since the BBC Panorama documentary “*Undercover care: the abuse exposed*” had revealed the ill-treatment of individuals at Winterbourne view.

The meeting began with **David Behan (Director General for Social Care, Department of Health)** providing details of the Department of Health review following Winterbourne View. **Dame Jo Williams (Care Quality Commission)** then spoke about the CQC’s review of 150 learning disability services, as a reaction to the Panorama documentary.



**Vivien Cooper** (CBF) and **Rob Greig** (NDTi) led a discussion on the “*Caring for Our Future*” consultation and agreed a response from the CB-NSG. **Karyn Kirkpatrick** (Housing Options) & **Jo Poynter** (SE Strategic Health Authority) led a group outlining housing and Mental Health Act issues that have been identified in the wake of the Panorama documentary to add to “*Time for Action*” and to feed into the Department of Health review.

Following this, **Angela Robinson** (Family carer) gave a family's perspective on moving from institutional care to supported living. **Liz Bruce** (ADASS Policy Network) then talked about the priorities in providing good quality care for individuals with challenging behaviour.



**Dr Sarah Bernard** (Maudsley Hospital) & **Dr Peter Baker** (Sussex Partnership NHS Foundation Trust) launched 2 new resources for commissioners.

- *Services for children and young people who display challenging behaviour. Well matched skilled staff* by Dr Sarah Bernard
- *Services for adults with learning disabilities who display challenging behaviour. Well matched skilled staff* by Dr Peter Baker

**Sophy Miles (Miles & Partners)** then gave a talk on the legal rights of individuals with learning disabilities and **Amanda Platts (Co-chair, National Forum)** discussed the importance of including people with learning disabilities and explained the work the national forum have done with the CQC.

3 action planning groups took place simultaneously:

- The Campaign Subgroup
- Time for action: Commissioning, Supporting staff & Checking services
- Time for action: Human rights, Good care companies & Visitors and advocates.

Finally, **Stephen Davidson (Tizard Centre, University of Kent)** presented a study on the role of Intensive Support Teams and encouraged participation and **Geoff Baines (SW Strategic Health Authority)** spoke about NHS Commissioning after Winterbourne View and the actions taken.

More information including copies of speakers presentations can be found at: <http://www.challengingbehaviour.org.uk/strategy-group/information-from-meetings/meetings.html>

## Updates

A whole range of action takes place between meetings to implement the 9 action plans developed by CB-NSG members as well as responding to relevant consultations and events. If there is a particular strand of work you would like to contribute to or if you have information about related work to share, please get in touch.

For regular updates visit the Strategy Group pages of the Challenging Behaviour Foundation website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

## 1. Panorama

On 31st May 2011, the BBC Panorama programme “*Undercover care: the abuse exposed*” showed systematic and pervasive abuse of people with learning disabilities at Winterbourne View.

There was widespread condemnation of the treatment of people with learning disabilities at Winterbourne View. Subsequently a collaborative group of 86 organisations and individuals sent a letter to the Prime Minister. The Challenging Behaviour – National Strategy Group developed “*Time for action*” to set out what action is required to improve the support and services people with learning disabilities who display challenging behaviour receive. A copy is in your delegate pack.

The Association for Supported Living (ASL) has written to every MP in the country calling for community-based supported living services to replace institutional services for people with learning disabilities. Kim Foo, chair of the ASL says: “*The message is simple and clear and unequivocal – there is another way – we are presenting to the Government evidence of a substantial number of alternatives to the abusive institution seen on Panorama in May.*” The ASL is also publishing a report with a collection of best practice examples.

## 2. Department of Health review meetings

The Government is conducting a review to be led by Bruce Calderwood (Department of Health) with input from Mark Goldring (MENCAP), Prof Jim Mansell (Tizard Centre, University of Kent) and Anne Williams (Former National Director for Learning Disabilities), which will consider the following:

- The Care Quality Commission (CQC) unannounced inspections of 150 hospitals for people with learning disabilities
- The Care Quality Commission internal review
- Serious case review by South Gloucestershire Safeguarding Adults Board
- Serious Untoward Incident investigations by the Strategic Health Authority
- Police investigation – 11 arrests

Challenging Behaviour – National Strategy Group members are contributing to the Government review via two meetings. A meeting to discuss the emerging issues was held in December 2011. A second meeting to report the emerging finding will be held later in March 2012.

The review will be published after the criminal investigations have concluded and the Serious Case Review, NHS review and CQC reviews are complete.

### **3. CQC review**

The Care Quality Commission is undertaking a programme of unannounced inspections of services for people with learning disabilities. This is a targeted programme of inspections of 150 services. More than 100 are NHS and independent services that provide services such as assessment and treatment, rehabilitation and longer term care. The others are adult social care locations. It is looking at whether people experience safe and appropriate care, treatment and support and whether they are protected from abuse.

The inspections teams include CQC inspectors, a professional advisor and two 'experts by experience' - people who have experience of using services, either first hand or as a family carer and who can provide the patient perspective.

The Care Quality Commission (CQC) published its latest batch of reports on 29<sup>th</sup> February 2012. The results showed just four out of 20 providers met essential standards for both care and welfare and safeguarding. Of 67 reports published so far, just 17 providers were compliant with both standards.

Mencap & the Challenging Behaviour Foundation have issued several joint press releases as the reports have been published. The latest press release was published on 29<sup>th</sup> February 2012:

“These latest CQC reports again reveal serious concerns about the care people with a learning disability are receiving in specialist assessment units, and it is extremely worrying that 16 of the latest 20 units inspected by the CQC are not fully compliant with essential quality and safety standards.

These post-Winterbourne reviews are providing a strong justification for moving away from institutional care where people are hidden away out of sight and mind, towards developing local services. It is crucial the Government ensures these changes are made to reduce the likelihood of the abuses seen at Winterbourne View happening again.”

### **4. Cost effectiveness research**

Viv Cooper, Peter McGill and Roger Banks have been working with Professor Martin Knapp and Amerah Amin at the London School of Economics to identify the cost effectiveness of a range of interventions. It is expected that the results of this analysis will be available later this month.

### **5. Campaign subgroup**

The Challenging Behaviour – National Strategy Group has a campaign subgroup led by MENCAP. A campaign plan and policy statement are currently under development and will be made available to CB-NSG members later this month.

The campaign will focus on people with a learning disability who have behaviour being described as challenging being sent to large Assessment and Treatment units, often far away from home, where they are isolated and at risk of abuse. Once in these units, many people remain there for long periods of time. Winterbourne View epitomises the failure of this approach, with its high level of risk, where unacceptable abuse has taken place.

## 6. Influencing NHS commissioners

Bill Love (NDTi) and Alison Giraud-Saunders, with support from Viv Cooper (CBF) and Sam Clark (Inclusion North), drafted a briefing as the basis for an article in Primary Care Commissioning's 'Commissioning Excellence' newsletter. The audience for this newsletter is mainstream NHS commissioners, so the briefing set out very basic explanations about learning disability, challenging behaviour, and what NHS commissioners should be doing. The editor is away, so we are waiting to hear if they will go ahead and publish.

## 7. Death by indifference: 74 deaths and counting - A progress report 5 years on

Mencap is calling on the government to make the NHS safe for people with a learning disability, following the publication of a new report 'Death by indifference: 74 deaths and counting', which finds continued institutional discrimination in the NHS.



Mencap's Death by indifference reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS. The publication of the Death by *Indifference* (2007) report prompted a number of families to contact Mencap, and they continued to do so in the weeks, months and years that followed. These cases – a total of 74 to date – highlight an NHS that continues to fail people with a learning disability. 'Death by indifference: 74 deaths and counting', looks into some of the traits which are repeatedly seen in the cases and the recommendations made by Healthcare for All.

The report can be downloaded from: <http://www.mencap.org.uk/74deaths>

## 8. Pathway

A number of CB-NSG members are working together to create a challenging behaviour pathway. The pathway will be an online interactive tool to identify what support is available, how to access it and where to get support and information. It will be evidence based and set out the involvement of the individual, their family carer and supporters. The pathway will be a general

template with the intention that local adaptations can be created and implemented.

To date an initial structure has been developed and contributor's guidelines are being drawn up. The steering group will be approaching members over the coming months to write information about their area of specialism. It will be published on the Challenging Behaviour Foundation website.

### **9. Guidelines on the design of the physical environment – Sue Osborn (Kingwood)**

The Kingwood Trust, Royal College of Art Helen Hamlyn Centre and Being have collaborated to produce a new resource "*Living in the Community. Housing Design for Adults with Autism*". This resource provides detailed guidance on how the built environment and housing design affects the health and wellbeing of people with autism. Available via [www.hhc.rca.ac.uk](http://www.hhc.rca.ac.uk)

### **10. Everybody Matters Film**

*Everybody Matters* will be a powerful new film that will provide an urgent call for the support and services that are needed to enable individuals and their families to lead good lives. We have made a short trailer, but we hope to make a 40 minute film that will feature family and professional experience that we can use to influence change.

"There's no doubt that we need to take action to stop these kinds of services being used in this way as dumping grounds as an alternative to developing proper local services for people." Professor Jim Mansell (who features in the film).

The film will be shown at today's meeting and further information is provided in the delegate pack including details of how you can support the film.

### **11. Charter sign up**

Members of the CB-NSG have worked together to develop a charter to set out a shared vision and action required to deliver it.

The label challenging behaviour has become misused over time. Rather than being used as a term to encourage carers and professionals to understand the underlying reasons for a person's behaviour, 'challenging behaviour' has been used as a diagnostic label, viewed as being intrinsic to the person.



We know that much better support and services could be provided for children and adults who are perceived as challenging. This charter sets out the rights of these individuals and the action that needs to be taken.

To date 107 organisations and 91 individuals have signed up to the charter. Recent sign up to the charter includes: The Association of Directors of Adult Social Services (ADASS); Bangor University and Inclusion North. A copy of the charter and easy read charter are included in your pack. If you would like additional copies to distribute in your local area, please email: [nationalstrategygroup@thecbf.org.uk](mailto:nationalstrategygroup@thecbf.org.uk) or see Gemma Honeyman today.

## 12. Publicity

The Challenging Behaviour Foundation has re-launched its website. The Challenging Behaviour – National Strategy Group (CB-NSG) section of the website has been updated and new information added. We have also added graphic facilitation and photos from meetings. Take a look and see if you are in any of the photos taken at meetings. To view the changes, please go to [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

The following additional publicity focussing on the work of the CB-NSG has been completed.

- a. A mailing to all partnership boards in England
- b. Publication of a review of *Developing better commission for individuals with behaviour that challenges – a scoping exercise* by Peter McGill, Viv Cooper & Gemma Honeyman in Community Living “The report is highly recommended reading. It provides an honest reflection of the issues relating to the commissioning of services for some of the most challenging and vulnerable in our society.”
- c. Roger Banks and Viv Cooper spoke at the BILD national conference on 7<sup>th</sup> October 2011.

Further publicity work planned over the coming months includes:

- a. Targeted dissemination of the resources:
  - *Services for children and young people who display challenging behaviour. Well matched skilled staff* by Dr Sarah Bernard
  - *Services for adults with learning disabilities who display challenging behaviour. Well matched skilled staff* by Dr Peter Baker
- b. An APPG led by the campaign subgroup
- c. A bid has been submitted to the National Children and Adult Service Conference (NCAS) conference, which provides a key opportunity to influence Directors of children’s and adult’s services.

## 13. Jim Mansell

We were delighted to learn that Professor Jim Mansell, a CB-NSG member, had been awarded a CBE in the Queen’s New Year Honours List.

“Jim is a real champion for people with learning disabilities whose behaviour is described as challenging and their families- he speaks with authority and eloquence, whilst retaining his sense of outrage about how we fail to support people well. This award is greatly deserved.” Viv Cooper.