

Updates from the CB-NSG steering group – March 2013

A whole range of action takes place between meetings to implement the work of the CB-NSG. Here the steering group have compiled the following information about a small selection of the progress made. **Many thanks to all CB-NSG members who have contributed to this work.** 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

Campaign subgroup update on recent campaign activity

The campaign subgroup led by Mencap and the Challenging Behaviour Foundation have been very active since the last CB-NSG meeting in October. Below is a summary of the work that has been completed.

November 2012

- **6 families met with Norman Lamb**
 - This meeting with the families was one of the most powerful ways the DH review was influenced.
 - The meeting was supported by Mencap and the CBF.



December 2012

- Lots of comments back and forth regarding the draft final report and concordat. Final launch date delayed.
- **Launch of DH final review and concordat** -Roundtable meeting with key stakeholders (it was very short notice but Mencap facilitated 4 families to attend). Norman Lamb read out oral statement in Parliament (with response from Liz Kendall MP – shadow care minister and discussion). Oral statement also read out in Lords and there was a discussion.

Media stats: 39 pieces of coverage for Winterbourne View. Total circulation/reach: 22 million:

- 19 pieces of national coverage
- 11 pieces of regional coverage
- 9 pieces of trade coverage

Media highlights:

- Front page of The Times and double page spread inside, focusing on the Government's report. This included an interview with David & Jill Jack and a comment piece by Mark Goldring.

- Interviews with Mencap and CBF spokespeople on Radio 4, Radio 5, Radio 2, BBC News, BBC News Channel, Sky News and Channel 5.
- Channel 5 and regional radio and TV stations interviewed the families involved.

Website hits (Between Oct 2012 and Jan 2013):

- 6,347 hits on Winterbourne/Out of sight webpage
- 2001 downloads of Out of sight (full report)
- 739downloads of Out of sight (easy read)

There has been a lot of social media – Facebook, twitter etc. over Out of Sight report, court case, final government report

- **Short debate in House of Lords (13th Dec) secured by Lord Rix**
“Ending the abuse of people with a learning disability: learning the lessons from Winterbourne View.” Lord Rix spoke.
 - 10 peers contributed. Issues that arose included corporate accountability, commissioning, workforce, access to therapeutic and mental health services.
- **APPG (18th Dec) Norman Lamb MP, Care Minister outlined to key stakeholders what is in final report and plans going forward**
 - Ann Early, Simon’s mum spoke – why what happened to Simon happened. Her hopes following launch of report.
 - Questions from the floor.
- **Written response to CQC consultation on its strategy**
 - Various points including CQC have and use the power to refuse to register or de-register services which are known to put people with a learning disability at particular risk of abuse and neglect. For example, large assessment and treatment units like Winterbourne View.

January 2013

- Mapping **campaign activities/campaign plan**
- **Mapping actions & progress** of actions from **Transforming Care**
- **CQC Mental Health Act report**
 - The CQC report highlights that mental health services are failing to protect vulnerable people.
 - Mencap & CBF joint press statement

February 2013

- **Campaign subgroup meeting** to plan next stages of campaign including:
 - **Equipping local campaigners** to put pressure on to get local change
 - **Exploring legal rights** e.g. using Human Rights Act (Right to family life)

- **Parliamentary work** around Draft Care and support Bill and Children and Families Bill (opportunities to reflect Winterbourne learning e.g. safeguarding, local offer for young people etc)
- **Media opportunities**, including other abuse cases coming to light
- **8 families met with Chris Bull**
 - During his meeting with the families, Chris Bull heard about the real-life experiences of those abused at Winterbourne View or units like it.
 - The Meeting was supported by Mencap and the CBF
- A place on the **Joint Improvement Board** chaired by Chris Bull was secured by the Challenging Behaviour – National Strategy Group. An election was held to nominate a representative following, in which **Beverley Dawkins** was elected as the CB-NSG representative. Sarah Bernard & Richard Whitehead were confirmed as deputies.



General updates

1. Core service specification

A core service specification is currently being developed to support Clinical Commissioning Groups in commissioning specialist services for adults with learning disabilities who display challenging behaviour around an agreed model of care. **Geoff Baines** joined us at the meeting on 8th March 2013 to provide further information and a PowerPoint presentation is available. The campaign subgroup is working to clarify the timescale for the core service specification for children and young people.

2. NICE clinical guidance: challenging behaviour and learning disability

A workshop is taking place on 18th April to inform the scope of the NICE guidelines on challenging behaviour. The scope will define what the guideline will, and will not cover. Consultation on the draft scope of the guidelines is expected to begin from May – June 2013. The guidelines will be published in Summer 2015.

3. Driving Up Quality Alliance- Provider Code

As part of the Winterbourne View delivery programme, several provider representative organisations and big providers have come together to form the Driving Up Quality Alliance. The alliance has drafted a code for services that support people who challenge. It is envisaged that providers and commissioners will publicly sign up to the code and report against it.

The code was drafted using the Challenging Behaviour Charter, the service model outline in the DH report and also makes reference to the culture and governance of the organisation.

Part of the drive behind this piece of work is to have a provider led response to drive up quality and drive out poor services and poor commissioning, and to increase the openness and accountability of providers to restore public confidence in good quality services.

A consultation exercise took place in various areas of the country last week to develop the code and to make the code effective. A draft will be available in the 3rd week of March and will be sent out for further consultation.

The Housing and Support Alliance are co-ordinating this piece of work.

4. Royal College of Speech & Language Therapists (RCSLT) – Good practice standards

As part of the Winterbourne View delivery programme good practice standards for commissioners and providers to promote reasonable adjustments to meet the speech, language and communication needs of people with learning disabilities are being produced. A first draft has been produced, this is going to the national forum for comment and then it will be written and get RCSLT ratification for July.

5. Joint Commissioning Panel of the Royal College of General Practitioner and Royal College of Psychiatrists

The Joint Commissioning Panel of the Royal College of General Practitioner and Royal College of Psychiatrists committed to produce detailed guidance on commissioning service for people with learning disabilities who also have mental health conditions as part of the Department of Health review. An Expert Reference group has met led by Ashok Roy from the Royal College of Psychiatry and Co-Chaired by Jo Hough of the National Valuing Families Forum. A further meeting is scheduled in March to complete this work and a consultation is taking place with People in Action and the Foundation for People with Learning Disabilities.

6. British Psychological Society – Positive Behaviour Support

As part of the Winterbourne View delivery programme the British Psychological Society undertook to promote training in and implementation of Positive Behaviour Support (PBS) across the full range of care settings. A number of experienced psychologists (13) are now enrolled for the Advanced Professional Diploma in Positive Behaviour Support run by Abertawe Bro Morgannwg University Health Board. The aim is to support them to consolidate their skills in PBS, which means that they can build on their use of this approach in their direct interventions with people with learning disability whose behaviour challenges services. They will also be able to disseminate these skills through their leadership roles in their employing services and by further supporting the development of skills in PBS in the different regional groups of the LD Faculty across the UK. As such, the 13 people are from a variety of locations in England, Scotland and Wales to try to ensure maximum geographical spread. The course takes up to 2 years to complete in its entirety, but it is anticipated starting to see an impact on practice prior to this as the cohort moves through the course and starts disseminating what they are learning.

7. Addressing the use of medication

Concerns were raised in the Serious Case Review and the Department of Health review about the use of anti-psychotic and anti-depressant medication. After the Serious Case Review was published the Challenging Behaviour Foundation wrote to the minister to highlight this issue and subsequently a meeting was arranged between the Department of Health, the Challenging Behaviour Foundation, Roger Banks and Ian Hall. It was agreed that a meeting would be held to take the concordat actions forward. This meeting took place on the 13th February 2013 and was attended by several CB-NSG members. A further meeting is planned later in the year to take forward this work including the possibilities of an audit of the use of medication for people with learning disabilities whose behaviour challenges.

8. Confidential Inquiry

The Confidential Inquiry into premature deaths of people with learning disabilities is due to report on 20th March 2013 and will be made available via the Public Health Observatory website: <http://www.improvinghealthandlives.org.uk/>

9. Next meeting

The next CB-NSG meeting will take place in Autumn 2013 in London.

If you have any updates you would like to share with members please contact us on nationalstrategygroup@theCBF.org.uk or telephone: 01634 838739