Update for the CB-NSG Steering Group – March 2015

A huge range of actions are undertaken between national meetings to implement the work of the CB-NSG. In this document the Steering Group highlights a small selection of the progress made, in various areas, since our last meeting. A big thank you to all CB-NSG members who have contributed to the work detailed here, as well as to members who have contributed to other pieces of work that we have not been able to include. 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 do get in touch.

For regular updates visit the Strategy Group pages of the Challenging Behaviour Foundation website: www.challengingbehaviour.org.uk/driving-change/national-strategy-group or email nationalstrategygroup@thecbf.org.uk

Campaign subgroup update on recent campaign activity

Winterbourne view Campaign. Mencap and the Challenging Behaviour Foundation (CBF) have continued to collaborate on a range of policy, parliamentary and media work to influence change on behalf of all children and adults with learning disabilities whose behaviour challenges. The following activity has been taken since our last CB-NSG meeting in October 2014.

LD census
The Learning Disability Census 2014 was released in January 2015. The key points are highlighted in the infographic to the right but include:

- 3,230 people in inpatient care
- 1,055 did not need inpatient care according to their care plan.
- 2,345 people (73%) had received antipsychotic medication either regularly or as needed in the 28 days prior to the census collection. Use of antipsychotic medication has increased between 2013 and 2014.
- 1,780 people (55%) had one or more incidents (self-harm, accidents, physical assault, restraint or seclusion) in the three months prior to census day.

NHS England has published another two sets of Winterbourne View Concordat Data.

- Five sets of quarterly data have now been published in total. The data shows that in the most recent quarter, the total number of patients in inpatient units has decreased.
- The graph to the right illustrates the difference between number of patients admitted to inpatient care and the number of patients transferred out of inpatient care.

CB-NSG steering group members have met with officials at NHSE to discuss data collection.

The National Audit Office (NAO) published a highly critical report into care services for adults with learning disability. The report addresses the failure of the government to meet its commitment to move people out of ATUS and concludes that it was partly due to there being no mechanisms for systematically pooling resources to build sufficient capacity in the community. It states that, so far, there has been no financial incentive for local commissioners to bring people home.

In response to the NAO report a meeting of the Public Accounts Committee (PAC) was held. Vivien Cooper (CBF), David Congdon (CBF Advisor) and Sir Stephen Bubb (ACEVO) gave evidence to the committee after which MPs heard from:

- Una O’Brien, Department of Health (DH) Permanent Secretary
- Jon Rouse, DH Director General of Social Care, Local Government and Care Partnerships
- Simon Stevens, NHS England Chief Executive
- Jane Cummings, NHS England Chief Nursing Officer

Failings were acknowledged, priorities re-examined, a continued commitment to addressing the issues was made and a long awaited closure programme was announced. CB NSG members will continue to monitor progress and support initiatives that result in positive outcomes for individuals and their families.

In December 2014, a group of families attended a day in London to provide their input to the CBF/Mencap campaign work. They met with key officials from the Department of Health, NHS England, Care Quality Commission, Association for the Directors of Adult Social Services and the Local Government Association. Families asked the officials questions and shared their lived experiences. All agreed the day provided valuable insight, and the officials requested that the meetings become regular. Meetings will be held three times a year. A second meeting was held in February and a further meeting is scheduled for June.
Media

Atlas

Media reported on the 22 care staff charged with offences including false imprisonment and ill treatment of residents at care homes run by Atlas Project Team Limited. Mencap and the CBF said, ‘we want to see a full and thorough investigation into these serious allegations. Anyone responsible for the abuse of people with a learning disability must be properly held to account.’

Inquest into the death of Stephanie Bincliffe

Mencap and the CBF supported Stephanie’s mother and sister, to talk to the media during the inquest into Stephanie’s death. The case was widely reported in major newspapers, including quotes from the Mencap and CBF press release which called for an independent inquiry into the death of all people with a learning disability.

CQC inspections

In December 2014, a CQC inspection found that Calderstones NHS Foundation Trust, a hospital for people with learning disabilities in Lancashire, had ‘serious deficiencies’ in its care. Mencap and the CBF wrote a blog post in The Guardian about the report.

Sir Stephen Bubb’s report and NHS England’s response (more information on these can be found under ‘policy’). The CBF and Mencap said they ‘welcome much of what is included in Sir Stephen Bubb’s report, but it must now lead to a clear plan and urgent action.’ Family carers Phill Wills, Leo Andrade and Lynne McCarrick were supported around a range of media activity, including national papers, radio and TV. The CBF and Mencap said that NHS England’s response ‘is the first recognition that collectively they understand the scale of the problem but does not do enough to take us nearer to delivering the key recommendations from the Bubb report.’

NAO Report & PAC hearing

There was significant coverage around both the NAO report and the PAC, with Mencap & CBF’s joint statement being used in many articles.
Sir Stephen Bubb was appointed to chair the NHS Transforming Care Steering Group and his report ‘Winterbourne View: Time for Change’ was published in November 2014. It provides a series of recommendations to NHSE and partners.

The NHSE and partners response to the Bubb Report ‘Transforming Care: Next Steps’ and the Department of Health ‘Winterbourne View: Transforming Care Two Years On’ report were published at the end of January 2015. “Winterbourne View: Transforming Care Two Years On” sets out a joint account from partners across the health and care system of the progress up to now: https://www.gov.uk/government/publications/winterbourne-view-2-years-on. “Transforming Care- Next Steps” sets out the plans for the next steps in this work: http://www.england.nhs.uk/2015/01/29/next-steps/.


PAC committee session is here: http://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2010/care-for-people-with-learning-disabilities/

The Government has launched a Green paper consultation that identifies potential areas of change: https://www.gov.uk/government/consultations/strengthening-rights-for-people-with-learning-disabilities. (more information on page 4)

Transforming Care Assurance Board meetings

Since the last NSG there have been 3 meetings of the newly formed Transforming Care Assurance Board. These boards have been chaired jointly by Gavin Harding and Norman Lamb (or Sarah Clinton from the DH in his absence).

The programme:
The focus of the meetings has been to report back on progress under these work streams:
1) Delivering the best care 2) Future care and design 3) Integrated local improvement support 4) Data and information 5) Supporting people and their families 6) Regulation and inspection 7) Cross system levers

The meeting in January rated the overall progress in these areas as RED due to the fact that whilst significant steps had been taken under each area, key targets had not been met, overall there had been less progress than hoped for and the programme had faced barriers that had not been anticipated.
At the March meeting it was confirmed that the programme has been re-organised and the diagram below summarises the streams that it will now report against and the agreed reporting structure.

This was the last meeting before the election. There were concerns about what would happen post-election and whilst the DH expressed the view that the programme would continue some participant were anxious that the programme could be de-prioritised. Norman Lamb reflected on the fact that for the first time the data was showing signs of progress with a small decline in the number of people in the A&TU system from 2615 on March 31st 2014 to 2453 on the 31st December 2014. Norman Lamb was thanked for his work on the programme. He commented that he had become very frustrated in trying to ensure that the programme was effective and thanked the organisations who he said had refused to accept failure and pressed for change.

Forthcoming events

The Green Paper came out for consultation on Friday 6th March. The closing date is 29th May. The paper can be downloaded at: https://www.gov.uk/government/consultations/strengthening-rights-for-people-with-learning-disabilities?dm_i=6N7.3820M.4AYL4R.BJKCV.1

The DH reported that the responses to this will form the basis of advice to the new government. We hope to be able to organise a CB-NSG consultation day, probably to be held in April, if you would be interested in attending please email nationalstrategygroup@thecbf.org.uk
Membership news

Noelle Blackman has become a Core Member of the CB-NSG, representing Respond.

Next Meeting
The next CB-NSG meeting will take place on Thursday 22nd October 2015 at Edge Hill University, Lancashire campus. Please see the flier in the delegate pack for more information.

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

General Updates

1. The development of the National Institute for Health and Care Excellence (NICE) guidelines on Challenging behaviour and learning disability has progressed. Draft guidelines have been out for consultation and the final version are due for publication in May 2015.

2. NICE are also developing guidelines on mental health problems in people with learning disabilities: management of mental health problems in people with learning disabilities. The draft guidelines will be out for consultation in Spring 2016, with the final versions due to be published in September 2016.

3. NICE has announced plans to develop guidelines on the ‘service model for people with learning disabilities and challenging behaviour’. A scoping workshop and the consultation around the draft scope will occur in June 2015. You can register as a stakeholder here: https://www.nice.org.uk/guidance/indevelopment/gid-scwave0770

4. The Children’s Commissioners research into the rights and well-being of children in residential special schools was published on 15 Dec 2014. http://www.childrenscommissioner.gov.uk/content/publications/content_910

5. The joint CBF and Council for Disabled Children Early Intervention Project published an early intervention evidence briefing paper and data supplement on 10 November 2014. The papers can be found here: http://www.challengingbehaviour.org.uk/driving-change/early-intervention/the-developing-vision.html. Close proximity to publication of the Bubb report helped to raise the profile among the intended audiences. Responses so far include: a commitment by the Children’s Health and Wellbeing Partnership board to ensure education input to the Care and Treatment Reviews of children in ATUs and a piece of work looking at how to change the system to prevent admissions, a commitment to use the evidence to influence coverage of children in NHSE commissioning framework; work by The Learning Disability Professional Senate children’s group to develop resources to support early intervention by professionals; and a better link into the CAMHs review. The forthcoming case studies resource Paving the Way will showcase good support and services for children, to encourage other areas to replicate. You can pre-order a copy at http://www.challengingbehaviour.org.uk/driving-change/early-intervention/resources.html
6. Mencap is running a ‘Hear my voice’ campaign, aiming to encourage people with a learning disability, and the millions of family members, carers and support workers connected to them to make their voice heard on the issues that matter to them in the run up to the 2015 General Election. The three main party leaders have joined the Hear My Voice campaign, promising to listen to people with a learning disability. For further information please visit their website: https://www.hear-my-voice.org.uk/.

7. The Care Quality Commission and the government published guidance on the fundamental standards regulations. It includes two regulations – the duty of candour and the fit and proper person requirement for directors. For more information see: http://www.cqc.org.uk/content/publishing-new-fundamental-standards


9. The last CB-NSG held a workshop on ‘Positive Behavioural Support (PBS) Academy for England’ and afterwards shared a survey monkey poll. The poll found that: 82% of respondents agreed that the Academy was a good idea (10% ‘don’t know yet’) and 83% felt that the academy would make either a significant or very significant difference to practice. The establishment of the academy was included as a recommendation in Sir Stephen Bubb’s report for NHS England ‘Winterbourne View – Time for Change’ (2014). This recommendation was not included by NHSE and partners in their response ‘Time to Change’. Instead, their workforce plans simply stated that they would ‘carry out scoping work with partners to identify current gaps in the provision of workforce development’. However the group has decided to proceed with some of their ideas under the name ‘PBS Coalition’. They will be publishing a PBS competencies framework and a special edition of the IJPBS will include an update on the work.

10. The Winterbourne View Joint Improvement programme is running a series of workshops. Details can be found here: http://www.local.gov.uk/place-i-call-home/-/journal_content/56/10180/6908091/ARTICLE. These have been informed by the CBF/CDC Early Intervention project and families have been talking to commissioners at the events to highlight the issues that need to be addressed by local services.