

## Update for the CB-NSG Steering Group – October 2014



making a difference  
to the lives of people with  
severe learning disabilities

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. **We would like to say a big thank you to all the 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 here.** 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](http://www.challengingbehaviour.org.uk/driving-change/national-strategy-group) or email [nationalstrategygroup@thecbf.org.uk](mailto: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 of 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 March.

#### Parliamentary activity

- Norman Lamb MP (Minister of State for Care) agreed to meet Fauzia, who lived in an assessment and treatment unit for 20 months during which time she was repeatedly restrained and heavily medicated. Norman Lamb also spent some time speaking to her family and afterwards commented *“People with learning disabilities have the right to lead their lives like anyone else, to have the same opportunities, the same rights and the same aspirations. It is absolutely unacceptable for people to be left in institutions if they are able, with the right support in place, to live in their own community.”*
- In July an All Party Parliamentary Group (APPG) was held at the House of Commons on the failure to meet the June deadline. The CBF & Mencap both spoke at the APPG and supported 15 families to attend the meeting to ask questions to hold NHS England and the Local Government Association to account.
- Following the APPG Tom Clarke MP led a debate in Parliament on the Government’s failure to meet the June deadline for getting people out of institutions like Winterbourne View. Norman Lamb also responded to the debate and gave



From left to right Dr Shahana Hussain (aunt), Muhammad Hussain (father), Sarah Hussain (mother) and Norman Lamb MP



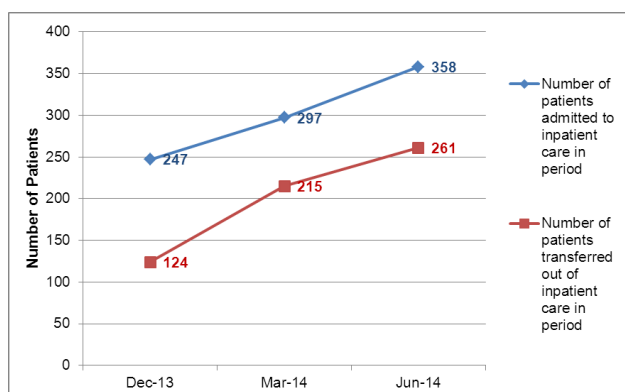
Families attending the APPG

figures on how many people currently in in-patient settings will move out in the next 12 weeks.

- Following the debate the Labour party called for a new 2 year deadline. Liz Kendall MP, Shadow Minister for Care and Older People, said: *“Ministers previously pledged to give people with learning disabilities support in the community or in their own homes – but it’s just not happening. I’m calling on the Government to commit to giving these patients the support they need in the community within the next two years. It’s time that Ministers made good on their promises.”*
- At the end of July, Lord Hunt, Labour Health spokesman in the Lords, asked a question on progress with resettlement and the June deadline. A number of Peers spoke, asking questions about finance, accountability and a new deadline for getting people out of in-patients settings. Little new information came out of the session from the Government.

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

- Three sets of quarterly data have now been published in total. The data shows that although the numbers of patients transferred to the community during each quarter has increased, the total number of patients in inpatient units has increased overall from 2577 in December 2013 to 2601 in June 2014. 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.



Graph illustrating some of the NHS quarterly data

The **National Audit Office (NAO)** is **conducting a study into care services for adults with learning disability**.

- Its key aims are to examine if the government is achieving the commitments outlined in the 2012 Winterbourne View Concordat, whether stakeholders are working effectively to build community based care and to examine arrangements for monitoring the quality of care for adults with learning disabilities. Upon our suggestion the NAO invited members of the CB-NSG to input into the enquiry earlier this month. The study is due to be published in early 2015.

## Media

### Learning disability census

In April the second report from the Learning Disability Census was published which revealed that out of 3250 people with a learning disability in units:

- 64% (2,064) had been given anti-psychotic medication on a regular basis leading up to Census day.
- 56% (1,841) had experienced self-harm, an accident, physical assault, hands-on restraint or been kept in isolation during the 3 months preceding the census
- 86% (2,795) costing up to £4, 500 per week
- 71% (2,2 97) don't have a plan in place to move them out

Following this Mencap and the CBF issued a joint press statement which was quoted in a number of local and learning disability media outlets.

We also published an infographic to explain the data in an accessible way (which can be seen below)

## Everyone should have a place to call home

The Government said places like Winterbourne View are 'not homes'. But 3,250 people with a learning disability still live in them. **For 71% there is still no set plan to move them out.**



**So why is it not happening?**  
 £ → The money and the people have to move out of units.  
**The NHS and local authorities must work together to get this right.**

## Missed June deadline

In June the CBF & Mencap published a report “*Winterbourne View: The scandal continues*” highlighting the failure to meet the government deadline and that the NHS data showed that more people with a learning disability were going into units than leaving them.

Following this the CBF & Mencap issued a joint press statement and undertook a range of national and local media work.

## Letter to David Cameron & e-action

Mencap & the CBF supported families to write an open letter which was published in the Telegraph. It called on David Cameron to take responsibility for the failure of the Government to meet its own deadline and to fulfill the promise made to get the right support, in the right place, for each and every person with a learning disability. Approximately 5000 people signed the e-action to David Cameron. An update will be issued to all who signed the e-action shortly.

## #BringJoshHome

The family of Josh Wills were supported to speak to local and national media to support their campaign to #BringJoshHome. Substantial national and local media coverage was gained including an interview on This Morning and articles in the Sunday Mirror, Daily Mail and the Guardian as well as on ITV.com and BBC online.



Phil Wills

Over 240,000 people supported a change.org petition and plans are now in place for Josh to return to Cornwall. Mencap supported Josh's family to thank his supporters on YouTube

## Atlas

In October Devon & Cornwall Police charged seven people with conspiracy to falsely imprison and conspiracy to ill-treat vulnerable adults residing in their homes. The charges relate to allegations surrounding the treatment of eleven residents at three care homes run by Atlas Project Team Limited in Devon between 1<sup>st</sup> January 2010 and 31<sup>st</sup> December 2011. Mencap & CBF issued a joint press statement and there was local and national media coverage including ITV.com.



## Policy

- In July 2014 the Winterbourne View Joint Improvement Programme (JIP) Board met and agreed governance changes for the Winterbourne View programme. The Board agreed that, in place of the previous JIP Board, there will be a **new Transforming Care Assurance Board**, with broadly similar membership but crucially it will oversee all the actions of the Winterbourne View programme, and not just the ones that the JIP lead on. It will be co-chaired by Norman Lamb, Minister for Care and Support and Gavin Harding. Sir Stephen Bubb joined this Board and there is a representative of the Winterbourne View families. All previous JIP Board members will remain members of the Transforming Care Assurance Board (Beverley Dawkins is your elected CB NSG representative). Marie Lovell from Skills for Care has been seconded to the Joint Improvement team to lead on workforce.
- Sir Stephen Bubb was appointed to chair the NHS Transforming Care Steering Group to address the lack of progress following Winterbourne View. The Steering Group will develop a report by the end of October 2014 describing a national framework for local commissioning. The national framework will be locally delivered in partnership with the third sector and the local government, it will create new pathways of care in the community, to support people with learning disability to live at or near home and not in hospital. The CBF and Mencap are both represented on the group and aim to ensure that the views of people with learning disabilities and family carers are central and that the report proposes solutions that will deliver change for people with learning disabilities whose behaviour is described as challenging.
- NHS England has produced a draft plan to address the issues. They are revising this and will present this at the next Assurance Board meeting. Beverley Dawkins continues to represent CB-NSG members on the board.
- St Andrew's have published a proposal to build a new 110 bed child and adolescent unit at its existing site in Northampton. The Challenging Behaviour Foundation and Mencap have written to the Care Quality Commission and the Department of Health to ask what action will be taken.

## Membership news

### Core Membership updates:

1. Valentina Lemmi is the new London School of Economics representative.
2. Helen Wheatley has left the Council for Disabled Children (CDC), and Amanda Allard is currently representing CDC.
3. Simon Shaw has replaced Sarah Lambert as the NAS representative.
4. Natspec have changed their representative to Maria Chambers.

### The Steering Group Membership was reviewed in June 2014:

- Dan Scorer represents Mencap.
- Beverley Dawkins is an independent adviser.
- David Williams, Peter Baker and Sue Turner all accepted invitations to join the steering group.
- All other steering group members agreed to continue.

## Next Meeting

The next CB-NSG meeting will take place on **Wednesday 11<sup>th</sup> March 2015** (venue TBC).

If you are able to offer a central a central London venue for the meeting please contact [nationalstrategygroup@theCBF.org.uk](mailto:nationalstrategygroup@theCBF.org.uk)

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

## General Updates

1. A proposal for a **Positive Behaviour Support Academy for England** has been put together primarily by Professor Richard Hastings and Professor David Allen (many other people have also contributed directly and indirectly). The PBS Academy for England has been proposed as a model to ensure the widespread delivery of high-quality support for people whose behaviour challenges. More details are available at the CB NSG workshop today.
2. **Positive & Safe:** Reducing the need for restrictive interventions, was launched in April 2014 by the Department of Health. It aims to end the use of outdated and damaging restrictive practices, including physical restraint. The 2 year initiative goes beyond the 'Positive and Proactive Care' and 'A Positive and Proactive workforce' guidance, aiming to deliver a transformation across health and adult social care. They will identify levers to bring about these changes including improving reporting, training and governance. Guidance is currently being developed for children, young people and individuals in transition. The Council for Disabled Children held a workshop to feed into the children's guidance. Skills for Care coproduced the workforce guidance with Skills for Health and the Department of Health.
3. New group for people with mild learning disabilities who display challenging behaviour? A number of people and organisations who are members of the CB NSG met because of concerns about support for people with mild learning disabilities who display behaviour described as challenging. There are early discussions about scoping what support is available, where, and who to link to and engage with to address some of the issues these individuals face. If you are interested in being involved at this early stage, please register your interest by emailing [nationalstrategygroup@theCBF.org.uk](mailto:nationalstrategygroup@theCBF.org.uk) marking your email heading as "MLD group".
4. **The Law Commission** began a project in summer 2014 looking into **mental capacity and detention**. This review was prompted by:
  - a. A House of Lords select committee about the Mental Capacity and Act and Deprivation of Liberty Safeguards (DoLS) in March 2014, which found that DoLS were not 'fit for purpose' and called for them to be replaced and extended to cover people in supported living arrangements
  - b. The Supreme Court ruling that a person will be deprived of liberty if they are under continuous supervision and control and if they are not free to leave.

The Law Commission project will consider how deprivation of liberty should be authorised and supervised in hospitals, care homes and community settings including considering the legislation underpinning DoLS in its entirety. Recommendations for reform and a draft bill will be published in Summer 2017.

5. **Improving Lives** is a programme that supports the work of the Winterbourne View Joint Improvement Programme. The team have been working with people with learning disabilities, family members and professionals to review the current experience and plans of the people who lived in Winterbourne View. It aims to assess the quality of care available. The first round of reviews is now complete, and the team are aiming to revisit each person. The Improving Lives Team are hosting two events entitled 'Learning from the Improving Lives Team review' in November to discuss what they have learnt, talk about what is making a difference and share ideas for how the work can continue into the future. The events are for commissioners, managers, regulators, practitioners and people with learning disabilities and their families.
  
6. The development of the National Institute for Health and Care Excellence (**NICE**) **guidelines on Challenging behaviour and learning disability** has progressed. The Challenging Behaviour Foundation was commissioned to facilitate two focus groups for family carers' to provide input into the developing guidelines. These were held in early October, with seventeen family carers' attending in total. Each day was focused around four main topics: access to assessment, medication, behavioural interventions and transition between services. A report detailing the family carers' views and comments on these issues (in addition to other key topics that arose on the day) will be submitted to the NICE Guideline Development Group by the 24<sup>th</sup> October. The topic engagement exercise quality standard for these guidelines will run from December 2014 to February 2015. They will release further details at the start of the engagement period. There will be a consultation period when the draft guidance is produced, and the final guidelines are due to be released in May 2015.
  
7. The National Institute for Health and Care Excellence (**NICE**) are developing **guidelines on mental health problems in people with learning disabilities**: management of mental health problems in people with learning disabilities. A scope of the guideline is now available on the NICE website. The scope outlines the key issues that the guideline will cover, these include: identification, recognition, diagnosis and assessment, interventions, accessibility of services, transitions between services, coordination and communication with key persons in the life of the person with learning disabilities, strategies to engage family and carers in interventions, service structures to support effective delivery of interventions and finally interventions, training and support for family and paid carers which aim to improve the health and well-being of the family and carers, as well as the person with learning disabilities. The guideline will not cover the care and treatment of co-existing disorders that have already been addressed for people with learning disabilities as part of other recent NICE guidelines. The guidelines are due to be published in September 2016.
  
8. The Children's Commissioners research into **the rights and well-being of children in residential special schools** has progressed. It was designed to understand young people's experiences – the good and the bad – of being schooled away from home. The CB-NSG workshop today will explore the lessons learnt from their research about eliciting the views of the children. The report of their research will be published later this year.
  
9. Over a year in, and **the joint CBF and Council for Disabled Children Early Intervention Project** continues to make real progress in working towards our aim of better support for children with learning disabilities and behaviours that challenge. We have *held 8 workshops* to hear what children and young people, family carers, professionals, commissioners and national experts have to say about what works and what needs to change. Pen Mendonca has developed two *graphics* for us with the results of the young people and family carer workshops, which CB-NSG members may wish to use to help raise awareness. We have

produced an *information sheet to support professionals and staff developing Education Health and Care plans* for children with learning disabilities and behaviours that challenge. A similar resource for families is also being produced, along with a sample EHCP, and will soon be available download from our website or order from a Resource Form. We are running a *video competition* to supplement the young people's focus group, so we have a way to participate which is more accessible to young people who find communication more of a challenge. We are in the final stages of developing *briefing paper on the evidence for early intervention*, with the academic expert consensus group. More information about the Early Intervention Project can be found on the CBF website: [www.challengingbehaviour.org.uk/driving-change/early-intervention-project.html](http://www.challengingbehaviour.org.uk/driving-change/early-intervention-project.html). If you want to use the graphics, to find out more about the video competition or to join our email reference group, please get in touch at [earlyinterventionproject@thecbf.org.uk](mailto:earlyinterventionproject@thecbf.org.uk).

10. The film **Everybody Matters** was launched in June of this year. As members might remember, Everybody Matters was a CBF initiative aiming to demonstrate the effectiveness of good, local support. The film follows the stories of Colleen and Shaun, who have previously experienced poor support resulting in unhappy, restricted, and unsafe periods of their lives, but who now have full and active lives in their communities. Everybody Matters can be ordered from the CBF website – it is free for family carers and half-price for registered charities. You can read more about the film on the Everybody Matters blog; [www.everybodymattersfilm.wordpress.com](http://www.everybodymattersfilm.wordpress.com). Everybody Matters has been produced with Frameworks for Change and has been supported by MacIntyre, United Response, Dimensions, the Milestone Trust and many others.
11. Mencap launched their '**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. For further information visit their website: <https://www.hear-my-voice.org.uk/>.
12. The **Care Quality Commission** launched a **consultation on their proposed guidance on meeting 'fundamental standards of care'** in August 2014. The consultation closes in October 2014. The new regulations set out the fundamental standards of quality and safety; introduce a new 'duty of candour' and a 'fit and proper person' requirement for directors, to enable greater accountability to directors. The fit and proper person requirement comes into force for NHS bodies in October 2014 and the full regulations will take effect for all health and social care services in April 2015.
13. The **Winterbourne Medicines Programme** aspires to ensure safe, appropriate and optimised use of medication for all people with learning disabilities who behaviour can challenge. The programme has the following six objectives:
  1. Ensure the service user is central to the work.
  2. To review and develop a deep understanding of issues around current medication processes.
  3. To identify and share notable practice.
  4. To identify a method of measuring change and improvement.
  5. Test new ways of working to improve process where appropriate.
  6. To improve awareness of the issues around medication.The programme is working with project sites to improve services and has developed a community of practice to share learning, guidelines, research papers, notable practice, case studies, blogs and has a forum to pose questions –Visit the community of practice via [www.6cs.england.nhs.uk](http://www.6cs.england.nhs.uk) and join the learning disability community. More information about



the programme can be found on the website – [www.nhs.uk/winterbourne](http://www.nhs.uk/winterbourne) and via the hashtag #winterbourne\_meds.

14. **Sir Robert Francis has asked NHS workers to speak up on whistleblowing** in the 'Freedom to Speak Up' Review. The call for contributions ended in September 2014. NHS workers views will be the form the heart of an independent review looking at how staff on the frontline can be supported to raise concerns and ensure safe care for patients. The focus of the Review is to identify measures to foster an open culture of reporting and protect those workers who do speak out in future. The Review aims to learn lessons from historic cases and about the existing culture in the NHS by listening to those who have experience to share, both positive and negative. Work should be completed by November 2014.
15. The Department of Health conducted a **consultation on the Mental Health Act (MHA) Code of Practice** which closed on 12<sup>th</sup> September. CBF and Mencap sent in information which included issues families have raised about how the MHA is used. A new Code, reference guide and 'easy read' version will be published by April 2015.
16. The Royal College of Nursing, Royal Society of Medicine, Intellectual Disability Forum, Mencap, Improving Health and Lives and the Department of Health co-hosted an event in September 2014 entitled '**Getting hospital care right for people with intellectual disabilities**'. The meeting aimed to raise awareness around the benefit of annual health checks, hospital liaison nurses as well as to aid understanding of policy, best practice and capacity issues. The day was successful, attended by a diverse range of professionals.
17. The National Development Team for inclusion (NDTi) have published summaries of **Reasonably Adjusted** (a report about how mental health services can make reasonable adjustments so that people with learning disabilities and autism can use them) and **The Green Light Toolkit 2013** (a guide to improving mental health services so that they are effective in supporting people with autism and people with learning disabilities) which can be downloaded from <http://www.ndti.org.uk/major-projects/current/green-light-toolkit-2013/>.
18. There is a call for **Workshop Papers** for the **BILD 2015 International Positive Behaviour Support Research and Practice Conference** in Dublin on 7 and 8 May 2015. Further information here: <http://www.bild.org.uk/our-services/positive-behaviour-support/>. The form needs to be completed and returned to Liz Howells at BILD by 31 October.
19. The **BILD PBS interviews** are now on their website. These are a series of interviews with leading practitioners and academics in the field of positive behaviour support conducted at BILD's PBS International Research and Practice Conference, Glasgow in May 2014. <http://www.bild.org.uk/our-services/positive-behaviour-support/pbsresources/pbsvideos/>
20. NHS England and Stephan Brusch have developed a booklet entitled '**Getting it right for people with learning disabilities: Going into hospital because of mental health difficulties and challenging behaviours: What families need to know**'. This booklet has been developed as a result of the collective experience and advice of parents and siblings of people with learning disabilities. The booklet was written by Angela Cole and Alison Giraud-Saunders. It can be found here: [https://www.myhealth.london.nhs.uk/sites/default/files/u1217/NHS%20England%20-%20Getting%20it%20right%20for%20people%20with%20learning%20disabilities%20v6%20\(Spreads\).pdf](https://www.myhealth.london.nhs.uk/sites/default/files/u1217/NHS%20England%20-%20Getting%20it%20right%20for%20people%20with%20learning%20disabilities%20v6%20(Spreads).pdf)