

Update for the Challenging Behaviour National Strategy Group (CB-NSG) – March 2016



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

The CB-NSG has two subgroups: The Campaign Subgroup and the Positive Behaviour Support (PBS) Subgroup.

Campaign Subgroup Report

Mencap, the Challenging Behaviour Foundation (CBF) and other members of the campaign subgroup 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 2015.

Campaign families' meeting with government, NHS and CQC Officials, 27 November 2015

November saw the last of four meetings that Jon Rouse, Director General at the Department of Health, sponsored and funded. Julie Higgins, Director of Transformation, from NHS England gave an overview of 'Building the Right Support', and Hertfordshire Transforming Care Partnership presented on their plans. The main session saw families present across key themes of pre-admission, experiences of being in an ATU, getting out of an ATU, and staying out. Viv Cooper followed up commitments made and key points with attendees. Whilst DH does not intend to fund further meetings, NHS England is keen to work with the campaign group of families. A session is being held in April to review Transforming Care Partnership plans.

2015 Learning Disability Census

On 15 December the Census was published by the Health and Social Care Information Centre (HSCIC). The Census was commissioned in the wake of physical and psychological abuse suffered by people with a learning disability at Winterbourne View Hospital exposed by a Panorama investigation broadcast in 2011.

New figures from 2015 Census showed that through combining the Transforming Care and Census data collections there are up to 3480 people with a learning disability in inpatient units. This is inclusive of 480 patients who were unreported in the Learning Disability Census, an increase of 235 from last year. For more details on this data see: www.hscic.gov.uk/catalogue/PUB19428/ld-census-initial-sep15-rep.pdf



Of the 3000 patients receiving inpatient care who were included in the Census:

- 72% had received antipsychotic medication, yet only 28.5% were recorded as having a psychotic disorder
- 1,670 had experienced one or more incidents (self-harm, accidents, physical assault, restraint or seclusion) in the 3 months prior to census
- Average length of stay in an institution is 4.9 years

- 670 people are 100km or more from home, an increase of 17% on last year
- Mencap and CBF have issued a joint statement, which you can read here:
www.mencap.org.uk/news/article/mencap-and-cbf-respond-learning-disability-census-2015

Steve Sollars, father to Sam, who has a learning disability and spent two years at Winterbourne View until 2010, said: "It is extremely upsetting to know that people are still experiencing what my son, Sam, went through. Sam was at Winterbourne View and was restrained 45 times over a 6 month period, as well as being emotionally tormented by staff there. When he returned home the son I knew was barely recognisable. We, the families, want to see the government and NHS England doing everything in their power to bring about change. After so many false starts I will only believe things are getting better when we finally see more people with learning disability and behaviour that could be described as challenging moving out of assessment and treatment units."



Planning policy and campaigning work for 2016/17

In January families, charities, lawyers and other allies met to review the last 4 years of work across the Transforming Care programme and related areas, in order to agree key areas of work for 2016/17. We were joined by Norman Lamb MP, former Minister of State for Health, who shared his reflections on his time in government trying to drive forward closure of in-patient beds and development of community services. The day saw presentations from families on their experiences as well as group and plenary sessions to agree areas of action over the next year and beyond.

Sir Stephen Bubb publishes final report 'Time for Change: The Challenge Ahead'

On 22 February Sir Stephen Bubb launched his third and final independent report into the progress of the Transforming Care programme. He welcomed last October's publication of the 'Building the Right Support' strategy, but expressed serious concern about the barriers to its delivery and made a number of recommendations. In the report, Bubb said: "failing to deliver this new programme is simply not an option. Another deadline, another target, cannot mean another broken promise." Recommendations made in the report include:



- A real-time independent evaluation of the programme, commissioned by the Department of Health
- For an office of Learning Disabilities Commissioner to be established. The holder of this office would have a statutory duty to promote and protect the rights of all people with learning disabilities and/or autism in England

CBF and Mencap issued a joint statement, which can be found here:
www.challengingbehaviour.org.uk/cbf-articles/latest-news/third-report-stephen-bubb.html

National Audit Office

We continue to be connected to the National Audit Office and members of the Steering Group recently met with NAO officials to share information. This work will be ongoing.

Transforming Care Board

Update from Beverley Dawkins the elected CB-NSG representative for the Transforming Care Board. The last meeting held on 19th January 2016 and was preceded by a pre-meeting for self-advocates, family carers and people representing other forums.

The main comment on these meetings to date is that whilst it is useful to receive updates on the current work strands in the programme, it remains difficult to achieve the level of discussion and challenge required to be assured of real progress. An example of the concerns we have raised is that the board received an update on Community Treatment Reviews (CTRs) and whilst this included the numbers conducted and feedback from

families and people with a learning disability, no evidence was included about outcomes e.g. how many CTRs had resulted from people moving from an ATU back to the community.

This feedback has been given to the Department of Health and there have been additional focus group meetings to create a dashboard for the programme and to consider what patient reported outcomes (PROMS) would be effective in tracking progress. We have also established that it would be more helpful to receive detailed feedback on one strand of the programme at each meeting, rather than to touch briefly on each area. In response to this at the January meeting, in addition to providing an update on the delivery programme, sharing the assurance dashboard that has been developed, there was a workforce 'deep dive' reporting on the combined programme being developed by Skills for Care, Skills for Health and NHS England. They are currently delivering phase 2 of the programme which included piloting the approach in some of the fast track areas. The minutes and papers of the TCAB can be found at: www.gov.uk/government/groups/transforming-care-assurance-board

PBS Academy

This update is from Richard Hastings on behalf of the PBS Subgroup of the CB-NSG.

The Positive Behavioural Support Academy launched a website in February: pbsacademy.org.uk

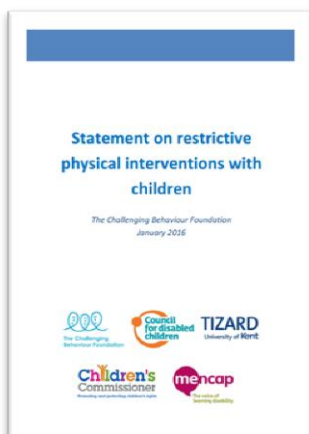
Included on the website are the PBS competencies framework, and a number of other PBS resources built upon the competencies framework. There are currently resources available for people with learning disabilities, service providers, and commissioners/care managers. All resources are available free for download and have been released under a Creative Commons licence. Resources for inspectors of services and direct support staff will be available soon. A family carer resource has been produced in partnership with the Early Intervention Project; please see New Resources below for more details.

Policy Updates

Closure Programme update

www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

In October, NHS England published Building the Right Support, outlining their closure programme of in-patient units and commitment to developing the right support and services for people in their local communities. They have allocated £45m over the next three years to help with this. This follows the government failure to meet their June 2014 commitment to ensure that people with a learning disability were supported to return to their communities from institutions like Winterbourne View. They have also outlined 48 Transforming Care Partnerships across the country. Details of your local area lead can be found here: www.england.nhs.uk/learningdisabilities/tcp/contact



Physical intervention statement

While guidance around physical intervention and restraint is under development by Council for Disabled Children (CDC) and the Department of Health, an "interim" statement has been issued as CB-NSG members are concerned about the ongoing use of prone restraint for children with learning disabilities. This statement aims to clarify our current position on the subject. Several organisations have signed-up to the statement including CBF, CDC, Tizard Centre, The Office of the Children's Commissioner and Mencap.

The statement outlines that there is little evidence to support the use of hands on restraint and seclusion when used in isolation and highlights the dangers associated with prone restraint. This is particularly important in relation to children and young people as the new census data shows they are more likely to be to experience these types of physical interventions. You can read the statement in full by following the link to the CBF website: www.challengingbehaviour.org.uk/learning-disability-assets/statementonrestrictivephysicalinterventionswithchildren.pdf

DH Response to the Law Commission's Review of DoLS

The Department of Health has released their response to the Law Commission's proposals for a legal framework to replace deprivation of liberty safeguards (DoLS). The main point from the response is that they view the plans as having the potential to be unnecessarily complex and expensive to carry out. DH comments that the plans fail to meet 'three tests' including:

- Being user-friendly
- A good use of public money
- Able to deliver 'real' benefits to people lacking capacity to consent to their care arrangements.

There is a suggestion within the response that similar outcomes to those proposed in the Law Commissions review could be achieved through cultural changes within the sector. See here for the full report: www.gov.uk/government/publications/deprivation-of-liberty-standards-dols-consultation-response

Media Update

There has been a range of activity in the media to highlight the issues for children and adults with learning disabilities whose behaviour is seen as challenging. High profile cases include:

- Phil Wills, father of 15-year-old Josh, appeared on Victoria Derbyshire to talk about Josh moving from a hospital unit in Birmingham back home to Cornwall after a three-year struggle. www.bbc.co.uk/programmes/p03kbj6v
- Steve Sollars, dad of Sam who was at Winterbourne View Hospital, appeared on BBC News to share his family's experience of assessment and treatment units and to make the call to action for better care for people with learning disabilities. This was in response to Sir Stephen Bubb's report Time for Change: The Challenge Ahead. See here for details: www.bbc.co.uk/news/uk-35629011
- Ann Earley, mother to Simon, a man with learning disabilities who was at Winterbourne View, featured on Good Morning Britain, in a news segment about the government's failure to close down assessment and treatment units www.itv.com/goodmorningbritain/news/care-crackdown-government-called-to-dramatically-improve-care-of-vulnerable

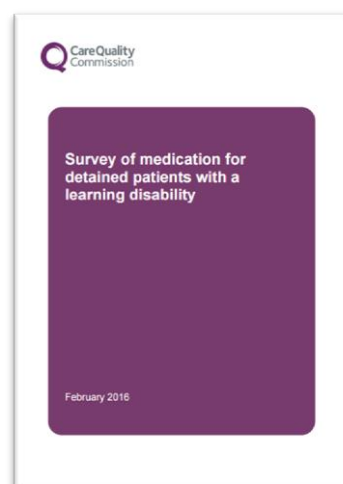


New Reports and Resources

Survey of medication for detained patients with a learning disability

The Care Quality Commission (CQC) has published the full report of its 'Second Opinion Appointed Doctor information' work. Second Opinion Appointed Doctors visit people detained under the Mental Health Act. They look at whether the medication being prescribed for people is appropriate. The report shows that when 945 requests (for a SOAD to look at medication prescribed for a person in a unit) were looked at:

- In a significant number of cases medication appeared to be prescribed primarily to manage behaviour that was perceived as challenging rather than for symptoms of mental illness.
- In general, there was limited rationale offered for the entirety of the treatment plan, particularly when polypharmacy (the use of four or more medications) and high dosage was used.



The report also explores whether changes were made following the intervention of a SOAD:

- Changes to the overall treatment plan only occurred in some 25% of cases.
- Many certified treatment plans still permitted the administration of multiple psychotropic medications and high doses of antipsychotic medication

See here for more information and to read the report in full: www.cqc.org.uk/sites/default/files/20160209-Survey_of_medication_for_detained_patients_with_a_learning_disability.pdf

Mazars Report

As a result of pressure from the Justice for LB Campaign following the death of 18-year-old Connor Sparrowhawk in an assessment and treatment unit, an independent review of deaths of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust from April 2011 to March 2015 has been published. The report indicates that Southern Health failed to investigate the unexpected deaths of more than 1,000 people blaming a "failure of leadership". The health secretary, Jeremy Hunt, apologised in the House of Commons for the failure describing them as "totally and utterly unacceptable". Key findings from the report include:

- There was a lack of leadership, focus and sufficient time spent on reporting and investigating unexpected deaths.
- 30% of all deaths (those reported as expected and unexpected) in Adult Mental Health services were investigated but less than 1% of deaths in Learning Disability services were investigated
- Timelines of investigations is a major concern - on average it took nearly 10 months from an incident to close an investigation
- The involvement of families and carers has been limited - 64% of investigations did not involve the family.

It is unclear how NHS England intends to address these and other issues raised by the report. Available here: <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

Resources from the Early Intervention Project

EIP and Learning Disability Professional Senate have produced a poster for families and a leaflet for professionals to raise awareness of challenging behaviour. The aim of the leaflet is to help children and adults with learning disability and behaviour that challenges access non-specialist services through providing professionals with information around understanding behaviour and the reasonable adjustments that can be made. The poster is intended to link families of children with learning disabilities and challenging behaviour to their local services.



PBS Academy have worked with the EIP to produce a PBS Resource for family carers who have a relative with a learning disability who is at risk of behaviour that challenges and may want to find out more about Positive Behavioural Support (PBS). This information pack aims to explain what PBS is; what it looks like in practice; provides questions to ask to check that PBS is being delivered well in the setting you are looking at; and guidance on how family carers can find out more including advice on training.

The Early Intervention Project website, pavingtheway.works, will be available to access from Monday 14th March 2016 and contains information and resources for children with learning disabilities and challenging behaviour, their families and professionals that work with them. See the flier included in your delegate pack for more information and where you can find these resources.



Disabled Children: A Legal Handbook 2nd edition

The second edition of "Disabled Children: A Legal Handbook" is now available for free online. This recent publication from the Legal Action Group (LAG) and the Council for Disabled Children (CDC) explains the rights of children with disabilities and their families. The book will be useful for families, professionals, support organisations and advocates, as well as those who practice the law. A digital version of the book is available for free on the CDC website. See the following link for more information: www.councilfordisabledchildren.org.uk/resources/disabled-children-a-legal-handbook-2nd-edition

Activate from Dimensions

CB-NSG members have been involved in developing research with Dimensions, which has informed their new support model 'Activate.' The model involves the use of Positive Behaviour Support, and encourages meaningful activity. By halving challenging behaviour and driving widespread improvements to quality of life,

Dimensions' new approach presents an opportunity for commissioners to achieve step change improvements in outcomes and in funding. You can read more about it and watch an animation regarding their work here: www.dimensions-uk.org/initiative/activate

Updates from CB-NSG Members

- The Voluntary Organisations Disability Group (VODG) have released a report concerning effective commissioning for learning disability services. The report, *Thought Leadership: Together we can deliver more effective commissioning and de-commissioning for people with learning disabilities and autism*, addresses five key issues identified by workshop participants as critical to making progress with this agenda. These include:
 - Communication and co-production
 - Commissioning and procurement
 - Training and the workforce
 - Resources and reinvestment
 - Honesty and trust

For each issue identified, a number of practical suggestions are proposed to support the reinforcement and generalisation of the positive developments seen in some places, and to tackle the barriers which still get in the way. The report is available here:

www.vodg.org.uk/uploads/pdfs/2016%20VODG%20Together%20we%20can.pdf

- CEDAR (Centre for Educational Development Appraisal and Research) are currently undertaking a new research study, aiming to improve quality of support for adults with learning disabilities whose behaviours may challenge. The aim of the study, which was developed in collaboration with people with a learning disability, is for social care staff to gain an understanding of the perspective and experiences of those who have been labelled as challenging, by attending a free half-day training course. For more details about this study and how you can participate information sheets are available at the registration table or you can visit their website: www2.warwick.ac.uk/fac/soc/cedar/whoschallengingwho
- The Royal College of Nursing (RCN) have released a report, *Connect for Change: an update on learning disability services in England*. They propose several recommendations in regards to workforce and services to address the issues highlighted. These include:
 - A long-term workforce strategy that connects workforce planning to the transformation and delivery of services for children and adults with learning disabilities.
 - Up-skill all general nursing staff to care for those with learning disabilities and/or autism, or those who display behaviour that challenges.
 - Ensure that quality community services are commissioned to support the appropriate transition of people from inpatient care to living more independently in the community.
 - Positive behaviour support to be embedded across organisations and training to be provided to those who may be caring for someone who presents behaviour that challenges.

The report is available here: www.rcn.org.uk/-/media/royal-college-of-nursing/documents/publications/2016/february/005525.pdf

- A new edition of Unified Approach will be available soon. Information will be circulated to members regarding the date of publication and where it will be available.

Next Meeting

The next CB-NSG meeting will take place in October 2016 in collaboration with Learning Disability Professional Senate. The theme of the meeting will be Making Sense Together.

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