

# **Challenging Behaviour National Strategy Group (CB-NSG)**

## **Update – October 2016**



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. 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 more information you can email us at [nationalstrategygroup@theCBF.org.uk](mailto:nationalstrategygroup@theCBF.org.uk) or visit the Strategy Group pages of the CBF website [www.challengingbehaviour.org.uk/driving-change/national-strategy-group](http://www.challengingbehaviour.org.uk/driving-change/national-strategy-group).*

### **What is the Challenging Behaviour – National Strategy Group?**

The Challenging Behaviour - National Strategy Group (CB-NSG) is motivated to drive change forward to make a real difference to the lives of individuals with learning disabilities and behaviour described as challenging.

An estimated 27, 000 people in the UK have been given the label of challenging behaviour and over time this label has become misused. The term challenging behaviour should encourage carers and professionals to find effective ways of understanding a person's behaviour and its underlying causes. Instead, it is often used as a diagnostic label, leading to stigmatisation and exclusion. Children and adults whose behaviour is described as challenging are often denied the right to live an ordinary life in their local community, and placed in institutional settings far away from their homes and families.



With this in mind, the Challenging Behaviour Foundation formed the CB-NSG. It is an action focused group that works together to break down the barriers to enable children and adults to get the right support to have a good life. The CB-NSG steering group directs the work of a larger core and associate membership. This work falls into three categories:

1. Gathering of evidence about current service provision and development
2. Establishing and sharing examples of best practice
3. Raising awareness at all levels, from individuals and families to regional and national governments.

The CB-NSG focuses on four core areas: (1) we work in partnership, (2) we coordinate and share good practice, (3) we are action focused, and (4) we are motivated to delivering real change. We have co-produced a charter which sets out a framework to deliver change.

Core members of the CB-NSG include family carers, people with learning disabilities, practitioners, researchers, service providers and representatives of various professional bodies and government departments. Core members meet twice a year to discuss how to drive change and agree action.

In addition, there are a large number of associate members who do not attend meetings but input their views to the group via email, telephone, letters and the website. For more information on the CB-NSG please visit our website on the link above.

## **PBS Academy**

*This update is from Richard Hastings on behalf of the PBS Academy, a former subgroup of the CB-NSG. See here for more details: [pbsacademy.org.uk](http://pbsacademy.org.uk)*



The PBS Academy is currently working on the development of a set of accreditations standards for PBS. This project builds upon the work of the PBS Academy to date and provides the basis for the establishment of an accreditation infrastructure for PBS. It is important to note that the project does **not** include the establishment of the accreditation process itself. Accreditation needs to be conducted by an incorporated organisation and the PBS Academy currently exists in an informal capacity. However, establishing standards is a first and necessary step of any accreditation infrastructure. The plan, as with previously published resources from the PBS Academy, is to make the accreditation standards available under a creative commons licence for any organisation wishing to provide the accreditation process. The current accreditation standards work that has begun as of September 2016, includes the following:

- Accreditation standards for services/teams delivering a PBS model (including team composition and competencies, supervision of staff, continuing professional development, regular review/audit and outcomes measurement)
- Accreditation standards for training courses targeted at all levels of the PBS competencies framework, and from a variety of different training providers
- Accreditation standards for individual PBS practitioners at different levels of competence (including initial training, and ongoing supervision/CPD requirements in order to maintain accreditation)

The PBS Academy is clear that all of these accreditation standards are needed to ensure high quality delivery of support to individuals whose behaviour challenges. Because PBS is a multi-component framework delivered within complex systems, accreditation of only one aspect would not lead to the best outcome.

The project brings together a small expert group from across the UK of PBS practitioners and academics that have led on the development of the PBS Academy work to date. As with all PBS Academy resources published so far, a critical part of the process will be the identification of key partners and engagement with stakeholders. Whilst the main goal is to make sure that the resulting standards set the quality threshold needed, they must also be doable and achieve buy-in across relevant stakeholder groups.

## **PBS Academy impact plan and evaluation**

*This update is from Louise Denne on behalf of the PBS Academy, a former subgroup of the CB-NSG.*

The PBS Academy and Challenging Behaviour Foundation are working together to conduct an evaluation of the impact of the work of the academy and the development of an impact plan to extend the reach of the work to date. The project has received Economic and Social Research Council (ESRC) funding for one year, starting at the end of September 2016. It will be carried out by a PBS intern based at the Challenging Behaviour Foundation, jointly supervised by Jacqui Shurlock (CBF) and Louise Denne (University of Warwick) and working in association with other PBS Academy partners.

The anticipated impact of the evaluation and impact development plan is that the PBS Academy's output goes beyond a set of recommendations and into a set of tangible activities that bring about the creation of an infrastructure that facilitates workforce development around PBS in the learning disability sector. This will require an alignment of all stakeholders including people with learning disabilities, families and carers, commissioners, provider organisations, direct support workers, training providers, government inspection teams, other health and social care professions and third sector organisations.

## Campaign Subgroup Report

Members of the campaign subgroup have continued to collaborate on a range of policy, parliamentary and media work to influence change on behalf of this group. The following activity has been taken since our last CB-NSG meeting in March 2016.

### 'Making it Happen' guide for campaigners

CBF, Mencap and National Autistic Society have worked together to produce a guide aimed at campaigners, family members in local areas, to support them to put pressure on and get involved in the work of local Transforming Care Partnerships. The guides and accompanying campaigns actions are available here: <http://bit.ly/2d0WO2A>



### Campaigns Families' Day

We are building up to our next Campaigns Families' group meeting in early November. We have a packed agenda, including updates from the National Audit Office on their investigation into services for people with a learning disability. We also hope the new Care Minister, David Mowat MP, will be meeting families and hearing their concerns.

### National Audit Office (NAO) – Surveys of family experiences

The National Audit Office is carrying out a study to examine whether the government is making progress in providing community support for people in hospital settings, and how effectively it has implemented recommendations made by the Public Accounts Committee in 2015. The study will also assess the health and social care support available to the wider population with a learning disability, and whether this support is improving outcomes. Further details can be found on the NAO website: <http://bit.ly/2ejmMTI>

### Data from NHS Digital

NHS Digital (formerly HSCIC) has continued to release monthly and quarterly statistics on Learning Disability Services. You can find the latest monthly and quarterly statistics here <http://bit.ly/2dwvIKZ>. Data collected at the end of August 2016 shows that:

- 2,540 people are currently in in-patient settings
- 140 children under the age of 18 are in in-patient settings
- The average length of stay in in-patient care is currently 1,983 days (5.4 years)

In March, NHS England launched a new CCG improvement and assessment framework. The first baseline assessment of all 209 CCGs has been published for Learning Disability to provide a snapshot of the current performance of CCGs. This baseline is available here: <http://bit.ly/2dsIMZ6>

The Learning Disability Census which has been carried out annually on the 30<sup>th</sup> September since 2013 will no longer take place. NHS England and the Department of Health are investigating solutions for obtaining the data that will be lost. This lost data includes information about medication and prescribing, the use of restraint and restrictive practices, and the cost of in-patient services.

CB-NSG members have formed a small group to look more closely at the data and what it is telling us.

### Transforming Care Assurance Board

*Update from Beverley Dawkins (CB-NSG representative for the Transforming Assurance Care Board).*

The post-Brexit re-shuffle has resulted in a change of minister (David Mowatt), which was likely to result in a series of changes of officials. This is always concerning as the new team come with varied knowledge and experience of the issues and will need time to catch up on these before they can become effective. Dame Christine Lenehan joined the meeting and it was agreed that whilst there has been increased focus on children, recent well publicised cases showed that much more needs to be done going forward. A

children's sub group to TCAB will now be set up and Christine will also be invited to join the board (see Lenehan Review below for more details).

The progress of the programme remains at 'amber-red'. The discussion focussed on two areas, (1) the availability of money to build the capacity of community services and (2) the creation of local risk registers. The local Transforming Care Partnerships have all completed their plans and some have achieved funding to support them with aspects of their programme delivery. In terms of the accuracy of data on numbers of people in ATU's, it was confirmed that the various data sets had largely been triangulated and there was greater confidence in the accuracy of the figures. The numbers of people in ATUs is for the first time going down month on month.

## **Policy Updates**

### **Stopping the over medication of people with Learning Disabilities (STOMP w/ LD)**

NHS England has made a call to action to reduce inappropriate use of psychotropic drugs in people with a learning disability in general practice and hospitals.



The goal is to improve the quality of life of people with a learning disability by reducing the potential harm of inappropriate psychotropic drugs that may be used wholly inappropriately, as a “chemical restraint” to control challenging behaviour, in place of other more appropriate treatment options. Further info: [www.england.nhs.uk/learningdisabilities/meds](http://www.england.nhs.uk/learningdisabilities/meds)

## **Lenehan review**

Allister Burt, while still in post as Minister for Care and Support, requested a review to look at the current systems of care, support and treatment for children and young people with complex needs involving mental health problems, learning disabilities and/or autism whose behaviours may challenge. Christine Lenehan has been appointed to undertake this piece of work which is a strategic overview that recommends practical actions that can be taken forward by Government Departments and other partners at a national level. The overall aim is to make the health, education and social care systems better able to coordinate care and support for this group of children. The review is commissioned by the Department of Health and is set to be published at the end of October 2016.

## **Change and improvement team**

Members of the CB-NSG steering group have been invited to be part of the Change and Improvement Steering Group as part of the post Winterbourne View work with NHS England. This is an umbrella group overlooking the work of 5 Task and Finish groups:

- Strategic Resettlement
- Provider Engagement
- Improvement
- Commissioner Development
- Clinical and Professional Leadership

The Steering Group will meet for the second time in November where we will continue to offer the expertise of the CB-NSG and its members to the work of these groups.

## **Transforming Care Partnerships**

The 48 Transforming Care Partnerships have published their Transforming Care plans, which outline how they will implement the programme over the next three years. There are around 20 areas that are yet to

release comprehensive information regarding their plans. To see the plan for your local area, visit: [www.england.nhs.uk/learningdisabilities/tcp](http://www.england.nhs.uk/learningdisabilities/tcp)

## In the News

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:

- May 2016 marked the 5<sup>th</sup> year anniversary of the Panorama programme that uncovered widespread abuse at Winterbourne View Hospital. Winterbourne families wrote to the former Prime Minister regarding the disappointing lack of progress in moving people out of assessment and treatment units. They received a personal response from the David Cameron promising progress and highlighting the work of Transforming Care. See here for coverage from the BBC [www.bbc.co.uk/news/uk-england-bristol-36410791](http://www.bbc.co.uk/news/uk-england-bristol-36410791) and The Telegraph <http://bit.ly/1WutJJE>
- In September 2016, Radio 4 broadcast a 40 minute programme on the Transforming Care Programme entitled *Homes Not Hospitals*. File on 4 asked “what progress has been made on the promise to get people with learning disabilities and autism out of hospital units and into homes in the community with good support.” You can watch again at the following link: [www.bbc.co.uk/programmes/b07v0fvc](http://www.bbc.co.uk/programmes/b07v0fvc)
- BBC News recently reported that face-down physical restraint is still being used in mental health wards in England, despite the government and the NHS saying it should stop. From the data collected in the 2015 Learning Disability Census, we know this is also true for people with learning disabilities and/or autism whose behaviours challenge who are in inpatient provision. See more at the following link: <http://bbc.in/2dDXrZA>

## New Resources

### Early Intervention Project

Funding for the Early Intervention Project from the Department of Health has now come to an end but we are pleased to inform you that the work started by this project will continue through the Challenging Behaviour Foundation. Since the last CB-NSG meeting in March where [pavingtheway.works](http://pavingtheway.works) was launched, the project has continued to update the site with blog posts and resources for families and professionals.



The CBF and Mencap have published a new report based on research with families whose children are in residential placements. The report is the first time guidance has been issued on how residential settings should ensure parents can keep in touch with the thousands of children and young people with a learning disability who often live hundreds of miles from home. You can read the **Keeping in Touch with Home** report and the accompanying blog post from Family Carers, Mal and Richard, at the following link: [pavingtheway.works/whats-new/keeping-touch-home](http://pavingtheway.works/whats-new/keeping-touch-home)

### Adult sibling support groups

The charity Sibs are currently supporting adult support groups for siblings of people with a life-long learning disability or autism. Many siblings face similar challenges around the long-term care and support of their brother or sister. The groups aim to (1) improve adults siblings' wellbeing and resilience, (2) empower adults siblings to be advocates for their brothers and sisters, (3) support adults siblings in the transition to more involved roles in the brothers' and sisters' care and support as their parents get older, and (4) give adult siblings a voice within services for carers and disabled adults. The groups are currently running in Nottingham, Brighton, London and Birmingham. For more information see: <http://bit.ly/1oHzzA5>

### Rights and Equality principles: LD Professional Senate guidance

The Learning Disability Professional Senate has published guidance on choosing and developing outcome measures based on Rights and Equality principles. They hope these will be used as core principles for

health and social care services to improve person centred approaches and reduce inequalities. For further information please contact us via email.

### **Problem-Solving Toolkit**

The University of Cardiff and Cerebra have published a problem-solving toolkit that aims to support disabled people and carers, as well as their families and advisers, who are encountering difficulties with the statutory agencies in relation to the provision of health, social care and education support services. The toolkit helps to unpick these problems and to develop effective strategies for resolving them. You can download the Toolkit here: <http://bit.ly/1LOquzq>

### **Life begins at home – Housing & Support Alliance**

Life begins at home is a guide for families of children with autism/learning disabilities that display challenging behaviour, to get the housing they need. It is also a training and development resource for housing, health and social care staff to assist families in the process of choosing the best housing options. Life begins at home was funded by NHS England and supported by the Challenging Behaviour Foundation. Available at: [www.housingandsupport.org.uk/life-begins-at-home](http://www.housingandsupport.org.uk/life-begins-at-home)

### **Updates from CB-NSG Members**

- The Positive Behavioural Support/Autism Training Fund was funded by the 'positive and safe programme' to contribute to the aims of the Transforming Care programme. The fund was administered and monitored by Skills for Care on behalf of the Department of Health, in partnership with HEE and Skills for Health. In total 169 grants were awarded through this fund to a range of providers across England providing approximately 2,900 training interventions.
- NDTi, with partners In Control, recently piloted a review of commissioning arrangements of services for children and young people with learning disabilities and/or autism who challenge services. Amongst the 7 areas of key findings from the review there are 3 that could have a profound effect on a young person's life;
  - The Transforming Care Programme has led to some confusion, often having an adult focus with children services being included as an afterthought
  - There needed to be more focus on Preparing for Adulthood (PfA) from children's services
  - There are still big gaps in support for families

More information is available here: [www.ndti.org.uk/blog/learning-from-the-reviews](http://www.ndti.org.uk/blog/learning-from-the-reviews)

- The BILD Annual Conference will be held on Friday 14 October 2016 in Birmingham. It is set to offer a vibrant and thoughtful celebration of good practice. See here for more: <http://bit.ly/2cW6ASG>
- Association for Real Change (ARC) are offering a number of events, workshops and training sessions on a range of topics including diversity in learning disability services, medication, Mental Capacity Act and Deprivation of Liberty safeguards. See here for a full list of upcoming events: [arcuk.org.uk/blog/category/events](http://arcuk.org.uk/blog/category/events)

### **CB-NSG Charter – Have you signed up?**

We will be reviewing how the Challenging Behaviour – National Strategy Group Charter that was developed in collaboration with members can be used to achieve better outcomes for this group of people. Will be contacting you all shortly but, in the meantime, please let us know via email or post how you are using it to change and improve practice.

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