



## **Challenging Behaviour National Strategy Group (CB-NSG) Update – June 2017**

*A huge range of actions are undertaken between national meetings to implement the work of the CB-NSG. We send round regular updates by email, but 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 get involved in, or if you have information about related work to share, please do get in touch. For more information, 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.

At least 35, 000 people in the UK are estimated to 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 is based on four core principles: (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 co-produced a charter which is our 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. CB NSG takes a life span approach and core members meet twice a year to discuss how to drive change and agree individual and strategic actions.

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)*



Since the last CB-NSG, the PBS Academy has been:

- Completing PBS Standards for services/teams, for PBS training courses and drafting Standards for individual practitioners. The steering group for the standards project is currently exploring how best to release these standards and whether there are opportunities to pursue mechanisms for accreditation.
- NHS England have supported a Theory of Change workshop on 15<sup>th</sup> June with transforming care partners focused on how to expand the availability of high quality PBS. The outcome from that workshop can be reported in the next update.
- The Challenging Behaviour Foundation and the University of Warwick are continuing the project funded by Warwick's Economic and Social Research Council Impact Acceleration Account to evaluate the impact of the PBS Academy's work to date. Louise Denne from the University of Warwick with Jacqui Shurlock and Suzi Scott (PBS Intern) from the CBF are working as a team on this project.

## **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. Key areas where we have influenced, or provided input since our last CB-NSG meeting in October 2016 are highlighted here.*

### **Learning, Candour and Accountability: CQC review into investigations of deaths**

The CQC published a review in December 2016 looking at how NHS acute, community healthcare and mental health trusts investigate deaths and learn from their investigations. Key findings from the report include:

- The commonplace acceptance and sense of inevitability that people with a learning disability or mental illness die early
- The failure to prioritise learning from deaths so that action can be taken to improve care for future patients and their families
- Many carers and families do not find the NHS to be open or transparent
- Families and carers are not routinely told what their rights are when a relative dies, what will happen, or how they can access support or advocacy

One of the CQC's recommendations was the development of a new single framework on learning from deaths. A first edition of '[National Guidance on Learning from Deaths: A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care](#)', was published in March 2017. It says it 'aims to kickstart a national endeavour on this front. Its purpose is to help initiate a standardised approach, which will evolve as we learn'.

## **Policing and Crime Bill**

The Bill was amended in the Lords to remove the current automatic entitlement that an inquest takes place when a person subject to a Deprivation of Liberty (DoL) dies. The reason given for the government's acceptance of the amendment is the large number of inquests (post Cheshire West) into the death of older people who have died whilst under a DoL that are regarded as taking place unnecessarily. Liberty and Rethink have been briefing on the unintended consequences of this amendment (e.g. that deaths of people with learning disabilities under a DoL do not have automatic entitlement to an inquest). Mencap have also been briefing key MPs to speak with Ministers.

## **Dispatches – Under Lock and Key**

Under Lock and Key was broadcast on Channel 4 in March to investigate young people with a learning disability, autism or both staying at St Andrews hospital in Northampton, and campaign group members worked closely with the Dispatches team. Following the programme, Shahana Hussain wrote an article for the [Huffington Post](#) and Leo Andrade set up a [petition](#) to ask Simon Stephens (Chief Executive, NHS England) to stop sending people with a learning disability and/or autism to large scale hospitals which did not meet their needs. We are pleased to share that the petition currently has almost 8,500 signatures – please share the petition with your networks. After the programme, a number of CB NSG members wrote a joint letter to Simon Stevens (CEO of NHSE) asking him to stop NHS funds being used to pay for places in institutional services as seen on Under Lock and Key. The NHSE response was disappointing and we will continue to press for specialist commissioners to stop purchasing institutional services that deliver poor outcomes at high cost.

## **Campaign Families' Day**

A group of families with lived experience of the Transforming Care programme are supported by CBF and Mencap to meet regularly to try to inform and influence the Transforming Care work, and keep the profile of people with learning disabilities whose behaviour challenges high. The next Campaign Families' Day is approaching at the end of June and we are excited to be presenting a busy day. The agenda includes sessions around the Building the Right Support Evaluation and Housing.

## **Data from NHS Digital**

NHS Digital continues to produce monthly data on learning disability services through both the Assuring Transformation dataset and the Mental Health Services Data Set. We continue to engage with the Department of Health and NHS England regarding our concerns about the loss of data from the Learning Disability Census and Quarterly Assuring Transformation publication, both of which have been discontinued, and a data group has been set up to look closely at what the current data is telling us, and what information is no longer collected.

## **Transforming Care Assurance Board**

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

The last meeting of the Transforming Care Assurance Board was held on 19th October 2016. The new Under Secretary of State for Community Health and Care, David Mowat MP did not attend the meeting. As the Minister has not attended a meeting since his appointment in July, we made the point that this gives the impression that the Transforming Care Programme is not a high priority. Previously the Minister reported to the Prime Minister's office monthly – that is no longer happening but Tamara Finkelstein, Director General for Community Care at the Department of Health, indicated that they now report to the Secretary of State instead.

During the meeting NHS England informed the group that evaluation of the TC programme “will commence at the beginning of January 2017” and the Department of Health has secured research funding for an evaluation. Bids will be open in by November.

A new children's group for the TC programme has recently been set up, and CBF (with other CB NSG core members) is a member of the group which meets regularly.

The programme still rates itself as amber/red and the question was asked ‘How long would it be rated as such before action was taken?’ It was anticipated that it would remain as amber/red until March/April 2017 – and if it was still the same then, “questions would be asked”.

The Board was asked how it would rate the programme. The response was that it was not possible to rate it on the sparse information provided i.e. no information on budget or financial input, and no sight of a detailed programme plan that indicates how the work is co-ordinated, prioritised or measured against agreed outcomes. Department of Health will discuss with the programme leads what information is needed and can be made available for assurance to take place.

Since October, a meeting planned for 24th January was cancelled on 13th January and no further meetings have been arranged. The challenge will now be to respond to whatever rationale is given for it ending and negotiate a way forward that brings stronger accountability and meaningful engagement of people with lived experience and their families.

## **Policy Updates**

### **Atlas Trials**

On Wednesday 7<sup>th</sup> June, reporting restrictions were lifted on the Atlas trials and there has been a range of media coverage (see below 'In the News'). Following allegations of abuse made by people with a learning disability at care homes run by Atlas Ltd in 2011, it was revealed that thirteen people have been convicted of charges relating to inappropriate seclusion in "punishment" rooms. Soon after the allegations were made Atlas Ltd went into administration and no longer operates. Residents were transitioned to alternative care arrangements.

### **See below for an extract of the response from Vivien Cooper (CEO, Challenging Behaviour Foundation) and Jan Tregelles (CEO, Mencap):**

"Throughout the three trials last year, juries have listened to horrific accounts of people with a learning disability being abused by those who were being paid to support them."

"Atlas Project Team claimed to provide specialist care for people with a learning disability, at a cost of up to £4,000 per week per person. Staff were paid to care for people with a learning disability but instead of doing so imprisoned them repeatedly for long periods, often in cold rooms with no sanitation. Despite several warning signs, it took far too long for the abusive practices at the care homes to be exposed. Poor commissioning by a number of local authorities and weak inspection allowed an abusive culture to develop and sustain itself with devastating consequences for individuals and their families."

The full statement is available on the [Challenging Behaviour Foundation website](#).

**Mersey Care Whalley Site (formerly known as Calderstones)** – Following a public consultation, on the 28<sup>th</sup> March NHS England announced that the Mersey Care Whalley site is going to close. The site is the only stand-alone NHS learning disability hospital left in England with 223 beds. This announcement follows the publication of "[Building the Right Support](#)" which sets out how the NHS and local government should work together to improve community support and seek to close up to half of the inpatient capacity for people with a learning disability and/or ASD in England. The CBF encouraged CB NSG members to contribute to the consultation, and submitted a response in favour of closing the site and developing more appropriate local provision, so we hope that the funding currently received by the hospital will be used to establish these much needed services.

**Public Accounts Committee** - On the 29<sup>th</sup> March, Viv Cooper gave informal evidence to the Public Accounts Committee inquiry on care for people with a learning disability alongside Dan Scorer from Mencap and Sarah Battershall from United Response. Formal evidence was then given to the Committee by Chris Wormald from

the Department of Health, Ray James the Immediate Past President of ADASS, Simon Stevens the CEO of the NHS and Jane Cummings the Chief Nursing Officer for England at the NHS.

The Committee asked for evidence on a number of areas including the barriers to improving services, how to measure outcomes for individuals, and the progress of the Transforming Care Programme. You can watch the session and see a full transcript of the inquiry [online](#).

Following the session, the Public Accounts Committee published their report on the 26<sup>th</sup> April. The report is called '[Local support for people with a learning disability](#)' and makes recommendations to the government about the Transforming Care Programme and supporting people with a learning disability in the community.

The recommendations include that NHS England should make updates to the Public Accounts Committee on progress to reduce the number of beds in mental health hospitals and progress to increase the effectiveness of care and treatment reviews. NHS England should also explain how they will make sure that money follows patients from inpatient to community settings and how patients and families will be supported to advocate for themselves or access effective advocacy. Recommendations to the Department of Health include to resolve issues created by changes to local housing allowance by the end of July 2017 and to create a cross-government strategy to improve access to healthcare for people with learning disabilities and increase opportunities for community participation.

**CETR addition to CTR Policy** – In March NHS England published new [Policy and Guidance on Care and Treatment Reviews](#). This includes a new section on Care Education and Treatment Reviews (CETRs) for children and young people.

## 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:

- On the 1<sup>st</sup> March a special Dispatches programme called 'Under Lock and Key' was broadcast about St Andrews hospital in Northampton. Bafta award winning director Alison Millar created a powerful film highlighting the issues surrounding large inpatient hospital settings being used to treat individuals with a learning disability and/or autism. News coverage of the programme included a piece on Channel 4 News and [articles in the Telegraph](#), the [Huffington Post](#) and the [Guardian](#).
- After the announcement on the 28<sup>th</sup> March that the Mersey Care Whalley site hospital was going to be closed, the BBC ran an [article](#) on the decision.
- In early April the BBC published an [article](#) on NHS data showing that people with a learning disability were often not receiving the health checks they were entitled to. The article highlighted that only around half of those eligible received an annual health check, and the large difference in life expectancy between those with a learning disability and the general population, among other issues.
- On the 9<sup>th</sup> April BBC Radio 5 Live broadcast a programme investigating the use of restraint in special schools. Our Children's Policy Lead at the CBF, Jacqui Shurlock was interviewed by the programme alongside family carers and other professionals including Norman Lamb. The programme is still available [online](#).
- With the reporting restrictions lifted on the Atlas trials on 7<sup>th</sup> June (see above 'Policy Updates'), there has been a wide range of media coverage. This has included coverage in the [Independent](#), the [Guardian](#), the [Telegraph](#), the [BBC](#) and [ITV](#), among others.

## **New Resources and publications**

**Building the Right Home** – In December 2016 the Local Government Association, ADASS and NHS England produced guidance for commissioners on developing community settings for people with a learning disability/autism and/or challenging behaviour called ['Building the Right Home'](#).

**NICE Quality Standard** - In January 2017 NICE published a new quality standard '[Learning Disabilities: Identifying and Managing Mental Health Problems](#)'. It provides a set of statements on high priority areas for quality improvement.

**Lenahan Review** – In 2016 the Department of Health commissioned Dame Christine Lenahan to review the current systems of care, support and treatment for young people with complex needs, including children with learning disabilities and behaviours that challenge. The outcome of this review called '[These are our children](#)' was published on the 26<sup>th</sup> January 2017 and includes recommendations to review the role of residential special schools and colleges (now underway), to review the needs of young people currently in inpatient provision, that individuals who are in inpatient settings or at risk of being admitted have a keyworker assigned to them and that skills gaps in the workforce should be identified and addressed.

**Law Commission Report on the Mental Health Act** – In March the Law Commission published a [report](#) on their review of the Mental Capacity Act and Deprivation of Liberty Safeguards (DoLS). The report recommends that DoLS are repealed and replaced by a different scheme called Liberty Protection Safeguards. They also recommend wider reforms to the Mental Capacity Act which are intended to provide greater safeguards before someone is deprived of their liberty.

**National Audit Office Report** - The National Audit Office report '[Local support for people with a learning disability](#)' was published on 3rd March 2017, which prompted the Public Accounts Committee inquiry on care for people with a learning disability later that month.

**TCP Involvement Resources** - The National Autistic Society has published [guidance documents](#) called 'How to check up on your Transforming Care Partnership' and 'How to involve the right people in your plans'. The first guidance is aimed at campaigners and the second at Transforming Care Partnerships with the joint goal that more people are involved in shaping the Transforming Care Programme.

**APPGC Report** - The All Party Parliamentary Group for Children (APPGC) published their report titled '[No Good Options: Report of the Inquiry into Children's Social Care in England](#)' in March. They found that children's social care is currently struggling to meet growing demand and needs to have a greater focus on early intervention. They make a series of recommendations which include the need to complete an investigation on the high levels of variation in access to children's services across areas of the country and to develop a strategy to reduce staff turnover in the social care system.

**STOMP – A Family Carer Perspective** – Earlier this month the Challenging Behaviour Foundation published the report of a consultation with family carers on their experiences of medication being suggested or prescribed for their relative. [Stopping the Over-Medication of People with a Learning Disability, Autism or Both: a family carer perspective](#) gives a powerful insight to the issues faced by family carers about medication and we would like to take this opportunity to thank the many family carers who shared their experiences with us.

## Updates from CB-NSG Members

The website Public Health England (PHE) has used to share information about their work on reducing the health inequalities experienced by people with a learning disability, [www.improvinghealthandlives.org](http://www.improvinghealthandlives.org) or [www.ihal.org](http://www.ihal.org) has now been archived and will no longer be updated. It will continue to be available on the national archive, here <https://tinyurl.com/ihalarchive>.

New information published by the learning disability team at PHE will increasingly be published on [www.gov.uk](http://www.gov.uk) and all learning disability related information published by government departments can be found on [www.gov.uk](http://www.gov.uk) by searching 'learning disability'.

A new Knowledge Hub group is also being set up, which will be a community of people interested in reducing the health inequalities experienced by people with a learning disability. The group will provide a place to share news, join discussions and hear about events.

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

We are in the process of reviewing the Challenging Behaviour Charter which sets out the rights and values that the Challenging Behaviour – National Strategy Group is based upon. We have decided to link a commitment to the Charter with membership of the CB-NSG so that we are all working within the same framework. If you or your organisation has not yet signed up to the Charter, please take some time to read the document and return a sign-up form to [nationalstrategygroup@theCBF.org.uk](mailto:nationalstrategygroup@theCBF.org.uk). Please let us know about any questions you have regarding the Challenging Behaviour Charter.

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

Thank you for your continued support.