



## **Challenging Behaviour - National Strategy Group** **Update Paper**

8<sup>th</sup> October 2020

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## **Introduction**

A huge range of actions are undertaken between national meetings to implement the work of the CB-NSG. These actions are pivotal to driving change forward to make a difference to people with learning disabilities whose behaviour challenges.

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 national 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 activity 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 related information 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: <https://www.challengingbehaviour.org.uk/driving-change/national-strategy-group/about-the-cb-nsg.html>

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

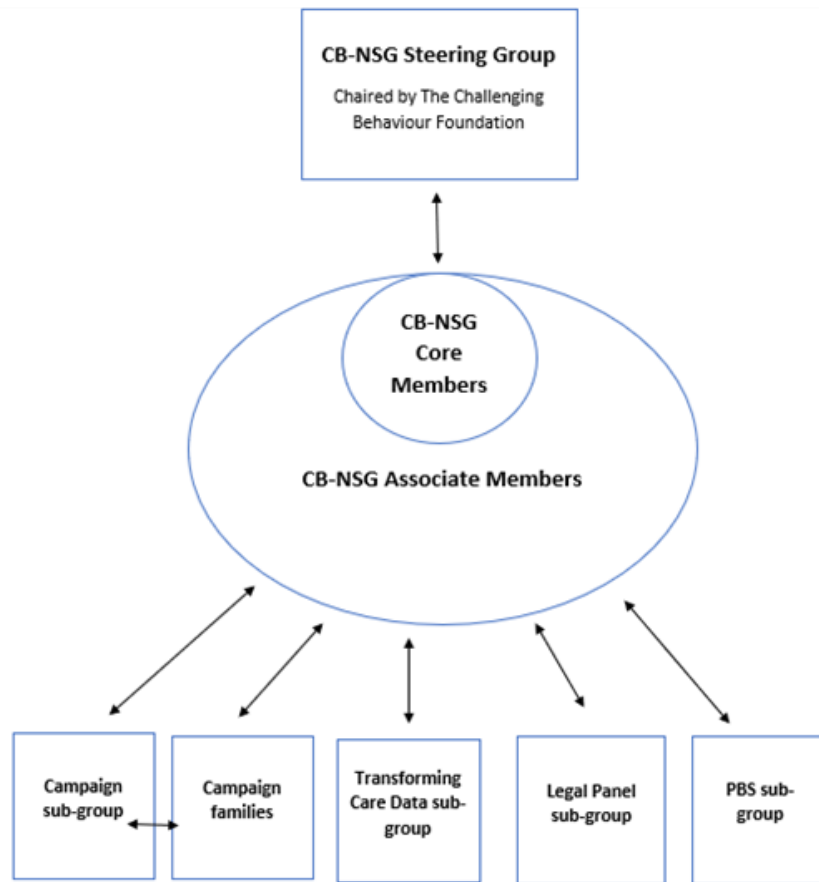
The Challenging Behaviour - National Strategy Group (CB-NSG) is made up of a range of different experienced stakeholders working together, motivated to drive change forward to make a real difference to the lives of individuals with learning disabilities whose behaviour challenges.

More information about the background and principles of CB-NSG can be found here: <https://www.challengingbehaviour.org.uk/driving-change/national-strategy-group/about-the-cb-nsg.html>

### **Challenging Behaviour – National Strategy Group subgroups**

The CB-NSG has five sub-groups focusing on specific areas of work: Campaign Families; Campaign subgroup; Legal Panel; Positive Behavioural Support and Transforming Care Data group. The sub-groups, attended by CB-NSG members with expertise, experience and interest in the relevant area, meet around four times a year to identify the current issues and actions to address these. This work is shared with the CB-NSG steering group who strategically co-ordinate the activity and actions of the subgroups and this is fed-back to CB-NSG members. CB-NSG members are welcome to apply to join one or more CB-NSG subgroups. Please do get in touch if you are interested in joining or contributing to the work of the CB-NSG through one of the subgroups.

The diagram on the next page illustrates the structure of the CB-NSG:



## **The Challenging Behaviour Charter**

The core framework of the CB-NSG is set out in the co-produced Challenging Behaviour Charter. All core and associate members of the CB-NSG sign up to the Challenging Behaviour Charter, as well as making a commitment to activity and driving change.

The charter is a 'live' document. CB-NSG members last reviewed it (November 2019) and made a few minor changes. The latest version is available on the CBF website here: <https://www.challengingbehaviour.org.uk/driving-change/national-strategy-group/cb-nsg-charter.html>

We are currently working to produce a document linking the charter to current relevant policy, guidance, and standards, to facilitate its use as a tool for implementation of the charter in practice.

## **Update on CBNSG Work Since the CBNSG in March**

### **Actions from CB-NSG 'Good outcome- good life' Meeting and Actions Identified due to the Covid-19 Pandemic**

The CB-NSG meeting in March 2020 focused on 'Good-outcome- good life'. In the CB-NSG workshops, individual and collective actions were identified to improve the delivery of outcomes to ensure children, young people and adults with learning disabilities whose behaviour challenges have good lives. The implementation of some of these actions have been delayed by the Covid-19 pandemic.

Due to the impact of the pandemic on people with learning disabilities and their relatives, the CBNSG steering group met to consider any additional actions needed due to the current situation. It was agreed to use this opportunity to consider what has worked well for people with learning disabilities during covid-19 and what have been the challenges and to use learning from this to help shape the 'new normal'. The 'new normal' should not involve returning to what was not producing good outcomes for many people with learning disabilities. This has resulted in two pieces of work:

1. SF-DARRIN has funded some work to explore family carers' experiences and suggested solutions to enable good outcomes for people with learning disabilities
2. The gathering of CBNSG members experiences during Covid-19, of good practice, practice developments, and how learning from Covid-19 will impact on future practice, via short survey. The outcomes of these pieces of work will be discussed at the CBNSG on the 8<sup>th</sup> October.

The findings will be analysed, along with findings from other published surveys, and mapped across to policy and best practice guidance (e.g. NICE, the Service Model etc) and the evidence used to influence "new normal" arrangements.

### **Update on Regional Expert Groups Development**

The idea of Regional Expert Groups was first suggested at the CB-NSG meeting in November 2019 and the CB-NSG steering group presented a proposal to Ray James in February 2020. These discussions have evolved into a "Doing Group" – i.e. a group of people who have worked together to agree "what we need to do" to get people out of inappropriate inpatient services.

The Doing Group brings together a number of individuals with significant practical experience in supporting individuals with complex needs in community settings- including developing individualised packages of support – and maintaining that support to provide good outcomes for individuals. Areas of expertise in the group include experience in clinical/medical practice; commissioning; inspection and regulation; research and evidence; advocacy; the third sector; family support.

The group members are motivated to help improve the quality of life and care provision for individuals inappropriately 'stuck' in hospital placements as well as influence systematic change and improve practice in the long term thus co-currently working

across both micro and macro systems. It will focus on practical doing *with* not doing *for* local teams and will adopt an investment approach- investing additional capacity and enhancing existing skills leaving a sustainable legacy. By working in partnership to achieve change at an individual level, the group will model and influence best practice and enhance ways of working to build more robust systems of support for the broader population of people with complex needs at risk of hospital placement.

For more information please contact [charlotte.newman@thecbf.org.uk](mailto:charlotte.newman@thecbf.org.uk)

## **Summary updates of the work of CB-NSG subgroups**

### **Data Subgroup**

The data group was formed due to concerns about the lack of evidence that data was being analysed and used to inform activities in the Transforming Care programme. The data group members discuss current issues in the data for children, young people and adults and agree key questions the data raises about the Transforming Care progress. Mencap and the CBF jointly produce monthly infographics and press statements highlighting the latest published Assuring Transformation data and some of the key issues. The latest infographic can be found here: <https://www.challengingbehaviour.org.uk/driving-change/transformingcaredata.html>

Latest data reported by NHS Digital show a continued high number of children, young people and adults with learning disabilities in inpatient units.

Since the last CBNSG in March, the group has focused on issues relating to the pandemic and the consequent restrictions for children, young people and adults with learning disabilities.

The group has been considering data on the number of Covid -related deaths of people with learning disabilities across the UK. The data group have also been looking at the increased number of restrictive interventions reported in the monthly MHSDS during the pandemic and raising concerns about the lack of reporting from both independent and NHS providers.

Most recently, the data group have inputted into the consultation on proposed additions and changes to the Assuring Transformation data set. The data group have been calling for the addition of data on the cost on inpatient services, and clarification to the data on time between agreement that the individual no longer requires inpatient care and discharge from inpatient services.

### **Legal panel subgroup**

5 Any queries / technology issues throughout the day please contact Jo, email [jo@thecbf.org.uk](mailto:jo@thecbf.org.uk) or phone 01634 477 145.

The legal panel was set up by the CBF to provide timely access to legal support for families of children, young people and adults with learning disabilities whose behaviour challenges. During the pandemic, this group has increased the frequency of the meetings in order to provide families with the legal support they need during this difficult time.

The legal panel have been answering questions from family carers about the changes resulting from Covid 19. The questions and answers have been published as FAQs on the CBF website here:

<https://www.challengingbehaviour.org.uk/information/covid19information.html#FAQs>

Topics covered in the FAQs include:

- Visiting restrictions
- Supported living
- Accessing education
- Accessing healthcare

These are continually updated, most recently with questions and answers related to Supported Living Guidance.

In addition to answering FAQs, the legal panel members have been working to challenge key issues including provision of education during the pandemic, lack of supported living guidance, and the announcement of a new 40 bed inpatient unit. The panel have also identified the need to map and co-ordinate the legal work taking place around learning disability. A legal strategy meeting was planned for April but was postponed due to Covid-19. It has been rearranged for early November.

### **Campaign Subgroup**

The campaign subgroup have met twice since March.

Based on recommendations in the Joint Committee on Human Rights report, published in November 2019

(<https://publications.parliament.uk/pa/jt201919/jtselect/jtrights/121/121.pdf>) '*The detention of young people with learning disabilities and/or autism*', the Campaign subgroup has formulated three key campaigning asks for Transforming Care

1. The establishment of a Number 10 delivery unit to drive forward the transformation of care and implementation of the 50% reduction in in-patient beds by March 2023/24 (from 2015 figure)
2. A legal duty on Health and Social Care commissioners to ensure the availability of sufficient community based services and that they work together to pool budgets or resources for care services for people with learning disabilities and/or autism

3. Reform of the Mental Health Act to ensure individuals with learning disabilities and/or autism are not detained inappropriately

The campaign subgroup has also been looking at reform to the Mental Health Act and are working on refining key campaigning calls related to this. The group are still waiting for the government to publish their response to the independent review of the MHA, chaired by Sir Simon Wessley.

### **PBS Subgroup**

In November 2019, an updated version of the CBF and PBS Academy's PBS resource was launched. The updated version combines the original separate resources into one accessible pack for families and was co-produced with family carers. To see the new resource please visit:

<https://www.challengingbehaviour.org.uk/understanding-behaviour/pbsguidesforfamilies.html>

### **Consultations (influencing and sharing best practice)**

It is important to ensure that the views and experiences of children, young people and adults with a learning disability whose behaviour challenges and their families are considered in consultations. We work with families and CB-NSG members to promote and share consultations and also submit responses. Recent consultations we have contributed to include:

#### **Supporting personal relationships (SCIE guidance)**

In February 2020, the CQC report *Promoting Sexual Safety Through Empowerment* recommended that Skills for Care update their guidance on Supporting Personal Relationships. This guidance has now been updated, and in the feedback survey, CBF highlighted that individuals with severe learning disabilities could be better represented in the examples and case studies included in the guidance. Similarly, non-verbal communication methods were not adequately addressed.

#### **NICE guidance for safeguarding adults in care homes**

At the beginning of October, NICE requested feedback on their guidance for safeguarding adults in care homes. CBF's response focused on the additional vulnerabilities of adults with learning disabilities who may be non-verbal and thus less able to communicate their distress. Additional safeguarding for this group is vital.



### Comprehensive spending review

In late September, the CBF responded to a government consultation on strengthening the UK's economic recovery from COVID-19 by prioritising jobs and skills improving outcomes in public services, including supporting the NHS and taking steps to cut crime and ensure every young person receives a superb education. We highlighted the importance of investment in early intervention; redirecting resources away from expensive inpatient units and towards community care and avoiding using unnecessary medication. We also stressed that investing in a skilled local workforce (including families) will help to deliver that better local support and reduce costs overall.

### AT data consultation

Members of the CBNSG Data group met to input into a joint response from Mencap and CBF to NHS Digital's consultation on proposed changes to the Assuring Transformation data collection. Overall, the changes were considered to be positive and feedback was given on specific additions that could be made including the cost of inpatient care and the time delay on discharge.

### Psychiatry curriculum

In September, the Royal College of Psychiatry reviewed and consulted on their curriculum for trainee consultant psychiatrists, including the Psychiatry of Intellectual Disability Curriculum. The CBF and other CBNSG members responded, highlighting key points including the need to include co-production with families, the importance of communication and behaviour, key issues surrounding the MHA, and the impact of trauma for people with learning disabilities and their families.

### Guidance on temporary modifications to the Mental Health Act Guidance on temporary modifications to the Mental Health Act

The CBF and Mencap submitted joint comments on the draft guidance on temporary modifications to the Mental Health Act. The response suggested points where the guidance could be strengthened and included recommendations for the inclusion of a specific section on learning disability and autism.

### Covid Testing consultation

The CBF responded to the NICE consultation on SARS-CoV-2 viral detection point of care tests and serology tests, sharing the impact of contracting Covid on people with a learning disability and their family carers, as well as pointing out the reasonable adjustments that may be necessary to enable individuals to take a Covid test. We also highlighted the need for individuals with learning disabilities and their family carers to be prioritised for testing.

### PBS standards adapted for school

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The CBF commented on the adaption of the Positive Behaviour Support Standards for Schools, emphasising that families should be regarded as an integral and influential part of the wellbeing of the individual rather than adjunct to the school and staff.

#### Education Committee Inquiry Education Committee Inquiry

The inquiry looked at how the outbreak of COVID-19 effected all aspects of the education sector and children's social care system. The CBF responded, highlighting how children and young people with learning disabilities whose behaviour challenges have been particularly disadvantaged by schools closing, with no access to therapies e.g. SLT and safeguarding concerns. We called for cross government guidance for this group of individuals aimed at professionals and family carers.

#### JCHR inquiry into the human rights impact of the government response to Covid 19 JCHR inquiry into the human rights impact of the government response to Covid 19

CBF and Mencap submitted a joint response to the Joint Committee on Human Rights highlighting the detrimental impact of the government response to Covid 19 on the human rights of children, young people and adults with learning disabilities. In particular, we highlighted our concerns around access to clear information, meeting health needs (include non covid related), visiting rights, the mental health act, and impact on challenging behaviour.

#### **Key Media Updates**

*We welcome media coverage and interest in order to highlight key issues of concern to the public.*

'Since March there has been lots of media coverage, especially linked to Covid. See our Key Covid-19 News page for a summary of some of the key headlines during the pandemic. <https://www.challengingbehaviour.org.uk/cbf-articles/latest-news/guidanceforfamilies.html>

Sadly, there has also been several recent scandals which have featured in the media, including Muckamore Abbey Hospital and [Yew Trees Inpatient Unit](#).

## **General Updates and Recent Announcements**

### **NHSE Trauma Collaborative**

Early this year NHSE commissioned a project to help scope the availability of trauma support for family carers of children and adults with learning disabilities and/or autism. The CBF, Respond, Three Cs, and the Tizard Centre came together on three strands of work:

- The first strand considers what is available to families and what they need. This was carried out by the CBF and the Tizard Centre through a family carer survey and literature review.
  - The second strand delivered sessions of trauma support to families and was conducted by Respond.
  - The third strand looked at professionals' experience of family carer trauma support, and was conducted by Respond, supported by the Tizard centre.
- All three strands will be brought together in a final overarching report.

The report from the first strand has been shared as an accompanying paper for the upcoming CBNSG and will also be available on the CBF website soon. This work will also be considered in the CB NSG meeting on the 8<sup>th</sup> October.

### **JCHR report on the detention of young people with learning disabilities and/or autism JCHR during Covid 19 report.**

On 12<sup>th</sup> June, the Joint Committee on Human Rights (JCHR) published *Human Rights and the Government's Response to Covid 19: the detention of young people who are autistic and/or have learning disabilities*. The Committee concludes that "Prior to the virus, the human rights of young people who are autistic and/or have learning disabilities in detention were being breached. Now that institutions are closed to the outside world the risk of human rights abuses are even greater. Prohibitions on family visits, the suspension of inspections, the increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection (due to underlying health conditions and the infeasibility of social distancing) mean that the situation is now a severe crisis."

CBF, Mencap and Leigh Day all wrote to the JCHR before their oral evidence sessions with CQC and NHSE to raise their concerns.

The JCHR's full report can be found here:

<https://committees.parliament.uk/publications/1434/documents/13091/default/>

The government has yet to respond to this report. We understand it will be issued "shortly".

### **CQC publishes data on deaths of people with a learning disability**

Data published by the CQC in June 2020 sadly shows that a significant number of people with learning disabilities have died as a result of Covid-19. To see the CQC data, please see: <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

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