



Challenging Behaviour – National Strategy Group

Update Paper

24th November 2022

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Introduction

Since our last meeting on the 27th June 2022, CB-NSG members have continued to take actions that will make a positive difference to the lives of people with learning disabilities whose behaviour challenges. Between then and now, members will have received regular updates on issues, reports and government reshuffles that impact on people with learning disabilities whose behaviour challenges and their families.

This paper provides a summary of the progress made by CB-NSG members since our last meeting, covering CB-NSG work, the work of the CB-NSG sub-groups, and consultation responses. For a summary of relevant policy updates since June, please see our Policy Updates Paper.

We would like to thank all CB-NSG members who have contributed to the work detailed here; it would not have been possible without your help and support. We would also like to thank members who have contributed in other ways and/or have contributed to other activities which we have not been able to detail here.

If you come across a strand of work you would like to get involved in, or if you have an update to share, please get in touch.

For more information, email us at nationalstrategygroup@theCBF.org.uk or visit the [National Strategy Group](#) pages of the CBF website.

What is the Challenging Behaviour National Strategy Group?

The Challenging Behaviour National Strategy Group (CB-NSG) is made up of a range of different stakeholders with a wide breadth of experience and expertise, working together to drive forward change and make a real difference to the lives of children, young people and adults with learning disabilities (who may also be autistic) whose behaviour challenges.

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 CB-NSG members sign up to the Challenging Behaviour Charter, as well as making a commitment to act and to drive change.

The latest version of the Challenging Behaviour Charter can be found on the CBF website [here](#). This webpage also includes an animation and an easy-read version of the Challenging Behaviour Charter. Please share the principles of the charter with your networks.

CB-NSG Sub-Groups

There are currently five CB-NSG sub-groups, each of which focus on a specific area of work.

1. **Campaign Families**
2. **Campaign Sub-Group**
3. **Legal Panel**
4. **Data Sub-Group**
5. **Housing Sub-Group**

These sub-groups are attended by CB-NSG members with expertise, experience and interest in the relevant area. These sub-groups generally meet every quarter to identify current issues and agree actions that will address these issues. This work is then shared with the CB-NSG Steering Group, who strategically co-ordinate the activity and actions of the sub-groups, and, following this, is fed back to CB-NSG members.

The CBF and the CB-NSG Steering Group are currently considering establishing additional sub-groups, such as Research, Funding and Transition. We will keep you updated on the development of these sub-groups and any opportunities to get involved.

CB-NSG members are welcome to apply to join one or more of these sub-groups. Further information on the CB-NSG subgroups can be found [here](#). If you are interested in joining or contributing to the work of the CB-NSG through one of these sub-groups, please get in touch by emailing Indigo.Starkey@thecbf.org.uk.

Updates on CB-NSG Work

This section includes some of the actions undertaken by the CB-NSG since June – for the actions of specific sub-groups and responses to consultations, please see the designated sections. For work undertaken by CB-NSG members outside of the CB-NSG which is relevant to the CB-NSG, please see the section ‘Key work and best practice updates from CB-NSG members’.

Supporting people with learning disabilities to input into the CB-NSG

We are keen to enable people with learning disabilities to participate and input into the work of the CB-NSG, to ensure that their voices are heard. To aid this, we are piloting a new approach with people with learning disabilities and Learning Disability England. From this pilot, a video featuring people with learning disabilities explaining what is important to them is being co-produced and, although unfortunately not yet completed, will be shown at the start of future CB-NSGs.

Learning Disability Nursing – Summary/Literature Review

Following the CB-NSG meeting in June, a piece of research is being undertaken (based on a group discussion) which looks at a ‘process-based approach’ for understanding the role of learning disability nurses. This research will compile existing studies and summaries of a process-based approach, and consider how it applies to learning disability nursing. The information gathered will be used to input into further work bringing family carers and learning disability nurses together to consider how they work together to ensure good outcomes for people with learning disabilities.

Updates on CB-NSG Sub-Group Work

Since June, the five CB-NSG sub-groups have undertaken a range of work to make a practical difference to the lives of people with learning disabilities whose behaviour challenges. You can read a summary of this work below.

Campaign Families

In September 2022, family carers from the Campaign Families Sub-Group, some new families and colleagues from the CBF and Mencap met in London to discuss a range of issues, including sharing experiences and knowledge on how to interact with the media, campaigning, and what support is needed for family carers.

In the morning the group discussed the recently published 'Building the Right Support (BTRS) Action Plan', and together discussed what an alternative action plan might look like. For more information on the 'Building the Right Support Action Plan' read our policy paper and see our statement on the website [here](#).

The group discussed what is needed to support people with learning disabilities whose behaviour challenges to have a good quality of life in the community. This included discussion around what measures need to be implemented to successfully support people who are currently in hospital to be discharged and avoid readmission. This CB-NSG meeting will be building on these ideas to co-produce an action plan that will make a practical difference to the lives of children and adults with learning disabilities whose behaviour challenges.

As well as this, the Campaign Families group has provided input into the CBF's responses to a range of consultations, including the National Disability Strategy call for evidence, the Draft Mental Health Bill consultation, and the Mental Capacity Act Code of Practice/Liberty Protection Safeguards consultation and the Human Rights Bill consultation.

Campaigns Sub-Group

The Campaigns Sub-Group has met regularly since June to discuss key issues affecting people with learning disabilities (who may also be autistic) and challenging behaviour and their families. The group has collaborated to respond to the BTRS Action Plan and has sent detailed questions to DHSC to aid our assessment of the quality of the plan.

Legal Panel

In addition to providing support and information for individual families referred by the CBF family support service, the Legal Panel has provided legal expertise to support our responses to several key consultations, including the consultation on the Mental

Capacity Act Code of Practice/Liberty Protection Safeguards, the Human Rights Bill consultation and the draft Mental Health Bill.

The Legal Panel met with the Equality and Human Rights Commission (EHRC), to discuss shared concerns and action regarding the 'Building the Right Support Action Plan'.

Legal Panel members sent a joint letter to NHS England offering to provide specialist legal support to individuals who are currently in an inpatient unit who are ready for discharge, and we are currently waiting for a response to this offer.

The next Legal Strategy meeting will take place on the 26th January and will bring together a wider group of those involved in this work to jointly consider the range of legal issues, agreeing priority areas and how to work together in a coordinated way to address these.

Data Sub-Group

The Data Sub-Group, which focuses on the Assuring Transformation (AT) and Mental Health Services Data Sets (MHSDS), has inputted to the CBF and Mencap's joint response to the AT/MHSDS consultation, raising concerns about what data is collected and published and suggesting improvements to the AT/MHSDS data sets. The Data Group has also identified other potential sources of data which could help provide a wider picture of hospital admissions and will continue to explore what can be learnt from this data.

Each month, the CBF and Mencap produce infographics of the AT/MHSDS data to outline the latest Transforming Care data. The most recent update, as well as previous infographics, can be found [here](#).

Housing Sub-Group

Since June, the Housing Sub-Group has drafted a letter to be sent to regional housing leads regarding the lack of appropriate housing for people with severe learning disabilities and the impact that this is having on delayed discharges, and asking how commissioners work with local housing providers to meet the needs of their residents.

The Housing Sub-Group are also in the process of producing an 'action plan' for the group, which will cover housing issues as well as the funding and legal issues that are linked to housing; the outcomes of the Housing Workshop at the CB-NSG meeting will be incorporated into this plan. Work has also begun on compiling a resource which will provide information and guidance around assessing a person's capacity to take on a tenancy agreement.

Key work and best practice updates from CB-NSG members

Positive Behavioural Support in the UK: A State of the Nation Report

'Positive Behavioural Support in the UK: A State of the Nation Report' was published in the International Journal of Positive Behavioural Support (IJPBS) in February 2022. This is an open-access report which aims to provide clarity around key issues relating to PBS, an overview of the existing evidence base, and a proposed logic model to guide future research and practice in the UK. The report also proposed an updated definition of positive behavioural support, which can be seen below.

Several of the authors of this report are CB-NSG members. You can read the full report [here](#).

Table 1: Key components of positive behavioural support included in the 2022 definition

Rights and values: A focus on rights and good lives	1. Person-centred foundation
	2. Constructional approaches and self-determination
	3. Partnership working and support for key people
	4. Elimination of aversive, restrictive and abusive practices
Theory and evidence base: Ways to understand behaviour, needs, and experience	5. A biopsychosocial model of behaviours that challenge
	6. Behavioural approaches to learning, experience and interaction
	7. Multi-professional and cross-disciplinary approaches
Process and strategy: A systematic approach to high quality support	8. Evidence informed decisions
	9. High quality care and support environments
	10. Bespoke assessment
	11. Multi-component, personalised support plans
	12. Implementation, monitoring and evaluation

External Support Group

The CBF convenes an 'External Support Group', which is made up of senior clinicians and professionals, many of whom are CB-NSG members, with significant expertise and practical experience in supporting people with learning disabilities (who may also be autistic) and complex needs in community settings. The External Support Group, or ESG, brings together this range of knowledge and experience to help people with learning disabilities whose behaviour challenges to be discharged from hospitals into the community. The ESG helps to support local teams to develop individualised support packages that truly meet the needs of the individual in question, while also helping to ensure that this support is maintained once a person has been discharged into the community to prevent readmission.

You can read more about the ESG on the CBF's website [here](#).

Consultations

Since June, CB-NSG members and family carers have contributed and/or responded to a number of consultations to put forward the views and experiences of children, young people and adults with learning disabilities, who may also be autistic, whose behaviour challenges. These include:

- ***the National Disability Strategy call for evidence***
 - contributed to by Core and Associate CB-NSG members

The CBF, with input from core and associate CB-NSG members and family carers, produced a response to the National Disability Strategy call for evidence. This response highlighted that the National Disability Strategy had thus far excluded the voices of people with a severe learning disability and family carers, as well as not considering issues that directly impact people with a severe learning disability whose behaviour challenges (for example, inpatient units, helping people with a severe learning disability to enter employment, and paying insufficient attention to social care). The consultation response also highlighted the need for additional support to help people with a learning disability and their families during the cost of living crisis.

- ***the Draft Mental Health Bill consultation***
 - contributed to by the Campaign Families Sub-Group

The CBF and Mencap, with input from the Campaign Families Sub-Group, produced a response to the consultation on the Draft Mental Health Bill. This response welcomed the change made which stated that a person having a learning disability or being autistic is not an acceptable reason for sectioning under the MHA. The response also emphasised that for a person who has a learning disability or is autistic (or has a learning disability and is also autistic), while also having a mental health diagnosis, to be detained under the Act, the reason must be due to the mental health diagnosis alone, and stressed the need to extend these changes in guidance to those under forensic sections, while also emphasising the need to provide suitable community support.

- ***the Human Rights Act Reform consultation***
 - contributed to by CB-NSG members and the Legal Panel

The CBF and Mencap, with input from family carers, CB-NSG members and the Legal Panel, produced a response to the consultation on reforming the Human Rights Act. The CBF and Mencap co-facilitated a family carer focus group, to which Legal Panel members were also invited, and also received written comments from family carers who were unable to attend the focus group. This response highlighted that the Human Rights Act is a key legal framework for individuals with learning disabilities and their families to ensure that their rights are protected and their needs are met, and that the proposed reforms would see these protections significantly reduced. The response also recommended that the government's focus should be on better implementing the existing Human Rights Act and ensuring that professionals are appropriately aware of and skilled in using the Human Rights Act in their work.

You can read the CBF and Mencap response in full [here](#).

- ***the Mental Capacity Act Code of Practice/Implementation of Liberty Protection Safeguards consultation***
 - contributed to by the Campaign Families Sub-Group and the Legal Panel

The CBF, with input from the Campaign Families Sub-Group and Family Carer email Network and the Legal Panel, produced a response to the consultation on the Mental Capacity Act Code of Practice and the Implementation of Liberty Protection Safeguards. The CBF and Mencap co-facilitated a family carer focus group on the Liberty Protection Safeguards and gathered feedback from family carers (including the Campaign Families Group) and the CB-NSG Legal Panel.

This response stated that, in order to meet the stated goal of ‘putting the person at the centre’, the Code of Practice needs to do more to improve the quality of life for people who may lack capacity, including people with learning disabilities whose behaviour challenges. The response also emphasised the need to consult and involve family members and advocates, as well as a lack of clarity in the Code of Practice.

- ***the Assuring Transformation/Mental Health Services Data Sets data consultation***
 - contributed to by the Data Sub-Group

The CBF and Mencap, with input from the Data Sub-Group, produced a joint response to the proposed changes to the AT/MHSDS data collection. The main recommendations of this response were that the data sets should include data on when people who have been found ‘ready for discharge’ by a Care, Education and Treatment Review C(E)TR are actually discharged, where people are against each element of the 12-point discharge plan, further data on under-18s and 18-24 year olds (such as broken-down length of stay), and data on where an individual has moved from a civil to a forensic section while in an inpatient unit. Additionally, the response emphasised the need to publish data on how many people are under a DoLS/LPS, in order to be able to monitor whether changes to the Mental Health Act impact the number of people under these. Finally, the response raised concerns over the continued discrepancy between the Assuring Transformation dataset and the Mental Health Services Data Set.

Other consultations that have been contributed to by members of the CB-NSG include:

- ‘A new approach to area SEND inspections’
- the Scottish government ‘Physical Interventions in Schools Guidance’ consultation