Introduction

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

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. We post regular updates on our webpages and send out regular updates to core and associate members.

For more information, email us at <u>nationalstrategygroup@thecbf.org.uk</u> or visit the <u>National Strategy</u> <u>Group</u> 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 <u>here</u>. 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 six CB-NSG sub-groups, each focusing on a specific area of work.

Campaign Families
Campaign Sub-Group
Legal Panel
Data Sub-Group
Housing Sub-Group
Transition 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 quarterly 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, it is fed back to CB-NSG members.

CB-NSG members are welcome and encouraged 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 ella.giles@thecbf.org.uk.

Updates on CB-NSG Sub-Group Work

Campaigns

CB-NSG members and other stakeholders, including people with lived experience, have collectively been engaging with the Government to share information about what is needed to improve the lives of children, young people and adults with a learning disability whose behaviour challenges, as part of a sector-wide approach from the learning disability and autism sector.

This has included producing <u>briefings</u> around the Mental Health Act reforms and community support, as well as engaging with Ministers and Peers around the Mental Health Bill as it has been going through Parliament; writing to Ministers and other key stakeholders about the issues facing people with a learning disability, such as housing, health and social care; and campaigning around changes to benefits (for more information, see here).



Legal Panel

The Legal Panel have fed into various consultations and policy work, in particular around the Law Commission's review of Disabled Children's Social Care and the Mental Health Bill.

Housing

Building on pieces of work including the <u>Housing</u> section of the <u>Co-Produced Lifelong Action Plan</u>, the CBF, CB-NSG members and other stakeholders have been working to raise the profile of housing issues that impact people with a learning disability, and how these can be overcome. Some of the work that has been done includes engagement with Ministers and officials in both the Department of Health and Social Care and the Ministry of Housing, Communities and Local Government.

Transition

The <u>Transition to Adulthood</u> section of the <u>Co-Produced, Lifelong Action Plan</u> has been expanded and updated. The CB-NSG Transition Sub-Group are also working on short films to raise awareness of the key issues facing young people with severe learning disabilities during their transition to adulthood, and their families.

CB-NSG Actions Update

Update on the Co-Produced, Lifelong Action Plan

The CBF, CB-NSG members and other partners who want to make a difference have been working together to co-produce an action plan that will address the barriers that are currently preventing children, young people, and adults with a learning disability from living good lives in their local communities. You can access the action plan, including an easy-read version, here.

Some of the updates to the action plan over the past few months include expansions to the <u>Transition to Adulthood</u> section (coordinated by the Transition Sub-Group), the production of resources including a '<u>Housing Pathway</u>' (plain English version <u>here</u>), and a <u>summary of the importance of using research to support policy and practice</u>.



What Matters to Me project update

What Matters to Me is an innovative, three-year project that involves engaging directly with young people with severe or profound and multiple learning disabilities to gather their experience, preferences and views, and use this learning to influence policy.

On 13th March 2025, the What Matters to Me project was launched at the House of Commons. We would like to thank Kevin McKenna, MP for Sittingbourne and Sheppey, for sponsoring the launch, which was attended by 9 of the 11 young people who participated in the project and their families as well as a range of key stakeholders, including representatives from the Department for Education and the Department for Media, Culture and Sport.

An online launch event for the What Matters to Me project also took place on 27th March to share learning from the project and present the multimedia manifesto. We would particularly like to thank Professor Jill Bradshaw from the University of Birmingham for her presentation on how alternative communication methods can be used to engage with people with severe or profound and multiple learning disabilities and Ellie Spirrett from Lewisham Speaking Up for sharing their "Ambient Jam" sessions – held in partnership with Entelechy Arts, Ambient Jam is a dance, music and art collaboration with people with profound and multiple disabilities. The recordings of this launch event can be seen here.

The project's multimedia manifesto, which includes four films and a 'toolkit' for practitioners wishing to replicate this work, can be found on the <u>What Matters to Me</u> webpage.

Forward Together

The CBF are currently undertaking a National Lottery-funded project, working in three areas across the UK (Kent and Medway, the West Midlands and Salford/Manchester) to set up a regional network in each location, bringing together family carers, practitioners and other stakeholders with an interest in improving support and services for people with severe or profound learning disabilities.

If you are interested in joining the regional network for any of these areas, please see the below flyers for more details. Members of the regional network will receive email updates regarding the progress of the project in their area and will be invited to attend bi-annual community of practice meetings. The first of these meetings will be held across learning disability week and carers week in June 2025.

- For family carers
- For professionals



Terminology: "Challenging Behaviour"

A group of CB-NSG members, including family carers, practitioners, and academics and researchers, have been doing some work around the term "challenging behaviour" - in particular, looking at how it developed, its intended purpose, the theoretical/academic underpinnings, and why this is important. Between now and the autumn, they are seeking to hold conversations/focus groups with CB-NSG members who are interested in sharing their views on the term. They are also keen for volunteers who might be interested in offering feedback/comments on e.g., an article. Information about what work is going on will be shared through a specific mailing list.

If you would like to join the mailing list, or to express interest in being part of a conversation/focus group and/or offering feedback on pieces of work, please fill out this form

A range of other work is being taken forward - do get in touch with any ideas or to share work that you are doing

Consultations

Law Commission review of Disabled Children's Social Care

Members of the Legal Panel shared their input into the CBF's response the <u>Law Commission consultation</u> <u>on Disabled Children's Social Care</u>, which was submitted at the end of January 2025. Members of the Transition Sub-Group also contributed to the three questions that specifically related to the transition from children's to adult's social care.

NHS 10-Year Plan

The consultation on the NHS 10-year plan accepted organisational submissions between mid-November and early December 2024. The CBF responded to this consultation, feeding in much of the work of the CB-NSG Sub-groups, and are awaiting the publication of the 10-year plan in late spring 2025.

ICESCR

In September 2024, the United Nations Committee on Economic, Social and Cultural Rights followed up on a previous report from 2022, compiling evidence on the United Kingdom's compliance with the obligations outlined in the International Covenant on Economic, Social and Cultural Rights (ICESCR). The work of the Housing Sub-Group in particular fed into the CBF's response to this consultation and has been included in the report published by the Committee. More details can be found in the Policy Papers.

