



Challenging Behaviour - National Strategy Group
Update Paper

26th May 2021

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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 this document 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 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.

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. Additional work is currently being undertaken regarding the establishment of a Research subgroup, which will bring together elements of the existing PBS subgroup and other CB-NSG members' work. The sub-groups, attended by CB-NSG members with expertise, experience and interest in the relevant area, meet approximately quarterly to identify the current issues and agree 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 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. It was last reviewed in November 2019 by CBNSG members. The latest version is available on the CBF website [here](#). We have recently made a new animated version of the charter which you can view [here](#). Please use it to share the principles of the charter with your networks.

CBNSG Work Since the Last CBNSG (October 2020)

Progress on Actions Identified in the CB-NSG October 2020 'Good outcome- good life'

The CB-NSG meeting in October 2020 focused on 'Post - Covid 19: A 'new normal' to deliver good outcomes.' In the CB-NSG workshops, attendees reflected on learning from the pandemic and individual and collective actions were identified to ensure services and work practices deliver good outcomes for people with learning disabilities as we move into the 'new normal'. Details of the CBNSG and agreed actions can be found [here](#). Progress on some of the agreed actions are detailed below.

- Update on New Normal Project

The New Normal project, a study conceived of as a result of the CB-NSG meeting in March 2020 and subsequent consideration of the impact of the pandemic on people with learning disabilities and their relatives, has progressed. The project consisted of two strands 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 CB-NSG members experiences during Covid-19, of good practice, practice developments, and how learning from Covid-19 will impact on future practice, via a short survey. The outcomes of these pieces of work were discussed at the CB-NSG on the 8th October 2020.

Strand two is complete and the findings can be found on the CBF website [here](#).

- Bringing together families and support workers

At previous CB-NSG meetings (over the last year), there have been several discussions around the barriers to good relationships between support workers and families, and the impact this can have on the quality of support for individuals. One action was to bring together families and support workers to think together about some of the challenges and how they can be overcome.

Paradigm and The Gr8 Support Movement have been working with the CBF to bring together support workers and families to identify the barriers, and what is needed for effective relationships to develop. Family carers and support workers were invited to complete a survey to share their views, and then a group met via Zoom in early May to discuss how to achieve good relationships and agree actions to take the work forward.

This was the first of several meetings planned and initial findings will be shared and discussed at CB-NSG on 26th May 2021.

Ongoing progress on actions identified at past CB-NSGs

- Update on action to feed into changes to the Mental Health Act: Responding to the Mental Health Act White Paper Consultation

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At the CB-NSG March 2020 meeting, several actions were agreed with the aim of influencing change in the Mental Health Act so that it delivered better outcomes for children, young people and adults with learning disabilities and autistic people. The CBF and Mencap submitted a joint response to the government's MHA White paper Consultation, filling in the online survey as well as sending in an additional document with more detail. The submission was directly informed by consultation with families and professionals with lived experience of the Mental Health Act and how it operates in practice for people who are autistic and/or have learning disabilities. Two consultation meetings with families and several Legal Panel meetings were organised through February and March 2021. On the 30th March 2021, CB-NSG members attended a virtual meeting to discuss specific sections of the White Paper and input into the consultation submission. You can read more about the CB-NSG meeting [here](#). Thank you to all who contributed to this important piece of work.

- Update on Regional Expert Groups development: The External Support Group

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 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 initiative has now been formally named the External Support Group (ESG).

The ESG 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 focusses on practical doing *with* not doing *for* local teams and adopts 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 models and influences best practice and enhances ways of working to build more robust systems of support for the broader population of people with complex needs at risk of hospital placement.

Since the last CB-NSG meeting in October 2020, the group has progressed through its development phase and is currently undertaking proof of concept work in the Black Country and Birmingham. Core groups consisting of 2-3 ESG members with the most relevant experience are supporting two individuals in these local areas. In addition, three ESG members have provided support to a local area at the urgent request of NHSE. Learning from the proof of concept work is being captured and will be used to shape the project as it develops.

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.

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

- The total number of children, young people and adults with a learning disability and/ or autism in inpatient services at the end of April 2021 was 2,040, including 215 under 18s.
- 95 had a delayed transfer of care, the key reasons identified were lack of social care and lack of suitable housing.
- Average length of stay in inpatient services remains 5.6 years.
- The total number of reported restrictive interventions in February 2021 was 3,390, including 820 on under 18s. (NB there continues to be a very high rate of under reporting)

Since the last CBNSG in October 2020, the group has continued to focus on issues relating to the pandemic and the associated health inequalities. The group gathered evidence to contribute to the campaign to include people with learning disabilities on the priority list for vaccination and will continue to monitor the uptake of the vaccine and the issue of reasonable adjustments.

The group has also focused on wider issues in the Transforming Care data including the issues in the analysis especially around regional/local data and the underreporting of restrictive interventions. The data group has highlighted these concerns to NHSE and the data group is continuing work to identify further ways to improve the utility of the Assuring Transformation Data set, including more information on admissions and delayed discharge.

Legal panel subgroup

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. Over the course of the pandemic, the panel met more frequently in order to ensure that families had access to timely support on urgent issues.

With COVID-19 and lockdown guidance often confusing and frequently changing, families had many questions regarding rights and the law. Questions received by CBF Family Support have been triaged and allocated to panel members, with responses uploaded as FAQs on our website so they are widely shared and available:

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

Legal panel meetings have also enabled panel members to discuss legal issues faced by families and to identify legal resolutions or routes to challenge. These have included pandemic related issues (such access to the COVID-19 vaccine, ensuring continued provision of services and educational entitlements during lockdown) and issues unrelated to

the pandemic (such as the construction of a new 40 bed low-secure unit, criminal law issues, and issues relating to residential care). Recently, legal panel meetings have included discussions around legislative issues - notably the Mental Health Act and the Health and Social Care White Papers – from which the CBF is able to collect lawyers' input to enhance our completion of consultation responses.

The panel have previously identified the need to map and co-ordinate the legal work which is taking place around learning disabilities. A legal strategy meeting, originally planned for April 2020, took place in November 2020. The meeting addressed strategic legal issues faced by individuals with severe learning disabilities and their families, and involved input from a diverse range of stakeholders including lawyers, advocacy organisations, family carers, practitioners and policymakers. The meeting included workshop sessions on the Mental Health Act, the Care Act, and how to ensure that families are aware of and are able to act on their rights.

Campaign Subgroup

The Campaign Subgroup have been working on preparations for the 10 year anniversary of Winterbourne View. Work has included a survey produced and analysed by Mencap; a report written by families including data analysis of the progress of the Transforming Care since 2015 and parliamentary and press engagement.

The Campaign Subgroup also helped to co-ordinate the top-line views and key calls for several consultations including the Mental Health Act White paper and an ongoing Health and Social Care Committee Inquiry into the treatment of autistic people and individuals with learning disabilities.

Campaign Families subgroup update

The Campaign Families inputted to the consultation on proposed changes in the MHA White paper. Families contributed by email and attended two consultation meetings in March where they shared their views and experiences in response to the key questions in the MHA white paper consultation. Input from the campaign families was collated and informed the joint CBF and Mencap response to the MHA White Paper consultation submitted in April 2021.

The Campaign Families have also been preparing to mark the 10 year anniversary on 31st May of the BBC Panorama programme exposing abuse at Winterbourne View Hospital. A group of families with relatives who were at Winterbourne View have been putting together a collection of family stories reflecting on the decade since Winterbourne View, and the lack of progress in Transforming Care. Several other campaign families have shared their experiences over the last decade as part of the report which will be published on 27th May and will be available to download from www.mencap.org.uk/transformingcare and www.challengingbehaviour.org.uk/news/winterbourne-view-10-years-on.

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>

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Work is being undertaken to re-orientate the PBS Subgroup as a collaborative Research subgroup that links together some key research initiatives with CB-NSG member involvement including the PBS academy, SF-DARIN and the Tizard Centre.

Updates from CBNSG members

Skills for Care- Personal workforce budgets

The PBS and autism training fund in 2016-17 was used to explore the use of 'personal workforce budgets' to train and develop the workforce to better support people with learning disabilities and/ or autistic people, who display or at risk of displaying behaviours which challenge. An evaluation showed how effective these can be and four years later we visited Paul and made a video so that him, his mum and his staff could tell us how this has worked out for him.

The PBS training peer review process continues to expand and the people who were reviewed during the pilot are now beginning the second round of reviews with around 6 new reviewers joining.

Paul's video and information about the peer review are [here](#).

Call for Expressions of Interest: Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge (MELD) study

The MELD project, a new NIHR study, is seeking Expressions of Interest from professionals working in community-based services for children with learning disabilities and behaviours that challenge in England.

The first stage of MELD is to map community services for children with learning disabilities and behaviours that challenge in England, and to describe distinct service models.

By registering your interest, you will be sent further information about the study (in May 2021). You are not committing to being involved in the research at this stage, and the researchers are not actively recruiting services. To register your interest, please email: meldstudy@warwick.ac.uk

New CBF website

The CBF has launched a new website which is easier to access on phones and tablets as well as on laptops and is more user-friendly. A key aim of the CBF is to make sure families get the practical information they need. That's why we are delighted the National Lottery Community Fund has enabled us to develop a new website as part of our 3 year '[Getting it Right](#)' project. Families have helped the CBF with the website's design process to ensure it meets their needs. However, the site is still being analysed and improved, offering tailored new resources to help anyone supporting children, young people and adults with severe learning disabilities whose behaviour challenges in these difficult times. If you have any comments or suggestions about the new website, please let us know by contacting communications@thecbf.org.uk.

Project and research updates

NHSE Trauma Collaborative

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In 2020 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, which will be brought together in a final overarching report. The first strand of work was shared at the last CB-NSG meeting and the report is available on the CBF website. ['Broken: The psychological trauma suffered by family carers of children and adults with autism and/or learning disabilities & the support required'](#)

NHSE have since commissioned a second piece of work to produce a trauma training resource. Respond, The Tizard Centre and the CBF have worked together with families to co-produce an awareness raising resource- a film that can be viewed as a "stand alone" resource, or that can be used as a training workshop with facilitated discussions, co-led with a family carer and a professional. We are in the final stages of this work and gathering input from focus groups for the film's final edit.

Seldom Heard Project

The Seldom Heard project is now well underway. The Challenging Behaviour Foundation and the Tizard Centre have been working on new and creative ways to improve how we listen to these individuals. We have been supported by an advisory group which includes family carers, providers, Mencap and PMLD Link. We have recruited communication partnerships and have gone through a personalised consent and best interest process with each of them. We are currently in the engagement phase, and the research team have had initial meetings with participants where we agreed the individualised engagement plan.

To begin sharing the learning from this project, we have [launched our webpage](#), where we have shared the rationale of the project, the work which informed the project and the first in our series of communication blogs by Jill Bradshaw, Senior Speech and Language Therapist. We have also written an interim report of our progress which we have shared with NHS England, and we hope to share a final report with you all later this summer.

Institute of Health Visiting Project

The CBF has been working closely with the Institute of Health Visiting on their Understanding Behaviour project. Since October, written resources, an animation and other training resources have been developed. Four awareness raising workshops have taken place. The project is now into the evaluation stage.

Coronavirus and People with Learning Disabilities Study

In March 2020, the 'Coronavirus and People with Learning Disabilities' research team published the results from the first wave of the study (December-February 2021). The researchers interviewed adults with mild/moderate learning disabilities, and surveyed family carers/paid supporters of adults with severe or profound and multiple learning disabilities who could not take part in an interview. For more information, check out the University of Warwick press release [here](#).

Links to the full 1st wave report are [here](#) and an easy read version of the report is [here](#).

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 represented in

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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:

Health and Social Care Committee inquiry

CB-NSG members have worked with ESG members and representatives from other charities to provide evidence for the Health and Social Care Committee inquiry into the treatment of autistic people and individuals with learning disabilities. In February 2021, the CBF, Mencap, Rightful Lives and Learning Disability England co-produced a written report, including anonymized case studies from Campaign Families on Transforming Care which was submitted to the Health and Social Care Committee. You can find the report online here: <https://committees.parliament.uk/writtenevidence/22342/pdf/>. CB-NSG and ESG members have continued to work with the Committee, with Viv Cooper, Dan Scorer, Theresa Joyce and Ken Courtenay providing oral evidence at the Committee sessions on the 9th February and the 13th April which you can watch here: <https://committees.parliament.uk/event/3666/formal-meeting-oral-evidence-session/> On the 27th April, the Committee heard from families with lived experience and questioned Helen Whately, Minister of State for Social Care and NHS Directors for Mental Health and Learning Disabilities. You can watch this [here](#).

MHSDS Data consultation

Members of the CB-NSG Data group inputted to a joint response from Mencap and CBF to NHS Digital's consultation on proposed changes to the Mental Health Services Data Set. Overall, the changes were considered to be positive and feedback was given on specific additions that could be made including addressing the continued discrepancies between the MHSDS and AT data sets and expanding data collection on restrictive interventions.

Keeping children safe in education- schools and colleges – proposed revisions 2021

In March 2021, Viv Cooper, chair of the [Reducing](#) Restrictive Interventions and Safeguarding Children (RRISC) group, wrote a letter to the Children's Minister for England, Vicky Ford. The letter was drafted with input from members of the RRISC group. The letter was written in response to the *Keeping children safe in education- schools and colleges – proposed revisions 2021* consultation. The letter raised that the proposed guidance fails to address the issue of restrictive interventions in a meaningful way.

Early Years Healthy Development Review Consultation

In October 2020, the Sharland Foundation Developmental Disabilities ABA Research and Impact Network (SF-DDARIN), a network of research practitioners (of which CBF is a member), submitted a joint response to the Early Years Healthy Development Review Consultation. The consultation asked, "What outcomes do you think are most important for an early years vision?". The response was informed by research conducted by SF-DDARIN network members and evidence gathered by the CBF.

The Independent Review of Children's Social Care Call for Evidence

In March 2021, SF-DDARIN submitted a joint response to the Independent review of Children's Social Care Call for Evidence. The response was informed by research conducted by SF-DDARIN network members and evidence gathered by the CBF and CB-NSG members (including findings from the New Normal project).

The CBF also submitted a joint response to the call for evidence in collaboration with Cerebra, Simpson Millar, Rook Irwin Sweeney and the Disability Law Service.

General Policy Updates

News and Policy Updates

Since March 2020 there has been lots of media coverage, especially linked to Covid and the vaccination programme. The CBF [Key Covid-19 News](#) page has a summary of some of the key headlines during the pandemic.

Scotland's Transformation Plan- March 2021

In March, Scotland launched its Learning/Intellectual Disability and Autism Transformation Plan. The purpose of the plan is stated as: *"We want this plan to shape supports, services and attitudes to ensure that the human rights of autistic people and people with learning/intellectual disabilities are respected and protected and that they are empowered to live their lives, the same as everyone else."*

The 2 year plan lists 32 actions, including one on the use of restrictive interventions in education settings:

Action 26- The Scottish Government will produce new standalone guidance on the use of physical intervention and seclusion in Scotland's schools. This will provide a clear human rights based policy on physical intervention and seclusion and will be presented as part of the Included, Engaged and Involved suite of guidance. We will also introduce a standard data set and oversee subsequent implementation, including a review one year from publication of the revised guidance to ensure its effectiveness.

Read more [here](#).

CQC Review into DNACR decisions- March 2021

CQC published their review into 'do not attempt cardiopulmonary resuscitation' (DNACR) decisions during the pandemic, finding *'some examples of good practice, they also found a worrying picture of poor involvement of people using services, poor record keeping, and a lack of oversight and scrutiny of the decisions being made'*. The full report and easy read version are available [here](#).

NIHRC Report- February 2021

The Northern Ireland Human Rights Commission (NIHR) recently published their 'Submission to the Northern Ireland Committee for Education on the Human Rights Implications of Current Guidance Relating to the Use of Restrictive Practices in Schools'.

You can read the full submission [here](#).

The submission draws extensively on the evidence in the [2020](#) and [2019](#) CBF and PABSS Reducing Restrictive Intervention of Children and Young People reports. The submission has also had contributions from members of the RRISC group in Northern Ireland.

The RRISC group is working together to develop a strategy to tackle the issue of restrictive interventions against children and young people across the UK. You can find out more on our webpage [here](#).

Monitoring the quality of care and safety for people with a learning disability and/or people who are autistic in inpatient care- February 2021

On the 1st February 2021, NHS published new guidance strengthening the oversight of inpatient care of people with a learning disability and/or autism, which can be found [here](#).

Independent review into regulation of Whorlton Hall- December 2020

CQC published the second phase of the independent review into regulation at Whorlton Hall, undertaken by clinical psychologist Professor Glynis Murphy. It outlines the progress CQC has made to implement the recommendations from the first phase of the review, published March 2020. You can find the report, and a summary of its recommendations [here](#).

CQC Report *Out of sight- who cares?* - October 2020

Following many media reports and significant concerns raised by individuals and organisations, the CQC was commissioned by the Secretary of State for Health and Social Care to review use of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition. The report has confirmed what families have been saying for many years, that many people with learning disabilities in hospital settings receive undignified or inhumane treatment and that everyone, including those with the most complex needs, is able to live a good quality life in the community with the right support. You can read the full report [here](#).

Huge thanks to all CB NSG members who continue to work hard to implement the values of the CB NSG charter. Please continue to share any work you are doing so that good practice and learning is shared and work is co-ordinated.