

## **Written evidence submitted by the Challenging Behaviour Foundation, Mencap, Rightful Lives and Learning Disability England (ADL0001)**

We have been working together with individuals and family carers of children, young people and adults with learning disabilities and autistic people for over 10 years on the issues to be examined in this inquiry. The summary below reflects our conclusions, based on evidence and lived experience, and widely agreed across the sector.

### **Summary**

**The “system” exists to deliver good outcomes for people.** To transform care, all parts of the “system” need to work in a co-ordinated way to focus on delivering those good outcomes. To make this happen knowledgeable leadership nationally and regionally is required to develop a comprehensive and cohesive, thought-through plan, that includes an implementation programme that is delivered locally, and supported and monitored.

*“Nothing will change while we keep building big services, so people have to leave their local areas and their families’ - and which are excellent breeding grounds for poor cultures that think it's ok to restrain people”.* (Senior health professional)

*“We do actually know what to do to help people struggling in these situations. The problem is scalability. Thus far, no government has had sufficient interest, investment and guts to address that. Until they do, little will change.”* (Senior health professional)

### **We must**

- Meet all the needs of children, young people and adults with learning disabilities as detailed in the Challenging Behaviour Charter (see Appendix V).
- Retain the vision – an ordinary life in the community.
- Keep everything as local as possible - but recognise compromise may be required in the interim.
- Recognise the vulnerability and scarcity of human relationships in this population – work with families, not against them.
- Promote “Can do – will do – want to” attitudes. Help service staff to avoid feeling they want to give up. Emotional support will probably be needed beyond frontline staff.

In practice this means:

- Organisational support for professionals – this is essential, but delegate function and responsibility to avoid inertia.
- Technical competence is needed in support for behavioural change – people are likely to need mentoring and peer support not just training.
- Resilience is something to work for, not something to be expected or a happy coincidence.

There needs to be a proper programme of skilling up staff, recognising that Skills for Health/Care has limited impact (if it was working well, we wouldn't be restraining people). Hospitals are not great at delivering individually based training for staff.

- Commitment and values are essential and need to be refreshed from time to time.

- Back-up or ‘fallback provisions’ for community services need to be planned and made available – using gradients of crisis prevention and management including deploying extra skilled help over the short term and the ability to accommodate over the short term.
- If we are to have treatment facilities make sure they treat. Any inpatient centres must be small and local with necessary sensory adaptations and highly skilled staff. Hospitals must know what they are treating and when that is appropriate. Good support and therapy is often the answer not medical treatment. Trauma must always be considered, and trauma informed support given where necessary.
- Crisis care with community teams and single occupancy crisis units is an essential and appropriate alternative to inpatient care for most.
- Treatment facilities must maintain enrichment and engagement between therapy sessions – not make it more difficult for people to earn their way out.
- Therapies must be co-ordinated - integrated (not fragmented), person-centred, evidence-informed, and derived from continuous assessment and evaluation.

If we are to have a readiness model for reducing restrictiveness, apply to service models not people (i.e. make the services ready to deliver the support needed, not expect the person to be ready to have what is available).

To deliver this we must:

- Apply human rights perspectives universally.
- Encourage compassion and nurturance across the board, not punishment and blame.
- Ensure greater scrutiny of the independent sector, who don't even report data sometimes, and deliver poor care often.

This requires strong, informed and skilled leadership – which is currently lacking.

But we know what to do and we know how to do it.

**Key question:** What is the government policy at present, is it Transforming Care or Reinforcing Institutions?

## Background

### **1.1 Winterbourne View Hospital abuse scandal in 2011**

In May 2011, BBC Panorama exposed shocking abuse taking place at Winterbourne View Hospital, a private hospital for people with learning disabilities. The scandal exposed **significant and multiple systematic failures**: people with learning disabilities were being channelled into inpatient services, services that were damaging people and causing significant human cost as well as a high financial cost. All parts of the system, including the legal frameworks and other safeguards in the system that should provide protection needed to be scrutinised and made fit for purpose for this population.

The conclusion was that care must be transformed – not tinkered with round the edges, but completely transformed. 10 years on this transformation has not happened.

### **1.2 Missed targets**

In response, the Government promised to address these failings and in 2012 set out its [national plan](#) to ‘Transform Care’ for children, young people and adults with learning disabilities and/or autism.

However, progress has been unacceptably slow and multiple targets for reducing inpatient numbers have been missed. The targets set in 2012 were not met in 2014, ([Winterbourne View: the scandal continues.](#)) Then in 2015, following a critical NAO report and a Public Accounts Committee hearing, the Government published the [Building the Right Support](#) plan, which extended the original deadline and committed to moving 35-50% of people with a learning disability and/or autism out of institutions and into the community by March 2019. Again, these targets were missed. In 2019 the targets were incorporated into the [NHS Long Term Plan](#). This extended the deadline again: 35% of people would be moved into the community by March 2020, and 35-50% by March 2024. The target was missed again in March 2020. (see appendix II for a snapshot of the recent Transforming Care data).

We suspect there has been a shift in attitudes in NHSE and that there is a policy that believes that a significant number of people do need to be in hospital. This is driven in part by the fact that some people with learning disabilities and/or autism find themselves in the criminal justice system yet there is no real in-depth examination of the reasons for that.

#### **1.4 Multiple reports and repeated recommendations**

Over the ten years, numerous reports have been published which repeatedly evidence that inpatient care provides poor outcomes for people with learning disabilities - and show why preventing inappropriate admissions and moving people out of inpatients units into the community is so important (see Appendix III).

It is widely accepted that we must invest in the right support and services and stop spending money on services that are harming people. In its 2015 report, the National Audit Office estimated that in 2012-13, the NHS spent £557 million on inpatient services for people with learning disabilities whose behaviour can challenge.

We know how to support people well. There are numerous reports clearly showing what good support looks like, along with NICE guidelines:

- Jim Mansell, *Services for people with learning disabilities and challenging behaviour or mental health needs* (1993), Revised (2007).
- *Challenging Behaviour: a unified approach* (2007)
- [NHSE, Building the Right Support](#) (October 2015)
- LGA and NHSE, [Ensuring Quality Services](#)
- NHSE, [Developing support and services for children and young people with a learning disability, autism or both](#) (2017)
- Learning disabilities and behaviour that challenges: service design and delivery. NICE guideline [NG93] (2018) [NICE](#)
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges NICE guideline [NG11](2015) [NICE 2015](#)

The reports highlighting the poor outcomes of current care provision have also repeatedly made the same recommendations:

#### **1) Targeted and sufficient investment to ensure the right community support is in place, including the right housing**

**2) Early intervention** – children, young people and adults should be able to get the right support early on, before needs escalate

**3) Build capacity in the workforce** – to ensure there are enough people with the right skills and expertise in supporting children, young people and adults with a learning disability and behaviour that challenges (e.g. social care providers, community health professionals, robust community multi-disciplinary teams)

**4) Remove perverse financial (and other) incentives and provide adequate funding** e.g. if local areas don't invest in the right community support and someone gets admitted to an inpatient unit under the MHA then 'Health' will pick up the bill. Once this happens there is often no financial incentive for local areas to work to get someone out as the cost will be transferred to them. Central government must provide local areas with adequate ring-fenced funding to transform care. Besides the direct financial self-interests, another self-interest relates to risk aversion. For example, another barrier is the risk aversion of the Responsible Clinician that the person "might do something" if discharged. The risk to the person of long-term detention is not considered.

**5) Work in partnership with families and individuals** Families are often deliberately excluded, despite their role in providing long term love, care and support.

**6) Improve poor commissioning** – serious concerns have been raised about commissioning – unsuitable community placements and unsuitable placements in inpatient units. Commissioning is a key function for Transforming Care- yet commissioners have no professional body or standards and are not regulated. (For example, see CQC Out of Sight report recommendations around the need for better commissioning). "Specialist commissioning" is often neither specialist nor commissioning- it is purchasing what is available. There seems to be little or no accountability for commissioners who fail to provide community solutions and who write the cheques that fund abuse. Commissioners have access to huge sums of money and have immense control over people's lives, yet they are not regulated in any way.

**6) Robust inspection and scrutiny of services by inspectors who know what they're looking for**

**7) Cross governmental strategy for Transforming Care with clear leadership and accountability**

There is a general lack of accountability throughout the system, especially where law is not upheld by public bodies and so the Rightful Lives 8 Point Plan recommends:

*"The establishment of an independent body led by people with learning disabilities, autistic people, families, lawyers and representatives of key stakeholder organisations, that has the remit to monitor and hold responsible bodies to account, in accordance with the requirements of existing legislation."*

These multiple issues cannot be addressed in isolation- there needs to be **a properly led, comprehensive plan that delivers these changes through a co-ordinated approach**. Until that happens progress will remain piecemeal, and the vision of transformation will not be achieved.

Nearly 10 years since the Winterbourne View abuse was exposed and the Government made a commitment to Transform Care for people with a learning disability and/or autism, children, young people and adults continue to receive inappropriate provision in inpatient units:

- In 2019, the abuse scandal at Whorlton Hall was exposed.

- In 2020, similar issues were uncovered at Yew Trees hospital, run by Cygnet.

After the 2019 Whorlton Hall scandal, one family carer told the CBF:

*"It is approaching 8 years since I viewed the dreadful images of my eldest son being abused at Winterbourne View. The Government's response was a clearly defined promise to empty Assessment and Treatment units and close them down. They have undeniably failed in this endeavour and thus failed over two thousand people, and their families, who are still incarcerated in hospitals and units across the country."*

**Key question:** Given that commissioning is such a crucial role why is there no accountability, regulation or professional body that provides training and sets standards?

**The rest of this paper will outline the consequences of this broken promise** in respect to:

- Restraint
- Length of time in inpatient services and its impact
- Mental Health Act
- Other key concerns

## **2. Restraint**

### **Key questions**

1. Given the low reporting rate of restrictive interventions in inpatient settings in the published data, what is the actual prevalence?
2. As the number of incidents of restrictive interventions is increasing/ remains high, what new actions has the government taken to reduce incidents in inpatient settings?
3. We know the EHRC is currently looking at the recording and reporting of RI in schools. What else is being done to investigate the impact of restrictive interventions on children, young people and adults and their families and to provide them with appropriate support?

### **2.1 Human cost of restrictive practices on individuals and their families**

- Restraint and seclusion have a significant human cost for people with learning disabilities and/or autism and their families. The impact is damaging, and long term, as illustrated in case study 1.
- The JCHR inquiry on detention of young people with learning disabilities and/or autism and the CQC *Out of Sight* report, show the shocking high levels of restrictive practices, including physical and chemical restraint and seclusion and isolation, that people with a learning disability and/or autism are experiencing in inpatient units - and the impact on individuals and their human rights.
- CBF's recently published report '[Broken : The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required](#)' highlighted that family carers experience additional trauma (as well as mainstream trauma) when services expected to meet their relatives needs fail to do so. This is also highlighted in case

study 3. The impact of this trauma on individuals and families is long term and wide ranging, and respondents to our survey reported feelings of guilt, relationship breakdown, depression and insomnia.

## 2.2 Data on restraint and seclusion in inpatient settings

- Data reported in the [MHSDS data set](#) shows a high number of incidents of restrictive interventions experienced by children, young people and adults with learning disabilities and/or autism in inpatient services.
- The most recently published data from NHS Digital shows there were 3,590 incidents of restrictive interventions in October 2020. This includes 315 reported incidents of prone restraint in inpatient services, including 60 on children (under 18s). This is particularly concerning given the [government guidance](#) for adults states *“There must be no planned or intentional restraint of a person in a prone/face down position on any surface, not just the floor.”* Children and adults are also subject to seclusion and segregation in inpatient services. Case study 3 highlights the misuse of restraint in inpatient and community settings and the long term consequences for individuals and their families.
- A 2019 report by the Children’s Commissioner [Far Less Than They Deserve](#) shows widespread mistreatment of vulnerable children and young people in Assessment and Treatment Units, including restraint and seclusion.
- Despite the high figures, published restraint data only accounts for a small proportion of providers. In the last publication of the MHSDS data set, only **2 out of 15 Independent providers and 31 out of 56 NHS providers supplied data, despite reporting supposedly being mandatory. This suggests the actual figure could be much higher.**
- Children and adults with learning disabilities and/ or autism are also subject to inappropriate medication. According to Public Health England, *“every day about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for.”* ([NHS England » Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#)) Case study 3 highlights how a lack of understanding amongst professionals of learning disabilities and autism and the causes of challenging behaviour can lead to inappropriate prescribing of anti-psychotic medication.

## 2.3 Children and young people being restrained in schools and other settings

- These practices are not confined to mental health units. A joint report by CBF and PABSS, published January 2019 [Reducing Restrictive Intervention of Children and Young People’](#) (2019), found evidence of hundreds of children injured through the use of restraint, seclusion and other restrictive practices in both mainstream and special schools, suggesting that staff do not have the skills and expertise they need to meet children’s needs using evidence-based approaches.
- 88.2% reported their child or young person had experienced physical restraint. 91% of children and young people who had been restrained or secluded experienced a negative emotional impact, and 58% were physically injured during restraint or seclusion. The emotional impact on

children and young people who had experienced restraint reported in the survey included anxiety, signs of depression, and meltdowns.

- This can be avoided through the use of Positive Behaviour Support – the best evidenced approach for supporting people with learning disabilities whose behaviours challenge, as recommended by NICE, the Department of Health, NHSE and the DfE [Guidance 'Reducing the need for restraint and restrictive intervention'](#) (June, 2019)
- Lack of the right support for children and young people early on can lead to behaviour escalating, exclusions from school and use of restraint. As well as this being traumatic and damaging in itself, it can begin a pathway into inpatient units.
- We must get it right for children with a learning disability and/or autism, which is why it is so important to have a robust cross governmental strategy for Transforming Care, which includes Education.

### **3. Length of time and experience in inpatient services**

#### ***Key questions***

1. It appears that the government's Community Discharge Fund is significantly smaller than funding provided to existing inpatient services and for the construction of new inpatient services.
  - What is the year-on-year increase in government funding that is being pledged to a) ensuring the provision of services in the community in comparison to increases in funding of b) existing inpatient units and c) the construction of new inpatient units?
  - How could the government justify figure a being smaller than b and c in light of its Transforming Care objectives?
2. What will the government do to ensure that Early Intervention remains a priority post-covid and that any budget cuts don't result in intervening only at crisis point?
3. While the CQC are making changes to their inspection framework in an effort to make it more rigorous, how will they ensure inspectors know what they are looking for? When will commissioning start being regulated?
4. What is the current situation regarding community support: How many TCP areas now have the full range of support for people with LD/autism as set out in the NHSE Building the right support service model? Could NHSE and the Minister give the committee this information, with reference to each element of the service model and which TCPs have it in place, including
  - Children and adult forensic teams etc.
5. How are families supported to be included and listened to, and what independent advocacy support do they and their relatives receive? How is this monitored to make sure it is available to everyone and delivers good outcomes?
6. Why have the perverse financial incentives not been addressed? If the local authority fails to support a person properly and they reach crisis then health will pick up the bill if the person goes into a unit. What incentive is there for the local authority to invest in the right community support to stop people going into units and provide the right support to get them out? What is the Minister and NHSE doing to address this long-standing issue?

The total number of children, young people and adults with a learning disability and/ or autism in inpatient services at the end of December was 2,055, including 210 under 18s.<sup>1</sup> Despite the purpose of admission to be short term assessment and treatment, people are staying for long periods and the average length of stay in inpatient units is 2,047 days or 5.6 years. People are often staying for long periods, the individual in case study 2 has been an inpatient for nearly 15 years and is still waiting for a discharge date.

### 3.1 Human and financial cost

- Inpatient units do not provide good quality care and support and people are at increased risk of abuse and neglect and are often placed many miles from their homes (see case study 1).
- Despite 9 years of a “Transforming Care” programme, the evidence of poor treatment of children, young people and adults with learning disabilities and/or autism in inpatient units continues. [The CQC’s State of Healthcare and Adult Social Care report 2019/20](#): *‘Among mental health services, we continued to find more poor care in inpatient wards for people with a learning disability and/or autistic people. The overall proportion of services rated as inadequate [the lowest rating possible] rose from 4% to 13%.’*
- Recently published reports, including by the [Joint Committee on Human Rights](#) and the CQC [“Out of Sight- who cares?”](#) report confirmed again what families have been saying for many years, that many people with learning disabilities and/or autism in hospital settings receive undignified or inhumane treatment - and that individuals with complex needs are able to live a good quality life in the community with the right support. It recognises that there is currently a failure to offer support at the point people need it, which often leads to restrictive interventions or inappropriate admissions which are often lengthy.

### 3.2 Lack of appropriate support in the community - leading to inappropriate admissions and people remaining stuck, often for years

- Each month the NHS Digital Transforming Care data show the top two reasons for delayed discharge from inpatient units is **lack of social care** and **lack of suitable housing**.
- Building the Right Support had the twin targets of reducing the number of inpatient beds and developing the right community support as set out in the NHSE service model. Both these targets were missed. **The success of ‘Transforming Care’ depends on the development of the right support in the community.**
- A Health Service Journal FOI (Dec 2018) found of 169 CCG respondents, 88 confirmed no short-term crisis accommodation for people in their area, and 49 did not have community support services for children and young people – key elements of the service model.
- NHSE published a [“Service Model” \(2015\)](#) which set out the components required in each area to support people with learning disabilities and autistic people. Almost 2 years after the BTRS target was missed we have still not had a proper analysis from DHSC or NHSE of the support available in local areas, mapped against the NHSE service model. It is not clear why this has not been done as it is crucial to measure support and services so that ‘gaps’ can swiftly be

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<sup>1</sup> NHS Digital, Assuring Transformation Dataset

addressed. In 2018, NHSE's own independent evaluation of BTRS described progress as uneven both geographically and in terms of the different aspects of the programme.<sup>2</sup> We have not seen a plan to address lack of progress – including funding needed.

- Local services and commissioners have failed to create local bespoke packages of care and support for children, young people and adults. This is compounded by the failure of NHSE and Government to compel /enable local areas to create those packages of support and tackle the issue of private providers, whose financial incentive is to fill beds in ATUs.
- LAs and CCGs and NHSE must invest in the right support for people with a learning disability and/or autism in line with the NHSE Service model. NHSE continues to directly fund places (through “specialist commissioning”) in the very type of institution that it has promised to close down.
- We know that while beds are available they will be used as an easy option where local areas fail to develop appropriate community support.
- People have moved out of inpatient units and are flourishing with the right support in the community (see case study 1 showing how individuals with learning disabilities and autism can be supported to live well in the community). However, it has often taken huge efforts from the family and pressure from lawyers and the media to make this happen.
- Pockets of good practice exist in some parts of the country (e.g. NDTi's ‘small supports’ project) which prove that people with ‘hefty reputations’ can live successful lives in the community. These examples tend to succeed because they focus on people and possibilities rather than restrictions and risk. See Books Beyond Words ‘Helping People Thrive’ case studies [here](#).
- A lack of the appropriate community support has resulted in some people being discharged and readmitted. Consistent with what families tell us, the VODG report (2018)<sup>3</sup> found people discharged from inpatient units are readmitted due to community placements failing within months. This is due to a number of reasons including lack of robust community support in place (including care providers with the right skills, timely input from community teams) meaning packages of care are fragile, lack of proper transition planning (including community staff supported to get to know the person whilst they are in the ATU), lack of appropriate housing, and some people being discharged from inpatient units into community settings providing ‘institutional-style’ care. The development of local support must be closely monitored to ensure that care is actually transformed, and that people are able to live in genuine homes, with the right person-centred support for their needs, and are enabled to be part of their communities.
- The cycle of discharge and readmission can also be attributed to a lack of proper transition planning. Staff teams are not given adequate time to visit individuals in inpatient settings before they are discharged to the community. Case study 2 highlights the importance of transition planning, and the additional pressures on this due to Covid 19.

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<sup>2</sup> *Evaluation of Building the Right Support: stakeholder feedback report* (July, 2018). More information on the BTRS evaluation can be found online: <https://www.strategyunitwm.nhs.uk/publications/building-right-support>

<sup>3</sup> Voluntary Organisations Disability Group *Transforming Care: The challenges and solutions* (2018)

- Multiple reports and investigations have clearly and consistently identified the issues that must be addressed to develop effective community support. These include:
  - an underfunded social care system and lack of suitable housing;
  - lack of investment in early intervention and prevention (to prevent crisis situations, which can lead to admission to inpatient units);
  - failure to listen to the expertise of people with a learning disability and their families;
  - commissioning of places that are not the current model of care;
  - lack of appropriate skills and specialism to meet the needs of individuals (even in high cost “specialist” services),
  - safeguards in the Mental Health Act not working for people with a learning disability and/or autism;
  - perverse funding incentives in the system and
  - a lack of joined-up working between health, social, education and housing, and across children and adults systems.

### 3.4 Early intervention

- Admission to inpatient units is largely avoidable with early intervention.
- Research has shown that challenging behaviour is highly preventable when evidence-based behavioural interventions are provided in the early years which look at the reasons for the behaviour and address them. For evidence of this, please see the [CBF and Council For Disabled Children Early Intervention Paper](#). Families need early support from specialists, emotional support and the right information at the right time in a form that is right for them.
- The children in inpatient settings are just the tip of the iceberg of those at risk of restrictive responses. Many more children are in residential special schools, outside of their Local Authority area, often far from home. In 2017 Dame Christine Lenehan found 6,146 children or young people boarding in residential schools or colleges, representing a spend in the region of £500m per annum.<sup>4</sup>
- 70% of those living in residential schools or colleges are children who display behaviours that challenge (Children or young people with autism, communication difficulties, severe learning disabilities and challenging behaviours or those with social, emotional and mental health needs and challenging behaviours). Dame Lenehan concludes that *“many of the children and young people currently in residential special schools could be educated in their local communities if better support was available. To achieve this, local authorities should in future work more closely with parents, clinical commissioning groups and all providers to develop a range of flexible, local solutions for these children and young people”*
- Research shows that children in residential settings often go on to residential settings as an adult<sup>5</sup>

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<sup>4</sup> Christine Lenehan, *Good Intentions, Good Enough? The Lenehan review into residential special schools* (2017).

<sup>5</sup> McGill, P. (2008). Residential Schools for Children with Learning Disabilities in England: Recent Research and Issues for Future Provision. *Tizard Learning Disability Review*, 13(4), 4-12.

- Alongside the benefits to the person and their family, early intervention reduces the need for more costly later interventions (such as crisis interventions or institutionalised care). The annual cost of keeping a child in an inpatient unit is £250,000, and the annual service cost for an adult who displays severely challenging behaviour is £379,000.<sup>6</sup> The cost savings of localised evidence-based early intervention have already been shown. A financial review found that The Bristol Positive Behavioural Support Service produced savings of £1.8 million in just four years.
- The ambitions behind the SEND reforms could transform the experience of this group of children and their families if implemented in partnership with the ambitions of Transforming Care. We point to value for money Positive Behaviour Support (PBS), which is crucial, but not enough on its own (See Bristol Positive Behaviour Support Service example in [Paving The Way](#)). Behaviour support must be underpinned by a good, holistic, person-centred package of support from Education, Health and Social Care. Joint commissioning, pooled budgets and greater use of personal budgets (with support for families to manage them) all have the potential to provide the person-centred, bespoke support this group of children need.
- However, historically, the most complex are the last to benefit from reforms. We would argue, that as a highly vulnerable, high cost group, children with learning disabilities and/or autism whose behaviours challenge should be a priority. Spending money in the right places at the right time for this group has the potential to both transform lives and to reduce costs.
- *“There is strong evidence that some of the key factors causing challenging behaviour can be changed, and when changed can lead to marked reductions in challenging behaviour”* Professor Eric Emerson (Lancaster University and University of Sydney).
- Despite the clear benefits, many families are currently not receiving early intervention when their relative begins to display challenging behaviour. A survey by the CBF and the Institute of Health Visiting (in development) found that 69% of families of children with a developmental delay whose behaviours challenge (from a sample of 113) did not receive any information about or support for challenging behaviour in the child’s early years.
- Instead, the kinds of preventative health and care services which make a difference (such as community teams, speech and language therapy, occupational therapy, respite, behaviour support, CAMHs, leisure and social activities) are being withdrawn, reduced or holding ever lengthening waiting lists during the pandemic. From a small sample of 48 families surveyed by the CBF (in development) we found that around half stated their child had not attended school since the March 2020 lockdown and did not have any behaviour support from school, LA, CAMHs or other services.
- The CBF, in partnership with the Council for Disabled Children, published “Paving the Way” setting out what good local support for children with learning disabilities whose behaviours challenge should look like.<sup>7</sup>

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<sup>6</sup> The Challenging Behaviour Foundation, *Early Intervention for Children with Learning Disabilities whose behaviours challenge* (November, 2014).

<sup>7</sup> <https://pavingtheway.works/whats-new/valuingtheviewsblog/>

- In 2017 Dame Christine Lenehan published [‘These are our children’](#) . Her report makes 11 recommendations for government departments and partners at a national level on how to improve the system to co-ordinate care, support and treatment for children and young people. We would like to see these implemented in full.

### **3.5 Robust inspection by CQC and Ofsted**

During inspections, not least because of vested interests, there should be a much higher emphasis and weighting on patient experience and the views of families, carers and independent advocates. Where family involvement isn't present or is restricted by the provider, the risk of a "closed culture" should trigger a much higher level of scrutiny.

There can be a disparity between the justification given at Mental Health Tribunal for detention and the care or discharge plan. We should reasonably expect these to be identified at inspection.

Inspectors need adequate training to understand the needs of the individuals (children, young people or adults) in order to recognise the provision of appropriate care and support. Current Ofsted guidance is not robust regarding reducing restrictive interventions and there are concerns that inspectors are not well trained or experienced on those issues so can, for example, inspect a school without seeing a seclusion room.

## **4. Mental Health Act**

### **Key questions**

1. What is the government doing right here and right now to address the known issues before the bill is passed to protect individuals? Specifically in regards to:
  - The support needed in the intermediate period between now and the MHA reforms coming in to place, and ensuring community provision is in place
  - The interface between MCA & MHA
2. What funding is being provided to implement actions and avoid unintended consequences?
  - Will additional funding be provided besides the £62 million non-ringfenced Community Discharge Fund?
  - Is the Community Discharge Grant sufficient, and if so what is the evidence?
  - How is the grant being planned for and spent, and how is the impact being evaluated?
3. Besides reforms to the powers of Tribunals, what measures will the government be taking to ensure that these operate effectively in practice for people with a learning disability and/or autism?
4. The MHA white paper acknowledges the importance of ward environment and the need to change risk averse culture. Apart from strengthening the detention criteria, what pro-active steps will be taken to address these issues, given the role they play in creating abusive environments? While providing patients with their own bedroom and ensuite is a welcome change, it does not address the issues of closed cultures.

We worked with families to input into the 2018 Wessely review of the Mental Health Act, highlighting the legislative changes, including fundamentally reconsidering the definition and criteria for detention, that were needed to ensure this Act worked for autistic people, people with learning disabilities or both.

Our engagement with the consultation on the Mental Health Act White paper is ongoing. We are seeking input from a range of stakeholders including family carers, practitioners, and lawyers. Once this work has been completed, we will be inputting into the consultation process as fully as possible. Appendix IV details key issues for people with learning disabilities and / or autism that need to be addressed in the Reform of the Mental Health Act.

The work we have done so far has highlighted the following:

#### Welcome changes

The principles of the reform seek to improve support for people with a learning disability and autistic people and reduce reliance on inpatient care. The White Paper addresses some of the concerns raised by individuals and their families, and the issues raised in the 2015 Green paper 'No voice unheard no rights ignored'.

We welcome the proposed changes to the detention criteria:

- Learning disability and autism will no longer be considered a mental disorder for which someone can be detained for treatment under section three of the act. In line with the rest of the population, people with a learning disability or autistic people will only be detained for treatment past the initial 28-day assessment stay (section 2) if a co-occurring mental health condition is identified by clinicians. However, we are concerned that mental health diagnoses, such as anxiety disorders or personality disorder, might be given to people in order to justify detention. We are also concerned that the Mental Capacity Act may be used as a vehicle for detention instead.
- The purpose of detention for care and treatment must be therapeutic benefit
- Strengthening the detention criterion for "own health or safety or with a view to the protection of other persons" to "*substantial* likelihood of significant harm to the health, safety or welfare of the person, or the safety of any other person"

We also welcome proposed new commissioning duties around ensuring adequate community support for people with a learning disability and/or autism (with the caveats earlier regarding the quality of commissioning). However, as market shaping duties already exist in the Care Act but are ignored, we wonder what will be done to enforce these new duties and what will be different this time.

Care and Treatment Plans have been put on a statutory footing and will be required to consider recommendations made in Care and Treatment Reviews. We welcome these changes, but we must see the reviews themselves be of sufficient quality and made mandatory so that they actually happen and deliver good outcomes for people.

#### What else is needed?

We need to look carefully at all the proposals to make sure they will actually work for children, young people and adults with a learning disability and/or autism and ensure adequate safeguards are in place to prevent them being inappropriately subject to other restrictive legislation or put at higher risk as they no longer qualify for the MHA safeguards.

There will always be room for interpretation – if key professionals retain the view that people with learning disabilities and/or autism should be detained, they will find a way to do so. It is possible that changing the detention criteria so that learning disabilities / autism will no longer be sufficient

for detention under s3., could lead people being detained under the MCA (DoLS or in the future, LPS) rather than the MHA resulting in no real change in their situation just the legal framework under which they are detained. There is a need for “changing hearts and minds” about what good support looks like for this population and how it can be delivered.

What is absolutely clear is that there must be the development of the right support – including care providers and community health professionals with the right skills, willingness to develop bespoke packages of care to prevent needs escalating and people ending up in crisis, robust MDT and forensic and intensive support teams in the community. It is of crucial importance that such services are developed to meet people’s individual needs which requires consultation with the people who are to receive such services and their families. This would need to be done at a local level and unless this happens, we are at risk of developing services that don’t meet people’s needs and as a result leads to crises situations and then hospital admissions.

**This community support is long overdue – it should have been in place by March 2019.**

- We welcome the government’s Community Discharge Grant to help fund the double running costs where people are being discharged, but there are unanswered questions over its sufficiency, allocation and evaluation.
- We want to see a clear plan for how the gaps in all community support (as set out in the NHSE service model) will be addressed, including funding for appropriate housing.
- We also need a robust, cross-governmental strategy and action plan which co-ordinates and joins up all parts of the care system to ensure the right support is in place for children, young people and adults. The government has committed in name to this but we are yet to see any progress (for instance, a comprehensive system-wide plan, an implementation fund and team, a programme start date).

The Rightful Lives 8 Point Plan recommends:

In the longer-term, **legislative** change to strengthen people’s right to independent living and a life free from the threat of detention, with community alternatives to hospital care:

- a. Drawing on the principles outlined in the Draft Disabled People (Community Inclusion) Bill 2015, also known as “the #LBBill” so that laws and systems change to safeguard people’s right to have community alternatives to a hospital or care home admission considered first.
- b. The United Nation’s Convention on the Rights of People with Disabilities;
- c. Giving CTRs and CETR’s statutory powers;
- d. Include strengthened rights to advocacy and independent support for people without families or whose families are not involved in their lives;
- e. Rights to peer advocacy and visits from friends and people who know them well;
- f. And strengthened rights for families whose family members have been detained.

## **5. Related concerns**

## **Key questions**

### *Provider collaboratives*

1. What will be done to ensure that these providers are not using their position to commission their own care over other, potentially better, care set ups and what will be done to ensure that care they do both commission and provide is set up in accordance with BTRS principles and doesn't simply become an extension of hospitals, run on a restrictive and medical model?

### *Proposed 40 bed unit*

2. Do the Minister, CQC and NHSE believe that the development of the new 40 bed unit in Maghull is in line with Transforming Care? NHSE recommended that low secure provision at Calderstones was replaced with smaller units for low secure care across the North West and community forensic support. This would have been in line with the principles of Transforming Care. Why has NHSE changed its position on this?
3. Why did the Government fund a large institution on an isolated site, against all the principles of Transforming care?
  - a. Why did CQC register it?
  - b. Who is buying places in it?
  - c. Will the Government provide £33m to fund the new 40 person institution?
  - d. What has been learned from the failure of the St Andrews 110 person unit, which was built during the Transforming Care programme?

### *Monitoring community provision*

4. How are DHSC and NHSE assuring themselves that people are getting the right support they need when they are back in the community? What are NHSE and CQC doing to monitor what is happening to people who have moved into the community to ensure they are getting the right support, living in genuine homes and are able to live a full life?

## **5.1 Downgrading NHSE National Learning Disability Director role**

We are concerned that the decision to move the NHS England National Learning Disability Director post from full time to part time, and at least a three month gap between Ray James and his successor indicates a reduced prioritisation of the Transforming Care agenda going forward. In addition, the independent chair of the Children and Young Peoples Transforming Care steering group resigned in December and has not been replaced.

## **5.2 Changes to service provision as a result of the pandemic**

The pandemic has repeatedly been used to explain delayed action and it will inevitably be used to justify future cuts to community services. This increases the risks that early support will be stopped, thresholds for support will be raised and that there will be a hastening trend towards crisis management rather than proactive intervention. We know this is the least cost-efficient approach, both financially and in terms of the human-cost of failure to provide the right support at the right time.

## **5.3 Provider collaboratives**

NHSE have marketed Provider Collaboratives as a way of redirecting funding away from institutions like Winterbourne View and Whorlton Hall towards the community. However, some of the providers which have been recruited into these collaboratives currently provide the type of services that do not fit the service model specification and have very poor track

records within their learning disability and autism services (e.g. claiming to be “specialist” when they are not). We know that private hospital providers are already developing residential care to which they discharge their own patients.

There are significant concerns about the make-up of some Provider Collaboratives. For example: [The East Midlands Provider collaborative](#) (called Team Impact) includes 5 NHS providers and 4 independent providers: St Andrew’s Healthcare, Cygnet, Priory and Elysium. As you will be aware St Andrews Healthcare and Cygnet are both institutions with records of poor care, which have been exposed on national media. (see, for instance: [Dispatches: Under Lock and Key, Channel 4 review – ‘The number of people kept in large hospitals stays stubbornly high’ \(theartsdesk.com\)](#); [Whorlton Hall: Hospital ‘abused’ vulnerable adults - BBC News](#))

#### **5.4 New large inpatient units are being built on isolated sites**

Despite the commitment to *reduce* the number of beds in these expensive and ineffective institutional settings, last year Mersey Care received planning permission for a *new* 40-bed unit at Maghull using £33m of government funding. This goes against NHSE’s own recommendation following the Calderstones re-provision consultation.<sup>8</sup>

The proposed 40 bed unit is to be built on the same site as a recently opened 123 bed Medium Secure Unit, completed in 2020 at the cost of £60m, including 45 beds for people with a learning disability and/or autism.

#### **5.5 Concern that some people are moving out of inpatient settings only to be in very restrictive ‘community’ settings.**

Anecdotal evidence from families in touch with our organisations suggests sometimes individuals with learning disabilities and/or autism are receiving care in the community, which in practice is very similar to care received in inpatient services. Services use very restrictive practices, do not listen to families, and are very expensive. We do not want ATUs by another name being created in the community.

This is particularly concerning given the reduced scrutiny and lack of rigorous inspection in community settings.

Individuals with learning disabilities and autistic people should be able to live in their own homes with appropriate and timely support. A key element to support this is robust multi-disciplinary community teams that can support individuals and providers. Unfortunately, we are hearing from families where that input is not available and support packages are fragile.

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<sup>8</sup> NHSE recommendation in relation to low secure provision to replace Calderstones: ‘Commence the development of **smaller units for low secure services across the North West**, which will provide approximately 70 low secure beds supported by community beds and specialist support teams. This new model of care has been developed in conjunction with the Transforming Care Partnerships (TCPs) across the North West and would be implemented to support the discharge of a number of service users as outlined in their Care and Treatment Review. **In addition, there would be a new community model for forensic support which would enable secure care to be provided in a different way, other than a hospital.**’

(See pg 6&7: <https://www.england.nhs.uk/wp-content/uploads/2017/03/nhs-consultation-proposals-redesign-ld-services-across-north-west.pdf> )

## **5.6 Addressing health inequalities for children, young people and adults with learning disabilities and autistic people**

Accessing healthcare can be challenging for children and adults with a learning disability and/ or autism under normal circumstances. It is well established that this group faces significant health inequalities and at risk of diagnostic overshadowing. During Covid-19 we are particularly concerned that people with a learning disability and/ or autism's right to life could be threatened or access to healthcare and treatment deprioritised.

The Learning Disabilities Mortality Review (LeDeR) every year now, reports on more avoidable premature deaths and issues such as discrimination and "unconscious bias" in clinicians treating people with learning disabilities. The unlawful, discriminatory, use of DNACPR orders has been mentioned in several LeDeR reports and recommendations, as it was in the original Confidential Inquiry into the premature deaths of people with learning disability, yet, incredibly, there was an apparent and immediate increase under Covid-19, which is currently subject to a review by The Care Quality Commission. Even today, and despite CQC's review, we know people have DNACPR's (or ReSPECT forms) issued citing "Downs Syndrome" or "Learning Disabilities."<sup>9</sup>

Adequate training in learning disability and autism for healthcare staff is essential to prevent diagnostic overshadowing and ensure necessary reasonable adjustments are made. We welcome the Oliver McGowan Mandatory Training in Learning Disabilities and Autism. To ensure all staff, managers and professionals receive necessary training, qualifications should be subject to scrutiny as part of CQC inspections.

*February 2021*

### **Appendices**

- I) **About the authors**
- II) **Transforming Care data table**
- III) **Bibliography of relevant reports, guidelines and other publications**
- IV) **Key issues that need to be addressed in the reform of Mental Health Act**
- V) **[Challenging Behaviour National Strategy Group Charter](#) (and separate document)**
- VI) **Case studies** (separate document)

### **Appendix I About the Authors**

#### **About Mencap**

We support the 1.4 million people with a learning disability in the UK and their families and carers. We fight to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want. See [www.mencap.org.uk](http://www.mencap.org.uk) for more information.

We are also one of the largest providers of services, information and advice for people with a learning disability across England, Northern Ireland and Wales.

[www.mencap.org.uk](http://www.mencap.org.uk)

#### **About The Challenging Behaviour Foundation**

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<sup>9</sup> DHSC, *The Government response to the third annual Learning Disabilities and Mortality Review (LeDeR) Programme report* (February, 2020).

The Challenging Behaviour Foundation (CBF) is a charity which exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy ordinary life opportunities when their behaviour is properly understood and appropriately supported.

The CBF supports families across the UK caring for individuals with severe learning disabilities. Information and support around understanding challenging behaviour and supporting behaviour change is provided through a range of written and DVD resources, email networks, family linking scheme, and through individual telephone support.

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### **About Learning Disability England**

Learning Disability England exists to make life better with people with Learning Disabilities and their families. We are a not for profit membership organisation bringing together people with learning disabilities, families, professionals and organisations.

Membership is open to any person, organisation or group that supports Learning Disability England's aims and wants to be part of making them happen. Currently there are more than 600 individual members and 130 organisations.

Find out more; <https://www.learningdisabilityengland.org.uk/>

### **About Rightful Lives**

Rightful Lives is a creative campaign that explores the human rights of autistic people and people with learning disabilities. All members of the Admin Team are people with lived experience. Our online exhibition includes many examples of the good lives people can lead as well as the traumas and injustices they face. [www.rightfullives.net](http://www.rightfullives.net).

Our 8 Point Plan, a review and plan for everyone in an ATU to get community support within 12 months, can be read here: <https://rightfullives.net/Stories/Resources/RL-8-Point-Plan-V5.pdf> and a summary video found here: <https://vimeo.com/353200697>

## **Appendix II Transforming Care data table**

Each month, NHS Digital brings together the Learning Disabilities and Autism (LDA) data from the Assuring Transformation (AT) collection and the LDA service specific statistics from the Mental Health Statistics Data Set (MHSDS). The full publication can be found here.

<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

The CBF and Mencap collect key statistics from this data to monitor the progress of Transforming Care and track the use of restrictive practices. There are significant inconsistencies between the AT data set and the MHSDS, which NHS Digital acknowledge and say they are investigating. Original figures are also often retrospectively updated, sometimes months after they are first published. In order to maintain as consistent a comparison over time as possible, the CBF and Mencap:

1. Only use the original figures published
2. Use the AT data set for inpatient numbers
3. The dates used in the table headings refer to the date the data was published, as the AT data set and MHSDS in each release are not for the same month. For example, the January 2021 publication includes the AT data for December 2020 but the MHSDS data for October 2020.

The table below is as accurate as possible given the quality of the raw data we are collecting from. If you would like more information on our larger data collection, please do let us know.

### **Transforming Care key figures from the last 6 months.**

Statistic	Published Aug 2020	Published Sept 2020	Published Oct 2020	Published Nov 2020	Published Dec 2020	Published Jan 2021
AT data	Jul-20	Aug-20	Sep-20	Oct-20	Nov-20	Dec-20
Total Inpatients	2100	2100	2060	2060	2075	2055
Under 18s	225	220	205	200	205	210
18-24	410	415	400	415	405	400
Delayed transfer	115	105	105	100	90	95
Key reason for delayed transfer	Lack of suitable housing (same)					
Ave. Length of stay in inpatient units	2049 days or 5.6 years	2052 days/5.6 years	5.7 years	5.7 years	2041 days/5.6 years	2047 days/ 5.6 years
Admissions	105	80	90	100	95	70
Discharges	135	105	155	125	110	115
Admitted and discharged within the month	15	10	10	10	10	5
MHSD Data	May-20	Jun-20	Jul-20	Aug-20	Sep-20	Oct-20
Total Restrictive Interventions (e.g physical, chemical, mechanical restraint, seclusion, segregation)	5520	3380	4810	4,360	4160	3,590
Under 18	845	620	660	1070	730	520
18-24	1750	1200	1265	1080	945	990
Restrictive intervention reporting						
Independent	6/16	2/14	4/15	3/15	4/14	2/15
NHS providers	27/56	30/58	29/58	27/56	29/57	31/56

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#### **Appendix IV Key issues that need to be addressed in the reform of Mental Health Act**

##### **Summary of current key issues for people with LD/Autism re: Mental Health Act:**

- People with LD/autism can easily meet the criteria for detention where they don't have a serious MH problem but their behaviour has escalated due to lack of the right community support. (Current definition of 'mental disorder' allows this)
- People with LD/autism can get 'stuck' in mental health detention for many years
- Not getting effective assessment or treatment
- Misuse of restrictive interventions
- Lack of meaningful activity/education/exercise/fresh air
- Too often physical health needs not met
- Hard to challenge detention - too often tribunals not working for people with LD/autism:
  - Very easy to meet the current criteria for detention

- Often a vicious circle of inappropriate care in inpatient units leading to challenging behaviour justifying continued detention
- Lack of the right community support in place
- Tribunals limited powers to make local areas provide/develop the right community support to enable discharge
- IMHAs and MHA solicitors don't always understand the needs of people with LD/autism or what good support looks like – which can impact on their effectiveness. MHA solicitors also have a narrow remit which can make it hard to help people get out where local areas unwilling to put in place community support that would enable discharge.
- Tribunals often reluctant to look at treatment in great detail and anyway the current test of 'appropriate treatment' is very broad. Too often, those involved in tribunals do not appear to understand what good support for people with LD/autism looks like and the principles of Transforming Care. (It is very important there is the right LD/autism expertise involved in tribunals and the test of 'appropriate treatment' must reflect up to date learning disability/autism policy eg. NICE guidelines.)