CB-NSG Report Summaries and Recommendations paper

This is a working document

Contents

Key themes from report recommendations:

Below is a table detailing **key recommendations** from reports published over the last 18months. The prevalence of each recommendation, citation in key reports and potential government response are also listed.

Theme	Reports cited	Govt response(s)?
Need to record and better regulate restrictive practices	Cited in ≥4 reports Including: - CQC: Out of Sight - MHA White Paper	DHSC response to CQC: - Accepts recs 'in full or in principle'
Increased accountability to improve safeguarding (across the system, CQC, in hospitals, LAs etc)	Cited in ≥7 reports Including: - CQC: Out of Sight - B. Hollins Review - CBF: Broken - Building the Right Support Evaluation	DHSC response to CQC: - Accepts recs 'in full or in principle' DHSC response to B. Hollins Review: - DHSC is 'in a position to support all … immediate recs' - Helen Whately MP expressed 'strong support for your recs'
Progress/accelerate discharges	Cited in ≥6 reports Including: - CQC: Out of Sight - MHA White Paper - B. Hollins Review	DHSC response to CQC: - Accepts recs 'in full or in principle' DHSC response to B. Hollins Review: - **'**Senior Intervenor role' to address diagnostic backlog - DHSC is 'in a position to support all … immediate recs' - Helen Whately MP expressed

		‘strong support for your rec.s’
LD/Autism training needs to improve (health/social care workers and assessors)	Cited in ≥5 reports Including: - MHA White Paper - B. Hollins Review	DHSC response to B. Hollins Review: - DHSC is ‘in a position to support all … immediate rec.s’ - Helen Whately MP expressed ‘strong support for your rec.s’
Trauma needs to be supported now, and prevented in the future	Cited in ≥3 reports Including: - ‘Tea, smiles …’	**(None found)**

(Please see the extended table below for more information.)

Main table of report summaries and recommendations

Cross-referencing: red text

Key:

PLD/AP: people with a learning disability and/or autistic people

MHA: Mental Health Act

LA: Local Authority

Govt: Government

Rec.s: recommendations

BTRS: Building the Right Support

DHSC: Department for Health and Social Care

REPORT	SUMMARY	REC.S	GOVT RESPONSE	CBF COMMENTS
1) 'Reducing Restrictive Intervention of Children and Young People' – Update of Case study results **CBF / PABSS (Feb 2020)** **HARD COPY**	There is an 'ongoing gap in knowledge and data collection on restrictive interventions taking place in schools.' **Key issues found –** Restrictive interventions Can **seriously negatively impact** children Appear to be used **in most school settings** represented by participants, on multiple occasions Appear to be used for **inappropriate reasons** 'Practices in some schools may not adhere to guidance' – '**abusive practices** are suggested' 'Parents are not always informed about restrictive interventions' 'Recording in schools maybe infrequent and/or inadequate' 'Training may not always result in better practice' Use of restrictive interventions likely to be **widespread across UK**	**Key recs:** 1. **Strengthen the law across the UK** – to safeguard children from restrictive interventions and to prosecute those who use unlawful force against children. 2. **Invest in intervention, prevention and training** in order to support both families and staff to use evidence-based approaches to address challenging behaviour. 3. **Gather more evidence** about what is happening and strengthen safeguarding and accountability. 4. **Fund trauma support** for children and families who require support following restrictive interventions. Rec 1 (similar) in report 4 (govt response), 7 (govt response), 12 (govt response), 18 (no govt response), Rec 2 found in report 16 (no govt response), 28 (no govt response) Rec 3 found in reports 7 (govt response), 19 (no govt response), 21 (govt response), 23, 28 (no govt response) Rec 4 in report 10 (no govt response), 16 (no govt response)		Restraint and seclusion - Challenging Behaviour Foundation Restraint in schools inquiry - Challenging Behaviour Foundation
2) 'Promoting sexual safety through empowerment' **CQC (Feb 2020)** **ASC Sexual Safety +Sexuality Draft.docx (cqc.org.uk)**	'The first step to protecting and supporting people is having a culture that of openness to talk about sexual safety and sexuality.' **Lessons** – People are not always protected from sexual harm or supported to express their sexuality. People are better protected when empowered to speak out about unwanted sexual behaviour and their sexuality	**Key rec.s:** - A lack of awareness in good practice in sexual safety and sexuality can place people at risk of harm - A culture must be developed where people and staff feel empowered to talk about sexuality and raise concerns around safety - As the regulator, we have strong role in making sure that people using services are protected and supported		CQC's sexual safety report - Challenging Behaviour Foundation

	People want to be able to form and maintain safe sexual relationships The impact of people's health conditions on sexual behaviour is not well understood Women, particularly older women, were disproportionately affected by sexual incidents There are some actions that providers can carry out to help keep people safe from sexual harm Concerns about the use of social media, mobile phones and the internet in sexual abuse Joint-working with other agencies is vital to keep people safe	(Study does not include adults in in-patient settings but many findings and rec.s are transferrable)		
3) 'CQC inspections and regulation of Whorlton Hall 2015-2019: an independent review' **CQC – Glynis Murphy (Mar 2020)** **20020218_glynis-murphy-review.pdf (cqc.org.uk)**	'The review noted that **alterations to the way CQC works might have made it possible for the abuse to have been detected**. These alterations include in-depth interviews with service users and families, CCTV, and the interviewing of short-term staff no longer employed by the provider.' (CBF summary)	**Key rec.s**: 1. Prioritising gathering information from people with learning disabilities and families during and between inspections via thorough interviews including the use of reasonable adjustments e.g. talking mats 2. Using information already gathered on services to create a list of 'red flags' for a service at risk of abuse or restrictive practices 3. More flexible inspections when there is a risk identified/continuous Requires Improvement rating i.e. longer and more thorough inspections; reduced need for overwhelming evidence allowing inspectors to go in earlier where there is a concern. 4. More inspections in the evenings and at the weekends including unannounced inspections 5. No longer allowing the registration or		CQC Review Whorlton Hall - Challenging Behaviour Foundation

		expansion of isolated services 6. Taking abuse seriously when it is uncovered and improving reaction to whistleblowing and complaints by recognising that this is probably the 'tip of the iceberg' Rec 4 in report 4 (govt response)		
4) 'Human Rights and the Government's response to COVID-19: The detention of young people who are autistic and/or have learning disabilities' **JCHR (Joint Committee on Human Rights)** **(June 2020)** **The Government's response to COVID-19: human rights implications (parliament.uk)**	'Now that institutions are closed to the outside world as a result of the Covid-19 pandemic, the **risk of human rights abuses are even greater**.' 'Unlawful blanket bans on visits, the suspension of routine inspections, the increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing) mean that the **situation is now a severe crisis**.' 'Claims of unprecedented progress and reports of new taskforces and strategies from those overseeing the detention system sound encouraging but **stand in stark contrast to the evidence we heard from mothers of young people** who are detained within it during the crisis.'	**Key urgent rec.s**: 1)'NHS England must write immediately to all hospitals… stating that **they must allow families to visit their loved ones**, unless a risk assessment has been carried out… and demonstrates that there are clear reasons specific to the individual's circumstances why it would not be safe to do so.' 2)'**Figures on the use of [all] restrictive practices**… detailing any incidences which go beyond 22 hours per day and amount to solitary confinement**, must be published** weekly by the institutions… [and] provided to the Secretary of State for Health and Social Care and reported to Parliament.' 3)'The Care Quality Commission **(CQC) should carry out all their inspections unannounced**; this is particularly important where any allegation of abuse is reported by a young person, parent, or whistle-blower.' 4)'The **CQC must prioritise in-person inspections** at institutions with a history of abuse/malpractice, and those which have been rated inadequate/requires improvement.' 5)'The CQC should set up a telephone hotline to enable all patients, families, and staff to report concerns or complaints during this period.' 6)'The CQC must report on reasons for geographical variation in practice with resultant harmful consequences.'	(Oct 2020): https://www.gov.uk/government/publications/jchr-reports-on-the-detention-of-young-people-with-learning-disabilities-or-autism-government-response 'Protecting the rights of people with a learning disability and of autistic people is a matter of the **utmost importance** to the Government. Rights must be upheld regardless of wider circumstances, no matter how unprecedented.' Govt 'welcomes' the JCHR's recommendations. Refers to the BTRS service model, to be reinforced by the new Autism strategy. In-patient settings must not be a 'last resort' care option for someone when community care is inaccessible/insufficient. Refers to Whorlton Hall review as evidence of govt looking into abuse scandals. Refers to Baroness Hollins'/Oversight Panel's review, plus – all inpatients in long-term segregation will have independent case reviews to assess whether this care is appropriate. Refers to NHS Long Term Plan and its aim to meet Transforming Care targets.	JCHR report during Covid-19 - Challenging Behaviour Foundation Government reply to JCHR - Challenging Behaviour Foundation

		7)'Now, more than ever, **rapidly progressing the discharge of young people to safe homes** in the community must be a top priority for the Government. The recommendations from the Committee's 2019 report must be implemented in full.' 8)'Comprehensive and accessible data about **the number of those who are autistic and/or learning disabled who have contracted and died of Covid-19 must be made available and include a focus on those in detention**, for whom the state has heightened responsibility for their right to life.' Rec 2 (similar) in report 1 (no govt response), 18 (no govt response) Rec 3 in report 3 (no govt response). Rec 7 in reports 12 (govt response), 26 (no govt response), 30 (no govt response)	DHSC is in the process of creating a **Building the Right Support Action Plan,** alongside other departments and families. The plan will clarify who needs to make which changes so that individuals receive the right care. Refers to Autism Strategy – aims to prevent people being admitted in the first place. Refers to the MHA white paper – rec.s here coincide with rec.s in the white paper, which we are addressing.	
5) Fourth annual LeDeR report **Uni of Bristol/LeDeR (Learning Disabilities Mortality Review)** **(July 2020)** **LeDeR_2019_annual_report_FINAL2.pdf**	In 2019, LeDeR were notified of 2843 deaths of people with a learning disability. The most common cause of death was respiratory conditions. Data in the report highlights that people with a learning disability are at a higher risk of dying than the general population.	**Key rec.s:** 1)Continued focus on deaths of children and adults from BAME backgrounds 2)'The standards against which the Care Quality Commission inspects **should explicitly incorporate compliance with the Mental Capacity Act** as a core requirement that must be met by all health and social care providers.' 3)'Adapt (and then adopt) the **National Early Warning Score 2** regionally, such as the Restore2TM in Wessex, to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities.' 4)Consider 'Specialist physicians for people with learning disabilities who would work within the specialist multi-disciplinary teams.' **5)'**Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention,	NHS - Action from learning report (england.nhs.uk) (July 2020) 'LeDeR steering groups to be asked to identify a **BAME lead**. We will explore the inclusion of the needs of people with a learning disability from BAME communities in the revised NHS Equality Delivery System.' 'We will **evaluate the use of NEWS2 and Restore2™** and other early warning approaches to ensure that they meet' needs. 'We will **implement at least one pilot programme using Restore2™,** virtual wards and oximeters to support care staff to identify early signs of deterioration.'	LeDeR report on deaths - Challenging Behaviour Foundation

		diagnosis and management of **aspiration pneumonia**. The outcome of such considerations should be shared with DHSC and NHSE.' Rec 4 (similar) in report 20 (no govt response) Rec 5 (similar) in report 17 (govt response)	'We will train 5,000 paid and unpaid carers in the use of Restore2™ mini' 'We have commissioned a toolkit and guidance from British Thoracic Society around bacterial and aspiration pneumonia.'	
6) 'The Government's response to COVID-19: human rights implications' **JCHR (Sep 2020) The Government's response to COVID-19: human rights implications (parliament.uk)**	'The central aim of the Government's response to the Covid-19 outbreak in the UK has been to protect lives.' 'Many have experienced the widest and deepest set of government interferences with their rights in their lifetimes.' 'Blanket use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices in care homes **constitutes a systematic violation of individuals' rights**. The Government must ensure that their blanket use is not allowed.' Disproportionate impact of Covid-19 restrictions on 'those in detention with autism and/or learning difficulties who were denied family visits during this time.' 'To fulfil the UK's obligations to consider structural issues contributing to Covid-19 deaths, it is very likely that a **public inquiry will be needed**.'	1)The effect of lockdown restrictions on young people with autism and/or a learning disability 'should be subject to a reasoned and transparent proportionality assessment.' 2)'School closures have particularly impacted the rights of those with Special Educational Needs and Disabilities (SEND). The Government must address any barriers that children with SEND may experience regarding their return to school.' 3)'In order to prepare for further waves of Covid-19 or future pandemics, the Government must take steps to ensure that the **allocation and prioritisation decisions and policies relating to the provision of PPE** are evidence-based and non-discriminatory.' 4)'Such a policy should make clear, amongst other things, that **DNACPR [do not attempt cardiopulmonary resuscitation] notices must never be imposed in a blanket fashion by care providers;** the individuals must always be involved in the decision-making process, or where the individual does not have capacity, consultation must take place with persons with an interest in the welfare of the patient.' 5)'The Government must ensure that local authorities and care providers are able to meet increased care and support needs during and resulting from the pandemic.' 6)'It is essential that Liberty Protection Safeguards are introduced in April 2022 and that there is no further delay.'	The Government's Response to the Joint Committee on Human Rights Report The Government's Response to COVID-19 Human Rights Implications (publishing.service.gov.uk) - Govt referred to size of face masks but not how allocation of PPE is being considered for future pandemics. - Govt reinforced that blanket use of DNACPRs is unacceptable to relevant bodies (NHS, health and care providers) and asked CQC to investigate use of DNACPRs - Govt addressed the support for health and care providers to meet increased needs during the pandemic in its Winter Plan. (i.e Infection Control Fund for local authorities and free PPE to providers till March 2021). - Govt will consider conducting an inquiry into deaths when it is the 'right time' - Program for implementing LPSs is a 'priority' for the govt, but the system must be	

		7)'The Government should immediately organise a **quick, interim review into deaths from Coronavirus** to ensure that key lessons are learned as soon as possible, and in advance of any second peak in the Autumn/Winter.' Rec 2 (similar) in report 19 (no govt response) Rec 4 (similar) in report 14 (no govt response) Rec 7 = report 8?	constructed effectively for it to be implemented - November 2020 Govt published guidance on Covid-secure care home visits - Govt published guidance on sending children back to school	
7) 'Out of sight – who cares?' **CQC (Care Quality Commission)** **(Oct 2020)** **Out of sight – who cares? (cqc.org.uk)**	Too many **experiences of restraint, seclusion and segregation** are occurring, in hospital and care settings. People were often admitted with 'no assessment, treatment or discharge plans in place'. Staff were often unable to meet care needs due to a lack of training and support, increasing 'the risk of people being restrained, secluded or segregated'. However, some care providers have been able to 'adapt and tailor' to even the most complex needs and provide care within the community. Staff, families and carers stated that the right care early on can avoid crises and hospital admissions. Covid-19 has intensified concerns for 'delays to people leaving hospital' and restrictions on family visitation. 'Comprehensive oversight of the care provided' and 'accountability for the commissioning of care, is lacking. As a result, people are 'kept in hospital indefinitely and	**Key rec.s:** 1. PLD/AP who may also have a mental health condition should be supported to live in their communities. This means prompt diagnosis, local support services and effective crisis intervention. 2. People who are being cared for in hospital in the meantime must receive high-quality, person-centred, specialised care in small units. This means the right staff who are trained to support their needs supporting them along a journey to leave hospital. 3. There must be renewed attempts to reduce restrictive practice by all health and social care providers, commissioners and others. We have seen too many examples of inappropriate restrictions that could have been avoided. We know in absolute emergencies this may be necessary, but we want to be clear – it should not be seen as a way to care for someone. 4. There must be increased oversight and accountability for PLD/AP who may also have a mental health problem. There must be a single point of accountability to	DHSC (H Whately MP – then Minister for SC) Response (21/7/21): DHSC's response to CQC's 'Out of sight – who cares?: restraint, segregation and seclusion' report - GOV.UK (www.gov.uk) 'I accept in full or in principle all recommendations where the DHSC is identified as the lead department.' Findings/rec.s from this report echo those from the JHRC review on detention of young PLD/AP. Govt actions in response to the JHRC review and MHA consultation 'align' with those necessary to respond to this CQC review. Rights 'must be upheld regardless of wider circumstances, no matter how unprecedented.' BTRS Delivery Board will now 'monitor and drive progress in improving care', and ensure action is taken on rec.s made by CQC. Govt will liaise with local authorities to undertake 'new burdens assessments' and ensure they are 'fully funded' to 'drive improvements in care'.	CQC who cares report - Challenging Behaviour Foundation

	experiencing increasing amounts of restriction.' Fundamental change to how care is 'planned, funded, delivered and monitored' is needed.	oversee progress in this policy area. Rec 3 (similar) in report 1 (no govt response), 12 (govt response), 18 (no govt response) Rec 4 in report 1 (no govt response), 19 (no govt response), 21 (govt response), 23, 28 (no govt response), 30 (no govt response)	CQC should now be the independent regulator for the BTRS Delivery Board. The Board has identified 'priority areas' which align with CQC rec.s from the review. Govt is committed to Oliver McGowan Mandatory Training for 'all health and social care staff'. £1.4 million to develop a standardised training package with HEE and Skills for Care. 'Officials are discussing how we put in place a stronger oversight arrangement and enhance accountability'. 'We can and must achieve this for everyone.'	
8) 'Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020' **PHE (Public Health England) (Nov 2020)** **COVID deaths of people with learning disabilities (publishing.service.gov.uk)**	'LeDeR and CPNS are incomplete sources. The study estimated that only 65% of eligible deaths are reported to LeDeR and 25% of deaths reported to CPNS have learning disabilities status recorded as 'not known'.' 'The number of deaths occurring between the start of February and 5 June reported to LeDeR as possibly or definitely due to COVID-19 represents a crude rate of 240 deaths per 100,000 adults with learning disabilities, 2.3 times the rate in the general population for the same period. The estimated rate, adjusting for the likely level of under-notification, was 369 per 100,000 adults with learning disabilities, 3.6 times the rate in the general population.' 'CPNS recorded 490 deaths of adults with learning disabilities with COVID-19 up to 5 June. This represents a	**Findings cont.d (no rec.s):** 'COVID-19 deaths in people with learning disabilities were spread more widely across the adult age groups than in the general population. The 10 year age band with the largest number of deaths was 55 to 64 years for people with learning disabilities but over 75 for the general population. This reflects the pattern of deaths in previous years, and in 2020 from causes other than COVID-19.' 'COVID-19 increased the number of deaths for people with learning disabilities by a greater margin than for the general population across the adult age spectrum. Age specific COVID-19 death rates per 100,000 population were higher for people with learning disabilities in all adult age groups but by a greater margin in younger age groups.' 'COVID-19 accounted for 54% of deaths of adults with learning disabilities in residential care in this period, slightly less than for people with learning disabilities generally, but still much more than in the general population.' 'COVID-19 accounted for 53% of deaths of adults with learning		Covid-19 related deaths - Challenging Behaviour Foundation

	rate of 192 deaths per 100,000 adults with learning disabilities, 3.1 times the rates for adults without learning disabilities. If people dying with learning disabilities status 'not known' included the same proportion with learning disabilities as those for whom a status was recorded, there would have been 651 deaths of adults with learning disabilities, giving a rate of 254 per 100,000 population, 4 times the rate for adults without learning disabilities.'	disabilities receiving community-based social care. It is hard to comment on the overall scale of deaths in these contexts because the numbers of people receiving care from providers likely to report their deaths is not clear. This level of additional mortality is similar to that seen in residential care.' This report = rec in report 6 actualised		
9) 'CQC inspections and regulation of Whorlton Hall: a second independent report' **CQC – Glynis Murphy (Dec 2020)** **20201215_glynis-murphy-review_second-report.pdf (cqc.org.uk)**	'This report includes a systematic review of the international research evidence in relation to the detection and prevention of abuse in services. The report also reflections upon progress towards the recommendations made in the first phase of the review.'	Key recommendations: 1. Services should not be rated as 'Good' or 'Outstanding' if they have used frequent restraint, seclusion and segregation. 2. Services should not be rated as 'Good' or 'Outstanding' if they cannot show how they support whistleblowing and reporting of concerns. 3. Trialling of the Group Home Culture Scale tool, to evaluate whether it helps inspectors determine which settings have closed cultures. 4. Trialling of the Quality of Life tool to gauge whether it helps CQC move from evaluating process, towards evaluating more relevant service user outcomes. 5. Development of guidelines for when evidence of the quality of care should be gathered from overt or covert surveillance. 6. Implementation of the new registration guide Right Support, Right Care, Right Culture		CQC phase 2, Whorlton Hall - Challenging Behaviour Foundation

10) 'Broken – The Psychological trauma suffered by family carers' **CBF (Dec 2020)** **Broken CBF final report (challengingbehaviour.org.uk)**	'What is not widely publicised or understood is the trauma experienced by the individual [with learning disabilities and/or autistic people] and their family in their daily lives, **caused by interaction with the systems of education, health and social care**. These systems are meant to support families to care for their loved one with a learning disability, yet we know that this is not always the case.' 'This survey shows that the **trauma of family carers of children and adults with a learning disability and/or autism is multi-layered and complex,** with many families experiencing a wide range of trauma and **receiving little to no support for this**. Families also experience an additional burden by needing to independently search for their own support.' 'Many family carers actively seek their own support at great emotional and financial cost. **When trauma does occur there needs to be a pathway in place with a range of support types available that can cater for individual needs**. The number of people who responded to a long survey on a very difficult topic highlights the extent of unmet need. A lack of research evidence suggests that more attention should be given to this area.'	**Rec.s:** **1)'**The system should not traumatise families in the first place. The system, including commissioners, local authorities, clinicians, support staff, professionals and senior officials must recognise and address the risk factors for trauma that families have identified in this survey.' - **Specifically –** Education, health and social care departments and bodies must work together in a joined-up fashion, to ensure that support continues to be provided for children and young people with learning disabilities and/or autism **2)'**When trauma does occur, there needs to be a pathway in place to offer individuals and their families a person-centred trauma support package. This should not be at a financial cost to the families.' - **Specifically –** every local authority must acknowledge the need for, and co-produce with families, a trauma pathway and invest in support for those experiencing trauma **3)'**Develop more widely available specialist trauma support for immediate effect to help those families who are already traumatised.' - **Specifically –** urgently increasing funding for trauma counsellors and professionals Recs found in report 1 (no govt response), 16 (no govt response), 28 (no govt response), 30 (no govt response)		
11) Pandemic research **Dimensions**	'93% of people with learning disabilities or autism feel more isolated from society due to the pandemic'			

(Dec 2020) #CovidLeadersList: People with learning disabilities and autism call for greater understanding and representation following the pandemic - Dimensions (dimensions-uk.org)	'76% have been made to feel like they do not matter, compared to other people' '75% worry that after the pandemic, they won't get the same opportunities they had before' '97% feel government should do more to address their specific needs' 97% say it's important that more people understand how coronavirus has affected people with learning disabilities and autism'			
12) 'Reforming the Mental Health Act' – white paper **(Jan 2021) Reforming the Mental Health Act (publishing.service.gov.uk)**	'We welcome the considered work and in-depth engagement undertaken by the [MHA] Review. We accept, and **we will take forward, the vast majority of its recommendations** for change.' 1)'**Four principles**, developed by the Review and in partnership with people with lived experience, will guide and shape our approach to reforming legislation, policy and practice. These are: •Choice and autonomy – ensuring service users' views and choices are respected • Least restriction – ensuring the Act's powers are used in the least restrictive way • Therapeutic benefit – ensuring patients are supported to get better, so they can be discharged from the Act • The person as an individual – ensuring patients are viewed and treated as individuals'	**Commitments cont.d:** 2)'We will seek to **revise and clarify the detention criteria for civil sections of the Act**, so that patients are only detained when it is appropriate and where there is demonstrable therapeutic benefit to the patient.' 3)'We will provide **high quality, tailored support** to everyone detained under the Act.' 4)'We will take steps to improve how the Mental Health Act works for people with a **learning disability and autistic people**.' (Altering definition of 'mental disorder') 5)'We will drive a **renewed focus on improving quality of care**, through improvements to the patient environment, training for the existing and new workforce, and through a dedicated Quality Improvement Programme to promote practical and cultural change across the system.' 6)'We are **improving access to community-based mental health support,** including crisis care, to avoid the need for detention and admission.'	DHSC (July 2021) Reforming the Mental Health Act: government response (web accessible) (publishing.service.gov.uk) Guiding '**principles**' – 'we will continue to work to take forward the principles' **Detention criteria** - 'Wide support for reforming the detention criteria as set out in White Paper…Respondents have also raised some important considerations, which we will bear in mind as we develop the Bill' 'We will continue to work with stakeholders to establish what contents are critical to ensuring Advance Choice Documents effectively inform patients' care and treatment' **Making care and treatment plans statutory** – 'We will seek to ensure that the new statutory Plan takes into account existing requirements around care planning, that it	MHA White Paper Consultation - Challenging Behaviour Foundation

		Rec 5 (similar) in 20 (no govt response), 21 (govt response), 23, 28 (no govt response), 29 (no govt response), 30 (no govt response)	encourages joint-working, and that there is flexibility regarding the contents of the Plan so that it is truly patient led' **Advocacy** - 'We will take forward legislative changes to extend eligibility of IMHA services to all mental health inpatients, including informal patients, and to add the proposed additional rights and powers relating to supporting service users with advance choice and care planning etc. We will also consider the requirements needed for an opt out service.' **MH Definition change to exclude LD/Autism** - 'We will continue to consider the best way to take forward these reforms' **Criminal justice system** – 'We recognise the importance of ensuring that reforms to the Act for people with learning disabilities and autistic people strike an appropriate balance in terms of application to the criminal justice system. We will therefore commit to exploring this issue further, including through an expert group.' 'We will continue to consider the options for pooled budgets' Govt will continue to consider strengthening the role of the CQC to monitor use of the MHA.	
13) 'Union of Equality: European Commission presents Strategy for the Rights of Persons with Disabilities 2021-2030'	'To ensure their full participation in society, on an equal basis with others in the EU and beyond, in line with the Treaty on the Functioning of the European Union and the Charter of Fundamental Rights of the European Union, which establish equality			

EC (European Commission) **(Mar 2021)** **Strategy for the Rights of Persons with Disabilities 2021-30 (europa.eu)**	and non-discrimination as cornerstones of EU policies.' **10 year strategy focusing on 3 main areas** – - **EU Rights** – a European Disability Card to be created for all EU countries which recognise disabled rights. - **Independent living and autonomy** – European Commission will develop guidance and launch an initiative to improve social services, particularly those in the community. - **Non-discrimination and equal opportunities**			
14) 'Protect, respect, connect – decisions about living and dying well during COVID-19' **CQC** **(Mar 2021)** **Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission (cqc.org.uk)**	'Our review, which took place between November 2020 and January 2021, looked **at how DNACPR decisions were made in the context of advance care planning, across all types of health and care sectors**, including care homes, primary care and hospitals.' **Findings –** 'If people and health and care staff are not fully informed about advance care planning, or given the opportunity and enabled to discuss DNACPR decisions in a person-centred way, there is a clear risk of inappropriate decision making and a risk of unsafe care or treatment. It also raises concerns that people's human rights and rights under the Equality Act	**Key rec.s** – 1) 'DNACPR decisions need to be recognised as **part of wider conversations about advance care planning** and end of life care, and these decisions need to be made in a safe way that protects people's human rights. 2) People must always be at the centre of their care, including advance care planning and DNACPR decisions. 3) Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions, that supports their human rights. 4) Clinicians, professionals and workers must have the knowledge, skills and confidence to speak		

	2010 had not been considered or were at risk of being breached.' 'There is a need for a consistent national approach to advance care planning and DNACPR decisions, and a consistent use of accessible language, communication and guidance to enable shared understanding and information sharing among commissioners, providers and the public.' 'There is an urgent need for regional health and care systems, including providers, clinical commissioning groups and patient representative bodies, to improve how they assure themselves that people are experiencing personalised, compassionate care in relation to DNACPR decisions.'	with people about, and support them in, making DNACPR decisions. 5) People, their families and representatives need to be supported, as partners in personalised care, to understand what good practice looks like for DNACPR decisions. 6) There must be comprehensive records of conversations with, and decisions agreed with, people, their families and representatives that support them to move around the system well. 7) Integrated care systems need to be able to monitor and assure themselves of the quality and safety of DNACPR decisions Recs (similar) in report 6 (govt response)		
15) 'Coronavirus and the social impacts on disabled people in Great Britain: February 2021' **ONS (Office for National Statistics)** **(April 2021)** **Coronavirus and the social impacts on disabled people in Great Britain - Office for National Statistics (ons.gov.uk)**	**Findings:** In **February 2021**, among people aged 16 years and over in Great Britain: A larger proportion of disabled people (78%) than non-disabled people (69%), said they were worried (very or somewhat) about the effect that the coronavirus (COVID-19) was having on their life. Disabled people more often indicated coronavirus had affected their life than non-disabled people in ways such as their health (35% for disabled people, compared with 12% for non-disabled people), access to healthcare for non-coronavirus related issues (40%	**Findings cont.d:** Among people who indicated coronavirus affected their well-being, disabled people more frequently than non-disabled people specified that the coronavirus was making their mental health worse (46% for disabled people and 29% for non-disabled people), they are feeling like a burden on others (25% and 10%), they are feeling stressed and anxious (67% and 54%) or they are feeling lonely (49% and 37%). Disabled people had on average poorer well-being ratings than non-disabled people across all four well-being measures (life satisfaction, feeling that things done in life are worthwhile, happiness and anxiety). For both disabled and non-disabled people, life satisfaction and happiness ratings were poorer in February 2021 than in September 2020; compared with a period prior to the coronavirus pandemic (in the year ending June 2019), all well-being		

	compared with 19%), well-being (65% compared with 50%) and access to groceries, medication and essentials (27% compared with 12%). Feeling stressed or anxious, feeling bored and feeling worried about the future were the well-being concerns most frequently cited by both disabled (67%, 62% and 57% respectively) and non-disabled people (54%, 63% and 52% respectively) in February 2021.	ratings of disabled and non-disabled people remained poorer in February 2021. Disabled people tended to be less optimistic than non-disabled people about life returning to normal in the short term: around a fifth (20%) of disabled people compared with over a quarter (27%) of non-disabled people thought that life will return to normal in less than six months. Positive sentiment towards the vaccine was high among both disabled and non-disabled people: 94% of both disabled and non-disabled people reported they had now either received at least one dose of a coronavirus (COVID-19) vaccine, were awaiting one, or would be likely (very or fairly likely) to have a vaccine if offered.		
16) 'Tea, smiles and empty promises' **Winterbourne View families (May 2021)** **Tea-smiles-and-empty-promises-family-stories.pdf (challengingbehaviour.org.uk)**	A group of families with relatives who were at Winterbourne View are publishing a collection of family stories 'Tea, smiles and empty promises', reflecting on the decade since BBC Panorama exposed abuse at Winterbourne View hospital and the lack of progress in Transforming Care. Several other families with relatives with learning disabilities and/ or autism have also contributed their experiences of support for their relative.	'Tea, smiles and empty promises' calls for **urgent action** to: **1)** Avoid traumatising children and adults with learning disabilities and autistic people in the first place by **providing the right support at the right time in the right place** 2) A focus shift **to early intervention** and preventing admission/ readmission, as well as getting people out of inpatient units 3) Provide appropriate **trauma support** for individuals and their families Rec 2 found in report 1 (no govt response), 3 (no govt response), 16 (no govt response), 28 (no govt response), 30 (no govt response) Rec 1,3 found in report 1 (no govt response), 10 (no govt response), 30 (no govt response)		

17) Fifth annual LeDeR Report **Uni of Bristol/LeDeR (June 2021)** **LeDeR-bristol-annual-report-2020.pdf (england.nhs.uk)**	LeDeR have been notified of **9,110 deaths** of people with a learning disability in England between 1st January 2018 and 31st December 2020. The report states that in 2020 LeDeR were notified of 3,531 deaths with the most common cause of death being respiratory conditions. **The most common condition-specific cause of death for adults with learning disabilities in 2020 was COVID-19.** It has already been established that people with learning disabilities are at greater risk of premature and avoidable deaths than the general population and the report released yesterday highlights this continuing inequality. **The combination of underlying health conditions and barriers to accessing timely healthcare have increased those risks during the current pandemic.**	Significant concerns highlighted in the report include: • 42% of people who died in 2020 didn't receive care that met good practice standards. • Adults and children from Black/African/Caribbean/Black British ethnic groups, and mixed/multiple ethnicities had a higher proportion of treatable medical causes of death than people from other ethnic groups. Investigating aspiration pneumonia – (similar) rec in report 5 (govt response)	NHS NHS England » LeDeR Action from Learning report 2020/21 (June 2021) – NHS actions post report 'Since May 2020 the NHS has put out the numbers of people with a learning disability who died after getting coronavirus.' 'Set up **online wards to check on people at home** or in a care home because they have coronavirus' '**Trained seven thousand carers** to help them notice when the person they care for is starting to get ill and report it quickly.' 'Worked to make the NHS 111 telephone service easier to use for people with a learning disability and autistic people.' 'Held monthly online meetings with GPs to make sure their learning disability registers included people at high risk from coronavirus.' 'Put out a Grab and Go Guide – which is a short **hospital passport'** 'Put out a guide for NHS workers about supporting people with a learning disability and autistic people' 'A guide on pneumonia and aspiration pneumonia will be written by the British Thoracic Society.' 'GPs got an easy read letter they could send to their patients with a learning disability about the flu vaccine.' 'GPs were asked to offer the flu vaccine to patients with a learning disability when they go to the	LeDeR report 2020 - Challenging Behaviour Foundation

			surgery for an Annual Health Check.'	
18) 'Restraint in schools inquiry: using meaningful data to protect children's rights' **EHRC (European Human Rights Commission)** **(June 2021)** **Restraint in schools inquiry: using meaningful data to protect children's rights (equalityhumanrights.com)**	**Findings:** Currently no mandatory requirement that schools **monitor/record** use of restrictive interventions. Restrictive interventions can have a **seriously negative** impact on children. Report highlights absence of data/guidance inhibits schools from effectively monitoring and understanding use of restrictive interventions. Also prevents those doing inspections from assessing a school's performance regarding restraint. Almost half of schools stated that clearer, national definitions of restrictive practices would help teachers understand restraint and how to use, avoid and record it.	**Key rec.s:** 1) National recording/reporting requirements to improve transparency, trust and knowledge of how restrictive practices are used. 2) Such recording will encourage restraint to be used safely and only as a last resort. Recs 1,2 (similar) in report 1 (no govt response), 4 (govt response), 7 (govt response), 12 (govt response)		
19) 'SEND: old issues, new issues, next steps' **Ofsted** **(June 2021)** **SEND: old issues, new issues, next steps - GOV.UK (www.gov.uk)**	**2009 SEND [special educational needs and disability] report** – 'called for greater ambition for children and young people with SEND. It cited a culture of low expectations and a system that too often failed to deliver what children and their families needed.' 'The **pandemic** has highlighted and intensified these issues.' **New issues found**: Visiting local areas, schools, early years settings, children's service providers and further education and skills providers…	**Next steps**: Govt policy has begun addressing longstanding problems but there is a 'long way to go'. 1)'Clarity about **who should provide** what at a local level, greater coordination of services and clearer accountability for all partners, all leading to more effective multi-agency working, are key.' '**Stronger cross-departmental working** between relevant government departments is likely to be an important factor in making effective multi-agency working happen, particularly for children and young people with the most complex needs. It is **not acceptable for parents to be the driving force** in ensuring that agencies work together.'		Restraint in schools inquiry - Challenging Behaviour Foundation

	‘Children and young people with SEND were often **not receiving education**.’ Some ‘**important healthcare’ had ‘ceased’**, leaving children and young people ‘immobile’ and ‘sometimes in pain’. Lack of speech and lang therapy/communication devices left some children ‘**unable to communicate properly’**. **Respite** provision for families was often not available. Parents/carers frustrated and exhausted. Many children/YP with complex needs **did not attend school** during first lockdown (many didn’t have an EHCP). Many schools said they could not meet their personal/health needs, in light of the pandemic, some children/YP were taught remotely (others struggled with this), in September 2020 if they went back to school their curriculum was often reduced. Greater concern from parents in Spring 2021. **Continuing issues** – ‘a lack of health and care provision, insufficient provision from schools, long waiting times for assessments’. The success of local areas to provide support to children/YP with SEND during the pandemic ‘appeared closely related to their quality of work with families before the pandemic’, and the extent to which 2014 reforms (C&Fs Act) were implemented.	Education ambitions for children/YP with SEND must improve. ‘SEND provision **in mainstream settings** must be part of a continuum of provision, not a ‘school within a school’. Moreover, it is crucial to recognise that for many children and young people, their needs change over time. Provision must adapt accordingly.’ ‘We must strengthen the quality of the curriculum and teaching in all education settings as the first step in meeting children and young people’s needs. This is particularly important in relation to the teaching of language and early reading. **No child should be labelled as having SEND because of weak education provision**.’ ‘The need for a tightly coordinated, well-led set of changes across education, health and social care, with the aim of securing the very best provision and outcomes for children and young people with SEND, **could not be clearer**.’ Recs (similar) in report 6 (govt response) Rec 1 (similar) in reports 2 (no govt response), 7 (govt response), 21 (govt response), 23, 28 (no govt response), 30 (no govt response)		

	Children/YP with SEND 'are now even more vulnerable than they were before.' Missing out on education/health care with a 'potentially permanent impact'. Safeguarding has been impacts, needs un-identified and assessed and transitions to adulthood interrupted.			
20) 'The treatment of autistic people and people with learning disabilities' – fifth report of 2021-11 **HSCC (Health and Social Care Committee)** **(July 2021)** **Treatment of autistic people and individuals with learning disabilities (parliament.uk)**	**It is a 'scandal' that issues relating to Winterbourne View have not been resolved.** Persistent 'lack of adequate community provisions' means PLD/AP are placed in in-patient facilities. PLD/AD 'treated as if their condition were an illness rather than a fundamental part of their identity'. Actions 'taken by govt to date are not sufficient for the scale of this issue', which requires the 'swift implementation of the tangible rec.s' in this report. Level of **community provision** – 'totally inadequate', greater funding is required to increase provision capacity, train skilled staff and integrate provisions in local services, to avoid admission to in-patient facilities. NAO found the 'absence of a mechanism for **pooling resources** to build sufficient capacity in the community' is a barrier to greater community provision. Denying PLD/AP 'independent, free and fulfilled lives in the	**Key rec.s** – 1)DHSC to provide a **complete financial assessment** of the cost of transferring all PLD/AP in in-patient facilities to community provision, alongside an assessment of joint NHS/LA funded community provision for **all** PLD/AP. 2)DHSC must redesign financial incentives for LAs to 'offload' PLD/AP to in-patient facilities. **3)Trieste model** to be implemented. 4)All long-term admissions banned. 5)PLD/AP with a severe comorbidity to have safeguards in place post-3-month stay at an in-patient facility. 6)Remove autism/LD from definition of 'disorder' in MHA. 7)No admission to facilities with 'inadequate' CQC rating. **8)ATUs closed within 2 years** and replaced by person-centred, community focused care. 9)All staff involved in treatment of PLD/AP must be **trained in person-centred care** planning (ICSs to ensure this training is mandatory). 10)Govt to analyse **speed of diagnosis** and set targets for early diagnoses by end of financial year 2021-22. 11)Establish **the 'Intellectual Disability Physician'** as a new professional discipline.		H&SCC report published - Challenging Behaviour Foundation

	community' is violating their human rights. We need action, not more reviews. BTRS Board seems to have no 'clear plan for improving community provision to prevent admissions.	12)Govt/NHSE pool financial and workforce resource to carry out **independent reviews of all deaths of PLD/AP in in-patient and community settings**, and structure review so that learning is disseminated 'across the system with clear actions to follow'. Rec 11 in report 5 (govt response) Rec 10 (similar) in report 4 (govt response), 12 (govt response), 21 (govt response), 26 (no govt response), Rec 9 (similar) in report 12 (govt response), 21 (govt response),		
21) 'Thematic review of the Independent Care (Education) and Treatment Reviews' **(July 2021) Thematic Review of the Independent Care (Education) and Treatment Reviews - GOV.UK (www.gov.uk)**	Identifying the **common concerns and issues relating to the care** and treatment of PLD/AP in **long-term segregation** (LTS).' **Findings** – For most individuals reviewed, 'segregation was being used as a response to challenging behaviour in the absence of the right therapeutic care and environment.' Mixture of 'home like', 'acceptable' segregation environments within hospitals, whilst many lacked facilities and comfort. Issues highlighted are likely to affect those in in-patient facilities who aren't segregated. The IC(E)TRs questioned 'the suitability of a psychiatric hospital environment to properly assess and care for PLD/AP, and particularly the lack of autism friendly environments [considered a reasonable adjustment].'	Oversight Panel's **improvement areas** – 1)To improve substantially the quality of diagnosis, treatment and care in hospitals 2)To commission skilled, safe, kind and appropriate person-centred support 3)To ensure there is accountability for action, particularly by commissioners 4)To listen to patients and families, put them at the centre of care-planning and ensure skilled and appropriate representation and advocacy 5)To make money work 6)To continue to provide oversight and independent scrutiny Consider finding that restrictive practices were 'an aggravating factor for aggressive or destructive behaviour, particularly for people with autism.' These are recurring issues and rec.s and 'require urgent and immediate action.' Rec 1 (similar) in reports 7 (govt response), 20 (no govt response) Rec 2 (similar) in reports 12 (govt response) 20 (govt	DHSC Response (21/7/21): Letter from Helen Whately MP, the Minister of State for Care to Baroness Hollins, Chairperson of the Independent Care (Education) and Treatment Review - GOV.UK (www.gov.uk) '… **strong support** for your rec.s and call for urgent and immediate action.' (See Annex A) - Annex A: DHSC's responses to the Oversight Panel's recommendations - GOV.UK (www.gov.uk) DHSC is 'in a position to support all of the immediate actions in your interim report.' DHSC/NHSE developing a pilot 'Senior Intervenor role', to address 'diagnostic backlog' (and reduce unnecessary segregation in in-patient facilities), and 'support intervention' (i.e transfer to appropriate community/less restrictive settings) to prevent escalations into crises. '…strongly support' (and DHSC/NHSE/CQC will consider proposals to	Inhumane conditions in ATUs - Challenging Behaviour Foundation

	Examples of better practice were 'rare'.	response), 23, 28 (no govt response), 29 (no govt response), 30 (no govt response) Recs 3, 6 (similar) in reports 1 (no govt response), 7 (govt response), 10 (no govt response), 19 (no govt response), 23, 28 (no govt response), 30 (no govt response) Rec 5 (similar) to report 20 (no govt response).	strengthen) IC(E)TRs for everyone in LTS. B. Hollins should consider how Panel's rec.s/findings feed into/support the BTRS Delivery board and wider governance.	
22) 'Institutionalising parent carer blame' **Cerebra/Uni of Leeds (July 2021)** **Final-Parent-Blame-Report-20-July-21-03.pdf (cerebra.org.uk)**	Report investigating – 'the experiences of disabled children and their families of the **process by which their needs for care and support are assessed** by children's services authorities in England.' **Findings** – 'National and local social care policies in England create a default position for those assessing disabled children, that assumes parental failings.' ''Working Together 2018' is not fit for purpose and arguably unlawful.' It 'fails to address the distinct assessment and support needs of disabled children for whom there is no evidence of neglect or abuse.' ''Working Together 2018' contains no requirement that those assessing the needs of disabled children have any expertise or experience in a particular condition, so that the needs of the child are accurately identified.'	**Urgent action rec.s** – 1. Separate statutory guidance must be issued to address specific needs of disabled children/families in the assessment, eligibility and care support planning process – 'Working Together' is not fit for purpose. 2. The new statutory guidance should require assessments of disabled children/families be undertaken by assessors who, through training and experience, have the necessary knowledge and skills of the particular condition. 3. There is a strong case – in the short term at least – for local assessment protocols to be abandoned and replaced by new statutory guidance. In any event, these protocols should cease to apply to disabled children/families (for which there is no cogent evidence of neglect or abuse). Rec 2 (similar) in reports 2 (no govt response), 7 (govt response), 20 (no govt response).		Institutionalising Parent Carer Blame - Challenging Behaviour Foundation
23) The National Autism Strategy for Autistic People,	Strategy envisions what the 'Govt wants autistic people and their families' lives to be like in 2026'.	The '**three enablers**' required to deliver the strategy by 2026 – 1)Improve research, innovation and examples of best practice		

Children and Young People 2021 to 2026 **(July 2021)** **The National Strategy for Autistic People, Children and Young People 2021 to 2026 | Local Government Association**	It includes the implementation plan for year one, which will be refreshed yearly with renewed government commitments to achieve strategy aims. Year one **implementation plan funding** – £74.88 million involving: - £40 million to NHS Long Term Plan - £31 million to 'build the right support in the community' - £25 million invested into building capacity of 'seven-day specialist multidisciplinary and crisis services' for PLD/AP **Priority areas for year one** – Improving **understanding and acceptance** of autism Improving autistic children and young people's **access to education**, and supporting **positive transitions into adulthood** Supporting more autistic people into **employment** Tackling health and care **inequalities** for autistic people Building the right **support in the community** Improving support within the **criminal and youth justice systems**	2)Improved data collection and reporting to drive system improvement 3)Strengthened governance, leadership and accountability **(Year one funding – more info)** 4)£15 million invested into 'keyworker pilots and early-adopter sites' to support children with the most complex needs in in-patient settings 5)£600,000 to train educational staff 6)£600,000 for the extension of the early-identification programme developed in Bradford 7)£180,000 for understanding autism campaign. Rec 3 (similar) in reports 7 (govt response), 10 (no govt response), 19 (no govt response), 21 (govt response). Rec 5 (similar) in report 12 (govt response), 20 (govt response), 21 (no govt response).		
24) National Disability Strategy	**Strategy vision**: 'to transform the everyday lives of disabled people' by levelling up 'opportunity at every stage of disabled	**Part 3** - Commitments from Departments – (key selection) **FIRST YEAR:** **1)** Consult on introducing workforce reporting for		NAS response: Government publishes National Disability Strategy (autism.org.uk)

(July 2021) **National Disability Strategy - GOV.UK (www.gov.uk)** **National-Disability-Strategy-Headlines-2021.pdf (vivocarechoices.co.uk)**	people's lives' and 'in all areas of disabled people's lives'. The strategy is rooted in everyday experience of disabled people. **Part 1** – immediate action focusing on: 'Rights and perceptions', housing, transport, jobs, education, shopping, leisure, public services. **Part 2** – including disabled people in policymaking and service delivery – Empower people by promoting fairness and equality of opportunity To promote inclusive/accessible services from the outset to avoid disabling experiences Support independent living Increase participation of disabled people in service/policymaking and delivery Work across 'organisational boundaries' to respond to complex issues affecting disabled people.	businesses with more than 250 staff on the number of disabled people they employ. **2)** Launch a new online advice hub for both disabled people and employers to provide information and advice on disability discrimination in the workplace, flexible working and rights and obligations around reasonable adjustments. **3)** Increase the accessibility requirements for new homes and adapt existing homes. **4)** Develop a UK-wide campaign to increase public awareness and understanding of disability. **5)** Consider how to support disabled people standing for public office and those who hold public office. **Post-Year 1, Govt aims to:** **6)** Ensure fairness and equality. **7)** Consider disability from the start. **8)** Support independent living. **9)** Increase participation. **10)** Deliver joined up responses. Rec 4 (similar) in report 23		
25) **Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK | BMJ Open**	'This study explores the hospital journey of patients with intellectual disabilities (IDs) compared with the general population after admission for COVID-19 during the first wave of the pandemic (when demand on inpatient resources was high) to identify disparities in treatment and outcomes.' **Findings:** **'**Subjective presenting symptoms such as loss of taste/smell were less frequently reported in ID patients, whereas	**Findings cont.d:** **'**ID patients were admitted with higher respiratory rate… and were more likely to require oxygen therapy (35.1% vs 28.9%). Despite this, ID patients were 37% … less likely to receive noninvasive respiratory support, 40% … less likely to receive intubation and 50% … less likely to be admitted to the ICU while in hospital.' 'They had a 56% increased risk of dying from COVID-19 after they were hospitalised and were dying 1.44 times faster compared with controls.' 'There have been **significant disparities in healthcare**		

Unknown (Aug 2021)	indicators of more severe disease such as altered consciousness and seizures were more common.'	between people with ID and the general population during the COVID-19 pandemic, which may have contributed to excess mortality in this group.'		
26) Cawston Park Serious Case Review **M. Flynn and Norfolk Safeguarding Adults Board (Sept 2021)** **SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf (norfolksafeguardingadultsboard.info)**	**Key failings:** **CPAP machines** for Joanna and Ben were not being used consistently (against medical advice). Joanna was meant to use CPAP machine at night but according to review CPAP was only used 29 nights in the last 209 nights of her life. Ben was also recorded not using CPAP on 115 occasions. No clear attempt by staff to desensitize them to CPAP. **Weight gain**. Both Joanna and Ben were obese and according to the review seems there were failing in looking after their weight and diet. Ben's mother comments on this in her statement. Lack of record keeping and knowledge about patients' **pre-hospital lives.** Lack of timetabling and patients **participating in activities**. **Lack of staff medical response and CPR by staff**, some staff did not have up to date first aid training. Review highlights issues with overuse of restraint, seclusion and sedative medication.	**Key rec.s:** **1)'**Norfolk's SAB should write to **the Law Commission proposing a review of the current legal position of private companies, their corporate governance and conduct** in relation to services for adults with learning disabilities and autism.' **2)'**Norfolk and Waveney CCG and Norfolk ASSD should review their commissioning arrangements to embrace "**ethical commissioning".'** 3)'NHS –England should ensure that (i)all placing CCGs are proactive in ensuring that they have up-to-date knowledge about the services they commission and how these are experienced.' 4)'Norfolk's SAB should make representation to the Department of Health and Social Care to ask what additional rights and **protections will be afforded to adults with learning disabilities and autism** who become vulnerable to detention in the same clinical settings under the Mental Capacity Act.' 5)'Norfolk's SAB should share this review with NHS –England since it was responsible for Jon's placement. NHS –England and the CCGs responsible for placing people at Cawston Park Hospital should visit services, host reviews and ask questions' 6)'NHS England is invited to **bring forward evidence of strengthened mechanisms** for: discharge dates; the stability of accommodation within a service; close attention to an inpatient's physical health needs and experiences, their mental health needs and experiences, and the service's track record in addressing these.' 7)'To maintain public confidence, **CQC may wish to confirm** (i)that it has no remit to determine whether patients should remain in such services, not least since this conflicts with national policy; and (ii) what specific actions it proposes to take in relation to locked wards in specialist hospitals and units.' 8)'Norfolk and Waveney CCG and the County Council should rebalance responsibility for Norfolk citizens away from "medical led admissions and social care discharges." **The reform of the Mental Health Act (1983)should anchor discussions and agreements between these public authorities concerning ethical commissioning**.'	No formal written response yet.	Cawston Park Serious Case Review - Challenging Behaviour Foundation

		9)'The taboo of addressing the **racism of people with cognitive impairments** remains to be explicit and made visible in all services. Norfolk's SAB should begin a process of (i) gathering the efforts and experiences of the county's service providers in challenging racism and racist stereotyping and (ii) convening "world café" conversations[116] with providers and other interested people, including those at the sharp end of injustice.' Rec 6 (similar) in report 4 (govt response), 12 (govt response), 21 (no govt response), 30 (no govt response) Rec 8 see report 20.		
27) State of Care Report **CQC (Oct 2021)** **State of Care | Care Quality Commission (cqc.org.uk)**	**Key findings:** **People's experiences of care:** 'We have previously highlighted the ongoing issues that people from some groups have faced in accessing and receiving high-quality care. Over the last year, the pandemic has further exposed and exacerbated these inequalities.' 'People with a learning disability have faced increased challenges as a result of the pandemic.' 'The strain on carers has intensified. Carers UK estimated in June 2020 that an additional 4.5 million people had become unpaid carers since the pandemic began.' **Flexibility to respond to the pandemic:** 'GP practices had to rapidly move to a more remote model of care in the pandemic – this was welcomed by many people needing GP care, but it did not benefit everyone and some struggled to get the appointments they wanted.'	**Key findings continued:** **(No rec.s)** **Ongoing quality concerns:** 'Through our reviews of high-risk mental health services, we are concerned that people continue to be put at risk in a small number of services where there are warning signs of closed cultures.' 'While services have largely maintained levels of Deprivation of Liberty Safeguards during 2020/21, they need to have a continued focus on people subject to a deprivation of liberty. We continue to have concerns about delays in authorisations, which mean that individuals are deprived of their liberty longer than necessary, or without the appropriate legal authority and safeguards in place.' **Challenges for systems:** 'There was a lack of integration of adult social care providers into system-level planning and decision-making.' 'Workforce planning is a major priority and challenge for local systems and providers. Recruitment and staff retention continue to be severe problems.' 'In adult social care, the situation is serious and deteriorating. There must be a sharp focus on	LGA response: LGA responds to CQC State of Care report | Local Government Association 'Responding to the Care Quality Commission's annual State of Care report, Cllr David Fothergill, Chairman of the Local Government Association's Community Wellbeing Board, said:' "Our incredible social care workforce has made an enormous contribution throughout the pandemic to provide vital care and support, despite facing immense challenges. "As this important report states, our care staff are depleted in number, leaving those remaining exhausted and working at maximum capacity. Losing them to other roles elsewhere will just compound problems for already overstretched services, which is likely to lead to even greater levels of unmet need. All of this will impact on the ability of people of all ages who draw on care and support, to live the life they want to lead. "Urgent action is needed as we approach winter to tackle the recruitment and retention crisis, including on staff pay, conditions, skills, training and development.	CBF response to CQC State of Care Report 2021 - Challenging Behaviour Foundation

	'Access to NHS dental care was an issue since before COVID-19, and there are clear signs that this has been compounded by the pandemic.'	developing a clearly defined career pathway and training, supported by consistent investment that will enable employers to attract and retain the right people.'	"The Spending Review and forthcoming white paper must set out how immediate and short-term pressures in social care will be addressed, involving councils, care workers and those with lived experience, if we are to build back better and develop a care and support system fit for the future."'	
28) Building the Right Support Evaluation Report **NHSE (Completion date, Sept 2019, Publication date, Nov 2021)** **Evaluation of Building the Right Support: Final Reports | The Strategy Unit (strategyunitwm.nhs.uk)** Key findings/rec.s: **B0952 - Report - Independent evaluation of Building the Right Support - Learning report.pdf (strategyunitwm.nhs.uk)**	**Key findings:** *2.1 Developing community provision through partnership working (p3-4)* Some Transforming Care Partnerships (TCPs), have improved their community provision for children, young people and adults with LD. 'The evaluation found that the most effective local commissioners had the skills and time to co-produce services; and were able work effectively across health, social care and housing to personalise care and support at the individual level.' 'Some case study TCPs such as Dorset had also worked closely with providers, people and families to develop improved procurement frameworks for care and support for people with the most complex needs.' *2.2 Developing the workforce in the community (p5-6)* There is still an urgent need to continue to build both a specialist workforce in the community that can support people with complex needs and their families / carers to	**'Ideas for the future'** ■ 'There should be an emphasis both nationally and locally on achieving fully integrated commissioning, spanning housing and community support.' (p17) ■ 'Commissioning plans should reflect the national emphasis on personalisation, giving priority to tools such as PHBs, personal budgets, individual service funds and personalised care and support planning across the whole life course (not just when a new 'package of care' is being sought). Family carers should also be considered as part of care and support plans for people in the community.' (p17) ■ 'Commissioners should improve collaboration with (and among) key providers that deliver, or might be able to deliver, care for people so that the whole system is able to support them better.' (p17) ■ 'Setting and monitoring quality standards for community support should be a priority for local partners; these should be co-produced and led by people and families.' (p17) ■ 'There is a clear need for workforce strategies and implementation planning (nationally and locally) that include social care as well as health. Building on the Learning Disability Improvement Standards, a workforce strategy should clearly define what multiagency professionals and capacity per population are required for learning disability /	None as of January 2022	BTRS Reports published - Challenging Behaviour Foundation

	live the lives they wish to lead in the community; but also to build the skills, values, awareness and confidence that more general services need … in order to enable people to stay in the community and work in more person-centred ways.' *<u>2.3 Care and support for children and young people</u> (p8-9)* 'Both local and national stakeholders thought that more needed to be done to bring adults' and children's services together locally, to ensure that there are early intervention and prevention services in place to prevent crises and so that families are supported earlier.' Some TCPs have invested in early intervention, and crisis and support services (e.g Greater Manchester). *<u>2.4 Housing</u> (p10-11)* 'It was an area where many NHS (CCG) commissioners had to upskill rapidly as, typically, many TCP NHS stakeholders lacked specific expertise in commissioning housing as part of personalised care and support.' 'There is now widespread recognition across TCPs that housing plans need to be clearly linked to a strong understanding of population need – at the present time and in the future. This is necessary so that local system leaders can consider: which existing housing can be adapted or brought up	autism teams and support teams working in the community.' (p18) ■ 'Ensuring that providers have access to a wide range of relevant training is also central to achieving the more mature provider market that is required in each local system by the LTP, to deliver effective care and support for people with the most complex needs. This will require continued investment.' (p18) ■ 'Mandatory learning disability and autism training should be implemented in every local system as soon as is practical, so that all NHS and social care staff nationwide see this as a core skill – in line with the key aims of the LTP.' (p18) ■ 'Lastly, workforce strategies, both nationally and locally, should also emphasise that relevant training should also be made available to families and carers.' (p18) ■ 'The emphasis in the LTP on children and young people confirms the importance of early support and intervention so that exclusions from school, crisis points and admissions do not constitute a threshold for intervention.' (p18) ■ 'Schools and families should be able to access support from intensive support teams where there is a risk of care and support breaking down, as well as accessing training as part of personalised care and support where needed (including training on PBS).' (p18) ■ 'Commissioning for children with complex needs should be improved to reduce reliance on institutions a long way from the family home – building 19 on the commitment to keyworkers in the LTP to improve oversight of such provision and planning for discharge.' (p19) ■ 'Capital investment should continue to be made available nationally and locally, to provide the investment needed in good local housing stock for a range		

	to standard; where new developments are needed; and where there are opportunities to make an investment. Housing plans also need to take account of choice and personalisation, and the different ways in which tenancies and home ownership might be supported. Lastly, plans must take account of the local workforce and access to health and specialist services that people and families need.' 'Many TCPs continue to find it challenging to develop the skills needed to create personalised housing options that can be delivered on time, while at the same time doing so in a way that makes the most effective use of limited resources (money and workforce).' *<u>2.5 Finance</u> (p11-13)* 'Ensuring that money can follow people as they move from inpatient care to living in the community remains a challenge for TCPs, including reaching agreement between health and social care commissioners as to how the costs of care and support in the community are met.' 'Feedback from local and national stakeholders suggested that, in part, [slow progress with joint commissioning] is because of severe cost pressures in social care more generally (and some participating CCGs were in financial special measures,	of purposes – both for ongoing living, as well as care and support in a crisis to minimise inpatient admissions and delays to discharge.' (p19) ■ 'The NHS and local authorities need to work more closely together to develop more integrated approaches to commissioning housing – not only around individual developments for people with multiple needs, but looking at how the whole housing stock and planning processes more generally can consider the needs of people with a learning disability and autism.' (p19) ■ 'Drive and support at the most senior levels for further integration across the system is key, and this will be an essential feature of ICSs. It is important that joint budgets and risk sharing (around integrated commissioning) are consistently put in place; and further national direction and guidance to enable this to happen may be necessary – for example, to introduce financial incentives (and addressing the financial disincentives) to keep people in the community.' (p19) ■ 'Those who have been in an Assessment and Treatment Unit (ATU) for over a year should have a ring-fenced budget (this could be via a personal budget) for at least 2 years after discharge.' (p19) ■ 'It will be important to develop further the business case for providing the right support, in the right place at the right time compared to institutional models of care. This could form part of the strategic commissioning function envisaged in the support offer from NHSE around the implementation of the LTP.' (p19) ■ 'Universal personalised care and the comprehensive model should be used to guide how care and support can be delivered in a much more person-centred way.' (p19)		

	compounding the challenge).' 'It is notable that Greater Manchester seems to have benefited from bringing all health and social care spending together under one umbrella.' *2.6 Personalisation (p13-14)* 'The evaluation found evidence that, over time, both commissioners and providers had focused on personalising services and improving the planning of care and support to meet individuals' needs. However, most case study TCPs did not yet appear to have a systematic approach to promoting and using tools such as personal health budgets (PHBs) or individual life planning.' *2.7 Co-production with people and families (p14-16)* 'Many TCPs (e.g Lincolnshire) had made significant progress with co-production over the length of the evaluation. Nonetheless, in many cases the strongest examples were found when there was a longer history of local infrastructure and supportive system leadership, which could make sure that TCP plans were made with the active engagement of experts by experience.'	■ 'The emphasis on the necessity for, and added value of, co-production should continue. This requires people having meaningful control of the agenda – including investment in the infrastructure for co-production; enabling people and families to set priorities and shape action locally and nationally.' Rec 2 (similar) in report 12 (govt response), 20, (no govt response), 21 (govt response), 30 (no govt response) Recs 2/4 (family carer involvement), in report 30 (no govt response) Rec 3 (similar) in report 1 (no govt response), 7 (govt response), 10 (no govt response), 16 (no govt response), 19 (no govt response), 21 (govt response), 30 (no govt response) Recs 9/10 (similar) in report 1 (no govt response), 16 (no govt response), 30 (no govt response)		

29) 'Out of Sight – Who Cares?' Progress report **CQC (Dec 2021)** **Restraint, segregation and seclusion review: Progress report (December 2021) | Care Quality Commission (cqc.org.uk)**	The progress report tracks the recommendations made in the November 2020 'Out of Sight – Who Cares?' report. **Key points:** 'Several important reports and legislation have been published that have continued to highlight issues raised in our Out of sight – who cares? report. Since the publication of Out of sight, stakeholders have been responding to the recommendations we made. In CQC, we have been implementing the recommendations by improving how we identify closed cultures and the way we regulate services for people with a learning disability and autistic people. Despite this progress, much still needs to be done to improve the health and care experiences of people with a learning disability and autistic people: • there are still too many people in inpatient hospital wards • when admitted, some people are spending too long in hospital and discharge can be very slow • well over 2,000 mental health inpatients were reported to have been subject to restrictive	**'What still needs to be done':** 'Most autistic people who need inpatient support will be using mental health inpatient services and not specialist learning disability and autism services. We also know that there is a long waiting list for a diagnosis of autism within the community.' 'The development of community services to enable alternatives to admissions and to ensure speedy discharge are vital [to reducing admissions for children and adults], as evidenced in State of Care 2020/21. If people with mental ill health are admitted to hospital, this needs to be for the shortest time possible, with a measurable objective in place and the correct therapeutic environment to reduce the need for restrictive interventions.' Shortage of housing and variety of house available. Community support must be responsive and long-term, to meet this need. 'Early intervention and crisis support need to run alongside this. Commissioners should ensure that the placements they are commissioning are able to meet individuals' needs, to enable them to lead fulfilling lives.' 'For people to be able to receive the right care, the right staff need to be in place.' Staff must be adequately trained and upskilled, however the UK is in the midst of a social care workforce crisis. 'There have been calls for the government to urgently review the needs of the workforce through qualifications, additional training and pay increases.' 'For an organisational approach to protecting and respecting people's rights to be successful, there has to be a skilled and motivated workforce, with good training in person-centred care and human rights. There also must be effective leadership, including oversight of how people's rights are being upheld in practice. This applies to both	None as of January 2022.	Out of Sight - Who Cares? CQC publish progress report - Challenging Behaviour Foundation

	interventions in August 2021 These findings indicate that we urgently need more appropriate housing provision, with a workforce in place who have the right skills to support people.'	providers and commissioners of care.' 'Additionally, we have been hearing worrying reports about the use of restraint in acute hospital settings. We will therefore also explore this in our Spring report.' Rec 3 (similar) in report 28 (no govt response) Recs 4/5 (similar) in report 12 (govt response), 21 (govt response), 28 (no govt response)		
30) Independent Review into the death of Clive Treacey **NHSE (Dec 2021) NHS England and NHS Improvement Midlands » Publications**	(p12) '**This review finds that Clive's death was 'potentially avoidable'(4) . There were multiple, system-wide failures in delivering his care and treatment that together placed him at a higher risk of sudden death** as set out in the report.' **Summary findings:** 1. 'The post-mortem5 and Pathologist's report that followed Clive's death failed to consider epilepsy / SUDEP (Sudden Unexpected Death in Epilepsy) as the cause of death.' 2. 'Clive's epilepsy care overall fell far short of acceptable practice for someone with complex intractable (drug-resistant) epilepsy…' 3. 'Clive experienced health inequalities throughout his life that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at greater risk of premature death.' 4. 'Commissioning organisations responsible for commissioning and	**Key recommendations:** (for full rec.s see pages 83-99) (p84) '2c) Regional NHSE/I Learning Disability and Autism Programmes should undertake a **capacity and training needs audit to review the capacity and skills of staff to commission safe care** for people with learning disabilities who have complex needs including epilepsy.' (p85-6) '2h) **With a view to providing better guidance for clinicians, carers and care professionals in relation to epilepsy and challenging behaviour linked to epilepsy and its management…(NICE) should consider reviewing current guidelines** in relation to: epilepsy and special consideration for people with a learning disability, challenging behaviour and learning disabilities.' (p86) '3c) Regional NHSE/I teams should work with health and care systems at a local level to ensure there is a clear focus on **diagnostic overshadowing** across primary, secondary and community care services and monitor progress.' (p88) '3m) The **CQC should fulfil its regulatory responsibility** to ensure that mental health hospital settings and **specialist hospitals for people with a learning disability, autism or both provide good physical healthcare, and meaningful engagement and activity** in	None as of yet. **Key rec.s continued:** (p94) '5f) There must be a **named community health team lead and a named community social work team lead** in addition to the inpatient team and any commissioning professionals for people with complex needs and their families.' (p95) '6c) **CCGs should ensure access to good quality advocacy,** which is an essential safeguard for people, especially people who are non-verbal or extremely mentally unwell, and may be unable to speak up for themselves.' (p95) '6d) NHSE/I should receive assurance from CCGs that providers of **all commissioned services have robust family and patient involvement**.' (p95) '7a) Local authorities and CCGs should urgently review and ensure that adult **safeguarding processes in place to protect people with a learning disability are robust** and in line with national guidelines.' (p96) '8a) Staffordshire County Council and	Independent Review into death of Clive Treacey - Challenging Behaviour Foundation

	monitoring Clive's care did not always place him in settings that could meet his needs and did not sufficiently monitor the quality of care he received. On some occasions, this placed him at risk of harm.' 5. 'There was a lack of good quality care and treatment for Clive's presenting needs, including NICE-compliant approaches to behaviour analysis and intervention, in the specialist hospitals in which he was detained. For the most part, responsible clinicians overseeing Clive's inpatient care did not see life outside of hospital as an option for Clive and failed to pursue a timely discharge for him...' 6. 'Clive and his family were not listened to, and opportunities were missed to listen to Clive and engage with his family on how best to meet his needs.' 7. 'Clive was not always kept safe from harm while in the care of some care providers. The response to the many complaints and safeguarding alerts raised by the family and professionals were inadequate.' 8. 'The safeguarding response to the alleged sexual abuse Clive experienced over several years failed to protect him from further harm and may also have failed to protect others.'' 9. 'The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic	line with established clinical standards and best practice.' (p89) '4a) Commissioners (health and social care) should ensure that all **staff who are involved in developing community-based packages of support are skilled in person-centred life planning.** Where achieving discharge is proving difficult, they should appoint an independent life planner.' (p90) '4c) Commissioning organisations (health and social care) should ensure that local commissioners of care for people with learning disabilities, autism or both **have the skills and expertise to commission care for people with complex health needs that is safe effective and personalised to meet individual needs**.' (p91) '4i) Health and social care commissioners should ensure that individuals, whether they are in specialist hospital settings, living in residential care, with family or independently, have a **named care coordinator** who has statutory responsibility for consistently maintaining contact with them and their family.' (p92) '4k) CCGs should actively work with carers and care providers to **identify and provide support to those at risk of admission at the earliest opportunity possible**.' (p93) '5a) Before admission to hospital, **people have assessments through community teams so that their needs are understood** and they have clear and measurable objectives set for their admission to hospital and receive care in an appropriate environment.' (p93) '5c) All specialist inpatient units provide a therapeutic environment to enable the delivery of **trauma-informed and person-centred care** in line with existing evidence-based models.'	Cheshire East Council **should jointly commission an independently chaired review of the safeguarding response to historic allegations of sexual abuse** in 1993, when Clive was placed with a care provider within the Cheshire County Council geographical boundary.' (p98-99) '10c) Where **multiple reviews are underway** in response to a death, the local integrated care system and wider partners should ensure **that the coordination and inter-relationship between them is effectively managed to ensure that deaths are looked at comprehensively in an integrated way,** to avoid duplication and to **minimise the trauma** for families.' (p99) '10d) CCGs and local authorities must ensure that Safeguarding Adult Reviews, Serious Incidents Requiring Investigation and other review processes investigating the quality of care or death of individuals, **involve families, document their concerns and clearly respond to the issues raised by them**.' Rec 5 (similar) in report 12 (govt response), 21 (govt response), 28 (no govt response), 29 (no govt response). Rec 8 (similar) in report 1 (no govt response), 16 (no govt response), 28 (no govt response), 29 (no govt response). Rec 10 (similar) in report 1 (no govt response),10 (no govt response), 16 (no govt response). Rec 11 (similar) in report 1 (no govt response), 12	

	and may further have reduced his chances of survival.' 10. 'The series of investigations and complaints handling that took place after Clive's death were inadequate and may have resulted in missed opportunities to take action to prevent harm to others.'	(p93) '5d) **Discharge planning must start before admission, without fail,** with a **clear timeframe** in place. Discharge planning must involve all relevant sectors, who will be involved in providing support in the community.'	(govt response), 20 (no govt response), 26 (no govt response) Rec 15 (similar) in report 1 (no govt response), 7 (govt response), 10 (no govt response), 19 (no govt response), 21 (govt response), 23, 28 (no govt response). Recs 14/17 (similar) in report 28 (no govt response)	

Appendix of reports included

1) ‘Reducing Restrictive Intervention of Children and Young People’ – Update of Case study results

CBF / PABSS
(Feb 2020)
HARD COPY

2) ‘Promoting sexual safety through empowerment’

CQC
(Feb 2020)
ASC Sexual Safety +Sexuality Draft.docx (cqc.org.uk)

3) ‘CQC inspections and regulation of Whorlton Hall 2015-2019: an independent review’

CQC – Glynis Murphy
(Mar 2020)
20020218_glynis-murphy-review.pdf (cqc.org.uk)

4) ‘Human Rights and the Government’s response to COVID-19: The detention of young people who are autistic and/or have learning disabilities’

JCHR (Joint Committee on Human Rights)

(June 2020)
The Government’s response to COVID-19: human rights implications (parliament.uk)

5) Fourth annual LeDeR report

Uni of Bristol/LeDeR (Learning Disabilities Mortality Review)

(July 2020)
LeDeR_2019_annual_report_FINAL2.pdf

6) ‘The Government’s response to COVID-19: human rights implications’

JCHR
(Sep 2020)
The Government’s response to COVID-19: human rights implications (parliament.uk)

7) ‘Out of sight – who cares?’

CQC (Care Quality Commission)

(Oct 2020)
Out of sight – who cares? (cqc.org.uk)

8) ‘Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020’

PHE (Public Health England)
(Nov 2020)
COVID deaths of people with learning disabilities (publishing.service.gov.uk)

9) ‘CQC inspections and regulation of Whorlton Hall: a second independent report’

CQC – Glynis Murphy
(Dec 2020)
20201215_glynis-murphy-review_second-report.pdf (cqc.org.uk)

10) ‘Broken – The Psychological trauma suffered by family carers’

CBF
(Dec 2020)
Broken CBF final report (challengingbehaviour.org.uk)

11) Pandemic research

Dimensions
(Dec 2020)
#CovidLeadersList: People with learning disabilities and autism call for greater understanding and representation following the pandemic - Dimensions (dimensions-uk.org)

12) ‘Reforming the Mental Health Act’ – white paper

(Jan 2021)
Reforming the Mental Health Act (publishing.service.gov.uk)

13) ‘Union of Equality: European Commission presents Strategy for the Rights of Persons with Disabilities 2021-2030’

EC (European Commission)

(Mar 2021)
Strategy for the Rights of Persons with Disabilities 2021-30 (europa.eu)

14) ‘Protect, respect, connect – decisions about living and dying well during COVID-19’

CQC
(Mar 2021)

Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission (cqc.org.uk)

15) 'Coronavirus and the social impacts on disabled people in Great Britain: February 2021'

ONS (Office for National Statistics)

(April 2021)
Coronavirus and the social impacts on disabled people in Great Britain - Office for National Statistics (ons.gov.uk)

16) 'Tea, smiles and empty promises'

Winterbourne View families
(May 2021)
Tea-smiles-and-empty-promises-family-stories.pdf (challengingbehaviour.org.uk)

17) Fifth annual LeDeR Report

Uni of Bristol/LeDeR
(June 2021)
LeDeR-bristol-annual-report-2020.pdf (england.nhs.uk)

18) 'Restraint in schools inquiry: using meaningful data to protect children's rights'

EHRC (European Human Rights Commission)

(June 2021)
Restraint in schools inquiry: using meaningful data to protect children's rights (equalityhumanrights.com)

19) 'SEND: old issues, new issues, next steps'

Ofsted
(June 2021)
SEND: old issues, new issues, next steps - GOV.UK (www.gov.uk)

20) 'The treatment of autistic people and people with learning disabilities' – fifth report of 2021-11

HSCC (Health and Social Care Committee)

(July 2021)
Treatment of autistic people and individuals with learning disabilities (parliament.uk)

21) ‘Thematic review of the Independent Care (Education) and Treatment Reviews’

(July 2021)
Thematic Review of the Independent Care (Education) and Treatment Reviews - GOV.UK (www.gov.uk)

22) ‘Institutionalising parent carer blame’

Cerebra/Uni of Leeds
(July 2021)
Final-Parent-Blame-Report-20-July-21-03.pdf (cerebra.org.uk)

23) The National Autism Strategy for Autistic People, Children and Young People 2021 to 2026

(July 2021)
The National Strategy for Autistic People, Children and Young People 2021 to 2026 | Local Government Association

24) National Disability Strategy

(July 2021)
National Disability Strategy - GOV.UK (www.gov.uk)

National-Disability-Strategy-Headlines-2021.pdf (vivocarechoices.co.uk)

25) Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK | BMJ Open

???
(Aug 2021)

26) Cawston Park Serious Case Review

M. Flynn and Norfolk Safeguarding Adults Board
(Sept 2021)

SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf (norfolksafeguardingadultsboard.info)

27) State of Care Report

CQC
(Oct 2021)

State of Care | Care Quality Commission (cqc.org.uk)

28) Building the Right Support Evaluation Report

NHSE
(Completion date, Sept 2019, Publication date, Nov 2021)

Evaluation of Building the Right Support: Final Reports | The Strategy Unit (strategyunitwm.nhs.uk)

Key findings/recommendations:
B0952 - Report - Independent evaluation of Building the Right Support - Learning report.pdf (strategyunitwm.nhs.uk)

29) 'Out of Sight – Who Cares?' Progress report

CQC
(Dec 2021)

Restraint, segregation and seclusion review: Progress report (December 2021) | Care Quality Commission (cqc.org.uk)

30) Independent Review into the death of Clive Treacey

NHSE
(Dec 2021)

NHS England and NHS Improvement Midlands » Publications