

Further supplementary written evidence from the Challenging Behaviour Foundation (ADL0014)

Inquiry into the treatment of autistic people and individuals with learning disabilities: Key areas for recommendations

Over the past few years there have been a significant number of reviews which have all concluded that in order to transform care and to ensure that the health and social care system delivers good outcomes for people with learning disabilities and autistic people, *significant* overhaul is required across a range of issues and sectors. Workforce, commissioning, housing, healthcare, education and social care services all need reforms in order to ensure that early intervention, joined-up working, effective community support and person-centredness become standard. This will require a number of both short and longer term key actions.

The below are some immediate, short-term recommendations that should be implemented alongside addressing the structural issues which undermine good outcomes more broadly:

- 1) **A new 'clinical contract' for inpatient admissions** should be instituted when a person is admitted to a mental health or learning disability inpatient unit, agreed between the inpatient Responsible Clinician and the referring community service. The contract will clearly state the expectations of the admission in terms of therapeutic benefit and actions to be taken by all during the period of admission. The purpose is to achieve 'active management' of admissions where community staff and in-patient staff are collaborating to support the purpose of admission that clearly works towards discharge. The clinical contract would stipulate in detail the actions to be taken during the admission by professionals and agencies, the timescales by which to achieve them, and to monitor progress against the expected outcomes. This should be implemented as part of an expansive plan to drastically reduce the length and number of mental health inpatient unit stays for people with learning disabilities and autistic people - see the [CBF and Mencap joint submission to the Mental Health Act review](#) for what else must be undertaken to reduce inpatient numbers.
- 2) Inpatient staff should be subject to **regular skills audits**, to ensure that specialist support is in place and available for individuals with learning disabilities and autistic people. Furthermore, we are aware that for many people with learning disabilities and autistic people their Care Plans are not followed sufficiently, with **a review of their effectiveness and stringency** in inpatient units and learning disability/autism services being urgently required.
- 3) An overhaul of the commissioning of services for people with learning disabilities is necessary. We recommend that **commissioners are regulated in their practice and are subject to professional standards**. In the immediate term, 24/7 commissioning services which have been demonstrated to successfully impact on outcomes in the Black Country should be replicated across all areas. This would contribute to meeting the wider aims to ensure that the standards for 'lifelong' commissioning [set out in NICE Guidance 93](#) are made a reality.
- 4) Implementation of the pilots which are currently underway of an **External Support Group**, a group of skilled and experienced specialist professionals who have experience of bringing people with complex challenging behaviour out of hospital and supporting them in local settings. They work with local teams

to build expertise, skills and confidence to discharge individuals from environments and detentions which are counter-therapeutic. The necessary clinical, mental health, and learning disability/autism expertise is required for both hospital services to develop their ability and competence in delivering discharge and for community services to develop and deliver appropriate and robust care and support for people with complex needs to ensure safe discharge. A version of this model was successful in previous hospital closure programmes (as described by Professor Mansell). Individuals, families and staff need access to additional support to bring about discharge as described under the Transforming Care programme, and reduce the use of restrictive interventions.

- 5) **A new professional post** for a ‘specialist physician’ (as proposed in [recommendation 4 of the 2019 LeDeR report](#)) should be created to support adults with learning disabilities and autistic adults and to enhance coordination of healthcare and mental health services, covering healthcare, lifestyle, disability-related issues, and other concerns. For children, this role is often undertaken by a paediatrician, and a corresponding role is required for adults. This specialised physician role will provide learning disability and autism expertise and should also coordinate the creation of and adherence to a **Health Action Plan**. This must be part of wider aims to ensure that joined-up working becomes a reality for health and social care services, in such a way as is not adequately reflected in Health and Social Care White Paper proposals.
- 6) **Using dynamic risk registers and wider implementation of the Key Worker** role is required to ensure that social care and other services are not excluding people with learning disabilities, autistic people, and their families from accessing support that they are entitled to.
- 7) The establishment of Regional Housing Networks which should involve experts with learning disability and autism specific housing knowledge. These networks can then be accessed to support the process of accessing, establishing and developing suitable housing for people with learning disabilities in a timely manner. This will include a collation of available housing resources to address the current hurdles and challenges in the housing process which we know leads to unnecessary lengthy inappropriate hospital admissions.

These proposals must be pursued in tandem with wider reforms to the health and social care system, which are outlined with practical solutions in the remainder of this paper. The proposals outlined below are practical actions which can be taken both immediately and as part of wider reforms, and reflect only some examples of the many actions which can and should be taken.

Key Issues and Recommendations for Actions

Issue	Examples of some short term actions to implement	Longer Term strategy
Workforce		
Non-specialist providers who can't meet the needs of individuals are chosen by Local Authorities, leading to placement breakdowns	Regulate the market on PBS “experts”, having qualifications for care which are easier for individuals, families and commissioners to identify	Co-production of care planning between individuals, families and care providers to deliver bespoke care, built around early intervention and PBS frameworks
National deficit of skills and capability in the workforce	Target services with poor CQC ratings. A successful model for delivering expertise and skills development to hospital and	The curricula of professional training schemes (especially psychiatry, psychology, SaLT, OT, physio etc) should be required to include direct experience of

<p>(qualified sections of workforce).</p> <p>Lack of trauma awareness and absence of trauma-informed approached</p>	<p>community services was developed by Prof. Jim Mansell, and a short-term (and reasonably quick) action that could be taken is to adapt this to work with identified hospitals. The aim is to work with existing services to support and enable them to discharge patients in a timely way. It also relates to the 'senior intervenor' model that has been piloted by NHSE.</p> <p>NHSE Trauma awareness training, co-produced by the CBF, the Tizard Centre and families to be rolled out.</p>	<p>working with people with learning disabilities. The core competence model can result in clinicians leaving training courses with very limited knowledge and experience of how to actually deliver good clinical care in this area.</p>
<p>National deficit of skills and capability in the workforce (frontline support staff)</p>	<p>Training needs to emphasise the importance of being compassionate, curious and creative. It should be in situ, (not only online) and should be peer-delivered, trauma informed and aim to change ideas and attitudes. It should include NHSE Trauma awareness training, co-produced by the CBF, the Tizard Centre and families.</p> <p>It is essential that professional staff are available to deliver focussed and person-centred training and advice to support staff in both hospital and community. The Faculties of the relevant professions could support implementation of good practice. The Professional Senate could assist with this.</p>	<p>Professionalisation of Social Care, with a training ethos centred on continuous skills building, personal reflection and good values. A culture of regular skills audits to ensure that specialist support is in place and available for individuals with learning disabilities and autistic people</p>
<p>Staff are undervalued and underpaid</p>	<p>Better rewards for staff – including both financial remuneration and better valuing the altruistic and caring aspects of the role, which often brings people into the field but are can be neglected rather than nurtured.</p>	<p>Professionalisation of social care (as above)</p>
<p>Lack of learning disability and autism knowledge across health, social care</p>	<p>Oliver McGowan training should be mandatory for professionals across all fields.</p>	<p>We recommend that professionals who hold senior managerial positions within learning disability and autism directorates are required to</p>

<p>and education and lack of trauma awareness</p>	<p>The Oliver McGowan training should include (or should be supplemented by additional training that includes) risk factors for trauma to ensure professionals adopt a trauma-informed approach.</p>	<p>evidence their knowledge of and expertise in learning disabilities and autism both prior to appointment and as part of their continuous professional development.</p> <p>We recommend that all professionals who may work with individuals who are autistic and/or have learning disabilities, are provided with trauma-informed training in learning disabilities and autism as part of their mandatory training.</p>
<p>Clinical, mental health, or learning disability/autism expertise is not always available in the local area to meet local need. Individuals detained in inpatient units must have access to external learning disability and autism expertise, knowledge, skills and evidence-based input.</p>	<p>National roll-out of External Support Group pilots which works in support of local teams to build expertise, skills and confidence to ensure individuals are supported well in the community and are discharged from lengthy detentions in unsuitable environments, which are counter-therapeutic to individuals detained.</p>	<p>Work with local areas to embed durable people-centric processes and create self-sustaining networks that can replicate successful community solutions. Encouraging and supporting peer-support across regions to share learning, promoting a culture of confidence, encouragement and collaborative problem solving.</p>
<p>Services are confusing to navigate. Individuals and families can feel isolated and unaware of their entitlements.</p>	<p>Key workers/care co-ordinators/ family advocates to help individuals and families navigate services and provide flexible and timely input to children and young people, adults, families and carers (as identified by the Dynamic Risk Register); ensuring that social care services and other services are not excluding people with learning disabilities, autistic people, and their families from accessing support that they are entitled to.</p>	<p>Families must be valued, equipped and empowered to advocate for their relative's human rights to ensure they receive the right support, in the right place at, the right time</p>
<p>Housing</p>		

Overarching issues: Lack of housing, and what is available is difficult to access in a timely manner.	Regional Housing Networks to be established including experts in learning disability and autism specific housing knowledge which can be accessed to support the process of planning, accessing, establishing and developing suitable housing for people with learning disabilities in a timely manner. This will include collation of available housing resources and addressing the current barriers and challenges in the housing process which we know leads to unnecessary lengthy inappropriate hospital admissions.	
There is a need for system-wide financial incentives	Disabled Facilities Grant – share and act on evidence of savings made to Local Authorities. E.g. 2017 research showing £300,000 DFG expenditure led to a minimum fivefold saving for the authority	
Housing is not thought about early enough; needs assessments are not of high enough quality	Housing needs to be better linked to Dynamic Risk Register in order to plan for the future A housing template checklist should be widely available (including to individuals and families) i.e. a resource with everything you need to know when planning and sourcing housing for individuals with learning disabilities whose behaviour challenges. This could be available through an app/other easily accessible platform	
Siloed working; housing and workforce need to be more joined up	Need clearer guidance (including on Sec. 117 of the MHA) on who should be at discharge/transition/other housing planning meetings. Improve learning disability housing knowledge and expertise amongst workforce , including social workers, commissioners, OTs.	
Commissioning		
There are 'Avoidable' admissions, especially out of hours	24/7 Commissioning teams; Commissioners on call 1 week in every 5. See Black Country for example (point 3 in key recommendations)	Evaluation of the 'on call' system currently in place in the Black Country to determine how to roll-out nationally
Targets-based culture that is centred around arbitrary numbers rather than outcomes e.g. 'reducing bed numbers'	Commissioners should adopt Outcomes Based frameworks. See the Black Country for example	Intelligent use of regional data to develop high-quality Commissioning that is encouraged to focus on meeting the needs of its local area rather than prescriptive national targets
Commissioners continue to purchase what is available rather than commission personalised services. There is a dearth of learning disability expertise and no	Implement the recommendations on commissioning made in: <ul style="list-style-type: none"> • CQC Out of Sight report; • Shelia Hollins review into seclusion; • Glynis Murphy reviews of Whorlton Hall 	Overhaul of commissioning of services for people with learning disabilities is necessary. Commissioners should be centrally regulated and subject to professional standards. The standards for 'lifelong' commissioning set out in NICE Guidance 93 need to be made a reality.

formal standards within Commissioning		
Failure to work in co-production with individuals with learning disabilities and their families	e.g. Pathway Panels, made up of members with lived experience, have been initiated to compliment Provider Collaboratives; an initiative that gives Providers (including private, profit-making providers) commissioning powers. Pathway panels must have the range of knowledge and expertise to cover the diverse population, real power and influence and the development of Provider Collaboratives should not be allowed to progress faster than the development of Pathway panels	Individuals and their families are to be placed at the heart of Commissioning; working in collaboration rather than in opposition to Commissioners to achieve the shared goal of providing the right support, in the right place, at the right time.
Care and Treatment		
Care and Treatment needs to be discharge-orientated, ensuring people can be safely treated in the community and preventing new admissions/ readmission	Institute a new 'clinical contract', between community services and in-patient services about the purpose of the admission, treatment to be provided, and the outcomes this will be checked against. This will provide accountability, ensure that detention is beneficial and in line with outcomes provided, and encourage planning for discharge to take place between inpatient and community services. Section 117 aftercare must be extended to those discharged following section 2 admission, to prevent trauma and possible readmission.	Prevention of the construction of new inpatient units. Bringing learning disability and autism expertise into discharge planning (see proposals on the External Support Group). Overhaul of Tribunals and Court of Protection procedures (to a greater degree than is set out in MHA review) which are protracted, bureaucratic and ineffective at working towards discharge. Advocacy will need to be made opt-out and centrally regulated to ensure coverage and quality.
Care and Treatment planning in inpatient units is often limited and takes place without learning disability or autism expertise nor individual, family/ community team input.	Care planning to take place prior to admission, with input of community team, individuals and families, covering all aspects of a person's needs and preferences, all aspects of care, and options for how similar treatment <i>could</i> be provided in the community (to avoid admission). C(E)TRs will similarly need quality assurance recommendations	Care and Treatment planning needs to be made person (not hospital) centred, leading to long-term aims of securing discharge as treatment is not solely built around inpatient units. Statutory guidelines are needed to ensure they Care Plans are of a high quality, and units need to be made accountable for their delivery. A review of Care Plans' effectiveness and stringency is urgently needed to inform these guidelines.

<p>Care and Treatment provided in inpatient units often fails to meet patients' needs or provide therapeutic benefit</p>	<p>implemented and outcomes for individuals tracked. Inpatient staff should be subject to regular skills audits, to ensure that specialist support is in place and available for individuals with learning disabilities and autistic people.</p>	
<p>Children, young people and adults are at risk of harmful restrictive practices in care settings. Latest case 9th June 2021 Ty Coryton children's home</p>	<p>Introduce reducing restraint frameworks, including the work of RRISC group. Take action to ensure Providers report their use of Restrictive Intervention to NHS digital. This is currently mandatory, but in data published April 2021, as few as 1/16 private providers and 31/56 NHS providers submitted their data.</p>	<p>Government guidance on 'Reducing the need for restraint and restrictive intervention' should be made statutory and expanded to cover mainstream schools and all other settings. We need a national, evidenced-based, early intervention approach to supporting individuals with learning disabilities whose behaviours can challenge and professionals trained in PBS across health, social care and education.</p>
<p>It is claimed that it is not currently clear what 'good' looks like in providing care and treatment. Decision makers may not take on board best practice documents, are hesitant to engage in training, or do not take on board examples of good practice instituted in other areas</p>	<p>Evidence based practice must be proactively shared and incentivised. Regulators need to investigate quality of learning disability and autism training provided, and outcomes they deliver to individual care and support. PBS training must be expanded and implemented as standard for those involved in providing care and treatment Care planning and training for professionals must be conducted in co-production with individuals and families.</p>	<p>Person-centred planning instituted more effectively as care and treatment must be built around meeting a person's needs, rather than simply providing what is available.</p>
<p>High-level of comorbidities for people with learning disabilities (on average 11 vs. general populations' 5). Medical staff in hospital not necessarily aware of how these present; diagnostic overshadowing</p>	<p>Introduction of a specialist Learning Disability Physician. Every trust in the country would have at least one physician, one skilled decision-making doctor within an organisation, who can work with people with learning disabilities and autistic people who have physical health problems. They can work with other colleagues, the doctors, individuals and families, as well as the GPs supporting them.</p>	<p>Reasonable adjustments are key to ensuring health needs are met – individuals and families often tell us that these are not made when entering hospital. This may be because a Learning Disability nurse is not available, because families do not know how to request them, or because they are simply not followed/told it is not possible. Diagnostic overshadowing is prevalent and physical health problems are attributed to having a learning disability.</p>

leading to unmet health needs	(Suggestion raised by Dr Ken Courtenay, replicating a model of learning disability healthcare operating in the Netherlands).	Families and individuals require greater access to reasonable adjustments and appropriate assessments to ensure health needs to do not go unmet.
Early Intervention		
Local areas rarely provide early intervention for children with learning disabilities whose behaviours challenge. Where funding is available for early intervention projects, they are often short-term pilots or provided with non-ringfenced funding, meaning early intervention is not prioritised despite wealth of evidence showing its financial and support benefits	<p>Implement commitments set out in NICE guidance and the NHS Long Term Plan to improve community support for children, including better access to CAMHS and the establishment of intensive support/PBS teams.</p> <p>Early Years development review to include a focus on children with learning disabilities whose behaviours challenge so broader early intervention is inclusive.</p>	<p>Evidence from the mapping and evaluating of children learning disability services (MELD) study to help inform policy, so that effective early intervention services are funded.</p> <p>Early intervention work needs to be better funded, with funding ringfenced and long-term. This will provide cost benefits for DHSC by lowering spending on (comparatively more expensive) crisis services.</p>
A range of reports, including the CBF Paving the Way report and the Lenehan review, recommend keyworkers to help co-ordinate services for children and families.	Evidence from pilots to be analysed to determine most effective approaches to key-working, so they can be rolled out nationally.	Key workers should be available <i>before</i> crisis as part of a package of prevention and early intervention for all those identified as being at risk of developing behaviours that challenge.
Lack of knowledge across the country about evidence and best practice	Community of practice/ network of professionals across country.	Quality standards for the provision of multidisciplinary support to children with learning disabilities whose behaviours challenge.
Joined up working		
System level issues not addressed by Health and Social Care White Paper	Details around tackling perverse financial incentives are largely absent, with discussions of pooled budgets limited. Proposals must recognise the scope of issue and lay out clear legislative, regulatory, and funding plans to address the financial obstacles to joined-up working. The	No apparent co-production or consultation undertaken with individuals or their families. The Health and Social Care White Paper and all future legislation must ensure that the voices of people with learning disabilities and their families are heard.

	Health and Social Care White Paper fails to address why joined-up working is not the norm for services – chronic underfunding, diffuse responsibility, and overwhelming complexity are not discussed in the proposals.	
Lack of coordination of healthcare and mental health services for individuals with learning disabilities	As suggested above, a new post of a ‘specialist physician’ with learning disabilities and autism expertise is needed to ensure healthcare and mental health services are joined-up and health needs are not unmet/misdiagnosed.	Health Action Plans implemented more widely and individuals and families to be made better aware of their availability, as part of attempts to address harmful ‘episodes of care’ culture.
Regional disparity in services available and effectiveness of joined-up working	Sharing good practice between areas and creating ‘joined-up working targets’ so that improvements undertaken by LA’s/CCGs (such as co-location practices existing in Local Authorities, for example in Ealing) must be replicated elsewhere where feasible.	Co-location and multi-disciplinary working should be implemented as-standard.
Decision makers not taking on board good practice documents nor engaging in training, leading to limited long-term effectiveness	All training to be co-delivered by people with lived experience and professionals. Training provided (including Oliver McGowan mandatory training) must ensure learning disability and autism knowledge is improved, and outcomes for individuals improve	Ensuring that decision makers all have (or all have access to) learning disability and autism expertise.
Managerialist cultures and institutional barriers preventing joined-up working. Organisational ‘siloes’ undermine provision of support to meet multifaceted needs (as outlined in Lenehan review)	Improving joint training (above) and co-location of professionals	End the ‘episodes of care’ approach to services, with long-term investment in people and early intervention at the core of service design.
Community services		
<p>It is absolutely clear that there must be the development of the right community support, including</p> <ul style="list-style-type: none"> • Sufficiently resourced care providers and community health professionals with the right skills, flexibility and willingness to develop bespoke packages of care to prevent needs escalating and people ending up in crisis; 		

- Robust Multi Disciplinary Teams that work in a co-ordinated fashion and in co-production with individuals families and;
- Forensic and intensive support teams to provide a community alternatives to admission.

It is of crucial importance that such support and services are co-developed to meet people's *individual* needs. Current failures of community support lead to inappropriate inpatient admission. We need national leadership with a clear and comprehensive vision for robust and resourced community support and a well-coordinated, cross-governmental plan to deliver the change that is needed. In the evidence session on the 27th April, the Minister said there is a "lack of clarity about what good looks like in the community" - but we do know what it looks like: it is well documented, this is not a valid excuse, it is happening for some people in some areas. The last 10 years has not delivered the intended progress. A new approach and learning from past failure needs to be put in place and there is currently no evidence this is happening.

