



JOINT BRIEFING

Community support for people with a learning disability and autistic people

- People with a learning disability and autistic people are currently not receiving the right support, resulting in serious inequalities and poorer outcomes compared to the general population
- This is a systemic issue that requires a cross-government approach to resolve
- This cross-sector briefing reflects the large body of existing good practice and research to make evidence-based recommendations for solutions to these issues, and we are willing and able to work with you to support this work
- If coordinated and concurrent actions to address the systemic issues are taken by government, this will lead to significant improvements in quality of life, cost-savings, and efficiency
- There must be a focus on early intervention, prevention and community support to prevent needs escalating and people being inappropriately detained in mental health hospitals at high human and financial costs

Learning Disabilities and Autism

A learning disability is a “reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life”¹. There are approximately 1.5 million people with a learning disability in the UK². Learning disabilities are not the same as learning difficulties, such as ADHD or dyslexia.

Autism is a “lifelong developmental disability which affects how people communicate and interact with the world”³. There are approximately 700,000 people who have been diagnosed as autistic in the UK.⁴

Neither learning disabilities nor autism are mental health conditions and cannot be ‘treated’ or ‘cured’.

¹ [Mencap: What is a learning disability?](#)

² [Mencap: How common is learning disability?](#)

³ [National Autistic Society: What is autism?](#)

⁴ [National Autistic Society: What is autism?](#)

UK policy context: Transforming Care and Building the Right Support

In May 2011, *Panorama* uncovered abuse at Winterbourne View, a private hospital for people with learning disabilities. It exposed how people with learning disabilities and autistic people were ending up in the wrong services - and getting stuck there - due to the failure of community support. In 2012 the national 'Transforming Care' programme was established to ensure that people with a learning disability and autistic people receive the right support in the community rather than being inappropriately detained in hospital. It committed to moving all people with a learning disability and autistic people detained in mental health inpatient units out of hospital to receive support in community settings⁵.

This target was missed due to:

- **financial disincentives to developing community support, (compared to detaining people with learning disabilities and autistic people under the Mental Health Act), and**
- **a failure to ring-fence funding and commission community support so that people who were currently detained could be discharged.**⁶

The number of people with learning disabilities and autistic people inappropriately and unnecessarily detained in hospital is a **symptom of systemic failure**. To rectify it the cause must be addressed - and **the cause is the lack of appropriate, timely, and properly funded community support**.

Focusing on the symptom

In 2015 NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) published 'Building the Right Support', which committed to reducing the number of people with a learning disability and autistic people in inpatient units by 35-50% by March 2019⁷. After this target was also missed, the NHS Long Term Plan stated new aims of moving 35% of people detained into the community by March 2020, and 50% by March 2024⁸ - neither of which were met.

Analysis of the data shows that at the current rate of change, **meeting the commitment of discharging 50% of people with a learning disability and autistic people will not be achieved until 2030 at the earliest**⁹. As of June 2024, there are **2025** people with a learning disability and autistic people in inpatient units¹⁰. The number of autistic people without a learning disability in inpatient units has **more than doubled since 2015**¹¹, and nearly half of people with a learning disability in inpatient units have been detained for **over 5 years**¹². To

⁵ [DH Winterbourne View Review - Concordat: Programme of Action](#)

⁶ [Winterbourne View: Time for Change \(the 'Bubb Report'\)](#); [NAO: Care services for people with learning disabilities and challenging behaviour](#)

⁷ [Building the Right Support](#)

⁸ [NHS Long Term Plan 2019](#)

⁹ [Mencap: Assuring Transformation data analysis](#)

¹⁰ [NHS Digital: Learning disability services monthly statistics from Assuring Transformation dataset](#) (May 2024)

¹¹ [NHS Digital: Learning disability services monthly statistics from Assuring Transformation dataset](#) (May 2024)

¹² [NHS Digital: Learning disability services monthly statistics from Assuring Transformation dataset](#) (March 2024)

prevent people with a learning disability and autistic people being inappropriately and harmfully detained, there needs to be a clearly resourced strategy and direction from government.

The Building the Right Support (BTRS) Action Plan, published by the Department of Health in July 2022, did not include SMART targets, failed to set out learning from previous measures and missed targets and how these issues would be addressed, and did not provide analysis of how the actions included would reduce admissions or effectively enable discharge¹³. As well as lacking a systemic approach, coherent detail and resources, this plan is now outdated, with many of the deadlines included within the plan having passed.

Focus on the cause

Community support and services to meet people's needs must be developed.

We echo the Joint Committee on the Draft Mental Health Bill's recommendation that the Building the Right Support Action Plan be reviewed, and recommend that it be significantly revised and updated. A co-produced action plan to support children and adults with a learning disability has been developed by people with lived experience, family carers, and people working across the sector¹⁴; this plan could be used as a basis for updating the Building the Right Support Action Plan.

Inequalities and human rights abuses faced by people with a learning disability and autistic people

People with a learning disability and autistic people face serious inequalities compared to the general population, including poorer health outcomes and shorter life expectancies¹⁵, being subjected to harmful and traumatic restraint, seclusion and segregation¹⁶, and a lack of access to the support and services needed to live good lives (see below sections for further details).

In order to get things right for people with a learning disability and autistic people - so that they have the right support to live in their local communities, are not detained inappropriately, and can access the same rights as everyone else - there must be a coordinated, cross-government, systemic effort to develop and resource high-quality community support.

Overcoming barriers to developing the right support in the community

Currently there are both financial and practical disincentives to developing the right community support for people with a learning disability and autistic people. When someone with a learning

¹³ [Building the Right Support Action Plan](#); [EHRC Statement on the Building the Right Support Action Plan](#)

¹⁴ [Co-Producing a Lifelong Action Plan: webpage](#); [Co-Producing a Lifelong Action Plan: PDF](#)

¹⁵ [KCL LeDeR report 2022](#)

¹⁶ [Baroness Hollins' Final Report](#); [CBF and PABBS: Reducing Restrictive Intervention of Children and Young People](#); [CQC: Out of Sight - Who Cares?](#)

disability/who is autistic is being supported in the community, the local authority is responsible for commissioning and paying for this support, but if they are detained under the Mental Health Act in an inpatient unit, this is funded by the NHS¹⁷. Since 2010, local authorities have seen rising costs while funding has decreased in real terms¹⁸. This means that there is:

- a) A perverse incentive to avoid commissioning community support that meets the needs of people with a learning disability and autistic people, (leading to them being sectioned and detained in inpatient units)
- b) Disincentive to develop the community support that enables people with a learning disability and autistic people to be discharged from inpatient units because the cost of the support is transferred

Too often, the support that people receive is not person-centred; instead of commissioning support based on what the person needs and what matters to them, decisions are based on what is cheapest and easiest to buy. This approach leads to poor and inappropriate support - such as the wrong environment, lack of meaningful activities, and staff who do not understand the person - which in turn leads to crises. When suitable community support is not available, detention in inpatient units becomes the 'default' - or the only - option left¹⁹.

Currently the Mental Health Act allows people with a learning disability and autistic people to be detained without a co-occurring mental health condition. This perpetuates the perverse incentive in favour of detaining someone with a learning disability/who is autistic rather than spending money on developing services that can meet their needs in the community. The current model also incentivises private for-profit providers - 37% of people with a learning disability and autistic people detained in inpatient settings are in beds run by the independent sector²⁰ - to run at full capacity, which disincentivises them to discharge people or question inappropriate referrals.

We strongly support reforming the Mental Health Act to prevent people with a learning disability and autistic people without co-occurring mental health conditions being sectioned under Section 3, Part 2 of the Mental Health Act, but this legal reform must be accompanied by proper, planned investment in developing the right community support to ensure that alternative poor outcomes for people with a learning disability and autistic people, such as being redirected into the criminal justice system, do not occur. **To be successful, these two reforms must occur concurrently.**

High-quality community support for people with a learning disability improves quality of life and is more cost-effective²¹, but because of the above perverse incentives and funding being

¹⁷ [CBF, Mencap, Rightful Lives, Learning Disability England: Written evidence](#)

¹⁸ [IFS: How have English councils' funding and spending changed? 2010 to 2024](#)

¹⁹ [Health and Social Care Committee: the treatment of autistic people and people with learning disabilities](#)

²⁰ [NHS Digital: Learning disability services monthly statistics from Assuring Transformation dataset \(May 2024\)](#)

²¹ [BASW: Three Examples of Best Practice Commissioning with Citizens and Communities; Investing in Early Intervention; Lemmi et al., 'What is standard care for people with learning disabilities and behaviour that challenges and what does it cost?'; McGill and Poynter, 'How much will it cost? Characteristics of the most expensive residential placements for adults with learning disabilities'](#)

distributed in the wrong places²², there is currently neither the necessary levels of investment nor the political will at national, regional and local levels to develop this.

There is also a serious issue with financial management. A significant amount of taxpayer money is being spent, but without effective oversight of what it is being spent on, or whether it is working. In 2022, RedQuadrant published its report on the Building the Right Support funding flows²³ - finding that the “limited ability to analyse financial data... [and] extract national or regional financing reporting”²⁴, which also meant that they had limited data to draw conclusions from, prevented the Department of Health and Social Care, NHS England, and other partners from being assured that “resources are being allocated and spent in the most effective way”, and from being able to identify the impact that investment was having²⁵.

Evidence-based policy and practice to improve community support

Investing in early intervention

Ensuring children and young people have access to early intervention and support both improves quality of life and outcomes and leads to future savings. The following reports provide further detail of these benefits and share examples of early intervention services, with recommendations and guidance for commissioning and implementing these in other areas:

- [Paving the Way](#)
- [Investing in Early Intervention](#)

When children and young people have access to support early on - including communication and speech and language support; early identification and timely autism assessments; and behavioural support - they have a better quality of life, can develop new skills²⁶ and have a reduced likelihood of developing challenging behaviours²⁷. These interventions improve outcomes, helping avoid inpatient admissions and the need for residential care (whether a school placement or as an adult), developing skills to support independent living, and supporting educational outcomes and future employment - leading to significant cost savings over time²⁸.

By ensuring that local areas have sufficient funding and that commissioners have the right knowledge to commission these services - engaging in market-shaping if these services are not currently available in their area - the government can reduce the need for inpatient/residential services, improving quality of life and saving money, which can then be invested more effectively elsewhere.

²² [VODG: Building the Right Support Position Paper](#); [ITV News/Mencap: Millions spent on keeping adults with learning disabilities locked up](#); [Autism Alliance: Doing the Right Thing](#)

²³ [Building the Right Support - An Analysis of Funding Flows](#)

²⁴ [Building the Right Support - An Analysis of Funding Flows](#)

²⁵ [Building the Right Support - An Analysis of Funding Flows](#)

²⁶ [Paving the Way](#)

²⁷ [CBF: Early intervention for children with learning disabilities whose behaviours challenge](#)

²⁸ [Pro Bono Economics: Wasting money, wasting potential](#); [Paving the Way](#); [Investing in Early Intervention](#)

Workforce

To ensure that people with a learning disability and autistic people can access skilled support in the community, the government must address the low rates of pay and high turnover within this sector. ARC England analysis shows that local authorities need to increase funding for providers by at least 12% in 2024/25 for them to be able to pay staff the National Living Wage²⁹. Low wages, combined with skilled and difficult work, has led to many support workers leaving the sector for better paid, less strenuous roles elsewhere³⁰. Having consistent and skilled support workers is crucial for people with a learning disability and autistic people, particularly those with complex needs and/or behaviours that challenge³¹. High staff turnover (in turn leading to staff not knowing the person well and potentially not having the necessary skills and knowledge to support them) leads to poorer outcomes.

Ensuring that local authorities have sufficient funding to meet these costs and matching pay for social care staff and support workers to NHS Band 3³² will increase the ability of skilled support workers to remain in the sector and address the interlinked issues of high staff turnover and reliance on expensive agency staff who may not have the appropriate skills³³. Matching pay for support workers to NHS Band 3 has widespread public support³⁴.

As well as tackling the high levels of support worker turnover, consistency of other professionals that work with the person also leads to better outcomes. The 2018 Named Social Worker pilot found that people who had a named social worker were discharged from inpatient units faster, experienced less restrictive practices, had better packages of support and experienced a better quality of life³⁵. The pilot also resulted in lower costs for care, improved skills and job satisfaction for the social worker, and more effective cross-service coordination³⁶. By building on the learning from the pilot and introducing the right to a named social worker, children, young people and adults with a learning disability will receive better and more effective support.

Suitable housing

A 'lack of suitable housing' is the most common reason that people with a learning disability and autistic people are unable to be discharged from inpatient units, with over half of delayed discharges resulting from this³⁷. Whether funding to buy, rent and/or develop housing is available can be dependent on where someone lives - creating a postcode lottery.

Research by the Learning Disability and Autism Housing Network and HousingLIN has found that 1,800-2,300 new units of supported housing will need to be developed per year to meet demand³⁸. Approximately 86.5% of capital funding for developing supported housing for

²⁹ [ARC England: Fee Rates for Learning Disability and Autism Services by Local Authority 2023-24](#)

³⁰ [Mencap: Why We Care report](#)

³¹ [CQC: Adrian Hartley \(blog\)](#); [Mencap: Why We Care report](#); [CQC: State of Care 2022/23](#)

³² [ARC England calls for minimum 12% fee rate uplift following publication of 2023-24 Fee Rate Maps](#); [Unfair to Care 2024](#); [VODG: New Analysis Demonstrates Stark Pay Inequalities for Social Care Workers](#); [LGA: Autumn Statement 2023](#)

³³ [Unfair to Care 2024](#)

³⁴ [Learning Disability England: Good Lives Manifesto](#)

³⁵ [SCIE: Named Social Worker Pilot - Summary of Key Findings](#); [SCIE: Named Social Worker](#)

³⁶ [SCIE: Named Social Worker Pilot - Cost Benefit Analysis](#); [SCIE: Named Social Worker Pilot - Summary of Key Findings](#)

³⁷ [NHS Digital: Learning disability services monthly statistics from Assuring Transformation dataset \(March 2024\)](#)

³⁸ [LDAHN and HousingLIN: Research summary](#)

people with a learning disability and autistic people since 2017 has come from private and non-public finance, compared to 8.5% NHS England, 3.5% Homes England, and 1.4% local authority funding³⁹.

Much can be achieved when NHS and local authority commissions work in partnership with third sector providers on capital investment programmes that enable the right kinds of accommodation to be secured. However, this good practice is currently far from mainstream.

Working with local areas and housing providers (including from the third sector) to understand local housing needs and to develop housing for people with a learning disability and autistic people **will both enable people to avoid admission to inpatient settings and enable those who are currently detained to be discharged into the community.**

Respite, short breaks and emergency accommodation

Respite care is “care provided to a person with a learning disability [or autistic person] by someone other than their usual carer for a short period of time so that the carer can have some time to look after their own wellbeing”⁴⁰. This can be in the form of short breaks, which are opportunities either for someone with a learning disability/who is autistic to go on a break - for example, to a holiday scheme, day service, or residential breaks service - or for family carers to go away while someone else provides care to their relative⁴¹. Respite and short breaks are crucial as they both provide support for someone with a learning disability/who is autistic and can enable family carers to support their own wellbeing and be able to continue caring for their relative sustainably - both of which avoid ‘crisis’ situations and inappropriate admissions to inpatient settings.

Emergency accommodation is temporary accommodation that someone with a learning disability or who is autistic can use in a crisis; for example, if their house is damaged or unsafe, or if they have had to leave a tenancy before a new provider has been found. Like respite and short breaks, emergency accommodation can stop people with a learning disability and autistic people from being admitted to inpatient settings - but there is a shortage of all three of these.

By supporting areas to assess their local population needs for respite, short breaks and emergency accommodation, and ensuring that they have suitable funds and the right knowledge to commission these services, the government will be able to reduce the number of people being detained in inpatient settings.

Coordinated support and services

One of the major issues that people with a learning disability and autistic people face is that support and services are disjointed. The ‘cliff edge’ of transition from children’s to adult services is well-recognised as a serious issue and can contribute to crisis and inappropriate

³⁹ [LDAHN and HousingLIN: Research summary](#)

⁴⁰ [Mencap: Short Term Care and Respite Care factsheet](#)

⁴¹ [CBF: Short Breaks](#)

admissions⁴². There is a lack of coordination between health, social care, education, and housing, which make it difficult for people to access the right support, and - if they have been detained under the Mental Health Act - for the right support to be put in place for them to be discharged.

When joined-up working is in place, people with a learning disability and autistic people experience better outcomes. An example of how joined-up working can be achieved, and the benefits that it has, can be seen in the introduction of keyworkers for autistic children and young people and children and young people with a learning disability (currently targeted at children and young people who have been, or are at risk of being, detained under the Mental Health Act) - with findings from pilot sites showing that having a keyworker makes the system more responsive and helps these children and young people, and their families, to access the right support more quickly⁴³. Extending this work to make keyworkers available as a proactive measure (i.e., before the risk of inpatient admission arises) is likely to deliver good outcomes and reduce crisis management.

Conclusion – a win-win opportunity

For the last 12 years, there has been universal recognition that better community support is needed for people with a learning disability and autistic people, and that without this, they will continue to be inappropriately detained in inpatient units. However, this recognition has not been translated into change. The policies that have been introduced and the reforms that have been made have been reactive, piecemeal and disjointed, rather than strategically addressing the systemic issues. There has been no effective and sustained oversight and accountability for these policies' success - or failure.

There are known solutions to these issues. This briefing, co-produced by a group of stakeholders with significant knowledge and experience, sets out a range of concurrent actions that would improve the availability and quality of community support for people with a learning disability and autistic people; help stop people being inappropriately detained and support people who are currently detained to be discharged; and be more cost-effective - stopping taxpayer money being wasted on harmful practices, and instead spending less money overall on better support that is provided in the right places, at the right time⁴⁴.

This government has a great opportunity to work with a range of stakeholders to deliver a coordinated and systemic approach and ensure that people with a learning disability and autistic people have their rights upheld in a system that supports them, is sustainable, is cost-effective, and above all delivers good outcomes.

⁴² [CBF: Transition from Children to Adult Services](#); [DHSC: Care and support statutory guidance](#); [Tizard Centre: Transition to adult social care](#); [Transitions to adulthood for disabled young people: literature review](#); [NICE: Transition from children's to adults' services for young people using health or social care services](#); [Mencap: 'Tom's Story'](#)

⁴³ [NHS England » Children and young people keyworkers](#)

⁴⁴ [Association for Supported Living: There is an Alternative](#); [Rightful Lives and Mark Brown: Written evidence](#)

Contact details

If you have any further questions or would like to arrange a meeting to discuss community support/the issues facing people with a learning disability and autistic people further, please refer to this list of key contacts for our organisations:

- **ARC England:** Clive Parry (England Director) - clive.parry@arcuk.org.uk
- **Autism Alliance:** Adam Micklethwaite (Director) - adam@autismalliance.org.uk
- **British Association of Social Workers (BASW):** Maris Stratulis (National Director) - england@basw.co.uk
- **Challenging Behaviour Foundation (CBF):** Vivien Cooper (Chief Executive Officer) - vivien.cooper@thecbf.org.uk
- **Learning Disability England (LDE):** Samantha Clark (Chief Executive) - samantha.clark@ldengland.org.uk
- **Mencap:** Jameela Khan (Parliamentary Affairs Officer) – jameela.khan@mencap.org.uk
- **National Autistic Society (NAS):** Sam Forrester (Policy and Parliamentary Officer) – sam.forrester@nas.org.uk
- **Rightful Lives:** Julie Newcombe (Co-Founder) - julienewcombe@rightfullives.net
- **VoiceAbility:** Stephen Hinchley (Senior Policy and Public Affairs Officer) – stephen.hinchley@voiceability.org
- **Voluntary Organisations Disability Group (VODG):** Sarah Woodhouse (Head of Policy and Influencing) - sarah.woodhouse@vodg.org.uk