

Written evidence submitted by The Challenging Behaviour Foundation

About the Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is a national charity which supports children, young people and adults with a severe learning disability whose behaviour challenges and their families. The CBF exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy ordinary life opportunities when their behaviour is properly understood and appropriately supported.

Further information about the Challenging Behaviour Foundation can be found on our website here: <https://www.challengingbehaviour.org.uk>

Importance of adult social care for people with a learning disability

Adult social care has a critical role in ensuring that people with a learning disability are able to live good lives in their local community. The amount of adult social care required can vary greatly (from a few hours a week to 24-hour support) as there is a wide spectrum of support needs across the population. This population is likely to require lifelong support, especially if the person has a [severe learning disability](#) and requires support with all everyday living tasks. Failing to provide this essential social care support has a significant detrimental effect on the individual as well as knock on effects and financial consequences for other parts of “the system” including health.

However, the social care system at present does not meet these needs. This failure includes a failure to invest in early intervention, support and services (with a crisis management approach adopted), and a lack of a valued and trained workforce. The lack of suitable community support and services for people with a learning disability means that people with a learning disability cannot access the social care support that they need and are often unnecessarily admitted to NHS-funded inpatient units¹, where they are at greater risk of seclusion and restrictive practices.² The average length of stay in an inpatient unit is over 5 years, with people with a learning disability not being discharged as there is no suitable community provision for them.³ The

¹ For evidence of people with a learning disability being unnecessarily admitted to inpatient units due to a lack of community support, please see: <https://committees.parliament.uk/publications/6669/documents/71689/default/>; ‘lack of agreed social care funding’, ‘awaiting care package in own home’, and ‘lack of social care support’ are key reasons listed for delayed discharge in the Learning Disability and Autism Assuring Transformation statistics: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

² [Out of sight – who cares?: Restraint, segregation and seclusion review - Care Quality Commission \(cqc.org.uk\)](#)

“urgent need for radical reform” in adult social care for people with a learning disability was highlighted by Baroness Hollins in her November 2023 letter to the Secretary of State for Health and Social Care⁴, but we are yet to see a plan that will adequately address these issues.

Significant evidence is available about what adult social care support is needed to ensure that people with a learning disability are supported to live good lives – and has been available for many years. We are deeply concerned that the government’s current adult social care policies will not meet these needs.

As many adults with learning disabilities live with and are supported by their family carers, adult social care also has a crucial role in supporting family members of people with a learning disability, many of whom are unpaid carers supporting their relatives. There are significant barriers to accessing the support that unpaid carers need⁵ – this has serious impacts on their quality of life, including health, finances, and emotional wellbeing, as well as their ability to support their relatives⁶. In worst case scenarios, as with individuals living in residential care or supported living without the right level of social care support, not being able to receive the adult social care support that unpaid carers both need and are entitled to can result in families being unable to continue supporting them, and their relatives being unnecessarily admitted to health funded inpatient units.

Lack of coordination and leadership

In *People at the Heart of Care*, the government affirmed a commitment to ensuring coordination between different parts of the system – including making “every decision about care a decision about housing”. However, there are still serious issues with coordination between care and housing, with people with a learning disability unable to access the housing that they need. A lack of suitable housing is the main reason for delayed discharge from inpatient settings⁷, and families that we support have told us that not being able to access housing that meets their relative’s needs is a major reason for admission.

We are also deeply concerned that there is no clear leadership from and across the government when it comes to responsibility for ensuring that adult social care meets the needs of people with a learning disability. The Building the Right Support action plan, published in 2022, was widely criticised for not only failing to contain a coherent overall strategy, but also lacking SMART targets.⁸ The Building the Right Support Delivery Board meets only 4 times a year, for 60–90-minute meetings, and the Minister responsible for chairing these meetings has changed multiple times since the board was established. Despite its name, this Board is not ‘delivering’ the transformation of care, but providing broad oversight and there is little or no evidence of its impact – the much revised and delayed targets to prevent inappropriate admission to inpatient services will be missed again in March this year.⁹

³ [Transforming Care data - Challenging Behaviour Foundation](#)

⁴ [Baroness Hollins' letter to the Secretary of State for Health and Social Care about the Independent Care \(Education\) and Treatment Reviews - GOV.UK \(www.gov.uk\)](#)

⁵ For further evidence on the barriers facing unpaid carers in terms of adult social care, please see: [Understanding unpaid carers and their access to support - The Health Foundation](#)

⁶ [Impact of caring on families - Challenging Behaviour Foundation](#); [State of Caring survey | Carers UK](#)

⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

⁸ [Health Department’s plan for detained patients falls well short of what’s needed | Equality and Human Rights Commission \(equalityhumanrights.com\)](#)

Across the sector there is a lack of clear leadership and ownership for ensuring a) that there is the right social care support for adults with a learning disability, and b) that the different parts of the system responsible for providing this support are communicating and coordinating with each other. The RedQuadrant report into funding flows of the Building the Right Support programme found that there is no national mechanism for measuring investment in preventative and crisis support programmes (which are set out in the Building the Right Support service model), and that there is limited oversight, on both a regional and national level, of council spending and investment on people with a learning disability and autistic people.¹⁰ There is also a lack of focus on social care specifically, with the focus instead being on health. Without clear leadership and a strong focus on social care, people with a learning disability will not get the support that they need and will be at risk of poor outcomes, including detention under the Mental Health Act.¹¹

Funding

We are seriously concerned at the reduction in funding for adult social care between what was promised in *People at the Heart of Care* in 2021 and the government's revised plans in 2023. The funding allocated in 2021 was already limited, particularly in relation to the funding allocated for supporting people with a learning disability, and the further reduction will seriously impact the effectiveness of the reforms. In addition to this, the numbers announced do not fully reflect the funding that will be available for adult social care, as highlighted by the Local Government Association in their submission prior to the 2023 Autumn Statement: <https://www.local.gov.uk/parliament/briefings-and-responses/autumn-statement-2023-lga-submission#appendix-2-adult-social-care->

There are two main issues with funding for adult social care for people with learning disabilities: firstly, ensuring that there is adequate funding available, and secondly, ensuring that this funding is invested in the right places. A major issue is that funding to support people with a learning disability is being focused in the wrong areas. There is a significant amount of funding focused on crisis support and in commissioning expensive inpatient and/or out-of-area services¹², rather than focusing on early intervention – ensuring that people with a learning disability and autistic people can get the right support early on, and that issues do not worsen and reach a point of crisis.¹³ Focusing investment and spending on these areas would both support people with a learning disability and autistic people to live good lives – a human benefit – and lead to cost benefits by reducing the need for high-intensity crisis and (often for-profit) inpatient services.¹⁴ Further integration and pooling of budgets would also be useful in ensuring

⁹ [One year on from the publication of the Building the Right Support Action Plan - Challenging Behaviour Foundation](#)

¹⁰ [Building the Right Support: An analysis of funding flows \(publishing.service.gov.uk\)](#), p.32

¹¹ Dan Scorer - [Draft Mental Health Bill oral evidence](#)

¹² The RedQuadrant funding flows report concluded that out of area inpatient placements contributed to increased costs across the system: [Building the Right Support: An analysis of funding flows \(publishing.service.gov.uk\)](#), p.83; we have also received evidence on this from our work and our conversations with people working within the system, including commissioners

¹³ For evidence that early intervention prevents reaching a crisis point, please see: [Paving-the-Way.pdf \(challengingbehaviour.org.uk\)](#); [Building the Right Support: An analysis of funding flows \(publishing.service.gov.uk\)](#), p.95; David Nuttall - [Draft Mental Health Bill oral evidence](#)

¹⁴ <https://cerebra.org.uk/wp-content/uploads/2022/05/EARLY-INTERVENTION-REPORT-A4-FINAL.pdf>; Lemmi et al.,

coordination between services, sharing risks of investing in new and innovative services, and tackling perverse incentives; as discussed in the final section of this response, investing in one part of the system can lead to savings in other parts, but as these savings would not necessarily be seen by the original investor, there is a reluctance to develop these preventative services.

Recent research suggests that closing the gap in provision for specialist social care services for autistic people with a moderate learning disability would cost £69.5-139.2 million - between 0.4-0.7% of the current overall adult social care spend.¹⁵ Research by the Learning Disability and Autism Housing Network and HousingLIN has found that approximately £340 million needs to be invested per year to ensure that the supply and quality of supported housing meets needs.¹⁶ The cost of providing care is rising faster than local, regional, and national investment.¹⁷ It is crucial both that there is an increase in funding, and that this funding is directed to the right places - this will have both human and economic benefits over the long term. This is a long-term issue, and certainty and stability of investment in social care for people with a learning disability is required.

Workforce

High turnover and a lack of consistency within the adult social care workforce leads to poorer outcomes for people with a learning disability.¹⁸ It is also crucial that there is high quality, specialised training for social care staff who support people with a learning disability, and in particular people with severe learning disabilities and/or behaviour that challenges, as specific and specialised skills are needed for them to receive the right support. While we recognise that there are many ways to improve staff retention and training, including by increasing training, progression opportunities and recognition of skills gained, it is crucial that any reforms are accompanied by sustained investment in the system – both families and care providers have told us that a lack of proper pay for care workers (with many receiving minimum wage, which can be reduced even further if providers do not include travel time within their hours or do not cover the costs of petrol for care workers who have to travel to multiple places) is one of the main reasons that they struggle to recruit and retain the skilled staff that are needed. This is exacerbated by low fee rates for Learning Disability and Autism Services – recent research

‘What is standard care for people with learning disabilities and behaviour that challenges and what does it cost?’, British Journal of Learning Disabilities, 2016, <https://onlinelibrary.wiley.com/doi/10.1111/bld.12168>; McGill and Poynter, ‘How much will it cost? Characteristics of the most expensive residential placements for adults with learning disabilities’, Tizard Learning Disability Review, <https://www.emerald.com/insight/content/doi/10.5042/tldr.2011.0170/full/html>

¹⁵ Autism Alliance, ‘Mapping supply and demand for care services for autistic adults in England’, November 2023

¹⁶ <https://www.housinglin.org.uk/Topics/type/Supported-housing-for-people-with-learning-disabilities-and-autistic-people-in-England/>

¹⁷ <https://www.adass.org.uk/adass-autumn-survey-part-2-final-report-press-release>

¹⁸ Murray et al, ‘Exploring the relative importance of factors that influence the job retention of social care staff working in intellectual disability services’, British Journal of Learning Disabilities, 2021, <https://onlinelibrary.wiley.com/doi/full/10.1111/bld.12365>; Stevens, ‘Commentary on ‘workforce development: perspectives from people with learning disabilities’, Tizard Learning Disability Review, 2018, <https://www.emerald.com/insight/content/doi/10.1108/TLDR-08-2018-0024/full/html>; ‘Tom’s Story’ and ‘Christopher’s Story’ <https://www.mencap.org.uk/sites/default/files/2022-03/2021.094%20Social%20Care%20Research%20Report%20FINAL.pdf#page=6>; Bengi O’Reilly - [Draft Mental Health Bill oral evidence](#); we have also heard this in focus groups with, and our work supporting, family carers

shows that 94% of local authorities do not pay rates for supported living services that allow providers to pay the National Living Wage.¹⁹ The government state that they do not have any current plans to create a national minimum wage for care workers in England (Scotland and Wales have already introduced policies mandating minimum care worker wages) – however, we echo calls for care and support worker wages to be matched with equivalent NHS bands, and believe this would lead to an improvement in both the recruitment and retention of staff and the quality of support received by people with a learning disability.²⁰

The separation of adult social care and children’s social care

A holistic and lifelong approach to social care support for children and adults with learning disabilities is required in order to adequately address social care needs. As stated above, investing in one area can lead to benefits – both in terms of cost savings, and in positive outcomes for people with social care needs – in others. For people with learning disabilities, significant benefits can be achieved in and by adult social care by investing in strong services for children and young people.

We would like to highlight that it is possible to create significant cost savings within adult social care by investing in children’s social care, and specifically in early intervention programmes for children with learning disabilities. Examples of the link between investing in early intervention programmes for children and young people with learning disabilities, and the costs of adult social care and support – as well as evidence of the cost impacts of early intervention programmes being unavailable – can be found here: <https://cerebra.org.uk/wp-content/uploads/2022/05/EARLY-INTERVENTION-REPORT-A4-FINAL.pdf>

NICE guidance recommends a lifelong approach to commissioning support and services for individuals with learning disabilities whose behaviour challenges²¹ but this rarely happens. We would also like to highlight the importance of adult social care being involved in the transition from child to adult services. Families that we support tell us that the ‘cliff edge’ of transition (and a failure to provide suitable adult social care for young people moving to adult services) is one of the main areas that can lead to them and their relative reaching crisis point, and that the lack of involvement of adult social care in transition planning is one of the key reasons for this – this is supported by large amounts of research and multiple reports.²²

Social care support is crucial to enable individuals with learning disabilities to lead the lives they have a right to. It needs to be delivered to a high standard where and when it is needed. The

¹⁹ Association for Real Change, [Fee Rates for Learning Disability and Autism Services by Local Authority](https://polimapper.co.uk) (polimapper.co.uk)

²⁰ [VODG | New Analysis Demonstrates Stark Pay Inequalities for Social Care Workers, as VODG Call on Government to Act Urgently; Unfair-To-Care-Summary-Report-Single-Pages.pdf](#) (unfairtocare.co.uk)

²¹ [Recommendations | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE; Arranging services for people with a learning disability and behaviour that challenges | Quick guides to social care topics | Social care | NICE Communities | About | NICE](#)

²² For examples: [Transition-from-Children-to-Adult-Services.pdf](#) (challengingbehaviour.org.uk); [Care and support statutory guidance - GOV.UK](#) (www.gov.uk); [Transition to adult social care - Tizard Research Projects - Research at Kent](#); [Transitions to adulthood for disabled young people: literature review - gov.scot](#) (www.gov.scot); [Overview | Transition from children’s to adults’ services for young people using health or social care services | Guidance | NICE; 'Tom's Story', Mencap](#)

current arrangements are failing individuals with learning disabilities – creating poor outcomes for people and high, and often unnecessary, costs for other parts of the system.

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