

## Written Evidence submitted by The Challenging Behaviour Foundation (ASC0077)

### Adult Social Care Reform: the Cost of Inaction – Challenging Behaviour Foundation response to Call for Evidence

#### 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. Adult social care is a vital component of ensuring that people with severe learning disabilities receive the support that they need, and when it is not operating effectively, people with severe learning disabilities experience significant negative consequences.

Adult social care plays a crucial role in ensuring that adults with severe learning disabilities are well-supported in their local communities. However, experiences of adult social care vary, including depending on postcode. When people with severe learning disabilities are unable to access effective adult social care that meets their needs, they experience significant negative impacts – at a cost to them and their families, but also often at high cost to the system.

A major consequence of adult social care not effectively meeting the needs of people with severe learning disabilities is that this can increase behaviours that challenge. Behaviours that challenge are a means of communication that are used by people with severe learning disabilities who may be non-verbal or have limited speech; these behaviours often are used to convey that needs are not being met. Examples of behaviours that challenge include self-injury, hurting others, destructive behaviours, and pica (eating inedible objects) - further information can be found [here](#). When someone with a learning disability exhibits behaviour described as challenging, they are liable to be detained under the Mental Health Act – many people with learning disabilities are therefore detained under the Mental Health Act if adult social care does not meet their needs. People that we support tell us that lack of community support, including adult social care, is a major reason for why their relative was detained under the Mental Health Act. Similar issues are faced by people with learning disabilities more generally, as well as autistic people, who likewise are liable to be detained under the Mental Health Act even if they do not have a mental health condition.

Failures in adult social care to meet the needs of people with learning disabilities also make it difficult for people to be discharged from inpatient units, even if they have been found to be clinically ready for discharge, as there is nowhere in the community that can meet their needs. The most recent figures

show that “lack of social care support” was a factor in 24% of delayed discharges for people with learning disabilities and autistic people, with “lack of agreed social care funding” a factor in 6% of cases.

Over the past decades there have been multiple proposals on how adult social care could be reformed to better meet these needs, but thus far few of these proposals have been implemented, leading to high human and financial costs. Some of these proposals were highlighted by Baroness Hollins in her [letter to the former Secretary of State](#) following her report into long-term segregation of people with learning disabilities and autistic people in inpatient units. It is disappointing that these were not taken forward and we hope that the new government will take the opportunity to ensure that these recommendations are enacted.

### **How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?**

#### Costs to the NHS

In financial terms, the reliance on inpatient care when adult social care fails to meet the needs of people with learning disabilities and autistic people has high costs. The average yearly cost of a bed in an inpatient setting for someone who is autistic and/or has a learning disability is **£237,000 (2023/24)**. This compares to the average cost of specialist supported housing and a care package, which in [2018](#) was **£1569** per week, or **£81,588** per year – adjusted for inflation, this would be **£103,997** per year as of October 2024. The average cost of detaining someone who has a learning disability and/or is autistic in an inpatient unit is therefore significantly higher than supporting them in the community.

Of the 2050 people with learning disabilities and/or who are autistic that were in mental health inpatient units as of [October 2024](#), the average total amount of time spent in inpatient units is almost 5 years, meaning that the high cost of detention is sustained over a period of several years (for comparison, the average length of time spent by someone in an adult acute mental health bed is [39 days](#)). As stated previously, as well as contributing to detention, a lack of social care support is a major reason for delayed discharges – so once someone with a learning disability/who is autistic is found to be ready for discharge, the delays caused by a lack of suitable adult social care support directly result in higher costs to the NHS.

#### Impacts on the person

Alongside these economic costs, there are the human costs to the person. There is considerable evidence of the unsuitability of mental health inpatient settings for people with a learning disability and/or who are autistic. The Joint Committee on Human Rights has published multiple reports detailing the harm caused by detention, including human rights violations; while these have primarily focused on

young people with learning disabilities/who are autistic, many of the same issues apply for adults. See [here](#) and [here](#) for more details.

Professor Sheila the Baroness Hollins was commissioned by the Government to undertake [a review into the use of long-term segregation](#), also referred to as solitary confinement, used against people with a learning disability and autistic people within inpatient settings. This report found that not only does long-term segregation not have any therapeutic benefits, but that it is traumatic and is understood to be punitive. The Care Quality Commission (CQC) has also produced [reports](#) highlighting human rights violations and harms within these settings, including restraint, restrictions on contact with family (both as punishment, and due to a shortage of staff), and failures to make reasonable adjustments due to disability which are required by law.

CQC found cases of people with learning disabilities/who are autistic that are detained and in seclusion being refused their own clothes, unhygienic environments, and widespread lack of dignity and privacy, with these being used without consideration of whether they are the least restrictive option and/or without less restrictive options being tried. The [most recent statistics](#) show that restrictive practices against people with a learning disability and autistic people in inpatient settings are widespread, with a total of 7520 restrictive interventions being used against people with a learning disability and autistic people within August. A recent [review of advocacy](#) for people with a learning disability and autistic people in inpatient settings found that not only is the current state of advocacy provision inadequate, but also examples of degrading treatment within inpatient settings – including one person who had been held in seclusion for weeks and who was required to pass their poo through a hatch. Mental health inpatient settings, particularly those for people with a learning disability and autistic people, are recognised as being high-risk for abuse, with factors such as closed cultures, distance from home and the placing commissioner/authority, and inadequate advocacy provision contributing to the risk of abuse being perpetrated against those within these settings – examples include [Winterbourne View](#) and [Whorlton Hall](#).

If people with a learning disability were able to access adequate social care support within their communities, many of those currently detained would have been able to avoid this, and those detained would also likely have shorter lengths of stay were the right support available for them within their communities.

### Impacts on the person's family

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 need – this has serious impacts on their quality of life, including health,

finances, and emotional wellbeing, as well as their ability to support their relatives. Further details on the impact of caring for someone with a severe learning disability can be found [here](#).

Additionally, research demonstrates that current experiences of navigating the system (including adult social care) to ensure that their relative can access support that meets their needs and which they are entitled to results in trauma, including complex post-traumatic stress disorder. Further details of this can be found [here](#), [here](#), and [here](#).

Social care reform, if it were to enable their relative to better access support, would in turn improve the wellbeing of family carers.

### **What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?**

As established above, a major cost of not reforming adult social care to ensure that people with learning disabilities can access support in their communities is that people end up detained under the Mental Health Act because there is nowhere else for them to go.

The Mental Health Bill, introduced in November, includes provision to prevent people with a learning disability and autistic people who do not have a mental health condition from being detained under section 3 of the Mental Health Act, but the Department of Health and Social Care have stated that these provisions of the Bill would not be enacted unless there were "strong community services"; this is because of concerns that currently adult social care is not able to meet needs and that, in cases where there is not community support available, detention in hospital is the only available option. Reforming adult social care to ensure that people with learning disabilities can access the right support is therefore necessary for these much-needed reforms to the Mental Health Act to be enacted.

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