

## Written evidence submitted by The Down's Syndrome Association (ASC0044)

### Adult Social Care Reform: The Cost of Inaction

Response from Down's Syndrome Association

#### Executive Summary

The Down's Syndrome Association (DSA) submits this evidence to highlight systemic failures in adult social care for working-age adults with lifelong disabilities, such as people who have Down's syndrome. Despite robust legal frameworks under the Care Act 2014, Human Rights Act 1998, and Public Contracts Regulations 2015, councils often selectively apply the law, prioritising financial considerations over statutory duties. This leads to inadequate care, escalating costs, and harm to individuals and families.

We recommend targeted reforms, including stronger enforcement of existing legal powers, proactive oversight of care providers, and integrated health and social care budgets. These measures are essential to reduce financial waste, improve outcomes, and restore trust in public services.

#### Key Themes and Evidence presented

##### *Selective Application of the Law*

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Councils frequently fail to meet assessed needs under Section 18 of the Care Act, citing budget constraints. This contravenes the statutory requirement to prioritise well-being and independence for individuals.

Safeguarding duties under Section 42 of the Care Act are inconsistently applied, with councils often ignoring or delaying responses to risks due to resource pressures.

##### *Delays and Reactive Approaches*

Delayed assessments and interventions exacerbate safeguarding risks, increase family strain, and result in avoidable hospital admissions.

Councils act reactively, addressing quality issues only after complaints or crises arise, rather than proactively managing care providers.

##### *Inconsistent Oversight of Care Providers*

Local authorities fail to enforce contractual and regulatory standards for care providers, allowing poor-quality services to persist.

Legal powers under the Public Contracts Regulations 2015, such as terminating contracts for non-compliance, are underutilised.

## ***Fragmentation of Health and Social Care Budgets***

Separate budgets lead to duplication, inefficiencies, and delays in hospital discharge and long-term care planning.

Disputes between NHS and local authorities over funding responsibilities often leave individuals without timely support.

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## Down's Syndrome Association

The Down's Syndrome Association is a national charity focusing on all aspects of life for people who have Down's syndrome. Established in 1970, we have over 50 years' experience of supporting people who have Down's syndrome, their families and carers, and professionals working with them. We have around 20,000 members throughout England, Wales and Northern Ireland. The Association provides direct support to 70 affiliated local support groups, and a range of professionals from different agencies. The overarching aim of the organisation is to help people who have Down's syndrome lead full and rewarding lives.

We are the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising primarily the family-carers of children and adults who have Down's syndrome and a growing membership of adults who have Down's syndrome aged 18+. We are well placed to reflect the needs and views of people we seek to serve. The Down's Syndrome Association provides lifelong support, in the form of information and advice for people who have Down's syndrome and their parents and carers. We offer a free Helpline (telephone and email), offering tailored information, advice and support.

We regularly engage with The Department of Health and Social Care, Department for Education, NHS, NICE and other Government departments and are working with Integrated Care Boards (ICBs) across England.

We have a commitment to inclusive participation and work closely with a diverse group of individuals who have Down's syndrome called "Our Voice", who come together regularly to help shape and inform our work.

We employ a specialist adult social care advisor, who has a background in local authority and NHS commissioning. He has also worked in supported living provider services. Families and carers can contact him in writing and via DSA's Helpline. In addition to the provision of rights-based advice, he will signpost appropriate information and support for families as well as providing advocacy and wording for correspondence with local authorities.

*We would be happy to provide oral evidence to this inquiry.*

## About Down's syndrome

Down's syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body's cells. People who have Down's syndrome will have some level of learning disability. This means they will have a range of abilities. Some people will be more independent and do things like get a job.

Other people might need more regular care.

In addition, there are several associated medical conditions, which affect some, but not all, people who have Down's syndrome, meaning the services that they access from the NHS and social care settings are of paramount importance to their wellbeing. It is recommended that people who have Down's syndrome should have extra health checks in early life, and regular health reviews throughout their lives.

We estimate there to be around 40,000 individuals living in the UK who have Down's syndrome.

### Forthcoming Down Syndrome Act Guidance

The Down Syndrome Act (2022) received Royal Assent in April of this year. The Act provided a commitment to provide statutory guidance on several key areas of life to ensure relevant public bodies follow appropriate steps to meet the needs of people who have Down's syndrome. These public bodies include Local Authorities and a range of schools and educational settings.

The Down's Syndrome Association has been involved in the development of the guidance, alongside other organisations. The DS Act Guidance has not yet been published; however, Stephen Kinnock MP recently advised it will be published early in 2025.

### Existing Legal Powers

#### Care Act 2014

Section 9: Councils must conduct needs assessments involving individuals and carers, ensuring assessments are person-centred and legally compliant.

**Section 18:** Local authorities have a duty to meet all assessed needs, regardless of cost considerations.

**Section 42:** Councils must investigate safeguarding concerns and take action to protect individuals at risk.

**Section 5:** Councils must oversee the care market, promoting diversity and quality among providers.

### **Public Contracts Regulations 2015**

Councils can terminate contracts with providers for breaches of quality standards or non-compliance.

Contracts can include penalty clauses to enforce accountability and incentivise high performance.

### **Human Rights Act 1998**

Councils must ensure care decisions comply with the European Convention on Human Rights, particularly Article 8 (Right to Private and Family Life) and Article 3 (Freedom from Inhuman and Degrading Treatment).

### **Children and Families Act 2014**

For young people transitioning to adult services, councils have a duty to provide continuity and ensure smooth transitions.

## Challenges in Practice

We have evidence that despite robust legal frameworks, councils often selectively apply the law, prioritising financial considerations over statutory duties. This leads to inadequate care, escalating costs, and harm to individuals who have Down's syndrome and their families.

Please refer to the case studies provided in Appendix 1.

Despite the robust legal frameworks detailed on the previous page, systemic issues persist due to:

- **Budget-Driven Decisions**

Councils frequently cite financial constraints to justify reducing care packages or delaying assessments, ignoring their statutory duties.

Some local authority Direct Payment rates are insufficient to source high quality support, especially for people who live in rural areas where it can be harder to recruit carers/personal assistants due to extra travel time and costs.

Annual reviews do not take place in line with statutory rights, meaning packages of support are not reviewed. This can mean that Direct Payment rates are not adjusted to consider inflationary uplifts/increases in the minimum wage, leading to difficulties in recruiting or retaining carers/personal assistants.

People are being forced into poverty due to levels of contribution required, leaving them with insufficient income.

People who have Down's syndrome who develop dementia at an earlier age may be forced to move into older persons residential 'specialist dementia' accommodation due to a lack of suitable housing and support.

- **Limited Enforcement**

Councils rarely face consequences for non-compliance, enabling repeated breaches of legal duties.

The Local Government and Social Care Ombudsman (LGSCO) lacks the power to impose significant penalties, limiting its deterrent effect.

- **Reactive Approaches**

Councils focus on addressing complaints and crises rather than investing in preventative care and proactive oversight of providers.

- **Provider Management Gaps**

Councils fail to monitor care providers effectively, allowing poor performance to persist.

Legal powers to terminate contracts or impose penalties are underused, leaving individuals in unsuitable placements for prolonged periods.

People who have Down's syndrome are not always presented with the full range of housing options available to them.

People who have Down's syndrome who have developed dementia are often forced to live in older persons' residential 'specialist dementia' accommodation.

- **Inaccessible assessments and poor information**

Assessments are not inclusive, and people who have Down's syndrome are not always given a full range of options and choices about how they can personalise the assessment process.

Support planning is often led by social workers and there is limited personalisation of the process which is what the Care Act stipulates.

People are not always routinely offered a Direct Payment or may be told that it is only to employ personal assistants (which is not true). Some local authorities offer a 'Direct payment rate' that is often insufficient to source high quality support. People and families are often unclear on the personal budget setting process and their right to have a 'sufficient' budget to buy support taking account of the costs of services locally.

The Care Act guidance makes it clear that local authorities should also develop an offer around Individual Service Funds but, in practice, most people and families have not been offered this option.

## Recommendations for Reform

We recommend targeted reforms, including stronger enforcement of existing legal powers, proactive oversight of care providers, and integrated health and social care budgets. These measures are essential to reduce financial waste, improve outcomes, and restore trust in public services.

- **Mandatory Transparency and Accountability**

Require councils to publish annual reports detailing compliance with Care Act duties, safeguarding actions, and provider oversight outcomes.

A PA-rate calculator tool could be developed which provides a model for local authorities to set Direct Payment amounts, depending on where the recipient lives, taking into account factors such as local salaries for comparable jobs and premiums for those living in rural areas, to ensure that Direct Payments are always sufficient to purchase appropriate care/personal assistant support.

- **Strengthened LGSCO Powers**

Empower the Ombudsman to impose financial penalties on councils for repeated or systemic failures.

- **Proactive Oversight of Providers**

Mandate independent audits of care providers annually, with clear requirements for local authorities to act on findings.

Regional enforcement teams monitoring local authority compliance, with powers to intervene when necessary.

- Introduce “Rapid Response” teams within local authorities to address quality concerns swiftly.

### **Integrated Budgets for Health and Social Care**

Expand pooled budgets to improve coordination between local authorities and NHS services, reducing delays and duplication.



- **Enforce Legal Duties Consistently**

Update statutory guidance to clarify that budgetary pressures cannot override legal obligations under the Care Act, Human Rights Act, or Public Contracts Regulations.

Establish regional enforcement teams to monitor council compliance and intervene where necessary.

- **Proactive Removal of Failing Providers**

Establish fast-track mechanisms for councils to replace failing care providers while safeguarding individuals' continuity of care.

Expand Care Quality Commission (CQC) emergency powers to address systemic issues rapidly.

- **Shift to Prevention and Independence**

Prioritise funding for community-based, preventative services that reduce reliance on crisis interventions and hospital admissions.

Reinvest in social housing, allowing more people to move into affordable housing options.

Consider passing housing benefit to local authorities, which would ensure that they have an interest in negotiating local rents to have cost effective local commissioning.

- **Changes to contributions for care for disabled people**

Centrally set a minimum income guarantee which increases in line with inflation/cost of living annually.

Contributions for care to be removed for disabled people of working age, or a premium to be added to the minimum income guarantee for them.

## Potential Benefits of Reform

We need to ensure that outcomes are improved for people who have Down's syndrome. The recommendations we have suggested aim to:

- **Improve Outcomes for Individuals**

Individuals who have Down's Syndrome would receive timely, person-centred care that promotes independence and well-being.

- **Enhance Economic Efficiency**

Reducing failure demand and duplication through integrated budgets and proactive oversight would save significant resources for councils and the NHS.

- **Increase Public Confidence**

Transparent and consistent application of legal duties would rebuild trust in the social care system, benefiting individuals, families, and communities.

## Appendix 1

### Case Studies - Introduction

The following case studies are real examples drawn from complaints that the Down's Syndrome Association (DSA) has helped to write on behalf of families. These cases highlight the systemic challenges faced by individuals with lifelong disabilities, such as Down's syndrome, in accessing equitable and high-quality adult social care.

They reflect recurring themes of councils failing to meet their statutory duties under the Care Act 2014, Human Rights Act 1998, and related legislation. Each case was escalated due to significant failures in the delivery of care, often requiring intervention from the Local Government and Social Care Ombudsman (LGSCO) or other authorities.

These case studies demonstrate:

- The selective application of statutory duties, often driven by cost-saving priorities.
- Delayed or inadequate responses to safeguarding concerns.
- Prolonged delays in assessments, care planning, and service provision.
- Persistent failures to monitor and act on poor provider performance.

The appended examples provide evidence of the human and financial costs of these systemic failures and underscore the urgent need for reform. They also illustrate the critical role of advocacy in ensuring individuals and families receive the care and support to which they are legally entitled.

These case studies are anonymised to protect the privacy of the individuals involved but represent real experiences that families have faced. They serve as a vital foundation for the recommendations outlined in this submission, showing the tangible impact of the issues discussed.

These case studies demonstrate how systemic failures, procedural delays, and cost-driven policies contribute to *failure demand*—the additional workload created by not getting it right the first time.

LGSCO findings consistently highlight the need for councils to act proactively, involve families, and comply with their statutory duties.

## **A. The Cost of Inaction to Individuals and Families**

### **Case Study: A's Struggle with Self-Harm and Isolation**

*A is a 32-year-old woman who has Down's syndrome and significant learning disabilities. For years, she thrived in a supported living environment tailored to her needs. However, after budget cuts by her local council, her care hours were significantly reduced, and she was moved to a setting that did not cater to her sensory or emotional needs. Over the past six months, A has stopped speaking entirely and has begun self-harming—a behaviour she had not exhibited for over a decade. Her family repeatedly requested reviews of her care plan under the Care Act, but the local authority delayed these by over eight months. In the meantime, A has been admitted to the hospital twice due to injuries resulting from her self-harm. Her parents, now in their late 60s, have had to step in to provide daily support, sacrificing their own health and financial stability.*

#### **Impact:**

- A's health has deteriorated due to unmet needs.
- NHS costs have increased due to emergency hospital admissions.
- Her parents have reduced working hours, losing over £20,000 annually in combined income.

### **Case Study: S and the Safeguarding Breaches**

*S is a 29-year-old man who has Down's syndrome living in an assisted accommodation block. Despite S's clear preference for a smaller, quieter living arrangement, the council placed him in a large LATC-run (Local Authority Trading Company) facility. S faced multiple incidents of neglect, including being left unattended for hours despite a documented risk of choking. His mother filed safeguarding alerts, but the responses were inadequate and failed to address systemic issues. When the family questioned the suitability of the placement, the council deflected, claiming it was "fair and affordable." S's emotional well-being has suffered, and he now requires counselling to address anxiety stemming from his care experience.*

#### **Impact:**

- The local authority failed to comply with the Care Act's co-production and safeguarding principles.
- S's mental health deteriorated, increasing reliance on NHS mental health services.
- The family spent £4,500 on private therapy and legal fees to challenge the council's decisions.

## **B. Strain on the NHS**

### **Case Study: L's Discharge Delays**

*L, a 24-year-old woman who has Down's syndrome, was admitted to the hospital with a respiratory infection. While medically fit for discharge after eight days, she remained in the hospital for an additional three weeks because the council could not identify an appropriate care placement. L's mother, who acts as her primary advocate, repeatedly asked the council to expedite the process, citing L's increased risk of hospital-acquired infections. The delay not only prolonged L's hospital stay but also worsened her anxiety and sensory processing difficulties.*

### **Impact:**

- L occupied a hospital bed for 21 unnecessary days, costing the NHS approximately £8,400.
- Her emotional health deteriorated, requiring additional therapy sessions.
- The family incurred £600 in transport and accommodation costs to stay near the hospital.

## **C. The Local Authority Perspective**

### **Case Study: J's Emergency Nursing Placement**

*J, a 35-year-old woman who has Down's syndrome and early-onset dementia, required urgent relocation when her supported living provider withdrew services due to staffing shortages. Despite her family's active involvement in advocating for her needs, the council moved J into an emergency nursing home without prior consultation. The placement, designed for elderly residents, lacked the expertise to support younger adults who have dementia. J became withdrawn and displayed behavioural challenges, which the home reported as "non-compliance." The family's repeated attempts to engage with the council were met with delays and minimal communication.*

#### **Impact:**

- J's condition deteriorated, requiring two crisis interventions by mental health teams.
- The council has spent over £3,000/month on a placement ill-suited to her needs, potentially incurring future costs for more intensive interventions.
- J's family has filed a formal complaint, escalating the administrative burden on the council.

## D. Human Rights and Ethical Considerations

### Case Study: S's Battle for Independence

*S is a 41-year-old woman who has Down's syndrome who has lived independently in her own home for over a decade with support funded through direct payments. When the council decided to review her care package, it proposed cutting her personal assistant (PA) hours by 50%, citing cost-saving measures. The council did not consult S or her family during this process, breaching the Care Act's principles of co-production. S's PA provided vital assistance with cooking, managing finances, and accessing the community. The proposed cuts would have left S unable to shop for food or attend her weekly social group, severely impacting her quality of life. After a lengthy dispute, the family secured legal representation to challenge the council's decision.*

#### Impact:

- The family spent over £6,000 on legal fees.
- S experienced a loss of confidence and independence, resulting in increased reliance on NHS mental health services.
- The council's failure to comply with statutory duties could expose it to Ombudsman action and compensation claims.

These case studies provide concrete examples of the human and financial costs of inaction in adult social care. They highlight systemic failures across the NHS, local authorities, and wider social care systems and reinforce the need for urgent, targeted reforms.

### Case Study: D's Endless Appeals for Support

*D, a 38-year-old man who has Down's syndrome and severe autism, had lived in a supported living environment for five years with a package tailored to his complex sensory and behavioural needs. Following a council review focused on savings, his care hours were cut by 40%, despite his assessed needs remaining the same. The family's objections were ignored, and D began displaying signs of distress, including refusing meals and becoming physically aggressive—behaviours not seen in years. The family filed a formal complaint, escalating to the LGSCO after the council delayed its response for over six months. The Ombudsman ruled in the family's favour, stating the council had failed to properly assess D's needs and co-produce his care plan. However, by this time, D's behaviour had escalated to the point that he required crisis intervention and a temporary hospital stay.*

#### Impact:

- The council incurred additional costs of £15,000 for crisis care.
- The family spent £4,200 on legal advice to escalate the case.
- The LGSCO awarded £2,000 in compensation but noted systemic issues that remain unresolved.

**Key Insight:**

- The council's failure to act early and uphold statutory duties led to spiralling costs and worsened outcomes, an example of *failure demand*.

**Case Study: F's Fight for Respite Care**

*F, a 25-year-old woman who has Down's syndrome, lived at home with her parents. The family relied on respite care to manage their caregiving responsibilities. After a reassessment, the council reduced her respite allocation by half, citing budget constraints. F's parents repeatedly appealed the decision, highlighting their increasing caregiving burden and their deteriorating health. The council delayed responding to these appeals, causing the family to escalate the matter to the LGSCO. The Ombudsman found significant delays and procedural failings, ordering the council to restore F's respite hours and pay the family £1,500 for their distress. By this point, F's mother had suffered a stroke, and the family had been forced to pay privately for care.*

**Impact:**

- The council's refusal to act promptly cost it additional legal fees and repetitional damage.
- F's family bore an unquantified emotional and financial burden due to the council's failure to act.

**Key Insight:**

- Proactive engagement and timely action could have avoided the escalation to the Ombudsman and the health crisis for F's parents.

**Case Study: T's Lost Opportunity for Employment**

*T, a 33-year-old man who has Down's syndrome, had been working part-time in a supported employment scheme for three years. Following the council's decision to reduce his transport funding, T was unable to travel to his job. His family challenged the decision, arguing that access to employment was a vital part of his independence and well-being. The council cited its "fair and affordable" policy and refused to reinstate the funding. After a year-long dispute, the family took the case to the LGSCO, which ruled that the council had failed to consider T's employment as part of his assessed needs under the Care Act. Despite the ruling, T lost his job due to prolonged absence.*

**Impact:**

- T's confidence and mental health deteriorated, requiring additional NHS support.
- The family lost trust in the local authority, complicating future engagement.
- The council faced repetitional damage and was required to revise its policies following the LGSCO's intervention.

**Key Insight:**



- The council's rigid interpretation of its policy ignored the holistic principles of the Care Act, resulting in personal and financial costs.

### **Case Study: P's Placement Crisis**

*P, a 29-year-old woman who has Down's syndrome and epilepsy, lived in a care placement that met her complex medical and social needs. When the council retendered its care contracts, P was moved to a cheaper provider without consultation. The new provider lacked training in epilepsy management, and P experienced two serious seizures requiring hospitalisation. Her family filed a safeguarding alert and a formal complaint, which the council failed to resolve within the statutory timeframe. The case went to the LGSCO, which ruled that the council had acted unlawfully by failing to consult with P's family and disregarding her medical needs. The council was ordered to fund an alternative placement and pay compensation, but P's health had already been severely impacted.*

### **Impact:**

- P's avoidable hospital stays cost the NHS approximately £10,000.
- The council incurred legal fees and compensation payments totalling £3,000.
- The family faced ongoing distress and loss of confidence in local services.

### **Key Insight:**

- Cost-driven decisions without adequate safeguards or consultation lead to systemic failures, unnecessary costs, and preventable harm.

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