

Written evidence submitted by Headway (ASC0010)

Health and Social Care Select Committee Call for Evidence

Adult Social Care Reform: The Cost of Inaction

Response from Headway – the brain injury association,

Headway – the brain injury association welcomes the opportunity to respond to the current Health and Social Care Select Committee inquiry. Our response focuses on:

- Where in the system is the cost of inaction on adult social care reform being borne the most?
- What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

1. About Headway – the brain injury association:

Headway is the UK-wide charity that works to improve life after brain injury by providing vital support and information services, including:

- A comprehensive [award-winning website](#) containing information on all aspects of brain injury.
- A [freephone nurse-led helpline](#) providing confidential support and information for those affected by brain injury.
- An award-winning [range of publications](#) designed to help people understand and cope with the effects of brain injury.
- An [Emergency Fund](#) to assist people dealing with the financial implications in the immediate aftermath of a brain injury.
- A [Brain Injury Identify Card](#) to help in everyday situations and if you come into contact with the criminal justice system.
- A [directory](#) of approved residential homes, rehabilitation units and respite facilities specialising in ABI.
- The charity also campaigns for better support and resources to be made available to people affected by brain injury and works to raise awareness of brain injury and its effects.
- **The Headway Network across the UK** is a [network of over 100 autonomous Headway charities](#) and volunteer-led branches across the UK and the Channel Islands providing a wide range of services, including rehabilitation programmes, carer support, social re-integration, community outreach and respite care to survivors and families in their own communities.

2. Where in the system is the cost of inaction on adult social care reform being borne the most?

From Headway's perspective, the cost of inaction is being borne at community level, by the local Headway charities commissioned by adult social care to provide services, and by the individuals who are meant to receive this support.

- Local Headway charities are often described as lifelines by the brain injury survivors and carers who benefit from them. However, these charities need to be financially independent and viable in their own right.
- The financial downturn, the cost-of-living crisis that is affecting society as a whole, and the instability of local authority funding are impacting heavily on local Headway charities.
- Over the last two years, four local Headway charities have had to close their doors, leaving many brain injury survivors and their families with no support.¹ Three more are scheduled to close in the next couple of months.² Additionally, three volunteer-led branches have also closed.³

Many more local Headway charities are now facing bleak financial circumstances for the following reasons:

- Local authority commissioning rates do not cover the costs of running local Headway charity services.
- Local authorities are taking increasingly longer to pay for local Headway services and carry out client assessments. This is leading to long waiting periods where survivors cannot access services and the progress they made in rehabilitation centres slips away.
- Local authorities are cutting Headway clients' hours or requiring them to contribute more towards their sessions, which many cannot afford.
- Headway charities are struggling to win funding from trusts and foundations as those pots are placed under ever-increasing demand. They are also struggling to draw in donations from local communities as the cost-of-living crisis continues.
- The proposed increases in National Insurance Contributions will add to the pressure and could have a catastrophic effect on Headway charities' financial sustainability and future. The lowering of the threshold will hit many Headway charities particularly hard, as they employ many part-time staff. Without any exemption for charities, this could result in a reduction of services and ability to support brain injury survivors.
- Local Headway charities have been propping up statutory services. Now that financial pressures are accumulating from all sides, this has become unsustainable.

To protect brain injury survivors, who are among society's most vulnerable members, Headway has repeatedly urged the Government to provide urgent, targeted financial support for local brain injury charities. Spending on local specialist brain injury services is a preventative measure – not doing so will result in far greater costs to the public purse.

Headway is currently carrying out a survey across the Headway Network regarding the impacts of delayed payments and delayed assessments on both local Headway charities and on brain injury survivors. The survey will close in January 2025, but the responses we have received so far help to evidence the issues we raise in this inquiry response.

Here are some of the responses regarding the **impact on local Headway charities of delayed payments from adult social care services:**

¹ Headway Salisbury and South Wiltshire, Headway Coventry and Warwickshire, Headway Cambridgeshire, Headway North London (merged with another group).

² Headway Northampton, Headway South East London and North West Kent, Fife Headway.

³ Headway Ennisrone, Headway Isle of Wight (please note Headway Southampton and West Wessex have begun providing support there), Headway Carmarthenshire. Headway Bridgend will close formally in April 25.

We run at a deficit most months due to the delays in funding. We are at a point where if these continue, we will have to close the service and the support we offer to 50+ individuals will be signposted back to the council, which ironically will cost the local authority more money than just paying our service directly.

We are currently in a financial position of loss.

And further responses regarding the **percentage of the contracted service that local authority payments cover:**

There are several different levels of funding for day services depending on level of need so can be different for each service user, however we did calculate the average across all service users and worked out that the LA/ICB funding covers 60% of the cost of providing the service.

This is LA dependent. In one LA the rate paid to us is two-thirds of cost. However, we are the lowest charging provider in the area charging approximately 40-50% less than other providers (half what others charge and these are not specialist).

And further responses regarding the **sustainability of local Headway charities:**

If we continue to have client hours reduced or lose client hours due to their contributions increasing and continue to wait 6 months or more for new clients to be assessed and receive funding it could be very difficult to continue to support local services with offering care for individuals with ABI. We may have to consider moving over to private individuals only and changing our business model.

Until LA's/ICB's start understanding that they need to pay more we won't be sustainable. They also need to realise that if we are very small charities, we do not have the "economies of scale" available to large profit-making organisations, or the staff time available to chase/update/perform the admin. It's also true that as a small charity provider we cannot compete when opportunities are put out to tender.

3. What is the cost of inaction to individuals?

Local Headway charities have told us about the impacts of Headway closures on brain injury survivors and their loved ones:

- The strain placed on families as survivors can no longer access specialist daycare services will be unsustainable. Many will not cope, leading to family breakdown due to family carers becoming unable to meet their loved ones' needs that previously were met by Headway services, and unable to access respite from caring.
- Survivors will need far greater state support than they currently receive. Statutory services will be called upon to provide more costly, long-term support because survivors will be unable to access specialist brain

injury services that are appropriate for their needs. E.g., residential or nursing home placements, residential respite placements, or increased care packages at home.

- Without the peer support provided by Headway charities, brain injury survivors and their carers will become isolated, and their physical and mental health will deteriorate, leading to increased pressure on the NHS services.
- Survivors, many of whom experience complex cognitive, emotional and behavioural issues as a result of their brain injury, will end up attending unsuitable placements – inappropriate both for the survivors and for the other attendees at these services.

Here are some survey responses regarding the impact on brain injury survivors of delays in assessments from adult social care services:

They often lose the motivation that has spurred them to act and contact us in the first place, the wait of over 6 months on occasion can be disastrous, leading to unhelpful coping mechanisms being used by the service user to cope in the interim (inc. substance misuse), mental health breakdown, carer breakdown, family relationships strained/breaking, exclusion from services due to their behaviours being misunderstood (without an advocate to help) etc.

Long assessment periods will ultimately lead to individuals relying more on NHS and authority services, potentially opening up the way to poorer health, falls, hospital admissions and social work allocation which could be avoided if the Headway branches are utilised and prioritised in funding expectations.

Isolation and loneliness, deterioration mentally, cognitively, emotionally and physically family break downs and issues.

Reduced health outcomes, impact on mental health, isolation, lack of access to support and networks, poorer cognition, deterioration in mobility and physical health, previous progress regression.

Delays in assessments for Headway services after brain injury cause brain injury survivors and their families numerous physical and mental health problems, which lead them to rely much more heavily on local state services.

Issues that existing Headway clients are facing on reassessment:

- Their personal contributions to attend local Headway services have been increased.
- Their hours at local Headway services have been cut.
- They have been told they are no longer eligible for local Headway services.

Further survey responses evidencing these issues:

*All of our social care funded clients have been allocated for a review this year regardless of length of contract. **Long term clients have been targeted for reductions on service and have had hours cut or funding reduced (so they pay more contributions towards their care). Some clients have been told they will now have Reaching for Independence services for 12 weeks instead to work them towards no longer needing permanent enabling contracts.***

Clients struggle to understand why long-term support has been reduced when their issues have not changed.

*Social Services assume individuals with long term conditions can get better with the right therapies and support - this is not the case with many individuals with brain injuries who cannot process and retain information - meaning **short therapy programmes like Reaching for Independence offer no solutions for them and leave them without critical support after their end, causing decline in health and wellbeing.***

*Awaiting reviews due to cost of fee increase for up to 12 months, when cost not need has changed. Financial difficulties, no allocation of social worker, long waits of up to 12 months. **Some have stopped attending due to having to make a greater contribution.** We also have clients paying for themselves whilst waiting an assessment. Lack of handover from ICB to LA's for funding/ assessment/ reviews.*

*We're seeing those who receive funded transport to the day centre from adult social care having their **transport withdrawn while their attendance remains as it was.** This then means that they cannot access the day centre because they cannot travel alone/use public transport and their PIP mobility element won't cover the costs of weekly taxis to the centre plus all of their other mobility related needs within any month.*

Further responses regarding the impact of these reassessment issues on brain injury survivors:

***Suicidal ideations**, especially when they receive backdated invoices.*

*The main concern is **mental well-being, the stress and impact of the assessments is huge**, it is a long process with many forms and written text that is not always summarised or streamlined, added with miscommunication or lack of, particularly by local authorities in our situation can then lead to a 'surprise bill' asking the client to contribute. The huge turnover in social workers does impact the length of time but also has a negative effect on individuals who are unclear about who to speak or go to with questions or queries. Additionally, **the lack of education within the social work team regarding brain injury** is surprising, many are unaware of communication or cognitive deficits and book in for hour long meetings, unaware of the effects of fatigue.*

***Extreme worry before the assessment** as they all expect to lose their funding/support to attend, **if they do lose funding they then panic, may try to self-fund their attendance which can then lead to financial distress for them.** We often see those who have to stop using the service slip backwards in their recovery, experiencing worsening mental health, family strain, carer breakdown and the use of unhelpful coping mechanisms.*

4. How might people's lives change with action on adult social care reform?

Headway's [2024 Election Manifesto](#) details our five most urgent calls to action, two of which are explained below:

Reform social care: make social care equitable and sustainable

Despite repeated government promises of reform, the social care system continues to let down brain injury survivors. This persistent issue is characterised by chronic underfunding and inadequate staffing levels.

Good social care is crucial for brain injury survivors to maintain independence and have choice and control over their lives. They deserve support from professionals specifically trained to understand their unique needs and challenges.

A recent King's Fund report demonstrated:

- The social care workforce vacancy rate is at its second highest-ever level.
- There is a continued tightening of people's eligibility to receive care, as financial thresholds not having changed since 2010/11.
- The cost to local authorities of purchasing care is increasing faster than inflation.
- There are fewer unpaid carers receiving direct support and fewer people receiving respite care than in 2015/16.

According to the Association of Directors of Adult Social Services 2023 Autumn Survey, 470,000 people are waiting for care, direct payments, or assessment of their care needs.

Effective social care for brain injury survivors can facilitate social connections, sustained employment, improved mental health, and overall life satisfaction despite significant challenges.

However, the current system falls short for the treatment of neurological conditions like brain injuries. A 2022 survey revealed that only 23% of adults with neurological conditions feel their social care meets their needs and over half reported feeling excluded from decisions about their care.

Recommendations:

- Commit to an ongoing increase in social care funding so that it is sufficient and sustainable, and brain injury survivors can access the care they need to lead fulfilling lives.
- Provide mandatory training for social care staff to understand and address the unique needs of brain injury survivors.
- Improve staffing levels by making social care careers more appealing through better pay, career prospects, and working conditions.
- Promote the closer collaboration of health and social services to ensure seamless transitions and continuity of care for individuals with complex needs living with acquired brain injuries.

Family care: enhance support for brain injury survivors' loved ones

Brain injury affects the whole family. Enhanced support for caregivers is crucial. A holistic approach addressing the needs of both the family and the survivor leads to better outcomes for all.

Families who receive appropriate support to understand and manage the effects of brain injury are more likely to stay together in the long term. Preventing family breakdown is crucial for the well-being of all family members and can lead to significant long-term savings in public resources.

Involving families in the patient's rehabilitation from the acute phase and providing them with personalised, high-quality information throughout the care pathway is essential. Brain injury can lead to personality changes, difficulties with anger and emotion regulation, lack of empathy, and apathy, all of which can strain family relationships.

For many families, the cost and time involved in travelling long distances to specialist neurorehabilitation settings makes visiting prohibitive and sometimes impossible. Headway understands this and provides grants to families in the immediate aftermath of brain injury.

During the post-acute phase, carers of individuals with brain injury often struggle to obtain sufficient support from local authorities. This lack of support can lead to long-term mental and physical health issues for the carers and contribute to family breakdown. In some cases, this can result in brain injury survivors needing care in specialised facilities funded by the state.

Many carers of brain injury survivors are forced to leave their careers to take on full-time caregiving responsibilities, often without adequate support or understanding from statutory services. There is an urgent need for greater support to address these challenges and prevent further strain on families and public resources.

Headway's recent survey demonstrated the impact of brain injury on those who care for survivors:

- Almost 70% of carers (68%) report that their mental health is worse after brain injury, with anxiety and depression being highly reported.
- Almost a quarter of carers (24%) are unable to work following the injury, with 18% being unable to work either now or in the future. 30% have returned to work but have had to either take on a new job/role or change their hours due to the impact of the injury.

- 70% of carers have less time to pursue their interests/hobbies since the injury.

These figures demonstrate the need for improved support and awareness for carers of individuals with brain injury, including better access to assessments, mental health services, and financial assistance. Addressing these challenges is essential to safeguarding the well-being of carers and enhancing the overall quality of care for brain injury survivors.

Recommendations:

- Enhance acute-phase support for families and carers by:
 - Providing facilities for families to stay close to brain injury survivors in specialised neurorehabilitation settings.
 - Establishing an accessible grant scheme (modelled on Headway's [Emergency Fund](#)) to assist families in the immediate aftermath of an ABI. Recognising that family members need to be near their loved ones during this critical period, this support acknowledges the likelihood that they are unable to work.
- Improve long-term support for families and carers by:
 - Ensuring improved and equitable access to community-based support and rehabilitation services for brain injury survivors.
 - Enhancing access to counselling and other support services for family members affected by ABI.
 - Facilitating the early identification of carers by clinical staff and hospital social workers. This allows for seamless connection to local authority services and ensures that every carer of a brain injury survivor undergoes a comprehensive carer's needs assessment.

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