

Written evidence submitted by RNIB (ASC0032)

RNIB submission to the Health and Social Care Select Committee Inquiry into Adult Social Care Reform - The Cost of Inaction

About RNIB

The Royal National Institute of Blind People (RNIB) is the UK's leading sight loss charity and the largest community of blind and partially sighted people.

We welcome the opportunity this inquiry provides to highlight the wide-ranging costs arising from inaction on social care reform. Our research shows blind and partially sighted people face multiple challenges when accessing vital services and the lack of reform in this space has resulted in additional pressures for health, social care and wider government services.

Introduction - about vision rehabilitation

1.1. Vision rehabilitation is an adult social care service that provides one-to-one training in daily living skills, mobility, and communications, to maximise people's independence, confidence and quality of life after sight loss.

1.2. Effective vision rehabilitation is life changing. Done well, it can help someone experiencing what could be sudden sight loss or a drastic change in circumstances with the vital support to retain their skills, confidence and sense of self.

1.3. Vision rehabilitation services are vital for ensuring that people who develop significant sight loss can continue to live confidently, safely, and independently. Once received, vision rehabilitation equips people with new ways to carry out daily tasks: to get out and about, remain in employment, shop and enjoy hobbies. This impact can be transformational, allowing people to remain active and self-reliant, contribute to the economy whilst also reducing additional costs to the NHS and social care.

1.4. Despite the legal right to this support under the 2014 Care Act, every year thousands of people with sight loss are not getting the support they need to thrive, holding people back from achieving personal goals and ambitions, or living the life they'd choose. Left unable to carry out everyday tasks safely, people are at risk of potentially fatal accidents, mental health crises and are giving up employment unnecessarily.

1.5. RNIB research shows vision rehabilitation is a forgotten, under-resourced system, lost among the many pressures facing local authorities. Findings show the reality is stark, with over a quarter of local authorities in England having left people waiting for more than a year for a vision rehabilitation assessment and subsequent support in the 2022 / 2023 financial year [1]. Our report, 'Out of Sight', detailing the full findings of our research can be found on our [website](#).

1.6. There is huge variation in the delivery of support across England, and without reform in this space to provide national oversight of provision, there is no accountability of services provided. This aspect of social care has not been addressed in any government health or care thinking since the duty was placed on local authorities by the Care Act 2014.

The cost benefit of vision rehabilitation

2.1. Local authorities will face greater costs because of inaction on improving vision rehabilitation services, nor reducing the waiting lists to access support. As a preventative service, not providing adequate vision rehabilitation support increases the need for additional and more costly care and support in the future. Early intervention reduces the need for referrals into other more costly services but also limits the development of additional care needs during the waiting period. In 2017, comprehensive cost-benefit analysis commissioned by RNIB [2] found that if just 25 per cent of expected positive outcomes were experienced by service users in Surrey, for every £1 spent on providing vision rehabilitation services, there was a cost reduction, avoidance or deferral of £9.33 within the local authorities budget; £8.63 within health and social care budget alone.

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?

3.1. Analysis by Fight for Sight estimates that the total economic cost of sight loss in England is nearly £24 billion in 2024 [3]. The largest contributors to these costs are informal care, productivity losses, quality of life costs and health and social care system expenditure.

3.2. As the prevalence of sight loss is expected to double to over four million people by 2050 [4], due to an aging population, the economic burden will only increase. Provision of the right support at the right time can enable blind and partially sighted people to achieve at the same level as their peers and continue to develop both personally and professionally, while reducing additional costs to the NHS and social care.

3.3. However, without a clear pathway through secondary and social care, people experiencing sight loss can often be unaware of what to expect from vision rehabilitation services and the importance it has in supporting them to relearn essential life skills. Even those who are referred for support may be waiting without specialist support for lengthy periods, essentially having to learn to 'get by' themselves.

3.4. In practice, this means people often rely on their pre-existing (potentially, very limited) knowledge about how blind and partially sighted people live their lives to envisage their future. Sadly, RNIB know this tends to lead to people reducing aspirations for themselves, dropping out of the workforce, curtailing their lives and experiencing mental health crises.

3.5. In 2023, RNIB carried out a series of focus groups and a survey to better understand experiences and perspectives of the vision rehabilitation support received by blind and partially sighted people [5]. We heard from participants about occasions when lengthy wait times led to accidents and injury, occasionally resulting in the need to seek further medical assistance. RNIB are also aware of a tragic fatality – while the person waited for local authority intervention. Such accidents and other near misses are common due to insufficient service delivery and lack of reform to improve services.

“I nearly got run over. This would be about six months [after receiving a diagnosis]. I’m in tears. I phoned up the social services and said: “You know, I really do need whatever it is that support is supposed to happen at this point.” A couple of weeks later, the Vision Rehabilitation Specialist came out.” **(Severely sight impaired respondent)**

3.6. Research has been conducted to understand expenditure associated with injurious falls attributable to sight loss. A 2013 study from Access Economics assessing the economic impact of

sight loss and blindness in the UK adult population found that £23.4 million was spent on such occasions. [6]

3.7. In addition, it is widely known and well documented that deteriorating vision is a highly emotional experience and people living with sight loss are at greater risk of developing mental health conditions for a variety of reasons [7]. Research has consistently found that blind and partially sighted people are more likely to experience poor mental health outcomes, such as depression and anxiety in their lifetime, compared to their sighted peers. The practical skills developed through vision rehabilitation can improve people's physical and mental health by increasing someone's confidence, self-esteem, and sense of purpose. It is essential effective mental health support is provided for those with sight loss, to improve people's outcomes and cut long-term costs.

What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?

4.1. Lack of reform to vision rehabilitation is hindering blind and partially sighted people's ability to live confidently and independently. It is vital vision rehabilitation services must be included as part of any drive to improve performance of the overall health and adult social care system.

4.2. To reduce the postcode lottery and ensure that everyone has timely access to vision rehabilitation, it is essential that the following three points are addressed. Firstly, adequate legislation needs to be introduced to hold services to account and provide clear guidance as to what a service should deliver. Secondly, the vision rehabilitation workforce needs to be sufficiently staffed and regulated, in line with other adult social care services. Finally, there needs to be better integration between health and social care services.

4.3. The biggest challenge is addressing the lack of resources to meet the growing demand for vision rehabilitation services. RNIB is concerned that future provision is at risk, given the ever-increasing demands on adult social care finances and the decline in the trained workforce needed to deliver this care.

4.4. It is imperative local authorities respond to the growing waiting lists for support, by providing timely and consistent access to vision rehabilitation for everyone with sight loss.

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

5.1. Sight loss can be a major, life-changing diagnosis. For people adjusting to life with sight loss they must regain their confidence and cope with what can be a persistent level of anxiety, needing to weigh up the risk in every situation, as they complete daily tasks that they once found easier, especially at home and getting out and about. Yet RNIB research [5] shows people are currently being left to manage alone. There is also a huge lack of awareness of available support among blind and partially sighted people:

- Only just over half (56 per cent) of blind and partially sighted people surveyed have received vision rehabilitation support.

- For the 35 per cent of blind and partially sighted people surveyed who had not received support, the main reasons cited were not being aware that support is available (58 per cent) and having friends and/or family who are happy to provide support (24 per cent).

· If this figure was representative of the entire adult registered blind and partially sighted population, at least 115,000 people would have been left without the support they're entitled to.

5.2. Our research further reinforced how in many places, the service offered is not meeting people's needs: Less than half of those participating in our research were confidently able to move around outdoors (43 per cent) or within the home (42 per cent), and even less feel they can travel independently (28 per cent) after support received [5].

5.3. RNIB findings show that the reality of current provision is stark: services vary across the country and waiting times for support are far beyond what is acceptable. 26 per cent of local authorities who responded to our FOI left people waiting for more than a year for a vision rehabilitation assessment and subsequent support in the 2022 / 2023 financial year [1].

5.4. It is evident from our research that access to this support via adult social care is effectively a postcode lottery which has gotten worse due to growing demands on already stretched resources. However, demand for vision rehabilitation will only grow, as more people in England live with sight loss.

“With the waiting time [for support], after diagnosis. [I felt] so vulnerable and trapped, it was horrible.” **(Severely Sight Impaired Focus Group respondent)**

5.6. Long waiting times in effect lead people in need of support to 'get by' alone. We hear from people who are not 'waiting well' for vision rehabilitation, meaning their care needs are far greater by the time they receive a specialist vision rehabilitation assessment. This is resulting in people requiring longer and more intensive forms of support.

5.7. Ultimately, without tailored and comprehensive provision that takes account of the emotional turmoil people experience, blind and partially sighted people are being failed. It's critical the Secretary of State for Health and Social Care and local authorities take immediate action to reform and resource this service, so it supports everybody who needs it, when they need it.

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

6.1. Blind and partially sighted people are paying the highest price due to longstanding inaction on social care reform, specifically in regard to vision rehabilitation services.

6.2. RNIB research shows the current postcode lottery of vision rehabilitation services is putting people in danger. Threadbare services mean people are currently waiting months without the support they're entitled to, at risk of physical accidents and injuries as well as being at increased risk of mental health crises.

“I didn't have the skills... my sight deteriorated to a certain degree while I was waiting as well, to the point I couldn't actually see to use the hob I used ... I was basically burning myself more than usual, catching my arm on the/in the oven and things like that, or touching the edge of the hob by accident, burning my finger.” **(Focus group participant)**

What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?

7.1. Vision rehabilitation is a preventative service, allowing blind and partially sighted people to continue to live confidently and independently whilst fulfilling personal goals and ambitions,

including staying in employment. Research indicates that lower employment for people with sight loss costs the UK economy billions per year. [3][6]

7.2. By providing effective vision rehabilitation this will allow blind and partially sighted people to remain in employment and contribute to the economy. People with sight loss represent at least 2% of the total personal income in the UK. By providing effective vision rehabilitation, thereby allowing people to get out and about confidently, this could increase blind and partially sighted people's access to shops, restaurants etc, which could potentially increase the amount spent towards supporting businesses and the wider economy.

To what extent are the costs of inaction on adult social care reform considered by the Government when evaluating policies, including within the Budget and Spending Reviews? How should these costs be assessed and evaluated

8.1. In RNIB's view, vision rehabilitation is not granted the same level of significance as other adult social care services, despite being a lifeline for many blind and partially sighted people, which has led to widespread ignorance of its benefits. As such, it is unclear to RNIB how the costs of inaction on social care are recognised by government when making economic policies. There also remains the significant issue that vision rehabilitation services have no national oversight, monitoring or data collection, meaning there is a huge lack of accountability and awareness of services provided.

8.2. Without this data, government cannot meaningfully consider the economic benefits or additional costs which arise out of inadequate service delivery. RNIB believe this oversight is essential to gain a valid understanding to the details of vision rehabilitation services around England, including the amount of people receiving and waiting to access services. With this data, more could be learned about the economic contributions, and implications, these services have on the economy.

8.3. More generally, RNIB believe the government must develop a consistent approach to recording data on disability across government. This is fundamental to tying initiatives happening across different departments together and understanding the effects of policies on people with disabilities. This should be mandated for departments and ministries to allow more transparent access to information about disability, and allow easier comparison of data.

References

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