healthwatch Somerset

Neuro Rehabilitation in Somerset for People with an Acquired Brain Injury

June 2025

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About us

Healthwatch Somerset is your local health and social care champion. We make sure NHS leaders and other decision makers hear your voice and use your feedback to improve health and social care.
We are independent and impartial. We also offer information and advice to help you to get the support you need.

As an independent Statutory Body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared. Healthwatch Somerset is part of a network of over 150 local Healthwatch across the country. We cover the unitary local authority area of Somerset Council.

Introduction/Background

One of Local Healthwatch activities is to make reports and recommendations about how local care services could or ought to be improved. In 2022 Healthwatch Somerset worked with NHS Somerset ICB to create a series of case studies, to support a business case for change, by interviewing people who had lived experience of an acquired brain injury (ABI) and neurological rehabilitation. An acquired brain Injury is any damage to the brain that occurs after birth and is not related to a congenital or degenerative condition. It can be the result of a range of causes, including traumatic events such as falls or accidents or medical issues like strokes, infections or oxygen deprivation. One key area of focus raised this year was support and care at home and the suggestion was made to us that we should link the two areas together. This gave us the chance to assess the current situation, review reports and projects that have been conducted both locally and nationally. This report builds on previous work and explores the current situation.

What we did – Who we spoke to

We worked closely with Headway Somerset. We visited their centres speaking to individuals with an ABI about their journeys accessing information and rehabilitation.

We interviewed several different people including.

- Clinical specialist Neurological Physiotherapist
- Stroke Clinician
- Probation Officer
- CEO Headway Somerset
- Dr Alyson Norman Associate Professor of Clinical and Health Psychology
- Consultant Clinical Neuropsychologist
- Programme Manager, for Stroke, Neurological conditions
- ABI - Survivors

We also attended the Headway Conference in 2024, attended group meetings – Neuro Rehabilitation Services Stakeholder and attended a workshop on the Societal and Economic-Impact of Brain Injuries.

We also explored wider issues that were being reported on at a national level.

Executive Summary

Healthwatch Somerset's engagement with ABI survivors and professionals has revealed critical gaps in the county's healthcare and rehabilitation pathways for ABI. Key issues include poor discharge planning, with many survivors reporting a lack of information and support, leading to isolation and loneliness. There is currently no offender-specific framework to support individuals with ABI in the criminal justice system, leaving significant rehabilitation needs unmet.

A shortage of neuropsychologists is delaying timely care, and the absence of a dedicated ABI case coordinator has resulted in fragmented service delivery. Referral pathways remain limited, with access to neuropsychology only for those who have been an inpatient at Somerset Neurological Rehabilitation Centre (SNRC), and there is no central system to track ABI survivor outcomes or evaluate service effectiveness.

Community rehabilitation teams lack access to essential cognitive and fatigue therapies, which are vital for those with neurological conditions. Broader systemic issues include a shortage of beds, limited funding, and low public awareness of ABI, impacting early intervention.

A coordinated, strategic response is needed should include post-discharge family support, offender rehabilitation framework, increased neuropsychology staffing, dedicated care coordination, robust data systems, expanded therapy provision and formal service evaluation tools, plus the need to look at whether the number and location of the inpatient beds is sufficient.

Key findings:

- There is a shortage of neuropsychologists in Somerset.
- There are gaps in the provision of appropriate information for ABI patients/families, especially on discharge from hospital.
- There is a lack of awareness of ABI in the general population.
- There is a lack of data tracking for ABI survivors.
- There is a need for standardised outcome measures.
- The support provided by Headway Somerset is invaluable.

Comprehensive care for neurological recovery at SNRC

Somerset Neurological Rehabilitation Centre (SNRC)

Dene Barton Community Hospital in Taunton is a 10-bed neuro rehabilitation unit that currently supports just 65 individuals with Acquired Brain Injury (ABI) each year – despite over 3,000 ABI-related hospital admissions annually. This stark disparity highlights an urgent need for increased investment and resource allocation to meet the growing demand for specialist inpatient rehabilitation and improve long-term outcomes.

SNRC provides level 2 inpatient neuro rehabilitation. Level 2 is a local specialist service, led by rehabilitation medicine consultants at a district level and covers circa 500 million population. This service caters to individuals in Somerset who have experienced a new onset or deterioration of a neurological condition. Conditions treated at SNRC include acquired brain injuries from falls, road accidents, infections like encephalitis, or injuries resulting from surgical removal of tumours.
SNRC are equipped with a dedicated team of specialists, including doctors, nurses, clinical neuropsychologists, physiotherapists, occupational therapists, speech and language therapists and dieticians. Additionally, patients have access to social workers, music therapies and Headway Somerset, an organisation that supports people with brain injuries.

Each patient is assigned a key worker upon admission. The key worker serves as a liaison between the patient, their family, and the multi-disciplinary team, setting goals, monitoring progress, and coordinating discharge plans to ensure a comprehensive and cohesive treatment experience.

Good practices highlighted during Healthwatch visit to Dene Barton:
The use of patient folders. These folders are kept outside each patient's and are updated regularly by staff and families. They include patient notes and goals, allowing families to easily track progress and stay informed. This transparency supports better communication and collaboration between families and the care

team. The families typically share feedback through letters or cards, which staff greatly value. However, there's currently no formal process in place for collecting or acting on feedback. A structured system could help identify areas for improvement and ensure families feel heard throughout the rehabilitation process.

Interview with a clinician with the rehabilitation service.

Healthwatch Somerset spoke to a leading clinician – One of the key rehabilitation facilities in Somerset is Dene Barton. Patients are referred to Dene Barton after being diagnosed with an ABI and undergoing care in a hospital to ensure they are ready for transfer and for rehabilitation. The clinician believes there is adequate resources available through Somerset Neurological Rehabilitation Centre (SNRC), however, they went onto say there are areas for improvement.

For example, it would be beneficial to have a dedicated breakout room that offers a calming and low-stimulation environment for patients. Currently, families and staff need to book a space in advance, which can create additional pressure particularly when a patient requires immediate access to a quiet space – benefitting health and well-being. A more readily accessible breakout room would be a step forward. This would alleviate the stress on both staff and families and ensure patients have a supportive space when they need it most.

The acute care provided for ABI patients in Somerset are:

- Musgrove Park Hospital
- Yeovil District Hospital

Individuals with a diagnosed ABI who have additional conditions, such as fractures or cardio issues, are often placed in other specialised wards. For example, a patient with a cardiac issue would be admitted under the cardiac team, as stabilising their heart condition would take priority before any rehabilitation could begin.

Musgrove Park Hospital offer a 6-bed unit in the Dunkery Ward, which is primarily a stroke unit, but now includes a neurological speciality.

The unit provides an important resource for ABI patients requiring specialised care before transitioning to a rehabilitation setting like Dene Barton.

Somerset's Neurological Rehabilitation Services

Interview with a Clinical Specialist Neurological Physiotherapist

Overview of current services

The community rehabilitation services in Somerset cater to all adults over the age of 18, supporting rehabilitation goals, including those with an Acquired Brain Injury. These services are delivered by multidisciplinary teams of physiotherapists, occupational therapists, pharmacy technicians, and rehabilitation assistants with varied clinical backgrounds. The collective expertise of these professionals ensures that patients receive a holistic approach to rehabilitation.

Other services that may see patients with ABI include neuro out-patient physiotherapy, spasticity services, neuro rehab medicine (Doctor), speech and language therapist, mental health services such as talking therapies, discharge to assess, and rapid response.

Personalised rehabilitation plans

Rehabilitation plans are highly individualised, with a strong emphasis on goal-orientated care. The specific goals of each rehabilitation plan vary depending on the patient's unique needs. Patients are actively encouraged to participate in setting their own rehabilitation goals, fostering a sense of ownership and personal commitment to their recovery.

NHS Somerset NHS Foundation Trust

Access to services

Patients with a rehabilitation goal can access community rehabilitation services through self-referral, hospital referrals, or other professional referrals. However, it can be challenging for out-of-area hospitals to know where to refer to. Delaying the start of rehabilitation may be due to waiting lists fluctuating. These barriers can delay the start of rehabilitation, affecting patient outcomes.

Family Involvement: Involving families in the development and adjustment of rehabilitation plans is recognised as important. However, this involvement depends largely on the patient's preference. In some cases, patients may not wish to share details of their condition with their families, which can complicate family participation in the rehabilitation process.

Identified gaps in services

Several areas have been identified where improvements are needed within the community rehabilitation service:

- Cognitive and Fatigue Therapy: There is a notable gap in the availability of cognitive and fatigue therapy services in Somerset. These therapies are critical for patients with neurological conditions. Due to the various backgrounds of healthcare professionals, this indicates what therapies are used in a patient's rehabilitation. There is also a lack of neuropsychology in supporting cognitive rehabilitation.

- Monitoring Success and Feedback: Currently, there is no formal system in place for monitoring the success of the community rehabilitation service. Gathering feedback from patients has proven to be challenging due to the lack of structured data collection and analysis methods. This lack of formal feedback mechanisms also makes it difficult to evaluate the overall effectiveness of the rehabilitation services in improving patient outcomes. However, there are imminent plans to capture data collection.

Challenges in service delivery

The community rehabilitation service faces several challenges that impact service delivery:

- Staff Shortages: One of the most significant challenges is the shortage of neuropsychologists in Somerset. This shortage places additional strain on the rehabilitation process and can delay care for patients with neurological conditions.

- Waiting Times: Patients can experience waiting times to begin rehabilitation, with target times at either two or six weeks, depending on how the referral is triaged to the Community Rehabilitation Service (CRS) criteria. However, due to high demand patients can wait longer than is hoped. For example, when in escalation, waiting time targets can be extended to 10 weeks. These delays can hinder recovery and prolong the rehabilitation process. Patients that need urgent rehabilitation are seen sooner by other services, for example 'rapid response' or 'discharge to assess'.

- Equipment Accessibility: Standard medical equipment is accessible for patients needing various equipment to support their rehabilitation. Patients requiring specialist equipment to include wheelchairs presents challenges, due to stock, waiting lists, delays in obtaining parts.

See Appendix B for questions asked to Clinical Specialist Neurological Physiotherapist (pages 34).

Enhancing patient care coordination: The important role of a case manager

We were told that one notable example comes from Dorset, where a case manager is funded by the NHS. This role significantly improves the coordination of staff and specialists, ensuring patients experience a more cohesive journey through their rehabilitation. Implementing a similar role in Somerset could be transformative for patient care. Also highlighted the excellent care provided by key workers who support stroke patients, emphasising that their approach to delivering information and care could greatly strengthen the neurorehabilitation teams in Somerset.

As reported in the NR (Neuro rehabilitation) Times it highlights the critical role of case managers for clients with acquired brain injuries (ABIs) during their intensive care unit (ICU) stays. Prolonged ICU admissions have been associated with increased risk of post-traumatic stress disorder (PTSD) among patients. Case managers are essential in mitigating these risks by actively listening to both the patients and their families, fostering trust, and establishing strong relationships.

While ICU follow-up care is typically provided, it often remains limited due to resource constraints. Integrating additional psychological support beyond the standard services and involving multidisciplinary teams can enhance rehabilitation outcomes and alleviate psychological effects following life-threatening injuries. Case managers play a pivotal role in sourcing and engaging psychologists with specialsed expertise, ensuring comprehensive, tailored care for each patient's unique needs. Further reading can be found at The role of the Case Manager supporting a client after an ICU experience

Stroke Association

Healthwatch met with a representative of the Stroke Association, who oversees operations across Devon, Dorset, and Somerset. Highlighting disparities in support services, noting that Cornwall benefits from three key workers-qualified counsellors funded by legacies and the local Integrated Care Board (ICB), who provide essential low-level counselling to stroke survivors. Unfortunately, these roles are not NHS-funded, and Somerset does not have equivalent positions, leaving residents without this crucial support. Jo described this situation as feeling like a postcode lottery for Somerset residents.

Regarding hospital discharge and care plans, it is acknowledged that the Stroke Association in Somerset receives referrals, although some patients slip through the net. Often, individuals may not recognise the need for support immediately after discharge, as challenges with day-to-day living associated with acquired brain injuries can emerge over time and not all stroke patients are admitted to the specialised stroke ward at Musgrove Park Hospital, with some placed in other wards instead.

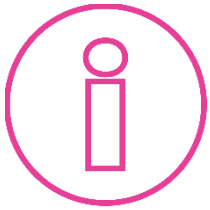
Somerset stroke patients are offered a six-week online exercise programme via video link. Additionally, support groups across the county provide survivors with opportunities for peer interaction and the formation of friendships, these are informal meetups rather than structured sessions.

The Stroke Association also offers a "Here for You" service, providing up to 8 weeks of telephone support in 30-minute sessions. This service is available both locally and outside the area, so expectations are managed as some patients request extended

support. A range of resources, including free downloadable booklets on topics such as fatigue, is available on the Stroke Association's website, where survivors and caregivers can self-refer via online forms.

In Somerset, a single key worker role exists to conduct low-level assessments, including home visits; this position is short-term funded. Jo emphasised the importance of expanding these roles to ensure comprehensive and equitable support for stroke survivors in the region. Further information can be found on the link: Stroke: Support and guidance.

Headway Somerset



Headway Somerset are the only charity in the County that specialises in raising awareness of, and providing support to, people impacted by acquired brain injury.
They were set up in 1990 by the parents of brain injury survivors when they realised how little help there was for them and their loved ones when they left hospital after suffering life changing accidents.

Headway Somerset strives to provide a universal service for adults impacted by Acquired Brain Injury across Somerset. Including:

- Telephone/information help line
- Hospital discharge liaison service
- Education and practical/emotional support and advice
- Support groups

Headway also provides specialist 1-1 rehabilitation in the community and ABI wellbeing centres, which can be commissioned or purchased on an individual basis. Headway Somerset believes that every person impacted by acquired brain injury should have access to high quality and specialist information, education, practical and emotional assistance and peer support, regardless of the cause of the injury, when it occurred or their individual circumstances.

Key facts shared from Headway:

- Every 90 seconds, someone in the UK is diagnosed with an acquired brain injury (ABI).
- Up to 60% of prisoners in the UK have an ABI.

- The effects of an ABI can vary and are often hidden.

For further information about Headway Somerset please click on link.

Headway Somerset | help for brain injury survivors and their supporters | Somerset, UK

For more information about an acquired brain Injury, see appendix A (pages 34,35).

Case Study – Hearing from the heart: ABI survivor shares their story

Healthwatch Somerset visited Headway's Centres to engage with ABI survivors, listening to their experiences and perspectives on neuro rehabilitation. The overwhelming consensus among participants was that Headway plays a vital role in their recovery and well-being. The groups expressed deep appreciation for the support and rehabilitation they receive on a weekly basis, emphasising that they highly value the service. Additionally, they praised the dedication and compassion of the staff, highlighting the positive impact of their ongoing support.

The ongoing rehabilitation journey of Mr P an ex-marine with Acquired Brain Injury

During a visit to Headway Somerset at Henton Centre. We had the opportunity to meet Mr P, who was a former marine with a remarkable story of resilience.

Mr P dedicated over 20 years to military service before transitioning to civilian life, while he worked in various roles, including road construction. A few years ago, while on assignment in Scotland, he faced a life-altering event. It was around 2:00 am. when Mr P and a fellow worker were on duty repairing roads. Spotting an oncoming car heading straight for them, Mr P selflessly pushed his colleague out of harm's way but took the full force of the impact himself. The collision, caused by an uninsured drunk driver, left Mr P in a coma for six months. Due to the severity of his injuries, he retains no memory of the incident.

As a result of the incident, Mr P sustained a significant brain injury. He experiences persistent challenges, including slurred speech, short-term memory deficits, and physical limitations. His mobility is impaired, requiring the use of a walking stick, and

he has lost the use of his left arm. Additionally, he wears a splint on his left leg to stabilise his foot, as his left heel does not naturally touch the ground. Despite the immense hardship, Mr P shared that he feels grateful to be alive.

Following his release from hospital, Mr P was referred to Headway Somerset for Neuro Rehabilitation services. He expressed immense appreciation of the staff at the Henton Centre, crediting the staff with significant improvements in his confidence and physical abilities. Initially, he relied heavily on a wheelchair, which, despite not being a necessity, became a source of comfort. The compassionate and persistent encouragement from Headway's staff gradually motivated Mr P to move beyond the wheelchair. Today, he can walk with the assistance of a stick, a milestone he attributes to unwavering support.

Mr P receives weekly physiotherapy sessions, which he reports have been instrumental in maintaining his mobility. Beyond physical therapy, he engages in activities to stimulate his cognitive functions, such as creating a weekly quiz for his Headway group. This activity not only helps sharpen his memory, but also fosters a sense of community and mutual support among group members.

> Mr P noted that due to recent funding cuts, the Headway group now meets only once a week, a reduction from their previous twice weekly schedule.

Mr P lives a few miles away from the Henton Centre, the journey takes approximately 40 to 50 minutes each way by taxi. Mr P commended Headway Somerset for maintaining excellent communication with him through regular texts and phone calls. He acknowledged that while the current level of support suffices for him (once a week), it may not be adequate for others facing similar struggles.

Beyond Headway, Mr P also receives assistance from a support worker who visits 4 times a week to help with cooking and household chores. However, he raised concerns about the limited availability of ABI related information and resources in his local area. He emphasised the importance of making this information more accessible to the public, highlighting a gap that could impact the well-being and awareness of other individuals living with ABI.

Despite the obstacles he continues to face, he remains optimistic and profoundly grateful for the organisation's role in his rehabilitation.

> Mr P describes Headway Somerset as **"brilliant",** acknowledging the critical impact that they have on people living with ABI.

Further case studies (pages 35–46) to include an interview with Dr Alyson Norman.

Extract – "Upon my brother's discharge, there was a critical missed opportunity to establish a comprehensive care plan. Deemed medically fit, he was placed by the council into a bedsit shared with six others who were substance users. This environment was wholly inappropriate for his rehabilitation needs. Although the council noted the ground-floor location provided wheelchair access, this alone was insufficient to meet my brother's requirements".

Challenges: hidden brain injuries.

In 2022, Headway Somerset highlighted the considerable difficulties experienced by brain injury survivors due to the concealed nature of their condition.

- Perceived unfair treatment: More than 55% of brain injury survivors feel they have faced unfair treatment because their brain injury is not visible.
- Impact on relationships: Two-thirds (67%) of friendships and more than (55%) of relationships with spouses, or partners have all been adversely affected by the hidden nature of the brain injury.
- Lack of understanding: An overwhelming 86% of brain injury survivors and carers cited a lack of understanding as one of the main challenges of living with a hidden disability.

These insights emphasise the urgent need for increased awareness and support for individuals living with hidden brain injuries.

ABI Week 2022: See the hidden me | Headway

Headway UK

Headway UK is the national charity dedicated to brain injury. Headway Somerset is one of their local networks of charities supporting people at a grassroots level.

Headway aims to work with the Crown Prosecution Service to recognise the role of ABI in offending behaviour when deliberating whether to prosecute an individual.

Sentencing offenders with neurological disorders:

The sentencing of offenders with neurological disorders is governed by established guidelines that emphasise the importance of fair treatment and addressing variations in outcomes.

These guidelines are applicable when sentencing individuals who, at the time of the offence and/or sentencing, have a mental disorder, or neurological impairment.

Offenders may be reluctant to disclose an acquired brain injury, or neurological impairment:

- Due to fear of stigma or discrimination.
- Presents a barrier to ensure that their condition is properly considered during sentencing.

Sentencing offenders with mental disorders, developmental disorders, or neurological impairments – Sentencing

MANAGING RISKS

Through structured risk assessments and support. offenders by adapting accredited learning materials to suit different learning styles.

Reasonable adjustments are also made for active learning sessions.

Success is measured through outcomes such as reduced reoffending rates and evidence of learning, which is demonstrated during three-way review sessions, with data related to these processes, is stored centrally.

Somerset Probation Service

Building awareness and better support for ABI within probation services

Healthwatch met with the Senior Probation Officer for Somerset to discuss how the probation service identifies and supports offenders with a diagnosed or undiagnosed acquired brain injury.

Probation uses a screening process that includes forms designed to gather information about neurodiversity and learning difficulties. Over time, probation

officers become familiar with their caseloads and can identify individuals who may face challenges with literacy, or cognitive understanding.
When such challenges are recognised, officers make reasonable adjustments, such as scribing or reading worksheets aloud, to support the offender's engagement.

When asked about data tracking offenders with a diagnosed ABI, it was confirmed that no specific data set currently exists. Regarding the impact of an ABI on offenders' behaviour or compliance, the officer highlighted that such conditions could cause stress, particularly around appointments. For example, offenders may require a short adjustment period (approximately 10 minutes) at the beginning of a session to calm down and prepare.
Currently, there is no specific framework in place for working with ABI survivors. If an offender displays consistent changes in behaviour or misses appointments, probation officers may contact the individual's GP surgery for further information.

> Prisoners with an ABI face significant challenges reintegrating into society upon release. The lack of rehabilitation for behavioural and aggressive tendencies associated with ABI can contribute to criminal behaviour and reoffending, often leading to reincarnation.

Training for probation officers:

When asked about training for staff to recognise and support offenders with ABIs, the officer confirmed that no formal training is currently offered.

Headway Somerset, who were also present at the meeting, suggested offering online lunchtime sessions or in-person training for probation officers. The service expressed interest in accessing more information and resources to better signpost support for offenders affected by ABI.

BIBIC

Healthwatch also engaged with BIBIC. BIBIC is a small national charity based in Somerset who offers holistic therapy to children and young adults with neurological, behavioural, and developmental challenges, enabling them to understand

themselves and the world around them. They indicated their ability to provide specialsed training for professionals. This training includes guided techniques and strategies to effectively support individuals with acquired brain injuries. Additionally, BIBIC expressed a willingness to collaborate with probation officers to enhance their understanding and support ABI survivors. Healthwatch later facilitated a connection between the probation service and BIBIC to promote partnership and support for individuals with acquired brain injury. Training Sessions - Bibic

Case for change

Healthwatch spoke to the Programme Manager within NHS Somerset ICB, for Stroke and, Neurological conditions.

Over the past decade, a reduction in specialist neurorehabilitation ABI services in Somerset has impacted both inpatient and community services, including workforce and bed number.
Whist Somerset Foundation Trust (SFT) are currently seeking to improve the community offer for some neurological conditions there is limited service for ABI, and these are the bigger numbers within neurorehabilitation and often the most complex and high-cost individuals.

The Case for Change indicates that:

- Somerset does not fully meet the British Society of Physical Rehabilitation Medicine (BSPRM) standards for specialised rehabilitation, or the national guidance for the management of ABI or spinal.
- There is limited access to specialist neurorehabilitation following discharge from Somerset Neurological Centre (SNRC)which leads to increased length of stay and poorer outcomes for patients.
- Service specifications are either out of date or not in place
- There are specific challenges with accessing Continuing Healthcare (CHC) funding.
- There is a lack of clinical psychology and neuropsychology outside the inpatient environment.
- Unidentified pathways result in poor-quality provision of clinical outcomes, with people either not recovering optimally and/or deteriorating.

- A scarcity of placements for younger cognitively impaired individuals often means placement in elderly care settings or out of county.
- Workforce sustainability – there are risks caused by ongoing challenges with recruitment and retention of specialist staff.

Maintaining people in good health will have a clear personal benefit enabling them to lead fulfilling lives, contribute to their local community and where appropriate, remain in active employment.

Key areas for improvement include:

- A full options appraisal process identifying appropriate inpatient ABI, spinal and neuropsychology service.
- Complete a pathway review for those with mild to moderate traumatic brain injury (TBI)
- Improve the collection of, and access to, reliable consistent, meaningful data to support effective development of specialist ABI services.
- Undertake a financial assessment of current service spend and how that could be used differently to provide better service within current resources and reduce out of county spend or bring additional resource into Somerset

By addressing these issues, services to those people with ABI would maintain them in good health and have a clear personal benefit enabling them to lead fulfilling lives, contribute to their local community and where appropriate, remain in active employment.

Somerset Neurological Rehabilitation Review (2023)

Somerset's vision is to provide a holistic, people-centred neuro rehabilitation service that offers a flexible and adaptable approach:

- Recognising the variable and lifelong care required of many neuro rehabilitation conditions.
- NHS Somerset's goals are to ensure that neuro rehabilitation offers patients and their families/caregivers high-quality care that is both efficient and well-led, and sustainable for years to come.

Neuro rehabilitation services engagement 2023 - NHS Somerset ICB

Government release report – Neuro Rehabilitation Hidden Epidemic

In 2018, the government released a report on Acquired Brain Injury (ABI) and neurorehabilitation, highlighting critical issues. The report emphasised the vital role of neurorehabilitation in the ABI pathway and advocated for rehabilitation prescriptions for all brain injury survivors post-discharge from acute care.

It addresses the high prevalence of ABI in reoffending and discussed the impact or neurorehabilitation on behavioural change and reoffending. Sport-related concussion concerns were also raised, along with the need for an improved and easily accessible welfare system.

Acquired Brain Injury was identified as a hidden epidemic affecting hundreds and thousands of individuals and impacting various government departments, including the Department of Health and Social Care.
Neurorehabilitation was shown to enhance functional independence, reduce caregiver burden, improve return-to-work rates, and boost productivity. Economic benefits were highlighted, such as reduced hospital stays, staffing costs, decreased need for residential and nursing care.
Acquired brain injury (parliament.uk)

Challenges remain including:

- Inadequate neurorehabilitation beds across the UK
- Variable service provisions
- Compromised long-term outcomes for ABI survivors
- Loss of income due to an inability to work further exacerbates the situation, particularly affecting quality of life.

Poor Neuro Rehabilitation services in the UK

A 2019 report by the UK Acquired Brain Injury Forum (UKABIF) highlights the poor condition or neurorehabilitation services in the UK. The report reveals that only 40% of individuals in major trauma centres receive inpatient neuro rehabilitation, indicating a shortfall of 350 beds and a shortage of health professionals, including consultants in rehabilitation medicine.

Neuro Rehabilitation is identified as one of the most cost-effective interventions available to the NHS. According to the report "Specialist Rehabilitation Following Major Injury," published in April 2019, only 40% of the 1,381 individuals assessed as requiring specialist rehabilitation received it. Those who did receive specialist rehabilitation showed significant improvement, with 94% becoming more independent in their daily activities, which in turn reduced ongoing care costs by an average of £536 per week.

40% of people assessed needed specialist neurorehabilitation.

The report further highlights the financial benefits of neuro rehabilitation, noting that the average net lifetime savings per patient amounted to just over £500,000. For the study group, this resulted in total savings of £525 million.

£525 million saved – benefits of neurorehabilitation.

These findings highlight the critical need for increased investment in neuro rehabilitation services to address the current shortfalls and to capitalise on the significant cost savings and improved patient outcomes associated with specialist rehabilitation.
Neurorehabilitation Services Continue To Be Inadequate: Evidence Mounts But Still No Action - United Kingdom Acquired Brain Injury Forum

The National Institute for Health and Care Excellence (NICE) has established quality standards to ensure rapid assessment of head injuries. Key standards include:

- CT head scan within 1 hour, individuals presenting to an emergency department (ED) with a head injury should receive a CT scan within one hour if a risk factor for brain injury is identified.
- CT head scan within 8 hours, individuals presenting to ED with a head injury and who are taking anticoagulants, but have no other risk factors for brain injury, should receive a CT head scan within eight hours of the injury - Overview | Head injury | Quality standards | NICE.
- New guidelines on rehabilitation for chronic neurological disorders to include acquired brain injuries – Publication due in September 2025. Project

information | Rehabilitation for chronic neurological disorders including acquired brain injury | Guidance | NICE

Systemic challenges in ABI care: Review of experiences and solutions.

A systemic scoping review, published online in March 2022, explored the experiences of individuals with an acquired brain injury and their families when interacting with community-based services. The findings reveal significant challenges in these interactions, highlighting barriers such as a lack of understanding among health and social care professionals regarding the long-term effects of ABI.

The review highlights critical gaps in the provision of appropriate information to individuals and families. Key difficulties include insufficient guidance on navigating the behavioural, physical, and cognitive challenges associated with ABI, particularly during the transition from hospital to community-based care. Families often lack awareness of available support services, leaving them ill-equipped to manage the complexities of living with ABI.

The report emphasises the need for health and social care professionals to deepen their knowledge of ABI and its long-term impacts. It calls for improved dissemination of information to ensure that individuals and families are better supported post-discharge, fostering a more informed and effective approach to long-term care and community integration.

Furthermore, the report highlights significant concerns regarding long-term rehabilitation and support for individuals.

- Service users report feeling forgotten and unsupported in their long-term rehabilitation journey after discharge from hospital care.
- Existing rehabilitation models – Stroke patients benefit from Early Supported Discharge (ESD), which facilitates early hospital discharge and continued rehabilitation at home. (ESD) effectively bridges the gap between hospital discharge and home-based care.

However, gaps remain for long-term rehabilitation needs, particularly for individuals with ABI

Returning to work

Returning to work after an acquired brain injury presents unique challenges for individuals, but being in familiar surroundings can play a significant role in supporting rehabilitation.

The workplace, with appropriate support and adjustments, can provide structure and purpose, contributing to an individual's recovery and reintegration.

According to the government website: Access to Work: get support if you have a disability or health condition: What Access to Work is - GOV.UK

Acquired brain injury survivors seeking employment can access support through local job centres. The Access to Work scheme offers grants to cover practical workplace support, including communication assistance (eg BSL interpreters for interviews), specialist equipment, assistive software, and travel support (such as a travel buddy, or transportation costs for those unable to use public transport).

Take each person's needs individually.

Applicants are assigned a disability advisor who assesses individual needs. These grants are non-repayable, and do not affect existing benefits, regardless of income.

Challenges that may be faced by Individuals with an ABI:

Memory problems: can significantly impact the individual's ability to perform in the workplace. These include challenges with learning new tasks, remembering instructions, and recalling important information.

Executive function impairments: Struggles with planning, organising prioritising tasks, and managing responsibilities. These difficulties may hinder workplace performance without targeted support.

Communication barriers: ABIs can affect an individual's ability to convey ideas, understand others, and engage in effective teamwork. This may create challenges in collaborative work environments and affect overall confidence.

Link: Returning to work after a brain injury - Brain Injury Group

Integrating ABI into special education: Raising awareness among educators

Education was also highlighted as crucial, with recommendations suggesting that ABI should be included in the Special Educational Needs and Disability Code of Practice. Additionally, all educational professionals should receive a minimum level of awareness and understanding about ABIs.

In 2020, the government revised the Special Educational Needs Policy to incorporate information about ABI for newly qualified teachers. This update included introductory training, videos aimed at providing helpful pointers, techniques, and advice on inclusive teaching strategies for students with special educational needs and disabilities (SEND) conditions, including ABI, Chloe Hayward, Executive Director of United Kingdom Acquired Brain Injury forum (UKABIF), stated that the project NABLES is dedicated it implementing the recommendations outlined in the All-Party Parliamentary Group on ABI report titled ABI Rehabilitation – Time for Change Link: appg-abi_report_time-for-cha.pdf

Challenges in community reintegration for individuals with ABI

The report also explains that a significant proportion of individuals with an acquired brain injury face increasing challenges in achieving successful community reintegration following their injury. There are gaps as reported, with a lack of information and studies exploring lived experiences from ABI survivors and their caregivers/families, with a lack of insight regarding interactions, and attempts to access community rehabilitation and seamless inclusion services.

The report also emphasises that rehabilitation for individuals with an ABI should be tailored to each individual, taking into account their unique needs and personal goals.

A further report was published in 2013/14, which explored the long-term care needs of individuals with ABIs. Participants of various ages, with both mild and severe ABIs,

shared their experiences and the causes of their injuries. The data revealed that road accidents were the leading cause of ABI at that time. As part of the study, participants rated three organisations based on their understanding of the challenges faced by survivors. Some individuals noted receiving excellent support from professionals, highlighting the variability of care.

Treatment escalation plans

For individuals with an ABI, the completion of a Treatment Escalation Plan (TEP) should be carefully considered in relation to their mental capacity.

Assessing mental capacity; Under the Mental Capacity Act (MCA) 2005, a person is presumed to have the capacity to make decisions unless proven otherwise. However, ABI patients may experience cognitive or communication deficits affecting their decision-making abilities.

Therefore, it's essential to assess their capacity to understand, retain, and weigh information regarding their treatment options, and to communicate their decisions. This assessment should be specific to the decision at hand and conducted at the time the decision is required.

If the patient lacks capacity: When an ABI survivor is assessed and found to lack the mental capacity to make decisions about their treatment escalation, healthcare professionals should involve family members or legal representatives in the decision-making process. Decisions should be made in the patient's best interests, considering their known wishes, feelings, beliefs and values. Where the patient lacks capacity, family involvement is crucial to ensure decisions reflect the patient's best interests. Timely completion and regular review of the TEP are vital components of patient-centred care**.** Somerset treatment escalation plan - NHS Somerset ICB

Backbench Parliament debate – Navigating the assessment and treatment of acquired brain injury

In 2018, the House of Commons extensively debated various issues, in the provision of services for ABI, treatments and rehabilitation in sports, and the integration of ABI care within the criminal justice system.

The assessments and treatment of ABIs are complex, with no single treatment pathway due to the varied nature of these injuries. Major trauma, including severe ABIs, is managed through regional trauma networks. These networks are structured around major trauma centres equipped to handle the most serious injuries. A triage system is used to assess injuries prior to hospital admissions, ensuring that patients receive appropriate and timely care.

The debate highlighted several key areas:

- Lack of beds and regional variation – a significant shortage of neuro rehabilitation beds and considerable regional variation in access to services.
- Early access and timely access to specialist neuro rehabilitation are essential for optimal recovery outcomes for ABI patients.
- Increase in resources, the debate advocates for a substantial increase in the number of neuro rehabilitation beds and professionals. Highlighting the need for every trauma centre to have a consultant in rehabilitation medicine, ensuring individuals with an ABI have access to the necessary neuro rehabilitation service.

Further national research regarding ABI

Hidden Consciousness in Patients with Severe Brain Injuries:

A groundbreaking study, published in The Harvard Gazette in August 2024, has revealed that 25% of patients with severe brain injuries, who appeared unresponsive were able to follow instructions using mental imagery. Researchers assessed 240 patients using advanced techniques such as Functional Magnetic Resonance Imaging (MRI),Functional Magnetic Resonance Imaging (fMRI) and Electroencephalography (EEG). Participants were instructed to think about opening and closing their hands, followed by stopping the thought after 15 – 30 seconds.

These findings suggest that some of the patients who were in comas, or a prolonged disorder of consciousness (PDOC) may retain hidden cognitive abilities, a phenomenon known as cognitive motor dissociation. Since its initial discovery two decades ago research has shown that this condition affects 15-20% of

Remarkably, brain responses in 60 patients consistently indicated they were adhering to these commands.

The study spanned six countries, including the UK, the US, and parts of Europe, emphasising a global significance. Recognising hidden unconsciousness has critical implications for patient care. Families have reported that identifying cognitive awareness leads to improved clinical interactions and personalised treatment strategies. Failing to detect such awareness can result in premature life support being withdrawn and missed opportunities for rehabilitation.
International study detects consciousness in unresponsive patients — Harvard Gazette

Family challenges NHS over care for brain-injured mother of three

In September of 2024, the BBC reported on a legal dispute between a family and Northumberland NHS Foundation Trust over continued care of a mother of three who suffered a severe brain injury following a cardiac arrest in July 2024. Diagnosed as minimally conscious, she remains in intensive care. While her son claims to have observed signs of improvement, clinicians argue there is no possibility of recovery. The NHS has sought a Court of Protection ruling to discontinue treatment, citing her best interests. https://www.bbc.co.uk/news/articles/ckgj6w3w2n1o.

Sports - Acquired Brain Injuries

Concussion in sport

The UK Parliament Committee has published insights into concussions in sport.

The report highlights links between certain sporting activities and long-term neurological conditions, including Dementia. The report emphasises the need for improved awareness, monitoring and medical response to head trauma at all levels of sport, particularly in grassroots participation. The report goes on to identify a connection between some sports and significant neurological issues, with dementia being a notable concern. Grassroots sports, such as football and rugby, pose risks due to incidents like head clashes and repeated heading of the ball, which can lead to concussions.

There are disparities between elite athletes who generally benefit from more comprehensive medical oversight, including access to expert neurological care. In contrast, participants in grassroots and amateur sports may not receive the same level of support, increasing the risk of undiagnosed ABI.

The report found that many individuals facilitating sports activities lack adequate awareness of concussion risks and protocols. This increases the knowledge gap and likelihood of sports participants continuing to play despite head injuries, potentially leading to severe long-term effects.

Highlighted in the report shows Scotland as a leader in addressing concussion in sport, particularly in multi-agency collaboration. Efforts in Scotland focus on improving education and awareness at grassroot level, ensuring that concussion management is a shared responsibility across health, education, and sports sectors. The full report can be read here. Concussion in sport

Sport England – Concussion Guidelines

Sport England has introduced updated concussion guidelines tailored for grassroots sports. These were developed by an expert panel of clinicians and academics specialising in neurology and sports medicine. The guidelines aim to standardise concussion management and ensure that best practices are followed across all levels of sports.

New concussion guidelines for grassroots sport | Sport England

Players safety under scrutiny: RFU faces legal action over brain injuries

In December of 2023, Sky News reported that former rugby players, including ex-Wales international Alix Popham, had launched legal action against England's Rugby Football Union (RFU) and the Welsh Rugby Union (WRU). Popham and over 220 other former players, under a Group Litigation Order (GLO), claim that inadequate health and safety measures during their playing careers led to severe brain injuries.

It is alleged these failures resulted in long-term health consequences, including early Dementia, Motor Neuron Disease, Epilepsy, and Parkinson's Disease. Highlighting the urgent need for improved player protection.

https://news.sky.com/story/gavin-henson-and-phil-vickery-among-over-200-ex-rugby-stars-taking-legal-action-over-brain-injuries-13020450

High speed car crash

In February 2024, Richard Hammond, renowned for his role in Top Gear, discussed his experience with acquired brain injury in an interview with Metro, Hammond revealed that he sustained frontal lobe damage following a serious car crash during the show. He shared concerns about memory lapses, questioning whether they stem from his injury or indicate early-onset Dementia as a potential consequence. Highlighting the risks associated with high-impact sports and activities, emphasising the importance of safety measures to mitigate long-term health impacts.
https://metro.co.uk/2024/02/20/richard-hammond-living-syndrome-18-years-top-gar-crash-20314369/

Safety for cyclists - Mandatory use of helmets for children: Considerations and challenges

An opinion-based blog by Mark Pawsey, former MP, advocated for the mandatory use of helmets for children when cycling. However, they acknowledge that implementing such legislation would be challenging and could place additional strain on the police.

According to information from the House of Commons Library, pedal cyclists who do not wear helmets are 23 times more likely to be involved in a casualty incident compared to motorists and face a higher risk of fatality on roads. The report further argues that, given the existing mandatory safety measures for car drivers, it would be reasonable to introduce similar protections for cyclists to enhance road safety.

Full report OPINION: cycle helmets should be mandatory, particularly for children

The impact of helmet uses on cycling and safety

Cycling UK has published an evidence-based briefing on helmet use, highlighting both the benefits and challenges associated with mandatory helmet laws. While the government acknowledges the significant health benefits of cycling, research suggests that enforcing helmet use can lead to a

decline in cycling participation – typically by at least 30% with even greater drop among young people. This reduction in cycling activity ultimately diminishes its associated health benefits.

There is ongoing debate regarding the effectiveness of helmets. Studies indicate that drivers tend to leave less space when overtaking cyclists who wear helmets compared to those who don't.

> Drivers must give cyclists at least 1.5 meters (5 feet) of space when overtaking up to 30 mph, speed more than 30 mph, the space becomes 2.5 meters (6 feet).

Improving more awareness is crucial to road safety and helps to create a safer environment for cyclists. The report states that 14% of those who chose to wear helmets have more collisions per mile, and there is a higher risk of injuries to the neck.

There is evidence that there is safety in numbers; studies have shown that in the Netherlands demonstrate this effect. – where higher cycling rates correlate with lower accident rates. Full briefing- What insurance are we offering

Recommendations:

- Give approval for recommendation from the case for change to be taken forward as stated on page 18-19.
- The presence of a traumatic brain injury (TBI) and the individual's mental capacity are central considerations in all professional assessments and referrals. Emphasis is placed on involving the family to better understand the ongoing, often unpredictable, and complex process of identity reconstruction following a TBI.
- Public Health, Somerset County Council and NHS Commissioners should set out how local practice and priorities match good practice concerning the support of people with brain injury, dual diagnoses and the expectations of the National Suicide Prevention Strategy for England.

- Targeted awareness/campaigns informing the public of ABIs. leaflets/notices – for example, promotion of ABI awareness week in May.
- To enhance the management and support of individuals in Somerset, to establish a centralised database dedicated to tracking ABI patients.
- Implement a standardised outcome measure across all ABI rehabilitation programs. Using tools such as the Glasgow Outcome Scale (GOS). Additionally, incorporating patient-reported outcome measure (PROMS), offering valuable insights to patient's perspective recovery.
- In order to enhance patient well-being at Dene Barton Community Hospital, a dedicated breakout room that is readily available for patients in need of a supportive space would be useful, providing a tranquil environment, contributing to their overall recovery.
- Extend the roles of key workers within the VCSFE sector for ABI survivors, broadening the scope of these positions. The implementation would provide a consistent point of contact, ensuring that patients receive necessary support throughout their recovery journey.
- Provide information and signposting for patients and their families about available support services. For example, guides/leaflets, information about the nature and consequences of a brain injury, resource information to help with decision making, and practical suggestions about ways to help family members care for their loved ones. This is particularly important on discharge from hospital.
- Provide healthcare staff with specialised training regarding challenges that ABI patients have during transition from hospital to community-based care.
- When commissioning decisions are being made, e.g. heads of all relevant services to be consulted.
- Pilot out-of-county clinical professionals such as Neuropsychologists, delivering services remotely, with the aim to support Somerset's Neuro Rehabilitation Services and establish a pioneering model for Somerset.
- Introduce an Advocacy Service at the point of hospital discharge for individuals, who require support navigating post-discharge care and services.

Next steps

Our findings will be shared with NHS Somerset ICB. This report will also be shared with NHS Somerset Foundation Trust, Headway Somerset, Somerset Neuro Rehabilitation Centre, Somerset Probation Office, BIBIC, and the Stoke Association.

Stakeholders' response

Kathryn White CEO – Headway Somerset

'Acquired brain injury is a long-term and chronic neurological condition, and people with ABI deserve to have equitable access to ongoing specialist rehabilitation services that can meet their specific and individual needs throughout their lives. Acquired brain injury is largely a hidden disability, and I am delighted that Healthwatch has produced this report and shone a light on the tangible actions that can be taken to improve services in Somerset. Headway Somerset look forward to working with all relevant parties to co-produce system and service delivery changes that will address some of the unmet and underserved needs discussed throughout the report and will ultimately help ensure everyone living with ABI is able to achieve their optimal outcomes post-injury.'

Dr Alyson Norman CPsychol, AFBPsS, Associate Head of Teaching and Learning; Associate Professor of Clinical and Health Psychology; Specialist in Brain injury and Visible difference.

This report from Healthwatch is incredibly important. For too long, brain injury has not been taken seriously at a local or national level. This report clearly highlights the areas where support and services are needed post-brain injury within Somerset.

Thank you

We would like to thank everyone who took the time to provide their views and experiences throughout this project, and the organisations who supported us. In particular, Kathryn White from Headway Somerset, and Dr Alysin Norman from the University of Plymouth. Additional thanks to all the ABI survivors for their candid stories.

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Appendices

Appendix A

Facts about Acquired Brain Injuries

Who is at risk from an ABI. Studies have shown that men are more likely to have an Acquired Brain Injury (ABI) Traumatic Brain Injury (TBI), than women.

Individuals over 65 years of age, are more likely to be hospitalised or die.

Symptoms of mild ABI

- Individual remaining conscious
- Headache
- Confusion
- Dizzy
- Tired eyes/blurred vision
- Ringing in the ears
- Bad taste in the mouth
- Ringing ears
- Memory problems

Symptoms of moderate or severe ABI

- Headache that gets worse
- Convulsions – Seizures
- Vomiting at nausea
- Slurred speech
- Weakness/numbness in arms and legs
- Not being able to wake from sleep
- Increased confusion

How is an ABI diagnosed

- Doctors will gather information about the injury, how it happened, and the severity of the impact, any loss of consciousness or confusion.
- Symptoms checked like headaches, dizziness, memory loss, difficulty concentrating, or changes in behaviour.

- Physical and neurological examinations – checked for visible injuries, such as swelling, bruising or bleeding.
- Assessment of motor skills, coordination, and reflexes.
- Evaluation of pupil response, speech clarity and mental alertness.
- Cognitive function, memory and problem-solving skills.

Doctors and medical clinicians will also complete a CT scan (Computed Tomography):

- Rapid imaging technique often used immediately after an injury to detect bleeding, swelling, skull fractures, or other abnormalities in the brain

MRI (Magnetic Resonance Imaging):

- Used for more detailed images of brain tissue and may help identify subtle injuries such as small contusions or lesions

Appendix B

Questions for clinician specialist neurological – physiotherapist

1. Can you describe the current community rehabilitation services offered to patients with neurological conditions?
2. What does a typical rehabilitation plan look like for a patient with a neurological condition and acquired brain injury?
3. How do patients typically access these services? Are there any barriers to entry?
4. How long do patients usually wait to start receiving community rehabilitation after being referred?
5. What is the composition of the multidisciplinary team involved in community rehab for neurological patients?
6. Are there adequate resources, like staff, equipment, and facilities, to meet your patients' needs?
7. How do you measure the success of the rehabilitation services provided, and what outcomes do you monitor?
8. In your experience, how effective is the current community rehabilitation in improving patient outcomes and quality of life?

9. How involved are patients and their families in the development and adjustment of their rehabilitation plans?
10. What feedback do you receive from patients about their experiences with community rehabilitation?
11. What are the biggest challenges you face in providing effective community rehabilitation for neurological patients?
12. Are there specific neurological conditions?
13. Are there any services, or interventions you feel are lacking in the current community rehabilitation setup?
14. Do you feel that the staff involved have sufficient training? And what is the training program?
15. Are there areas where additional training or support could improve the service provided?

Appendix C - Case Studies of ABI individuals

Case study No 1

A female survivor suffered a sudden brain injury 30 years ago after a fall from a horse, resulting in a prolonged coma and significant long-term impairments.
Key details:

- Impact on life – mobility severely affected, now relies on a wheelchair.
- Lost the ability to live independently.

Requires care.

No clear plan provided by the hospital upon discharge, and the family were left to navigate post-discharge care on their own. The individual's husband became the primary carer and hires a professional caregiver for support. Transition to home care was difficult due to the absence of medical guidance.

Lack of clear care plan: The lady explained that having a structured discharge plan would have greatly helped her family's lives, alleviating significant strain, with better communication and planning between support organisations and hospitals. The lady explained that there was no follow-up support from her GP during critical recovery stages.

The individual received physiotherapy, but sessions were hindered by a lack of empathy from her Occupational Therapist, whom she described as rude. The lady had regular gym sessions on a treadmill, but no comprehensive rehabilitation plan to ensure consistent progress.

The lady attends Headway Somerset sessions once a week, where she has attended for many years and found it to be a vital resource for managing life post-ABI. This has provided her with a supportive community where she connects with others facing similar challenges. The service helps to improve her quality of life and adapt to long-term challenges.

Case Study No 2

Mick's experience with Acquired Brain Injury

In 2013, Mick sustained a severe head injury resulting in a fractured skull. An X-ray revealed 5 skull fractures, although it remains unclear whether all fractures occurred simultaneously, or across multiple incidents. Mick explains that he had suffered a fall and was found unconscious at home by a friend, with a split lip and significant injuries. He was rushed to a hospital in Bristol for emergency treatment.
Before his friend discovered him, Mick had attempted to call his mother. However, his speech was so impaired that his mother could not understand him and assumed he might be under the influence of a substance. Concerned, she asked Mick's close friend to check on him. It was later determined that is impaired speech was a result of an ABI.

Mick does not recall being taken into the ambulance or admitted to the hospital, and much of the initial incident was recounted to him by his friend. He received six weeks of intensive rehabilitation in the hospital's brain injury unit, where he also received speech therapy during his hospital stay, which was crucial for his recovery, a period he describes as critical yet believes may not have been long enough. Upon attempting to discharge himself, his doctor strongly advised him to stay longer, emphasising that Mick was not yet fit to return to work. Recognising Mick's financial concerns, the doctor took swift action, referring him to a link worker for support.

Mick praised the assistance provided by the link worker, highlighting how instrumental she was in stabilising his finances; "she was amazing" Mick stated, adding that her support included helping him claim benefits, organise bill payments,

and navigate financial planning.

Mick has been attending sessions at Headway Somerset for several years, where he continues to receive significant support from the staff. He commended the team for their dedication but expressed concerns about capacity. If the group wants to expand, he fears there may not be enough staff to adequately support everyone. Mick emphasised the importance of maintaining a manageable group size to ensure that each individual receives the necessary attention.

Mick expressed his concerns regarding the availability of specialised medical professionals, specifically psychiatrists and physiotherapists, as well as the challenges faced by individuals with an acquired brain injury in obtaining consistent and coordinated medical care.

Mick raised significant concerns of the inadequate availability of psychiatrists and a physiotherapist. He believes that the current shortage of these professionals has a detrimental impact on the quality of care and recovery outcomes for individuals with an ABI.

Mick advocates for individuals with an ABI to have a single, dedicated GP to manage their ongoing care. He believes that having one consistent GP greatly improves communication, understanding, and the overall quality of treatment.
Mick explained a positive example. Mick requested, to work with one GP who has provided consistent and exceptional care. He describes his doctor as “brilliant” and appreciates the open line of communication, noting that he can call his GP anytime for assistance or advice, highlighting the critical need for better access to specialised medical professionals and the importance of continuity in care for individuals with an ABI. Mick’s experience demonstrates the potential benefits of a personalised and consistent approach in managing long-term health conditions.

Case Study No 3

The ongoing rehabilitation journey of Mr P an ex-marine with Acquired Brain Injury

During a visit to Headway Somerset at Henton Centre. We had the opportunity to meet Mr P, as a former marine with a remarkable story of resilience.

Mr P dedicated over 20 years to military service before transitioning to civilian life, while he worked in various roles, including road construction. A few years ago, while on assignment in Scotland, he faced a life-altering event. It was around 2:00 am when Mr P and a fellow worker were on duty repairing roads. Spotting an oncoming

car heading straight for them, Mr P selflessly pushed his colleague out of harm's way but took the full force of the impact himself. The collision, caused by an uninsured drunk driver, left Mr P in a coma for six months. Due to the severity of his injuries, he retains no memory of the incident.

As a result of the incident, Mr P sustained a significant brain injury. He experiences persistent challenges, including slurred speech, short-term memory deficits, and physical limitations. His mobility is impaired, requiring the use of a walking stick, and he has lost the use of his left arm. Additionally, he wears a splint on his left leg to stabilise his foot, as his left heel does not naturally touch the ground. Despite the immense hardship, Mr P shared that he feels grateful to be alive.

Following his release from hospital, Mr P was referred to Headway Somerset for neuro rehabilitation services. He expressed immense appreciation of the staff at the Henton Centre, crediting the staff with significant improvements in his confidence and physical abilities. Initially, he relied heavily on a wheelchair, which, despite not being a necessity, became a source of comfort. The compassionate and persistent encouragement from Headway's staff gradually motivated Mr P to move beyond the wheelchair. Today, he can walk with the assistance of a stick, a milestone he attributes to the unwavering support.

Mr P receives weekly physiotherapy sessions, which he reports have been instrumental in maintaining his mobility. Beyond physical therapy, he engages in activities to stimulate his cognitive functions, such as creating a weekly quiz for his headway group. This activity not only helps sharpen his memory but also fosters a sense of community and mutual support among group members.

Mr P noted that due to recent funding cuts, the Headway group now meets only once a week, a reduction from their previous twice-weekly schedule. Mr P lives a few miles away from the Henton Centre, the journey takes approximately 40 to 50 minutes each way by taxi. Mr P commended Headway Somerset for maintaining excellent communication with him through regular texts and phone calls. He acknowledged that while the current level of support suffices for him (once a week), it may not be adequate for others facing similar struggles.

Beyond Headway, Mr P also receives assistance from a support worker who visits 4 times a week to help with cooking and household chores. However, he raised concerns about the limited availability of ABI related information and resources in his local area. He emphasised the importance of making this information more

accessible to the public, highlighting a gap that could impact the well-being and awareness of other individuals living with ABI.

Despite the obstacles he continues to face, he remains optimistic and profoundly grateful for the organisation's role in his rehabilitation. He describes Headway Somerset as "brilliant", acknowledging the critical impact that they have on people living with ABI.

Case Study No 4

Alex's experience with neuro rehabilitation

Healthwatch Somerset met with Alex, an individual who has faced significant health challenges in recent years. Initially hospitalised for a stomach condition, Alex suffered a stroke during their hospital stay. Unfortunately, the stroke was not immediately identified by hospital staff, which may have contributed to the deterioration in their overall condition. Prior to their stroke, Alex led an active lifestyle and worked as a plasterer, a physically demanding profession they took pride in. However, since the stroke, Alex has experienced limited mobility and now primarily relies on a powered wheelchair.

They benefit from the support of a dedicated carer and unwavering assistance from their partner who has been instrumental in navigating the complexities of accessing necessary services and support.

To aid their recovery, Alex underwent physiotherapy aimed at improving their mobility, however, adapting their home to meet their needs proved to be a lengthy process. Securing funding and approval from the local council took nearly two years. Eventually, modifications to the ground floor and an extension were completed, significantly enhancing quality of life.

Alex demonstrated remarkable determination throughout their rehabilitation journey. They have made substantial progress, particularly in speech therapy, which has improved their communication skills. While the stroke resulted in some memory loss – including an absence of childhood memories - Alex remains deeply connected to their family, speaking warmly of their partner and their young child.

Keen to maintain an active lifestyle, Alex participates in activities such as swimming and regularly visits ARK, an intergenerational land-based service designed for people of all ages, and abilities. ARK provides a safe environment where individuals

can relax, engage socially, and enhance their overall health and well-being. Alex particularly enjoys gardening and planting at ARK, where planters have been thoughtfully adapted to accommodate wheelchair users.

Alex has joined Headway Somerset, where they appreciate the opportunity for social interaction and cognitive stimulation. They have expressed a strong desire for their voice to be heard, highlighting concerns over limited availability of neurorehabilitation services in Somerset for individuals recovering from acquired brain injuries.

Alex's journey demonstrates the challenges faced by ABI survivors and the critical importance of timely medical interventions, comprehensive rehabilitation services, and adequate community support.

Case Study No 5:
Mr R's Journey with ABI and support of Headway

Healthwatch visited a Yeovil Group and spoke to Mr R about his experience living with an ABI. Mr R sustained his ABI 26 years ago following a severe road accident. While travelling between towns in Somerset, he skidded on oil spilt from a lorry, causing his vehicle to crash into a tree. A friend, travelling a few cars behind, witnessed the accident. An ambulance was called.

Mr R was taken to Musgrove Park Hospital where he remained in a coma for an extended period and remained in a prolonged disorder of consciousness (PDOC) and an unresponsive wakefulness. Doctors informed his mother that if he did not wake up soon, they would turn his machines off, fearing the worst. The severity of the brain injury was yet to be determined at this stage. His mother requested additional time, and after four more days, Mr R regained consciousness. He was later transferred to a hospital in Bristol for surgery and subsequently moved to a treatment center near Taunton – Mr R wasn't sure which treatment Centre. Mr R received physio to regain mobility. A metal rod was inserted in his left side from his hip to his knee, and he also underwent rehabilitation to regain his speech.

Once discharged from adult social care, Mr R found himself without a care plan or support structure. He initially lived with his mother before relocating to another county where he had grown-up. Uncertain of how he got there, he believes he may have taken a bus. During this period, he lived with a friend but later experienced homelessness. The Citizens Advice Bureau (CAB) provided critical assistance,

securing his finances and helping him find a flat. It was through CAB that Mr R was referred to Headway.

Mr R faces ongoing challenges due to his ABI, including seizures and instability on his left side, which causes his foot to turn in and drag leading to falls. He shared that he has lost his confidence and struggles with social isolation. The friends he once had drifted away, and the only person he considers a friend is his former driving instructor, who remembers teaching him to drive. They meet every Friday for a meal and a movie.
Mr R describes Headway as his lifeline, providing neuro rehabilitation support and practical assistance, such as helping him manage his post. In addition, he receives care from a support worker twice a week, whom he deeply values. Mr R's experience highlights the long-term challenges faced by ABI survivors and the critical role of Headway in providing rehabilitation, social support, and practical help, along with brain training activities such as problem-solving questions.

Mr R also undergoes an annual an EEG (Electroencephalogram, Electro -refers to electrical activity, Encephalo – relates to the brain -gram – means a recorded picture or tracing) The EEG is a non-invasive test that records the brain's electrical activity using electrodes placed on the scalp, it detects abnormal electrical patterns. This practice can help with studies of seizures and any changes in the brain's activity.

Appendix D

When systems fail: Missed chances to protect a life post-ABI with complex needs

Background

Tom sustained an acquired brain injury in his early 20s following a significant road accident in December 2011. This injury left him with cognitive, physical, and psychological challenges, including hemiplegia, aphasia, and epilepsy. His struggles were compounded by dependencies on drugs and alcohol and a lack of cohesive support throughout his life. Prior to this accident, Tom experienced multiple brain injuries, including childhood concussions and motorbike accidents during his teenage years.

Key challenges and life events:

- Medical history and rehabilitation - Tom's initial treatment included a three-week hospitalisation and subsequent neuro rehabilitation, with incorporated

speech therapy. Despite frequent patient appointments at Musgrove Park Hospital, the follow-up actions requested by other agencies remained unclear.

- Family involvement and lack of support - Tom's family reported limited communication from health and social care providers regarding his condition and care. The family contacted Headway Somerset for specialist support, which became the only structured assistance available to him.

- Substance use and mental health - from the age of 20, Tom struggled with drug and alcohol misuse. By 2003, he was a daily cannabis user and relied on prescribed medication for pain relief. His depression deepened, and in 2004, he declined support for addictions and counselling. He was diagnosed with post-traumatic epilepsy and bilateral temporal lobe atrophy. Despite referrals to support services, including Turning Point, he failed to engage consistently.

- Behavioural issues and social challenges - Tom's substance misuse led to anti-social behaviour, straining relationships with family and care providers. He became known to the police for associating with drug dealers and creating unsafe environments for himself and his vulnerable partner.

Safeguarding concerns: NB Tom has been the subject of a SAR.

Inadequate assessments and fragmented care – Tom's care assessment lacked a holistic approach, failing to address his capacity to manage risks effectively. Professionals often perceived him as coherent and mentally capable despite his cognitive impairments and depression.

Homelessness and safety risks - in 2013, Tom was evicted, making him homeless. Social services did not provide timely support to secure accommodation, exacerbating his vulnerabilities.

Mental health crisis - with reports of suicidal ideations. Despite escalating concerns from his family, professionals assessed Tom was low risk for deliberate self-harm or suicide. His mental health struggles were attributed to life events rather than acute mental illness.

Tom's life was marked by fragmented care and missed opportunities for intervention. His substance misuse, exacerbated by his acquired brain injury, remained an essential issue. In June 2014, Tom was found dead from a drug

overdose, whether accidental or otherwise. Highlighting the critical gaps in coordinated support and safeguarding efforts.

In-depth interview with Tom's family member

Questions for Dr Alyson Norman - Associate Professor of Clinical and Health Psychology.

Personal Journey and Family Experience:

1. Can you share more about how you and your family were impacted by your brother's brain injury?

I was 13 years old at the time of my brother's accident – he was 23. I was about to go out swimming with a friend when police officers arrived at my home to speak with my mum and stepdad. Despite the unfolding crisis, I was encouraged to proceed with my plans. Later, I learned that my brother had been in a severe accident and was on life support, leaving us uncertain about his survival. The impact on our family was traumatising and very distressing.

2. At what point did you and your family notice significant changes in his behaviour and mental health?

We immediately observed significant changes in my brother's behaviour and mental health following his brain injury. During periods when he was brought out of a medically induced coma, he exhibited aggressive and violent behaviour, including screaming and thrashing. To protect him, nurses placed soft toys around his bed rails, taken from the children's ward. He was unable to speak, required constant care, and seemed unaware of his surroundings and what was going on. He spent two months in a rehabilitation unit.

Healthcare Support Systems:

3. In your view what were the key gaps-missed opportunities that could have made a difference?

Upon my brother's discharge, there was a critical missed opportunity to establish a comprehensive care plan. Deemed medically fit, he was placed by the council into a

bedsit shared with six others who were substance users. This environment was wholly inappropriate for his rehabilitation needs. Although the council noted the ground-floor location provided wheelchair access, this alone was insufficient to meet my brother's requirements.

The situation highlighted the necessity for a tailored post-discharge planning for individuals with acquired brain injuries (ABI). Inadequate discharge processes and inappropriate living environments can severely hinder recovery and community reintegration. Ensuring suitable housing and support services is essential to address the unique challenges faced by ABI patients.

4. How well did healthcare professionals communicate with your family during his treatment and recovery process?

During my brother's rehabilitation, the healthcare professionals communicated effectively with our family, providing excellent support and information. However, upon his discharge, there was a notable lack of preparation and guidance for our family regarding his continued care.

Effective discharge planning is crucial to ensure a smooth transition from hospital to home care. It involves clear communication between healthcare providers, patients, and families to prepare for the post-discharge needs. This includes educating family members about the patient's condition, necessary care routines, and available support resources. A well-structured discharge plan could have significantly impacted my brother's recovery.

In this case, the absence of such planning left us unprepared to manage my brother's complex needs, demonstrating the importance of comprehensive discharge processes.

5. Were there barriers to accessing mental health or addiction services for your brother?

For many years following his brain injury, my brother did not receive the mental health support he needed. It wasn't until a decade later that he was referred to a neuropsychologist, but he was granted only a single appointment and was deemed ineligible for future sessions. Additionally, he sought assistance from the substance misuse team to overcome his addiction. However, due to his brain injury, he often forgot his appointments and was eventually removed from the sessions. The team failed to recognise that his memory impairments were a direct result of his brain injury. This situation highlights significant barriers in accessing appropriate mental health and addiction services for individuals with an ABI. A lack of understanding and

accommodation for cognitive impairments, such as memory deficits, can lead to inadequate support and exclusion from essential treatments, like my brother experienced.

Psychological and Social Factors:

6. How do you think his brain injury influenced his decision making, emotional regulation, and vulnerability to addiction?

My brother's acquired brain injury significantly impaired his decision-making abilities to include looking after his finances. Emotional regulation was very difficult for him with outbursts, this varied from day to day, before his injury he didn't exhibit aggressive behaviour. However, after his post-injury, he experienced frequent outbursts of anger and emotional instability, with mood fluctuations varying daily. Additionally, he suffered from fatigue and insomnia, which are common consequences of brain injuries. Understanding the impact is crucial for developing effective support and rehabilitation strategies for individuals with ABI.

7. From both personal and professional perspective, what role do you think stigma played in his ability to seek or receive help?

There was an unconscious bias toward my brother, and stigma hindered my brother's ability to seek and receive appropriate care. His preference for wearing army camouflage and heavy boots led to assumptions about his character and lifestyle. Healthcare professionals often misjudged him as being intoxicated based on his appearance and speech, even when he was sober. The experience shows how unconscious bias can adversely affect patient care. Perceived notions based on appearance can lead to inadequate care.

8. How might the effects of isolation, homelessness, and substance use have compounded the challenges from his brain injury?

Reflecting on my brother's journey, several interventions could have significantly altered his life's trajectory. Appropriate housing on discharge, the environment of the bedsit was detrimental to his recovery. Securing suitable supportive housing would have provided a stable foundation for his rehabilitation. Immediate physiotherapy upon discharge, which he never received. He had complications with his finger contractions over time. Early intervention with physiotherapy would have prevented these issues, as regular movement and stretching could have maintained muscle and joint function.

Future Improvements:

9. What advice would you offer to healthcare professionals working with patients facing similar challenges?

To engage with open dialogue, encouraging patients to share their experiences and challenges, aiding with trust and providing insights into a patient's unique needs. Understanding cognitive impairments and recognise cognitive deficits that are common in ABI patients, that can affect rehabilitation outcomes, having awareness of these impairments is crucial for effective care and planning. Offering appropriate referrals, directing patients to specialists, such as clinical neuropsychologists, whilst timely referrals can significantly impact recovery.

10. How can public services – healthcare, housing, and mental health better coordinate to support individuals with complex needs like your brother?

A key strategy with coordinating care and support, to have a named social worker who serves as a central point of contact, managing and streamlining all pertinent information, simplifying the navigation of various support systems. Given the challenges posed by staff turnover, having a consistent social worker ensuring continuity of care reducing the burden on individuals and their families. Social workers can play a pivotal role in care coordination, facilitating communication among different service providers and ensuring that all aspects of a person's needs are addressed cohesively. Learning to improve outcomes for those with complex needs like my brother.

11. What changes in policy or community support would you advocate for - to prevent similar situations?

I would advocate the implementation of comprehensive rehabilitation guidelines, adopting a standardised protocol, through the National Institute for Health and Care Excellence (NICE), to ensure that individuals with acquired brain injury (ABI) receive consistent and effective care. Guidelines to include assessment, goal setting, and tailored rehabilitation plans addressing physical, psychological, and cognitive needs. Overview | Head injury | Quality standards | NICE

Personal Reflection and Advocacy:

12. How has this personal experience influenced your research and work in health and psychology?

Motivated by my brother's acquired brain injury (ABI), I sought to understand the psychological challenges faced by ABI survivors and the support structures available in neuro rehabilitation. ABI often leads to significant cognitive, behavioural, and emotional changes, including personality shifts, impulsivity, irritability and apathy.

Effective neuro rehabilitation programs are essential to address these challenges.

Image attributes

Cover	Two people in lab coats looking at a computer screen	https://unsplash.com/photos/a-man-showing-something-on-the-computer-5VkNa1LrS8A
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