

Dear Petitions Committee,

Thank you for the actions you have already taken concerning our petition, and for also sharing the letter of 22 February 2022 from Eluned Morgan - Minister for Health and Social Services, regarding the provision of services and support for people with Acquired Brain Injury (ABI) in Wales.

ABI is a hidden epidemic affecting many hundreds of thousands of people in Wales. It is a chronic condition with hidden disabilities and life-long consequences, where many individuals require early and continued access to neurorehabilitation to optimise their recovery and maximise their long-term potential. However, the provision of services and support for people with ABI extends beyond the Health and Social Services sector, and rests on the cooperation between multiple sectors and departments.

Indeed, in our recently published 2021 *'Acquired Brain Injury and Neurorehabilitation in Wales: Time for Change'* report (appended with this letter - <https://ukabif.org.uk/page/TFCWales>), we make a number of recommendations across five key areas – Neurorehabilitation, Education, Criminal Justice, Sport-related Traumatic Brain Injury, and the Welfare Benefits System - with each highlighting the urgent need for the provision of services and support for people with ABI in Wales to be reviewed.

However, the letter - which we have gratefully received from Eluned Morgan –addresses only one of these five key areas. Consequently, we hope that the petitions committee are able to give their full consideration to our recommendations across all five key areas during their discussions:

1. Neurorehabilitation

- There is an urgent need in Wales to review the incidence of ABI and ensure existing neurorehabilitation services are adequate and 'fit for purpose' for children, young people, and adults, with new services implemented as required
- Children, young people, and adults with ABI in Wales should have access to high quality inpatient and community-based neurorehabilitation. Their neurorehabilitation needs should be assessed shortly after admittance to hospital, delivered during the inpatient phase, and continued, if required, in the local community.
- There is a need for cooperation between Health, Social Care, and Education departments, and funding for inpatient and community neurorehabilitation services needs to be reviewed.
- Neurorehabilitation must be a key consideration in the new Major Trauma Network for South and West Wales and South Powys, with a clear pathway to appropriate services.
- It should be mandatory for the Rehabilitation Prescription to be given to all individuals with an ABI, not just those who have been in a Major Trauma Centre, on discharge from hospital. Copies should also be sent to their General Practitioner and given to the patient and family.

2. Education

- There is a need to review the incidence of children and young people with ABI in the education system in Wales.

- All education professionals should have a minimum level of awareness and understanding about ABI and the educational requirements of children and young people with this condition (i.e., completion of a short online course for all school-based staff), with additional training for the named lead professional supporting the individual with an ABI and Additional Learning Needs Coordinators.
- Many children and young people with ABI require individually tailored, collaborative and integrated support for the return to school, and throughout their education.
- An agreed 'return-to-school' pathway plan is required, led, and monitored by a named lead professional, to provide a consistent approach and support for the individual, their family, and teachers.
- There is a need to ensure that Statements of Special Educational Needs (and Individual Development Plans in future) have consistent input from neuropsychological services to ensure that provision is fit for the individual's needs. The advice in the Statement should be specific - with no room for interpretation - to ensure that each individual receives appropriate support consistently.

3. Criminal Justice

- Criminal justice procedures, practices and processes need to be reformed to take into account the needs of individuals with ABI.
- Training and information about ABI is required across all services including the police, probation, prison services and the Courts.
- Brain injury screening for children, young people and adults is required routinely, and at the earliest point of contact with the Criminal Justice System.
- If an ABI is identified, neurorehabilitation is required with the appropriate interventions planned and implemented depending on injury severity. This could include ABI Awareness training for current Criminal Justice System staff to adapt their practices. In the cases of more severe brain injury, they may require specialist intervention with trained professionals.

4. Sport-Related Traumatic Brain Injury

- Funding for collaborative research is required to evaluate and improve assessment tools, develop objective diagnostic markers, and better understand the recovery process including post-concussion syndrome and potential long-term risks of sport-related brain injury.
- An education campaign is required in schools and communities to improve awareness and understanding of sport-related brain injury.
- Government should take the lead with clear sport-independent concussion guidance and policies. Sport associations should work collaboratively with government and professional clinical bodies to implement these policies and to improve health professionals' knowledge of concussion management.
- The National Health Service should develop better pipelines for the diagnosis and care of sport-related brain injury, including post-injury follow-up for earlier detection of post-concussion syndrome.

5. Welfare Benefits System

- Training is required for all assessors involved with individuals who have ABI.
- Re-assessment for welfare benefits should only take place every five years.
- A brain injury expert should be on the consultation panel when changes to the welfare system are proposed.

In addition, we also have the following comments and/or queries in response to the letter of 22 February 2022 from Eluned Morgan - Minister for Health and Social Services:

1. Thank you for confirming that the United Kingdom Government plans to publish a cross government strategy on neurological conditions and are liaising with the Department of Health and Social Care to ensure that any such strategy takes into account that health services are devolved in Wales, as well as consideration of the Welsh Government National Clinical Framework and developing quality statements. As you know, Chris Bryant MP, has been working closely with the United Kingdom Acquired Brain Injury Forum (UKABIF) regarding this, and has confirmed that there is representation from the Welsh Government at all levels in this work. It will be good to see how this translates, and we hope that at a *minimum*, the recommendations arising from the cross-government strategy on neurological conditions will be applied equally in each of the nations of the United Kingdom.
2. Concerning the Neurological Conditions Delivery Plan which sets out the Welsh Government's vision for people living with all neurological conditions in Wales, £900k has been allocated for neurological rehabilitation services annually. We note that Stroke and dementia are not covered in this plan as individuals with these conditions have their own delivery plans, but that still leaves coverage of approximately 250 recognised neurological conditions under the plan. How much of this £900k budget is allocated to ABI specifically? Additionally, as it is anticipated that the number of people with neurological conditions will increase in the future due to increased longevity, improved survival rates and improved general health care, how do you envisage that future levels of demand will be met and that the Delivery Plan continues to evolve to further improve provision? As recognised in the Neurological Conditions Delivery Plan, there is need to not only raise awareness of these conditions, but to also deliver a quicker pace of change going forward.
3. Improvements in the quality of neurorehabilitation are a long-standing aspiration across the United Kingdom, although its implementation has been somewhat neglected over the last two decades. As a requisite example, in 2001 the Parliamentary Health Select Committee published a report on 'Head Injury' rehabilitation containing over 20 recommendations. Though these recommendations were for the UK in general, they were also highly relevant to Wales as a devolved nation. However, whilst many of the recommendations related to acute care have been implemented to some extent, we have not seen substantial implementation of those recommendations in the last two decades (please refer to Page 16 in the appended '*Acquired Brain Injury and Neurorehabilitation in Wales: Time for Change*' report for further details). Therefore, and regarding the National Clinical Framework, what is the timescale for the quality statement for neurological conditions, and how do you envisage that these high-level policy intentions will be implemented at service level?
4. Further, the publication of the National Rehabilitation Framework and underpinning population specific guidance (published May 2020) is certainly welcome news, with this intended to help services to better understand the increasing demand for rehabilitation, reablement and recovery throughout health and social care services. However, does the implementation of this guidance, at least in part, also rest on the successful delivery of the data dashboard for ABI which as recognised, is an ambitious project? The development of the data dashboard is long overdue, but how will those with ABI who are not admitted to hospital and/or not attending for emergency and unscheduled care be identified and in turn, supported in the care pathway?
5. Thank you for sharing that health boards have invested additional rehabilitation provision for patients with major trauma injuries, including the implementation of the Rehabilitation Prescription. However, Rehabilitation Prescriptions are not made available to all individuals with an ABI, and General Practitioners do not always receive a copy when one is available, so cannot facilitate access to neurorehabilitation services post-discharge. Individuals with an ABI treated outside of a Major Trauma Centre in Wales are also still unlikely to receive a rehabilitation

prescription. Instead, we believe that a Rehabilitation Prescription should be given to all individuals with an ABI, not just those who have been in a Major Trauma Centre, on discharge from hospital. Given the inconsistent and limited use of Rehabilitation Prescriptions, is the implementation of and use of these under review, and are there plans to expand provision further? Additionally, whilst we welcome the recent investment in rehabilitation provision by health boards, do enough specialists currently exist to meet demand and are there plans for further investment?

6. We are very pleased to learn that Betsi Cadwaladr University Health Board (BCUHB) has been actively trying to address the issue of the lack of inpatient Level 2 Neuro Rehabilitation services in North Wales since 2019/20, including the establishment of the BCUHB Neuro Rehab Project Board in response to the report submitted to the Executive Team in April 2021. Thank you also for your suggestion of contacting Megan.Vickery@waes.nhs.uk. We will of course do this and look forward to further updates on progress, as well as the opportunity to be involved with this work.
7. In addition to a specific lack of neurorehabilitation services in North Wales, we also wish to highlight that such services are particularly limited for children in Wales. From April 2010, neurorehabilitation for children with ABI was transferred to the seven Health Boards, and planning undertaken through a joint committee, the Welsh Health Specialised Services Committee (WHSSC). As we understand, individuals who meet the criteria for specialist inpatient paediatric neurorehabilitation under the Welsh Health Specialised Services Committee policy are referred to Alder Hey Children's Hospital, Liverpool (North Wales) or Noah's Ark Children's Hospital for Wales in Cardiff (South Wales). The latter also provides secondary and tertiary services for children and young people, in areas relevant to trauma care. However, there are no other specialist NHS paediatric neurorehabilitation services in Wales, either inpatient or long-term in the community. How and when will this be addressed?

Thank you once again for considering our petition and for allowing us the opportunity to respond to the letter. Please do not hesitate to contact us should you have any queries or require further information. We would welcome the opportunity to work collaboratively and alongside you to ensure improved provision of services and support for people with ABI in Wales.

Yours Sincerely,
On behalf of my fellow petitioners

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