

P-06-1235 Ensure appropriate provision of services and support for people with Acquired Brain Injury in Wales – Correspondence from the Petitioner to the Committee, 4 June 2022



Faculty of Medicine, Health and Life Science
Y Gyfadrn Meddygaeth, Iechyd a Gwyddor Bywyd

4 June 2022

Dear Petitions Committee,

Thank you for the actions you have already taken concerning our petition “P-06-1235 - *Ensure appropriate provision of services and support for people with Acquired Brain Injury in Wales*”, and for sharing the letters of:

- 12 May 2022 from Eluned Morgan - Minister for Health and Social Services
- 25 April 2022 from Jo Whitehead - Chief Executive for Betsi Cadwaladr University Health Board

In response, we have the following comments and/or queries:

Neurological Conditions Plan: Thank you for confirming that the £900k funding was allocated to health boards to develop Community Neurorehabilitation Teams, and that those teams are not condition specific (typically) and see people dependent on need. However, the needs of those with ABI are often vastly different to those living with other neurological conditions, and we believe that survivors of ABI deserve a strategy that recognises and meets their specific needs.

Further, is the allocated annual funding of £900k sufficient for supporting the vast number of neurological conditions (~250) recognised under the plan? All too frequently, our impressions from both service users and those working across community neurorehabilitation teams in Wales, is that services are incredibly stretched, there are lengthy waiting times, and that the range of services provided and to whom, varies across locality. Given pressures and demands on such community neurorehabilitation services, there are also often stringent eligibility criteria for accessing such services also, with variation in criteria across individual teams and by geography, meaning that many people with ABI in need of support are still missing out on vital community-based neurorehabilitation services.

Additionally, and as conveyed previously in our response letter of 14 March 2022, it is also 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. We recognise that the ABI data dashboard will help inform health boards with regards to funding allocations and resource review, but how do you envisage that future levels of demand will be met and that the Delivery Plan continues to evolve further, during the period when the ABI data dashboard is still being developed?

ABI Data Dashboard: Regarding the data dashboard, we agree that a national data repository is pivotal for understanding the demand for, and impact of services for people with ABI, as well as monitoring equity of access and quality of services across Wales. As Digital Health and Care Wales are developing the national repository, we are also pleased to learn that it should be possible to include data from additional services to enable to whole patient journey to be mapped at national and local level. Even so, data collection and quality has been a recognised issue for many years, with

the urgent need to find ways of improving methods of data collection, capture and maintenance recognised in the Parliamentary 2001 Health Select Committee Report '*Head Injury: Rehabilitation*'. Therefore, whilst the development of the ABI data dashboard is certainly welcomed news and we believe it will be of significant value, we have only witnessed partial progress against the cited 2001 recommendation; progress has been slower than hoped. Of course, we recognise that the data dashboard is a significant undertaking and will only be as good as the data populating it, but could you provide an indication of the likely timescale of this work? It would be useful to be able to chart its progress against a roll out plan, and to also gain an understanding of the anticipated functionality of the data dashboard at various points of release.

National Clinical Framework: When available in summer 2022, we would very much appreciate access to the respective Quality statement, alongside the agreed priorities and workplan for the next 12-18 months.

National Rehabilitation Framework: We are heartened to see recognition that access to services should not be dependent on data dashboards given its developmental timescale, with everyone supported equitably, in the way that best suits their needs. We also agree that there is need to work across Wales to improve access with more self-referral options, patient initiated follow up, and 'see on symptom' responses – particularly so for ensuring that those with ABI who are not admitted to hospital and/or not attending for emergency and unscheduled care be identified and captured on the ABI dashboard, and in turn, supported in the care pathway.

Although, there is need to consider within this that initiation and self-advocacy is a common issue for individuals with ABI, and they may also lack awareness and insight of their own problems and subsequently fail to report/and or be aware of relevant information as a result. 'See on Symptom' responses also hinge on increased knowledge and understanding of ABI, where there is need for enhanced training for professionals, such as GPs and Social Workers, so that they are better equipped to identify and recognise symptoms. All too often, presenting problems to an agency may not indicate that a person has a brain injury, there may be no physical outward signs of such an injury, and reported symptoms and difficulties may overlap with other conditions and/or not be immediately apparent or visible also – yet an identified ABI is responsible for many of the reported long-term issues and difficulties. Consequently, are there plans to develop and deliver enhanced ABI training to health and social care professionals across Wales, including those operating in community settings without specialism in ABI?

Further, thank you for sharing that a modelling tool and evaluation framework have been developed to support the Rehabilitation Framework, with usage already evident across '*some neurorehabilitation services*' to facilitate understanding of demand and capacity, as well evaluating current and future service provision. We trust that there will be more consistent adoption of such tools and frameworks going forward and as the neurorehabilitation workstream (Neurological Conditions Implementation Group) progresses. In the meantime, could you confirm which neurorehabilitation services are already using the modelling tool and evaluation framework?

Rehabilitation Prescription: We agree that the Rehabilitation Prescription is not a replacement for constant assessment and thorough clinical, co-produced goal setting, but it is an extremely valuable tool for supporting effective discharge planning, communication, and onward referrals. Thus, we maintain the position that 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 acute care. Therefore, whilst there are currently no plans to extend the use of the Trauma Network Process, we hope that this position is reconsidered in the Autumn when the National Clinical AHP Lead for Rehabilitation reviews the Rehabilitation Framework and underpinning

guidance.

Importantly though, even if/when Rehabilitation Prescriptions are provided, their success rests on whether the recommendations contained within them are met, which depends on support pathways being clear and sufficient availability of community services, resources, and specialist expertise – which at present, can be variable, inconsistent, and inequitable. As referred to elsewhere, there are currently few specialist neurorehabilitation services in Wales, and even fewer paediatric services.

We also know that many individuals with ABI present first to other public services (e.g., social services, criminal justice). In such instances, an equivalent to the Rehabilitation Prescription would be extremely beneficial, as these individuals often end up ‘going round in circles’ and have trouble accessing relevant ABI support services via established pathways. As referred to above, there is also need for enhanced training for public service professionals, so that they are better equipped to advise and support those with an ABI.

Neurorehabilitation Services for Children: Thank you for recognising that gaps exist in provision of services for children and young people with ABI. As captured in our *‘Acquired Brain Injury and Neurorehabilitation in Wales: Time for Change’* 2021 report (<https://ukabif.org.uk/page/TFCWales>), NHS paediatric neurorehabilitation services, whether inpatient or long-term in the community, are limited overall. We sincerely hope that the ABI data dashboard – which we believe is likely to capture more accurate data for children (index event; parent advocacy; inclusion of data from birth) - proves fruitful in identifying needs, directing additional resources within health boards, and highlighting the critical need for investment and expansion of existing services. However, what about the here and now? What advice can we provide to parents in Wales who routinely contact us and associated groups/services (e.g., UKABIF, the Child Brain Injury Trust, the Children’s Trust), distressed that they cannot access vital, timely, ongoing, and local support services for their child who has sustained an ABI?

Education: We agree that a central component of the Additional Learning Need (ALN) system should be *“a fair and transparent system for providing information and advice, and for resolving concerns and appeals”*. Connected to this, it is vital that such a system is also accessible and user friendly, where utilisation and outcome does not depend on parents seeking legal support and advice to navigate the system, make an application, or challenge a decision. Parents of children with an ALN should feel and be supported by schools and key coordinators, rather than feeling like they must do battle.

Thank you for also confirming that an extensive package of training, core skills development and ongoing professional development has been developed for practitioners. Is this provided to all professionals involved in the assessment and delivery of ALN support, and does this package include specific information and awareness training about ABI? The National Acquired Brain Injury in Learning and Education Syndicate (N-ABLES) have developed resources that could support the training package: <https://ukabif.org.uk/page/ABIReturn>.

Additionally, it is also important to ensure liaison with external agencies and psychology services, including Educational Psychologists (EP). With the latter, we note that EP numbers are limited in Wales, meaning that schools currently have variable access to them. When the *‘Additional Learning Needs and Educational Tribunal (Wales) Bill’* was originally discussed (<https://business.senedd.wales/ielssueDetails.aspx?IId=16496&Opt=3>), evidence session 15 received information from the Association of Educational Psychologists, including:

- *“Would the Committee consider asking the Welsh Government to direct local authorities to*

employ more EPs and expand services, rather than making any further cuts?”

- *“...serious considerations should be given by the committee to recommending now a substantial increase in the number of postgraduate training places in Cardiff University from the current level of just 11 per year. It should be noted that between 2012 and 2018 there has been a 25% increase in commissioned university places for initial training of EPs in England from 120 to 160 – in Wales there has been no increase at all.”*

What steps have been taken to employ more EPs and expand services, and how many university training places have been commissioned annually in Wales since 2018? Are EP services appropriately resourced to meet demand and to successfully deliver the ALN and Education Tribunal (Wales) Act and ALN Code for Wales?

Criminal Justice: Thank you for sharing the information received from Her Majesty’s prison regarding the Link Worker Programme (Cardiff and Swansea), in-reach service (Disabilities Trust) and developments at the Cynnwys Unit (HMP Parc), which are all very encouraging. We look forward to seeing the current initiatives rolled out further across Wales. Notably though, training and information about ABI is required across the entire spectrum of criminal justice services (e.g., police, probation, prison services, and the courts). Are there plans in place to meet this need?

Further, does the population of the Cynnwys Unit currently include individuals with ABI? We would also welcome an update regarding progress against the following recommendations in the ‘2021 HMP Parc Health and Social Care Needs Assessment 2021 Report’ (<https://ctmuhb.nhs.wales/about-us/our-board/board-papers/2021-board-papers/7-july-2021/3-5-1-appendix-3-hmp-parc-health-and-social-care-needs-assessment-pdf/>):

- Recommendation 19: *“There should be a specialist resource available in HMP Parc to meet the needs of residents with acquired brain injuries and enable access to timely diagnosis.”*
- Recommendations 20-22: Support needs for the Cynnwys Unit, including access to Occupational Therapy, Speech and Language Therapy, and specialist LD Psychiatry and Psychology support.

Sport-Related Traumatic Brain Injury: We are pleased that the Welsh Government, other devolved administrations, and the UK government will all be working together on a joint strategy to address key issues. We hope that this work will cover the breadth of our 2021 recommendations (<https://ukabif.org.uk/page/TFCWales>), including the need for collaborative research, educational campaigns, concussion guidelines and policies, and better pipelines for the diagnosis and care of sport-related brain injury.

Welfare Benefits System: We wholeheartedly agree that the people in Wales deserve a social security system that is delivered with compassion, is fair in the way it treats people, and is designed to be as simple as possible. We are also pleased to learn that the Minister for Social Justice wrote to the Secretary of State in 2021 over concerns Welsh Government have with capability assessments undertaken by health professionals (PIP claims), and that you have also advised that the principle should be to avoid repeat assessments that place unnecessary strain on a person with a serious health condition/s. We also appreciate your continued efforts to raise awareness of both devolved and non-devolved benefits to ensure people are aware of the different benefits available and their entitlements.

In ongoing work with the Department for Work and Pensions (DWP), we hope that Welsh Government will continue to push for improvements in the system and give serious consideration to the following:

- The application process attached to welfare benefits can indeed be challenging, stressful and complex, and this is further pronounced in the context of ABI. Individuals with ABI frequently have cognitive problems which makes the application process extremely challenging, from understanding the information required through to communicating the answers. Put simply, individuals with ABI are often unable to complete the process owing to the very reason they are applying – their ABI.
- In line with your existing response to DWP's Health and Disability Green Paper, we also strongly believe that assessments should be undertaken by someone with an understanding of the realities of the condition. All too often, assessors have limited awareness and knowledge of ABI, as well as a lack of empathy with both the individual and their family.
- The need for specialists with an understanding of ABI is also critical because initiation and self-advocacy can be very difficult for those with an ABI, and they may also lack awareness and insight of their own problems and subsequently fail to report/and or be aware of relevant information as a result.
- There is a group of individuals with ABI that have prefrontal cortex damage who perform well in interview and test settings, despite marked impairments in everyday life. Consequently, the interview setting may mask an individual's care and support needs. This further reiterates how vital it is that evidence is sought from other health professionals and support organisations to ensure a more reliable and holistic assessment. Consequently, we implore you to continue to push DWP on this point as we believe it would make an enormous difference to those affected by ABI.
- We also strongly advocate for the inclusion of a brain injury expert on consultation panels when changes in the welfare system are proposed.

Betsi Cadwaladr Health Board: Thank you for the information contained within the letter dated 25 April 2022 from Jo Whitehead, Chief Executive for Betsi Cadwaladr University Health Board. The level of detail provided is very helpful and there are some promising developments and planned changes that seek to address the significant gap in the provision of ABI services in North Wales. In addition to contacting Megan.Vickery@wales.nhs.uk, we will also disseminate the response received to our partners and key stakeholders in North Wales. As they are best placed to determine whether the developments, planned changes, and the neuro-navigator role will meet the needs of their respective population, they may wish to raise additional comments/queries in due course.

Thank you once again for the detailed and helpful information received to date, as well as the opportunity to respond further. We welcome the opportunity to work collaboratively and alongside you to ensure improved provision of services and support for people with ABI in Wales, and please do not hesitate to contact us should you have any queries or require further information.

Yours Sincerely,

On behalf of my fellow petitioners and members of the South Wales Acquired Brain Injury Forum

Dr Claire Williams



Associate Professor and School Education Lead
School of Psychology, Faculty of Medicine, Health and Life Science
Claire.williams@Swansea.ac.uk

