



Eich cyf/Your ref P-06-1235
Ein cyf/Our ref EM/01512/22

Jack Sargeant MS
Chair - Petitions committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

12 May 2022

Dear Jack,

Thank you for your letter of 4 April on behalf of the petition committee, regarding the provision of services and support for people with Acquired Brain Injury in Wales. I have noted the further comments from the petitioner and have provided responses below.

Neurorehabilitation:

Neurological Conditions Plan

It is for health boards to prioritise how best to use the £900k funding to improve support for people waiting for neurological treatment, including for those with Acquired Brain Injury (ABI). The money was allocated to health boards to develop Community Neurorehabilitation Teams. These are not condition specific teams and they do not provide a condition specific service but see people dependant on need. As this is not a useful metric for these teams to collect, the proportion of people with ABI of the overall case load is not known.

An ABI data dashboard is in development and is a collaboration between The Value in Health Team and a Neurological Conditions Implementation Group (NCIG) Clinical Reference Group. As Digital Health and Care Wales (DHCW) develop the national data repository it will be possible to include data from additional sources to enable the whole patient journey to be mapped at a national and local level. Understanding the demand for, and impact of services for people with acquired brain injury, will help health boards to direct funding to the most appropriate place. It will enable NCIG to monitor equity of access and quality of services across Wales and in our English providers. The ABI dashboard is in its early developmental stage and will only be as good as the data populating it, so continually improving data quality is a focus of this work.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

National Clinical Framework

The NCIG has developed a draft Quality Statement with input from a service user stakeholder group. This has been submitted to Welsh Government for consideration and it is anticipated this will be published in the summer. The NCIG has already agreed priorities for work for the next 12-18 months and is developing a workplan to ensure these are delivered. Implementation remains the responsibility of health boards and WHSSC.

National Rehabilitation Framework

Accurate data and monitoring is essential for delivering the most effective rehabilitation to all who require and receive it. Implementation of the National Rehabilitation Framework does not rely on the data dashboard, but good data will certainly enhance our intelligence and our effectiveness to improve outcomes. Access to services and care pathways should not be dependent on data dashboards and everyone should be supported equitably, in the way that best suits their needs, regardless of location of services or route through which they reach services or where they are on the care pathway.

As part of the suite of underpinning guidance for the Rehabilitation Framework, a modelling tool and evaluation framework have been developed. These should be used by each rehabilitation service to ensure that demand and capacity are understood and that all care is evaluated and action taken from the learning from that evaluation to improve service delivery. These are already being used in some neurorehabilitation services. They will be important in the neurorehabilitation workstream that has been identified by NCIG.

The developing ABI data dashboard will only be as good as the data that has been collected and the sources of data that can be accessed. The Value in Health and clinical reference group continue to work with DHCW as they develop the national data repository to see how additional sources of data can be included for the whole pathway. We need to work across Wales to improve access with more self-referral options, patient initiated follow up and 'see on symptom' responses rolled out in line with the planned care pathway.

Rehabilitation Prescription

Rehabilitation prescriptions are not a standardised tool with a specific structure. They are a required part of UK Trauma Network auditing. The intention is to support excellent transfer of information about a person's rehabilitation needs when they move services. It is good practice for all rehabilitation services to coproduce realistic rehabilitation goals with those using the service, and identify what support and interventions are needed to support the individual achieve those goals. Different people need services provided to them in different formats, depending on their cognitive, communication and emotional status. Good handover information between services should always include:

- Setting out the nature of the rehabilitation needs.
- Recording baseline values for the core measures that are used to record complexity and outcomes that are required as part of routine evaluation within the specialist rehabilitation services.
- Recommendations and referrals.

Good practice will require constant assessment to keep rehabilitation goals up to date. A single document is not a replacement for thorough clinical, co-produced goal setting. There are therefore no plans to extend the use of the Trauma Network process. However, the recent appointment of a National Clinical AHP Lead for Rehabilitation, working alongside a Clinical Fellow in Rehabilitation in HEIW, is expected to result in a revised Rehabilitation Framework and underpinning guidance by the Autumn. The National Clinical Lead is establishing a network to support identifying and sharing good practice across Wales.

The Rehabilitation Framework recommends the use of the Modelling tool to better understand demand for rehabilitation. Health Boards will continue to monitor waiting times and determine

the requirements for investment and expansion of rehabilitation services and Allied Health Professionals.

Neurorehabilitation services for children

With regards to paediatric neurorehabilitation services in Wales, it is for the health boards to identify the needs of their population and commission/provide appropriate services. All health boards have community paediatric teams and the Allied Health Professionals working within them will have neurorehabilitation specialist skills. As referred to above these teams are not condition specific teams or services but assess and support people according to need rather than specific condition or diagnosis.

Understanding the demand for, and impact of services for people with ABI is critical and this is an area where gaps do exist. However, the ABI dashboard referred to above is using data across the life-course with the inclusion of data from birth. This is therefore starting to provide data on the incidence of ABI in children and is something that can be built upon. This will be vital to ensure health boards, and others, have the information and intelligence required to plan effective services and direct resources.

Education

With regards to education, Equity and inclusion are at the heart of our education reforms in Wales. As part of this programme of reform, a new ALN system is gradually being introduced in Wales to replace the current SEN system. The new ALN system is underpinned by the ALN and Education Tribunal (Wales) Act and ALN Code for Wales which strengthens support for learners aged 0-25 with additional learning needs (ALN) by creating:

- a unified legislative framework to support all children of compulsory school age or below with ALN and to support young people with ALN who are in school/ PRU or further education;
- an integrated, collaborative process of assessment, planning and monitoring of the support provided to ALN learners which facilitates early, timely and effective interventions; and
- a fair and transparent system for providing information and advice, and for resolving concerns and appeals.

Under the ALN Act all learners with ALN, which may include learners with ABI, will be entitled to an Individual Development Plan (IDP) irrespective of the severity or complexity of their needs, and the views, wishes and feelings of children and young people and their parents must be considered at all stages of the IDP process.

One of the statutory roles created by the ALN Act is the Designated Educational Clinical Lead Officer (DECLO). The DECLO role will help strengthen liaison and joint action between the health and education services, assist in the removal of barriers to partnership working, and ensure that IDPs contain evidence based health interventions.

A skilled education workforce is essential to ensure improved learner outcomes. Under the ALN Act schools and colleges must have an ALN Co-ordinator (ALNCo) who co-ordinates ALP for learners; provides a strategic leadership role and is the first port of call for professional advice and guidance. We have developed an extensive package of training, core skills development and ongoing professional development for all practitioners.

The Welsh Government's guidance, '[Supporting Learners with Healthcare Needs](#)' contains both statutory guidance and non-statutory advice to assist local authorities, governing bodies, education settings, education and health professionals and other organisations to support learners and ensure minimal disruption to their education. The guidance includes

advice on integration after diagnosis and reintegration of learners with healthcare needs including the need to work with other agencies and other learners; staff training to assist the learner's return; and the need for support to be considered by all parties and reflected in the learner's individual healthcare plan.

Criminal Justice

Some of the points made in your letter focus on the practice of criminal justice agencies. Although we work closely with criminal justice partners, justice is not devolved to Wales and the specific practice of organisations is not within our direct remit. Her Majesty's Prison and Probation have provided the following information on how they are supporting people with Acquired Brain Injuries:

Linkworker programme in prison and probation settings

Since 2017 the Disabilities Trust have been delivering a whole-systems approach operating across custodial and community settings in Cardiff and Swansea. The Trust provide an in-reach service in HMP Cardiff and HMP Swansea and Approved Premises to deliver bespoke advice and consultation on a case-by-case basis.

The service includes brain injury screening, the provision of a specialist Linkworker and consultancy/training for other professionals. The in-reach Linkworker uses a range of interventions and support, to equip individuals with the tools and techniques to help them recognise and manage the injury's impact on their memory, cognition, emotions, and behaviour. Additionally, the service provides resources and training to professionals in relation to brain injury and its consequences and assist with the management of prisoners with a brain injury, within and outside the prison.

Cynnwys Unit at HMP Parc

In 2019 a review of the Supported Living Plan to Assisted Living Plan was undertaken and with the wider changes of the Offender Management in Custody model and the implementation of the Key Worker scheme there was a unique opportunity to enhance the current and planned delivery on the Supported Living Unit by relocating to a more suitable area – C Block.

Early in 2019 work began to complete the re-role of Credwch Unit into an Assisted Living Unit for men with Learning Difficulties, Disabilities or Autistic Spectrum Disorders that may make them vulnerable in the main population and who may require a level of assisted living. The unit was renamed Cynnwys, meaning 'inclusion' in Welsh and has a clear Mission Statement which focuses on the need for multi-departmental working as well as a person centred and tailored approach to men with LDDs and ASDs.

As well as the work to re-role Cynnwys, they have reviewed their pathway for men with LDDs/ASDs including how they identify, assess and cater for the needs of this group. All referrals prompt a series of assessments and discussion at an MDT meeting held twice a week on the Cynnwys Unit. In addition, men can also complete a self-referral using the CMS terminals located on each unit. All staff are encouraged to make referrals through this process.

Sport-Related Traumatic Brain Injury

The Welsh Government has agreed to work alongside the UK Government and the other Devolved Administrations to develop and share across the sport and education sectors, shared protocols for concussion in sport; one of the steps in the UK Government's action plan on tackling concussion in sport. Sport Wales is working with national governing bodies of sport to consider how to support the implementation of the other actions in the plan, including those to improve data collection and research.

Welfare Benefits System

Powers over the welfare systems sit with the UK Government, however, people in Wales deserve a social security system that is delivered with compassion, is fair in the way it treats people and designed to be as simple as possible, promoting efficient administration and helping people to easily understand and access their entitlements

The Welsh Government has previously voiced concerns over the stress applicants are placed under when submitting the same evidence for different claims such as PIP and ESA. In June 2021 the Minister for Social Justice wrote to the Secretary of State to highlight the concerns Welsh Government have over the capability assessments undertaken by healthcare professionals for PIP claims. In addition, in our response to the Department for Work and Pensions (DWP) Health and Disability Green Paper we advised the principle should be to avoid repeat assessments not putting additional strain on a person with a serious health condition.

Many people who claim welfare benefits struggle to secure relevant and timely evidence from health professionals to support their claims. It is essential therefore that clear guidance and instructions are provided to people of the level of evidence that is necessary. The needs of the applicant should be central and what works best for them during the assessment process – it should also be made clear that they can have someone with them during the assessment. We believe it is important individuals should be able to change their choice of assessment if they have a fluctuating health condition. e.g. if they have a mental health condition they may be happy to have an assessment via video call on one occasion, but may not feel confident to do that at a subsequent occasion.

In our response to the DWP's Health and Disability Green Paper we also stated DWP seek evidence from other health professionals or support organisations, this provides a more holistic assessment. DWP may wish to include assessments and intelligence from Health Care Professionals who know and work with the person, assessments undertaken by someone with an understanding of the realities of the condition will aid a Decision Maker to reach the right decision first time.

In Welsh Government we are raising awareness of both devolved and non-devolved benefits to ensure people are aware of the different benefits available and their entitlement. We have also liaised with DWP communications while taking this work forward and welcome the opportunity to take part in discussions which improve the benefits system.

I hope this information is helpful.

Yours sincerely,



Eluned Morgan AS/MS

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services