Eluned Morgan AS/MS
Ysgrifennydd y Cabinet dros Iechyd, Gofal Cymdeithasol a'r Gymraeg
Cabinet Secretary for Health, Social Care and Welsh Language

Llywodraeth Cymru
Welsh Government

Eich cyf/Your ref EJ1271
Ein cyf/Our ref EM/06106/24

Elin Jones MS/AS
Member of the Senedd for Ceredigion

elin.jones@senedd.cymru

July 2024

Dear Elin,

Thank you for your letter of 12 July on behalf of your constituent about her son's wait for a neurodivergent assessment and I can understand the frustration and worry this is causing.

I am sorry that your constituent felt they had no option but to pay for private treatment. I must add any decision on seeking private treatment has to be entirely a personal decision and one I cannot comment on.

I hope you understand that neither I nor my officials are able to comment on, or intervene, in specific cases as these are matters which must be dealt with by the health board, as it is responsible for treatment decisions about individual patients.

Paying privately for treatment - including private prescriptions - is entirely a personal decision for your constituent's family and there is no provision for NHS Wales or Welsh Government to refund all, or part, of the costs.

I would suggest that if your constituent has not already done so, she should bring her concerns to the attention of the Hywel Dda UHB, the contact details can be found here: [Patient support services (complaints & feedback) - Hywel Dda University Health Board (nhs.wales)]

I appreciate it can be difficult to make a complaint, however the concerns process gives the health service an opportunity to look into things that may have gone wrong and to make improvements.

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1SN

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400
Gohebiaeth.Eluned.Morgan@llyw.cymru
Correspondence.Eluned.Morgan@gov.wales

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.

Putting Things Right is the procedure for dealing with complaints, serious incidents and claims (concerns) within NHS Wales. NHS Wales complaints and concerns: Putting Things Right | GOV.WALES

In dealing with concerns raised by patients or their families regarding health services Welsh health boards are required to follow detailed guidance. If your constituent chooses to write to the health board, I would expect them to provide her with a satisfactory reply which addresses the concerns raised.

Your constituent may also wish to know that a new national citizen voice body called Llais is in place to provide as much or as little support as necessary to ensure everyone has equal access to the complaints process. This body can be contacted for further assistance by clicking on the following link: West Wales | LLais (llaiswales.org)

I note the concerns raised about access to medication for attention deficit hyperactivity disorder (ADHD), general practitioners are responsible for their prescribing decisions. Whilst some GPs feel sufficiently knowledgeable and experienced to prescribe in specialist areas like ADHD, others do not. In these situations, prescribing will be continued by specialists in secondary care. Even where GPs are content to continue prescribing a medicine which has been initiated by a specialist, they may feel unable to amend that prescription without referring patients back to secondary care.

The increasing demand for ADHD assessments has resulted in increased waiting times, which are much longer than we would want them to be. The work we are now undertaking as part of our Neurodivergence Improvement Programme, which is backed by £12m of additional funding, over three years, will focus on needs based service development, including streamlining referrals and reducing waiting times. The funding will also improve pre and post assessment support services.

In the coming months we will also be reviewing current pathways into neurodevelopment services to ensure equity and accessibility. This will include the provision of guidance on what information is required to make a ‘good’ referral and we are currently exploring other approaches and innovative projects across the UK. Our aim for this work is a consistent, national approach avoiding postcode lottery and variance where possible.

The NHS Executive have undertaken a formal audit of all children’s neurodevelopmental services. This will have identified current best practice and areas for improvement. Each health board area will have received an individual report, we will follow up on any actions required to make improvements. We are awaiting a final report which will support further understanding around current practice and over-arching issues which we need to address from a Welsh Government perspective.

Our work is also focusing on supporting people to ‘wait well’ whilst awaiting a diagnostic assessment. There are many services that people can access to support their general well-being. Your constituent’s GP will be able to provide information on accessing Primary Care Mental Health Support Services and other local services. Many organisations such as Mind also provide useful information, access to courses etc. The NHS website has information on the ‘Five Ways to Well-Being’ and many other well-being topics.

The NHS online Silvercloud service is a further, free resource that offers support. SilverCloud. Making Space For Healthy Minds (silvercloudhealth.com).

The Equality Act requires schools to make reasonable adjustments for disabled students (including students with neurodiverse conditions like ADHD). Some learners with disabilities may have Additional Learning Needs (ALN) and an Individual Development Plan (IDP). I have attached a link here to information for parents about the ALN system and rights under this system. ALN is identified by either a school, pupil referral unit, college or local authority. It is not necessary for a child to have a medical diagnosis to receive Additional Learning Provision (ALP) and support should not be delayed whilst waiting for any diagnosis if needs and relevant support can be identified.

If your constituent has concerns regarding the support [Redacted s40(2)] is receiving I would encourage her to engage with the school, including the ALN Co-ordinator (ALNCo) who - with full support from teaching staff and members of the school's senior leadership team - is responsible for leading on the access arrangements/ reasonable adjustments process within the school.

Your constituent may also wish to liaise with SNAP Cymru, a non-profit making organisation which works with families, learners, parents, their carers and professionals working with those who have or may have ALN. Contact details for SNAP Cymru and further information can be found on their website via this link.

Yours sincerely,

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