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Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref JMEWL/01179/23

Rocio Cifuentes
Children's Commissioner for Wales

31 July 2023

Eleri.Bingham@childcomwales.org.uk

Dear Rocio,

Thank you for writing to me about this important issue.

I am aware of the concerns regarding the delays in diagnosis for children and young people and my officials are working with colleagues across departments and with external stakeholders who are taking action to reduce waiting times.

The points you raise regarding the status of private medical assessments is important and I will ensure they are brought to the attention of the ALN Reform National Steering Group. This group provide strategic leadership with the Welsh Government, including oversight over the essential multi-agency collaboration required under the ALN system.

Early identification, intervention and prevention

The early identification of ALN and the timely intervention of additional learning provision (ALP) are key principles of the ALN system. We know that providing the right ALP as early as possible can be the most effective means of addressing ALN and preventing the need for further intervention in the future.

Therefore, it is important to stress that ALP does not depend on an assessment or a medical diagnosis. Neither do individual development plans (IDPs) require an assessment or diagnosis before they can be issued to a child or young person with ALN. IDPs and the ALP they describe should not be delayed as a consequence of NHS waiting times.

Where a school or local authority has decided that a child or young person has ALN, that body must prepare an IDP for the child or young person.

Evidence for IDPs

Those with a role in writing IDPs may need to consider a wide range of evidence when preparing or reviewing an IDP. Although private assessments by qualified practitioners can be useful, they should never fully determine the contents of the IDP. All IDPs must involve the child, the child's parent or the young person, along with any other appropriate contributors following the person-centred practice approach.

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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.

Additional learning needs co-ordinators (ALNCoS) are qualified individuals with clear duties as set out in the ALN Code. We expect them to use their knowledge and experience to ensure the evidence they use to help determine the ALP required by their learners with ALN is always appropriately sourced. We certainly would not expect designated co-ordinator or ALNCoS to use private assessments by unqualified individuals to help inform IDPs.

The ALN Code sets out in paragraph 20.13:

Examining whether there is a marked disparity of evidence provided by different individuals/agencies and where the child or young person is in different settings, will give a more accurate understanding of the child or young person's needs. Where there is marked disparity it might suggest a need to consult with professionals with the relevant expertise in order to consider the child or young person's needs in a holistic manner.

Local authorities may request information or other help from NHS bodies and other relevant persons using section 65 of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 (the ALN Act). This may be useful when preparing an IDP for a child or young person with healthcare needs or require ALP that is delivered by a health professional. For example, if a private assessment has been sought for a learner with ALN, the designated co-ordinator or ALNCo may seek the advice of their Local Health Board to help them consider the appropriateness of the evidence.

School and FEIs may also make such requests which could help reduce the burden on local authorities, although there are no specific duties or timelines on health bodies to respond to schools and FEIs as they would with local authorities.

Designated Education Clinical Lead Officers (DECLOs) may also have a role to play as the strategic leaders of ALN in each Local Health Board in Wales. Amongst their duties, DECLOs are responsible for co-ordinating the request for information or other help from local authorities.

Consistent approach to private medical diagnoses

The Neurodivergence Improvement Programme will shortly be exploring ways to bring a consistent, Wales-wide approach to private medical diagnoses, with a view to publishing operational guidance and a framework for clinicians. The DELCOs will also play a role in developing this approach which will support consistency across Local Health Boards in addition to developing a common understanding with local authorities. I will ask my officials to update you on this workstream at an appropriate time.

Tackling waiting times

The Welsh Government is committed to tackling waiting times for neurodivergent conditions and I want to assure you that we are taking action to improve services. In July last year, the Deputy Minister for Social Services announced a [Neurodivergence Improvement Programme](#), backed by £12m up to 2025. This programme includes reducing waiting times and providing more support for families and carers pre and post assessment and diagnosis.

In 2022 we allocated an initial £1.4m to Regional Partnership Boards to provide urgent support for existing neurodivergence services, including assessment and diagnosis.

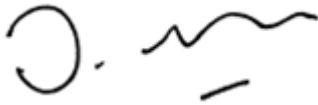
In 2023/24 we have allocated an additional £4.5 million to Regional Partnership Boards. We are working with them to ensure monies are spent in a way which will make the greatest difference. This not only includes reducing waiting times, but also piloting innovative

approaches to reducing barriers in referral pathways and the provision of pre-assessment advice and support.

In May 2023 we held an inaugural event for children's neurodivergence services and heard directly from your office the challenges highlighted by families in your 'A No Wrong Door Approach to Neurodiversity: A Book of Experiences'. We spent the day working with services to identify priorities for improvement. This work will be taken forward through a national working group, this will include scaling up identified pockets of good practice to a national model.

I hope you find this information useful and that it provides you with the assurance that the Welsh Government is working at pace to understand these issues to help provide direction for those with statutory responsibilities for delivering the ALN system in Wales.

Yours sincerely,

A handwritten signature in black ink, consisting of a large 'J' followed by a series of wavy lines and a short horizontal stroke at the end.

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