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Llywodraeth Cymru
Welsh Government

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Lynne Neagle AM
Chair
Children, Young people and Education Committee

17 February 2017

Dear Lynne,

Follow-up to evidence on 18 January 2017

Thank you for your letter of 2 February requesting additional information on a number of areas following our attendance at the Children, Young People and Education Committee on 18 January 2017.

Neonatal services at University Hospital Wales, Cardiff

Cardiff and the Vale University Health Board published the Corporate Risk and Assurance Framework on 9 February 2017. The risk from implementing service changes from the South Wales Programme is considered by the Health Board to have reduced.

A key part of the South Wales Programme is to ensure that neonatal services are safe and sustainable for the future. On 13 January, we announced £25.139m Welsh Government capital funding for the delivery of the second phase of development at the University Hospital of Wales between 2016 and 2019. The investment will provide:

- eight extra intensive care cots, in a redeveloped neonatal unit with expanded facilities for patients and families including a bereavement suite;
- new obstetric facilities including a ward with eight extra inpatient beds with ensuite facilities; and
- a new dedicated obstetric operating theatre with a dedicated recovery area.

Risks to new born babies and high risk mothers as a result of providing on-going care in a clinically unsuitable environment remains a high score on Cardiff and Vale University Health Board's Corporate Risk and Assurance Framework.

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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.

Previously, in November 2015, Cardiff and Vale University Health Board received £7.472m Welsh Government capital funding for the first phase of works for an interim neonatal unit following the closure of the existing unit due to an infection outbreak and the refurbishment of a permanent unit. The neonatal unit has relocated to an interim facility to allow for the creation of the new permanent neonatal unit with a significantly improved clinical environment. Phase one has been completed and is awaiting handover following completion of the link corridor. To mitigate the risks identified, the Health Board has agreed a contingency for escalation across the neonatal and maternal divisions.

The two other constituent health boards are continuing to work on the detailed implementation plans for the South Wales Programme. To date, we have approved capital proposals, funded by the Welsh Government, for additional capacity and improvements for:

- Neonatal intensive care unit at Royal Gwent Hospital, Newport: capital funding of £2.120m was agreed in October 2016 to refurbish and modernise the current unit and provide space for a further 6 cots. The scheme is scheduled to complete in Spring 2017 and was approved in advance due to issues of infection control and the need to manage decant over the winter period;
- Capital funding of £6.580m between 2016 and 2018 for Cwm Taf University Health Board was agreed in January 2017 for the delivery of remodelled neonatal services at Prince Charles Hospital, Merthyr Tydfil; and,
- £1.851m was agreed in December 2016 for Hywel Dda University Health Board to finalise the Full Business Case for next phase of development at Glangwili Hospital, Carmarthen which is expected to be submitted to officials for scrutiny in summer 2017.

In addition, we have provided £18 million Welsh Government funding for the Sub Regional Neonatal Intensive Care Centre (SuRNICC) in Ysbyty Glan Clwyd, Bodelwyddan which is due to open in March 2018. The SuRNICC will provide care for mothers and their babies across North Wales, centralising intensive care at Ysbyty Glan Clwyd.

A Framework for a School Nursing Service in Wales

In response to the matters arising from the Children, Young People and Education Committee on 14 September 2016, a letter was sent in October outlining the actions and timeframes for the publication of the refreshed Framework for School Nursing in Wales. As indicated in this letter, the development work involved stakeholder consensus events held in 2016 and guidance from an expert reference group, which had membership from the national school nursing and health visiting forum. This engagement work enabled officials to complete the drafting of the content of the refreshed framework by end of December 2016. The framework is now going through the normal internal processes ready for its publication and launch. The launch event will be held in a school and currently negotiations are being held with the head of the chosen school along with school nursing services from the health board to agree the date. Once agreed, a separate note will be sent to the Committee confirming the launch details.

Neurodevelopmental services

The all Wales neurodevelopment pathway was launched in 2016. Progress on implementation was assessed at the National Neurodevelopment Community of Practice event held in November 2016. All health boards have been reconfiguring their neurodevelopment assessment and diagnostic services to establish a single point of access with new staff posts funded under the additional £2m Welsh Government funding for neurodevelopment service development. This has required most health board

neurodevelopment services to establish suitable team offices/bases to co-locate the relevant staff to better facilitate and enable multi-disciplinary team assessments.

The pathway has six nationally agreed service standards, these are;

1. There is a single point of access for diagnostic assessment of all neurodevelopment disorders.
2. The decision as to whether to accept a referral or not is made on the quality of information provided (as outlined in NICE guidance). Where there is adequate information to support concern, access should not be subject to permitted referrers, the use of screening questionnaires or other specifications.
3. When referrals are not accepted, the referrer is provided with rationale for this, alongside advice on how to improve the referral or which other service to refer to as appropriate.
4. Assessments are planned in a child centred way ensuring sufficient information to create a profile of the child's need is gathered (as outlined in NICE guidelines), whilst ensuring a prudent, flexible approach to the use of resources.
5. There is a timely multi-disciplinary discussion involving all those involved in the assessment process which leads to a decision about the outcome of the assessment, a profile of the child's strengths and difficulties and agreement on future actions. The implementation of this process can be locally determined.
6. A professional who has been involved in the assessment process will communicate the outcome of the assessment with the family (and where appropriate the child). This is followed up in writing, and where consent is given, should be shared with other professionals who support the child. Advice about how best to meet the child's needs and signposting is provided.

Progress on implementation shows almost all health boards can demonstrate delivery to standards one, two and three and are working towards the remaining three standards. The neurodevelopment service improvement programme is coordinated by a National Steering Group which meets at least quarterly, chaired by Dr Cath Norton from Cardiff and Vale University Health Board, and reports to the Together for Children and Young People Programme Board. The National Steering Group is supporting the delivery and full implementation of all six standards across all health boards. This is being assessed on an ongoing basis and will take stock of the position nationally at a Community of Practice event being arranged for the autumn. The neurodevelopment work stream is in the process of developing measures to locally test the reliability of implementation during 2017.

Update on the 26 week neurodevelopment waiting times

Unlike CAMHS, the 26 week Neurodevelopment target is not at present an official measure recorded by Stats-Wales. We are in the application process of the Neurodevelopment assessment target to become an information standard (an official measure), once this application has been accepted and completed all health board's will be required to report, on a quarterly basis, the number of weeks a patient waited for a Neurodevelopmental assessment.

The Neurodevelopment work stream (through the Together for Children and Young People Programme) will be holding a workshop in early March 2017, where Health Board's will agree the methodology for measuring the target.

Health boards have confirmed that multi disciplinary neurodevelopment teams have been established and therefore they are on track to meet the 26-week waiting time target in 2017, this was done with the help of the £2m Welsh Government funding.

We have sought an update from health boards on the percentage of children and young people waiting under 26 weeks and the percentage of those waiting longer. We will pass this information onto the committee once received.

Maternal Health and Well-being

Welsh health board data on breastfeeding rates at 6 months are reported via the National Community Child Health Database. This data is hoped to be sufficiently complete for a summary to be published in this summer's births release <http://gov.wales/statistics-and-research/births-national-community-child-health-database/?lang=en>

Previously, data on infant feeding has been collected as part of the UK Infant Feeding Survey. In the last report in 2010, less than one per cent of Welsh mothers were exclusively breast feeding at six months. This is typical of the picture across the UK, indicating that very few mothers were following UK health departments' recommendations that babies should be exclusively breastfed until around the age of six months. This is despite there being increases in the prevalence of exclusive breastfeeding at birth and lower fall-out rates at three and four months.

Autism Spectrum Disorder Advisory Group

An Implementation Advisory Group will be established to monitor delivery and progress of the Autistic Spectrum Disorder (ASD) Strategic Action Plan. The first meeting is scheduled for the end of March 2017 and membership will include people with autism, parents and carers, as well as representatives from statutory and third sector organisations. The terms of reference and definitive membership will be confirmed shortly, however, we expect the remit to include:

- Feedback on progress in delivering the refreshed ASD Strategic Action Plan at a regional and local level;
- Advice and guidance on improving service delivery in identified areas;
- Advice and guidance on addressing any identified gaps in provision and new priorities for action as they emerge.

Your letter also asked for information on referral to assessment and treatment. We wrote to the Committee on this aspect in a letter dated 2 February.

Yours sincerely,



Vaughan Gething AC/AM

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