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2 Tachwedd 2018

Dai Lloyd AM/AC

Cadeirydd y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon / Chair, Health, Social Care and Sport Committee

Cynulliad Cenedlaethol Cymru / National Assembly for Wales

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Annwyl Dai Lloyd

During your latest evidence session on the Autism (Wales) bill, the Committee asked a number of questions on the development of the integrated autism service that is funded by the integrated care fund up until 2021.

As part of the Welsh Government's evidence it said that the funding was given to areas that did not have an integrated service to help with the preparatory work to get the services up and running.

This means that the Betsi Cadwaladr Health Board spent £508,000 of funding in April 2017-April 2018 with no service in place. Likewise, Western Bay and West Wales each received £318,200 in the same period, with no service in place. This is significant investment from the Welsh Government but there is no information on how this spend benefitted autistic people and their families in those areas.

Similarly the Welsh Government said that the service would have a 'staged roll-out'. The service was planned to begin with Aneurin Bevan, Cardiff and the Vale, Cwm Taf and Powys in October 2016 with Hywel Dda operating from October 2017, Abertawe Bro Morgannwg from January 2018 and Betsi from August 2018. However, as the Committee heard, the timetable isn't being met and autistic people and their families who were promised a service are still waiting for it to be launched.

Furthermore, at the recent meeting of the Cross Party Autism Group, the North Wales IAS said that although it had launched its service in June 2018, it wasn't staffed to capacity and couldn't for example provide diagnosis for adults, despite this being a core element of the service.

We remain concerned about where funding for the IAS has been directed, lengthy delays in developing the services across Wales and the services' capacity to assess and meet the needs of those whose expectations have been raised by commitments that have not been followed through. The Cabinet Secretary painted a picture of calm, considered and timely roll-out of the service, however we are not aware of any evidence to support this description.

A table of the ICF funding for the integrated service is attached to this letter for Members along with the timetable for the staged roll-out.

Committee Members asked the Cabinet Secretary about the outcome measures and reporting arrangements for the integrated autism service. We understand that an evaluation of the integrated autism service and action plan is due to be published in January 2019.

While we welcome that report, we are concerned that, to our knowledge, there is no consistent reporting framework being used across the services to measure performance, and outcomes. This inconsistency was raised by Committee Members during the evidence session as each service may be measuring slightly different things. Committee Members also asked when we could expect specific evaluation of each service, and it was suggested that this could be after about 12 months of the service being launched. Three services have been in operation for over a year and it is therefore concerning that this data wasn't available to Committee Members.

During the scrutiny process there have been a number of discussion on the use of NICE guidelines in relation to the Bill. As the Committee may be aware the guidelines are based on clinical excellence, cost-effectiveness and, according to NICE's website, supported by five of the Royal Colleges and the British Psychological Society¹. There seems to be a discrepancy therefore between the evidence given by the Royal Colleges to the Committee and their actual support for NICE quality standards.

The Cabinet Secretary said there was an increase in demand for a diagnosis in Northern Ireland as a result of autism legislation there. The WG written submission says that according to the Department of Health report on implementation of the Act found that:

'it was not possible to guarantee early intervention as outlined in the Autism Strategy without additional funding to further develop autism-specific assessment services, and to extend the portfolio of available family support.'

However the same paragraph goes on to say that:

'provision of general support is not predicated on a diagnosis.'

We would question the validity of tying this increase in demand to legislation. In Wales, where similar legislation doesn't exist, a similar increase in demand has also taken place. In Duncan Holtham original evaluation report on the ASD Action Plan, it says:

'Increased awareness of ASD has contributed to increased rates of identification. This in turn has contributed to sharply increased rates of diagnosis among school age pupils in Wales, from approximately 0.2 per cent in 2003/2004 to 1 per cent by 2012/13.'

Finally, I was concerned to hear that the integrated autism service practitioners were describing the 26-week diagnostic timescale as 'aspirational', and therefore welcome the commitment from the Cabinet Secretary that he will provide the Committee with the waiting times.

I hope the Committee will find this additional information helpful

Yn gywir iawn

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¹ NICE Quality Standard 51; *Supporting Organisations*: <https://www.nice.org.uk/guidance/qs51>

Appendix : ICF Funding and Implementation Chart for the Integrated Autism

	April 2016 – March 2017 (£)	April 2017 – March 2018 (£)	April 2018 – March 2019 (£)	Total since April 2016	IAS Launch
Cardiff and Vale	204,000	367,000	367,000	938,000	Sept 27 th 2017
Cwm Taf	204,000	367,000	367,000	938,000	March 5 th 2018
Gwent	249,000	458,000	458,000	1,165,000	August 2017
West Wales		318,200	398,000	716,200	Not Launched
North Wales		508,000	652,000	1,160,000	27 th June 2018
Powys	188,000	336,800	337,000	861,800	July 12 th 2017
Western Bay		318,200	398,000	716,200	Not Launched
Total	845,000	2,673,200	2,977,000	6,495,200	

Source: Integrated Autism Service indicative allocation spend in ICF Guidance for 2016/17, 2017/18 and [2018/19](#), Welsh Government

Implementation

The service will be developed and implemented on a health board footprint and will be delivered through regional partnership boards, this will promote partnership working between health, local authorities and third sector organisations.. The programme roll out will be supported by the Welsh Government in partnership with WLGA/PHW. It is essential that the service is developed as a national approach to ensure there is consistency of practice across Wales. A repeated criticism of autism services is that because of local and regional differences in how services are configured there is a perception of a post-code lottery, as services can be very different in often neighbouring areas.

To support consistent delivery of a national approach and to share good practice across areas, a time limited implementation team will be established. This team will be managed by the ASD National Lead who will have national oversight of the programme delivery. The team will be based within WLGA/PHW.

There will be a planned and phased approach to implementation. Each area will be supported to develop supportive governance structures, agreements and work plans developed and staff recruited before the service can begin. This staged approach will mean that learning can be shared and approaches cascaded to ensure a cost effective roll out.

The development of the integrated ASD service will take place over three years with additional health boards coming on stream each year.

	YEAR 1												YEAR 2												YEAR 3														
	A	M	J	J	A	S	O	N	D	D	J	F	M	A	M	J	J	A	S	O	N	D	D	J	F	M	A	M	J	J	A	S	O	N	D	D	J	F	M
Aneurin Bevan																																							
Cwm Taf																																							
Cardiff and Vale																																							
Powys																																							
Hwyl Dda																																							
ABMU																																							
BCUHB																																							

Source: National Autism Service: Background and Guidance Information. Welsh Government, Welsh Local Government Association and Public Health Wales.