

Gwenda Thomas AC / AM  
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol  
Deputy Minister for Social Services



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-492  
Ein cyf/Our ref GT/00296/14

William Powell AM  
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*Dear William,*

Thank you for your letter of 30 April seeking an update on the actions the Welsh Government is taking to address the concerns raised by petitioners about Autistic Spectrum Disorder (ASD) diagnostic waiting times for children.

Since my last letter to the Committee in March I have written to both Abertawe Bro Morgannwg UHB and Cardiff and the Vale UHB to ask them to provide the waiting times information that was not included in their first response. I am pleased that both health boards have now provided further data on diagnostic waiting times which is summarised below. I also attach the full summary of the responses received to my original request for information, which can be shared with the NAS Pembrokeshire branch as they have requested.

Cardiff and the Vale UHB	ASD diagnostic waiting times for children are captured as part of the overall waiting times for community paediatrics, which currently stands at 20 weeks. A considerable amount of work has been undertaken to improve the ASD diagnostic pathway which should result in ASD specific waiting times being available shortly.
Abertawe Bro Morgannwg UHB	Average waiting times for ASD children's diagnosis referral to assessment are Swansea 15 weeks, Neath Port Talbot 17 weeks and Bridgend 13 weeks. There are different models of care in place based upon local arrangements for joint working.

I am grateful to the Petitions Committee and the parents group in Pembrokeshire for bringing this issue to my attention. Such is my concern that urgent action is required to address diagnostic waiting times I will be establishing a Task and Finish Group on children's diagnosis which will report to me with recommendations for actions to be taken forward in the implementation of the refreshed ASD Strategic Action Plan. I will ask this group to consider the points raised by the Pembrokeshire parents group in their letter to the Committee to which you refer. The refreshed ASD Strategic Action Plan will be published for consultation later this year and I do hope that members of the Pembrokeshire group will take the opportunity to respond.

Yours Sincerely

A handwritten signature in black ink, appearing to read 'Gwenda'.

**Gwenda Thomas AC / AM**

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<b>Local Health Board</b>	<b>Waiting times for children's diagnosis and Support, and compliance with NICE guidelines</b>	<b>Waiting times for Adults diagnosis and support and compliance with NICE guidelines</b>
<i>Abertawe Bro Morgannwg</i>	<p>Swansea and Neath Port Talbot localities use the same diagnostic pathway, Bridgend have their ASD assessment co-ordinated by the local authority. Although there are different pathways, Child and Adolescent Mental Health (CAHMS) services are involved in a multiagency assessment of ASD across the health board. The pathway in Swansea and Neath Port Talbot for reception age (5) children and under, is that referrals are made to a consultant community paediatrician and referrals for children over five years old are sent to CAMHS. In Bridgend the consultant community paediatrician prioritises referrals for children aged 10 years and younger. CAMHS leads for children aged 11 and over. Because of the complexity of the diagnosis pathway, it is very difficult to provide an average length of wait between initial referral and diagnosis, but this could be provided through retrospective audit of patients assessed. This has been requested.</p>	<p>Waiting times for diagnosis are within the <b>12 weeks</b> waiting time limit for individuals seen either in the Learning Disability Community teams or those referred to a specialist ASD diagnostic team, which is working to the standards agreed by the Adults ASD diagnostic network. An audit is also being undertaken to ensure that diagnostic standards are being adhered to. An action plan has been developed to raise levels of awareness and expertise within the local community learning disability teams, this includes a training plan.</p>
<i>Aneurin Bevan UHB</i>	<p>Current waiting times for ASD assessment by community teams is <b>12 months</b> due to staff vacancies, reconfiguration of services and changes in referral criteria. A new multi agency neurodevelopmental service is being created. An assessment service for children with a complex presentation such as co-morbidity and differential diagnosis has a waiting time of 11 months. The assessment process is in accordance with NICE guidelines.</p>	<p>An extended ASD assessment service has been established as part of the All Wales ASD Pre/Post Counselling Network for Adults, the pathway is based on NICE guidelines. In the last 12 months the waiting list has reduced from 2 years to <b>12 months</b>. A neurodevelopmental working group has been established to join up learning disabilities and mental health, and offer an ASD consultation service and peer support group for clinicians newly qualified Diagnostic Interview for Social and Communication Disorders (DISCO) assessors for ASD.</p>

<p><i>Betsi Cadwaladr UHB</i></p>	<p>Diagnosis undertaken by the Child and Adolescent Mental Health Service (CAHMS) teams across North Wales. The time taken from initial referral to completion of assessment varies across the health board area. The waiting time target for initial assessment is 4 weeks. However, current waiting time is between <b>6-26 weeks</b>. The waiting time for completion of assessment ranges from 30 weeks in Conwy and Denbighshire, 73 weeks in Flintshire, 59 weeks in Gwynedd and Ynys Mon and 90 weeks in Wrexham.</p> <p>Reducing waiting times is an urgent priority across health board areas in particular in Wrexham where a recovery plan is in place. More generally, team and individual job planning across all teams has ensured that direct clinical contact time is maximised and that additional capacity can be re-directed as required. The CAMHS service has experienced an unprecedented increase in ASD referrals over the last 4 years and has had significant staffing issues over the last 12 months. However, a significant reduction in waiting times is anticipated during 2014 because of the actions listed above that are now being taken.</p> <p>The standards for ASD assessment has been developed by clinicians based on three documents, one of which is NICE.</p>	<p>The service has been established in accordance to the All Wales ASD diagnostic and pre/post counselling network. Current waiting times between the date of referral to offer of diagnosis is from <b>40 weeks, the average is 16 weeks</b>.</p>
<p><i>Cardiff and the Vale UHB</i></p>	<p>Child and Adolescent Mental Health Services are provided by a regional network, managed by Cwm Taf Health Board. Cardiff and Vale did not therefore provide any information about children's diagnosis. It has subsequently been contacted to request individual health board data given that this has been provided by other members of the same regional</p>	<p>Waiting times for referrals for diagnosis are assessed within the medical outpatient waiting time target of <b>70 days</b>, however as the lead clinician has suddenly and unexpectedly resigned, new referrals will not be accepted until February 2014. Adult ASD services are currently being re-designed, with a new service – the Cardiff and Vale Autism Project - currently being developed. It will</p>

	network (Cwm Taf and Aneurin Bevan)	provide specialist diagnostic support, pre and post diagnostic counselling and an expert resource for Community Mental Health Teams for second opinion services. Diagnosis is undertaken using the DISCO tool in accordance with NICE guidance.
<i>Cwm Taf UHB</i>	Current waiting times for commencement of Community Paediatric assessment from receipt of referral to initial assessment are approximately <b>17 weeks in North Cwm Taf but 52 weeks in south Cwm Taf</b> . A multi agency task and finish group has been established to review and develop a local pathway for the recognition, referral and diagnosis of children and young people with ASD in accordance with NICE guidelines. Issues affecting waiting times include staff vacancies.	Diagnosis is undertaken in accordance with the diagnostic pathways and standards developed by the All Wales ASD Diagnostic, pre/post counselling network for adults. Current waiting time figures are not collected, but they are below the <b>14 weeks</b> waiting time recommended by the pathway.
<i>Hywel Dda UHB</i>	Waiting times for children including first assessment are in <b>the region of two years in Carmarthenshire and Ceredigion and four years in Pembrokeshire</b> .  An action plan has been developed to address waiting times over the next year, which is based on NICE guidance and will require local authority collaboration. A dedicated clinical team to focus solely on ASD diagnosis has been created and recruitment has now been undertaken to fulfil the necessary roles. There is also a commitment to broaden expertise around diagnosis across the health board so that there is a consistent clinical approach. Strategic planning will be undertaken by the newly convened population health group for mental health and learning disabilities and the operational structures needed to deliver the ASD plan are now in place.	The service was established in 2012, in accordance with the All Wales Autistic Spectrum Disorder pre/post counselling network, which takes account of NICE guidance. Over the 12 month period from December 2012 to November 2013, there were 83 referrals into the service. 24 people have been diagnosed, 50 are waiting and 6 people are on the pathway having received or been invited for pre-counselling are waiting diagnostic appointment. Of those diagnosed waiting time from referral to diagnosis varied from 2 months to 7 months with an average wait of four and a half months. For those people still waiting to enter the pathway waiting time to date ranges from 1 month to 10 months.

<i>Powys THB</i>	Waiting times calculated from the date the request for assessment was accepted by the Powys Social Communication Assessment Team to the date of the first assessment appointment. For 2013/14 ( <b>up to December 2013</b> ) <b>maximum wait was 13 weeks 3 days (average seven weeks)</b> . The assessment pathway has been developed in accordance with NICE guidance	The longest waiting time for adult's diagnosis is <b>16 months</b> , from the date the request was received. It is anticipated that the majority of the waiting list (20 people) will be assessed by March 2014 as an ASD pre and post diagnostic counsellor has been appointed. Assessment is carried out in accordance with NICE guidelines.
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