



Bwrdd Iechyd Prifysgol
Cwm Taf
University Health Board

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Mr William Powell AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Powell

Petition: P-04-492 Diagnosis of Autism in Children

Cwm Taf University Health Board Autistic Spectrum Disorder Waiting Times May 2013

The term 'Autistic Spectrum Disorder' (ASD) used throughout this response includes all diagnoses covered by the condition including, for example, Autism, Kanners Autism, Asperger's Syndrome.

ASD is defined as "...a lifelong developmental disability affecting social and communication skills. People with the disability can also have accompanying learning disabilities but, whatever their general level of intelligence, everyone with the condition shares a difficulty in making sense of the world... The degree to which people with autistic spectrum disorder are affected varies, but all those affected have impairments in social interaction, social communication and imagination. This is known as the triad of impairments."

Context of ASD Diagnosis in Children and Young People

The need for a clear diagnostic pathway was outlined in the ASD Strategic Action Plan for Wales which was published in April 2008 and in the local ASD Action Plan published in 2009.

The last few years have seen significant development in services since the launch of the national strategy which has raised awareness and understanding of autism and, as a result, more and more children are being identified earlier, particularly around the time they are about to commence school.

In September 2011 National Institute for Clinical Excellence (NICE) published a guideline for the recognition, referral and diagnosis of children and young people on the autism spectrum.

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This requires a clear pathway to be in place which was in line with identified local need and had been included in local action plans. Mapping of services had found that diagnosis of ASD was inconsistent, lengthy and geographically variable for children and young people across Cwm Taf and indeed the whole of Wales.

NICE and best practice indicate that diagnosis of ASD should include assessments from a range of staff including Child and Adolescent Mental Health Service (CAMHS), Paediatrics, Speech and Language Therapy (SLT), Occupational Therapy (OT) and Educational or Clinical Psychology. However, referral for assessment is reliant on a variety of other front-line professionals such as Health Visitors, Teachers, etc identifying, referring and informing the assessment process for children and young people.

In order to support and strengthen assessment across all services within Cwm Taf and to ensure consistency, 3Di training has been provided to approximately 20 professionals inclusive of Therapies, Paediatrics, CAMHS and Educational Psychology. We have also provided ADOS training for 23 staff in February and March 2014. ADOS and 3Di are evidence based assessment tools recommended by NICE and used locally to assess and diagnose children and young people with ASD.

ASD is not normally diagnosed at a very young age even though parents may have had concerns for some time and this is for a range of reasons:

- Problems that the child is displaying and presenting with are rarely specific to autism and therefore professionals need to ensure that they are not misdiagnosing. It would be inappropriate for non-specialists to make a diagnosis and they often do not want to 'label' the child or worry the parents unnecessarily until they have ruled out other possible diagnoses. What sometimes appears to be an apparent reluctance to diagnose autism is actually the professionals need to ensure that they get the diagnosis right.
- ASD is a complex condition which is demonstrated by the wide spectrum of difficulties that may be experienced from those at the severest end to those who are high-functioning and / or only have mild autistic traits. The child / young person should be assessed by a range of multi-disciplinary professionals (as highlighted above) in order to reach a diagnosis which will include observations of their behaviour and in order to be thorough this can be a very timely process. Clearly, the diagnosis of ASD is not just the responsibility of health as we rely on professionals from a variety of other settings, eg schools, to identify and assess the needs of these children and young people.
- Some aspects of ASD may only become more apparent as the child gets older and the extent of their problems may not become clear until, for example, they enter new social situations such as school.

Unfortunately the diagnostic process for ASD can be lengthy but this should get shorter as awareness of ASD is increased amongst the public and professionals.

Waiting Times across Cwm Taf

Since the creation of the new Health Boards in Wales it is recognised that service delivery in the previous NHS Trusts varied. As part of our work locally to review the assessment and diagnosis process it has been highlighted that different services took the lead in different areas.

Currently, waiting times for commencement of Community Paediatric and CAMHS assessment (from receipt of referral to initial assessment) are approximately 60 weeks. Within this approximate waiting time please be aware that the final diagnosis will also be dependant on a number of assessments and provision of information via other frontline professionals such as:

- Occupational therapy
- Speech and language Therapy
- Educational Psychology etc

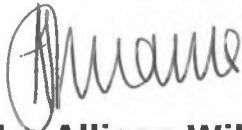
The ongoing work looking to implement the South Wales Programme and redesign local services is looking to review all our processes and to determine how we can ensure more equitable service provision across our local communities jointly with our partners.

Key staff from Cwm Taf University Health Board are also represented on the National ASD Assessment and Diagnosis steering group looking at a National position to improve and support families awaiting assessment and diagnosis of their children's needs.

For Adults who are referred for assessment and diagnosis of ASD Cwm Taf Health Board are funded to provide a diagnostic and advice service for Autistic Spectrum Disorder. This is led by a Consultant Psychiatrist and Psychologist.

There are currently no waiting time issues for adult services across the Cwm Taf University Health Board area.

Yours sincerely



Mrs Allison Williams
Chief Executive/Prif Weithredydd

