

P-04-492 Diagnosis of autism in children

Petition wording:

We call upon the National Assembly for Wales to urge the Welsh Government to:

- ensure timely diagnosis for children with Autism Spectrum Disorder [ASD], regardless of where they live, so that children with autism can be supported and lead fulfilled lives; and
- review implementation of and ensure compliance with the NICE guidelines on recognition, referral and diagnosis of children and young people on the autism spectrum as part of the Welsh Government's refresh of its ASD Strategic Action Plan.

Supporting information:

Diagnosing can be a critical milestone for people with autism. For children, it can help ensure that the right support is put in place from an early age.

Diagnosing autism can be difficult because autism is complex condition that affects each person in a different way. We therefore support the view that a number of different specialists should be part of the process to ensure a correct diagnosis.

However a timely diagnosis is vital in order to minimise anxiety and stress for children with autism and their families. The Deputy Minister for Social Services supports this view and in response to a question from Rebecca Evans AM said: 'I fully recognise the importance of receiving a timely diagnosis.' We also know that early intervention for children with autism is crucial in their educational, emotional and social development and for their longer-term health.

While there are good examples of diagnostic and assessments services in Wales, we are very concerned that not everyone can access a timely diagnosis and that not every area is following the NICE guidelines on recognition, referral and diagnosis of children and young people on the autism spectrum.

Our experience in Pembrokeshire has been particularly difficult, with some members of the branch waiting up to seven years for a diagnostic assessment. This lengthy wait for diagnosis is having a huge impact on families across Pembrokeshire.

We have tried on several occasions to engage with Hywel Dda Local Health Board. We have also met with local AMs Paul Davies and Angela Burns outlining our concerns. Paul Davies has written to Hywel Dda Health Board

urging them to meet with the branch. We are still waiting for the Health Board to act on that request.

One of the branch members has 'waited over six years for my one son to get a diagnosis. Now I'm waiting for the other it's been about two years and it fills me with dread.'

We want to ensure timely diagnosis for all children with an Autism Spectrum Disorder across Wales so that they can be supported appropriately to lead fulfilled lives.

About autism

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships;
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice; and
- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. Asperger syndrome is a form of autism.

Research has shown that 1 in 100 people have autism. By applying the 1 in 100 figure we estimate that over 30,000 people in Wales have autism. Together with their families, they make up over 100,000 people whose lives are touched by autism every single day.

About the NAS and Pembrokeshire Branch

The National Autistic Society Cymru [NAS Cymru] is Wales' only member-led charity for people affected by autism. The National Autistic Society was founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. In Wales, since 1994, we have been

providing local support, services and actively campaigning so that people with autism get to lead the life they choose.

NAS Cymru believes that the right support at the right time makes an enormous difference to the lives of those affected by autism and we are committed to ensuring that their voices are heard.

Across Wales we have over 900 members and 11 local branches including the one in Pembrokeshire. Launched on the 1st April 2011, the branch is for parents of children with autism to provide a network of support for people connected through autism living in Pembrokeshire and surrounding areas. The branch meets on a regular basis holding formal and informal events, as well as campaigning and fundraising locally.

Petition raised by: National Autistic Society Pembrokeshire Branch

Date petition first considered by Committee: 18 June 2013

Number of signatures: 902