

Epilepsy Action welcomes improvements made following the introduction of the Rights of Children and Young Persons (Wales) Measure 2011. However, we are concerned that there remain several areas where the Welsh government are not fulfilling the measures in the UN Convention on the Rights of the Child, and where children in Wales are not receiving the help and support they need.

Article 23 (children with a disability) & Article 24 (health and health services)

Data from Epilepsy Action's Health Services report¹ indicated a lack of Learning Disability Epilepsy Specialist Nurses in Wales. The report highlighted that of the three Welsh Health Boards who responded, none had a learning disability epilepsy specialist nurse. This is very concerning given the prevalence of learning disabilities among people with epilepsy and the increased risk of epilepsy related mortality. Epilepsy is more common in people with a learning disability than in the general population:

- About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy
- The more severe the learning disability, the more likely that the person will also have epilepsy
- Around 1 in 5 people (20%) with epilepsy also have a learning disability

Children with epilepsy are at particularly at significant risk of learning and behavioural difficulties. Learning Disability Epilepsy Nurses are needed to fully support people with epilepsy and learning difficulties.

¹ https://www.epilepsy.org.uk/sites/epilepsy/files/professionals/data-visualisation/epilepsy_health_services_2017_full_version.pdf

This data also highlighted an absence of neuropsychologists and neuropsychiatrists for children in Wales –

- Of the three Health Boards that responded to Epilepsy Action’s Epilepsy Health Services report Freedom of Information requests, none said that they provided access to neuropsychology through paediatric epilepsy services:
 - Abertawe Bro Morgannwg University Health Board – no access
 - Aneurin Bevan University Health Board – no access
 - Hywel Dda University Health Board – no response

- Of the three Health Boards that responded to Epilepsy Action’s Epilepsy Health Services report Freedom of Information requests, one said that they provided access to neuropsychiatry through paediatric epilepsy services:
 - Abertawe Bro Morgannwg University Health Board – yes
 - Aneurin Bevan University Health Board – no access
 - Hywel Dda University Health Board – no response

The Welsh Government’s Neurology Delivery Plan identified that the psychological needs of children and young people with epilepsy are not being met. The increased prevalence of mental health needs within the epilepsy patient community is well recognised however mental health support within epilepsy services around the UK, including Wales, is often not available.

The recent 2018 Epilepsy 12 nation audit² conducted by the Royal College of Paediatrics and Child Health noted the percentage of Health Boards and Trusts that facilitate mental health provision within epilepsy clinics.

Both network groups that include Welsh Health Boards tabled below the England and Wales average with the South Wales Epilepsy Forum reporting 0%.

- Mersey and North Wales network 'Epilepsy in Childhood' interest group – 11.1%
- South Wales Epilepsy Forum – 0%
- England and Wales combined (average) - 12.8%

² <https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-report-2018>

We are also concerned that adequate provision of paediatric epilepsy specialist nurses in Wales has not yet been met.

Epilepsy Specialist Nurses (ESNs) are essential in providing high quality, cost effective care for children with epilepsy and their families. They are experts in epilepsy and are an essential part of a multidisciplinary team providing information and support for people with epilepsy.

In order to meet their obligations under Article 24 (health and health services) of the UN Convention on the Rights of the Child, we would urge the Welsh Government to ensure that there are an adequate number of ESNs, and Learning Disability ESNs, to provide children with epilepsy access to the best possible health care services.

We also remain concerned that waiting times for an epilepsy diagnosis in Wales remain high.

Waiting times for an initial epilepsy appointment remain high with the Aneurin Bevan Health Board reporting an average waiting time as 22 weeks, as of 31 March 2017. The same Health Board reported waiting times of 16 weeks for an initial first seizure clinic appointment. NICE guidance recommends a waiting time of 2 weeks.

(<https://www.epilepsy.org.uk/professional/epilepsy-data-visualisation/health-services-report>)

We are also concerned about the shortage of neurologists in Wales, particularly those specialising in epilepsy. We understand that there are only 2 neurologists specialising in epilepsy in Cardiff, 2 in Newport, 2 in Swansea, and 1 in Cwm Taf (Royal Glamorgan). There are also significant shortages of neurologists (general and epilepsy) in Hywel Dda and North Wales.

Article 28 (right to education) & Article 29 (goals of education)

Currently, only around 13% of pupils with Special Educational Needs (SEN) in Wales have a Statement of Special Educational Needs³. Statements are viewed as the best way to secure help and support for SEN children, as they provide legal certainty of the care that a child will receive. It is concerning, therefore, that such a small proportion of SEN children receive this support,

³ <https://statswales.gov.wales/Catalogue/Education-and-Skills/Schools-and-Teachers/Schools-Census/Pupil-Level-Annual-School-Census/Special-Educational-Needs/pupilssen-by-localauthorityregion-provision>

and raises questions as to whether the educational needs of SEN children in Wales are being met.

We are aware that the current SEN system is due to be replaced in September 2021, by Additional Learning Needs (ALN). However, these reforms are expected to be implemented over a three year period. In the meantime action should be taken to ensure that SEN children are receiving the necessary help and support to fulfil their educational potential to ensure that the Welsh Government is fulfilling Articles 28 and 29 of the UN Convention on the Rights of the Child.

In addition, when the new ALN system is introduced, there needs to be robust monitoring to ensure that children are receiving the necessary help and support.