

Cyngor Sir CEREDIGION County Council

REPORT TO:	Learning Communities Overview and Scrutiny Committee
DATE:	8 December 2022
LOCATION:	Hybrid
TITLE:	The current referral pathway to a diagnosis of autism
PURPOSE OF REPORT:	To provide information on the current referral pathway to a diagnosis of autism. To look at the challenges and how the Schools Services is meeting the needs of children who have or who are waiting for a diagnosis.
REASON SCRUTINY HAVE REQUESTED THE INFORMATION:	The current waiting time for a diagnosis of autism is extremely long and assurance is required that the educational needs of Children and Young People with autism are being met.

BACKGROUND:

Autism is a lifelong developmental condition which affects how people communicate and interact with the world. One in a hundred people are on the autistic spectrum – with some people facing greater challenges than others as a result of this condition. For some, their difficulties make accessing the usual curriculum very difficult and specialist provision is required. For others, they thrive in educational tasks because of their particular focus, attention to detail and tenacity.

Children and young people who are suspected of having autism may demonstrate differences in social communication, in their behaviour patterns which may involve interests or involvements in repetitive and restricted activities and/or sensory differences. Up until recently, all Ceredigion children and young people were referred to our local Social Communication Assessment Team (SCAT) via our paediatric health secretary. The SCAT consists of a consultant paediatrician (with specialism in autism); a highly specialist speech and language therapist (SALT); an educational psychologist; representation from Team Around the Family (TAF) and a member of the Children's Disability Team. Referrals are sent to the paediatrician who meets with the child and parents to gather information before deciding on the appropriateness of the referral to SCAT. Once the child's name is on the SCAT list, multi-disciplinary assessments and information is gathered to determine whether the diagnosis is appropriate. While this process progresses, the children are regularly reviewed by the team at the meetings. Once a decision is made as to the appropriateness of the diagnosis or not, parents are informed by the paediatrician and another professional from health or education of the decision. At this point, parents may decide that they would rather not have the formal diagnosis but permission for the information on the child's needs to be shared is usually given.

Until recently, the length of time that a child/young person remained on the Ceredigion SCAT list (from referral to diagnosis) was approximately twelve months (with approximately 100 children and young people on the list), with some receiving a diagnosis much sooner than others.

In 2015, policy development for the establishment of Neurodevelopmental (ND) services across Health Boards in Wales started with the launch of the Together for Children and Young People programme (T4CYP) which was to reshape and refocus emotional and mental health services for children and young people and to improve access and support for young people and families. One of the programme's priorities was improving ND services, and the work stream, to support this. This included plans for developing care pathways for autistic children and young people.

The Hywel Dda ND service was launched in November 2015 and it follows a nationally agreed model around service configuration and diagnostic pathways which promotes equitable access for diagnostic assessment. The T4CYP programme was extended for a further 2 years in 2019 to further develop the work around ND services. The ND service complies with the National Institute for Health Care Excellence (NICE) guidance around diagnostic assessment and good practice.

From the outset, Carmarthenshire and Pembrokeshire transferred their referrals for ASC to the new NDT (Neurodevelopmental Team). The two local authorities already had very long waiting lists for assessment before the establishment of the service. Ceredigion preferred its method of assessment and for many years continued with the SCAT service for all pupils as it was felt to meeting the needs of the children and young people. However, Hywel Dda felt that it was important that the service delivery model was consistent and equitable across its footprint and a decision was taken by the Health Board that all assessments for ASC were to be undertaken by its central NDT. In 2020, the majority of Ceredigion's children and young people awaiting assessment were therefore transferred to the NDT.

CURRENT SITUATION:

Although the majority of referrals for an ASC assessment are now referred via the central NDT, Ceredigion continues to run the SCAT and undertakes assessments for those children who are under the age of five years.

169 pupils have a diagnosis of autism in Ceredigion schools currently.

There are currently 2192 children and young people in the Hywel Dda Health Board area who are awaiting an assessment via the NDT. This equates to over a three year wait. 143 of those on the waiting list are Ceredigion pupils.

A Welsh Government Demand and Capacity Review was commissioned and completed in March 2022. Emerging findings suggest that the demand for ND services across Wales does not match capacity. Further investment has been pledged by Welsh Government over the next 3 years to continue to develop services.

How does this impact children and young people in Ceredigion schools?

It is important to state, from the outset, that provisions and interventions in School Services are not dependent on a diagnosis of autism. Schools respond to the needs of the individual child in their community, irrespective of diagnosis. The lengthy waiting list for a diagnosis, therefore, has little impact on the support which a child with social communication difficulties receives at school.

Educational Psychologists (EPs), Advisory Teachers and SALT (and occasionally Physiotherapists, Occupational Therapists, Inclusion Officers and Key Workers etc) work together to assess and identify the needs of the individuals and person centred planning meetings held at schools ensure that the child, their family and professionals work towards outcomes which are important to the child.

Supporting schools to understand and support pupils with ASC has been high on School Services' agenda for a number of years and schools have been encouraged to attain the Autism Wales 'Autism Aware Certificate.' 70% of schools in Ceredigion have now attained that award and some schools are in the process of completion. Ceredigion also invested in training a number of Autism Champions in schools. These teaching assistants (TAs) received training on individual differences and support strategies by specialist education staff and partner agencies within the Health Service (e.g. SALT and Occupational Therapy). The Autism Champions are on hand within those schools to offer everyday advice and strategies.

Numerous training packages in the form of playlists have also been produced by specialist staff within the Additional Learning Needs (ALN) Department to provide teaching staff and school personnel with information and useful strategies:

- Making Reasonable Adjustments
- Simple Differentiation Strategies
- Teaching for Neurodiversity
- Autism in Girls
- Executive Functioning Skills in the Classroom
- An introduction to Sensory Processing Difficulties
- Sensory Play
- Sensory Circuits
- Writing Sensory Stories
- Developing Early Language Skills
- An introduction to speech, language and communication needs
- Top tips and useful resources for supporting learners with ALN in the classroom
- What is anxiety and how can I support an anxious pupil in my class?
- Emotionally Based School Avoidance

We work closely with our speech and language therapists who offer training to schools at all levels of communication need:

- ELKLAN training to TAs (specific programme to develop the speech, language and communication skills)
- Attention Autism
- Intensive Interaction training (for pupils who are pre-verbal)
- Total Communication strategies, including signing, communication boards etc.
- Communication devices and appropriate software

- Talkabout (social communication groups)

For those pupils who require more intensive/ specialist educational provision, School Services offer Specialist Resource Centres (SRCs) at primary and secondary level. These centres are staffed by trained and experienced specialist staff. Children and young people do not need a diagnosis to access these provisions.

We are very proud to say that Ceredigion is an inclusive authority and we all work together to ensure that the needs of our pupils are met locally. Despite not having any special schools, we only have one pupil currently educated in a specialist school out of county because of the severity and complexity of need.

Support for Parents

The Team Around the Family Service (TAF) offers a 10 week programme to the parents of children/ young people who have either received a diagnosis or who are waiting on the SCAT/NDT list. This is a comprehensive programme, with each topic covered being delivered by a range of professionals from Health, Education and Social Services. The programme covers:

- The Road to Diagnosis
- Social Communication, Social Interaction and Social Imagination
- Sensory Needs
- Sensory Needs in Education and Behavioural responses and strategies
- Dietary Differences
- Bowel and Bladder Needs
- Occupational Therapy Needs
- Educational Psychology perspective
- Speech and Language and Communication Needs
- Nurturing Ourselves and Further Support

Parents can also enquire about further support via Clic. Requests are considered and a proportional response is applied. On diagnosis parents are offered an information pack. Further assessments by Social Services may be offered to parents under the Social Services and Wellbeing Act to determine whether further support is necessary for the child/young person and their family to help the individual to meet their outcomes to achieve well-being. Some may be supported through Direct Payments or by accessing DASH play schemes or through respite. Close collaboration with health colleagues allows for targeted support in specific areas of development of the individual's skills.

WELLBEING OF FUTURE GENERATIONS:

Has an Integrated Impact Assessment been completed? If not, please state why

Summary:

Long term:

Integration:

Collaboration:

Involvement:

Prevention:

RECOMMENDATION (S):

To be informed on the current referral pathway to a diagnosis of autism in Ceredigion .

To be informed on how the Schools Services is meeting the needs of children who have or who are waiting for a diagnosis.

REASON FOR RECOMMENDATION (S):

To raise awareness of the current referral pathway and the support that is being provided by the Ceredigion Schools services.

Contact Name: Angharad Behnan
Designation: Principle Education Psychologist
Date of Report:

Acronyms:

Autism Spectrum Condition (ASC)

Social Communication Assessment Team (SCAT)

Speech and language therapist (SALT)

Neurodevelopmental (ND) Team Around the Family (TAF)

teaching assistants (TAs)
Occupational Therapy (OT)
Additional Learning Needs
(ALN)
Specialist Resource
Centres (SRCs)
Educational Psychologists
(EPs)
National Institute for Health
Care Excellence (NICE)
The Team Around the
Family Service (TAF)