



FAQs about the Neurodevelopmental Pathway

There appear to be a number of confusing messages out there for families that hopefully this information will help to clarify. These FAQs have been put together by professionals from health, education and the Special Educational Needs and Disability Service (Coventry SEND), as well as parents and carers.

Where can I find good quality advice and information about autism?

The National Autistic Society (NAS) has an extensive website which explains about autism, provides some facts and figures, and explores a wide range of relevant topics. The link is:

www.autism.org.uk/

In Coventry, Dimensions is a tool to help people identify what support is available locally for a range of difficulties including ASD. This is accessed via:

<https://dimensions.covwarkpt.nhs.uk/>

Will my child get the help he or she needs in school without a diagnosis?

Yes

- Most schools in Coventry and Warwickshire have received additional training on supporting students with autism and social communication needs
- A diagnosis does not tell you what help a child with social communication difficulties may need at school. All children are unique individuals in terms of their strengths and needs, and those with social communication difficulties are no different
- It is the school and other SEN services who can provide the right help, by assessing the child's autism and learning needs and putting in place strategies based on these
- Children do best when schools and parents work closely together – the school's Special Educational Needs Coordinator (SENCo) is usually the main point of contact between parents and schools

Does my child need a diagnosis of autism to get an Education, Health and Care Plan (EHCP)?

No

- All schools receive extra funding to help make special educational provision for children with additional needs, and should be making every effort to meet the needs of children with autism out of this funding
- EHC Plans were brought in to the SEN system to support children and young people with significant additional needs, regardless of whether or not they have a diagnosis
- Having a diagnosis for your child will not guarantee s/he is granted an EHCP
- More information about your school's policies can be found on its website

Information about Coventry City Council's Local Offer can be accessed through: <http://www.coventry.gov.uk/sendlocaloffer>

Does my child need a diagnosis to get support for his or her exams/SATs (Standard Assessment Tests)?

No

- The Department for Education (DfE) for primary school pupils, and the Joint Council for Qualifications (JCQ) for secondary school pupils, publish detailed regulations and guidance on examination access arrangements and reasonable adjustments for pupils with identified needs
- Schools use these regulations and guidance and their knowledge of their pupils, to determine whether special arrangements need to be made for specific individuals. A diagnosis is not necessary in order to make such decisions
- If support is in place on a daily basis for a child, it is expected that this will be considered, but it is not automatically guaranteed in a test setting/situation



It has been suggested that my child receives Early Intervention. I don't know if my child has autism, so, will using these strategies be harmful for my child'?

No

- The strategies used to support children with autism, will benefit any child who has social communication needs
- The strategies typically include: simple communication, visual structure and clarity, support with change and routine, behavioural strategies and developing social skills
- There are a range of parenting groups locally that teach similar strategies
- If your child goes through the specialist ASD assessment process, you will be asked for information about what has been tried and how your child responded, as this is helpful to the professionals in the Neurodevelopmental Service

If I use strategies and they help, does that mean my child won't get a specialist assessment or get a diagnosis?

No

- As part of the diagnostic process it is important to understand what strategies are being used to support your child and how they may help
- The diagnosing clinicians are highly skilled and trained in working with children and young people with ASD and other neurodevelopmental disorders. They are experienced in recognising the entire spectrum and also identifying how it presents differently in females
- However, you may want to consider the added value a diagnosis may or may not bring to your child and your family. If the support is already helping, you may want to consider if the diagnosis will change anything?



Will a diagnosis of ASD be the key to receiving lots of support?

No

- Your child will be the same child after the assessment as she or he was before, with the same individual strengths, personality and challenges
- There is no known cure for ASD and the main focus following a diagnosis is therefore to enable children/young people and their families to understand how ASD impacts on their daily lives and how to use strategies to support them more effectively
- If children need on going services, it is typically due to additional needs, such as mental health concerns often associated with ASD, for example anxiety, depression and ADHD. Children with these needs may benefit from some treatment within the Neurodevelopmental Service or if more significant, within mental health services
- Advice is available from parent education sessions and also on-line. However, be aware that the quality and accuracy of information on-line is very variable. Often, these are parents' personal experiences and perspectives, which may not be relevant to your child's needs and autism characteristics
- Parent-led groups in most areas are a valuable support
- The Neurodevelopmental Service will provide advice on local services following a diagnosis, and also offer these sessions prior to the child's assessment
- Most agencies no longer require a diagnosis of ASD in order to accept referrals. School based support from SEN services is now open to all and is based on need, as part of a new service delivery model

Are children and young people with autism more likely than to be anxious than their peers?

Yes

- ASD is as it says, a spectrum; everyone is unique and experiences the world differently, as do people without autism
- However, it is known that people with ASD can be more vulnerable to feelings of anxiety. The strategies to support people with ASD can help reduce anxiety
- As ASD is a neurodevelopmental condition, a child will not automatically require or access mental health services. If, however, their anxiety is significant this may be an additional mental health need and would require these specialist services

Does having a diagnosis mean that my child can't be excluded from school?

No

- Decisions to exclude a pupil are not made on the basis of whether or not a child has a diagnosis, but on a wide range of factors
- Schools are required to support children with additional needs by making reasonable adjustments such as adapting the curriculum and learning environment
- There is statutory guidance on the exclusion of pupils from school, which sets out the legal responsibilities of schools, governing bodies, and local authorities. Rigorous processes are in place, and parents/carers have the right of appeal against the decision to exclude, including access to an independent review panel, with the involvement of a Special Educational Needs expert
- However, it is important to acknowledge that some children with a diagnosis may be excluded and it may be that the school environment (for example physical, social, sensory factors) is not appropriate for them

Can I claim Disability Living Allowance (DLA) or Personal Independence Payments (PIP) without a diagnosis?

Yes

- DLA for children and PIPs are awarded based on a person's needs in comparison to another person of the same age. There are set eligibility criteria and thresholds which apply, regardless of a diagnosis
- Many people with ASD would not qualify for these benefits as they are able to go to school/work, take care of themselves and need very little support from others
- It is worth checking the criteria to see if your child might qualify given his or her individual circumstances. The following website provides further information: <https://www.gov.uk/disability-living-allowance-children>



Is it only GPs who can refer a child/young person for an ASD assessment?

No

- GPs have reported that in their limited time with the child and their family, it can be hard to make the decision to refer for an assessment. Some GPs also acknowledge that they do not have in-depth understanding of ASD
- The Neurodevelopmental Service recommends that schools complete referrals for children, in partnership with parents. Parents and teachers know the child best, and the referral form is designed to be completed jointly by them. Information from school is required so that the assessment complies with the NICE guidelines and the DSM V
- If you have concerns as a parent you are entitled to a specialist assessment. However before you make a referral, health and education professionals strongly recommend that you meet with the school SENCo and discuss what support can be put in place
- Sometimes there are no outward signs of children's difficulties in school, which can then make it hard for a teacher or SENCo to complete the referral. If this is the case the Neurodevelopmental Service has requested that schools still make the referral where needs are identified in the home
- There are many complex reasons for children experiencing difficulties with their behaviour and social skills, for example other neurodevelopmental conditions, significant mental health needs, difficult social and family circumstances and so on. These other factors may be present in addition to ASD and should continue to be considered alongside the assessment for ASD



If you need this information in another format or language please contact Jennet Gabriel on 024 7678 8400 or e-mail: jennet.gabriel@coventry.gov.uk