

SWINDON NEURODEVELOPMENTAL CONDITIONS (NDC) PATHWAY: MYTHS DEBUNKED



Swindon Educational
Psychology Service



NHS

Bath and North East Somerset,
Swindon and Wiltshire
Integrated Care Board

SIAS

SEND Information
Advice & Support

This leaflet has been developed in co-production with Swindon Educational Psychology Service, Swindon SEND Families Voice, SIAS and a SENCO Champion to debunk some of the common myths around the NDC pathway, which provides a diagnostic service for children who are neurodiverse or who have developmental disabilities.

INTRODUCTION

This leaflet has been developed in co-production with Swindon Educational Psychology Service, Swindon SEND Families Voice and a SENCO Champion to debunk some of the common myths around the NDC pathway, which provides a diagnostic service for children who are neurodiverse or who have developmental disabilities.

Certain groups will be followed by Community Paediatrics either because they have medical needs associated with their conditions or because they are on medication. Many children will have a diagnostic assessment and then be discharged.

When children are referred to the NDC pathway they are being referred to have an assessment, **not** to get a specific diagnosis.

Young people, who are able, from 11 years an over **must want to be assessed and give their consent**.

Many children will present with needs in school, at home and in the community but they may not go on to get a neurodevelopmental diagnosis.



WAIT TIMES

Our wait times are not as long as people think and we update the Local Offer monthly.

The wait for routine cases as of September 2024 was 18 months.

The wait for expedited cases, which includes **most under 5 year olds as of September 2024 was 10 months** but may be shorter for children with complex needs and neurodisabilities, such as those with cerebral palsy.



NEURODEVELOPMENTAL CONDITIONS

To get a diagnosis of a neurodevelopmental condition children must have significant functional difficulties in multiple settings, particularly social settings.

Whilst it is possible for children to hold in their anxiety at school or suppress tics (commonly associated with neurodevelopmental conditions) during the day, we would expect the key features of ASD or ADHD to be apparent to education staff during at least part of the school day. However, when ADHD presents with inattention alone it can be difficult to identify in a busy classroom. However, it is important to have a discussion with the teacher to alert them to the possibility.

Support can be put in place without a diagnosis, such as classroom adaptations and access to community services for you and your child.

IF MY CHILD GETS A DIAGNOSIS WILL THEY GET MORE SUPPORT?

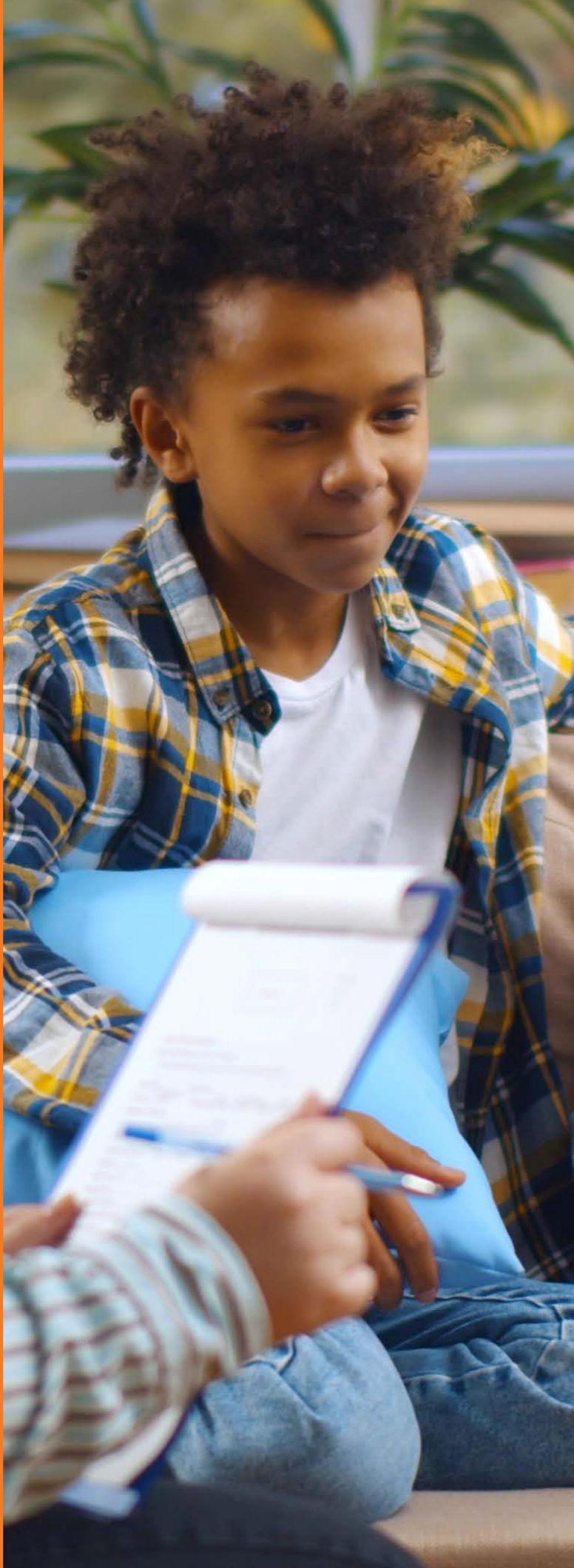
Your child's needs will be the same with or without a diagnosis and it is the needs as they present in school that determines the level and type of support they get in that setting. The label does not tell us anything about the needs of an individual child and is not necessary to access a wide variety of support.

Most support will not change after an ASD diagnosis. If ADHD is diagnosed they may benefit from medication but behavioural supports will be largely the same and are crucially important in the home and at school.

Getting a diagnosis or being told your child has a genetic change does not automatically mean that your child will have Special Education Needs (SEN).

A child or young person has SEN if they have a learning difficulty or disability significantly greater than the majority of others of the same age, or has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

- **Children and Families Act 2014**
- **The Equality Act 2010**



SHOULD MY CHILD BE ASSESSED BECAUSE THERE IS A FAMILY HISTORY?

Children should only be referred if they themselves are presenting with significant functional difficulties.

Even if there is a family history of ASD, other children in the family are more likely **NOT** to have ASD.

80% of children with a brother or sister with ASD will **NOT** have the condition.

90% of children with a parent with ASD will **NOT** have ASD.

In all cases it is important to focus on how the child presents and not any family history.



DO YOU PROVIDE A SLEEP SERVICE?

We are not a sleep service. We provide limited support to certain children who have neurodevelopmental conditions and we can prescribe short courses of melatonin. However, behavioural sleep support should be provided in the community and there is an expectation that sleep hygiene should have been addressed before any referral for medication. Support can be accessed through the Swindon local offer.

Children referred for sleep support will not be prioritised over children who are awaiting an initial assessment.

DO YOU PROVIDE SUPPORT FOR ANXIETY?

We are not a mental health service and do not have any staff to provide mental health interventions.

Your child's school can refer to mental health services and resources are available on the Swindon Local Offer.



DO YOU PROVIDE BEHAVIOURAL SUPPORT?

We do not have any behaviour specialists nor any psychologists in our team. We are therefore not able to provide behaviour interventions, which are provided in the community.

In particular, if children have experienced early trauma their presentation may overlap with neurodevelopmental conditions but it is essential that the trauma is considered before making a referral to the neurodevelopmental pathway.

Your child's school can refer to behavioural support services and resources are available on the Swindon Local Offer.

DO YOU SEE CHILDREN WITH SPECIFIC LEARNING DIFFICULTIES?

We cannot assess children and young people for Specific Learning Difficulties, such as dyslexia, these are identified and managed through the education system.



HOW HAS COVID LOCKDOWN AFFECTED CHILDREN'S DEVELOPMENT?

Many children developed educational, social, emotional, and behavioural gaps in their development; they lost skills to deal with everyday problems due to social isolation. This means that they have difficulty managing their emotions when around other children.

They may have difficulty communicating at an age appropriate level and have poor social skills. It is vital that children are given opportunities to interact with their peers to learn these skills.

WILL MY CHILD BE SEEN SOONER IF I GO PRIVATELY?

It is your right to have your child assessed privately. Within the NHS children who have been seen privately will not be advantaged nor disadvantaged if they are seen privately. This means that your child will be seen in date order in the same way as any other child referred to the community paediatric service.

WILL MY CHILD BE SEEN SOONER IF THEY ARE REFERRED BY THE GP?

No, all children referred to our service are seen in strict date order regardless of who refers them. Children may be seen sooner than others based on their clinical needs.





WILL SEEING THE DOCTOR HELP MY CHILD GET MORE SUPPORT IN SCHOOL?

Doctors, regardless of whether they are NHS or private cannot make recommendations to schools about interventions / support / or EHCP applications. Physicians are not in a position to determine the needs of a child in school nor are they aware of the available / appropriate educational interventions available in any particular school.

If you have concerns about the support your child has in school, you can arrange to speak to their teacher, tutor or SENCO. If you would like impartial information, advice or support about your child's education then you can contact your local SENDIAS service.

In Swindon this is **SIAS**, www.swindonSIAS.org or visit **Swindon Local Offer**.

WHY IS IT IMPORTANT TO ENSURE CHILDREN ARE NOT MISDIAGNOSED?

There are lifelong implications in getting a neurodevelopmental diagnosis as there are no cures. It is very important therefore that children are given the correct diagnosis or not given a diagnosis when it does not apply. We must ensure children are not given medication incorrectly for example. Sometimes when children and young people are given a diagnosis of ASD or ADHD other needs are overlooked and not addressed. Having certain diagnoses can impact career choices and insurance.

Information online or on social media can make it look as simple as checking off a list of symptoms but the accurate assessment is complicated. There are many factors to consider as symptoms can overlap with those of early trauma, learning difficulties, mental health needs and genetic syndromes.

For Swindon support family to family contact:

Swindon SEND Families Voice

www.swindonsendfamiliesvoice.org.uk

