

Getting It Right For Every Child with **PANS** or **PANDAS**



Understanding the Additional Support for Learning (ASL) model for families in Scotland living with **PANS** or **PANDAS**

PANS

Paediatric Acute-Onset Neuropsychiatric
Syndrome

PANDAS ICD-11: 8E4A.0 / 8A05.10

Paediatric Autoimmune Neuropsychiatric
Disorder Associated with Streptococcal
Infections



www.panspandasuk.org

SHANARRI indicators.

These indicators are the primary measure
used in Scotland for assessing children and
young people's health and wellbeing.

PANS and PANDAS can impact health and wellbeing across all eight indicators.

Safe - Children and young people with PANS
or PANDAS may have intrusive thoughts, or
exhibit self-injurious behaviour.

Healthy - PANS and PANDAS are medical
conditions and require diagnosis and
treatment.

Achieving - Many children or young people
experience cognitive issues, and some may
struggle to attend school.

Nurtured - Widespread lack of understanding
of the conditions may lead to children or
young people not feeling supported.

Active - Anxiety, fatigue, motor difficulties,
and social withdrawal can impact on activity.

Respected - Misunderstanding of diverse and
fluctuating symptoms can lead to feelings of
not being listened to or believed.

Responsible - Children and young people
should not be held responsible for symptoms
that are as a result of their condition.

Included - Children, young people and their
families can become socially withdrawn due
to the challenges of living with the conditions.

What are **PANS** and **PANDAS**?

PANS and PANDAS are acute-onset
neuropsychiatric conditions with a broad
spectrum of symptoms, including obsessive-
compulsive behaviours, tics, severe eating
restrictions and cognitive, behavioural or
neurological changes.

Triggers may include strep throat, influenza,
chicken pox, pneumonia, allergens, anxiety,
trauma or other environmental factors.

Children and young people are often
misdiagnosed with psychiatric
conditions, ASD or ADHD.

About **PANS PANDAS UK**

It is our mission to raise awareness of
these life-changing conditions, engage
with and inform health, education and
social care professionals and create
support networks for all families who are
affected by **PANS** or **PANDAS**.

Contact us

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Additional Support

Children and young people (CYP) with PANS or PANDAS may develop new, fluctuating Additional Support Needs (ASN) that vary in type and severity.

Supporting these needs will require a flexible, agile approach and, depending on severity, a **Child's Plan** maybe needed.

Symptoms which may lead to a CYP requiring additional support include:

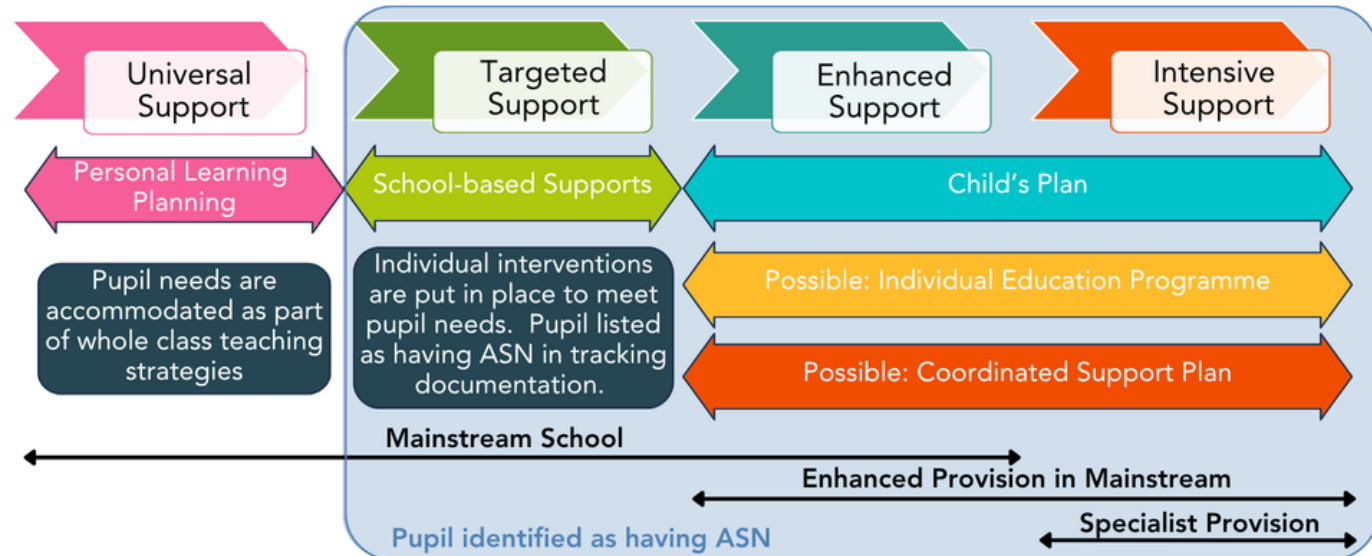
- Tics and motor impairments
- Regression in fine and gross motor skills
- OCD rituals
- Food sensitivities
- Sensory issues
- Cognitive impairments
 - Executive functioning difficulties
 - Processing / concentration difficulties
 - Working memory changes
- Anxiety - in particular separation anxiety
- Emotional dysregulation
- Communication difficulties
 - Speech and behavioural regression
 - Onset of stuttering
 - Selective mutism
 - Friendship issues
- Behavioural issues
- Sleep issues
- Toileting issues
- Hallucinations and Psychosis



Education is needs-based. A child or young person does not require a diagnosis for support in school.

The Additional Support for Learning model

This diagram provides an overview of the model that schools in Scotland follow when putting in support. Each local authority will have its own specific model with more details on its website. CYPs with PANS or PANDAS may require 'Targeted' or 'Enhanced' support:



- A **Child's Plan** is used to assess a CYP's needs against the SHANARRi indicators. It should be developed at a meeting involving everyone supporting the CYP, including parents, carers, and the CYP themselves. Meeting minutes and the finalised Plan should be circulated to everyone.
- An **Individual Education Programme** (IEP) is used to plan specific aspects of education for learners who need some, or all, of their curriculum to be individualised.
- A **Coordinated Support Plan** (CSP) is a legally enforceable plan of agreed supports for a CYP.
- It will only be considered if needs are complex, significant and expected to last more than a year.

Some CYPs with PANS or PANDAS may struggle to attend school.

In this case, the school should be following the Scottish Government's 'Guidance on education for children and young people unable to attend school due to ill health'.



The level of support a CYP receives will increase if supports at the current level have been demonstrated to be ineffective.



Parents or Carers should discuss with the school if they feel their CYP is not receiving the right level of support.