

Confirmation Statement - Use of Generative AI

I confirm I have not presented any AI generated text as my own word. I confirm I have copies of my own drafts, notes, and resources that I previously used before, and after the use of AI tools which I may be asked to provide in evidence.

Introduction:

Noonan Syndrome (NS) is a genetic disorder involving RAS signalling pathway variants, affecting cellular processes like neural plasticity. Physical symptoms of NS include distinctive facial features, joint pain, scoliosis, and sensory impairments (NHS, 2021; SSBP, 2022). While some children thrive in maintained settings, others require specialist support (Noonan Cantata, 2023; Shiels *et al.*, 2021). However, it may be argued that, the UK education system often fails to look beyond surface-level behavioural presentations. Despite being the 'most common rare disease you have ever heard of', NS lacks visibility within the UK education system. This leads to a systemic 'diagnostic overshadowing' where children are placed on the SEN register, without teachers recognising the genetic basis for their slower processing speeds (Loughborough University, 2025). This lack of specialised knowledge essentially means that intervention are often generic rather than tailored to unique RASopathy profile, potentially limiting the academic ability of these learners.

Objectives:

- Analyse the barriers that might impact children's learning with NS in the curriculum.
- Explore how professionals might provide the highest quality provision for children with NS.
- Consider the effectiveness of inclusive practice in achieving positive developmental outcomes later in life.

Methodology:

This paper utilises Douglas *et al*'s (2016) 'inclusive assessment framework' to consider whether students with Special Educational Needs and Disabilities (SEND) - such as those with Noonan Syndrome - are included in or excluded from the wider national curriculum. Despite legal mandates from *The Equality Act 2010* (s 6.), *Additional Learning Needs and Education Tribunal (Wales) Act 2018* (WG, 2018), and *The Additional Learning Needs Code for Wales 2021* (WG, 2021), practical classroom support requires flexibility than policy suggests. Employing this framework allows us to challenge whether current assessment approaches are truly 'fair' and 'inclusive' to those pupils with SEND.

An 'inclusive assessment framework' allows professionals to communicate their ideas effectively, and to articulate their reasoning with greater confidence, ensuring that diverse needs are met without compromising rigour (Oxford University, 2026). Some critics, though, argue that this approach is inherently flawed. Assessment tools fail to capture the small, crucial progress steps that are unique to children with NS. Moreover, the focus on progress should not override the curriculum's emphasis on promoting child-led, play-based learning (Kefallinou *et al.*, 2016).

Analysis:

Studies highlight that children with NS face neuro-developmental challenges, such as acting impulsively, and facing emotional dysregulation (NSAA, 2018; Pierpoint *et al.*, 2023). Crucially, these behaviours are often biological symptoms of the condition rather than a child trying to be difficult (Roberts *et al.*, 2014). Similarly, children face difficulty in understanding social cues, therefore, impacting their interpersonal relationships and classroom engagement (Naylor *et al.*, 2023; Elizondo *et al.*, 2026). Consequently, such barriers prevent the child's ability to navigate their 'nested' environments - from the immediate interactions within the microsystem to the wider, broader cultural influences of the macrosystem (Bronfenbrenner, 1994; Sadownik *et al.*, 2024). When a child's progress is being blocked from these systems, the Social Model of Disability, suggests that the problem isn't the syndrome itself, but instead it is the world around them was not build for their needs. From this perspective, it can be argued that the child is disabled not by their biological symptoms, but by a society and support system which is rigidly designed around neurotypical standards of interaction (Mladenov, T, 2022; Disability Wales, 2024). Because of this, children with NS are subject to persistent emotional distress. This has a lingering, lasting impact on children's outcomes later in life (Ding *et al.*, 2019; Serur *et al.*, 2025).

Moreover, children with Noonan Syndrome and their parents faced constant stigmatisation and 'social ostracisation' (Broomhead, 2019). They encountered public humiliation by individuals in the public domain due to the syndrome's marked appearance and the child's so-called 'abnormal' behaviour, despite the fact it was not their fault. This happens because society often follows the 'Medical Model of Disability', where children's impairments - such as those with Noonan Syndrome - are seen as a direct cause of them being 'unable to get access to goods and services or being able to participate fully in society.' Essentially, this perspective shifts the blame onto the children's biology, suggesting that their exclusion is an inevitable result of their condition, rather than a failure of social design (Crutchley, 2018; Davies, 2025). This experience has been 'traumatic' for parents, and that such incidence reflects how society's perceptions towards neurodivergent people are negative. On the other hand, though, this marginalisation violates the *Convention on the Rights of Persons with Disabilities* (OHCHR, 2016; EHCR, 2020; Abreu, 2022). By treating children with

NS as 'inferior' and denying them enabling environments, the system creates an exclusionary barrier, that shut down their potential. It leaves them sidelined from their peers and pushed to the margins of the wider community.

Lastly, in the UK, fast-paced and language-heavy curricula often exceeds the cognitive capacity of children with NS (WG, 2022). Due to the RAS-MARK signalling, they process information slowly and struggle with working memory, regardless of their intellectual ability (Noonan Syndrome Association, 2022). Unfortunately, instruction heavy-based teaching can push children beyond the ZPD if scaffolding is not well embedded. Without proper scaffolding, tasks can become difficult for children with NS to handle, leading to inconsistent performance and disengagement. They may feel stressed out, therefore, their nerves might be 'erupted' in a school environment (Vygotsky, 1978; Yusof, 2023). Especially if the assistant is working with these individuals without any prior knowledge of experience (NHS Wales, 2026).

Support in Place/Provision:

An essential strategy within mainstream curriculum is differentiated instruction. Differentiation enables teachers to adapt learning activities, teaching methods, and assessment approaches that tailor children's needs with NS (Welsh Government, 2022; European Commission, 2025). Effective differentiation for pupils with NS might include: breaking tasks into manageable steps, simplifying and clarifying simple instructions, providing visual supports alongside verbal explanations, and reducing cognitive overload through scaffolded activities (NASEN, 2026). Pupils with NS benefit from repetition, modelling, and opportunities for overlearning, particularly where working memory and processing speeds are affected. Appropriate and relevant use of scaffolding promotes both achievement and long-term independence for those individuals by gradually bridging the gap between what they can do with guidance and what they can do entirely on their own (Zenker et al., 2022; ESTYN 2025).

Secondly, professionals should use Makaton to give students with NS an alternative, multimodal way of communicating directly with them. They can do this through physical signs and visual symbols, creating a high-quality pedagogical environment that reinforces cognitive development (Anna Sin, 2009). This approach should be unhurried, allowing students to take part in these dialogues, using physical gestures to strengthen memory and 'map' information into mental frameworks or schemas. In doing so, professionals bridge the gap between a student's independent ability and collaborative challenge, effectively embedding Vygotsky's theory of social constructivism into daily practice (Siraj-Blatchford, 2009; Neuman, 2021; Waters-Davies, 2022). However, while Makaton serves as a powerful scaffold for learning, a Piagetian critique might suggest that its effectiveness is ultimately bounded by a child's biological stage of development (Piaget, 1964). From a Piagetian perspective,

while these signs are great for helping a child organise their thoughts, there's a limit to how much they can grasp. Essentially, a child's current stage of brain development might mean they aren't quite ready to understand the deeper, abstract meaning behind some symbols yet, particularly those with NS, no matter how much help an educator provides (Wadsworth, 2004).

Lastly, whilst current support for professionals regarding NS in schools is growing, a more tailored approach is required, with ongoing calls for greater mainstream awareness. Calls for dedicated resources remain prominent within the sector, and especially those that detail the syndrome's causes, and offer practical classroom management strategies. Such specialised knowledge is essential for recognising and meeting the specific needs of these individuals (WG, 2025; NHS, 2026). However, whilst understanding of NS is important, an over-reliance of medical labels can lead to a reductive view of the child. Professionals must be careful not to fall into the 'trap' of 'diagnostic overshadowing', where every learning hurdle is attributed to the syndrome rather than explored through a pedagogical lens (Hallyburton, 2022). So, therefore, true inclusion requires a shift from just simply being 'aware' of the issue, but also actively addressing it in the confines of the school environment, being responsive about it, and ensuring that a student with NS is not further disabled by its surroundings (WG, 2023; ESTYN, 2025).

Conclusion:

In summary, support for children with NS can be embedded in the EYFS, when grounded in inclusive, play-based pedagogy and aligned with the New Curriculum for Wales. However, its effectiveness may be diminished by staffing capacity, funding constraints, and inconsistent specialist knowledge and confidence in managing rare conditions. To ensure the highest quality possible, professionals should be trained and guided on how to provide an effective and appropriate classroom support that is registered and bespoke to their needs.

Questions and responses:

What specific experiences led you to choose Noonan Syndrome as part of your primary research topic?

I chose to focus my presentation on Noonan Syndrome because I previously worked with a child who had this condition in a mainstream setting. At the time, I had very little knowledge, which made it difficult to fully understand how to support the child. This experience showed me the lack of training, support, and funding available for staff working with children with rare conditions (WG, 2021). It encouraged me to learn more about Noonan Syndrome and how it can affect children's learning, development, and social interaction within the wider curriculum (Noonan Syndrome

Association, 2023). I became very interested in the topic and how it links to the Early Years Curriculum.

As an Early Years Practitioner, it is important to understand conditions like this so children can be supported in an inclusive way (Vale of Glamorgan, 2021; Department of Education, 2026). However, many practitioners do not receive specialist training, which can make it harder to meet children's needs confidently. Through this research, I wanted to improve my own knowledge, and show how small changes in practice, good communication with families and professionals, and an inclusive environment can help children with Noonan Syndrome feel supported and achieve their potential (WG, 2022; NHS, 2026).

What adaptations to the environment or routine for those with Noonan Syndrome can make the biggest difference? And why?

For people with Noonan Syndrome, the biggest help often comes from simple and flexible support. This can include clear routines, breaking tasks into smaller steps, and giving extra time and rest breaks (Noonan Syndrome Association, 2022). These strategies can help with difficulties linked to slower processing, tiredness, and coordination (Tiemens et al. 2023). It is also important for schools, healthcare staff, and therapists to work together. Support should not just be seen as an "extra" adjustment, but as a way to help people take part equally in learning and everyday activities (Zenker et al., 2022; Rasopathies, 2023; Loughborough University, 2024; Stagi et al., 2025).

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