

Supporting children and young people with Noonan Syndrome in Education: Co-production of an educational toolkit

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A collaboration between The Noonan Syndrome Association and Loughborough University

Rationale

- Findings from the Living with Noonan Syndrome Project (2022-24) identified education as a key area where families wanted more support
- Challenges:
 - Low awareness of Noonan Syndrome in educational settings
 - Difficulties accessing educational support; fighting for EHCPs and specialist settings or mainstream settings that would meet medically complex needs
 - Learning difficulties, disabilities, ADHD and ASD are common
 - Educational needs are not always being recognized or met
 - School work can be source of conflict at home
 - Frequent reports of bullying and social exclusion
- Some examples of good support but this is very variable

He really wanted to do well at school, he worked so hard... **he was really bright but that didn't translate into passing exams** so that was that frustrating for him. (Laura)

Since day one, he's had a teaching assistant who is with him all the time. He got his EHC plan before he even started school, which is brilliant because the lady that he started with when he was four is still his TA. [Their] relationship is wonderful. He trusts her and he's confident with her. She always constantly reassures him and tries and keep him engaged in what's going on. (Sarah)

Aims of the toolkit are to:

1

Explain what NS is in simple terms

2

Promote recognition of how NS can impact on learning

3

Outline practical strategies for supporting children with NS in educational settings

The Toolkit version 1

Noonan Syndrome & Parent-Friendly Version

Introduction

Noonan Syndrome (NS) happens because of a **genetic change that is potentially present in every cell of a person's body**. This means it can affect many different areas of development, but it affects each child differently. A range of **neurodevelopmental differences**—including Autism, attention-related differences, Dyslexia, Developmental Coordination Disorder (sometimes called Dyspraxia), Dyscalculia, and sensory processing differences—are **more common in children with NS**. These differences are part of natural human variation and do not mean a child has less ability or potential.

Understanding your child's profile

Children with NS often have a **unique mix of strengths and needs**. Differences may appear in movement, coordination, energy levels, sensory processing, learning, or health, and these can **change from day to day**. No two children with NS are the same.

If your child is also autistic or has other neurodivergent traits, you may notice additional differences in **communication, sensory needs, emotional regulation, or processing speed**, but these are all part natural neurodiversity—not signs of reduced capacity.

Executive Functioning across all children

Executive Functioning (EF) skills—organising, planning, remembering instructions, managing emotions, and switching between tasks—are skills that all children develop over time. EF differences are common across many neurodivergent profiles, including Autism, ADHD-type traits, Dyslexia, Dyspraxia (DCD), and Dyscalculia. Support with EF is helpful for all children with NS. Many children with NS benefit from extra support in these areas, especially when they are tired, overwhelmed, or facing new demands, [whether or not they have a specific diagnosis of EF difficulties](#).

How this may feel for your child

How different needs can add up

Because NS can affect health, physical development, learning, and sensory processing, children may be coping with several things at once. Even when each difference seems small on its own, the combined effect can make school more tiring or more difficult to access. A child may be managing:

- tiredness from health or medical needs
- coordination or motor challenges
- sensory overload
- slower processing when stressed

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- difficulties with organisation or switching tasks
- attention differences
- challenges with reading, writing, or maths

When several of these happen together, it can affect how easily your child can take part in lessons, keep up with the pace, or show what they know. This is about the demands of the environment, not about your child's ability. Their potential remains intact; they may simply need the right support and flexibility to thrive.

Learning and development

Many children with NS reach milestones **later than other children**, but this reflects natural differences in development—not lower ability. With the right support, high expectations, and flexible pathways, children with NS can **thrive and achieve well**.

Support that works

If a child with NS also has neurodivergent traits, the **same proven strategies** used for other neurodivergent children are helpful here too. Schools can access training and support through local education and health services.

What this guidance offers

This document explains the **strengths and needs** that may be seen in children with NS and gives practical ideas for supporting them in school. It draws on approaches such as **Emotion Coaching, sensory regulation, and helping children understand their own learning**. The aim is to support **flexible, child-centred planning** that helps each child feel safe, confident, and able to succeed.

Understanding Your Child's Profile

Area	What This May Look Like
Physical & Health	Tiring more easily; joint flexibility; low muscle tone; heart or lymphatic differences; day-to-day variation
Learning & Thinking	Differences in attention, memory, processing speed, or problem-solving; slower pace when stressed
Executive Function (EF)	Finding it harder to plan, organise, remember instructions, start tasks, or switch between activities
Reading & Writing (Dyslexia-type)	Slow reading; difficulty sounding out words; spelling challenges
Maths (Dyscalculia-type)	Difficulty with number sense, time, money, or patterns
Motor Skills	Tiring during handwriting; clumsiness; difficulty with PE or fine motor tasks

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Sensory Processing	Feeling overwhelmed by noise or busy spaces; needing quiet time
Emotions & Communication	Finding it hard to name feelings; big emotions; masking distress; needing time to recover
Everyday Independence	Needing help with organisation; finding new routines or social situations tricky

How These Differences Can Affect School Life

Area	What This Might Mean Day-to-Day
Fatigue	Getting tired quickly; needing breaks; slower pace
Executive Function	Losing track of instructions; difficulty getting started; needing reminders
Processing	Taking longer to respond; forgetting steps; needing things repeated
Reading & Writing	Avoiding literacy tasks; feeling frustrated or embarrassed
Maths	Worry or anxiety around number tasks; difficulty remembering facts
Motor Skills	Slow handwriting; discomfort; avoiding PE or long writing tasks
Sensory & Social Overwhelm	Shutdowns; withdrawing; big feelings in busy places
Asking for Help	Wanting to please adults; masking; not saying when they're stuck
Independence	Finding routines hard; needing support to stay organised

What Helps: Practical Strategies

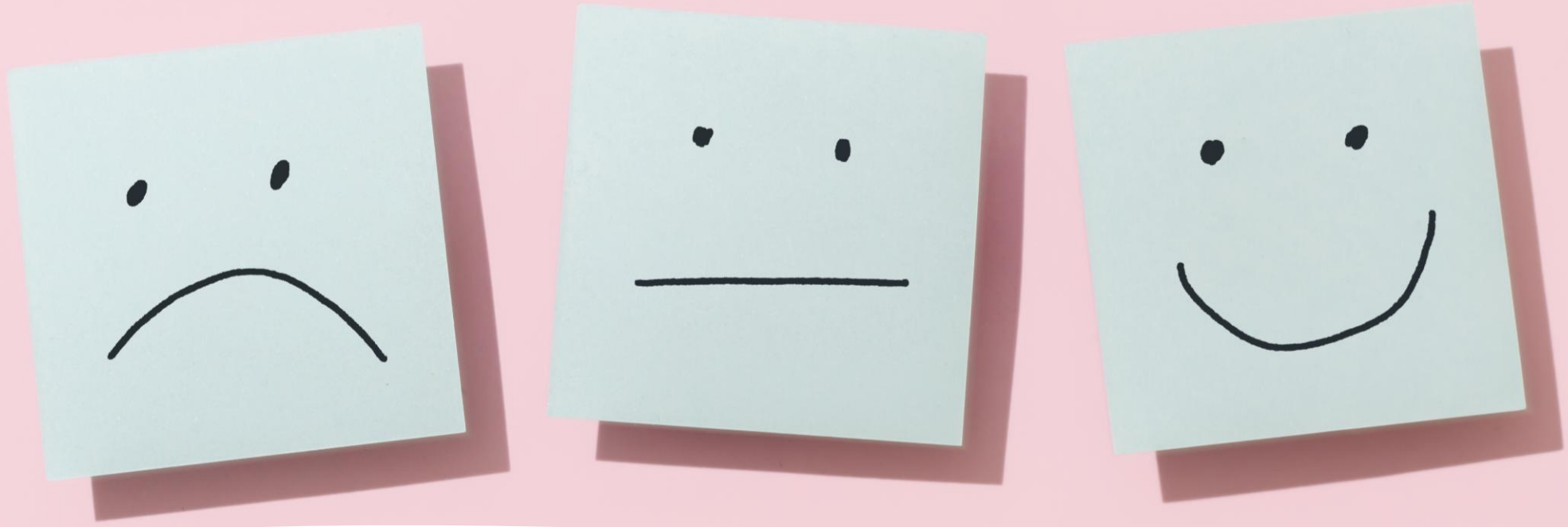
Area	Helpful Approaches
Executive Function	Visual steps; checklists; "What's next?" prompts; breaking tasks down; extra time; gentle reminders
Processing	Slower pace; repeating instructions; visuals; small steps; patient wait time
Reading & Writing	Coloured overlays; audio books; phonics support; writing frames; reader pens
Maths	Hands-on materials; visual models; practising in small steps; pre-teaching

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Motor Skills	Keyboard or voice-to-text; movement breaks; comfortable seating; OT strategies
Sensory Needs	Quiet space; sensory tools; predictable routines; planned breaks
Emotional Support	Emotion Coaching; naming feelings when calm; co-regulation; trusted adult check-ins
Social Confidence	Practising social scripts; gentle support in group work; clear expectations
Independence	Practising routines; visual timetables; modelling; small achievable steps
Assessments	Extra time; rest breaks; using technology; quieter rooms

Approaches Used Across the School Day

- Emotion Coaching
- Helping children understand how they learn
- Predictable routines and clear expectations
- Sensory-friendly spaces
- Encouraging independence step-by-step
- Working with your child to shape what helps them



Community Feedback

- 6 Focus Groups with parents, young people with NS and siblings
- 3 written reflections from parents and 3 'child voice' submissions

11 parents (3 of whom are also teachers)
6 children with NS and one sibling

Why the toolkit is needed

- Families are carrying too much of the explanatory work
- Parents are left to research the educational impacts of NS themselves
- Valued the idea of a tool to support opening conversations with educators and support planning
- Important to support continuity during transitions (between settings, classes)

I've spent the past year going into meetings with educators saying we have this diagnosis and them being like, oh, what is that? Tell us more. And I've been like, I don't know. **If someone had handed me this at the same time as they'd given me (child's) Noonan's diagnosis, I would have had a very different year.** Like that would have saved me hours of everything.

FG3, Parent

Challenges families are facing

Difficulties with emotional regulation, sensory processing, memory, recognizing danger and attention often read as 'bad behaviour'

The cumulative impacts of NS on education are not recognized – impacts go beyond academic learning

Abilities and needs fluctuate from one day to the next

Pain and fatigue are often invisible

Anxiety around medical appointments not always recognized

Toileting, eating and personal care as significant issues shaped by school rules and routines

Children do not always want to ask for help

Social relationships can be impacted by children 'feeling different' or being treated differently – some reports of bullying

Having support on paper does not always translate into receiving support in practice

Some reports of parents not being believed, reported to social services by schools for neglect or harm (e.g. bruising, sores, minor injuries)

I think the stress on the cumulative effect of the condition is more the biggest issue rather than just one difficulty. **It's not just one thing, it's everything.**

FG3, Parent

She's really clever, but it's accessing, do you know what I mean? She just found it so difficult. She'd have days where she'd have English - she loves English - and she'd write and write and write and write and she'd have these beautiful stories, and then she'd have days where she was just an absolute mess and just couldn't do anything. She wouldn't be able to write a word.

FG4, Parent

I think **the school hasn't really understood fully what they needed to be doing.** And I think, they haven't done as well as they probably could have done in helping [child] achieve their potential.

FG1, Parent

He can find lunchtime quite stressful because he doesn't want to sit there and eat. He can get a bit hyper and chaotic.[It said in his end of year report that] sometimes he can struggle to focus... And that's not something we'd even been aware of. **Maybe if [the teacher] was more aware of the fact that that could have been due to Noonan's she would have come to us with that earlier.**

FG5, Parent

Sometimes I have pain at school, but **I don't tell the teacher** because sometimes they're very busy. And I don't like to interrupt when we're like in the middle of something.”

FG1 Child

I think that teachers need to realise like, they can't just put your feelings back. If like, say (Child) feels a bit like dysregulated and you know, **she just needs a minute to step out of the class**. And then sometimes the teacher will just be like, oh, (Child), you're fine. Just don't worry about it. Just get on with it.

FG2, Sibling



(Child voice, submission 2)

Well, sometimes Miss (name) helps me a bit, but because there's like thirty something children in our class. **She can't just keep her eye just on me**. No. So yeah, I wasn't getting extra help, but I'm getting a bit of help.

FG2, Child

Examples of good practice

Individualized support

Feeling safe – calm, kind
staff help build trust

Inclusion - Playing to the
child's strengths,
supporting activities they
enjoy, providing
opportunities for them to
succeed

Importance of social
relationships – supporting
friendships

Proactive and practical
strategies to help e.g. visual
road map for tasks

Open, two-way dialogue
between parents and
teachers

Her teacher basically said she is behind, but I don't care. I just want her to be happy. And it's like, OK. I think that's important, which is lovely. It's great just to have them there and enjoying the process of going to school... **they saw her for who she was.**

FG6, parent

A calm approach really, really helps her because she now really trusts her teacher because he doesn't shout at her. She really responds to people who she feels **that they care about her and about her well-being.** One of the really big things for her was just to be like she's been included and not that she's been a pain.

FG4, Parent

(child's) Keyworker at nursery has also really **got to know him well and has helped him integrate well** into his class. She has more recently really taken on board the advice from physio, OT, SLT and tries to spend some time with him each day 1:1 working on specific skills through games and activities.

Parent, written submission 3

We've had a **constant open dialogue**, and that is, to be honest, the best, because it's communication both ways.

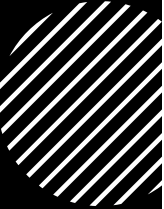
FG3, Parent

What is missing from the toolkit?

Topic to add	What participants asked for
Pain and fatigue	How pain and tiredness affect a child, delayed pain, and what staff can offer
Asking for help	Children find it hard to speak up; staff should check in and offer options
Toileting	Urgency, not making children wait, time limits, privacy and safeguarding
Eating, lunchtime and feeding	Low appetite (don't push them to eat), tube feeding, gastrostomy care, reminders to eat (daughter forget to eat), not forcing food
Personal care, hygiene and puberty	Face wiping, handwashing, periods, delayed puberty
Bruising	Easy, severe bruising, so staff aren't alarmed and families aren't wrongly suspected
Medical devices, scars, mobility	PEG/gastrostomy training, wheelchairs, private changing, lift keys
Appointments and attendance	Impact of appointments, frequent infections, attendance pressure, anxiety
Growth hormone	Side effects to watch for, such as headaches and hip pain
Emotional wellbeing and relationships	Emotional regulation, mental health, friendships, height and difference
Strengths	Much more on strengths, interests and a 'spiky profile'
Transitions	Planning for Year 7 and later transitions within secondary school



Next steps



Consolidate feedback into a new draft of the toolkit



Seek further feedback from parents, children and teachers and other professionals



Give your feedback today, or contact us over email later



Pilot the toolkit in schools Jan - March (if you are interested let us know!)



Produce a final version (April/May)