Policy briefing
Earlier support and earlier outcomes

The case for strengths and needs-based support before or without an autism or ADHD diagnosis.

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The International Classification of Functioning, Disability and Health (ICF) is the World Health Organization's internationally recognised framework for understanding health, disability and participation.[1] It provides a common language for describing a person's strengths, support needs, daily participation, and the environmental factors that help or hinder them across health, social care, education and policy.[2]

The ICF Toolkit™ is one example of an ICF-aligned assessment tool. Developed using the autism and ADHD ICF Core Sets, it translates the framework into a practical, scientifically validated digital assessment for autistic and ADHD children and young people.[3,4] Instead of focusing only on diagnosis, it creates a personalised strengths and needs profile that families, schools and professionals can use to take earlier action and improve outcomes.[5]

Why waiting harms children and systems

More than 250,000 people in England are waiting for an autism assessment, including over 140,000 children and young people. Hundreds of thousands more are waiting for an ADHD assessment, and fewer than 5% receive a first appointment within the recommended timeframe.[6]

Formal autism and ADHD diagnoses still determine access to support. Until a young person is diagnosed, the system rarely responds, even though waits are now measured in years, not months.

This diagnosis-gated system increases pressure on young people, families and schools, leaving needs unmet that should be addressed much earlier.[7]

Schools often lack the understanding and resources to support autistic and ADHD young people without a formal diagnosis. The result is poorer mental health, lost education and employment opportunities, and worse long-term outcomes.[8]

Support arrives too late. While waiting for an autism or ADHD diagnosis, many young people receive no targeted support.

Needs do not start at diagnosis. Families and schools spot strengths and difficulties early, but cannot access evidence-informed support.[9]

Diagnosis matters. It is clinically meaningful and important for developmental outcomes. Many autistic and ADHD people also say a formal diagnosis supports self-understanding and identity.

This report does not argue against diagnosis. It argues for needs-led support that does not depend on diagnosis alone.

Instead of asking, **"Does this young person meet diagnostic criteria?"** we should ask, **"How can we support this young person right now to thrive in their environment?."**

Why the ICF matters

One profile. One language. Multiple systems.

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organization (WHO).[1] It provides a shared framework for describing strengths, support needs, participation and environmental barriers across education, health and social care.

Research shows that diagnostic labels alone do not fully describe a person's support needs or everyday functioning.

More than a decade of international research with autistic and ADHD people, families, clinicians, educators and researchers has led to validated ICF Core Sets for autism and ADHD.[2,3] These offer a scientifically grounded way to understand strengths, support needs and participation across ages and settings.[10] These Core Sets provide the foundation for condition-specific assessment tools, such as the ICF Toolkit™, while maintaining alignment with the broader ICF framework.

The ICF is not a diagnostic tool. It does not determine whether a young person is autistic or has ADHD. Instead, it looks at how a person and their environment interact, helping identify the support needed for participation and wellbeing.[11]

The ICF creates a personalised profile that gives parents, teachers and health professionals a shared, evidence-informed view of a young person's strengths, difficulties and the factors shaping daily participation. When informed by people across a young person's life, it reflects the contexts that matter most.[5]

A shared understanding of a young person's needs is the foundation for tailored support, whether or not a formal diagnosis has been made.

Integrating support from day one: the role of schools and nurseries

Schools and nurseries often identify a young person's support needs early. They are also where the absence of support is felt most sharply.[7] Educators and support staff can complete strengths-and-needs assessments to support every young person.

The profiles can help children thrive by:

- Reducing the time between a young person's needs arising and receiving effective support.
- Helping staff recognise and describe a young person's unique abilities in a structured way.
- Providing both a personalised and consistent framework for support planning.
- Strengthening coordination between a young person's education, health, and social care documentation and supports.

Global evidence with local relevance

Diagnosis and strengths-and-needs profiling serve different purposes. Diagnosis identifies whether someone meets criteria for a condition. The ICF strengths-and-needs profiling identifies what support they need to participate and thrive. Both matter, but support should not wait for diagnosis.[4,5,11,12] Different ICF-aligned assessment tools may be appropriate in different contexts and populations. In this study, we evaluated an autism- and ADHD-specific assessment developed from the ICF Core Sets.

What international research shows

Research using ICF-based autism and ADHD assessments shows that families find strengths and needs profiles accurate, useful and empowering.[5,10,12]

Parents report that these profiles help to:

- Better understand a child's strengths and support needs
- Communicate more clearly with professionals
- Support decision-making across education, healthcare and social services

Together, these findings show how ICF-based approaches can turn assessment into practical action by helping families and professionals build a shared understanding of what matters most and what support is needed to help a young person thrive.

Our research

We explored whether strengths and needs assessments could help educators better understand a young person's needs and identify effective support. We also examined whether tailored support could improve wellbeing, school attendance and quality of life.[13]

Who took part

Our research involved 35 children and young people aged 2–15 across eight education settings in South East England, including nurseries, primary schools and secondary schools. Some were waiting for an autism or ADHD assessment. Others had clear support needs but no diagnosis and were not on a waiting list.

What we did

Families and teachers completed ICF strengths and needs assessments for each young person. They then met to develop a personalised school support plan informed by the ICF profile. Our partners at West Sussex County Council Autism in Schools Project Team facilitated this planning process.

How we measured early outcomes

Families and education staff completed surveys and standardised questionnaires on young people's participation, wellbeing and school attendance at three points: before the ICF assessment, immediately afterwards, and one to three months after support planning was completed.

What we found

Our early findings indicate that tailored, timely support for autistic and ADHD children may help to improve their wellbeing and quality of life waiting for formal diagnostic assessment.

Education professionals and families highly valued the ICF profiles to build a shared understanding of the young person's needs. Both groups described positive experiences of completing the assessment, describing it as useful, convenient, accessible, relevant and worthwhile.

Families reported that profiles:

- Helped them understand their young person's needs
- Gave them clearer language to use with schools
- Improved their knowledge and confidence to advocate for their young person's needs

Educators at schools and nurseries reflected that the ICF profiles gave them a better understanding of the young person's needs and how to support them in school. They valued the structure and shared language the ICF assessment provided.

After collaboratively developing support plans, parents and teachers reported greater confidence in identifying, communicating and advocating for the support needs of autistic and ADHD children and young people. They also felt better equipped to help young people participate in activities that were important to them and to provide support in areas they found challenging. Parents reported greater confidence that their child was receiving appropriate support within school or nursery.

Within one to three months of tailored support planning, parents and teachers reported improvements in several aspects of young people's wellbeing and everyday functioning, including emotional wellbeing, social functioning, and the ability to tolerate and adapt to change. Many also observed improvements in classroom engagement and behaviour. Although changes in longer-term school-related outcomes, such as attendance, were more variable, parents and teachers consistently described meaningful benefits from earlier, needs-led support.

While these findings are preliminary and require further evaluation at scale, they suggest that strengths and needs profiling may help translate understanding into practical support and improved outcomes.

> **Some days [my child] comes out of school calmer than [they] did before. Having time with the learning mentor has made a difference. Verbal feedback from some of the staff of when they have helped [them] talk through various situations has made a huge difference, [they] no longer come[s] home from school still feeling very angry about things that happened during the day.**
>
> - Annonymous parent/caregiver shortly after the strengths-and-needs assessment

From research insights to implementation recommendations

Educators valued the practical guidance and stewarding from local authority SEND and autism specialists, which helped to translate the ICF profiles into practical day-to-day supports for young people. They described how they were able to transfer this knowledge to support other young people, becoming more confident after learning and doing it once in partnership with the local authority specialists and then being able to put that knowledge into practice.

This collaborative approach shows how knowledge sharing can:

- Build capacity in education settings
- Increase staff knowledge and confidence
- Consistently support more young people

Our recommendations are informed by the research insights to guide needs-led support planning for autistic and ADHD young people. These insights further inform the case for large scale testing and evaluation of the ICF Toolkit™ across education and clinical pathways, to meet support needs early.

For autistic and ADHD young people to experience the most benefit from strengths and needs assessments, it is essential to:

- Make it easy to act on the profile. For example, by providing template support plans and a directory of support resources that map onto the ICF profile structure.
- Build knowledge and confidence among the education workforce. Providing short, practical training for teachers, SENCOs, early years practitioners, and teaching assistants to identify needs early and provide tailored needs-led support informed by high quality evidence.
- Protect capacity in schools and nurseries. In our trial three to four hours of staff time per young person was adequate to complete strengths and needs assessments, support family involvement, and carry out collaborative support planning.

Turning opportunity into action: priorities for policymakers

There are currently three core policy initiatives as timely and practical opportunities to embed needs-led support within system design:

- The Independent Prevalence Review[7]
- Special Educational Needs and Disabilities (SEND) Reform[14]
- The Autism Strategy[15,16]

Our recommendations support the core aims of these policy initiatives.

Strengths and needs assessments are not a substitute for an autism or ADHD diagnosis. Instead, they should be used as soon as a young person's support needs emerge, so help can begin earlier rather than after years of waiting for a formal assessment.

Importantly, the ICF is one of the few internationally established frameworks specifically designed to provide a common language across healthcare, education, social care and policy systems, making it particularly relevant to current SEND reform and efforts to improve cross-sector coordination.

Below, we set out five practical recommendations for policymakers, organised across three phases to support evaluation, build capacity, and enable implementation at scale.

Immediately (0-6 months)

1. **The Department of Health and Social Care and the Department for Education should endorse and embed the use of ICF-informed strengths and needs profiling approaches**

   Why now: Public endorsement of the ICF as a shared framework for understanding strengths and support needs would help services move towards earlier, needs-led support. It would also remove schools and services' perceptions of needing permission to act or wait for a diagnosis. The ICF Toolkit™ provides one example of how this framework can be operationalised for autistic and ADHD children and young people. Understanding how it can work in practice would avoid creating a parallel agenda and unlock local action straight away. SEND Reform and the Interim Prevalence Review are the natural mechanisms to achieve this.

2. **The Department of Health and Social Care and the Department for Education should convene an early adopter cohort**

   Why now: Our feasibility study shows that strengths and needs assessments are valuable in identifying and informing needs-led support. Next, we need to understand whether the approach scales. Convening a group of experts as early adopters, that includes professionals, autistic and ADHD young people, and families, will help evaluate the impact of this approach in everyday settings. This knowledge will inform practical evidence with local examples in nurseries, schools, and NHS services that can guide further research.

Within 6-18 months

3. **The Department of Health and Social Care and the Department for Education should commission a funded multi-site independent evaluation**

   Why now: A larger regional evaluation of the ICF Toolkit™ in NHS trusts and mainstream and specialist schools, for young people across developmental stages is the essential next step. A scaled trial will test how the ICF can be applied in practice, for joined-up working between families and education, health and care services. Testing this approach early can inform a national framework for its use across the UK, to support the needs and outcomes of autistic and ADHD young people earlier in school settings, and to provide interim support and signposting while waiting for diagnostic assessment on NHS waiting lists. The scalable trial will also surface lessons for national implementation across diverse local contexts.

4. **The Department of Health and Social Care and the Department for Education should build workforce capacity across health and education**

   Why now: Developing the workforce capacity building alongside the pilot readies the education system to act on findings quickly. This must include recruitment and retention of SENCOs, early years SEND leads, teachers, teaching assistants, external staff who may support SEND reform as part of the Experts at Hand offer. Similarly in health policy, training for CAMHS triage staff would help signposting to strengths and needs assessments, and increasing autism and ADHD assessment capacity will reduce waiting lists and the negative impacts which long waits for diagnosis bring.

Within 2-3 years

5. **The Department for Education should ensure that Individual Support Plan (ISP) assessments are designed and adopted based on strengths and needs assessments as standard**

   Why now: If the larger evaluation confirms the promise of ICF strengths and needs assessments, young people should not have to face another generation of waiting. We hope the Department and the expert panel developing National Inclusion Standards sees the benefit of the established and tested ICF framework in informing standardised yet highly flexible and personalised ISPs.

   Aligning strengths and needs assessments with ISPs would also have the benefit of statutory guidance and statutory inspection of assessments through Ofsted.

   By 2028, national adoption of ICF-informed strengths and needs profiling could help ensure that every young person with additional developmental needs is appropriately supported from the moment their needs arise.

Our research team, advisors and partners

The research in this report was conducted by Autistica team of scientific and lived experience experts in collaboration with our academic and community partners.

Our team and partners:

Autistica: Dr Amanda Roestorf (Principal Investigator), Dr Michelle Newman (co-investigator), Adam Jones (research associate) and Paul Callaghan (policy lead).

West Sussex County Council Autism in Schools Project Team: Jane Crawford, Jessica Bubb, Sasha Slade and Nicole Williams.

Karolinska Institute, Sweden: Professor Sven Bölte (Professor of Child & Adolescent Psychiatric Science; our ICF clinical lead and advisor).

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About Autistica

Autistica is the UK's leading autism research and campaigning charity. Our Mission is to create breakthroughs that enable all autistic people to live happier, healthier, longer lives. We do this through research, shaping policy and working with autistic people.

We know that every autistic person is different. And we know that being autistic comes with both strengths and challenges. But there's lots we don't know.

Research is the best way to improve understanding, find new ways to support people, and change lives for the better.

We are making more of a difference by:

- Delivering and partnering on research across the UK
- Developing new therapies
- Campaigning for better services and shaping national policy
- Sharing evidence-based tools, resources and information

Our 2030 Goals

We have six visionary and ambitious 2030 Goals, which are based on priorities set by the autistic community.

References

1 World Health Organization (2001). *International classification of functioning, disability and health: ICF*. World Health Organization, Geneva https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

2 Bölte, S., Lawson, W. B., Marschik, P. B., & Girdler, S. (2021). Reconciling the seemingly irreconcilable: The WHO's ICF system integrates biological and psychosocial environmental determinants of autism and ADHD. BioEssays, 43(9), 2000254. https://doi.org/10.1002/bies.202000254

3 Bölte et al. (2014). Development of ICF core sets to standardize assessment of functioning and impairment in ADHD: the path ahead. *European Child & Adolescent Psychiatry, 12*,1139–1148

4 Mahdi et al. (2018). An international clinical study of ability and disability in Autism Spectrum Disorder using the WHO-ICF Framework. *Journal of Autism and Developmental Disorders, 48*(6), 2148–2163. https://doi.org/10.1007/s10803-018-3482-4

5 Hasslinger, J., Alehagen, L., Bilir, K., & Bölte, S. (2024). Autism and ADHD Strengths and Needs in a Nutshell – ParentalEvaluation of a Digital ICF-Based Assessment Summary Report. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-026-07376-3

6 NHS England (2026). *Autism Waiting Time Statistics, April 20-25 to March 2026*. NHS England Digital. Retrieved on 31 March 2026 from https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics

7 UK Government (2026). *Independent review into mental health conditions, ADHD and autism: interim report*. GOV.UK. Retrieved 31 March 2026 from Independent review into mental health conditions, ADHD and autism: interim report - GOV.UK

8 Knapp et al. (2024). The Economic Case for Prioritising Autism in Policy and Reform. Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science (LSE). https://www.lse.ac.uk/cpec/assets/documents/Autismeconomics.pdf

9 O'Nions et al. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health–Europe, 29*.

10 Bölte, S., Alehagen, L., Black, M. H., Hasslinger, J., Wessman, E., Lundin Remnélius, K., Marschik, P. B., D'Arcy, E., Crowson, S., Freeth, M., Seidel, A., Girdler, S., & Zander, E. (2024). The Gestalt of functioning in autism revisited: First revision of the International Classification of Functioning, Disability and Health Core Sets. Autism, 28(9), 2394–2411. https://doi.org/10.1177/13623613241228896

11 Alehagen, L., Hasslinger, J., Wessman, E., Black, M., Lundin Remnélius, K., Helander, J., Zander, E., & Bölte, S. (2025). Operationalizing the ICF Core Sets for Autism and ADHD: A Multiple-Methods Feasibility Study. Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s10803-024-06717-4

12 Hayden-Evans et al. (2025). Validating the International Classification of Functioning, Disability and Health Core Sets for Autism in a Sample of Australian School-Aged Children on the Spectrum. *Journal of Autism and Developmental Disorders, 55*, 1424–437. https://doi.org/10.1007/s10803-024-06295-5

13 Autistica (2026). *Earlier support and earlier outcomes. The case for strengths and needs-based support, before or without an autism or ADHD diagnosis*. www.autistica.org.uk

14 Department for Education. (2026). SEND reform: Putting children and young people first [Government consultation]. GOV.UK. https://www.gov.uk/government/consultations/send-reform-putting-children-and-young-people-first

15 Department of Health and Social Care & Department for Education. (2021). National strategy for autistic children, young people and adults: 2021 to 2026. UK Government. https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

16 Select Committee on the Autism Act 2009 (2025). *Time to deliver: The Autism Act 2009 and the new autism strategy*. HL Paper 205. London: Authority of the House of Lords. Retrieved on 23 November 2025 from https://publications.parliament.uk/pa/ld5901/ldselect/ldautismact/205/205.pdf