



## **Understanding the rise in diagnosis of ASD in children and young people**

### ***Commentary from the SEN Policy Research Forum Lead Group***

1. Recent research by Ginny Russell and colleagues, published in the Journal of Child Psychology and Psychiatry, shows an exponential rise in the number of people (of all ages) diagnosed with autism (787% increase between 1998 and 2018). The research suggests increases could be due to increased reporting and application of diagnosis rather than an increase in levels of need.
2. The DFE's statistical release on incidence of different types of special educational needs and disabilities in schools also shows a significant rise in numbers of pupils with ASD as their primary need, from just over 50,000 in 2009 to around 163,000 in 2020/21 (226% increase over a shorter time period).
3. Interestingly, for both years, the majority of these pupils had statements/EHCPs, with fewer identified by schools as on school action/SEN support. Over 30% of pupils with EHCPs in 2020/21 had ASD recorded as their primary need, compared with only 7% of the total number of pupils on SEN Support.
4. What is the reality behind these trends? Is it just that there is 'more of it about' and 'needs are getting more complex'? Or are there other factors at play?
5. As with the rise in medical diagnoses, there is some evidence that growth in numbers in schools is partly related to increased levels of identification, both in mainstream and in special schools. Social and behaviour issues and language and communication difficulties are being viewed in other ways.
6. However, there is also evidence that ASD diagnosis can be seen as providing positive benefits in terms of access to resources and special consideration, in a world of increasing consumer power. The current statutory assessment system for SEND in this country is particularly susceptible to this. Appeals registered with the SEN &

Disability Tribunal relating to ASD have risen from just over 300 in 1998/9 to over 3,700 in 2019/20 (from 13% of total number to 47% over the last 20 years), with overall registrations reaching nearly 8000 in 2019/20, from just over 2400 in 1998/9.

7. One reason for these appeals is to contest Local Authorities' refusal to carry out a statutory assessment, but another significant reason relates to parents/carers' increasing desire for more specialist solutions, against the more historic trend for people with disabilities to push for mainstream inclusion.
8. There is also some evidence that parents/carers are more likely to pursue ASD diagnosis (and/or an EHCP) when they consider their children's needs are not being met. There are signs that mainstream school expectations have become increasingly convergent as accountabilities are narrowed, with less flexibility to make adjustments for individual needs or to take account of different learning styles. In some schools, there can also be a lack of confidence and ability to demonstrate the necessary skills and knowledge for meeting ASD needs, even though a significant amount of this overlaps with good teaching and pastoral care.
9. There is evidence of increasing incidence for some pupils of 'emotionally-based school refusal' and applications for home-based education, as a means of avoiding the social and work demands of the current mainstream school environment. For some pupils, lockdown during the recent pandemic has been a positive experience, with less pressure to conform to current expectations.
10. In deciding how we respond to these issues, it is important to strengthen confidence and capacity in *all* schools. Approaches such as those produced by the Autism Education Trust (AET) help provide a structure for this. But it also requires a commitment from all teachers and schools to support and prioritise this development. There is an interesting parallel here with provision for pupils with specific learning difficulties (SpLD). In 1998/9, they accounted for the highest proportion of appeal registrations (around a third). Numbers have significantly reduced. SpLD is no longer seen as a rare condition requiring highly specialist approaches, but part of the 'business' of all teachers. The growing incidence of ASD in our education system (whatever its origins) suggests we need something similar.
11. A further key consideration is the need to recognise differences as well as commonalities between pupils identified as ASD. They are not all the same and do not all have the same level of difficulties or special educational needs. The high percentage of ASD pupils with EHCPs (compared to those on SEN support) suggests a system in which 'ASD' is not sufficiently differentiated, where it is 'all or nothing'. We also need to develop 'ordinary available provision' so that this can meet the needs of

more pupils with ASD without resort to statutory assessment, with additional resources and specialist provision being focused more consistently on those whose needs cannot be met from that provision.

**Useful references:**

Acklaw J. & Gupta, Y. (1991) Talking with parents of 'dyslexic' children: the value of skilled discussion methods. *Support for Learning* 6,1,37-39

Davidovitch, M., Shmueli, D., Rotem, R.S. et al. Diagnosis despite clinical ambiguity: physicians' perspectives on the rise in Autism Spectrum disorder incidence. *BMC Psychiatry* 21, 150 (2021). <https://doi.org/10.1186/s12888-021-03151-z>

Dockrell JE, Ricketts J, Palikara O, Charman T and Lindsay GA (2019) What Drives Educational Support for Children With Developmental Language Disorder or Autism Spectrum Disorder: Needs, or Diagnostic Category? *Front. Educ.* 4:29. doi: 10.3389/feduc.2019.00029

Uta Frith response: [https://www.ucl.ac.uk/news/headlines/2021/sep/rise-autism-makes-diagnosis-meaningless#:~:text=Professor%20Uta%20Frith%20\(UCL%20Psychology,and%20has%20outgrown%20its%20purpose.%E2%80%9D](https://www.ucl.ac.uk/news/headlines/2021/sep/rise-autism-makes-diagnosis-meaningless#:~:text=Professor%20Uta%20Frith%20(UCL%20Psychology,and%20has%20outgrown%20its%20purpose.%E2%80%9D)

Gross, J. (1996) The weight of evidence: Parent advocacy and resource allocation to children with Statements of SEN. *Support for Learning* 11,1,3-9

National Autistic Society: School report 2021: <https://www.autism.org.uk/what-we-do/news/school-report-2021>

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A. and Ford, T. (2021), Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *J Child Psychol Psychiatr.* <https://doi.org/10.1111/jcpp.13505>

**Note:** SENDIS Tribunal data: appeals registered

1998/99 = 2412 (313 ASD; highest = 818 SpLD) =13%

2012/13 = 3602 (1231 ASD; SpLD = 421) = 34%

2019/20 = 7917 (3729 ASD) = 47%

<https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-july-to-september-2020/tribunal-statistics-quarterly-july-to-september-2020#special-educational-needs-and-disability-send>

A copy of this commentary is also on the SENPRF website at:

<https://senpolicyresearchforum.co.uk>