

Meeting the needs of autistic children in and out of school

Tim Nicholls, Policy Manager



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What we will cover

- Making sure doctors and nurses understand autism
- Getting an autism diagnosis
- Getting to see CAMHS
- What impact is the Children and Families Act having?



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Understanding autism

- Autism Act: all health and care professionals to have appropriate training. (This is only for adults, but many professionals will work with both adults and children.)
- Autistic children tell us it's the most important thing for them.
- It's not just professionals but the public too – *Too Much Information*

What's the impact of poor understanding?

- 87% of families say people stare at their autistic child's behaviour
- 28% of autistic people have been asked to leave a public space
- 79% of autistic people and 70% families feel isolated.



www.autism.org.uk/tmi

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Can you make it to the end?



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Hot off the press! – GP records

- GPs and nurses are the frontline of healthcare.
- Autistic people face an unacceptable health inequality. There is some evidence (from Sweden) of premature mortality.
- Accessing primary care is vital to helping tackle this.
- NICE recommended a GP register:
 - Reasonable adjustments
 - National data to build an anonymous picture of autistic people's health needs.
- What next?
 - The NHS needs to adopt it.
 - QOF? Watch this space...



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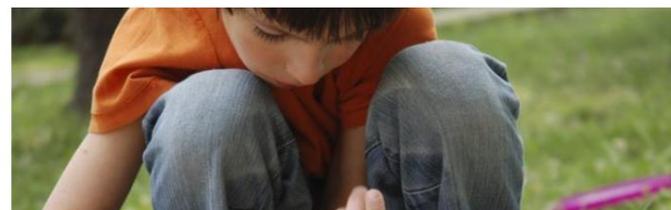
Autism diagnosis crisis

Children in the UK wait on average 3.6 years after seeking help to getting an autism diagnosis. (Goldsmith's University)

- Each area arranges its diagnosis services differently, but issues revolve around:
 - **Capacity.** Having the staff.
 - **Resources.** Having the money.
- We have seen examples of diagnosis pathways being restricted (LD or MH only).



The screenshot shows the BBC News website interface. At the top, there is a navigation bar with the BBC logo, a 'Sign in' button, and a menu with categories: News, Sport, Weather, iPlayer, TV, and Radio. Below this is a red banner with the word 'NEWS' in white. Underneath the banner is a secondary navigation bar with links for Home, UK, World, Business, Politics, Tech, Science, Health, Education, and Entertainment. The 'Health' link is highlighted. Below the navigation is the article title 'Autism diagnoses 'could be reduced under NHS plan'' in bold black text. The author is listed as 'By Jane Dreaper, Health correspondent, BBC News'. The date is '27 May 2017' and the category is 'Health'. There are social media sharing icons for Facebook, Twitter, Messenger, Email, and a general 'Share' button.



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Autism diagnosis crisis (cont.)

The impact

- Diagnosis is a crucial milestone. It helps unlock vital support.
- Without that support, children struggle to get the help they need to reach their potential.
- This can impact the whole family.

What can be done?

- Measure diagnosis waiting times across England.
- Include in NHS assurance frameworks.
- Help commissioners design services and dedicate the resources needed.



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Mental health – *You need to know*

Autism isn't a mental health condition, but...

71% of autistic children develop mental health problems during their childhood. One in 10 children in CAMHS is on the autism spectrum. (Siminoff)

- NICE Guidelines
- *You need to know* charter
- CQC CAMHS Review
- *The Five Year Forward View on Mental Health* and its autism pathway (2018 and beyond)



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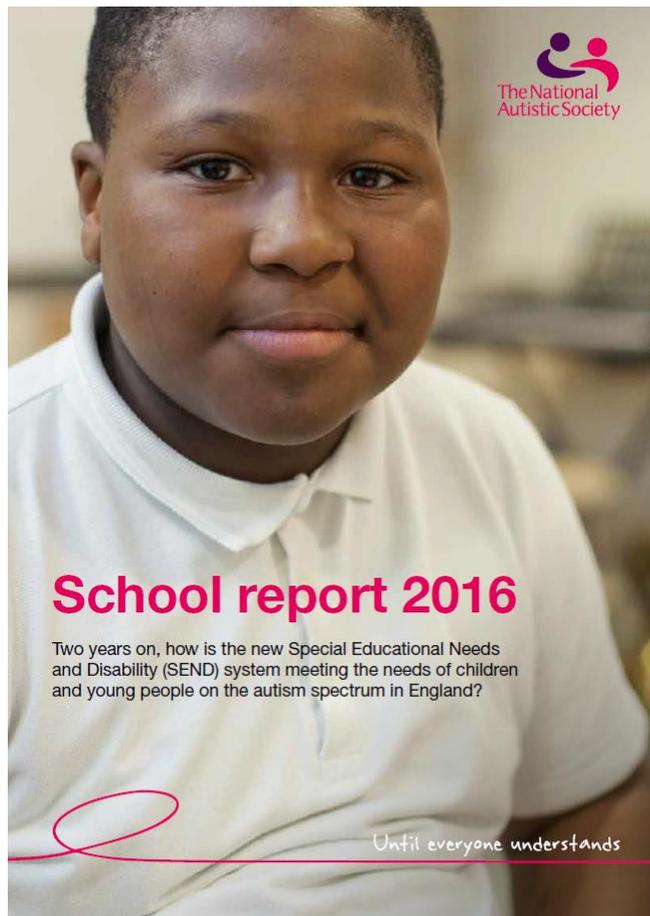
Children & Families Act 2014: a new system to support children with SEND



- The intention of the new system:
 - Simpler to navigate
 - Gives families a greater say
 - Puts support in place early in a child's life and continues supporting them into adulthood (0-25)
 - Encourages services to work together towards agreed outcomes (BUT duties remain on education & SEND Tribunal can only rule on education elements of the new Education, Health and Care (EHC) plans)
- The process of transferring children from statements to EHC plans is due to be completed by April 2018
- 'Local Offer' in every local authority area, providing accessible, up-to-date information about all the education, health and care services for children with SEND in the area and how these services can be accessed

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School Report 2016



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Parents perceive their experience as a battle

Parents reported that:

- They are still waiting too long and fighting too hard to get the help their child needs
- They are unable to access the range of non-educational support their child needs to help them achieve their potential
- The right 'mix' of support isn't available locally
- Education staff need more understanding of autism to better support their child in the classroom



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Accessing the right support at the right time

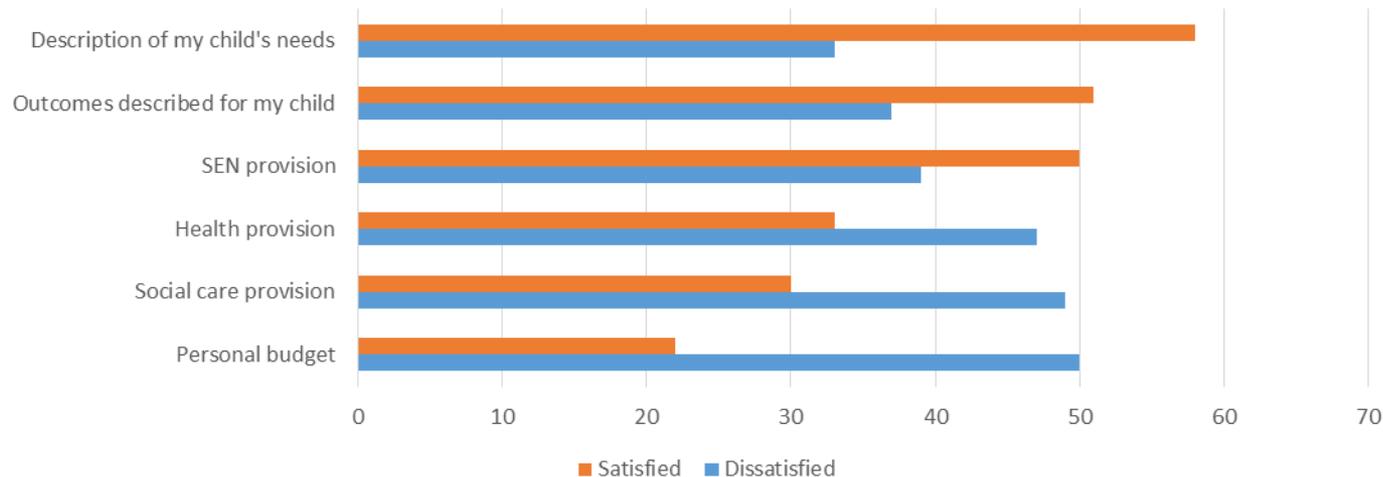
- 74% of parents say it has not been easy to get the educational support their child needs
- The time taken between parents raising concerns and their child receiving support varies greatly – 69% of parents say they waited more than a year, and 15% report waiting more than three years
- 39% of children are not in their parents' preferred type of school
 - Of these, 42% would prefer their child to attend an autism-specific special school
 - 24% would prefer their child to be educated in an autism-specific unit attached to a mainstream
- Parents who are dissatisfied with their child's current school place express a wish for their child to be educated in a place where autism is a specialism and is well understood



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Satisfaction with Education, Health & Care (EHC) plans

Many parents report that after having to fight for an EHC plan, they are relatively satisfied with the final plan. But there are significant challenges with getting the right help outside education.



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Comments from parents

On waiting:

“Children shouldn’t have to wait months or longer to have the necessary support in place to assist with learning. Autistic children often fall behind educationally while this long process takes place.”

On EHC assessment:

“The reports from professionals used for [my child’s] EHC plan were the ones used for the original statement six years ago. Despite requests, I have not been able to have a reassessment.”

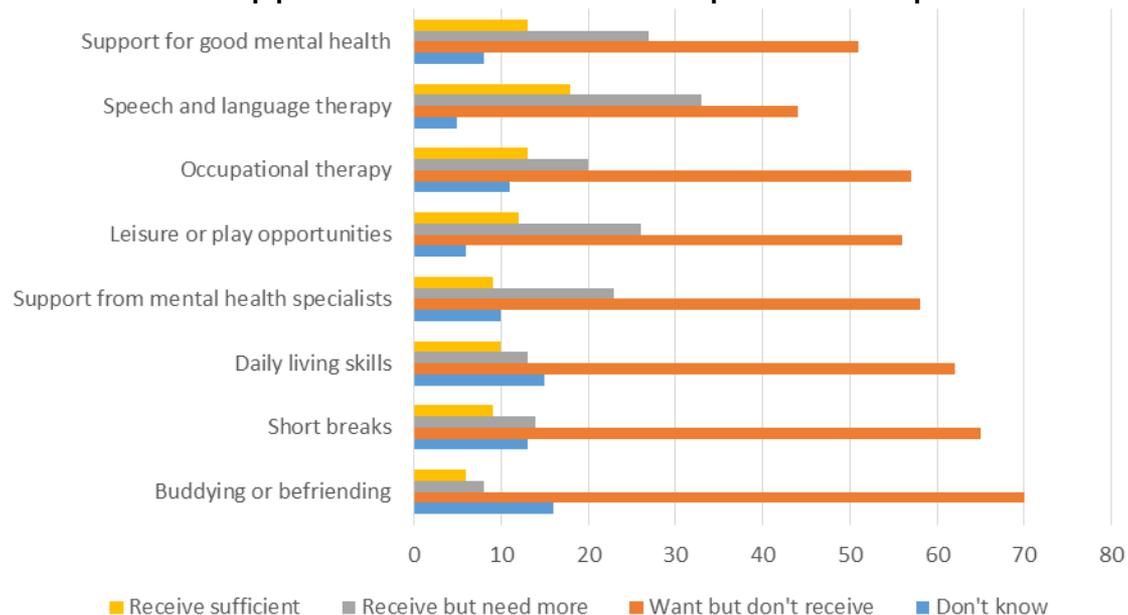
“We got there in the end and are happy with the final EHC plan, but the process was very stressful and deadlines kept changing. We think the County Council couldn’t cope with the workload and their own statutory deadlines.”



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Types of support children need

The range of support children on the autism spectrum need is often not purely educational. The need for support services far outstrips current provision.



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The Local Offer

Parent: *“It’s just a list of random things that may or may not actually be happening and may or may not be available to your actual child.”*

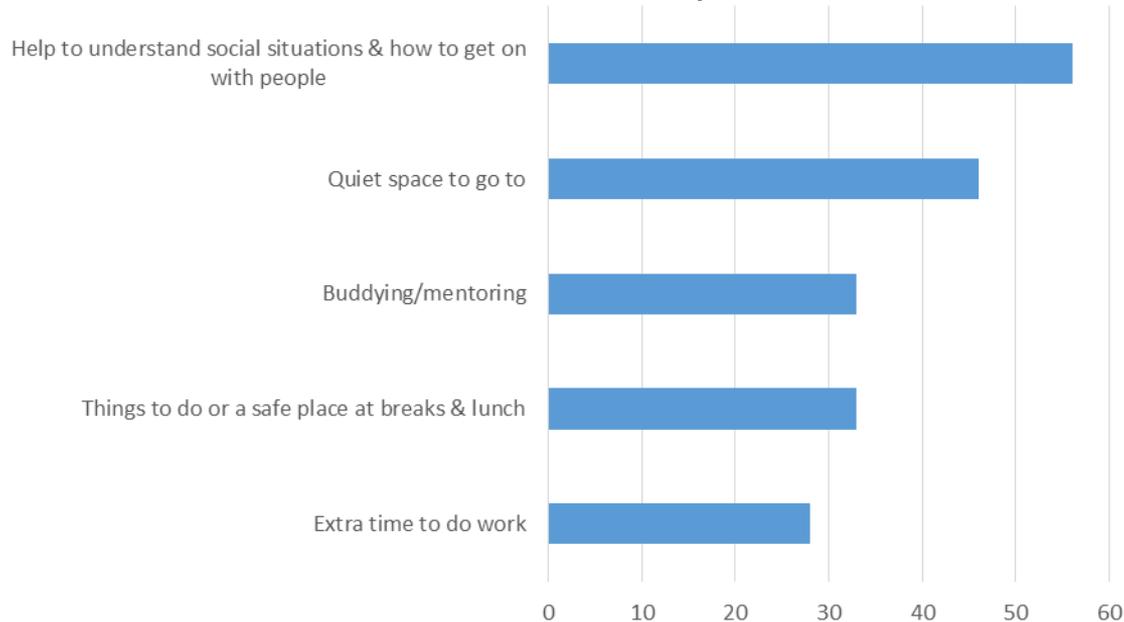
- SEND Code of Practice is clear that the Local Offer has two purposes:
 - Provide clear, comprehensive, up-to-date information for parents
 - Make local service provision more responsive to local needs and aspirations – and identify where the gaps are
- 52% of parents had looked at the Local Offer in their area, 42% had not
- 44% of parents who had looked at the Local Offer said it was ‘quite’ or ‘very’ easy to find information about services for autistic children, 55% said it was ‘quite’ or ‘very’ difficult
- 28% of parents who had looked at the Local Offer said they had been able to access services for their child as a result, 72% had not



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What help children and young people would like that they do not get

Schools and colleges are required by the Equality Act 2010 to make reasonable adjustments for individual disabled children. But the picture is variable.



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Next steps

All Party Parliamentary Group on Autism inquiry into how well the SEN system works for children and young people on the autism spectrum

- Surveys of parents/carers and young people: to find out whether the picture has changed over the last year
- Survey of teachers: to find out how much autism training they have received, and how well they perceive the SEN system to be working
- Parliamentary hearings with a range of witnesses: to identify what the specific problems and challenges are, and how these could be resolved
- Report and recommendations to be published in the autumn: to highlight what needs to change, so that children on the autism spectrum get the educational support they need



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Sign up to MyWorld!



<http://www.autism.org.uk/professionals/teachers/myworldhub>

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Any questions?

tim.nicholls@nas.org.uk



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