

School report 2015

A health check on how well the new Special Educational Needs and Disability (SEND) system is meeting the needs of children and young people on the autism spectrum



by The National Autistic Society

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Introduction

The challenges faced by children and young people with autism

There are an estimated 120,000 school-aged children with autism in England, with the vast majority in mainstream schools. Their families want the same things from the education system that other families want. They want a high-quality education that understands their child's strengths and needs, supports their educational progress and their personal and social development, and helps them prepare for adult life.

Our *Great Expectations*¹ report in 2011 revealed significant challenges for families with a child with autism in getting the right school and the right help. Many parents told us they were dissatisfied with their children's educational progress or felt they were in the wrong school. Many children and young people on the spectrum felt unhappy and unsafe at school, and told us their teachers did not understand autism.

Families also told us of the struggle to get the right educational support for their children. The special educational needs and disability (SEND) system was supposed to help them, but was difficult to negotiate. Many told us they only got the right support after several years, including legal challenges against initial refusals to support or even assess their child. The system was letting families down.

The promise of the new system

A new system for children and young people with SEND was introduced by the Children and Families Act in September 2014. The Government has said that the new system will be simpler to navigate and will give families a greater say over the support a child or young person with SEN receives.²

New Education, Health and Care (EHC) Plans are replacing statements and aim to better join up support from different agencies. EHC plans will be for children and young people from 0 to 25, and are intended to focus much more on life outcomes, including employment and independence.

Importantly, for those without a statement or EHC plan, under the new system councils must also publish a 'Local Offer', which gives families clear information on the support available for all children and young people with SEND in the area. Under the new legislation, families and children with SEND should be involved in developing the local offer and this process should inform what provision is actually available locally.

The experiences of young people on the spectrum and their families

One year on from the beginning of the implementation of the new system, we decided to find out about the current experiences of children and young people on the autism spectrum and their families in the education system and how these compared with our research in 2011.

¹ Reid, E. (2011) *Great Expectations*. London: The National Autistic Society

² Department for Education and Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years*. London: Department for Education and Department of Health



We received a range of responses from people who have and have not been through the new system, which together reveal:

- longstanding and continuing challenges for parents in the SEND system, which in some cases have gotten worse over the past few years, before the introduction of the new system; families we spoke to are still reporting having to fight every step of the way to get the help they need
- dissatisfaction with the processes of the SEND system among those who have been through assessment for EHC plans, although those who have a plan are, on the whole, happy with its contents
- ongoing difficulties that are outside the direct remit of the SEN reforms, notably around autism training for school staff and wider awareness in schools.

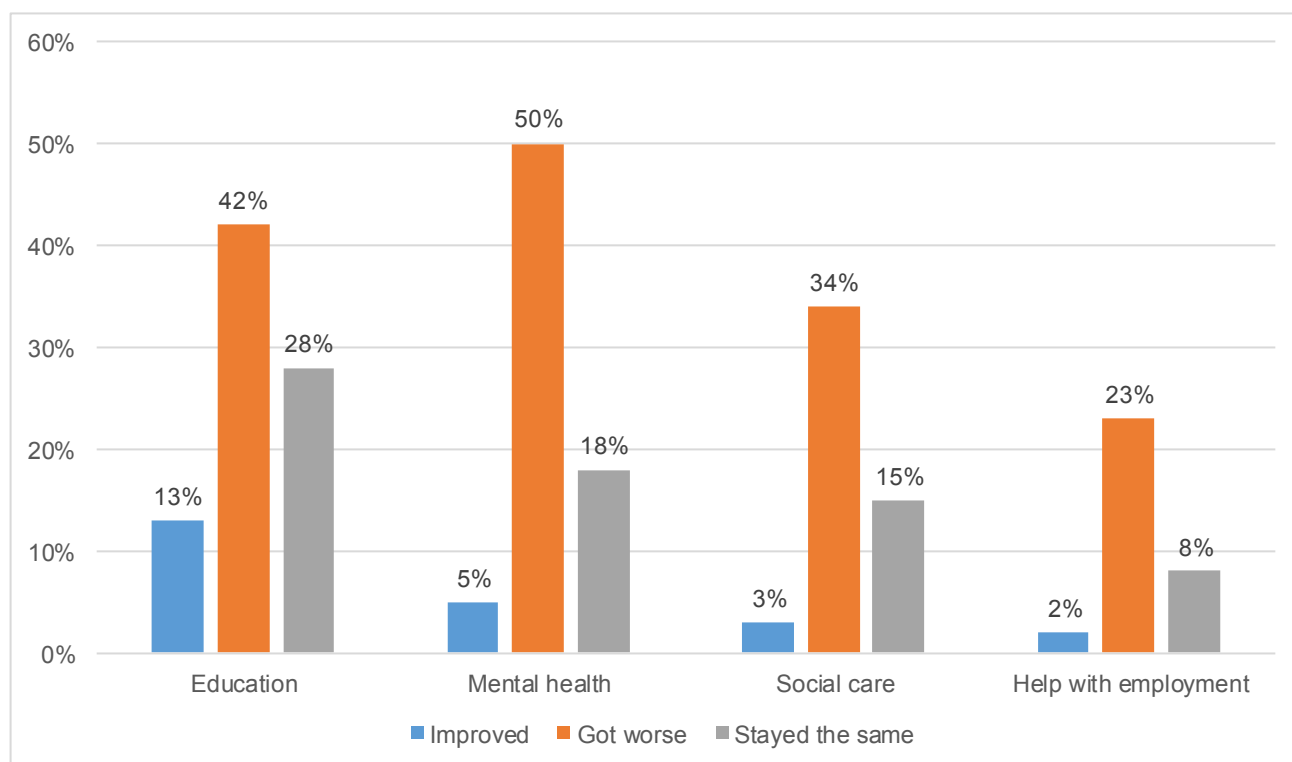
1. The same battles, but harder

Since our 2011 report, families' battles to get the right help for their children appear to have gotten harder.

Parents report that the help their child needs isn't available, that there are lengthy delays in accessing help, that they are not being listened to and that more families than ever before are using stressful legal routes in order to get the right education for their child.

Much of these experiences date from before the new system was introduced.³ Indeed, far more parents told us that support has gotten worse rather than better in the last three years, including in education, mental health, social care and employment support, indicating that the reforms have greater difficulties to overcome than when they were first conceived.

Parent's views on whether provision has got better or worse in last three years:



* Excludes 'Don't know'

Accessing the right support at the right time

Three quarters (75%) of parents who responded to our survey say it has not been easy to get the educational support their child needs, compared with 68% in 2011. The time taken between parents raising concerns and getting support varies greatly. Only 40% received support within a year of concerns being raised about their

³ Around two thirds of respondents had not been through the new process.

child's progress, a slight improvement on 42% in 2011. Fifteen per cent reported waiting for over three years – the same proportion as in 2011.

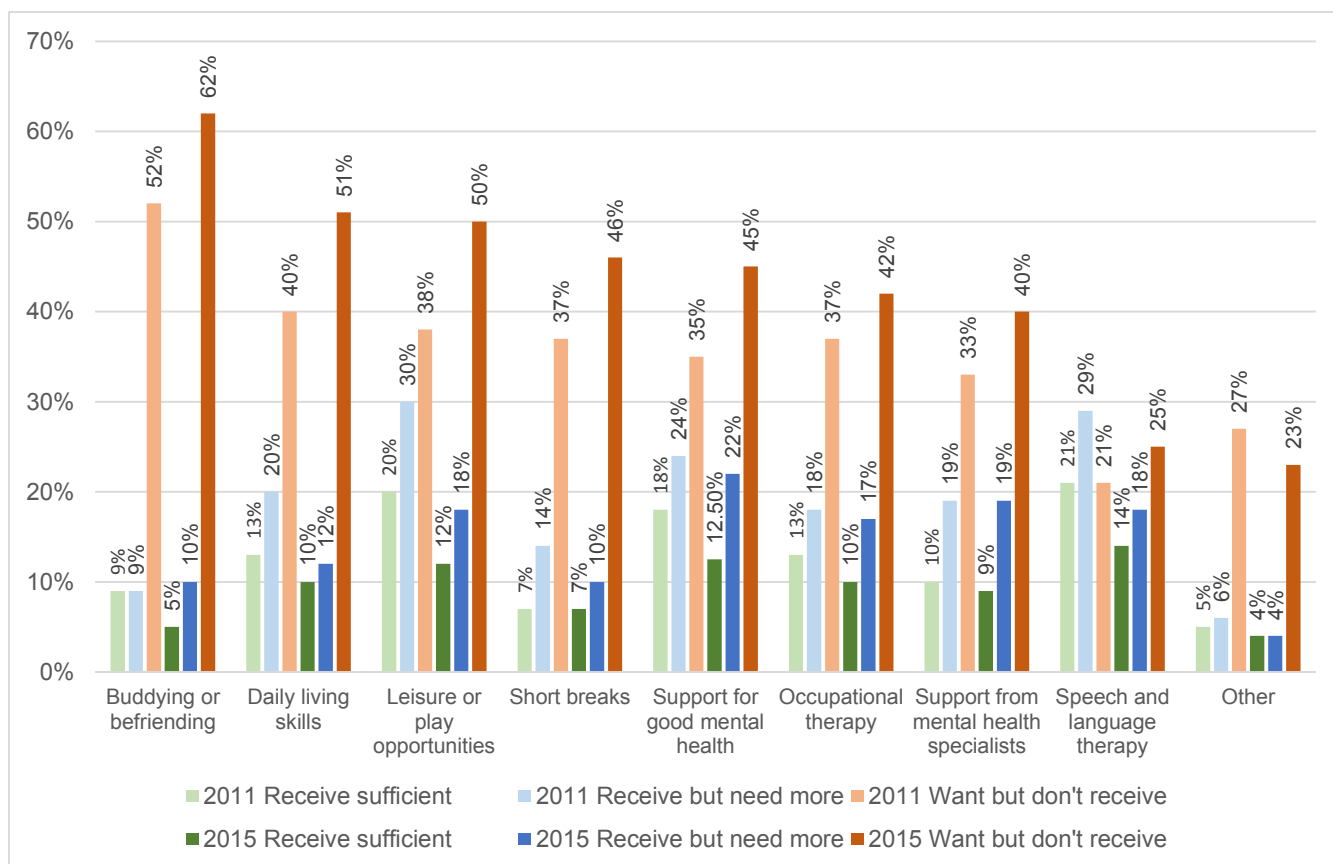
Meanwhile, one in four children are not in their parents' preferred type of school. Of those parents not happy with their child's current type of school, what they want most is more autism specialism, whether that's with in a mainstream or special school. A third of families told us they would prefer an autism-specific unit attached to a mainstream school (32%) and another third said they would prefer their child to be at an autism-specific special school (31%). Satisfaction with provision was highest in parents whose child is at an autism-specific special school.

In our survey, families also told us about the types of support that they felt their child either needed to access more than they do currently, or needed but were not able to access at all. These included services outside of school, such as clubs and NHS services. The gap between children's needs and what is provided appears to have got wider over the last four years.

The type of support most families identified as being what their child needs, but doesn't receive, is buddying or befriending (62%), followed by daily living skills (51%) and leisure or play opportunities (50%). 'Other' unmet support needs which parents identified include sensory integration, safety awareness, developing social skills and studying for exams. A test of the new system will be whether the more joined-up approach of the EHC plan will be able to unlock support across the NHS and social care and whether the local offer will ensure that the help available locally is more responsive to need.



Which types of support does your child have enough of, and which do they need?*



* Excludes 'Don't need this type of support' and 'Don't know'

Consequences of getting it wrong

The vast majority of parents agreed that a lack of timely support has had a negative impact on their child, including their social and communication skills (80%), self-esteem (80%) and educational progress (77%).

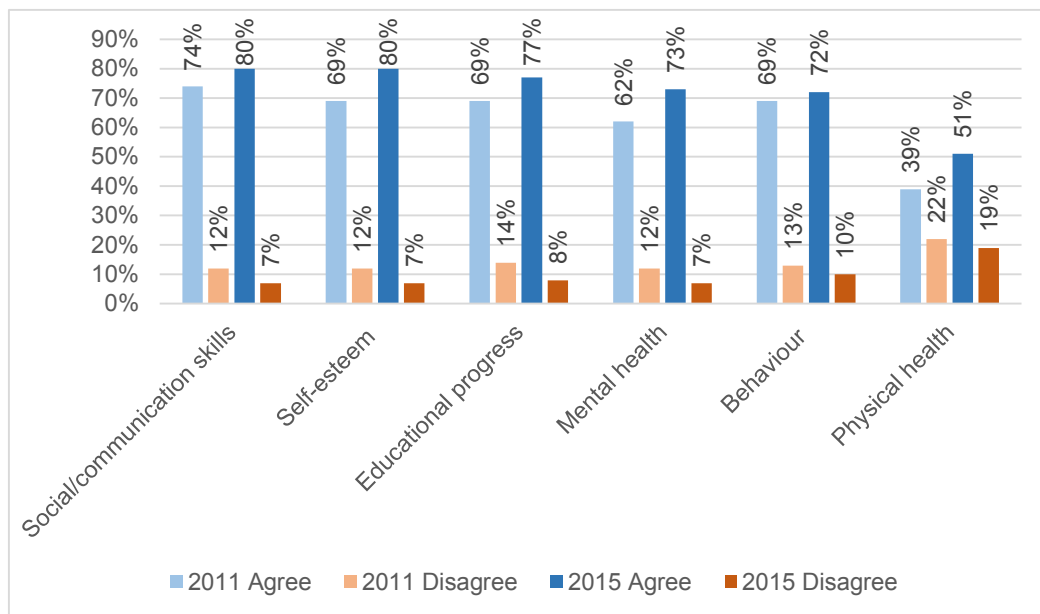
These consequences seem to have become more widespread over the last four years, with the largest deteriorations recorded for physical health and self-esteem. They threaten to reduce the life chances of young people with autism and cause greater health and support needs.

"My child's school took away his one-to-one teaching assistant, who was trained in autism, Makaton and visuals, and placed him with general class TAs...When he was with his previous TA, he loved school and was making good progress. Now he hates school and will self-harm and force himself to be sick upon seeing his uniform each morning." **Parent**

"My son ended up suicidal and on Prozac aged ten, due to lack of understanding, lack of appropriate educational placement and no support. The SEN Tribunal Judge put his

serious mental health difficulties down to his inadequate education and a lack of understanding of his needs, rather than his autism.” Parent

To what extent, if at all, do you agree with the following statements?* ‘A lack of timely support has had a negative impact on my child’s...’:



* Excluding ‘Neither agree nor disagree’ and ‘Don’t know’. Agree= ‘Strongly agree’ or ‘Tend to agree’. Disagree = ‘Strongly disagree’ or ‘Tend to disagree’

Resorting to legal challenges

Families tell us that this dissatisfaction with the support their child is getting and because they feel they aren’t being properly listened to means that getting a statement or EHC plan – a legal document that sets out in detail the support their child will receive – is more important than ever to them to make sure their child gets the help they need. However, increasingly they feel they are having to turn to legal action to secure a statement or plan and to secure the right support within that statement or plan⁴.

“The LA manager knew I was going to win, she said as much, but when she took 'legal advice' they still decided to take me all the way to Tribunal and pitched me against a solicitor advocate. Such a waste of time and money and emotion. It brought my family to its knees. I have two complex children and had to teach myself the law and spend about 100 hours preparing documents etc with no help from anyone. My family fell to

⁴ Parents can challenge local authorities’ decisions not to carry out an assessment, not to create a statement/EHC plan, to provide less support than parents want or to allocate their child to a certain school.

pieces in the meantime. My son wasn't getting the support he needed at school or at home in the end.” **Parent – appealed since September 2014**

There was an alarming 33% increase in families with a children on the autism spectrum appealing to Special Educational Needs and Disability (SEND) Tribunals between 2012-13 and 2013-14⁵. In addition, autism-related appeals made up 40% of all SEND Tribunal cases. Seventy nine per cent of these cases were conceded or withdrawn before going to decision. Of the appeals that proceeded to a decision, 83% of decisions were in favour of the parent. Local authorities are making wrong decisions to limit support for children with autism, which are therefore overturned – but only for those parents who can put up a fight.



⁵ Ministry of Justice (2014). *Tribunals and gender recognition certificate statistics quarterly: July to September 2014*. London: Ministry of Justice

2. The new system

The process for replacing statements with EHC plans began in September 2014 and will continue until 2018. Children who are new to the system are also being assessed for EHC plans rather than statements. Our surveys give an early indication of how parents and young people are finding the process.

Overall satisfaction with EHC assessment and planning process

So far, many parents are feeling let down by the new system. Only 23% of those affected by the new EHC assessment and planning process are satisfied with it.⁶ Nearly half (48%) are dissatisfied. Parents have told us about long waits for assessment and plans, extending beyond statutory time limits and local authority staff who do not understand either the new system or their child. Local authorities are struggling to process reviews of young people on statements (initially those leaving school) and new applications in a timely way, which may continue as statements are reviewed until 2018.

“During the review, myself and the teams around my children were confused about the process. They couldn't answer my questions, and admitted that they didn't understand the new system. I still have no information on the outcome of these reviews. All they say is that the process is held up.” Parent

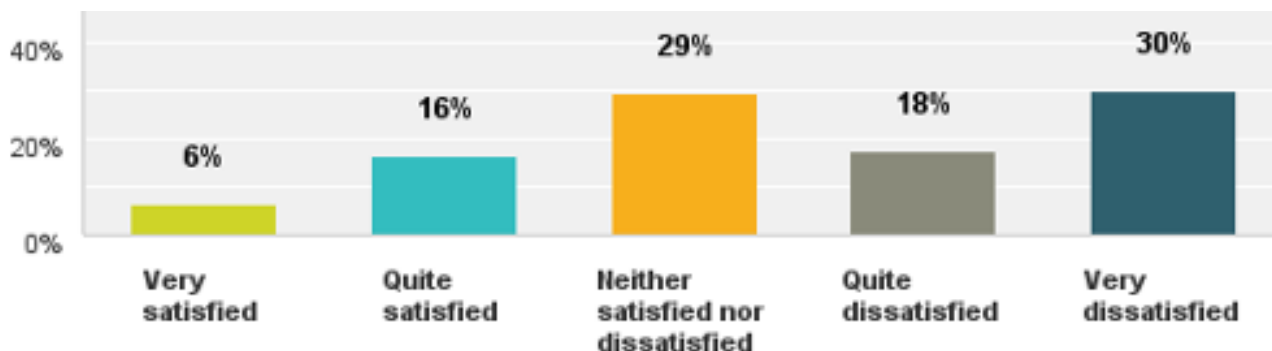
The Government recently extended statutory time limits for transfers from statements to EHC plans to recognise some of the challenges in the system and give greater clarity to parents. While we welcome this change, we also believe that there needs to be an overall review of the timeframes of transferring children and young people from statements to EHC plans to make sure that local authorities have the capacity to do this effectively and ensure that the right support is in place in a timely way.

“My child has a statement and has had a review in order to convert it into an EHC plan. Our LA is very behind – they have told us they will not meet the legal deadline, therefore she will start college in September with no support in place.” Parent

In sum, so far, the new system does not appear to have solved some of the longstanding problems parents face. They continue to report feelings of not being listened to and support being withheld due to local authorities' budgetary constraints.

⁶ A total of 512 parents in our survey have been affected by the new process.

Parent satisfaction with the EHC assessment and planning process:



A reduction in support?

Worryingly, Government figures⁷ also suggest that even though eligibility for EHC plans was intended to be the same as for statements, so far it seems that fewer EHC plans are being issued. Indeed, 15% of children and young people whose statement was reviewed in 2014 as part of the transfer to the new system are not receiving an EHC plan. It should also be noted that in the year leading up to the introduction to the reforms, fewer new statements were issued than in previous years. This may help explain the increase in families going to Tribunal as outlined above.

The Department for Education needs to look seriously at why this is happening and work with local authorities to ensure that children and young people with SEND are not being denied the support they need.

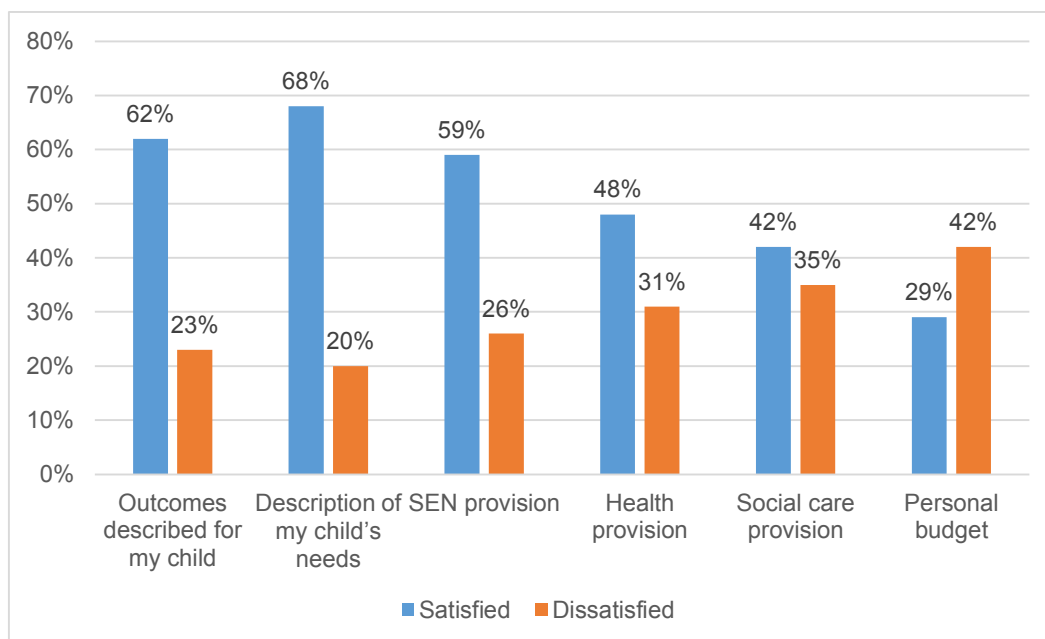
Satisfaction with elements of EHC plans

Promisingly, whilst parents find the application and planning process for EHC plans typically difficult and distressing, those whose child received an EHC plan report significantly higher satisfaction with the contents of their plans.

More parents whose child has a plan are satisfied than dissatisfied with the outcomes described for their child, the description of their needs and the specific provision for SEN, health and social care.

⁷ Department for Education (2015) *Statements of SEN and EHC plans: England 2015*. London: Department for Education

Parent satisfaction with elements of EHC Plans:



* Not including 'Neither satisfied or dissatisfied'

Supporting the aspirations of young people with autism

The extension of support from age 16 to 25 is one of the most promising of the reforms. Post-16 EHC plans should include clear outcomes to prepare young people for adulthood, and support to move into employment, live independently and participate in the community.

The support identified as most needed by young people we surveyed was: help with social skills and confidence (70%), help with facing and planning for adult life (66%) and work placements in settings where people understand autism (60%). Similarly the parents survey⁸ identified the following as important for preparation for adulthood: social skills (92%), further education and training opportunities (91%), support for good mental health (91%), social groups (88%), employment support (88%) and help to live more independently (87%).

It is important that the welcome extension of provision to the post-16 age group is accompanied by the specific services they need.

However, the experiences of those parents we surveyed, whose son or daughter has a final post-16 EHC plan⁹, are mixed. There is reasonable satisfaction with outcomes and post-16 education provision, but higher

⁸ Rated very important or quite important

⁹ 80 in total

numbers of plans are unclear about support to prepare young people with autism for adulthood after education.

Parent satisfaction with Post-16 EHC plans:

	Agree	Disagree
The outcomes and provision in the EHC plan reflected what was important to my child	67%	16%
The post-16 education provision in the EHC plan met my child's needs	48%	20%
My child and I were clear about the support they could receive for preparing for adulthood after education	38%	33%
The final EHC plan was clear what support for preparing for adulthood was provided by whom and how it will be delivered	32%	41%

Whilst these results are based on a small subsample, we remain concerned that post-16 EHC plans do not deliver on the key promise to support young people's transition to adult life. From further discussions with local authorities and parents, there is a sense that the policy on support post-16 is not as clear as it could be, eg how do EHC plans work with apprenticeships? We would welcome a further discussion with the Government on how to make post-16 support work more effectively.

Accessibility of the Local Offer

According to the *Children and Families Act* and the statutory Code of Practice that followed local authorities' new 'Local Offers' must explain what support is available for all children and young people with SEND in their area, how they should be identified and assessed for support, and how parents and young people can challenge their decisions. They should be clear, comprehensive and accessible and set out the support for all children with SEND, regardless of whether they are eligible for an EHC plan. It is also important that they are developed with local people to reflect local need.

However, our survey findings suggest that more work is needed to make sure that the Local Offer delivers. Just over a third (36%) of parents had looked at their local offer. Fewer than four in ten of those found it easy to access information in it about support for children and young people with autism, and roughly half found it difficult.

"I have not been able to locate the local offer anywhere on their website. It mentions it, but when you click on the link it tells us nothing." **Parent**



3. What the reforms don't cover

Some ongoing challenges for children and young people on the spectrum in school are outside the scope of the new reforms. Most notably, understanding of autism among teachers and the wider school environment and culture. In addition, too many children on the autism spectrum are subject to exclusion, although many of these exclusions are under the radar.

Understanding of autism in schools

“He is regularly misunderstood, as he is articulate. Therefore assumptions are made that he can communicate his worries as others can. He is often in trouble for getting things wrong or ‘not listening’ when this is often due to his autism, or overload.” Parent

According to our survey of young people, the thing most identified as something which would make school better is if teachers understood autism (58%). This is followed by people being less noisy or annoying in class (46%), pupils understanding autism (37%) and other school staff understanding autism (33%).

“No one dealing with my child had any training in ASD. He has been excluded twice. TAs and lunchtime staff are the worst. There is a complete lack of understanding or compassion among the support staff. Even teaching staff tell me they are at a loss as to how to help my child. They do not feel they have the skills needed.” Parent

Some teachers are very effective at meeting the needs of children with autism, often thanks to specialist training. Others have minimal knowledge of autism. Parents overwhelmingly rate ‘teachers with good autism knowledge and training’ as the most important factor in getting the right education for their child. They report transformations in their child’s progress and wellbeing, for better and worse, following the introduction of a new teacher with a different level of understanding. ‘Teachers’ understanding of autism’ came top in our poll of young people for the worst thing about school, as well as for the best thing about school, demonstrating what a difference it makes.

Parents are generally more satisfied than dissatisfied with teaching staff, but levels of dissatisfaction are high and appear to be getting worse. 37% are dissatisfied with their primary school teachers, compared to 25% in 2011, 36% with secondary school form teachers, compared to 18% in 2011 and 44% with their secondary school subject teachers, compared to 30% in 2011.

Satisfaction among young people with autism appears to be considerably lower. Most of those we surveyed (61%) thought their teachers did not know enough about autism, compared with 24% who thought they did.

“My school experience was made much easier by having teachers and TAs who understood autism and the difficulties I faced. It meant that I wasn't called on in class, that if I needed to leave the classroom because I was getting stressed then I could, no question asked, that I could have a stress ball with me and that I would be warned of any changes and given alternatives to group work or assignments.” Young person with Asperger syndrome

Following a Government review of initial teacher training (ITT) earlier this year, which recommended a greater emphasis on SEN, the Government is developing a new core framework for ITT. It is vital that these new framework includes competencies in autism. On an ongoing basis schools can access training through the Autism Education Trust (AET). The AET has three levels of training and schools can access the first level for free.¹⁰

Behaviour and exclusions

Government figures shows that pupils with autism are four times more likely to receive a fixed period exclusion as pupils without SEN.¹¹ Exclusions can be a particular problem for children on the spectrum because of the failure of schools to understand and meet the needs of children with autism, including inappropriate responses to behaviour. Twenty two per cent of children with autism in our survey had had a fixed-term exclusion compared with 17% in 2011. Most of these have been had a fixed-term exclusion three or more times. Six per cent have been permanently excluded from at least one school, compared with 4% in 2011.

“My son was in a mainstream school and he received no support for over three years. They sent him home at least three times a week as he was so distressed. I took him out and he attended an ASD unit for less than six weeks. The head told me she felt he wasn't a mainstream child and supported an application for special. He has been there since and has flourished.” **Parent**

Thirty nine per cent of parents have been asked to take their child home early or at lunchtime for a reason other than sickness, compared with 32% in 2011. These ‘informal exclusions’ are illegal. Twenty four per cent reported this happening on four or more occasions. This has an obvious impact on parents, including their ability to work.

“I have been suspended from school three times and when I look back, they were all unjustifiable as shouting at a teacher is something you expect from an autistic child, particularly when a teacher shouts at them in the first place.” **Young person with autism**

The key to tackling exclusions is ensuring that children are properly supported by staff that understand them. Relevant adjustments for pupils with autism should be made within schools, including in their behaviour policies, in line with the *Equality Act 2010*. The National Autistic Society provides tips and resources for teachers on supporting children in school and the types of reasonable adjustments that can be made through its MyWorld campaign.¹²

The Government has commissioned an external expert, Tom Bennett, to develop new training for teachers on behaviour management. This new training needs to look at the underlying causes of behaviour, including whether a pupil has autism, and strategies for how to deal with this behaviour

¹⁰ See: <http://www.autismeducationtrust.org.uk/> for more details

¹¹ Department for Education (2014). *Permanent and fixed-period exclusions in England: 2012 to 2013*: www.gov.uk/government/statistics/permanent-and-fixed-period-exclusions-in-england-2012-to-2013 (Accessed: 10 June 2015); Department for Education (2014). *Children with special educational needs: an analysis – 2014* (SFR31/2014: absence exclusions table: www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2014 (Accessed: 10 June 2015)

¹² Go to <http://www.autism.org.uk/myworld> to sign up

Conclusions

The battle for support appears to be getting harder for parents of children with autism. They believe services are deteriorating and are increasingly locked in lengthy and traumatic legal action to get their children's needs met.

The new SEN system promises to make things better, but one year on, the process itself is taking too long and facing clear challenges in the transition process between the two systems. Promisingly, parents and young people who have received EHC plans are more satisfied, although the number of plans being issued is lower, meaning we could see an even bigger increase in tribunal figures.

Local authorities need to engage with parents and young people throughout the new process. They should be involving parents and young people in the development of their local offers and make sure they are clear and accessible. Post-16 EHC plans, a key part of the reforms, need to meet the needs of this age group by supporting further education, employment and independent living as young people become adults, with clear plans and outcomes. Local authorities have said greater clarity in this area would be helpful.

Teachers and understanding of autism at school are the key to educational progress for children with autism, yet parents and young people feel that more understanding and training is needed. Moreover, schools need to urgently look at their behaviour policies for children on the spectrum.



Recommendations

The Government should:

- conduct and publish the results of a systematic review of local authorities' implementation of the new SEN system and make sure that there is compliance with the time limits on assessment for EHC plans and transfer reviews
- work with local authorities and the wider sector to determine whether the overall timescales for the transition should be re-considered
- work with relevant stakeholders, including the voluntary sector, to develop further guidance on how the system should work in post-16 education and training
- collect good-practice examples of local offers and publish further guidance to local authorities on how to develop a good local offer
- use the review of initial teacher training (ITT) to make sure that SEN, including autism is included in all ITT programmes in the future
- ensure that new training on behaviour management for teachers includes specific elements on looking at the underlining reasons for behaviour issues.

Local authorities should:

- make sure relevant staff understand the implications of the *Children and Families Act* and are complying with the *SEN Code of Practice*
- make sure that they consult with children and young people on the autism spectrum and their families when they are developing their local offer; funded by DfE, the NAS produced the *Local Voices, Local Choices* guide on how to consult with young people with autism in developing a local offer
- use autism-specific data such as the *Pupil Level Census* to inform their planning and ensure that there are a range of appropriate educational options available for the local population of children on the spectrum.

Schools should:

- make use of training offered by the Autism Education Trust (AET) to ensure that their staff are equipped to support children with autism in their class
- make sure that their behaviour policy takes into account the specific needs of children on the spectrum and in line with Department for Education (DfE) guidance acknowledges the school's legal duties under the *Equality Act 2010*, in respect of pupils with special educational needs (SEN).

Teachers should:

- Take full advantage of the free resources and tips that are available around how to better support children on the autism spectrum in their classroom, through signing up to the NAS' MyWorld campaign for example (www.autism.org.uk/myworld).

Methodology

The surveys for this report were carried out online in June and July 2015. The survey of parents and carers of children and young people with autism was completed by 1,431 people. The survey of children and young people with autism was completed by a sample of 231 people with autism under 25 in England.



About The National Autistic Society

We are the leading UK charity for people on the autism spectrum (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people on the autism spectrum.

Around 700,000 people in the UK are on the autism spectrum. Together with their families they make up around 2.8 million people whose lives are touched by autism every single day. From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

The National Autistic Society

393 City Road
London EC1V 1NG

Switchboard: 020 7833 2299

Autism Helpline: 0808 800 4104

Minicom: 0845 070 4003

Email: nas@nas.org.uk

Website: www.autism.org.uk