



# The right start: reforming the system for children with autism

Report on reform of the special educational needs and disabilities system by the All-Party Parliamentary Group on Autism



APPGA  
All Party Parliamentary Group on Autism



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# Executive summary

One in every 100 children has autism.<sup>1</sup> Too many of these children, and their families, are being let down by the special educational needs (SEN) system and are struggling to access the support they need.

The All-Party Parliamentary Group for Autism (APPGA) welcomes the Government's decision to reform the system, through the forthcoming *Children and Families Bill*. The Government must ensure this once-in-a-generation chance for change benefits all children with SEN, including those with autism.

This report is based on a public survey and expert evidence from young people with autism, parents, teachers and other professionals. It offers key recommendations for a new system in which everyone with autism is supported to gain the skills they need to realise their aspirations and live full and independent adult lives.

## Training and best practice

84% of respondents to our survey said teachers were not given enough training to teach and support children with autism effectively. Yet we know that training is essential to understanding this complex disability. The Government should therefore continue to fund the development of successful training programmes. We also believe that where specialist knowledge exists it should be shared: schools should be able to draw easily on expertise from neighbouring schools.

## Specialist support at school

Children with autism can have a range of complex difficulties and often need specialist support in order to thrive at school. Even with training, teachers cannot be experts on everything. A range of professionals may need to support a child with autism. Far too often, parents say this expertise is not available. The Government must ensure that

all children with autism have access to the support they need, including those without a statement or an Education, Health and Care Plan (EHCP). Crucially, every school should have a lead teacher for autism.

## Involvement of parents and young people

In our survey, fewer than half of parents and children with autism (43%) thought they were involved in shaping the support the child receives at school. Autism professionals agreed, as did 30% of teachers. 94% of parents said they should be more involved. The reforms must encourage schools and local authorities to work closely with parents, sharing information and ensuring a consistent approach is taken at school and at home. As the SEN system is extended to 25 years old, young people must also be involved in decisions.

## Transition – extension of the SEN system up to 25

For too many families living with autism, the struggle for services intensifies as young people reach adulthood. It often feels like “falling off a cliff” as statements of SEN come to an end. The Government has rightly decided to extend the system to 25 years old which will particularly benefit those in further education. The Government must also ensure many more young people with autism can access the support and opportunities they need to live independent adult lives and enter apprenticeships and employment, for those who are able.

## Accountability

A vital aspect of the reforms must be greater accountability for parents. Far too many have to fight to access the support their children need. There must be an effective complaints system encompassing all state-funded schools and it must be a priority to ensure that parents have confidence in this system. Clear action plans could make accountability a reality for families of children with autism without statements or EHCPs.

<sup>1</sup>In this report we use the term autism to refer to all conditions on the autism spectrum, including Asperger syndrome

# Foreword

As a parent of a child with autism, I know at first hand the challenges that often face families of children and young people with this lifelong condition. For far too many families, securing the right support at school can be a very difficult task, and for some families it becomes an all-consuming battle. This cannot be right.

I am delighted that the Coalition Government has taken on the challenge of reforming the special educational needs (SEN) system so that more children and young people with conditions such as autism have access to the education they need in order to prepare them for a full and independent life.

As an MP, I know that parents, teachers, teaching assistants and other support staff work tirelessly with children and young people with autism and SEN at home and in the classroom. However, there are too many instances where parents are left feeling that their child's needs are not being met and far too many instances where teachers are left without the necessary specialist training or resources.

Ensuring that children and young people with autism thrive at school is no easy task, but it is one that we must tackle. Only one in four young people with autism accesses any form of education or training after they finish school.<sup>2</sup> Just 15% of adults with autism are in full-time employment<sup>3</sup> and 26% of graduates with autism are unemployed, which is the highest rate among any disability group.<sup>4</sup> A transformation of the SEN system is vital if we are to ensure that people with autism have the same life opportunities as everyone else, namely the ability to contribute to society, to enter the workplace and to realise their aspirations. We cannot afford to shirk the challenge.



**Robert Buckland MP**

<sup>2</sup> Ambitious about Autism, *Finished at school* report: [www.ambitiousaboutautism.org.uk/page/get\\_involved/finished\\_school/index.cfm](http://www.ambitiousaboutautism.org.uk/page/get_involved/finished_school/index.cfm)

<sup>3</sup> Rosenblatt, M. (2008). *I Exist: the message from adults with autism in England*. London: The National Autistic Society

<sup>4</sup> AGCAS Disability Task Group (2010; 2011). *What happens next? A report on the first destinations of 2009/2010 disabled graduates*. Sheffield: AGCAS

# Introduction

## What is autism?

Autism is a serious, lifelong disability that affects the way a person communicates with, and relates to, other people. It is a spectrum disorder which affects each individual in different ways. Some people with autism are able to live independent lives with little support, whilst others need specialist support throughout their lives.

People with autism have difficulties in three areas:

- **social interaction:** recognising and understanding their own and other people's feelings, which can make it hard to form friendships
- **social communication:** understanding verbal and non-verbal language, including gestures, facial expressions and tone of voice
- **social imagination:** ability to imagine situations outside their normal daily routine, plan ahead and cope with change.

People with autism may also have sensory sensitivity, meaning they are over or under sensitive to stimuli such as sound, touch, taste, smell, light or colour. This can make busy, brightly lit or noisy environments including classrooms, playgrounds or workplaces, difficult to cope with.

Around 1 in 100 people has autism – together with their families they make up over two million people across the UK or 3,000 in the average constituency.<sup>5</sup>

There are an estimated 88,000 school-aged children with autism in England, accounting for 1% of the total population. Children with autism account for the largest group with special education needs 'statements' meaning they will be significantly affected by any changes to the SEN system.

The Government's Green Paper *Support and aspiration: a new approach to special educational needs and disability*, published in March 2011 and the forthcoming legislation, as announced in the 2012 Queen's Speech present a unique opportunity to transform the SEN system in England and the educational experience of children with autism in particular.

The All-Party Parliamentary Group for Autism (APPGA) welcomes the Government's ambition for change in this area. The Government's proposals include:

- replacing statements of SEN with Educational Health and Care Plans (EHCPs) for children and young people aged 0-25. This will afford parents the same statutory protections and will be determined through a single multi-agency assessment process
- funding for new scholarships and continuing professional development for teachers and support staff developing skills in supporting children with SEN (some of this is already underway)
- special schools to share their expertise and services to support the education and progress and development of pupils in other schools
- better transition support for children post-16 and opportunities for vocational and work placement.

<sup>5</sup> The Information Centre for Health and Social Care (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 adult psychiatric morbidity survey*. Leeds: The Information Centre for Health and Social Care

This report outlines recommendations in five key areas, which the APPGA believes would significantly improve the educational experiences of children with autism and their families:

- training and best practice
- specialist support at school
- involvement of parents and young people
- transition – extension of the SEN system up to 25
- accountability and transparency.

#### **Methodology: a note on the survey**

This report is based on an inquiry conducted by the APPGA in 2012. This included a public survey, featuring almost 1,000 responses from members of the public across England.<sup>6</sup>

About four out of five respondents were parents, carers or family members of someone with autism<sup>7</sup>, while about one in three (29%) were teachers, local authority staff members or autism professionals. Some respondents were both parents and professionals.

Respondents based their answers on experiences of mainstream primary schools (67%), mainstream secondary schools (30%), generic special schools (25%) and autism-specific special schools (20%). Many had experience of more than one category.

Similarly, respondents had experience of children with a variety of autism diagnoses: autism with a learning disability (16%), Asperger syndrome or high-functioning autism (37%), autism spectrum disorder (30%).

MPs and peers also heard evidence from young people with autism, parents, teachers, academics and other autism professionals during two oral evidence sessions at the House of Commons.<sup>8</sup>

See Annex (page 25) for details.

<sup>6</sup> There were 957 respondents to the survey living in England

<sup>7</sup> In this report where we refer to parents in relation to the survey, we are referring to parents, carers and other family members

<sup>8</sup> See Annex for a full transcript of both sessions and a list of participants



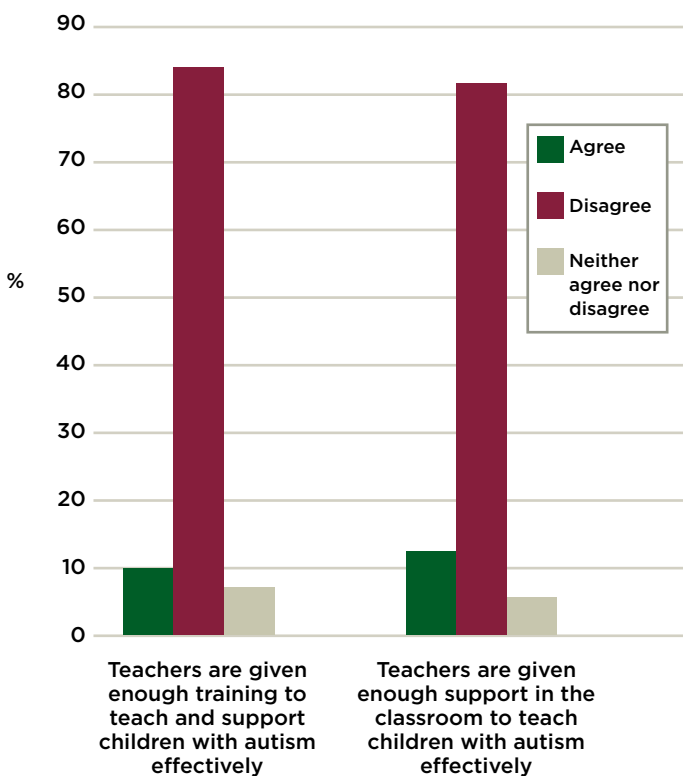
# 1. Training and best practice

## Training

The need for more training for teachers and other staff working with children with autism was a recurring theme in the evidence presented to the Commission.

84% of respondents to our survey said teachers are not given enough training to teach and support children with autism effectively. Concerns about training are particularly high among respondents who were parents or teachers of children with Asperger syndrome or high-functioning autism (89%). There could be a number of reasons for this disparity: notably, we regularly hear from parents that because the needs of children with Asperger syndrome or high-functioning autism are more likely to be “hidden”, and this group is more likely to achieve average or above average academic results, they are less likely to receive the support they need

Figure 1



for their autism-related needs. In addition, they are also more likely to be in mainstream schools. While this in itself should not be a barrier to accessing support from trained staff, knowledge of autism will vary considerably between mainstream schools.

A lack of training can mean that some teachers have limited understanding of autism. Josie Ryan, a young person with autism, told the Commission:

**“Mainstream schooling wasn’t really a good experience for me at all. I really didn’t enjoy it, because the lack of understanding from teachers is quite ridiculous, actually. Most teachers don’t even know it exists. When I was in mainstream schooling, they didn’t have any idea what it was.”**

According to Dr Glenys Jones of the University of Birmingham:

**“School is one of the most challenging places if you’ve got autism in terms of the social demands for communication and standing sensory overload. [Children with autism are] often misunderstood, viewed as over-anxious or difficult by the professionals and not given the support they need, particularly with the able and verbal group.”**

Because of the “hidden” nature of autism, difficulties are not always recognised, correctly identified or understood. Training is therefore vital.



Training must be accompanied by appropriate support in the classroom so that teachers can adapt the principles they have learnt to the needs of the children they work with. According to Professor Neil Humphrey, Professor of Psychology, University of Manchester:

**“People entering the teaching profession need to be better equipped to support children with particular needs, and autism is a perfect case example of that. These children’s needs may be very different and the way that they learn may be very different from the majority of children in a classroom, particularly in a mainstream school.”**

The vast majority of survey respondents felt that there is not enough support for teachers in the classroom to allow them to teach children with autism effectively (figure 1).

It is also vital that training is not just for teachers, but for all staff working with children with autism. It is especially beneficial for teaching assistants working one-to-one with individual students.

According to Kate Fallon, General Secretary of the Association of Educational Psychologists (AEP):

**“We will very often get some of the least qualified members of our workforce being asked to work with some of the most vulnerable and most complex of our children.”**

According to Alice Stow, Leader of the Special Resourced Provision for Pupils with ASD, King’s Oak Primary School:

**“I believe in hands-on practical training and consultancy. Schools could offer that kind of thing – that would be a statutory requirement.”**

Autism-specific training for teachers can have benefits beyond improving expertise in relation to teaching children with this condition. According to Dr Glenys Jones at the University of Birmingham, good teaching practice in relation to autism is founded on many of the “core teaching competencies”. These include a calm, confident manner, use of clear and literal language and allowing sufficient time for children to respond to questions, as well as the ability to adapt to an individual child’s needs.

While these skills are likely to benefit many pupils, they are especially important for those with autism.

Where possible, training and practice should be based on evidence-based research, led by autism professionals, with input from people on the spectrum or their families.<sup>9</sup>

## Developing autism training<sup>10</sup>

The Autism Education Trust was awarded a two-year grant from the Department for Education (DfE) in 2011 to work on developing a three-tier training programme for staff in schools, as well as national autism educational standards. There are seven regional training hubs.<sup>11</sup> As a result, 5,000

<sup>9</sup> One example of such research is a project funded by the Economic and Social Research Council (ESRC) on inclusive education for pupils with autistic spectrum disorders: [http://asdinclusion.info/ASD\\_Inclusion/Welcome.html](http://asdinclusion.info/ASD_Inclusion/Welcome.html)

<sup>10</sup> Further information is available at [www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)

<sup>11</sup> The regional training hubs are The Bridge School in Islington, London, Ambitious about Autism in London, The National Autistic Society in the South East, Leicestershire County Council in the East Midlands, Norsaca and Nottinghamshire County Council in the East Midlands, Birmingham City Council in the West Midlands and Oldham Local Authority in the North West. More information at: <http://www.autismeducationtrust.org.uk/en-gb/resources/research.aspx>

school staff will receive tier 1 training by 2012/13, leading the way in improving autism awareness.<sup>12</sup> People with autism are involved in the development of the training materials and their delivery.

Level 1 training is available free of charge to primary and secondary schools. It delivers basic autism awareness training for teaching and non-teaching staff who need an understanding of autism in their role, such as lunchtime assistants, caretakers, office staff and school governors. Level 2 is for teaching staff working directly and frequently with children with autism, and level 3 is appropriate for staff who require in-depth knowledge of autism or those in a leadership role, such as a special educational needs coordinator (SENCO).

The programme is already reaching a broad range of frontline staff working at and on behalf of schools who have direct contact with young people with autism. For example, in Birmingham, more than 600 taxi drivers and escorts who provide school transport for pupils with autism will receive tier 1 training.

Those working on the project are finding that staff working regularly with children with autism are currently doing so with no relevant training whatsoever. There is therefore evidence of significant unmet need, which this project is seeking to address.

## Recommendations

- The Government should continue funding for the Autism Education Trust (subject to evaluation) to enable it to expand the development of a three-tier training programme beyond March 2013. In particular it should include areas of the country not already covered. These are the South West, East and North East of England as well as Yorkshire and Humberside. It should be extended to provide training to staff in post-school settings, such as further education colleges, in line with plans for a holistic 0-25 SEN system.
- In developing their local offer, local authorities should map local training needs in the main areas of SEN, including autism, and work with schools to ensure those needs are met.
- The Government should ensure initial teacher training providers emphasise the relevance of core teaching competencies (such as effective communication) for teaching children with autism and SEN. Teachers must be equipped to adjust their practice as appropriate to meet the specific needs of these children.

## Sharing knowledge and best practice

We believe that where good practice exists it should be shared. Some specialism is likely to exist in each area of the country – for example in a special school or in an autism unit in a mainstream school. Too often, the opportunity is missed to solve a problem by capitalising on local expertise.

<sup>12</sup> [www.autismeducationtrust.org.uk/resources/research.aspx](http://www.autismeducationtrust.org.uk/resources/research.aspx)

According to Professor Neil Humphrey:

**“One of the key challenges, moving forward, is to find out how we can best disseminate the practice in pockets of excellence, where there are schools who do excellent, really great work to support children and young people where they have low levels of exclusion to children attaining to the best of their ability and find out what’s different about those schools.”**

**“There must be ways of ensuring that expertise is shared at a local level.”**

We welcome the Government’s Teaching Schools initiative, which will give outstanding schools a leading role in the training and professional development of teachers, support staff and headteachers, as well as contributing to the raising of standards through school-to-school support.<sup>13</sup>

There could be a similar model for sharing autism-specific best practice, enabling schools with particular autism expertise to benefit other local schools. This could build on the three-tier autism training initiative undertaken by the AET (see page 9).

## **The NAS Thames Valley Free School: a new educational model**

The National Autistic Society (NAS) has submitted an application to the Department for Education to

set up a special free school for pupils with autism between the ages of 5 and 16.

This small, community-based school would meet the needs of 44 pupils with Asperger syndrome and high-functioning autism who find it difficult to maintain a mainstream placement but for whom a special school (primarily catering for children with learning disabilities) may not be appropriate. The school will also provide enhanced provision for six pupils who have the highest levels of complex needs.

Central to the school’s purpose is that it will work closely with parents, neighbouring special and mainstream schools, further education colleges, local respite provision, other social care providers and local authorities. There will be a strong focus on collaborative working so that non-specialist schools in the region benefit from the school’s specialist expertise.

## **Recommendations**

- **There should be a system for ensuring that all state-funded schools are able to draw on the expert knowledge of autism that exists in other schools within their area.**
- **As part of the local offer, local authorities should identify where specialist autism knowledge is available in schools in their area, and support schools to share this knowledge.**

<sup>13</sup> [www.nationalcollege.org.uk/index/professional-development/teachingschools.htm](http://www.nationalcollege.org.uk/index/professional-development/teachingschools.htm)

## Exclusions

**“My son is very articulate and very bright, but he’s autistic. The headteacher just thought that he was a naughty boy, who needed some anger management, and he got excluded on a couple of occasions.”**

Michele Hart, mother of a child with autism.

Too many children with autism are excluded from school.

Seventeen per cent of children with autism in a major survey by The National Autistic Society had been suspended from school at least once, and more than 4% had been permanently excluded from at least one school.<sup>14</sup>

Furthermore, 32% of parents surveyed had been asked to collect their child at lunchtime or before the end of the school day, for reasons other than illness. As many as 19% reported this happening on more than four occasions.<sup>15</sup> Unless this is officially recorded, this is a type of “informal exclusion”, which is illegal.

Exclusions are often the result of a lack of awareness of and support for autism. Penny Barratt of The Bridge School pointed out:

**“[Regarding] exclusion and behaviour... when a child comes to school in a wheelchair, they’re not expected to get**

**out of their chair and do PE with the rest of the class. Whereas, a child with Asperger’s syndrome, they have got to get on with it. That is a huge, huge issue. That goes to basic understanding.”**

According to Professor Neil Humphrey:

**“Almost every single case of exclusion from mainstream school could have been avoided were staff more aware of children’s needs and were there better planning at the school level to support children with autism.”**

This gives a crucial insight into how exclusions, which are extremely damaging to children’s education in the long-term, and which have a significant detrimental impact on their families, can be avoided.

Evidence shows that in some cases schools finding it difficult to manage the behaviour of children with autism (and other special educational needs) even exclude these children as a means of securing specialist provision or support.<sup>16</sup>

<sup>14</sup> Reid, B. (2011). *Great Expectations*. London: The National Autistic Society

<sup>15</sup> Reid, B. (2011). *Ibid*

<sup>16</sup> [www.childrenscommissioner.gov.uk/info/schoolexclusions](http://www.childrenscommissioner.gov.uk/info/schoolexclusions)

## Recommendation

Children with SEN are eight times more likely to be excluded from school<sup>17</sup> and evidence shows that schools with poor behaviour management are more likely to exclude large numbers of students. Therefore there should be a presumption that where a school has high levels of permanent or fixed term exclusion, Ofsted should not award it Good or Outstanding grading for its students' behaviour.<sup>18</sup>

<sup>17</sup> Department for Education (2011). Permanent and fixed period exclusions from schools and exclusion appeals in England, 2009/10: [www.education.gov.uk/rsgateway/DB/SFR/s001016/sfr17-2011.pdf](http://www.education.gov.uk/rsgateway/DB/SFR/s001016/sfr17-2011.pdf)

<sup>18</sup> This reflects recommendation 23 of the Children's Commissioner's School Exclusions Inquiry: <http://www.childrenscommissioner.gov.uk/info/schoolexclusions>

## 2. Specialist support at school

We consistently hear from families and teachers that there is not enough specialist support available, whether in mainstream or specialist settings.

Children with autism have particular needs which can present challenges for schools. Although every teacher should have some knowledge of autism, they cannot be experts in everything. Therefore they need to work with a range of other professionals, which can include specialists in autism, educational psychologists, speech and language therapists and occupational therapists.

Research has found that 30% of parents say their child's educational placement is not adequate, and only half (52%) of parents who responded to a survey feel their child is making good educational progress.<sup>19</sup> The lack of available specialist support often leads parents to feel that schools do not understand autism.

In the current climate there is also concern among professionals about the potential impact of local authority cuts on specialist services.

According to Kate Fallon of the AEP:

**“One of our key concerns is how to make sure that we continue to have a knowledgeable and skilled specialist workforce, in which I would include education psychologists, speech and language therapists, to advise parents, teachers and other education staff.”**

### What is specialist support?

**“Having the correct professionals, with the correct training and the correct knowledge of working with children with autism is essential.”** Parent of a child with autism

### Speech and language therapists

Assess and treat speech, language and communication problems including social communication difficulties to enable people to communicate to the best of their ability.

**“A godsend to my child.”** Parent of a child with autism

### Autism advisory teachers

Use experience and training in working with children and young people with an autism spectrum condition to support inclusion in mainstream schools, provide advice and training for school staff and parents and liaise with other local groups.

**“All authorities need a well-trained team of autism outreach professionals who are willing to demonstrate how recommendations translate into practice... and offer ongoing consultation and support.”** Parent of a child with autism

### Educational psychologists

Tackle problems encountered by young people in education, including learning difficulties and social or emotional problems.

<sup>19</sup> Reid, B. (2011). *Op cit*.

**“Should be the first port of call for schools for advice, strategies and monitoring.”**

Parent of a child with autism

## Occupational therapists

Assess and treat physical and psychiatric conditions, including sensory sensitivities and difficulties with motor skills to promote greater independence in daily life.

**“Huge value, well worth the investment. They have a great breadth of skills and yet we don’t seem to make the most of them.”**

Parent of a child with autism

## Behaviour support teams

Support schools to bring about positive change in the behaviour of children and young people experiencing difficulties, and reduce the risk of exclusion from school.

**“Without behaviour management it is the difference between a child accessing education and not accessing it at all.”**

Parent of a child with autism

Jacob Denness, a young person with autism feels that:

**“It is because many people with autism do not receive this help that they do not gain the opportunity to develop their abilities.”**

## Recommendations

- The new system must ensure that children with autism can access the specialist support they need to help them thrive at school, regardless of whether they have an SEN statement (or an EHCP under the new system).
- Local authorities should publish details of the specialist support they will provide to ensure their pupils with SEN thrive, including specialist autism teachers, as part of the local offer.
- There should be a lead teacher for autism in every school, as recommended for dyslexia in the Rose review.<sup>20</sup>
- All sections of EHCPs must have statutory force, including the health and social care elements.

In our survey we asked which professionals, apart from classroom teachers, make a real difference in supporting children with autism at school. Speech and language therapists, autism advisory teachers, educational psychologists, occupational therapists and behaviour support teams were all crucial. Survey respondents noted that speech and language therapists and autism advisory teachers were particularly valued, perhaps as they often work to address specific aspects of autism in the educational context.

<sup>20</sup> [www.education.gov.uk/publications/eOrderingDownload/00659-2009DOM-EN.pdf](http://www.education.gov.uk/publications/eOrderingDownload/00659-2009DOM-EN.pdf)



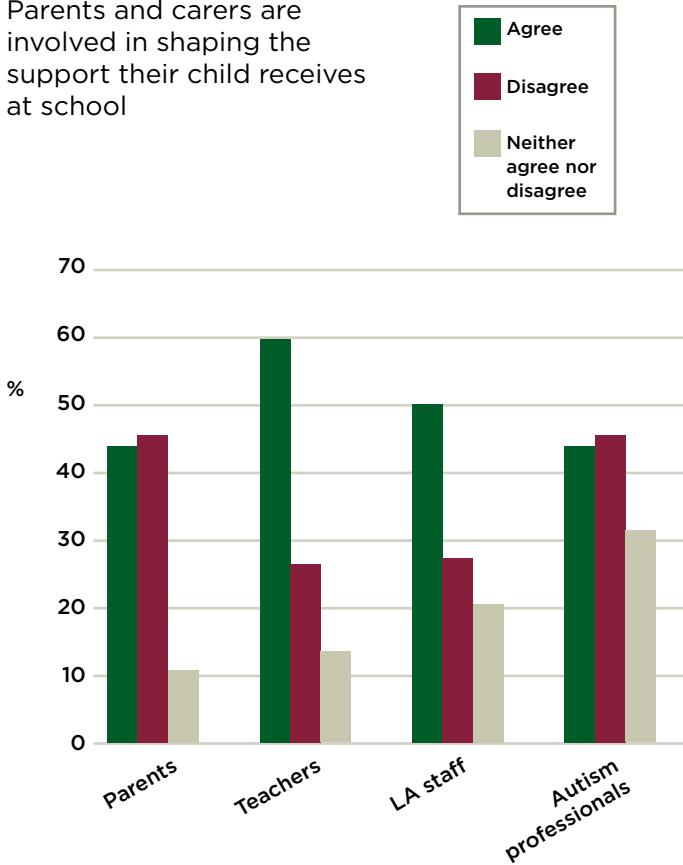
# 3. Involvement of parents and young people

Parents consistently tell us they want to be more involved in decisions about the support their children receive at school. The extension of the SEN system to include children and young people aged 0 to 25 means it is more important than ever that young people, as well as their parents, are directly involved in decisions about the support they receive.

In response to our survey, fewer than half of parents of children with autism (43%) told us they agreed that parents and carers are involved in shaping the support their child receives at school, and a similar proportion of autism professionals agreed. Significantly, while opinion was more divided among teachers, as many as 27% told us they disagreed that parents were involved (figure 2).

**Figure 2**

Parents and carers are involved in shaping the support their child receives at school

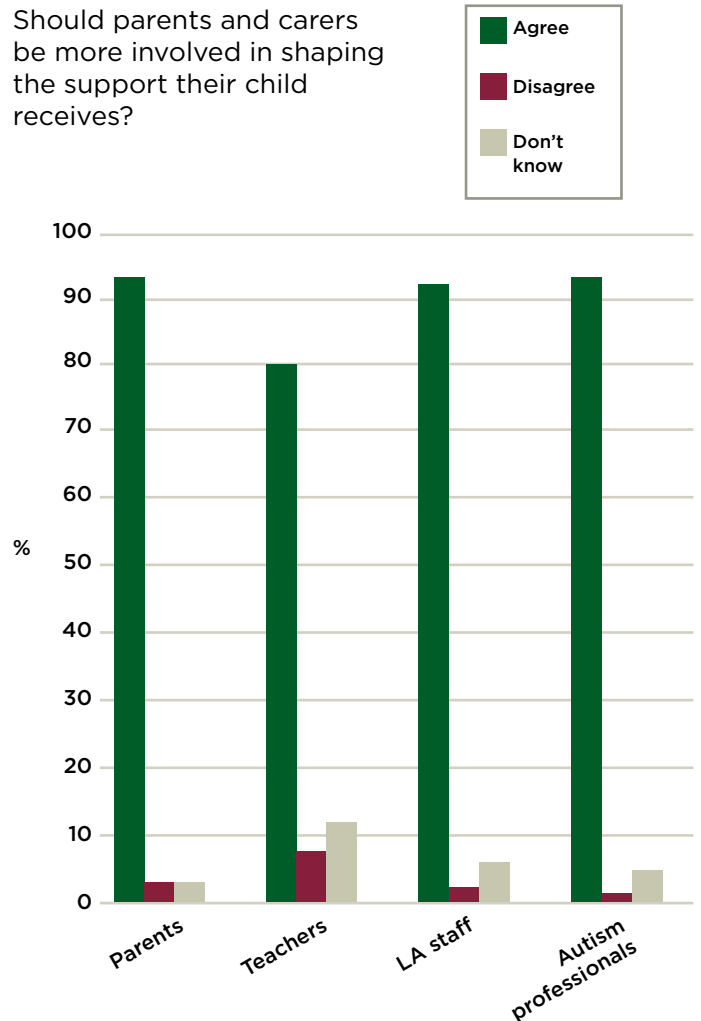


94% of parents and 80% of teachers told us they thought parents should be more involved in shaping the support their child with autism receives (figure 3).

Communication between parents and teachers can be vital in developing a better understanding of a child’s needs and how best to support them and to manage behaviour at school and at home. Some parents do not feel that the right channels are in place to enable this exchange of information and joint working to happen effectively. Introducing regular “structured conversations” between parents and teachers can be the key to preventing and reducing tensions. The Achievement for All<sup>21</sup> project has demonstrated how successful this can be.

**Figure 3**

Should parents and carers be more involved in shaping the support their child receives?



<sup>21</sup> Achievement for All is a Government-sponsored programme; see page 17 for more information

According to Michele Hart, mother of a child with autism:

**“I have offered on numerous occasions to go and speak to the entire teaching body, but I’ve never been taken up on it.”**

Michele told MPs she would like to share her knowledge with teachers about how best to interact with her son, who has autism. She described how on one occasion her son had hidden under a table and a teacher had tried to pull him out, further exacerbating the situation. She believes this and other such incidents could have been prevented if teachers had understood her son better.

Michele believes the Government should:

**“Create opportunities to recognise the huge resources we’ve got as parents, and the huge willingness among the parent community to help with that education process. It doesn’t even have to cost any money – just bring us together and allow us to develop that understanding... and don’t see us as trouble makers!”**

It is equally important to involve children, and ensure their views are taken into account in assessing what kind of support they need.

According to Dr Glenys Jones, when determining what a child needs to thrive at school, schools should ask the child, “What’s school like for you? What would make it even better?” as well as consulting with parents and professionals.

**Achievement for All** is a Government-sponsored programme which ran in 450 schools over two years, and is now available across the country. Children with SEN and disabilities who were involved made significantly greater progress than the national average for all children in maths and English, as well as improvements in behaviour, bullying and attendance. The programme included a focus on strong school leadership, assessment and tracking of pupils’ progress and adopting a whole-school approach to supporting pupils with SEN.

One of the most successful aspects of the programme was the development of structured conversations with parents. Although some were initially sceptical, the proportion of schools reporting “excellent” relationships with parents rose from 12% to 48%. The conversations allowed a more holistic picture of the child to develop, helped parents feel more engaged in their child’s education and resulted in stronger partnerships between schools and parents.

More information is available at [www.afa3as.org.uk](http://www.afa3as.org.uk)

## Recommendations

- The forthcoming reforms should encourage schools to work closely with parents to capitalise on their knowledge and understanding of their child’s autism, so as to maximise the consistency between school and home.
- Local authorities should involve young people, parents and carers in the development of their local offer to ensure it reflects local need.
- The Government should send a clear message to local authorities that young people should be supported to take ownership of their EHCP as they progress into adulthood.

## 4. Transition – extension of the SEN system up to 25

Many parents fear that when their child with autism reaches the age of 16 or 18 they will “fall off a cliff”, meaning that there will suddenly be a dearth of support and services available. This is because the current system of children’s care and support is disconnected from adult systems in many areas, and the legal rights of young adults with SEN are currently much weaker and less understood than those for children.

Too many young people across the autism spectrum find themselves unable to realise their ambitions, because they do not have access to the right support for their transition to adulthood.

- Only 1 in 4 young people with autism accesses any education or training beyond school.<sup>22</sup>
- Only 15% of people with autism are in full-time employment.<sup>23</sup>
- 30% of young people with a statement of SEN at 16 are not in education, employment or training by the time they are 18.<sup>24</sup>
- 26% of graduates with autism are unemployed, the largest percentage of any disability group.<sup>25</sup>

According to Ivan Corea of the Autism Awareness Campaign UK, who is also a parent of a child with autism:

**“Every parent and carer thinks about the future. I always think to myself what would happen to my son when I die. My hope is that my son would lead an independent life and that he might be able to hold down a part time...or full time job with support and raise a family. But we have serious concerns at so many levels.”**

**“When my son leaves school he has no future.”**

**I suggested work experience placements for young people with autism. At the moment they have nothing.”**

We welcome the Government’s announcement that statutory protections in the proposed EHCPs will continue up to the age of 25. However, we know there is a significant shortage of appropriate expertise, support and provision for young people with autism in post-school settings.<sup>26</sup> This must be addressed if the 0-25 EHCP is to deliver meaningful opportunities for people with autism.

According to Dr Glenys Jones:

**“The schools do a great job... and then there is nowhere supportive for them to go, either in FE [further education], HE [higher education] or in supportive employment.”**

In order to develop more and better education options for young people with autism when they leave school, SEN initiatives, such as the recent bursaries for staff development, must cover the 0-25 age range, and include colleges and other post-16 providers, rather than being simply focussed on schools.

Furthermore, the needs of young people with autism and SEN must also be taken into account in relation to the raising of the education participation age to 18 by 2015. Without a specific strategy for supporting 16 and 17 year-olds with SEN to participate, the Government will not be able to reach its target of full participation.

It is crucial that young people with autism and SEN have the same opportunities to start a career as their peers. Importantly, the Government’s apprenticeship programme must be accessible to this demographic.<sup>27</sup>

<sup>22</sup> Ambitious about autism. *Op cit.*

[www.ambitiousaboutautism.org.uk/page/get\\_involved/finished\\_school/index.cfm](http://www.ambitiousaboutautism.org.uk/page/get_involved/finished_school/index.cfm)

<sup>23</sup> Rosenblatt, M. (2008). *Op cit.*

<sup>24</sup> National Audit Office (2012). *Oversight of special education for young people aged 16-25*. London: National Audit Office

<sup>25</sup> AGCAS Disability Task Group (2010, 2011). *What happens next? A report on the first destinations of 2009/2010 disabled graduates*. Sheffield: AGCAS

<sup>26</sup> Ambitious about Autism. *Op cit.*

At the moment, there is confusion as to whether qualification for an apprenticeship depends on requirements such as five GCSEs, including English and maths. This can mean that some young people with autism and SEN are likely to miss out on an opportunity which could greatly benefit them and their potential employer.

For many people with autism, and their families, the struggle to access the right support only increases after reaching adulthood. While the forthcoming *Children and Families Bill* will only cover young people up to the age of 24, we continue to call for supported transition into adult services and the right social care for everyone with autism and other disabilities.

Young people with autism have told us that they have ambitious plans for the future.

**“I worry about the future a lot. I hope I will have friends and things won’t be too scary or dangerous. I want to open a big theme park with an aquarium where people can go for holidays, and poor children can stay for free.”**

**“[I want a] university [education], a good job, marriage, children. People having the understanding as what autism is all about.”**

**“[I hope] that I will be able to get a job and live independently, that I will have some friends and maybe even a wife and children.”**

**“[I want] to have a job, and to be able to share a house with my friends, with someone to help us. I want to live in a house close to mum and dad, so I can see them.”<sup>28</sup>**

## Recommendations

- EHCPs must have statutory protections at least as strong as the current statement of SEN, for all children and young people up to the age of 25.
- The Government should announce a bursary programme for staff in post-school settings to develop specialist qualifications in working with young adults with autism and other disabilities, to match their announcement for school staff working in this field.
- Funding streams for post-16 education should be joined up to ensure they can be used to create more personalised programmes.
- The revised Ofsted framework should include measures relating to how well further education providers are meeting their *Equality Act* duties to provide equal access to their services for disabled young people.
- Every young person with autism, including those without a statement or EHCP, must have an individual transition plan to address the difficulties associated with moving on from school.
- Along with the raising of the education participation age, the Government must provide sufficient additional funding to local authorities to create educational opportunities for the young people with SEN aged 16-18 who are not currently in education.
- The Government should issue new regulations to clarify the accessibility of apprenticeships for young people with SEN.
- We welcome Employment Minister Lord Freud’s commitment to double the number of people with autism in full-time employment, from 15% to 30%. Government departments including the Department for Education, the Department for Business, Innovation and Skills, and the Department for Work and Pensions must work together to realise this aim.

<sup>27</sup> Under the *Apprenticeships, Skills, Children and Learning Act 2009* (ASCLA) there was a requirement that those qualifying for the scheme should have “key skills and functional skills”, meaning five GCSEs including English and maths. This disadvantaged some young people, including those with SEN, who could not, due to learning difficulties or disabilities, achieve these grades, though they would benefit greatly from an apprenticeship and could contribute to the workplace through undertaking one. This requirement was removed under the *Education Act 2011*. Furthermore, under the ASCLA, apprenticeships are available to people under 25 who are subject to a learning difficulty assessment.

<sup>28</sup> Bancroft, K. et al (2012). *The way we are: autism in 2012*. London: The National Autistic Society

## 5. Accountability and transparency

Building greater accountability into the SEN system is a vital ingredient for the Government's reforms. Schools must serve the needs of local young people and their families. Currently, too many parents have to fight to get the support their children need. Autism cases make up the largest proportion of cases going to the Special Educational Needs and Disability Tribunal.

Research shows that a quarter (27%) of parents of children with autism surveyed had to wait more than two years to get the support their child needs at school. One in five parents (18%) had to go to tribunal to achieve this. On average these families went to tribunal three or four times each.<sup>29</sup>

According to Michele Hart, mother of a child with autism:

**"I have done nothing but fight for my little boy since he was two...an awful lot of kids, because they haven't got that family support, will just get completely lost in the whole education system. My son is lucky because he's got me. I can get out there and I will speak my mind, and I have got no qualms about going to the head teacher's office and ranting, raving and putting it right."**

We very much welcome Children's Minister Sarah Teather MP's assurance that:

**"My ambition is that parents will no longer have to fight for the services their children need."**

The aim of new legislation must be to reduce the likelihood of parents finding it necessary to resort to tribunal or engage in complicated and often stressful negotiations to achieve the support their child needs.

As discussed in section 3, one cause of dissatisfaction is that parents often feel they are not as closely involved in decisions about their child's education as they should be.

However, while better communication between parents and schools is vital, there must also be a clear formal process by which parents can have their concerns addressed and clear appeal mechanisms. This must extend to children who do not have statements (or EHCPs under the new system). We strongly welcome the Government's inclusion of the SEN statutory framework within funding agreements for new academies but there must be a clear complaints process to enable individual families to have their concerns addressed swiftly and effectively.

Accountability procedures must not rely solely on parents to ensure schools are meeting their children's needs. Ofsted and school governors have important roles to play in ensuring there is effective provision for children with SEN.

The Northern Ireland Assembly has proposed introducing duties on governors to give them increased responsibility for overseeing children's progress. This could usefully be adopted in England.

<sup>29</sup> Reid, B. (2011). *Op cit.*

## Recommendations

- The Department for Education should develop an effective, well-resourced complaints system for all state-funded schools and monitor parental confidence in this system.
- The local offer proposed in the Green Paper must have a statutory basis and be clearly enforceable.
- Every child with autism (including those without a statement or EHCP) should have an “action plan” that is regularly updated and sets appropriate objectives against which progress can be measured.
- School governors should have increased responsibility to ensure all children with special educational needs make effective progress against the objectives in their SEN statements, EHCPs, and the action plans proposed above.

# Conclusion

The APPGA Commission consulted a wide range of families, teachers and autism professionals on how the special educational needs system could be improved. Our evidence shows that as things stand, parents face a constant battle, teachers and schools need more training and help in the classroom, and children and young people with autism are missing out on the support they need.

Crucially, there must be a spectrum of support to reflect the different needs of young people with autism, and the challenges they face. Those without statements or EHCPs must not lose out.

This is a once-in-a-generation opportunity to make sure that all children with autism have access to the same opportunities as their peers: to continue their education, to acquire everyday skills, and to live as independent a life as possible.



# Summary of recommendations

## 1. Training and best practice

- The Government should continue funding for the Autism Education Trust (subject to evaluation) to enable it to expand the development of a three-tier training programme beyond March 2013. In particular it should include areas of the country not already covered. These are the South West, East and North East of England as well as Yorkshire and Humberside. It should be extended to provide training to staff in post-school settings, such as further education colleges, in line with plans for a holistic 0-25 SEN system.
- In developing their local offer, local authorities should map local training needs in the main areas of SEN, including autism, and work with schools to ensure those needs are met.
- The Government should make sure that initial teacher training providers emphasise the relevance of core teaching competencies (such as effective communication) for teaching children with autism and SEN. Teachers must be equipped to adjust their practice as appropriate to meet the specific needs of these children.
- There should be a system for ensuring that all state-funded schools are able to draw on the expert knowledge of autism that exists in other schools within their area.
- As part of the local offer, local authorities should identify where specialist autism knowledge is available to schools in their area, and support schools to share this knowledge.
- There should be a presumption that where a school has high levels of permanent or fixed-term exclusion, Ofsted should not award it Good or Outstanding grading for its students' behaviour.<sup>30</sup>

## 2. Specialist support

- The new system must ensure that children with autism can access the specialist support they need to help them thrive at school, regardless of whether they have an SEN statement (or an EHCP under the new system).
- Local authorities should publish details of the specialist support they will provide to ensure their pupils with SEN thrive, including specialist autism teachers, as part of the local offer.
- There should be a lead teacher for autism in every school, as recommended for dyslexia in the Rose review.
- All sections of the EHCPs must have statutory force, including the health and social care elements.

## 3. Involvement of parents and young people

- The forthcoming reforms should encourage schools to work closely with parents to capitalise on their knowledge and understanding of their child's autism, so as to achieve a consistent approach both at school and at home.
- Local authorities should involve young people, parents and carers in the development of their local offer to ensure it reflects local need.
- The Government should send a clear message to local authorities that young people should be supported to take ownership of their EHCPs as they progress into adulthood.

<sup>30</sup> This reflects recommendation 23 of the Children's Commissioner's School Exclusions Inquiry: [www.childrenscommissioner.gov.uk/info/schoolexclusions](http://www.childrenscommissioner.gov.uk/info/schoolexclusions)

## 4. Transition – extension of the SEN system up to 25

- EHCPs must have statutory power for all children and young people up to the age of 25 (regardless of whether they are still in education).
- The revised Ofsted framework should include measures relating to how well further education providers are meeting their *Equality Act* duties to provide equal access to their services for disabled young people.
- Every young person with autism, including those without a statement or EHCP, must have an individual transition plan to address the difficulties associated with moving on from school.
- The Government must provide sufficient additional funding to local authorities to create educational opportunities for young people with SEN aged 16-18 who are not currently in education, in line with the raising of the participation age.
- The Government should issue new regulations to clarify the accessibility of apprenticeships for young people with SEN.
- We welcome Employment Minister Lord Freud's commitment to double the number of people with autism in full-time employment, from 15% to 30%. Government departments including the Department for Education, the Department for Business, Innovation and Skills, and the Department for Work and Pensions must work together to realise this aim.

## 5. Accountability

- The Department for Education should develop an effective, well-resourced complaints system for all state-funded schools and monitor parental confidence in this system.
- The local offer proposed in the Green Paper must have a statutory basis and be clearly enforceable.
- Every child with autism (including those without a statement or EHCP) should have an “action plan” that is regularly updated and sets appropriate objectives against which progress can be measured.
- School governors should have increased responsibility to ensure all children with special educational needs make effective progress against the objectives in their statement or EHCP, and in the action plans proposed above.

# Annex

The APPGA Commission held two oral evidence sessions in March 2012. Full transcripts of the sessions are available at [www.appga.org.uk](http://www.appga.org.uk)

## Oral evidence session one

Tuesday 6 March, 2-4pm  
Committee Room 21, House of Commons

Please note there may be omissions in places where the recording did not work.

### Panel

**Chair:** Robert Buckland MP (Con)  
Steve Brine MP (Con)  
Jonathan Reynolds MP (Lab)  
Lord Touhig (Lab)  
Charlotte Leslie MP (Con)  
Neil Parish MP (Con)  
Karen Lumley MP (Con)  
Sir Peter Bottomley MP  
Russell Brown MP

### **Witnesses:** *young people with autism and parents of young people with autism*

1. Josie Ryan – youth patron of Ambitious about Autism
2. Jacob Denness – National Autistic Society young campaigner
3. Jonathan Meth – parent and trustee of Ambitious about Autism
4. Michele Hart – parent and National Autistic Society ambassador

### **Witnesses:** *teaching professionals*

5. Dr Rona Tutt – former head teacher and former president of the National Association of Head Teachers

6. Mr Paul Williams – Chair, National Association of Head Teachers' SEND Committee and head teacher of Shaftesbury High School, Harrow
7. Mrs Alice Stow – leader of the special resourced provision for pupils with ASD, King's Oak Primary School
8. Ms Penny Barratt – The Bridge School, Islington

## Oral evidence session two

Tuesday 13 March, 2-4pm  
Committee Room 21, House of Commons

Please note: there may be omissions in places where the recording did not work.

### Panel

**Chair:** Robert Buckland MP  
Steve Brine MP  
Russell Brown MP  
Jonathan Reynolds MP  
Lord Clement-Jones  
Graham Stuart MP  
Lord Touhig

### **Witnesses:** *autism experts*

1. Dr Glenys Jones, Lecturer in Autism, School of Education, University of Birmingham
2. Ms Kate Fallon, General Secretary, Association of Educational Psychologists
3. Professor Neil Humphrey, Professor of Psychology, University of Manchester
4. Ms Kamini Gadhok, Royal College of Speech and Language Therapists

### **Witnesses:** *politicians*

5. Sarah Teather MP, Minister of State for the Department for Education
6. Sharon Hodgson MP, Shadow Minister of State for the Department for Education

# About the APPGA

The All-Party Parliamentary Group on Autism (APPGA) is a formal cross-party backbench group of MPs and Peers who share an interest in autism and Asperger syndrome. It was set up in February 2000. Its role is to campaign in Parliament for greater awareness of autism and Asperger syndrome, and to lobby the Government for improved services for people with autism and Asperger syndrome, and their carers.

The official objective is:

**“To raise awareness of issues affecting people with autism and Asperger syndrome, their families and carers; to raise Parliamentary awareness of autism; to campaign for changes to government policy to benefit people with autism and Asperger syndrome and improve diagnosis or, support for, people with autism and Asperger syndrome.”**

The APPGA does not have any powers to introduce legislation, nor is it part of Government. But it provides a useful platform for important and topical issues around autism to be discussed and raised in Parliament.

## Officers

Robert Buckland MP (Chair)  
 Steve Brine MP (Vice-Chair)  
 Annette Brooke MP (Vice-Chair)  
 Robert Ffello MP (Vice-Chair)  
 Jonathan Reynolds MP (Vice-Chair)  
 Charlotte Leslie MP (Treasurer)  
 Russell Brown MP (Secretary)

## Advisory group

Professor Tony Charman (Chair)  
 Christine Swabey – **Autistica**  
 Dr Juli Crocombe – Clinical Psychiatrist  
 Simon Baron Cohen – academic  
 Peter Barrett  
 Kate Williams – **Ambitious about Autism**  
 Carol Rutherford – parent of children with autism  
 Melissa McAuliffe – social worker  
 Tom Madders – **The National Autistic Society**  
 Grace Hsieh – parent of a child with autism  
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 Ann Memmott – autism adviser and adult with autism  
 John Phillipson – **Autism Alliance**





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