The right start: reforming the system for children with autism

A Report on improving the Special Educational Needs and Disabilities System by the All-Party Parliamentary Group on Autism

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Summary

One in every hundred children has autism.¹ Too many of these children and their families are having problems with the special educational needs (SEN) system. Many find it difficult to get the support they need.

The All-Party Parliamentary Group for Autism (APPGA) welcomes the Government’s decision to improve this system. It will happen because of a new law called the Children and Families Bill.

This report is based on a public survey and on expert evidence. The evidence was from young people with autism, parents, teachers and other professionals. It has recommendations for a new system. This will be one where everyone with autism is supported. This support will let people gain the skills they need to live full and independent adult lives.

Training and Best Methods

84 out of every 100 of people in our survey said teachers did not have enough training to teach and support children and young people with autism. We know that training is important to help them understand this often “hidden” disability. The Government should continue to pay for the design of very good training programmes. If there are good specialists, they should share their knowledge. Schools should be able to use expert knowledge from schools nearby.

Specialist support at school

Children with autism can have many different needs. They often need specialists to support them properly at school. Teachers cannot be experts on everything. The right support for children with autism will often include specialists in autism, educational psychologists, speech and language therapists and occupational therapists. Parents often say those experts are not available. The Government must ensure that all children with autism can have the specialist support they need. This should including those without a Statement of SEN or Education, Health and Care Plan (EHCP). Every school should have a specialist teacher for autism.

Involvement of parents and young people

In our public survey, fewer than half of parents and children with autism (43 out of every 100) felt they were allowed to help guide the support the child receives at school. Autism professionals agreed. So did 3 out of every 10 teachers. 94 out of every 100 of parents said they should be more involved. The reforms must encourage schools and Council education departments to work with parents. They must share vital information about the child. They must make sure that school and home life support each other. As the SEN system will include people up to 25 years old, young people must also be supported to help make the decisions.

¹ The term autism is used throughout this report to refer to all conditions on the autism spectrum, including Asperger syndrome
Transition – extension of the SEN system up to 25
When young people become adults, many families have to struggle even harder to get good services. The Government has decided to give help to people up to 25 years old. This will greatly help those in further education. The Government must also help many more young people with autism; they need to get the right support so that they have the skills to live good independent adult lives. There must be good support and good opportunities to join apprenticeships and find a good job, for those who are able.

Accountability
Far too many parents struggle to get the support their children need. There must be a useful complaints system which is for all state-funded schools. Parents must be able to have confidence in this system. Families of children with autism who do not have Statements or EHCPs also need support. They must have good “action plans” so that they can measure progress.
Foreword by Robert Buckland MP

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. Just 15% of adults with autism are in full-time employment and 26% of graduates with autism are unemployed, which is the highest rate among any disability group. 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.

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2 Ambitious about Autism, Finished At School report: http://www.ambitiousaboutautism.org.uk/page/get_involved/finished_school/index.cfm
Introduction

What is autism?

Autism is a serious, lifelong disability. It affects the way a person communicates with, and relates to, other people. It may affect each person in a different combination of ways. Some people with autism are able to live lives with little support. Others need specialist support throughout their lives.

People with autism have difficulties with three things:

**Social interaction**: recognising and understanding their own feelings, and the feelings of other people. This can make it hard to form friendships

**Social communication**: understanding the social meaning of words, and the meaning of body language, including gestures, face expressions and tone of voice.

**Social imagination**: ability to imagine social situations which are different to their normal daily routine. Difficulties planning ahead and coping with change.

People with autism may also have sensory sensitivity. This means they are over or under sensitive to sound, touch, taste, smell, light or colour. This can make busy, brightly lit or noisy places difficult to cope with. These include classrooms, playgrounds or workplaces.

About 1 in 100 people has autism. Together with their families they make up over two million people across the UK. There are about 3,000 in an MP’s constituency (the town or area looked after by an MP).5

There are about 88,000 school-aged children with autism in England. That is 1 in every 100 pupils. More children with autism have special education needs ‘statements’ than any other group of children. This means that they will be very affected by any changes to the SEN system.

The Government’s Green Paper called “Support and Aspiration: A new approach to special educational needs and disability”, was published in March 2011. If we add this new law too, it means that many more children and young people with autism should have better experiences in education.

The APPGA welcomes the Government’s wish to improve the SEN system. The Government’s proposals include:

- Replacing Statements of SEN. Instead, there will be Educational Health and Care Plans for children and young people aged 0-25 who used to get statements. This will give parents the same legal protection as before. However, it will mean all of the professionals working together as one team to assess the child for autism. (“A single multi-agency assessment process”).

• Funding for new scholarships and training for teachers and support staff. This is to help them develop good support skills for children with SEN.
  (Some of this is already happening)
• Special schools to share their expertise and services. This will help to support the education and progress of pupils in other schools.
• Better support for young people who are older than 16 when they leave school. There should be chances to go on work placements.

This report recommends five things which the APPGA believes would really improve the education experiences for children with autism.

1. Training and best practice
2. Specialist support at school
3. Involvement of parents and young people
4. Transition - extension of the SEN system up to 25
5. Accountability

How We Got the Results: A note on the survey
This report is from survey data collected by the All-Party Parliamentary Group for Autism in 2012. This included a public survey, with almost 1000 responses from members of the public in England.6

About four out of five people who answered the questions were parents, carers or family members of someone with autism7. About one in three (29%) were teachers, local authority staff members or autism professionals. (Some were both parents and professionals.)

People who answered the questions were talking about mainstream primary schools (67 out of every 100), mainstream secondary schools (3 out of every ten), generic special schools (1 out of every 4) and autism-specific special schools (1 out of every 5). Many had experience of more than one category. The children they were talking about had different sorts of autism diagnoses. eg autism with a learning disability (16 out of every 100), Asperger syndrome or high functioning autism (37 out of every 100), and autism spectrum disorder (30 out of every 100).

MPs and peers also heard evidence from young people with autism, parents, teachers, academics and other autism professionals. This happened in two spoken evidence sessions at the House of Commons.8

See Annex at the back for more details.

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6 957 people from England answered the survey
7 In this report where we refer to parents in relation to the survey, we are referring to parents, carers and other family members.
8 See Annex for a full transcript of both sessions and a list of participants
1. Training and Best Methods

i. Training
In the evidence heard by the Commission, many people mentioned the need for more training for teachers and other staff working with children with autism.

84 out of every 100 people surveyed said teachers are not given enough training to teach and support children with autism properly. That figure was 89 out of 100 for parents or teachers of those with Asperger syndrome or high functioning autism. This could be because the needs of children with Asperger syndrome or high functioning autism are more hidden. This group is more likely to achieve average or above average exam results. Because of this, they may be less likely to receive the support they need for their autism-related needs. They are also more likely to be in mainstream schools; some of those schools do not know as much as the others about autism.

A lack of training can mean that some teachers do not have much 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."

Dr Glenys Jones, of the University of Birmingham said:

"School is one of the most challenging places if you've got autism, in terms of the social demands for communication and withstanding 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 spotted, correctly identified or understood. Training is therefore vital. So is appropriate support in the classroom. With those things, teachers can adapt what they have learnt so that it matches the needs of the children they work with.

According to Professor Neil Humphrey, Professor of Psychology, University of Manchester (pictured below):

"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.”

Nearly all of the people in the survey felt that there is not enough support for teachers in the classroom to let them teach children with autism properly.

It is also vital that training is not just for teachers. It must also be for all staff working with children with autism. It is very important for teaching assistants working one-to-one with individual students.

Kate Fallon, General Secretary of the Association of Educational Psychologists (AEP) who is pictured left, says:

“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.”

Alice Stow, Leader of the Special Resourced Provision for Pupils with ASD, King's Oak Primary School, says:

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

Autism training for teachers can have many other benefits. Dr Glenys Jones at the University of Birmingham says good teaching practice for autism also helps teachers to have a calm, confident manner. They learn to use clear and literal language and to allow enough time for children to respond to questions. They also learn to adapt to an individual child’s needs.

Where possible, training and teaching needs to use methods that are proved to work. The training needs to be led by autism professionals, with input from people on the spectrum or their families.  

Recommendations

• The Government should continue funding for the Autism Education Trust. This will make sure it can expand the successful development of a three-level 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 offer SEN training to staff in further education colleges and other places offering training for all those aged 0 – 25.

9 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
• In developing their Local Offer, local authorities should find out about local training needs in the main areas of SEN, including autism. They should work with schools to make sure people have the training they need.
• The Government should make sure that teacher training providers emphasise the importance of good teaching (such as effective communication) for teaching children with autism and SEN. Teachers must be able to adjust their methods for children with autism.

Developing Autism Training\textsuperscript{10}

The Autism Education Trust (AET) was awarded a two-year grant from the DfE in 2011. This money is so they can write a three-stage training programme for staff in schools, and writing national autism educational standards. There are seven regional training centres.\textsuperscript{11} As a result, 5,000 school staff will receive level 1 training by 2012/13. This will help improve autism awareness.\textsuperscript{12} People with autism are involved in writing the training materials and doing the training.

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

The programme is already reaching many staff working for or with schools who have young people with autism. For example, in Birmingham, more than 600 school taxi drivers and escorts for pupils with autism will receive tier 1 training.

Those working on this project say that staff who work regularly with children with autism have no relevant training. There is a high level of need for this, which this project is trying to solve.

ii. Sharing knowledge and best practice

We believe that where good practice exists, it should be shared. Each area of the country will have something useful to offer. For example they may have a good special school or a good autism unit in a mainstream school.

According to Professor Neil Humphrey:

\textsuperscript{10} Further information is available at www.autismeducationtrust.org.uk
\textsuperscript{11} 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 info at www.autismeducationaltrust.org.uk/resources/research.aspx
\textsuperscript{12} www.autismeducationtrust.org.uk/resources/research.aspx
“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. This will let the best schools help with the training and professional development of teachers, support staff and headteachers. It will also let them help improve standards through school-to-school support. We could do the same for autism. This could start with the three-level autism training initiative by the AET (as above).

The NAS Thames Valley Free School

The National Autistic Society (NAS) has put in 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 pupils with Asperger syndrome and high functioning autism. They find it difficult to cope in a standard school, but don’t find it useful to be in a special school where many have learning disabilities. The school will have 44 pupils and will also give extra support to 6 pupils who have the highest levels of complex needs.

This new school will work closely with parents; neighbouring special and mainstream schools; FE colleges; local respite provisions & other social care providers and local authorities in the region. There will be lots of working in partnership with all of those, so that they all benefit from the expertise.

Recommendations

- There should be a system so that all schools can use the expert knowledge of autism in other schools within their area.
- As part of the “Local Offer”, local authorities should find where specialist autism knowledge is, and make it available to local schools and support schools.

13 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 or a child with autism

Too many children with autism are excluded from school.

In a survey by the National Autistic Society, 17 out of every 100 children with autism had been suspended from school at least once. More than 1 in every 25 has been told to leave at least one school. 14 32 out of every 100 parents they surveyed had been asked to collect their child at lunchtime or before the end of the school day. As many as 19 out of every 100 reported this happening on more than four occasions. 15 Unless this is properly recorded by the schools, this is a type of “informal exclusion”, which is illegal.

Exclusions are often because of a lack of knowledge and lack of support for autism. Penny Barrett 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 shows how exclusions can be avoided. They are extremely damaging to children’s education, and to their families.

Some schools find it hard to manage the behaviour of children with autism (and other special educational needs). They sometimes exclude these children to prove how much they need extra specialist support. 16

Recommendation

Children with SEN are eight times more likely to be excluded from school. 17

Schools with poor behaviour management are proved to be more likely to

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16: http://www.childrenscommissioner.gov.uk/info/schoolexclusions
exclude large numbers of students. If a school often excludes pupils, Ofsted should not award it a Good or Outstanding grade for its students’ behaviour.18


18 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 often hear from families and teachers that there is not enough specialist support available. This is true 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. They need to work with other professionals. These might be specialists in autism, educational psychologists, speech and language therapists and/or occupational therapists.

3 out of every 10 parents say they feel their child's school or college is below average, and only half (52 out of every 100) of parents feel their child is making good progress in school or college.19

The lack of specialist support often means parents feel that schools “do not understand autism”.

There is also concern among professionals about local authorities not giving as much money for specialist services.

According to Kate Fallon, 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

These assess and treat speech, language and communication problems. This includes social communication difficulties.

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

Autism advisory teachers

These provide advice and training for school staff and parents. They also liaise with other local groups.

“All authorities need a well-training 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

These help to tackle challenges such as learning difficulties, social difficulties or emotional problems.

“Should be the first port of call for schools for advice, strategies and monitoring.” (Parent of a child with autism)

Occupational therapists
These assess and treat challenging features of autism, including any sensory sensitivities or difficulties with physical skills. It leads to 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
These support schools to improve the behaviour of children and young people who have difficulties. It helps prevent 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)

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 very important. People in the survey said that speech and language therapists and autism advisory teachers were particularly useful. Perhaps this is because they often work in schools to help 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 mean that children with autism can get the specialist support they need to help them thrive at school. This must be true even if they don’t have an SEN statement (or an Educational, Health and Care Plan under the new system).
- When they are doing a Local Offer, local authorities should publish details of the specialist support they will provide. They should explain how it will make sure that their pupils with SEN thrive. This should include specialist autism teachers.
- There should be a main teacher for autism in every school. This was recommended for dyslexia in the Rose review.20
- All sections of the Education, Health and Care Plans must give legal rights that people have to obey, not just ideas. This must include the health and social care parts.

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www.education.gov.uk/publications/eOrderingDownload/00659-2009DOM-EN.pdf
3. Involvement of parents and young people

Parents keep telling us that they want to be more involved in decisions about the support their children get at school. The SEN system will now cover people from 0 to 25 years old. It means it is more important than ever that young people and their parents are directly involved in decisions about the support they receive.

Fewer than half of parents of children with autism (43 out of every 100) told us they agreed that parents and carers are involved in shaping the support their child receives at school. That figure was about the same for autism professionals. More teachers thought parents were involved, but 27 out of every 100 still told us they didn’t believe that parents were involved (figure 2).

![Figure 2: Parents and carers are involved in shaping the support their child receives at school](image)

94 out of every 100 parents, and 80 out of every 100 teachers told us they thought parents should be more involved with the support their child with autism receives (figure 3).

Communication between parents and teachers can be vital. It helps both to really understand a child’s needs. Both can then discover the best ways to support them and to manage behaviour at school and at home. Some parents do not feel that this is happening properly. Regular “structured conversations” between parents and teachers can reduce worries. The Achievement for All\(^{21}\) project has shown how successful this can be.

\(^{21}\) Achievement for All is a Government-sponsored programme; see within this document 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 hid under the table and a teacher had tried to pull him out. This made the situation worse. She thinks events like this 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 listen to their views when assessing what kind of support they need.

According to Dr Glenys Jones, when finding out what a child needs to thrive, 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 was done in 450 schools over two years. It is now available across the country.
Children with SEN and disabilities who were involved made much more progress than the national average for all children in maths and English. They also improved their behaviour, had less bullying and had fewer days off. The programme taught strong school leadership. It also showed the best ways to see how much progress pupils made, and it showed how to use a whole-school way of supporting pupils with SEN.

This programme taught how to have good structured conversations with parents. As a result, 48 out of every 100 schools reported “excellent” relationships with parents. At the start, that was true for only 12 out of every 100 schools. It helped everyone understand more about all of the needs and abilities of each child. It also helped parents feel more involved in their child’s education, and it meant there were better partnerships between schools and parents.

More information is available at www.afa3as.org.uk

Recommendations

- The planned reforms should encourage schools to work closely with parents. This will let schools benefit from better understanding of the child’s autism. Home and school can then make sure they are using the same methods, instead of confusingly different ones.
- Local authorities should involve young people, parents and carers when planning their Local Offer. This should mean it will reflect local need.
- The Government should tell local authorities that young people should be helped to make good decisions about their own Education, Health and Care Plan when they are older.
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, their support will stop. This is because at the moment there is almost no link between care and support for children and the care and support for adults. The legal rights of young adults with SEN are currently much worse and less understood that those for children. Too many young people across the autism spectrum find they cannot live the good lives they want. At the moment they can’t get the right support to help them plan life when they become an adult.

- Only 1 in 4 young people with autism has any education or training beyond school\(^\text{22}\)
- Only 15 out of every 100 people with autism are in full-time employment\(^\text{23}\)
- 30 out of every 100 young people with a statement of SEN at age 16 are not in education, employment or training by the time they are 18\(^\text{24}\)
- 26 out of every 100 graduates with autism are unemployed. This is the largest percentage of any disability group\(^\text{25}\)

According to Ivan Corea, parent and founder of the Autism Awareness Campaign UK:

“All 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 suggest work experience placements for young people with autism. At the moment they have nothing.”

We are pleased that the Government’s says that the new EHCPs will continue up to the age of 25. However, we know there is a big shortage of proper experts, support and services for young people with autism when they leave school.\(^\text{26}\) This must be changed if the 0-25 EHC Plan is to work properly for people with autism.

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\(^{22}\) Ambitious About Autism, Op cit
\(^{26}\) Ambitious about Autism, Finished at School report (as before)
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 supported employment.”

SEN planning must include young people from age 0-25. It needs to include colleges etc for those older than age 16, not just for schools. This should include the monies for staff training.

There also needs to be a plan for how to support 16 and 17 year olds with SEN when they have to stay at school or college until age 18. This will happen by 2015. If there is no planning for this, the Government will not able to reach its targets for participation.

Young people with autism and SEN must have the same chances to start a career as their peers do. This needs to be true for the Government’s apprenticeship programme too. 27 At the moment, there is confusion about getting into an apprenticeship means they need five GCSEs including English and maths. This can mean that some people with autism and SEN are likely to miss out on the chance to do an apprenticeship. Yet these could greatly benefit them and their future employer.

For many people with autism, and their families, the struggle to get the right support increases when they become adults. This Children and Families Bill will only be for young people up to the age of 24. We are also asking for proper support and services for adults, and the right social care for everyone with autism and other disabilities.

We know that young people with autism 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.”28

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27 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.

Recommendations

- Education, Health and Care Plans must be able to protect young people at least as strongly as the current Statement of SEN. This should be true for all children and young people up to the age of 25.
- The Government has said that teaching staff in colleges (or other places training those aged 16+) need to have good specialist qualifications for working with SEN. The Government should make sure the money is there to make this happen.
- Funding for post-16 education should be linked properly, so that money can be used to create more personalised programmes.
- The new Ofsted rules should ask how well further education providers are meeting their Equality Act duties. The providers must allow equal access to their services for disabled young people.
- Every young person with autism (including those without a statement or Education Health and Care Plan) must have an individual transition plan. This will help remove the difficulties of moving on to new things from school.
- The Government must make sure there is enough money for local authorities to educate young people with SEN aged 16-18 who are not in education at the moment.
- The Government should give clear new regulations to explain who can do apprenticeships.
- 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 Department for Education, Department for Business, Innovation and Skills and the Department for Work and Pensions must work together to make this happen.
5. Accountability and transparency (being responsible for decisions you make)

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 are the largest group going to the Special Educational Needs and Disability Tribunal.

Research shows that about a quarter (27 out of every 100) of parents of children with autism surveyed had to wait more than two years to get the support their child needs at school. About one in five parents (18 out of every 100) had to go to tribunal to achieve this. On average these families went to tribunal three or four times each.29

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 you know, putting it right.”

We very much welcome Children 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 laws must be to reduce how often parents have to go to tribunals. These are complicated and stressful ways to get the support their child needs.

As discussed in section 3, parents often feel they are not closely involved in decisions about their child’s education.

Better communication between parents and schools is vital. But there must also be a good set of rules for parents to have their concerns dealt with. There must also be sensible ways to appeal if a decision seems wrong. This must also happen for to children who will not have statements or Educational Health and Care Plans. We strongly welcome the Government saying that new academies have to obey the law on SEN. There must also be a clear complaints process, so families can have their concerns dealt with swiftly and effectively.

Ofsted and school governors must make sure there is effective support for children with SEN.

The Northern Ireland Assembly has proposed that school governors have more responsibility for making sure children make good progress. This could be useful in England.

**Recommendations**

- The Department for Education should develop an effective complaints system for all state-funded schools. It should have enough money, training and staff. They should keep checking how confident parents are with this system.
- The “Local Offer” in the Green Paper must have a legal basis and be clearly enforceable. (Not just be a recommendation.)
- Every child with autism (including those without a statement/Education, Health and Care Plan) should have an “action plan” that is regularly updated. It must have appropriate goals, so that people can measure progress.
- School governors should be responsible for making sure all children with special educational needs make good progress. This needs to match the aims in their SEN statements/EHCPs and in the action plans proposed above.
Conclusion

The APPGA Commission consulted a wide range of families, teachers and autism professionals. We asked how the special educational needs system could be improved. Our evidence shows that parents face a constant battle. Teachers and schools need more training and help in the classroom. Children and young people are not getting the support they need.

There must be a spectrum of support for the needs and challenges of young people with autism. Those without SEN statements or Education, Health and Care Plans must not be left without support.

This is a once in a generation chance 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. This will make sure it can expand the successful development of a three-level 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 offer SEN training to staff in further education colleges and other places offering training for all those aged 0 – 25.
- In developing their Local Offer, local authorities should find out about local training needs in the main areas of SEN, including autism. They should work with schools to make sure people have the training they need.
- The Government should make sure that teacher training providers emphasise the importance of good teaching (such as effective communication) for teaching children with autism and SEN. Teachers must be able to adjust their methods for children with autism.
- There should be a system so that all schools can 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 local schools and support schools to share this specialist 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.  

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 Educational, Health and Care Plan 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 Education, Health and Care Plans must give legal rights, 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

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30 This reflects recommendation 23 of the Children’s Commissioner’s School Exclusions Inquiry: http://www.childrenscommissioner.gov.uk/info/schoolexclusions
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 Education, Health and Care Plan as they progress into adulthood.

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

- Education, Health and Care Plans 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 Education Health and Care Plan, 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 the 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 DfE, BIS and DWP 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 legal basis and be clearly enforceable.
- Every child with autism (including those without a statement/Education, Health and Care Plan) 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 in the action plans proposed above.
Annex

The APPGA Commission held two oral evidence sessions in March 2012.

Full transcripts of the session are available at 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 (Con)  
Russell Brown MP (Lab)

**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 Teacher  
6. Mr Paul Williams – Chair, National Association of Head Teachers’ SEND Committee and Head teacher of Shaftesbury High School in 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 of Education, 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 of Education
6. Sharon Hodgson MP, Shadow Minister of State for the Department of 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 Flello 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
Amanda Batten - The National Autistic Society
Grace Hsieh - parent of a child with autism
Carol Cullen - parent of a child with autism
Ann Memmott - adult with autism
John Phillipson – Autism Alliance