All Party Parliamentary Group on Autism
2016 Consultation Report
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APPGA: 2016 Consultation Report

Introduction

The All Party Parliamentary Group on Autism (APPGA) was set up in 2000. It is a group of Members of the House of Commons (MPs) and House of Lords with an interest in autism. They work in Parliament to improve services and support to people with autism and their families. It is this group of Parliamentarians that makes the key decisions about the subjects the APPGA considers.

The APPGA is unique in that its work is informed by reports from an Advisory Group. This is a group of interested organisations, people and families affected by autism.

This Advisory Group hosts open consultations to listen to anyone with a connection to autism in order to hear about what they think the priorities for the APPGA and Parliament should be. This is a report of the 2016 findings.

Consultation Pathway
Summary Recommendations

Introduction
This is a short summary to the long report that the Advisory Group have produced after running a consultation on what the APPGA should prioritise.

Background
In previous years the priority areas agreed by the Group were seen as hooks for separate meetings. However, this year the group agreed that the consultation would be wider, but also more long-term in its thinking. To that end we asked people to consider priorities between now and the currently scheduled end of the Parliament, which is May 2020.

Process
777 people filled out an online survey on their priorities and 52 people attended a discussion event in London. A discussion involving the Advisory Group and a number of MPs was also held at the APPGA AGM. There were also 3 separate discussions at Advisory Group meetings. People were also invited to submit their thoughts in writing. We are now narrowing submissions down to five suggested long-term APPGA objectives as follows.

1. 2019: Ten Years since the Autism Act
Mentioned by most groups at the discussion event as, after deliberation, it was felt that most of the concerns adults with autism had regarding services could be addressed through better implementation of the Autism Act. In her report to the discussion event Cheryl Gillan MP said that act itself was ‘imperfect, but the act I could pass at the time’. Government Ministers have also referred to implementation as ‘uneven’.

In terms of press and Parliamentary interest, a ten year anniversary report or series of meetings and activity would be as an excellent hook for activity. The lead in time gives the Advisory Group an excellent window to think about objectives and tactics that could ensure we meet our policy goals.

Quotes:
“"The Autism Act remains an aspiration rather than a reality”
“(The Autism Act) is so far ignored as an "advisory" by local boroughs”
“"The autism act needs review if we are going to keep it current and in the public eye. It needs more statutory clout””

2. Education Review
Education was split across two points in our survey, one covering Education Health and Care Plans (EHCPs) and the other covering teacher training. Both had also come through strongly in recent consultations. The two options came first and fourth in the results of our survey.

However, although there are problems, the EHCPs are a result of recent legislation that the Government would be unwilling to reform until there’s more evidence. The Government has also committed to give autism training to all new teachers from 2018. In light of the above and the numerous other education suggestions made throughout the consultation, as well as other upcoming Government reforms to education through new grammar schools legislation, we are recommending that between now and the end of the Parliament the APPGA undertakes some form of autism and education review. The detail can be worked on by the Advisory Group, and the two MPs who agreed to lead on education work over the coming years, Huw Merriman MP and Maria Caulfield MP.

Quotes:
“This EHCP process needs to be less confrontational, personally attacking of parents and provide support in consultation with the child”
“Many children on the spectrum fail to complete their schooling. My own son has found it very difficult to obtain work and be successful in his employment”
“I frequently come across young adults coming into our service that have not received the support they need through education. It is much harder to support these issues once they have become entrenched.’"
3. Mental Health and Autism
Under the heading of ‘Raising awareness of the other health issues/conditions that autistic people experience’ it was people on the spectrum’s mental health that came through most strongly.

This year’s report by Autistica showed how people with autism are dying on average 16 years earlier than others, with two leading causes of early death being epilepsy and suicide. This shocking revelation saw a greater focus in the media on the issue. The current Government focus on mental health offers opportunities for improving the system for autistic people, especially given the commitment to developing an autism pathway in the Five Year Forward View on Mental Health.

Quotes:
“There is a big issue with people with autism being turned away from mental health services despite having clear mental health needs in addition to their autism”
“A lot of young people with Autism suffer from mental health conditions as well as the spectrum disorder, sometimes this is because they recognise how different they are and that can make them lonely and isolated, leading to depression and sometimes even suicidal thoughts.”
“My son has been unemployed for over 7 years. His mental health is badly affected and is paranoid about people watching him and listening in via the TV, phone and computer”

4. Diagnosis and post diagnostic support
Outside the seven areas we asked people to comment on, diagnosis and support were the top issues. It was also the area of work Parliamentarians took most action on in the 2015/2016 Parliamentary year. The Government has also accepted that waiting times must come down.

During our work on this issue the APPGA managed to secure some significant government concessions around data collection and review. However, turning these hard won commitments into the reducing of wait times may require significant campaigns and Parliamentary pressure.

Quotes:
“My daughter is an adult and we cannot get a diagnosis, and as such we cannot access the mental health support she needs”
“Diagnosis. Diagnosis. Diagnosis. The process was hostile and personal and completely broke down at school”
“To improve the waiting time for ASD assessment at CAHMS. In our local area it is currently 22 month”

5. Raising awareness of the needs of autistic people in the criminal justice system
Although this didn’t score high on our online survey, it came through very strongly in our discussion event and it’s also true that the best attended APPGA meeting was on this subject. It doesn’t affect many people, but the impacts on the individual are life-changing and often disastrous.

As demonstrated by the lack of cut through in the survey, awareness of the problem is low, therefore I am suggesting we accept this recommendation’s aspiration to ‘raise awareness’ through the APPGA, whether this is through PQs or initiatives like the Feltham prison visit or a public meeting.

Quotes:
“The Criminal Justice system is light years away from anything approaching an understanding of autism and its relationship to offending.”
“There is growing awareness of autism within the criminal justice system, but this is still very low. Without understanding of autistic people as either offenders, victims or witnesses, they cannot be catered to very well and will end up being discriminated against as a result”
“It scares me that one day my son will almost certainly encounter the police, and they won’t have the understanding or compassion to talk to him in a way that won’t frighten him into a meltdown”
2016 Consultation Process

Background
Since 2012 the APPGA Advisory Group has run an annual consultation event in London to try and identify four topics for discussion and work throughout the year.

This year the Advisory Group reviewed that process as it was identified that.

a) One event in London spoke to a narrow set of people.
b) The one topic, one meeting approach only narrowly represented the work the APPGA does and gave little scope for long-term work.
c) The topics we debated were largely chosen at one meeting of the Advisory Group and we needed to get a wider steer on those from both our members and stakeholders.

To address these issues it was agreed we would:

a) Have an online survey running alongside the event. Also explicitly give people an opportunity to put their thoughts in writing and invite more expert stakeholders to our consultation event.
b) Extend the ambitions for the consultation beyond this year and talk about ‘to the end of the Parliament’.
c) Use additional topics collected at last year’s consultation to narrow down a shortlist of topics with the Advisory Group and then ask the Members of the APPGA to comment on the short list.

The Topics

1. Training for teachers and others who work in schools and education.
   Education is always a popular topic with campaigners and ‘having my child’s needs understood at school’ was the number one issue with education as identified by a recent National Autistic Society survey.

2. Making sure that autistic adults can get specialist help to get a job.
   While the APPGA already agreed to this being a long-term focus of work last year, with both Ambitious About Autism and the National Autistic Society doing work on this area it would be counterproductive not let participants talk about it. It also ranks as the top issue in recent National Autistic Society surveys of adults.

3. Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse).
   This year’s report by Autistica on suicide and people on the autism spectrum saw a greater focus by the media on some of the other issues that people on the autism spectrum face. The Group wanted to give people an opportunity to examine some of the other underlying issues.

4. Making sure the changes to education and the introduction of Education, Health and Care Plans (EHCPs) to replace statements are working for autistic children and young people.
   As education was so strong in previous years the Advisory Group wanted to include two different topics. Recent Government reforms meant children on the spectrum were also transitioning from statements to EHCPs and the Advisory Group wanted to see how these reforms were working. It’s also true that many MPs reported parents coming to them with problems around implementation.

5. Reviewing the Autism Act and identifying where changes are needed (note: 2019 will be the 10th anniversary of the Act).
   The upcoming anniversary of the act was identified by the Advisory Group and Parliamentarians as an excellent hook for further campaigning and reform. The long lead in time would also allow for a wider
discussion about the kinds of reforms campaigners would like to see to the act.

6. **Raising awareness of the needs of autistic people in the criminal justice system.**
   Whilst this scored low on recent consultations many of our most engaged campaigners have a passion for reform with our busiest ever public meeting being on the topic. It was also highlighted as area where very little campaigning had been done.

7. **Making sure that NHS plans on getting people out of secure hospital placements work for all people on the autism spectrum.**
   Following the Winterbourne View scandal the Government announced a fixed target of moving people out of inpatient units and into community care based settings. The Advisory Group wanted to have a discussion about whether this approach was working people with autism.

**What’s Missing?**
The Advisory Group and the MPs also wanted to make sure people responding didn’t feel limited to the seven topics we wanted to know more about. Therefore respondents were also asked at every opportunity what else they thought we should discuss.
Online Survey Results

Background
In order to broaden participation in the consultation the Advisory Group launched an online survey. The survey asked participants to identify their chosen three priorities based on the previous work the Group had done identifying topic areas. The seven areas were:

1. Training for teachers and others who work in schools and education.
2. Making sure that autistic adults can get specialist help to get a job.
3. Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse).
4. Making sure the changes to education and the introduction of Education, Health and Care Plans to replace statements are working for autistic children and young people.
5. Reviewing the Autism Act and identifying where changes are needed (note: 2019 will be the 10th anniversary of the Act).
6. Raising awareness of the needs of autistic people in the criminal justice system.
7. Making sure that NHS plans on getting people out of secure hospital placements work for all people on the autism spectrum.

The survey also asked for demographic information, such as age and race, and also the respondents’ relationship with autism. We asked if they were themselves on the autism spectrum, were writing it on behalf of someone on the spectrum, if they were the parent of someone on the spectrum, and whether they were a professional or a campaigner. This is so we can further breakdown the information we were given. The following pages give a breakdown of the top three priorities on overall results and also broken down by the respondents’ relationship to autism.
Results

Overall results by every respondent

- Training for teachers and others who work in schools and education: 58%
- Making sure that autistic adults can get specialist help to get a job: 51%
- Raising awareness of the other health issues/conditions that autistic people experience: 50%
- Making sure the changes to education and the introduction of Education, Health and Care Plans to replace statements are working for autistic children and young people: 46%
- Reviewing the Autism Act and identifying where changes are needed (Note: 2019 will be the 10th anniversary of the Act): 31%
- Raising awareness of the needs of autistic people in the criminal justice system: 30%
- Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism spectrum: 20%
Results from people who self-identified as being on the autism spectrum

- Making sure that autistic adults can get specialist help to get a job: 60.66%
- Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse): 59.02%
- Training for teachers and others who work in schools and education: 50%
- Reviewing the Autism Act and identifying where changes are needed: 44.26%
- Raising awareness of the needs of autistic people in the criminal justice system: 22.95%
- Making sure the changes to education and the introduction of Education, Health and Care Plans to replace statements are working for autistic children and young people: 20.49%
- Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism spectrum: 18.03%
People who said they have a family member on the autism spectrum

- Training for teachers and others who work in schools and education: 62.75%
- Making sure that autistic adults can get specialist help to get a job: 55.88%
- Making sure the changes to education and the introduction of Education, Health and Care Plans to replace statements are working for autistic children and young people: 53.59%
- Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse): 48.37%
- Reviewing the Autism Act and identifying where changes are needed: 31.70%
- Raising awareness of the needs of autistic people in the criminal justice system: 21.24%
- Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism spectrum: 16.99%
People and who said they worked with those on the autism spectrum

- Training for teachers and others who work in schools and education: 56.61%
- Making sure the changes to Education, Health and Care Plans to replace statements are working for autistic children and young people: 52.38%
- Raising awareness of the other health issues/conditions that autistic people experience: 48.68%
- Raising awareness of the needs of autistic people in the criminal justice system: 46.56%
- Making sure that autistic adults can get a job: 35.98%
- Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism spectrum: 24.87%
- Reviewing the Autism Act and identifying where changes are needed: 21.16%
Where respondents lived

- England - 92.0%
- Northern Ireland - 0.3%
- Scotland - 3.4%
- Wales - 2.5%
- Other - 1.9%

Age of respondents

- 0-18 - 26.8%
- 18-35 - 24.1%
- 36-64 - 46.1%
- 65 or over - 1.8%
- Rather not say - 1.2%

Gender of respondents

- Male - 40.6%
- Female - 56.3%
- Trans - 0.8%
- Rather not say - 2.2%
- Other – 1.2%

Ethnicity of respondents

- White British - 85.5%
- White Irish - 2.0%
- Any other White background - 3.8%
- Mixed: White and Black Caribbean - 0.2%
- Mixed: White and Black African - 0.0%
- Mixed: White and Asian - 0.6%
- Any Other Mixed Background - 0.8%
- Asian or Asian British: Indian - 0.6%
- Asian or Asian British: Pakistani - 0.2%
- Asian or Asian British: Bangladeshi - 0.2%
- Any other Asian background - 0.2%
- Black or Black British: Caribbean - 0.6%
- Black or Black British: African - 0.4%
- Any other Black background - 0.4%
- Chinese - 0.6%
- I would prefer not to say - 3.0%
- I don't know - 0.0%
- Any other ethnic group - 0.8%

What was the respondent’s relationship to autism?

- On the autism spectrum - 18.4%
- Written on behalf of someone on the autism spectrum - 1.5%
- Have a family member on the autism spectrum - 45.4%
- A professional who supports or works with people on the autism spectrum - 30.2%
Why did respondents pick those issues?
We asked why they picked those three issues in the form of a free text box. 68% of respondents (529 of 777) took the opportunity to do so. Below are a summary of responses and quotes from people who took part. Some details have been changed so that responders remain anonymous.

The majority of comments were about the need for **training for teachers** and how a lack of training or understanding by teachers affects children’s development in schools, the impacts on future outcomes beyond school.

> “Awareness is so important so that teachers understand behaviours that come with anxiety are not just a naughty child. We need to bring out the best in autistic people”

> “It’s key that children & Young people are understood & supported in education for positive self-esteem & enabling them to reach their potential so they can confidently go on as adults. To be labelled as ‘difficult’ & threatening expulsion from school from even the one teacher can have dire consequences as experienced with my son”

> “I chose the issue of training for teachers and schools as I frequently come across young adults coming into our service that have not received the support they need through education. It is much harder to support these issues once they have become entrenched and without the structure of the education system to support input”

> “Many children on the spectrum fail to complete their schooling. My own son has found it very difficult to obtain work and be successful in his employment. It is a grave concern that so many people on the spectrum end up in (prison)”

> “Because training for teachers is poor and patchy across the country and children are not having their needs recognised at an early age”

> “More training is needed in schools to make it possible for our children to be able learn and build acceptance from an early age”

**Specialist help for adults into employment** was raised by many, especially because respondents on the spectrum wanted to move into work. Respondents identified the need for better training for Job Centre Plus staff, more specialist staff to assist with getting employment, access to a wider range of vocational training, more support to stay in employment, more awareness training for employers, and more flexible working arrangements.

> “At 23 I am struggling to gain meaningful full time employment. I dropped out of university due to lack of support around my anxiety issues”

> “There can be a lack of information about available jobs, opportunities for jobs and understanding about how difficult the processes can be when it feels like you’re being taken blindfolded to be judged for your crimes and then executed. It’s an extremely stressful and anxiety provoking process, especially when you get people that are very adversarial and confrontational in their approach to questioning you”

> “Interviews are about demonstrating your ability to perform in a process, not your ability to do a job. I know that I have struggled with finding jobs and attending interviews as well as dealing with managers who lack appropriate social skills in dealing with their staff, which can make work extremely stressful”

> “Over 40 autistic adults (in my service) need specialist help in getting employment.”
“It is almost impossible for Autistic people get employment because the general public & the Jobseekers advisers have had no awareness training on Autism”

“We need to understand the positive elements that people with autism can bring to the workplace - Autism is much more than a list of challenges”

“My son has been unemployed for over 7 years. His mental health is badly affected and is paranoid about people watching him and listening in via the TV, phone and computer”

“Help is not just needed in getting a job, but keeping it too”

“Access to a wider range of vocational training to support aspirations and goals rather than traditional academic routes”

“Awareness raising with employers. Traditional job shortlisting techniques and job design is archaic and does not reflect the complex needs of people with different social and mental attributes. Perversely some of the best people for certain roles will have heightened skills because of Asperger’s or autism, but will not be able to get past the shortlisting process”

Comments about raising awareness of the other health conditions experienced by autistic people included the need to raise awareness about mental health, sensory, neurodiversity, and atypical forms of autism.

“People are frequently told they cannot access health services because of their diagnosis and our service is expected to resolve every issue for an individual even when we don't have the relevant expertise. In my locality there is a big issue with people with autism being turned away from mental health services despite having clear mental health needs in addition to their autism”

“Health wise I feel there are a multitude of ailments that are related to autism that are entirely overlooked by GPs. The root cause of certain ailments come from very different places and so the way GPs look at it or treats it has to take the autism into account too”

“A lot of young people with Autism suffer from mental health conditions as well as the spectrum disorder, sometimes this is because they recognise how different they are and that can make them lonely and isolated, leading to depression and sometimes even suicidal thoughts. Often people with autism suffer from sensory integration issues, and are hypersensitive to sound and texture and general overstimulation which can lead to other problems, all of which those who might find themselves supporting with an autism need to be aware of. The whole of society needs to be more aware, as more and more people are diagnosed”

Many raised the issue of Education Health and Care Plans (ECHPs) and wanting to ensure they serve the needs of autistic children but concerned that they are ineffective. Many had trouble with the process of getting an assessment or faced a lack of understanding of autism by assessors.

“I think there are still gaps in the way EHC plans have been rolled out which feed into all of the areas highlighted above for young people with autism. In particular, the barriers in accessing an EHC plan to start with and access to impartial support in identifying long term aspirations and the support needed to achieve these. Although pockets of excellent work, this is not currently consistent for all young people who require it”

“I work for (an organization who supports) young adults to train and find employment and more is needed to support this both awareness and funding. The EHCPs are key to our funding and LAs are not processing them or allocating funds quickly enough... People close to 25 may not even be allowed to apply for them.”

“Failure of Social Services Departments to attend Transfer Reviews for EHC Plans”
“Persistent failure of Social Services (in my area) to input to Sections H1 and H2 of EHC Plans, so that the social care provision required always reads ‘none’”

“This EHCP process needs to be less confrontational, personally attacking of parents and provide support in consultation with the child”

“The EHCP doesn't really give the help an autistic child needs in mainstream school”

“I am still awaiting EHCP assessment which is being diverted as much as possible due to LA not wanting to fund as no provision locally to meet need”

Comments on the Autism Act tended to state that it needed to be reviewed more regularly, to be enhanced, to be more specific and enforceable – particularly to ensure local authorities deliver on what they ought to do.

“Legislation is an integral part of the process of change and creating a society that recognises its duty in helping, understanding and supporting people. Sometimes, raising awareness just isn't enough to help shape the process of change but through legislation and reviewing this legislation it will help change the mind-set and attitudes of people that will help shape a more positive society”

“The Autism Act should be regularly reviewed. Just because it exists doesn't mean it's being implemented, and cultures can change a fair bit in ten years so it's worth reviewing it”

“The autism act needs review if we are going to keep it current and in the public eye. It needs more statutory clout”

“(The Autism Act) is a good start but needs enhancing”

“The Autism Act remains an aspiration rather than a reality”

“The Autism Act says little about those at the more severe end of the spectrum. It should be modified to protect people who also have a learning disability and who are likely to challenge services and be subjected to restrictive, damaging interventions”

“The Autism Act has helped in some ways but not enough and not enough regarding funding to provide support for those with autism”

“I hope reviewing the Autism Act would cover the NHS, EHCPs and criminal justice system”

“The implementation of the Autism Act…. It is so far ignored as an ‘advisory’ by local boroughs”

“Having an autism act isn't enough unless it’s regulated. I work for a local authority and they systematically fail to comply with the act and are never held accountable”

Raising awareness of the needs of autistic people in the criminal justice system generated much comment despite being ranked no.6 in the list of priorities. Issues identified included poor understanding of autism by police, proposing a police autism lead officer, better identification of and support for autistic prisoners, more training for professionals in the criminal justice system, support for parents of autistic people who are in court and generally more awareness of autism in criminal justice.

“There is growing awareness of autism within the criminal justice system, but this is still very low. Without understanding of autistic people as either offenders, victims or witnesses, they cannot be catered to very well and will end up being discriminated against as a result”

“A high proportion of young people have been identified as being on the spectrum in the criminal justice system. These young people struggle to sustain interventions set for them not because they won’t comply but
because they often don’t fully comprehend the processes and structure required. There is a serious need for early intervention and schools must be more aware of the condition and provide the necessary support including EHCP's where necessary”

“The Criminal Justice system is light years away from anything approaching an understanding of autism and its relationship to offending”

“It is essential young people get a good start in life. The Criminal Justice System knows little of Autism & how it impacts lives. My local police now have an Autism Lead officer. People with Autism want the independence of employment like anyone else, we just need support to gain employment”

“If they are working in the police/criminal justice, how they can recognise the signs of someone who may have autism (without making assumptions) and help them if they ever find themselves in trouble with the law, or on the receiving end of criminal activity”

“So much needs to be changed in the criminal justice system to help people with autism … police on the beat need to all have training in autism, alongside general training in people skills … my dealings with police have been largely negative, and have required patience and calm from myself … It scares me that one day my son will almost certainly encounter the police, and they won’t have the understanding or compassion to talk to him in a way that won’t frighten him into a meltdown”

Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism did not generate much comment but those that did were concerned that while its aims were desirable, a clear enforceable strategy was needed to ensure delivery. In addition there was a concern to ensure adequate funding support services were available in the community.

“The Transforming Care Programme (TCP) sets out some highly desirable aims which need an appropriately focused enforceable strategy to ensure those changes are delivered. The details of what would be an effective strategy are not defined by NHS England and the DH in their plan so the TCPs will have to design their own strategies and priorities. I am concerned that because our area meets the guidelines with regard to inpatient beds, no additional funding has been offered to support the transformation process. …The opportunity to deliver the stated aims and intentions of Transforming Care should not be missed …The APPG should seek to ensure that Transforming Care is delivered ‘as advertised’ in a way that is holistic and prevents admission to services that simply contain people by means of restrictive interventions such as chemical restraint, physical restraint and seclusion”

“The NHS plan to remove large numbers of people from secure hospital placements before adequate support is in place, is another ill-considered broad brush move that will soon make its impacts evident through widespread problems on multiple fronts”

“I am a LD Nurse and … feel that although it is vital that we move people from restrictive environments in secure hospitals it must be evident that what we are replacing this with is robust and an improvement”

“Our son ended up in an Assessment and Treatment Unit for 18 months. This did not help him at all, and he was stuck in the system as there wasn’t enough support in the Community”
Consultation Event Summary

Introduction
On the 14th November a discussion event was attended by over 50 people. The format of the event largely followed the same route as the survey and attempted to find out if people’s views changed after discussion and to dive deeper into some of the reasons as to why people had different views. Discussions were held in groups of roughly 6 to 8 people. A full minute of the discussion event can be found in appendix one.

Discussion headlines
The top items that attendees thought should be discussed in their groups were EHCPs, teacher training and employment.

On EHCPs it was noted that parts of the plans were not enforceable by tribunals and that it was those parts that tended to be the weakest with agencies not attending meetings or engaging with the process. This led to discussions over co-ordination between different government agencies. There were discussions over the time it took to get plans in place with some local authorities using inappropriate providers.

For teacher training attendees broadly welcomed that autism would be included in the new framework of initial teacher training. However, it was noted that there is still a need to make sure existing teachers are trained and that all staff at schools get some basic level awareness training. Participants also highlighted the need to continue to feed into the framework of that training to ensure schools helped autistic pupils prepare for life after they finish school. The training of SENCO, teachers at special schools and also in Higher and Further education was also touched upon.

On employment attendees pointed to the need to both help people get a job and also support them once in work, with Access 2 Work being underutilised by business. Attendees were also critical of both the work programme and the support they received through Job Centre Plus. The need to raise awareness amongst employers was also highlighted as a key issue.

Other topics
Raising the awareness of other health issues was also discussed. It was noted that it was important to not just talk about ‘co-morbidities’ but to touch on areas like anxiety, depression and other health impacts that people on the autism spectrum face. Co-ordination between different government agencies in dealing with this issue was also touched upon.

On the Autism Act many participants felt that the issues which were touched on in other areas like employment, other health issues and the criminal justice system, could be worked on through the prism of a review of the autism act. It was also highlighted that a ten year anniversary could be an opportune moment to look at the issue again.

Finally discussions on the criminal justice system centred around training and consistency throughout the whole system (police, courts, prisons, probation). Some attendees also remarked that disability hate crime was thought to be on the rise.

No groups chose to discuss making sure that NHS plans on getting people out of secure hospital placements work for all people on the autism spectrum.

Conclusions
The discussion event closely followed the events of the survey, as you would expect. It’s clear that Education remains a key issue but that the concerns many have fall outside the remit of ITT or EHCPs and are indicative of a much wider set of issues. It is also clear that after discussion that both a review of the autism act and the criminal justice system were at the forefront of many in the group. It’s also clear that the majority wanted to see the APPGA continue to work on employment.
What are we missing?: Potential topics for future discussion

Introduction
We wanted to make sure that the seven topics we consulted on were the right topics so we gave both respondents to the survey and attendees at the consultation the opportunity to express which topics outside the seven they thought we should discuss.

Online Survey
On our online survey 37% of respondents (286 of 777 respondents) made comment about the areas they would rather see covered, that 63% chose not to gives us a good indication that the seven topics were in the right area.

Social Care and other support outside Education
The generic need for ‘more support’ was raised by many, including a lack of help for people on the spectrum in the social care system. Comments related to the need for more early intervention, more specialist support in schools, support to transition from school to adulthood, more specific support for autistic girls, mentoring and training for parents, more support for family members – including working parents, more mental health support, and more support for high functioning autistic people.

People also spoke about the fact that they now seems to be less support available for people than previously. Respite care also came through strongly, especially from those who have no relatives to help take care of their child. Support for families who home-schooled their autistic was also mentioned. It was cited that they felt they got no support from the government.

School transport was also raised a number of times. With respondents saying it should be free of charge. People also said the medical and other information that is collected for the EHCPs should be made available to those dealing with school transport.

More specialist adult specific services in general and in particular for older autistic people including more support for late-diagnosed adults was also mentioned a lot, especially in conjunction with awareness, housing and employment.
“All expenses have to be met by the carers because the law says that we carers ‘elected’ to home-school when, in fact, there is no other alternative. If the child receives financial support at school from the local authority, then once the child is home-schooled the funds should be used to support the child”

“There is a lot of emphasis on, and support for, children and young people with autism, which is great, but too often adults tend to get left out, and adulthood is mostly where the problems start”

“Don’t forget this growing group of adults (especially those over 40) who did not have the benefit of support when they were younger”

“I feel overall that there is limited knowledge that adults are also effected by autism as main campaigns about autism are done by parents of children so concentrating on children with autism”

**Diagnosis**
Diagnosis was a key issue, whether it was about an inability to access a diagnosis assessment, or more timely access to a diagnosis or a process that could be more autism-friendly to people on the spectrum and their families. Better training for and understanding from assessors about autistic people or better access to services post-diagnosis was also highlighted.

“My daughter is an adult and we cannot get a diagnosis, and as such we cannot access the mental health support she needs”

“Ensuring all who are affected have equal access to diagnostic assessments… this is not currently the case”

“Improving the speed of access to assessment, support and treatment for very young children with Autism emphasising the importance of early intervention”

“To improve the waiting time for ASD assessment at CAHMS. In our local area it is currently 22 months. This is causing untold anguish for families who are struggling to cope with behaviours that relate to ASD”

“Diagnosis. Diagnosis. Diagnosis. The process was hostile and personal and completely broke down at school”

“Our journey to diagnosis was made so hard by those that should have been helping us that our family nearly didn't survive it”

“Finding the right people from the beginning of diagnosis is very important. You need the right support from the start of your child’s diagnosis otherwise like myself you have to fight to get the right support and as parent carers we shouldn’t have to fight for the support our child needs”

**Training**
Training for all professionals was considered important, particularly those working in the health, social care and criminal justice systems. The need to be more “compassionate”, “to not stereotype”, and how to communicate and develop a good working knowledge of autism and autistic people was highlighted. More awareness of autism in girls and more inclusion for people on the spectrum in mainstream society was also raised.

“Attitudes need to change towards ASD. I’ve never been so embarrassed and angry at the disgusting way (my recently diagnosed husband) is treated by people like DWP, ATOS, NHS and the Job centre. Lots of training needs to be given to those in positions who are going to come into contact with people with autism, and it needs to happen fast”
“In particular, teaching GPs the limitations and specialist considerations when interacting with high functioning autistic adults. I knew I had something wrong, but my anxious communication style impeded access to specialist services”

“Ensuring that qualifications for working with/teaching people on the autistic spectrum are valid and consistent in ensuring all staff are appropriately trained across all areas of support”

“Hospital staff are very much in need of training on Autism - how it can affect people in a clinic/hospital environments and learn about what reasonable adjustments can be made...... Staff ignorance of Autism can cause great distress; ‘unusual behaviour’ is so often put down to mental health issues (and) the needs of patients with Autism are not met”

“Training for NHS staff in both in-patient and out-patient situations involving autistic adults. To raise awareness and provide training for people in the health and police services to understand in particular the challenging behaviour aspects of autism”

“In particular making sure that doctors/nurses who do the ATOS assessments are knowledgeable to a decent standard in Autism Spectrum disorders before they even go near a claimant with the condition. My partner has recently had a breakdown following his ATOS assessment, because the nurse who took the assessment didn’t understand anything at all about Asperger’s Syndrome”

**Housing**

Finally accommodation and housing was also identified as an area that needed more consideration. Views ranged from more housing being needed to a better system of allocating housing and more choice in supported accommodation. Making it easier to live in supported accommodation closer to families, and more flexible housing assistance was also mentioned.

“More help needed for young adults who want to live on their own in a flat or one bedroomed house and help them become more independent to be able to live on their own”

“Local Authorities struggle to house young adults when they reach the end of their residential care, this can be very upsetting for them and their families. A better housing system and allocation of housing needs to be agreed and planned well before the transition stage”

“A bigger commitment to making it possible for adults with autism to live in specialist supported living close to their families”

**Discussion Event**

Attendees at our discussion event were also asked to write down any topic or issue they felt should be discussed at future events. These are collected verbatim in appendix one. In terms of topics, training for professionals came through the strongest, but funding, issues with our social care system and a variety of problems in the criminal justice system were also highlighted numerous times.
Recommendations

NB: A summary of recommendations can be found page 4.

Recommendation 1: Focus on ‘2019 Ten Years since the Autism Act’

Mentioned by most groups at the discussion event as, after deliberation, it was felt that most of the concerns adults with autism had regarding services could be addressed through better implementation of the Autism Act. In her report to the discussion event Cheryl Gillan MP said that act itself was ‘imperfect, but the act I could pass at the time’. Government Ministers have also referred to implementation as ‘uneven’.

In terms of press and Parliamentary interest, a ten year anniversary report or series of meetings and activity would be as an excellent hook for activity. The lead in time gives the Advisory Group an excellent window to think about objectives and tactics that could ensure we meet our policy goals.

Recommendation 2: Focus on an Education Review

Education was split across two points in our survey, one covering Education Health and Care Plans (EHCPs) and the other covering teacher training. Both had also come through strongly in recent consultations. The two options came first and fourth in the results of our survey.

However, although there are problems, the EHCPs are a result of recent legislation that the Government would be unwilling to reform until there’s more evidence. The Government has also committed to give autism training to all new teachers from 2018. In light of the above and the numerous other education suggestions made throughout the consultation, as well as other upcoming Government reforms to education through new grammar schools legislation, we are recommending that between now and the end of the Parliament the APPGA undertakes some form of autism and education review. The detail can be worked on by the Advisory Group, and the two MPs who agreed to lead on education work over the coming years, Huw Merriman MP and Maria Caulfield MP.

Recommendation 3: Mental Health and Autism

Under the heading of ‘Raising awareness of the other health issues/conditions that autistic people experience’ it was people on the spectrum’s mental health that came through most strongly.

This year’s report by Autistica showed how people with autism are dying on average 16 years earlier than others, with two leading causes of early death being epilepsy and suicide. This shocking revelation saw a greater focus in the media on the issue. The current Government focus on mental health offers opportunities for improving the system for autistic people, especially given the commitment to developing an autism pathway in the Five Year Forward View on Mental Health.

Recommendation 4: Focus on diagnosis and post diagnostic support

Outside the seven areas we asked people to comment on, diagnosis and support were the top issues. It was also the area of work Parliamentarians took most action on in the 2015/2016 Parliamentary year. The Government has also accepted that waiting times must come down.

During our work on this issue the APPGA managed to secure some significant government concessions around data collection and review. However, turning these hard won commitments into the reducing of wait times may require significant campaigns and Parliamentary pressure.

Recommendation 5: Focus on ‘Raising awareness of the needs of autistic people in the criminal justice system’

Although this didn’t score high on our online survey, it came through very strongly in our discussion event and it’s also true that the best attended APPGA meeting was on this subject. It doesn’t affect many people, but the impacts on the individual are life-changing and often disastrous.
As demonstrated by the lack of cut through in the survey, awareness of the problem is low, therefore I am suggesting we accept this recommendation’s aspiration to ‘raise awareness’ through the APPGA, whether this is through PQs or initiatives like the Feltham prison visit or a public meeting.

**Recommendation 6: Omissions**

A number of topics came through strongly but are omitted from the four priorities in our summary note.

Employment came through very strongly as a topic that many wanted to see followed. Especially amongst people who were themselves on the spectrum. It’s worth noting that the National Autistic Society has recently launched a new campaign on employment, with the support of the APPGA. Therefore for the time being the APPGA does not need to pursue particular actions in this area. However, given its prominence, this is something we should continue to monitor between now and the end of the Parliament.

**Recommendation 7: Future consultations – potential topics**

Outside the topics mentioned above I am highlighting the following topics which were mentioned by a number of participants. We may want to consider whether these could be part of other topic areas or whether they need further action:

- Housing
- Training of Health Professionals and/or Benefits Assessors
- Access to support (e.g. in the social care system)

**Recommendation 8: Future consultations – processes**

At the end of this process we will have a framework between now and the end of the Parliament, therefore I am proposing that any consultation we do between now and then would be more closed and focus on the agreed topics. For example, in 2018 we will want to start work on the ‘10 years on from Autism Act’ work and so the 2017 consultation event should help shape what that looks like.

It’s important we start with a look back at what the act has achieved before moving on to a discussion about what we can realistically achieve in terms of putting the act on a stronger footing. There should also be work on the different policy areas affected by the act and a look at where the gaps are.

It is also worth noting that our demographic breakdown does not represent the population as a whole. In particular, BAME voices and the issues they face are hugely under-represented. It would be worth exploring how we can make sure we have a more diverse perspective inputting into our work.

Finally, there is potential for an early General Election as a result of Brexit. It should be noted that the APPGA would need to be re-constituted and this work reviewed in light of the new membership.
Appendix 1: Consultation Event Minutes

NB: Each group moderator feedback on their groups three chosen topics and feedback on the reasons why. Groups feedback in different ways and some also gave us additional notes. For that reason the format is not consistent across groups.

Group 1

1) Making sure autistic adults get help to get a job:
   - making sure employers and autistic people have the right information, in addition to specialist support to help people in work and to help people into work
   - perhaps a jobs passport for autistic people

2) EHC plans:
   - Ensure there is training for all staff including higher education and further education
   - There is no autism specific services around transition
   - Involve parents where you can
   - Life skills should be included in the transition plan

3) Reviewing Autism Act:
   - supports based on skills and strengths and wants, but recognising challenges
   - addressing regional disparity
   - Access to services that are for autism, ensuring people can get the right support

Group 2

Review the autism act and identifying where change is needed:
   - Move beyond awareness – need to move to inclusion and acceptance.
   - Need to look at the meaningful aspects of autism and make specific improvements to the Autism Act, which is nearly 10 years old
   - Also need to move beyond the act only catering to adults and find a way to build in children and young people
   - Umbrella term to make improvements in provision of state services and resources

Raising awareness of the needs of autistic people in the criminal justice system:
   - Think this should be opened up to THE justice system to include; not just criminal, but civil, family and tribunal
   - Lack of consistency – need same continuity throughout the system from police officers to court/prisons/probation and also a diversion pathway for autistic adults and young people (barriers): autism card
   - Strategy in place and raise profile of the issue of Hate Crime on the rise (especially disability) - autism specific hate-crime under reported

Raising awareness of other health issues/conditions that autistic people experience
   - Move beyond to the wider effects of autism not just co-morbidities
     i.e., non-gender conformity in autism, mental health conditions (i.e. anxiety, depression), drug and alcohols use, self-medicating
   - No holistic view: communication, co-ordination, manage between groups of professionals – very little contact between both, CAHMS swamped (18 month waiting)
• Co-locating and joining up services, as well as specific autism training
• Voices of individuals, alongside voices of experts

Overall; it’s understanding, training and inclusion of autism – front line professionals and those on the ground i.e. police, teachers, healthcare – not through lack of willing, its provision and resources. Tie into each other.

**Group 3**

**EHCPs**

• Needs to be flexible
• Needs to be consistent across Local Authorities
• Parts of the plan is not enforceable, social care and life skills training are not enforceable.
• Some funding pays up to post-25
• Not always using the most suitable providers
• Has basic info about what specific needs the has child has & what training/support the staff needs
• Need to Pick-up additional needs e.g. mental health, identity (e.g. transgender)
• Needs to be more co-ordination between all health professionals
• Local Authority taking over corporate parenting if the child needs 52 wks schooling, which is getting drawn into Looked After Child legislation – stigma associated with this
• Children without diagnosis get no EHC, and also get into Youth Justice system
• Youth Justice – children can be seen as ‘non-compliant’ because they aren’t coping with the system
• Young people with learning disabilities are having their mental health needs underestimated

**Employment**

• Specialist help to get a job
• Training for teachers will help with this early on
• Job Centre and DWP work programme don’t work, some people are not on ESA and so not eligible for Specialist Training
• Incentives and training for Employers – e.g. to sponsor people
• Job Centre staff and assessors have poor training and
• Needs to be life skills training before work
• Job coaching – Access to Work is underutilised
• Equality Act isn’t enforced, employers need to be supported
• Are people really given a choice of careers?
• Can be quite complicated to explain the diversity in the spectrum

**Teacher Training**

• What happens after teachers training, no feedback from schools
• SLT
• Autism is very broad. Recognised training programmes need to be specialised for each target audience and group.
• SEN should be an enforced training requirement
• Need practical skills and what is the content?
• Transition is a key time, and needs to look at Planning After School
• Training needs to be ongoing
• Inconsistencies year to year depending on who the teacher is
• SENCO shortages, what will their training be?
• Will all existing teachers have the same training rolled out
Making sure to keep stats
Gov’t should allocate money for autism training
Underestimating / diagnostic shadowing makes it difficult to address other health needs
Whole school should be trained regarding positives of having autism to reduce stigma

Group 4

Teacher training priorities:
While the ITT change was welcome, there was broad support for training for existing teachers, governors and pupils. This should include the co-morbidities which present alongside autism. One participant suggested training should include how to create an autism-appropriate learning environment. Several people were concerned about fragmentation with academies, free schools and independent schools all bending or breaking the rules around SEN, seemingly with impunity. Ofsted could be charged with rating schools on their SEN provision. PRUs were highlighted as a key place to improve autism awareness. Referral to a PRU should automatically trigger a diagnostic process with diagnosticians explicitly tasked with looking for autism and other co-morbidities like mental health issues, ADHD etc.

Employment:
There was widespread support for the idea of employer training to combat myths about autism and encourage employers to look at the positives autistic people can bring. We should avoid ghettoising autistic people into menial or data entry roles. Could employers be offered grants or tax breaks for taking on autistic staff? Employers should be made aware of the co-morbidities which exist. Accommodations might be made for autism but what about ADHD, epilepsy or mental health issues? Autism shouldn’t overshadow these other needs. Zero hours contracts, short term contracts and roles where hotdesking or constant change are integral were all raised as likely to cause distress in autistic people. Job Centres should take this into account. Two examples were shared of people taking a short contract job of a few days then losing access to benefits for months because the system didn’t catch up with them.

EHCPs:
Some local authorities are not transferring statements to EHCPs because they want to avoid paying for people post 16. Families with children diagnosed with Asperger’s struggle to get support as their academic ability puts them over the threshold. Many plans lack any care or health elements – has the pendulum swung too far in the education direction? Given what we know about co-morbidities, health is particularly important in EHCPs in autism.

Group 5

Training for teachers and others who work in schools and education
- Getting ITT right
- Training for existing teachers
- Basic awareness training for all staff working in schools

Making sure that autistic adults can get specialist help to get a job
- Employer support to help them understand and keep people in employment
- Help and training in the practical skills like interviews and CV’s
- Wide spread awareness and education in what autistic persons can bring to work place and the benefits in employing them

Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse
• Awareness training for a wide range of service providers such as within the criminal justice system, police, health services and MPs!
• Finding ways deal with and work on root courses not simply looking at the treatment such as medication
• Early intervention and prevention

**Group 6**
• Teachers Training – should be training for teachers as well as for frontline health workers. Care Act also has no minimum standard about training, people are being assessed not following the NICE guidelines.
• Criminal Justice system a key priority.

*NB it was noted that many of the attendees in this discussion fed in using the flipchart*

**Flipchart notes: What are we missing?**
*NB: We asked attendees to write about the topics we are missing on a flipchart in the room. Below is the verbatim write-up of that discussion*
• Little training CSJ in autism, they had some SLT training
• Impact of Brexit on care staff
• Funding – long term projections of need
• GPs won’t send for brain scans
• Hate crime and bullying – we need to keep stats on this for autism
• Many organisations are not being consulted because they are too small
• Autism innovation Fund – what happened to phase 2?
• HCPC Review Social Work Training

**BAME – Diverse Perspectives**
• Awareness raising/ support/ outreach/ peer support/ cultural/ holistic approach
• Involve community/ faith sector/ reduce isolation. Data/ transition/ reduce isolation/ EHCP involvement
• Reduce stigma
• Enable/Involve/ Value

**Mental Capacity Act – 2006 and Court of Protection**
• The act needs 3 categories not 2, as it is presently
• Finance
• Health
• Legal matters – ability to instruct a solicitor
• Legal safeguard: Person holding Power of Attorney can be jailed if they fail to act in the interests of the autistic person

**Legal representation:**
• Please could the MPs sort out the problem of legal representation for autistic adults in the family court
• Sir James Munby – Family Justice Council
• October 2016 – problem is being sorted out the Attorney general needs to enact this simple change.
• Please can the judiciary and parliament co-operate to amend the 2012 act on Legal Aid.

**SPA**
• Local councils (single point of access) social services

**Data**
Important to record how many autistic people demographics in a locality in order to plan, monitor and evaluate services.
Care Act Advocacy:
  - It’s a social workers duty to refer for this, yet too often people are been left without this support as referrals are not made. How can we better regulate this and enforce?

LGBT:
  - 50% of young people at National Centre (a gender identity clinic) have autistic traits

Westminster commission:
  - Following up on Westminster commission report about premature deaths and access to health care provisions like annual health checks
Appendix 2: Written Submissions

NB: In previous years we asked those who couldn’t attend our discussion event to feed their thoughts into the consultation in writing for which we supplied a form to enable this. We did similar this year and received two requests for forms. These were supplied with a two week deadline for responses for which we received one back. This is much lower than previous years and is probably because the online survey, which had many opportunities for people to make their views known in writing took its place. The one submission we had was from the Royal College of Speech and Language Therapists who consult a group they call their ‘autism experts’ and have submitted previously. Their two responses from their ‘autism experts’ are below in full.

Question One
The Advisory Group are suggesting seven things that we might want to achieve as the APPGA over the next 4 years. We want to know what you think are the top three priorities.

Between now and 2020, the APPGA will work on:

- Training for teachers and others who work in schools and education.
- Making sure that autistic adults can get specialist help to get a job.
- Raising awareness of the other health issues/conditions that autistic people experience (e.g. mental health, substance misuse).
- Making sure the changes to education and the introduction of Education, Health and care Plans to replace statements are working for autistic children and young people.
- Reviewing the Autism Act and identifying where changes are needed (Note: 2019 will be the 10th anniversary of the Act)
- Raising awareness of the needs of autistic people in the criminal justice system.
- Making sure that NHS plans on getting people out of secure hospital placements works for all people on the autism spectrum.

Respondent 1

1. Making sure the changes to education and the introduction of Education, Health and care Plans to replace statements are working for autistic children and young people.
2. Making sure that autistic adults can get specialist help to get a job.
3. Raising awareness of the needs of autistic people in the criminal justice system.

Respondent 2

1. Training for teachers & others who work in schools & education.
2. Making sure that autistic adults can get specialist help to get a job.
3. Raising awareness of the needs of autistic people in the criminal justice system (CJS).
Question Two
Of the three you chose, what are the three most important things we need to remember if we doing work in this area?

Respondent 1

1. Making sure the changes to education and the introduction of Education, Health and care Plans to replace statements are working for autistic children and young people.
   a. Ensuring that families receive adequate support and intervention at home
   b. Ensuring that all services i.e. health, social services and education contribute equally
   c. Making sure that families receive a carer’s assessment as part of the process

2. Making sure that autistic adults can get specialist help to get a job.
   a. Providing a functioning assessment and support service for adults with autism with and without LD
   b. Providing ongoing support for employees with autism and their employer (often employers think they have ticked the box by employing a person with autism but they do not recognise the need for that person to progress in their job and promotion is often impossible
   c. Working with organisations to ensure that all departments understand their role in supporting adults with autism

3. Raising awareness of the needs of autistic people in the criminal justice system.
   a. Making sure that representation and advocacy are regularly provided in all contexts
   b. Providing information and support for families of individuals with autism going through the criminal justice system
   c. Helping individuals in the system learn skills to help them stay out of trouble when they are released
Training for teachers & others who work in schools & education.

- Every autistic person is individual. General autism awareness training for those in schools/education needs to be followed by individualised training re the particular person -> individual profiles of strengths & needs.
- Training (general & individualised) needs to include a weighty focus on sensory perceptual issues in autism. Each individual autistic person needs to receive a personalised sensory profile.
- Autism training in education should extend into university/college settings. There should be a focus on not only the autistic individuals needs within the college setting but on enabling skill development re seeking employment. The type of support & adjustments needed during the journey into employment (job interviews, job application forms etc) should be addressed within the college setting.

Making sure that autistic adults can get specialist help to get a job.

- The transition from the education system into the world of work should be as seamless as possible.
- Communication issues are core characteristics of autism spectrum condition. I strongly believe that there is an important role for Speech & Language Therapy during all stages of employment – from the recruitment stage onwards. My recent Professional Doctorate dissertation ‘Communication matters: the employment experiences of adults with Asperger Syndrome. A phenomenological study.’ supports this belief.
- The personal voices of autistic adults are vital. Their experiences of job recruitment should be instrumental in planning/shaping the specialist services & support that they receive at this stage of employment.

Raising awareness of the needs of autistic people in the criminal justice system (CJS).

- Over the past 2 years I have been working as a Court Intermediary within the CJS. There is a need for autism awareness training to be offered to professional groups such as solicitors.
- The police are usually the first people to become involved after an incident/ crime has been committed. They need to receive training about how to communicate & interact with autistic ‘offenders.’ Autism friendly frameworks need to be established when interviewing autistic ‘offenders’.
- The probation service may be involved post trial of the autistic person. Autism awareness training needs to be offered within this service.

What’s Missing?
The Advisory Group wants to know what you think is missing from our seven topic areas.

Respondent 2

- When considering employment the topic area concerning ‘specialist help to get a job’ should be extended from gaining employment to also sustaining employment. It is essential that
autistic employees receive the necessary support & adjustments within the workplace. Employers & co-workers need to receive autism awareness training (general & individualised to the particular employee).

- During all consultations which consider the needs of autistic individuals the power of personal voice from such individuals needs to be paramount.

NB: Respondent 1 did not respond to question 3