

APPGA: Annual Consultation Report: 2015

Event 22nd July, Friend's House Euston.



Background

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 and people and families affected by autism. This Advisory Group hosts an annual open consultation to listen to anyone with a connection to autism to hear from them about what they think the priorities for the APPGA and Parliament should be. The feedback from the consultation event will then be passed to the Officers of the APPGA including the chair, Cheryl Gillan MP. For example, last year's discussions on employment and the criminal justice system fed directly into Parliamentary meetings on those two subjects.

This year's open vent took place on 22nd July and people were also encouraged to submit their thoughts in writing. The below is a digest of some of the discussions and written inputs.

Discussion Topics

The Advisory Group identified seven key topics to look at in more detail this year. The topics were chosen to fit the following criteria:

- Attendees at last year's event wanted to see them discussed.
- There are opportunities to make change in this area over the next year.
- The Members of the APPGA (the MPs and members of the House of Lords who are members of the group) have indicated these are their priorities and would like the Advisory Group's input.

The agreed topics were:

- Support for adults (including adult social care, Winterbourne View reforms and adult autism strategy)
- Employment
- Access (including the built environment and transport)
- Welfare Benefits
- Criminal Justice System
- Education
- Support for children outside of education (this includes social care support for children and families as well as children's mental health services)

At this stage however it's worth noting that anyone taking part in the consultation was welcome to submit more ideas for topics and discussion. A digest of these appears near the end of this document.

Support for adults

Background

In 2009, in recognition of the lack of services and support available for adults with autism in England, Parliament passed the Autism Act, with cross-party support. The Act led to the publication of the adult autism strategy, and accompanying statutory guidance, which puts duties on local authorities, and the NHS on how to organise support for adults with autism across England. However, while areas that have gone further in implementing the Act have seen an improvement, implementation has been slow and uneven. Chronic underfunding of social care and the

tightening of eligibility criteria for care and support has also contributed to many people with autism not getting the support they need.

Alongside work on the Autism Act, the Government is also working to make sure that people with complex needs are supported more appropriately in the community rather than in in-patient settings. This programme of work is also looking at making sure people aren't being sent far away from family and friends to get the help they need.

Headline Contributions

- Diagnosis was highlighted as key issue by with many having to wait a long time for a diagnosis.
- It was suggested there was more need for specialist autism services that aren't hundreds of miles away from users.
- Community placements are perceived as cheaper alternative to local services but can be costly in long-term as often cause deterioration in care if their family are unable to advocate for them.
- A Local Authority Speech and language therapist fed back that they were limited to 12 maximum sessions with people. This was not long enough and did not reflect the needs of the people being referred to them.
- A lack of awareness with some service managers still suggesting that people on the spectrum with high IQ's and educational attainment do not need support finding jobs and meeting own care needs.
- It was suggested there is a need for joined up approaches between NHS and Local authority and other bodies in some parts of the UK
- Incredibly difficult to meet the criteria for bus passes and freedom passes in some areas, as they do not recognise autism without learning disability as meeting the criteria. Suggestion for more clear guidance on autism.
- There is currently a massive funding gap for people aged 16-18. In theory CAMHS and children services are able to continue to support a young person up to the age of 25 but contributors felt this isn't the reality.
- Transition care needs to be made more smooth and easier as adult services are not able to offer the same kind of services education and children services can offer and this causes a great deal of distress to the individual and their family and affects the persons level of success in adulthood.
- Suggestion made to amend Mental Capacity Act so power of attorney can protect autistic people from having to manage interactions with police, courts, social work etc. Group thought that the Act might be protected autonomy though.
- Some parts of the UK have little or no coverage of appropriate social care providers who are willing to support autistic people, particularly rural areas, small towns and places with high costs of living/
- It was felt the Police force, particularly the British Transport Police who are separate from the main police constabularies were key people to target.
- Housing associations and housing officers that work for local councils, frontline social care workers, the criminal justice system and courts, employers were also key people to target for further awareness and understanding.
- It was felt the Winterbourne view process is very slow and the barriers to its implementation are a lack of autism specific services but also a lack of awareness.
- It was stated that the government is putting pressure on local authorities to deliver but is not providing the resources for them to successfully bring people out of hospital settings.

Employment

Background

Employment is a key issue affecting people with autism and their families. NAS surveys indicate:

- Only 15% of people with autism are in full-time paid work.
- 79% of people with autism on out-of-work benefits want to work.

- 26% of graduates with autism are unemployed compared to 4% of graduates as a whole.
- 65% of adults with autism rely on their families for financial support.

The Government has pledged to halve the disability employment gap. To do this effectively they must address the autism employment gap which studies show is even bigger. Many issues contribute to the employment barriers that people with autism face, such as misunderstanding from employers and potential colleagues. Currently, it is apparent that the Government's back-to-work schemes do not address the specific and long-term needs that autistic adults may require in order to enter and remain in the workplace.

Headline Contributions

- Any policy must consider the different factors in access to employment including (but not limited to) job adverts and public transport.
- There are often no existing employment services in local areas, and often people on the spectrum are not eligible for what is there.
- It was also suggested there is a lack of awareness on where autism fits in with mental health and learning disability criteria.
- It was suggested that Job Centres should have autism specialists
- It was discussed how workplace cultures can be alienating for people on the spectrum and that there is a need for continued support in the workplace - managers, HS inspector who takes responsibility for stress, and trade union support must all play a role.
- It was discussed that some will prefer to work part-time or as a volunteer rather than immediately working full-time. There is a need for flexibility and not one size fits all in employment for example options for remote working.
- Awareness is still a key challenge for employers, politicians, job centres and employment support providers. Especially relating to what constitutes a reasonable adjustment for someone on the spectrum.
- It was noted that '2-ticks' did not seem to have much oversight.
- 'Champions schemes' and Employability training were noted as positive and should be an aim for every employer.
- There was a suggestion to scrap the Work Programme, instead we should identify what support actually helps individuals.
- Government has key role in awarding contracts and needs to be pro-active in ensuring under employed groups.
- Late diagnosis and trouble getting the right support were also mentioned as reasons people on the spectrum struggled to find work.
- It was suggested we need to focus on providing systematic support for anxiety in workplace – including awareness training and specialist work programmes
- Using MPs connections with local employers was also suggested.
- Using examples of good practice e.g. Hampshire police making promotion structure more autism friendly, could help with awareness.

Access (including the built environment and transport)

Background

While the impact of the built environment on someone with a physical disability is more widely understood, the reasonable adjustments needed for people on the autism spectrum so that they can access public transport, businesses and other buildings are not.

Feedback from previous consultation events has made clear that more attention is needed to issues like lighting, noise and signage, training of particular staff (e.g bus drivers) that allow people on the spectrum to more easily maintain employment, access community facilities and use public transport.

Headline Contributions

- Focusing on adjustments that can be made in public and commercial buildings, for example supermarkets, schools, changes to light bulbs.
- Discussed conflict between direct regulations vs. adapting to specific needs as it may be hard to meet all of these needs or whether to focus on small adjustments like noise cancelling headphones.
- There are many different factors to consider around access, such as incorporating needs into building design plans, transport accessibility in first place.
- It was suggested we could use a test case going through the courts to apply pressure.
- We should highlight good examples of autism-friendly buildings like Stormont and the Welsh Assembly.
- Any argument should use the self-interest case – particularly for employers and business owners.

Welfare Benefits

Background

The July 8th Budget announced a £30 a week reduction in the money paid to those in the Employment Support Allowance's (ESA) Work Related Activity Group (WRAG) from April 2017. This means those on ESA WRAG will receive the same level of payment as those in receipt of Jobseekers Allowance (JSA). The WRAG ESA is a benefit paid to those with a disability who are able to undertake 'work related activity' but who will need additional support to find a job.

The Summer Budget also announced a freeze on the rate of working age income replacement benefits for the next 4 years, including Jobseekers Allowance and ESA WRAG. The support group rate will continue to rise in line with inflation.

Headline Contributions

- It was noted that we need to raise autism awareness throughout whole benefits system including Work Programme providers, Job Centre +, DWP staff and WCA contractors.
- £30 a week cuts to ESA/WRAG were discussed at length it was also asked whether the wider workforce had the skills and training to work with people on spectrum
- The support cut for people at age 20 in Further Education was also raised and discussed.
- Various other barriers to employment support, including criminal justice and housing support were raised by participants.
- The need to make apprenticeships and employment schemes accessible and autism-friendly was highlighted.
- In terms of the debate it was suggested the framing shouldn't just be about employment as end in of itself, but about meaningful work and activities.
- It was highlighted that there is a need for proper accreditation and certification for all parts of the system
- Discussed lack of relevant knowledge about benefits systems and where Job Centre staff might guide people for benefits support e.g. about permitted work, and training staff up to accredited status
- Participants noted the WCA can be confusing and causes anxiety. Many felt it not fit for purpose.
- WCA Assessments are too reliant on yes or no questions with not enough understanding of anxiety and the diversity of the spectrum – for example a person's eloquence can disguise support needs.
- Further support is needed during the benefits appeals process as it can be very stressful.
- It was suggested that the next Autism Strategy needs a renewed focus on benefits and housing.
- Could there be more national policy coordination? For example between the benefits workforce and social housing.

- There is further need for public awareness and education about what benefits people are entitled to. People on the spectrum with children were highlighted as particularly lacking this advice.
- More unified campaigning and joint action groups between community and local steering groups including working with other disability groups and identifying gaps from area to area.

Criminal Justice System

Background

Last year's APPGA meeting on the Criminal Justice system with the Prisons Minister was attended by over 100 people. Andrew Selous MP, the Minister for Prisons, moved by the experiences he heard and the number of people present subsequently wrote to every prison and encouraged them to undertake Autism Accreditation. Currently over 20 prisons have expressed an interest and will be working towards accreditation.

People with autism are less likely to become offenders or victims if their needs are identified early and they are properly supported. It can be social isolation that leads to people being exploited and either being led to commit crime themselves or becoming a victim of crime. Low level services, like social skills training, anti-victimisation classes and mentoring can have a significant impact in preventing people on the spectrum entering the criminal justice system.

The Prison Reform Trust report on the experience of prisoners with learning disabilities and difficulties within the criminal justice system stated that "people with learning disabilities or difficulties and people on the autistic spectrum represent some of the most vulnerable people in the offender population". The same report proceeds to identify that the "prevalence in the prison population remains unclear".

Headline Contributions

- Increasing training and awareness throughout justice system processes was highlighted.
- Identification of those on the spectrum being done as early as possible through ACPOs.
- Discussed the idea for an Autism Passport or alert card for interactions with police.
- The need to consider not just reasonable adjustments in criminal cases but also family courts for example having intermediaries, Legal Aid, Equality Act and Autism Act.
- Clear guidelines for people on the spectrum needed for all stages of the Criminal Justice process, including a breach of orders.
- Protections for adults in PACE codes but not actual courts - Fitness to Plead raised as an issue.
- Hate crimes, and conversely being profiled as offenders when often been exploited and the need to reflect this in sentencing guidelines discussed.
- The extension of the Pegasus database which logs people who have communication difficulties to aid emergency situations was also raised.
- Legal aid to be automatic for all diagnosed adults so that they can have trained person in court supporting them through the process was suggested.
- Is the safeguarding agenda a campaign opportunity?
- In terms of the Prevent Strategy, how many have been found to be on the spectrum?
- Can Autism guidance in public services be expanded to include the Home Office and Ministry of Justice?
- Expansion of Autism Accreditation to prisons was discussed.

Education

(includes school transport)

Background

Special Educational Needs (SEN) has been a long-standing interest of the APPGA and education has been a feature of the Group's work in every Parliament. The Government's recent Children and Families Act led to reforms of the Special Educational Needs (SEN) system. This is now been in place a year and there some opportunities to start analysing whether these reforms are either working or being implemented.

Headline Contributions

- There was a discussion about the reforms to the way we train teachers which could have implications for children with SEN.
- School transport was raised as an issue by members of the APPGA Advisory Group as well as parents of children on the spectrum.
- A 'Passport of needs', similar to the NAS Hospital Passport, was suggested. Rather than having to re-explain to every new person in every educational setting, transport situation or after-school club. Could a standardised form or smartphone app be the answer?
- Are all Local Authorities are 'reinventing the wheel' with EHCPs? It was suggested there was a lack of firm guidance and a standardised format for them to follow.
- It was asked why do EHCPs do not cover University education?
- Delays on ECHP were mentioned with some parents told to instigate it themselves, often with poor consequences due to a lack of expert knowledge.
- Training, in common with other areas discussed, there is a desperate need for good autism training to be embedded in teacher training including transport operatives and companions, for OFSTED inspectors, and for all others involved in the lives of young people accessing education.
- It was raised that teachers are still regularly getting barely an hour of training in autism. The contributor thought the bad awareness of autism can lead to the criminalisation of behaviour and a fast-track to the expense and waste of youth justice appearances.
- In transport it was suggested there are serious safeguarding issues including 'reverse auctioning' which means that the lowest bidder is getting the contract, whether they are suitable or not. No proper checks on employees in many places.
- A report was provided by Rachel Cotton on transport concerns. Specific incidents included children being left unattended; taxi and bus companies not considering children's needs; escorts and drivers not receiving training which can exacerbate challenging behaviour and anxiety; the route/driver changing regularly; provisions not made for late buses or for noises causing sensory overload – all of which can effectively take a day off school for children if a meltdown occurs. Solutions including certified online training, anonymous complaints and reporting system, compulsory travel passports for the children.
- It was suggested that apprenticeships need to be much more widely available, along with more vocational approaches to education.
- It was raised that OFSTED-type 'must get five GCSEs' schooling can be highly detrimental to some on the autism spectrum. OFSTED insisting on schools covering every surface with clutter to 'enrich' the environment were also mentioned as not being autism friendly.

Support for children outside of education

(this includes social care support for children and families as well as children's mental health services)

Background

While much thought and energy has – rightly – been put into educational reforms, the issue of what support children on the spectrum receive outside of their formal education has not received the same level of attention in Parliament.

Over 70% of children and young people with autism also have a mental health problem and may need support from mental health services.

Families also tell us they struggle to access short breaks for their children and other types of family support post-diagnosis. There are also the challenges with obtaining a diagnosis itself.

Headline Contributions

- An idea for developing something like 'Autism Friends' modelled on Dementia Friends.
- Having something similar to Autism Passport as for hospitals, or a single recognisable symbol e.g. for buildings to show ASD-friendliness, as part of EHCs? Bracelets to signify if non-verbal was suggested.
- It was raised that respite access and support for carers and support for children when they come home from residential services, is often arbitrary and needs to be more consistent nationwide.
- Discussed training in autism for social workers and balance of not shifting blame to parents.
- Variations in individuals on the spectrum are not reflected in government assessment frameworks was raised.
- The need for access to commercial services and accreditation for public services including the police, Ofsted, medical services etc. Can organisations like the NAS Autism Alliance could deliver something like Kitemarks?
- Challenges in implementation of Autism Act, NICE guidance, DDA were discussed.
- The need for general awareness campaign around autism was raised.
- The need for Government to recognised it's crucial to help people on the spectrum to self-advocate was discussed.
- It was discussed if the move to CCGs has affected diagnosis rates overall and in particular the rates of autism in girls and Black and Minority Ethnic communities.
- The idea of increasing online support for children in rural areas was raised.
- It was suggested we could use Winterborne View review as a policy lever to push through policy change.
- Can the APPGA create opportunities for interaction between MPs and people on spectrum so as to increase understanding?
- A discussion linking up with other APPGs e.g. on dementia took place. Partnership working with other APPGs was encouraged.

Other issues

There are obviously many other issues that affect people with autism and their families which are not covered in the suggested topics. We therefore asked for other ideas and areas of discussion. The below is a summary of the ideas we received.

- Housing – including social housing and flexibility regarding what households look like and further opportunities to be independent.
- Family justice system and the bias against people on the spectrum.
- Autism and ageism – particularly women receiving late diagnosis.
- National awareness and health promotion campaigns.
- Ensuring support for profound/severe needs aren't ignored, particularly around forcing people known to be severely disabled to reapply for benefits in stressful process.
- Communication between autism professionals and agencies, sharing knowledge about good practice schemes/services that can be applied nationally.
- Loneliness as part of social care agenda for elderly with people on spectrum and carers being factored in.

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- Autism research, including involving people on the autism spectrum and their families in setting research priorities, boosting state funding for research and ensuring that research findings lead to changes in policy and practice.
- Deprivation of Liberty safeguards.