

Response ID: ANON-YWQM-P7VQ-V [Type here]

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Response to autism strategy consultation

<https://www.gov.uk/government/consultations/review-of-the-national-autism-strategy-think-autism-call-for-evidence/review-of-the-national-autism-strategy-think-autism-call-for-evidence>

The Autism Policy Team
Dementia and Disabilities Unit
Room 1N14
The Department of Health and Social Care
Quarry House
Quarry Hill
Leeds
LS2 7UE

Re: response ID ANON-YWQM-P7VQ-V

Review of the National Autism Strategy 'Think Autism': call for evidence.

Dear Sirs,

Further to our submitting of the response with the above ID, to on the Review of the National Autism Strategy 'Think Autism' consultation, we are worried that the online pdf version is very difficult to read. We are therefore providing this pdf copy of the original submission in a format that makes it more readable.

Sincerely,

For the group:

Response ID ANON-YWQM-P7VQ-V

Submitted to **Review of the National Autism Strategy**

Submitted on **2019-05-16 22:55:22**

What is your name

First name:

[REDACTED]

Last name:

[REDACTED]

Please give the first half of your home postcode.

Postcode:

W1J 5DL

What is your email address?

Email:

asap2pf@gmail.com

Is it okay for the Department of Health and Social Care to contact you in relation to your response?

Yes

What gender do you tell people you are?

Other (please specify)

If other, please specify:

Not relevant (we are a group where all of the above gender descriptors are represented)

What is your ethnicity? Choose one option that best describes your ethnic group or background

Prefer not to say

White

Choose one option that best describes your ethnic group or background

English/Welsh/Scottish/Northern Irish/British

Other, please specify: Not relevant

About you - how old are you?

How old are you?

I am over 14 years old but prefer not to give my age

About you - continued

In what capacity are you responding?

An organisation in England that works with autistic people

Survey for autistic people

Have you been diagnosed as autistic?

Yes

Paid carers and organisations

In what role do you provide paid care, support, information or any other services to anyone who is autistic?

Independent Advocate

Voluntary sector

Other (please specify):

We are a group of people late diagnosed in adulthood as ASD without intellectual disability ranging in age from 30 to 70 and our response to the consultation comes from extensive public discussions on our experience of late-diagnosis and living with autism as an adult. We are currently in the process of constituting as an independent advocacy organisation.

Group members include

[REDACTED]

[REDACTED] We are concerned at the overwhelming public presentation of autism as a condition primarily affecting children and the people who care for them. The majority of the conversation concerns the impact of autism on family and economy rather than on people living with autism. We find this skewed perspective also structural to this review. We believe that the way that autism is presented to the UK public gives an overwhelming impression that ASD individuals are suffering from a mental health issue which is primarily of concern to parents and caregivers. When a perspective is given by an autistic child this is heavily inflected as the voice of a 'patient'. The high-functioning adult ASD voice is almost entirely absent from the discussion and is framed within the historic power imbalance between the 'mental health patient' and the professional. About half of adults with ASD have average or above-average intelligence - yet there is very little discussion of high-functioning ASD. Why is the voice of adults with high-functioning ASD so absent from public debate? Autistic adults have an understanding from within and lived experience of the condition and a relevant contribution to make into the understanding, the priorities and the effective solutions to the challenges autistic people face. We are not passive patients, but people with agency and autonomy and have an important contribution to make into decisions about ourselves. Most of the systems and interventions are designed to help autistic people to behave and function in a 'normal' neurotypical way, rather the helping autistic people to develop from within their own strategies based on their innate way of processing the world. High functioning autistic individuals can guide autistic peers and professionals in developing more effective and more relevant interventions and support services via participatory processes, building on established practices of participatory and action research. High functioning autistic people are a resource, not a cost to society. <https://journals.sagepub.com/doi/full/10.1177/1362361318786721> The individual questionnaire to this consultation conflates difficulties with everyday activities with intellectual disability. This does not reflect the latest revision of DSM-5 which removed the distinction between high and low functioning based on intelligence, because it is not a binary choice but a spider diagram, where autistic people

have spiky profiles. The learning disability should not be used as a criteria for support for autistic people. Importantly high functioning individuals face huge challenges in everyday functioning, which do not feature in social care criteria but cause huge stress and anxiety and are the root causes of their health costs unemployment and family breakdown and do require tailored support. Whilst the impacts for ASD individuals without learning disability are less catastrophic, there is still a very significant negative impact on life expectancy and employment: "Individuals in the control group died at a mean age of 70.20 years (s.d. = 24.16, median = 80), whereas the corresponding figure for the entire ASD group was 53.87 years (s.d. = 24.78, median = 55), for low-functioning ASD 39.50 years (s.d. = 21.55, median = 40) and high-functioning ASD 58.39 years (s.d. = 24.01, median = 63) respectively. The time period between registered ASD diagnosis and death (regardless of cause of death) was on average 5.30 years (s.d. = 4.85) for low-functioning ASD and 3.79 years (s.d. = 4.17) for the high-functioning ASD group".

<https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4C9260DB64DFC29AF945D32D1C15E8F2/S0007125000279385a.pdf/div-class-title-premature-As> "Just 16% of autistic adults are in full-time employment, and another 16% are in part-time employment, even though at least 70% want to work."

<https://www.unlimitedpotential.org.uk/sites/default/files/users/upadmin/Research%20report%2C%20project%20proposal%20-%20meaningful%20employment%20of%20autistic%20There%20is%20a%20strong%20economic%20argument%20plus%20an%20incontestable%20moral%20case%20to%20provide%20appropriate%20assistance.pdf> There is a strong economic argument, plus an incontestable moral case to provide appropriate assistance. These figures mean that over 100,000 adults would

like to be in full time employment. We are no more desirous of being a financial burden on society than we are of continuing to struggle with suicidal thoughts. If the autistic community were to be given the resources to change these figures, I am certain we would be successful. We are more knowledgeable about the condition than any number of 'experts' who have demonstrably failed us and consequently, society. These factors alone contribute enormously to the overall national cost of ASD. The costs of supporting children with ASDs were estimated to be pound 2.7 billion each year. For adults, these costs amount to pound 25 billion each year. The lifetime cost, after discounting, for someone with ASD and intellectual disability is estimated at approximately pound 1.23 million, and for someone with ASD without intellectual disability is approximately pound 0.80 million.

[<https://www.ncbi.nlm.nih.gov/pubmed/19369391>] High functioning adults with ASD are a less costly group - not least because we are not usually offered any support unless we are in acute crisis. Nevertheless, the cost of supporting someone with ASD as an adult without learning disabilities could be greatly reduced if, instead of largely ignoring us as a 'less needy' group and engaging with us only in acute crisis, we were given resources to organise ongoing mutual support networks working with employers, education providers, families, local authority and NHS provision. The paper on the cost of autism includes loss of employment for high functioning autistic adults. Often there are several autistic individuals within the family, which puts huge strain on all family members. Autistic parent's employment and the stability of the family unit are essential protective and supporting factors for all the autistic individuals involved. The loss of employment and relationship breakdown leads to mental health crisis, unemployment, and an escalating cost in health and benefits. Support and services preserving the employment and family unit of high functioning autistic adults would represent a cost saving. High functioning adults in employment and good health make an economic contribution and make good parents - therefore can raise our own autistic children with far less intervention. Loss

of employment is rather the cost of exclusion and discrimination than a lack of capability to make a valuable contribution.

How long ago was the person you provide care or support for diagnosed as autistic?

10 years or more – mis-click – it's 3-5 years

Additional information:

As a group, we have all been late-diagnosed in the past 5 years, many of us are in our 50s and 60s and have struggled with an undiagnosed condition for decades.

Paid carers: Getting the right support at the right time

How long did the person you care for and or support, have to wait for an initial assessment following referral from their GP or another professional?

Longer than two years

Additional information:

We are responding as a group which has experienced diagnosis as an adult within the previous 5 years. We are aware that diagnostic process is a 'regional lottery' with routes to access, diagnostic process, and waiting times being widely divergent. We know of people who have waited up to 3 years and 18 months seems an average wait across the country. The process is extremely stressful, often very little information is given and the diagnostic process itself is often extended across many months causing enormous anxiety to people who already struggle to manage anxiety and need support with events such as bullying, loss of employment or family breakdown which are often the cause of seeking diagnosis. The process presses the individual to explore their life challenges and personal history in detail and discuss these with family bringing up feelings of powerlessness, bullying, distress, isolation etc - which, again, an ASD individual is already likely to struggle with. Once diagnosed (or not) little or no support is offered to help the individual to cope.

Another key concern we share is that individuals diagnosed as an adult - frequently after a lifetime of struggling with an undiagnosed or mis-diagnosed disability - are then offered very little post-diagnostic support. At best, post-diagnostic support consists of 4-6 informational group sessions and ongoing monthly 'group therapy' sessions which are entirely unsuitable for ASD individuals and where people with and without intellectual disabilities are often mixed inappropriately.

There are isolated examples of excellent practice, particularly in terms of employment support, but this provision is extremely patchy and has no 'teeth' - employers frequently ignore the efforts of ASD employment services to implement reasonable adjustments.

We are a group of people late diagnosed in adulthood as ASD without intellectual disability ranging in age from 30 to 70 and our response to the consultation comes from extensive public discussions on our experience of late-diagnosis and living with autism as an adult. We are currently in the process of constituting as an independent advocacy organisation.

Group members include

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We are concerned at the overwhelming public presentation of autism as a condition primarily affecting children and the people who care for them. The majority of the conversation concerns

the impact of autism on family and economy rather than on people living with autism. We find this skewed perspective also structural to this review. We believe that the way that autism is presented to the UK public gives an overwhelming impression that ASD individuals are suffering from a mental health issue which is primarily of concern to parents and caregivers. When a perspective is given by an autistic child this is heavily inflected as the voice of a 'patient'. The high-functioning adult ASD voice is almost entirely absent from the discussion and is framed within the historic power imbalance between the 'mental health patient' and the professional. About half of adults with ASD have average or above-average intelligence - yet there is very little discussion of high-functioning ASD. Why is the voice of adults with high-functioning ASD so absent from public debate? Autistic adults have an understanding from within and lived experience of the condition and a relevant contribution to make into the understanding, the priorities and the effective solutions to the challenges autistic people face. We are not passive patients, but people with agency and autonomy and have an important contribution to make into decisions about ourselves.

Most of the systems and interventions are designed to help autistic people to behave and function in a 'normal' neurotypical way, rather than helping autistic people to develop from within their own strategies based on their innate way of processing the world. High functioning autistic individuals can guide autistic peers and professionals in developing more effective and more relevant interventions and support services via participatory processes, building on established practices of participatory and action research. High functioning autistic people are a resource, not a cost to society. <https://journals.sagepub.com/doi/full/10.1177/1362361318786721>

The individual questionnaire to this consultation conflates difficulties with everyday activities with intellectual disability. This does not reflect the latest revision of DSM-5 which removed the distinction between high and low functioning based on intelligence, because it is not a binary choice but a spider diagram, where autistic people have spiky profiles. <https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/>

The learning disability should not be used as a criteria for support for autistic people. Importantly high functioning individuals face huge challenges in everyday functioning, which do not feature in social care criteria but cause huge stress and anxiety and are the root causes of their health costs unemployment and family breakdown and do require tailored support. Whilst the impacts for ASD individuals without learning disability are less catastrophic, there is still a very significant negative impact on life expectancy and employment:

"Individuals in the control group died at a mean age of 70.20 years (s.d. = 24.16, median = 80), whereas the corresponding figure for the entire ASD group was 53.87 years (s.d. = 24.78, median = 55), for low-functioning ASD 39.50 years (s.d. = 21.55, median = 40) and high-functioning ASD 58.39 years (s.d. = 24.01, median = 63) respectively. The time period between registered ASD diagnosis and death (regardless of cause of death) was on average 5.30 years (s.d. = 4.85) for low-functioning ASD and 3.79 years (s.d. = 4.17) for the high-functioning ASD group". <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4C9260DB64DFC29AF945D32D1C15E8F2/S0007125000279385a.pdf/div-class-title-premature-As>

"Just 16% of autistic adults are in full-time employment, and another 16% are in part-time employment, even though at least 70% want to work." [https://www.unlimitedpotential.org.uk/sites/default/files/users/upadmin/Research%20report%2C%20project%20proposal%20-%20meaningful%20employment%20of%20autistic%](https://www.unlimitedpotential.org.uk/sites/default/files/users/upadmin/Research%20report%2C%20project%20proposal%20-%20meaningful%20employment%20of%20autistic%20)

There is a strong economic argument, plus an incontestable moral case to provide appropriate assistance. These figures mean that over 100,000 adults would like to be in full time employment. We are no more desirous of being a financial burden on society than we are of continuing to struggle with suicidal thoughts. If the autistic community were to be given the resources to change these figures, I am certain we would be successful. We are more knowledgeable about the condition than any number of 'experts' who have demonstrably failed us and consequently, society.

These factors alone contribute enormously to the overall national cost of ASD. The costs of supporting children with ASDs were estimated to be pound 2.7 billion each year. For adults, these costs amount to pound 25 billion each year. The lifetime cost, after discounting, for someone with ASD and intellectual disability is estimated at approximately pound 1.23 million, and for someone with ASD without intellectual disability is approximately pound 0.80 million. [<https://www.ncbi.nlm.nih.gov/pubmed/19369391>] High functioning adults with ASD are a less costly group - not least because we are not usually offered any support unless we are in acute crisis. Nevertheless, the cost of supporting someone with ASD as an adult without learning disabilities could be greatly reduced if, instead of largely ignoring us as a 'less needy' group and engaging with us only in acute crisis, we were given resources to organise ongoing mutual support networks working with employers, education providers, families, local authority and NHS provision.

The paper on the cost of autism includes loss of employment for high functioning autistic adults. Often there are several autistic individuals within the family, which puts huge strain on all family members. Autistic parent's employment and the stability of the family unit are essential protective and supporting factors for all the autistic individuals involved. The loss of employment and relationship breakdown leads to mental health crisis, unemployment, and an escalating cost in health and benefits. Support and services preserving the employment and family unit of high functioning autistic adults would represent a cost saving. High functioning adults in employment and good health make an economic contribution and make good parents - therefore can raise our own autistic children with far less intervention.

Loss of employment is rather the cost of exclusion and discrimination than a lack of capability to make a valuable contribution.

Getting the right support at the right time - continued

How well supported is the autistic person you care for, or how well supported were they throughout their education?

Poorly supported

Additional information:

Older people being diagnosed later in life may already have dropped out of school or HE due to challenges related to their undiagnosed ASD and so lack of education is added to lack of employability skills leading to life-long challenges with employment. Whilst provision for children who have been diagnosed earlier is improving, this is still failing to support ASD individuals into adulthood.

Inadequate provision at school are at the origin of or contribute to mental health problems in adulthood. There is a cliff -edge after school, it is not rare that autistic students, even with EHCPs experience a breakdown, school refusal and mental health crisis in late stage of 6 form or there after, because their maturity and ability to cope does not keep up with the expectations

for their age. Often their emotional, social needs, life skills gaps are not fully understood and there is no support and coaching available for transition to independence. They lose confidence and fail to cope. They are suddenly considered adults with the coping skills and understanding, which autistic young people often didn't have the opportunities to develop such understanding (because of limited social inclusion, limited employment, limited involvement in the aspects that make their peers more mature), so they did not experience the things and did not develop opinions and coping mechanisms to the same extent. So they find themselves unable to cope with the full demands of the post 18 life.

Example threads about a 19 years old, 15 years old.

<https://community.autism.org.uk/f/parents-and-carers/15510/my-daughter-is-24-has-asd-anxiety-depression-etc---i-don-t-know-what-else-to-do-to-help-her-anyone-else-feel->

<https://community.autism.org.uk/f/parents-and-carers/15481/when-to-pull-the-cord-parents-of-adhd-aspie-19-yo-need-help-transitioning-him-to-independence>

<https://community.autism.org.uk/f/parents-and-carers/15468/help-getting-my-15-year-old-daughter-back-into-a-routine>

Many autistic teenagers who did not have all the right support in place at school (EHCPs or inadequate SEN provisions) develop mental health problems, school refusal and find the transition to adulthood very hard. Sometimes schools start winding down provisions in 6 form arguing about transitions to independence. Often it triggers anxiety, lost of confidence, mental health crisis and an even bigger loss of independence as young people seek refuge at home as they can't cope with the transition.

The transition from school to 6 form college is also damaging. The college commissions provisions differently, so the young person loses the provisions and specialists support that worked and starts anew with the college being slow to recognise and understand needs, resulting in needs not being met and a mental health crisis in addition. It did not result in saving money, but is devastating for the young person. Putting EHCP in place early and maintaining the provisions in transitions is essential, it would save money in the long term in terms of resilience, employability and health.

There was research about mental health of young people, feeling stressed, anxious and depressed being their normal'.

<https://www.ambitiousaboutautism.org.uk/understanding-autism/know-your-normal-research-four-out-of-five-young-people-with-autism-experience>

Access to MH services is necessary, but even more important is addressing the causes of this anxiety, stress and MH deterioration by

- Making SEN provisions,
- Facilitating/creating peer buddies, senior peer mentors,
- Peer ASD acceptance training (awareness presentation)..
- Skills coaching - how to cope with particular challenges, not basic bus rides
- Counselling/psychotherapy for emotional understanding and support

PhD students reporting anxiety for being completely isolated from their peers, health limiting levels of stress, failing to cope and not knowing how to access support.

<https://community.autism.org.uk/f/health-and-wellbeing/15475/advice-needed-i-think-i-might-be-damaging-my-health>

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/15367/has-anyone-reversed-social-exclusion>

Autistic people are not asked about their needs and support in transition! Transition problems are not understood, parents are ill equipped to support effectively through transitions, other services lack the essential ingredients of 1:1 life coaching and psychotherapy.

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/9520/the-transition-into-adulthood>

Women in particular seem to experience serial breakdown in employment as they may successfully mask but become increasingly fatigued by the effort involved leading to mental health problems and/or breakdown of the employment.

How well were you supported when the autistic person you care for or provide support to moved within schools or between schools?

Not Answered

Additional information:

This question is not asked of autistic people, it should be!

Parents of young autistic adults do not have the relevant advice and resources to support autistic young people through transition. The crisis comes as a surprise and parents are improvising without the right help and support. Often MH support, counselling and 1:1 coaching, work experience placements etc are needed for autistic people, but parents don't have the access to that.

Sometimes parents struggle to cope financially with the transition because of demand for transport etc.

For transitions, there is a need for compulsory ASD acceptance training for the peer group, appointed/volunteer peer buddies, senior peer mentors to support and guide into coping with new emerging demands of the new setting. Coaching into independence, individual 1:1 life skills and independence coaching by the relevant peers - e.g, for a university student on how to cope with university challenges relevant to the individual, high level skills they struggle with from those who successfully coped with those specific skills. Not a one size fits all about taking a bus trip or going to the local shop... People also need sources of emotional support.

What would help:

- Life skills 1:1 coaching relevant to the individual, understood in broad terms, not in terms of bus trips
- transition coping skills,
- university coping skills,
- career skills,
- independence skill,
- relationship skills,
- Psychotherapy / counselling.
- A supportive community - autism forum,

- asd acceptance training, buddies mentors

If the autistic person you care for has experienced physical health problems, how effective were healthcare professionals in supporting them to manage these or get better?

Mixed, some good support but also short comings

Q22 Additional information:

Within the NHS understanding of the needs of ASD individuals is improving once a diagnosis has been achieved. However, there are issues with third-party providers who often seem to have been given no information and whose systems are not set up to take it into account. ASD people often find communication very difficult, and health providers can become irritable. ASD people need very clear instructions to take home and providers need to give enough time for an ASD person to think about their answers.

If the autistic person you care for has experienced mental health problems, how effective were healthcare professionals in supporting them to manage these or get better?

Not effective at all

Additional information:

The help that's really helpful is scarce. An integrated lifespan approach would be more effective. It is difficult to access appropriate mental health support, there are long delays. There is no access to affordable psychotherapy, insufficient capacity Peer support is very rarely available - we would like it but we have (collectively in different regions) never been offered it so cannot comment on its effectiveness. We would like to explore this area and develop better provision.

Life skills coaching 1:1 is nonexistent, but would make huge difference. It should be defined more flexibly as skills relevant to the barriers individuals face in their specific circumstances.

Research has indicated that young adults with autism are in a continuous state of stress, anxiety and depression that at times escalates into a crisis.

<https://www.ambitiousaboutautism.org.uk/understanding-autism/know-your-normal-research-four-out-of-five-young-people-with-autism-experience>

This continuous anxiety needs alleviating via availability of peer emotional support and advice, life coaching and psychological counselling, 1:1 or in a group, but based on individual needs.

Many high-functioning ASD individuals use their abilities to research and adapt to explore self-help strategies including meditation, yoga and other holistic strategies. Whilst these can help retain balance in the context of overall support, they cannot substitute for adequate life-coaching. We are also aware of an increasing tendency towards 'app-based' support and we have tried various app-based support offers including those informed by research with autistic people. However, we have found these to be orientated towards children and, furthermore, we would question the research base informing them - in some cases, we have found such apps actually increase anxiety. Much of development, like google glasses for autism, is informed by ABA, the coercive normalising of autistic behaviour to appear normal, rather than function well on the inside, which many autistic individuals experience as emotional abuse and trauma. Research indicates that many children subjected to ABA programmes develop PTSD.

There may be some positive possibilities for using technology-based solutions to assist with specific issues such as challenged executive functioning as they can be very useful in scheduling, planning, navigating etc along the lines of 'extended cognition'.

We have found schemes such as the 'sunflower' schemes at airports to be a very simple way of reducing anxiety by signalling discreetly to staff that the individual may experience communication challenges. If such schemes were integrated with a programme of increased awareness this could considerably help ASD adults navigate everyday life with lowered anxiety.

There may be a scope for organisations to have policies to handle communication, not to force interaction and demand the expected socialising from autistic people, for example on supermarket check-out.

As a group we are exploring how we might sustainably develop an online mutual support network for ASD adults without intellectual disabilities. This will need specialist moderation but should be designed, built, and run by and for ASD adults themselves with ASD adults trained in moderating, safeguarding more vulnerable participants, and giving advice in a safe way. We believe that such a facility will significantly positively impact the mental health of ASD adults without learning disabilities. Isolation is a major cause of depression and suicide as well as the relentless pressure of negotiating everyday life and communication. Peer to peer support from autistic people will enable to harness skills and experience with dealing with our everyday challenges and share it with people who face similar challenges and need advice and support.

If the autistic person you care for has been admitted as a mental health inpatient (for example to an Assessment and Treatment Unit, or to hospital) was a Care and Treatment review carried out or a Care, Education and Treatment Review ?

Not relevant to me

Additional information:

How well was the autistic person you care for supported by health, social care, education and employment services from aged 18 and older?

Poorly

Additional information:

There is a total disconnect, services are disjointed, not integrated and do not address the issues and priorities that make the biggest difference to the autistic people. They provide what they have, not what is needed. We feel strongly that there should be frameworks for involving ASD adults in the design of ASD services at an early stage at local and national level so that ASD adults understand resource limitations and can work with providers to involve ASD adults as a resource to inform and extend provision. This could call for autistic expertise on the national scale, so the quality of input is not limited by local fragmentation. It could take form of an expert patient /expert user participation in the design of the service.

An online autistic community and peer to peer support network at a national scale could help isolated autistic individuals to find their communities of interest and sources of advice and support that is specifically relevant to their individual problem or interests. This way a scale could be achieved for a service, or activity that would never make the short list at the local level.

What would AS services look like in a perfect world?

- Holistic, integrated, preventative, life span
- National framework, no post code lottery and variation
- Defined and designed by autistic people
- Based on progressive vision of autism, social model of disability, autism acceptance
- Supporting personal growth and life skills as defined by autistic people themselves, support and coaching in coping with autism in achieving life goals.
- Support for health needs, for the entire family, for employment, aging, housing.
- Life skills defined individually in broad and flexible terms by autistic individuals. For some it is taking a bus, for others it is avoiding fall into depression, starting a family, or even retaining their job in professional capacity.

How would you rate the understanding of the following people, if you have come into contact with them,

Rate professionals - GPs:

2

Rate professionals - Nurses:

2

Rate professionals - Hospital doctors:

2

Rate professionals - Mental health professionals:

2

Rate professionals - Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists:

2

Rate professionals - Social workers:

2

Rate professionals - Headteachers:

1

Rate professionals - Teachers:

2

Rate professionals - Nursery workers/ Child Carer:

2

Rate professionals - Teaching assistants in classrooms:

4

Rate professionals - Solicitors:

1

Rate professionals - Police officers:

1

Rate professionals - Magistrates:

Rate professionals - Staff in the bank:

Rate other types of staff - GP Receptionist:

3

Rate other types of staff - Hospital porters:

3

Rate other types of staff - Transport staff:

3

Rate other types of staff - Social care staff helping you in the home such as a Care Assistant:

Does not apply to me

Rate other types of staff - Staff working in social services departments:

1

Rate other types of staff - Staff working in the jobcentre or on the telephone helpline:

1

Rate other types of staff - Staff working in the Local Authority housing department including benefits assessors:

1

Rate other types of staff - Staff working in the Local Authority benefits department:

1

Rate other types of staff - School receptionist:

2

Rate other types of staff - Special Educational Needs Officer (SENCOs) in schools:

3

Rate other types of staff - Lunchtime staff in schools:

2

Rate other types of staff - Probation staff:

Does not apply to me

Further information:

Being part of the local community

Has the autistic person you provide either unpaid or paid support to told people, such as their friends and the people they may study, work or take part in leisure activities with, that they are autistic?

No

Additional information:

There are prejudices and stigma in society, discriminatory attitudes.

- Autistic people experienced not being taken seriously after disclosure,
- 'friends' cutting contact
- Opponents use autism to invalidate autistic opinions and contributions : ('She's a patsy', <https://www.spiked-online.com/2019/04/22/the-cult-of-greta-thunberg/>),
- Attack their very human rights and autonomy (Letter from Human Rights Watch: By denigrating the young Swede's commitment because of her autism, the author attacks people with disabilities and their recognition as full-fledged citizens with an important role to play in societal issues. By deciding to target Greta Thunberg's autism to try to disqualify her speech, Laurent Alexandre harms all people with disabilities. <https://www.hrw.org/fr/news/2019/04/18/lettre-de-human-rights-watch-lexpress-en-reponse-la-tribune-de-laurent-alexandre-sur>),
- Pathologize their normal behaviour <https://www.mumsnet.com/Talk/relationships/3552950-does-dh-have-asperger-s>
- People experience isolation and discrimination.
- Some people want to use understanding of autism to humiliate and autistic people in public for fun or to undermine their ability to fully participate in society <https://twitter.com/HelenDale/status/1120759250387701767?s=20>
- Social media organisations preclude autistic people from participating in discussion that spread false stereotypes and prejudices about them, segregate, silence them and delete their contributions in violation of their own moderation guidelines, thus subjecting autistic people openly to less favourable treatment . Such open endorsement of segregation and

no-platforming of autistic people based on discriminatory pseudoscience promoted by autism hate groups is totally shocking

<https://www.mumsnet.com/Talk/relationships/3524836-Married-to-someone-with-Aspergers-support-thread-4-replacement-one?pg=1>

- After disclosing employers ignore the disclosure and keep on arguing 'we all do that' and start using the knowledge about autism to find faults, to undermine autistic people.
- Disclosure often leads to dismissal.
- Predominant stereotypes and conceptions about autism act as a barriers for true good communication and acceptance even within the family, they are disabling. Brett Heasman (LSE) discusses his recent study published in the journal Autism, "Perspective-taking is two-sided: misunderstandings between people with Asperger's syndrome and their family members".
https://www.youtube.com/watch?v=TSMF_3f0Q0c&feature=youtu.be
- Focus on autistic problems like theory of mind distracts from seeking two sided understanding <https://semioticspectrumite.wordpress.com/2018/01/26/the-belief-in-theory-of-mind-is-a-disability/>

Women with ASD may present differently from the 'masculine' model leading to further discrimination including refusal by communities, employers, and health professionals to believe that a woman is living with ASD (even when medically diagnosed). The 'masculinisation' of ASD can also lead to distressing gender confusion among women living with ASD.

There are also particular concerns around safeguarding young adult ASD women who are exceptionally vulnerable to childhood victimisation, sexual exploitation and relationship abuse.

"More recent research interviewing 182 parents of children with ASC found high rates of reported physical abuse (18.5%), sexual abuse (12.2%), or both kinds (4.4%), though no information on the sources of this abuse was noted (7). Studies have also found high rates of peer victimization in children [65–77%; (6, 9)]. Studies of adults with ASC have largely focused exclusively on sexual victimization. In a college sample, students with ASC were twice as likely to report unwanted sexual contact compared to students without ASC (10). In an online survey, 70% of adults with ASC reported experiencing some form of sexual victimization after age 14 and into adulthood, compared to 45% of those without ASC (5). Authors have suggested that increased risks of bullying, physical, and emotional abuse may also be present in adults with ASC due to heightened social vulnerability (11, 12)."

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5980973/>
Such experiences are traumatic and yet victims and survivors are only offered psychological support in acute crisis. We would like to see more research exploring to what extent social and communication issues experienced by people living with ASD – and particularly women with ASD - are exacerbated by the legacies of traumatic victimisation. No significant differences were found between groups on perpetration. Therefore stereotypes on websites such as Mumsnet that ASD men are 'abusive' in relationships is not supported by research.

Women with ASD may appear to be masking effectively whilst experiencing health-threatening levels of stress and exhaustion: <https://www.emeraldinsight.com/doi/abs/10.1108/AIA-09-2018-0036>

There is a strong need for more research and for the appropriate education of diagnostic services as well as the wider public in the gender-specific implications of ASD. Much regional provision omits support for young adults in particular which might do much to safeguard young ASD people from this prevalent legacy of traumatic abuse.

Do you think the person/people you support can take part in the things that are important to them within the community?

Some but not all activities

Additional information:

Local 'community' in its current meaning is too fragmented and restricting for many autistic people. Being a minority of about 1% of the population, autistic people need a community at a national scale to access advice, support, skills, knowledge, relevant to their specific problem, to find friends and people with common interests. At the local community level the diverse and specific problems and interests of autistic people might never have the scale and priority to be funded and delivered. There is a need to achieve this on a 1:1 or small group basis, specific to the need of the individual and it is only possible on a national level.

The activities described are too narrow and are insufficient to lead a full fulfilled life on the par with NT people (For an adult, shopping, travelling, taking part in sports and other leisure activities. For a child this may be going to school, taking part in hobbies and interests outside of school).

- Shopping is a necessity, not community participation.
- An odd trip once a month with a volunteer/stranger is not a meaningful community participation. Autistic people need to find their 'tribe', be part of a community that is actually understanding and supportive, they need social support.
- They need to partake in meaningful pursuits and form meaningful relationships, on the par with NT people. This means full participation in education, employment, leisure and family life.

Start to address the underlying difficulty of autistic people - support their personal development and life coaching in attaining their goals. Professionals to guide us of all ages to develop, be independent as possible (which is probably individual). Support individual development. Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who understand ASD and actually listen to autistic people, process what is actually said.

Another resource that I would like to have would be life skills development summer camps. They have a lot of these summer camps for AS children and teenagers in the U.S., but there aren't many for adults. It would be very useful to be able to attend a 2-week summer camp, where they can teach some basic life skills and provide some team-bonding training. It would be a great way to make friends and learn skills.

Ideally there should be support groups in every area, separate from social groups. These should be run by someone from the local autism services and should perhaps cover a different topic that people diagnosed with AS as adults may be struggling with. Even if they only ran once a month, it would be good to have the option to be able to go along, learn new information, meet other adults newly diagnosed with AS and swap ideas with both them and the person running the group.

Do you think the autistic people/person you care for has ever experienced any of the below because they are autistic?

Do you think you have ever experienced any of the below because you are autistic? -

Hate crime:

Yes, they have sometimes experienced this

Do you think you have ever experienced any of the below because you are autistic? -

Bullying:

Yes, they have often experienced this

Do you think you have ever experienced any of the below because you are autistic? -

Discrimination:

Yes, they have often experienced this

Do you think you have ever experienced any of the below because you are autistic? -

Harassment:

Yes, they have sometimes experienced this

How would you rate the understanding of the following people, organisations and businesses if you have come into contact with them?

Rate the understanding of people - Autistic person's family and friends:

4

Rate the understanding of people - Staff in shops, banks, restaurants and pubs:

2

Rate the understanding of people - Transport staff – buses, trains, taxis, underground trains ('the tube'), trams:

2

Rate the understanding of people - Staff at leisure centres, sporting events, libraries, theatres and cinemas:

2

Rate the understanding of people - Staff running youth activities:

2

Rate the understanding of people - Staff in other leisure facilities:

2

Rate the understanding of people - Employers:

1

Rate the understanding of people - The general public:

2

Additional information:

As previously noted, extension of the 'sunflower scheme' at airports to other travel, shopping, sport, leisure and community facilities could be massively beneficial. Some of autism awareness has led to stigmatisation of autism due to the language of deficits and assumed primacy of the neurotypical way of communication and empathy. Accommodating the autistic way of being and functioning is marginal to the discourse. For many autistic people this created as many problems as it solves.

The 'problem' of autism is primarily the double empathy gap that needs to be bridged by both sides. There is no point in putting all the burden of bridging this gap on autistic people, they can't do that alone, it doesn't work. The framework of developing intervention and services based on the power imbalance in the professional- patient model and involvement of the

knowledge of autistic people only on a limited tokenistic level should evolve toward more participatory model lead by autistic (self-)knowledge.

The increasing pressures on communication and sensory intensity of the modern life cause an increasing number of autistic adults to seek diagnosis, often triggered by life events like loss of employment or family breakdown. Autism doesn't have to lead to these outcomes. The diagnosis should be the key to unlocking the understanding and removing the barriers.

There is no point in stigmatising and isolating, pushing autistic people out of mainstream society into the confined space of being care receiver - this undermines the value and health of autistic people and increases the cost to society due to the need to provide for the treatment of mental health and physical comorbidities, unemployment, family breakdown, poverty etc.

By creating a culture where autistic people are equal, with valuable contributions to make, by supporting and coaching autistic people to function well in line with their potential, we will improve health, wellbeing and reduce costs...

To achieve this is it essential at this point in time to change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.

In line with the Equality Act, disability is a different way of doing things, the reasonable adjustment for autism is to accept and respect the autistic way of being, of communicating, understanding and processing the world.

The equality in law of disability hate crime, disability hate speech and regulation of autism hate content online have a role to play in fostering autism acceptance in society.

Support:

It should be holistic. The holistic approach to health needs and life skills, family support, personal development. all the services integrated better. Psychologists, psychiatrists and developmental disorder services, 1:1 support, life skills coaching, family support, employment, social care, housing. The probable pattern within many families is undiagnosed autism followed by years of difficulties then initial contact with services due to related problems (depression, anxiety, OCD, psychosis) which are picked up as if they've suddenly come out of nowhere. When really I think the undiagnosed autism with no awareness, insight, support or help was the soil on which all of the other issues grew.'

Start to address the underlying difficulty of autistic people - support their personal development and life coaching in attaining their goals. Professionals to guide us of all ages to develop, be independent as possible (which is probably individual). Support individual development. Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who understand ASD and actually listen to autistic people, process what is actually said.

A national service framework for autism, like the one for older people. Care needs to be standardised throughout the UK, autistic people need to be recognised as having as many differences between us as NTs at the moment we all seem to get lumped into the same mould

for garnering all of this support . There should not be post code lottery, national standards that we can expect will be adhered to from assessment to diagnosis and beyond.

Some service to help with symptom management [also for co-occurring conditions]. Autistic people have to put a lot of effort every day into symptom management with minimal or no support.

Support for people, including HFA into employment, not means tested, not only for families on benefits. People wasting their talents at home and going through circles of depression are more expensive to society than people who are having fulfilling work and paying taxes. Every large employer should have a link person who is an advocate for autistic adults who could also cascade train their teams where needed, much as in nursing we have link nurses who specialise in say, diabetes or palliative care and cascade any new info to the rest of the team.

Employment mentoring and coaching, aiming to also help people in professional and managerial roles to cope and retain their highly skilled employment. Like business mentors and career coaches, but autism focussed. Too many people here are managers and engineers hopping from job to job, ending up in lower skilled roles. They could even be fee based to those who can afford. It is not like Access to Work, about paying for reasonable adjustments, but about personal effectiveness coaching for coping and getting acceptance in those managerial occupations, it should be 1:1 for the person, not dependent on the employer like access to work, it should not require disclosure and formal dx.

Mental health support, diagnosis and counselling services for family members, family therapy, relationship counselling and coaching. Not based on models promoted by some autism hate groups, but based on the double empathy model and using ethical counselling. This could be a 'buddy' system where NT's are trained in communicating with AS people and can give advice on handling NT's in one's life (work and personal) and T partner are trained by autistic buddies to connect with autistic partners .

Signposting. Continuous 'hand-holding'. A co-ordinator to act as a kind of hub for an autistic individual and signpost, reliably and promptly, to services that can help with specific needs as they emerge. A detailed, agreed plan would help. Psychological support: Individually tailored psychological support involving a detailed assessment and formulation of issues, thus maintaining causes and a collaboratively constructed way forward. The support MUST be informed by autism awareness and NOT off the peg.

Family support: Autism is a family issue and once one person is diagnosed, others should have the offer of assessment straight away. Family dynamics can be affected in a number of ways so this should be recognised and acted upon. Too many individual issues dealt with by separate departments, with no autism awareness and no joining the dots.

Life coaching for adults through the life-span. This could also be fee-based for those in work.

More research needed:

- Why people are bullied, discriminated against at work, why disclosure often leads to dismissal? What would normalise acceptance in workplace?
- How to bring ASD teenagers with MH breakdown back into health, studying and being productive?

- High quality ethical research into the relationships and marriage, based on the non-ableist model of the relationship and double empathy gap. Assessing and understanding both partners focussing on improving communication.

There should be more research in interventions and models of support that are effective and make a real difference to the wellbeing and quality of life of autistic people, more effective therapies for autistic individuals with co-occurring health conditions. There appears to be less research in this area than there is in trying to prove theories behind a deficit model that perpetuates exclusion of autistic people in society. Other less derogatory theories have gained credence lately but do not attract the same level of financial support, while in fact many autistic people identify with their analysis and recognise it as yielding more effective and relevant interventions. Research needs to be more collaborative and inclusive.

Developing skills and independence and working to the best of abilities

If the person you care for is over 16 years old, how well were they supported when they left school or college and moved to make decisions about independent living and/or training or work?

Poorly

Additional information:

It is token activity.

Many autistic people are late bloomers and their psychological maturity and life skills are often not in sync with their age. School leavers are expected to conform to the standards and skills of a NT 18 years old, while autistic people are not ready, so they struggle with the skills and psychological factors which are hidden from professionals, autistic people's main struggles are not recognised, there are no provisions through SEN, DSA and anything else.

<https://community.autism.org.uk/f/parents-and-carers/15481/when-to-pull-the-cord-parents-of-adhd-aspie-19-yo-need-help-transitioning-him-to-independence>

This is a spot on description,

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/9520/the-transition-into-adulthood>

The transition into Adulthood

CASE STUDY:

Hiya, I'm a student who will soon be embarking on the second year of university. I feel like an utter mess. Well to be honest i always have, since the age of 2 and 1/2 yrs old (from what i can remember).

However ever since i have been classed as an adult, I've felt immense amounts of pressure to fit that perfect model of a "Normal Adult". I've always felt different but when i was younger i just always told myself that one day I'll be normal and just "get" things like other people do. Nope.... that didn't happen and probably never will.

I try and please everyone in my life, as i really dislike being criticized and making people upset. I try and change myself to fit everyone's standards but it just isn't possible. Either way someone who i care about always gets hurt. I'm fed up and just don't feel like I'm smart enough to live this complicated life. I'm always stressed, as somehow I'm frequently doing something wrong.

I've hit a point now where I feel like giving up. I put in hours and hours into studying but with the second year approaching very near, it scares me. The only thing I really have going for me is my education. Other than that I'm a failure at life (dealing with social situations, and making the right choice). I get really hurt by people who tell me that "You're not normal", "You're weird", "You need to change". I've been altering my self my whole life. Just how much more do I need to change? When will it stop? I feel like if I change anymore I won't be myself, I'll become a robot. I get it, I'm weird for having the mentality of a child, but that's me.

I'm always eager for trying new things and when I like something I can get deeply invested. I'm told "people your age are nothing like you. They act mature, and let go of their childish habits. They prioritise what's/ who's more important better than you do".

I can't sleep at night and feel like I'm going mad. I don't know what's right and what's wrong. Life is too complicated and I don't think I'm doing things "properly". To be honest I haven't told anyone how I feel because no one in my life understands me, they just pity me and think I'm not up to scratch. I hope someone here will understand how I feel.

It's an empty token exercise. Form filling with no difference being made to the autistic person. It is all down to ourselves or the families, their research, resources and connections of the parents. At college we asked about work experience, they said use your personal network... which autistic people don't have.

What would help massively:

Early at school, in year 8 or 9 and in year 10/12 a work experience trying different professions everyday for a week or two. To get a taster, to understand what different industries do, what different departments within the company do. One of the problems is that autistic young people can't imagine what it is like, what is involved and how they can react to that environment, how they are suited to that. Autistic people really need a taster. This would also help to motivate and make plans, to research careers and make applications - it would really engage from within, not because they have to do it but because they are really interested in a career and motivated to work towards it..

There should be a scheme whereby all big companies offer such work experience to autistic teens, at the appropriate level,. For some vocational, for others various departments in the company, so young people could understand, what do finance do, what does engineering do, what is marketing analytics, etc.

Autistic people should be offered such work experience and internships free of selection designed for the NT pool and increasingly and unnecessarily focussed on personal characteristics modelled on NT 'norm'. First because it is primarily to enable autistic people to understand the work requirements and how they are suited to this. It also excludes autistic people through psychometric testing, through 'assessment centres' and interview processes that focus on demonstrating that the candidate meets perfectly the mental image modelled on the NT way of functioning. The definition of disability is doing things differently and this important factor is insufficiently understood and researched in relation to autism.

Autistic people need 1:1 life coaching in preparing and managing the transition, which could also take form of job coaching similar to executive coaching but focussed on coping with autistic barriers, enabling personal growth.

Supported employment services tailored to the individual and the level of work they aspire to do should be developed and delivered by autistic people with suitable experience relevant to the career aspirations of the applicants. Autistic adults often have employment gaps and supported employment services and employer policies should be developed to help autistic people of all ages to regroup, review their skills in a structured way, to build confidence and autism coping skills in finding a new employment or career.

There is good support available to autistic people at many universities primarily driven by the respective departments that frequently encounter autistic students (just one of a few good examples is the department of Computer Science at the University of Southampton). Support at the secondary school and Further Education level is primarily dependent on parental social capital.

The facts speak for themselves. 77% of autistic people want to work, while only 16% are in employment.

Management attitude and peer bullying or isolation are biggest problems. Too often disclosure leads to disciplinary procedures and loss of employment. Disclosing can just be used as grounds to find faults. Many autistic people feel they are not being taken seriously, their careers and development stalling after disclosure. Their needs being dismissed as 'we all have to do that', there is a misconception that reasonable adjustments are unjustified favours and excuses, for which autistic people are facing peer disapproval and victimisation. Reasonable adjustment are often tokenistic, rather than addressing the real barriers for the individual.

Autistic people live in a continuous anxiety about isolation, bullying and loss of employment. 1:1 long term job coaching, career coaching, similar to executive coaching but focussed on coping with autistic barriers, tailored to the individual could help to develop the coping strategies.

There needs to be a link between Occupational Health, Mental Health First Aiders, Diversity Champions and associated contacts (Mental Health Services/Condition advocates) in all large employers along with autism positive progressive acceptance training training for Management and staff, delivered by actually autistic people. Senior Managers should be seen participating in such training and role modelling inclusion and acceptance.

To achieve this is it essential at this point in time to change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.

To what extent do you agree or disagree that the autistic person you care for or support has been supported to get a job if they wanted to get one?

Disagree

Additional information :

The facts speak for themselves. 77% of autistic people want to work, while only 16% are in employment.

- Management attitude and peer bullying or isolation are biggest problems.
- Too often disclosure leads to disciplinary procedures and loss of employment. Disclosing can just be used as grounds to find faults.
- Many autistic people feel they are not being taken seriously, their careers and development stalling after disclosure. Their needs being dismissed as 'we all have to do that'.
- There is a misconception that reasonable adjustments are unjustified favours and excuses, for which autistic people are facing peer disapproval and victimisation.
- Reasonable adjustment are often tokenistic, rather than addressing the real barriers for the individual.
- Autistic people live in a continuous anxiety about isolation, bullying and loss of employment. 1:1 long term job coaching, career coaching, similar to executive coaching but focussed on coping with autistic barriers, tailored to the individual could help to develop the coping strategies.
- There needs to be a link between Occupational Health, Mental Health First Aiders, Diversity Champions and associated contacts (Mental Health Services/Condition advocates) in all large employers
- There needs to be autism positive progressive acceptance training for Management and staff, in all large employers delivered by actually autistic people. Senior Managers should be see participating in such training and role modelling inclusion and acceptance.

To achieve this is it essential at this point in time to change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.

If the autistic person you care for, provide a service to or support has a job, how supportive do you think their employer and the people they work with have been to them?

Not supportive

Additional information:

There are islands of good support. Access to Work scheme has been a good step forward, however it's capacity and scope is limited and the adjustments often tokenistic and limited in impact.

Predominant stereotypes and conceptions about autism get in the way of positive inclusion policies within the businesses. Reasonable adjustments are often ineffective and tokenistic, especially in skilled occupations with complex requirements, often they fail to address the real barriers autistic people face. The knowledge base, the capacity of organisations providing access to work support is inadequate, the inclusion criteria leave too many people without the help they need.

On a practical level

- There is a need for government policy to change the discourse about autism in society.
- There should be compulsory autism acceptance training delivered by autistic people with experience relevant to the employer, so they could engage with specific realities of the business.
- Senior managers should be encouraged, be seen participating in autism acceptance training and role modelling the inclusive accepting behaviours
- Given insufficient depth of understanding of the autistic barriers, a process of reviewing practices should be developed to identify barriers autistic people face in work places and effective reasonable adjustments for those barriers identified by autistic people to inform good practice.
- There is a need for research to understand the dynamic of isolation and bullying in the workplace, feeding into good practice. This isolation is a source of continuous anxiety for high functioning autistic people.
- Internal appraisal practices and processes should also be reviewed to identify hidden barriers and move away from measuring performance and potential by comparison with the neurotypical model ways. Disability is a different way of doing things and autistic way of being, processing and achieving goals should not be a barrier to autistic talent contributing to full potential.

About progress and priorities for future action

Based on your experience and perspective, please give an example of where you think progress has been made in your local area to improve the lives of autistic people and of their families and carers?

Based on your personal experience, please give us an example of where you think progress has been made in your local area to improve the lives of autistic people?:

The sense is that nothing has happened to us to make us think that.

There is no doubt activity is going on as it was going on before, but it is not making the impact on real issues that matter to us and improve the lives of our families as otherwise we would have noticed.

Please give us an example of where you think progress needs to be made in your local area to improve the lives of autistic people and of their families and carers?

Please give us an example of where you think progress needs to be made in your local area to improve the lives of autistic people?:

High functioning autistic adults are a resource, not a cost to society. The voice and contributions of high functioning autistic adults should be fully utilised and their needs should not be left unmet. We are a resource and source of knowledge in supporting autistic people in guiding and designing services and organising and delivering it ourselves, creating a space and a process where autistic people can connect and support each other, contribute to the public debate.

There is a thriving autism industry that does not sufficiently use the talent and skills of autistic people who are underemployed.

The prevailing deficit based medical model of autism has left the voice and the needs of high functioning autistic people out of the public discourse and without support we need. Whilst the

impacts for ASD individuals without learning disability are less catastrophic, there is still a very significant negative impact on life expectancy and employment. Autistic adults have an understanding from within and lived experience of the condition and a relevant contribution to make into the understanding, the priorities and the effective solutions to the challenges autistic people face. We are not passive patients, but people with agency and autonomy and a key contribution to make into decisions about ourselves.

As “Just 16% of autistic adults are in full-time employment, and another 16% are in part-time employment, even though at least 70% want to work.” There is a strong economic argument, plus an incontestable moral case to provide appropriate assistance. These figures mean that over 100,000 adults would like to be in full time employment. We are no more desirous of being a financial burden on society than we are of continuing to struggle with suicidal thoughts.

If the autistic community were to be given the resources to change these figures, I am certain we would be successful. We are more knowledgeable about the condition than any number of ‘experts’ who have demonstrably failed us and consequently, society.

The cost of supporting someone with ASD as an adult without learning disabilities could be greatly reduced if, instead of largely ignoring us as a ‘less needy’ group and engaging with us only in acute crisis, we were given resources to organise ongoing mutual support networks working with employers, education providers, families, local authority and NHS provision.

Autism acceptance. The increased autism awareness did not result in desired level of inclusion and acceptance of autistic people in employment and social life. The prevailing discourse focuses on deficits reinforcing the perception that autistic people are only able to contribute if they are ‘performing’ communication in a neurotypical way on the neurotypical terms. This is a circular argument that is a barrier in itself to inclusion and acceptance of autistic people. The masking required to ‘perform’ in a neurotypical way is the very cause of distress and mental health problems. Essential and primary to all this is the active effort in changing the public discourse about autism from the medical deficit model towards accepting and accommodating our differences and recognising the value of our talents and contributions, removing the structural barriers and enabling autistic people to overcome our difficulties from within.

To achieve this is it essential at this point in time to **change the language and discourse about autism in society**, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits. The definition of disability in the Equality Act and doing things differently and the significance of autism as a different way of being and processing the world is insufficiently understood in this context.

The language about autism in public discourse research and social media should be reviewed with the full participation of autistic people. There is a need to establish Equal Justice of criminalising disability hate and autism hate crimes on the par with racial hatred. There is a need for the prohibition of disability and autism hate speech and relevant regulation of harmful content on social media.

Support and services preserving the employment and family unit of high functioning autistic adults would represent a cost saving. High functioning adults in employment and good health make an economic contribution and make good parents - therefore can raise our own autistic children with far less intervention.

Loss of employment is rather the cost of exclusion and discrimination than a lack of capability to make a valuable contribution.

Access to Psychotherapy and Mental Health support to address the co-occurring and comorbid mental health needs and high suicide rates of autistic people of all ages, on an ongoing preventative basis and not only at the time of crisis.

Support and coaching of autistic adults, especially those without intellectual disability **into employment**, tailored to their aspirations, talents and skills. Such support should be specialised, tailored to autism and not fragment and limited by the postcode lottery and scale at the local level. All autistic people who can and want to work should receive help that is relevant to their aspirations. A support that is not means tested, linked to ESA and not limited otherwise by the current criteria that exclude most high functioning autistic adults.

Most importantly there should be tailored support and job coaching for high functioning autistic people **to retain employment** and progress their careers, to overcome the specific barriers they face, tailored to the individual.

Support during diagnosis. There is a need to increase the capacity and reduce lead times and remove the postcode variation in access to the diagnosis and offer people who initiated the diagnostic process and are often in crisis a sign posting coordinator, a hand holding guidance, an introduction into the ASC, an access to a supportive community and peer to peer advice on specific barriers affecting the individual.

Support, assessment, diagnosis and relationship counselling for the whole family and spouses in coping with challenges of autism and disability within the family and in developing and maintaining effective communication and bridging the double empathy gap, informed and supported by double empathy based science. Such family support and relationship counselling cannot be developed based on dehumanising ableist model of the relationship, pseudoscience and emotionally abusive practices promoted by autism hate groups. Rather it should harness the full scope of peer to peer support and knowledge within the autistic community.

Front loading and fast tracking diagnosis and SEN support. Much of the angst and mental health problems affecting autistic adults originate in delayed diagnosis and inadequate SEN provision at school and the adversarial fraught process of getting this support. This contributes to MH problems and employment prospects of the young people and also affects the MH of the parents, siblings, puts strain on the whole family and could lead to family breakdown. Front loading support and fast tracking the diagnosis and support for all members of families affected by autism would release the pressure.

Life coaching, to address the underlying difficulty of autistic people causing their anxiety and mental health problems - support their personal development and life coaching in attaining their goals. This way disjointed 'interventions' and theories could be brought together into practical use by autistic people in addressing their real needs. Professionals to guide us of all ages to develop, be independent as possible, support individual development. Life skills defined individually in broad and flexible terms by autistic individuals. For some it is taking a bus, for others it is avoiding fall into depression, starting a family, or even retaining their job in professional capacity. Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who respect autistic people and actually listen to what is actually said.

Coaching in transitions. Autistic people are late bloomers and face particular challenges in transitions. Transitions time is where autistic people are particularly vulnerable, and need tailored 1:1 support in developing the coping strategies and life skills. There is a particular difficulties for young people leaving school and failing to cope with the new changes and demands, often resulting in educational placement breakdown, mental health crisis and a state of confusion with which parents and services are ill equipped to deal. A tailored 1:1 life coaching services for individuals of all functioning level and all ages, tailored to their particular challenges and informed by experience of autistic people who have successfully overcome those barriers would address the real factors underlying continuous stress and anxiety in which autistic people live.

Ethics of ASD research and service development. The genetic research into autism is in urgent need of ethical safeguards. Research ethics for ASD research has insufficient regard towards the agency and autonomy of autistic people. The focus should shift for genetics in rodents towards informing support systems that improve the health, wellbeing and quality of life of autistic people. It is also weak in relation to a range of ethical concerns. These topics include the very concept of autism itself, the question whether autism is primarily an identity or a disorder, the ethical questions that parents of autistic children face, metaethical questions, the ethical consequences of epistemological questions, and a cluster of questions related to social justice, stigma, and paternalism.

Based on your experience and perspective, what do you think the most important things are that the government should do to improve the lives of autistic children, young people and adults?

1.:

De-stigmatize autism in the public discourse, de-normalise ableist bias of NT behaviour being the only right behaviour, provide Equal Justice - same laws for disability and autism hate speech as for racial hatred, regulation of autism hate content online

2.:

Psychotherapy, MH, suicide

3.:

Personal coaching, counselling, mentoring, peer to peer support, non means tested, not only to those eligible for social care, not only for those on MH pathway

4.:

Support to gain and retain employment, HFA, non means tested

5.:

Support for relationships, starting and the family and keeping it together. Informed by the double empathy model and equality. Not based on autism hate groups like Faaas and Different Together, not based on Maxine Aston discriminatory and degrading ideology

Before you submit your response

How did you hear about this consultation?

Social Media

If you answered other, please specify:

How satisfied were you with using the digital online consultation form?

Disappointed

How could we improve this service?:

Response ID: ANON-YWQM-P7VQ-V [Type here]

[Type here]

There should be clearer layout and numbered questions. Autistic people should be asked the same questions as carers

About you

What is your name

First name Marie

Last name: Paula Graham-Gazzard, Marie Djela, and Graham Mead on behalf of the group

Please give the first half of your home postcode.

Postcode W1J 5DL not relevant

What is your email address?

Email: asap2pf@gmail.com

Is it okay for the Department of Health and Social Care to contact you in relation to your response?

Yes

About you - continued

We are a group of people late diagnosed in adulthood as ASD without intellectual disability ranging in age from 30 to 70 and our response to the consultation comes from extensive public discussions on our experience of late-diagnosis and living with autism as an adult. We are currently in the process of constituting as an independent advocacy organisation.

Group members include paula@fossbox.org.uk, gilpurplemage@gmail.com, simon@simonselectronics.co.uk, digger5@hotmail.co.uk, helenjuliet1980@yahoo.com, learndifferentuk@gmail.com, heather.ritchie@gmx.com,

We are concerned at the overwhelming public presentation of autism as a condition primarily affecting children and the people who care for them. The majority of the conversation concerns the impact of autism on family and economy rather than on people living with autism. We find this skewed perspective also structural to this review. We believe that the way that autism is presented to the UK public gives an overwhelming impression that ASD individuals are suffering from a mental health issue which is primarily of concern to parents and caregivers. When a perspective is given by an autistic child this is heavily inflected as the voice of a 'patient'. The high-functioning adult ASD voice is almost entirely absent from the discussion and is framed within the historic power imbalance between the 'mental health patient' and the professional. About half of adults with ASD have average or above-average intelligence - yet there is very little discussion of high-functioning ASD. Why is the voice of adults with high-functioning ASD so absent from public debate? Autistic adults have an understanding from within and lived experience of the condition and a relevant contribution to make into the understanding, the priorities and the effective solutions to the challenges autistic people face. We are not passive patients, but people with agency and autonomy and have an important contribution to make into decisions about ourselves.

Most of the systems and interventions are designed to help autistic people to behave and function in a 'normal' neurotypical way, rather the helping autistic people to develop from within their own strategies based on their innate way of processing the world. High functioning autistic individuals can guide autistic peers and professionals in developing more effective and more relevant interventions and support services via participatory processes, building on established practices of participatory and action research. High functioning autistic people are a resource, not a cost to society. <https://journals.sagepub.com/doi/full/10.1177/1362361318786721>

The individual questionnaire to this consultation conflates difficulties with everyday activities with intellectual disability. This does not reflect the latest revision of DSM-5 which removed the

distinction between high and low functioning based on intelligence, because it is not a binary choice but a spider diagram, where autistic people have spiky profiles.

The learning disability should not be used as a criteria for support for autistic people. Importantly high functioning individuals face huge challenges in everyday functioning, which do not feature in social care criteria but cause huge stress and anxiety and are the root causes of their health costs unemployment and family breakdown and do require tailored support.

Whilst the impacts for ASD individuals without learning disability are less catastrophic, there is still a very significant negative impact on life expectancy and employment:

“Individuals in the control group died at a mean age of 70.20 years (s.d. = 24.16, median = 80), whereas the corresponding figure for the entire ASD group was 53.87 years (s.d. = 24.78, median = 55), for low-functioning ASD 39.50 years (s.d. = 21.55, median = 40) and high-functioning ASD 58.39 years (s.d. = 24.01, median = 63) respectively. The time period between registered ASD diagnosis and death (regardless of cause of death) was on average 5.30 years (s.d. = 4.85) for low-functioning ASD and 3.79 years (s.d. = 4.17) for the high-functioning ASD group”. <https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4C9260DB64DFC29AF945D32D1C15E8F2/S0007125000279385a.pdf/div-class-title-premature-mortality-in-autism-spectrum-disorder-div.pdf>

As “Just 16% of autistic adults are in full-time employment, and another 16% are in part-time employment, even though at least 70% want to work.”

<https://www.unlimitedpotential.org.uk/sites/default/files/users/upadmin/Research%20report%20C%20project%20proposal%20-%20meaningful%20employment%20of%20autistic%20people%20FULL%20REPORT.pdf>

There is a strong economic argument, plus an incontestable moral case to provide appropriate assistance. These figures mean that over 100,000 adults would like to be in full time employment. We are no more desirous of being a financial burden on society than we are of continuing to struggle with suicidal thoughts.

If the autistic community were to be given the resources to change these figures, I am certain we would be successful. We are more knowledgeable about the condition than any number of ‘experts’ who have demonstrably failed us and consequently, society.

These factors alone contribute enormously to the overall national cost of ASD. The costs of supporting children with ASDs were estimated to be pound 2.7 billion each year. For adults, these costs amount to pound 25 billion each year. The lifetime cost, after discounting, for someone with ASD and intellectual disability is estimated at approximately pound 1.23 million, and for someone with ASD without intellectual disability is approximately pound 0.80 million. [\[https://www.ncbi.nlm.nih.gov/pubmed/19369391\]](https://www.ncbi.nlm.nih.gov/pubmed/19369391) High functioning adults with ASD are a less costly group - not least because we are not usually offered any support unless we are in acute

crisis. Nevertheless, the cost of supporting someone with ASD as an adult without learning disabilities could be greatly reduced if, instead of largely ignoring us as a 'less needy' group and engaging with us only in acute crisis, we were given resources to organise ongoing mutual support networks working with employers, education providers, families, local authority and NHS provision.

The paper on the cost of autism includes loss of employment for high functioning autistic adults. Often there are several autistic individuals within the family, which puts huge strain on all family members. Autistic parent's employment and the stability of the family unit are essential protective and supporting factors for all the autistic individuals involved. The loss of employment and relationship breakdown leads to mental health crisis, unemployment, and an escalating cost in health and benefits. Support and services preserving the employment and family unit of high functioning autistic adults would represent a cost saving. High functioning adults in employment and good health make an economic contribution and make good parents - therefore can raise our own autistic children with far less intervention. Loss of employment is rather the cost of exclusion and discrimination than a lack of capability to make a valuable contribution.

In what capacity are you responding?

We are responding as an organisation that works with autistic people.

An organisation in England that works with autistic people

Paid carers and organisations

In what role do you provide paid care, support, information or any other services to anyone who is autistic?

Advocate

Voluntary sector

How long ago was the person you provide care or support for diagnosed as autistic?

3 to 5 years

Additional information

As a group, we have all been late-diagnosed in the past 5 years, many of us are in our 50s and 60s and have struggled with an undiagnosed condition for decades.

Paid carers: Getting the right support at the right time

How long did the person you care for and or support, have to wait for an initial assessment following referral from their GP or another professional?

Longer than two years

Additional information

We are responding as a group which has experienced diagnosis as an adult within the previous 5 years. We are aware that diagnostic process is a 'regional lottery' with routes to access, diagnostic process, and waiting times being widely divergent. We know of people who have waited up to 3 years and 18 months seems an average wait across the country.

The process is extremely stressful, often very little information is given and the diagnostic process itself is often extended across many months causing enormous anxiety to people who already struggle to manage anxiety and need support with events such as bullying, loss of employment or family breakdown which are often the cause of seeking diagnosis. The process presses the individual to explore their life challenges and personal history in detail and discuss

these with family bringing up feelings of powerlessness, bullying, distress, isolation etc - which, again, an ASD individual is already likely to struggle with. Once diagnosed (or not) little or no support is offered to help the individual to cope.

Another key concern we share is that individuals diagnosed as an adult - frequently after a lifetime of struggling with an undiagnosed or mis-diagnosed disability - are then offered very little post-diagnostic support. At best, post-diagnostic support consists of 4-6 informational group sessions and ongoing monthly 'group therapy' sessions which are entirely unsuitable for ASD individuals and where people with and without intellectual disabilities are often mixed inappropriately.

There are isolated examples of excellent practice, particularly in terms of employment support, but this provision is extremely patchy and has no 'teeth' - employers frequently ignore the efforts of ASD employment services to implement reasonable adjustments.

Getting the right support at the right time - continued

How well supported is the autistic person you care for, or how well supported were they throughout their education?

This includes for example:

- **early years such as nursery**
- **primary school**
- **secondary school**
- **further and higher education after 16 years such as College or University**

Poorly supported

Additional information

Older people being diagnosed later in life may already have dropped out of school or HE due to challenges related to their undiagnosed ASD and so lack of education is added to lack of employability skills leading to life-long challenges with employment. Whilst provision for children who have been diagnosed earlier is improving, this is still failing to support ASD individuals into adulthood.

Inadequate provision at school are at the origin of or contribute to mental health problems in adulthood. There is a cliff -edge after school, it is not rare that autistic students, even with EHCPs experience a breakdown, school refusal and mental health crisis in late stage of 6 form or there after, because their maturity and ability to cope does not keep up with the expectations for their age. Often their emotional, social needs, life skills gaps are not fully understood and there is no support and coaching available for transition to independence. They lose confidence and fail to cope.

They are suddenly considered adults with the coping skills and understanding, which autistic young people often didn't have the opportunities to develop such understanding (because of limited social inclusion, limited employment, limited involvement in the aspects that make their peers more mature), so they did not experience the things and did not develop opinions and coping mechanisms to the same extent. So they find themselves unable to cope with the full demands of the post 18 life.

Example threads about a 19 years old, 15 years old.

<https://community.autism.org.uk/f/parents-and-carers/15510/my-daughter-is-24-has-asd-anxiety-depression-etc---i-don-t-know-what-else-to-do-to-help-her-anyone-else-feel-blamed-for-their-kid-s-symptoms>

<https://community.autism.org.uk/f/parents-and-carers/15481/when-to-pull-the-cord-parents-of-adhd-aspie-19-yo-need-help-transitioning-him-to-independence>

<https://community.autism.org.uk/f/parents-and-carers/15468/help-getting-my-15-year-old-daughter-back-into-a-routine>

Many autistic teenagers who did not have all the right support in place at school (EHCPs or inadequate SEN provisions) develop mental health problems, school refusal and find the transition to adulthood very hard. Sometimes schools start winding down provisions in 6 form arguing about transitions to independence. Often it triggers anxiety, lost of confidence, mental health crisis and an even bigger loss of independence as young people seek refuge at home as they can't cope with the transition.

The transition from school to 6 form college is also damaging. The college commissions provisions differently, so the young person loses the provisions and specialists support that worked and starts anew with the college being slow to recognise and understand needs, resulting in needs not being met and a mental health crisis in addition. It did not result in saving money, but is devastating for the young person. Putting EHCP in place early and maintaining the provisions in transitions is essential, it would save money in the long term in terms of resilience, employability and health.

There was research about mental health of young people, feeling stressed, anxious and depressed being their normal'. <https://www.ambitiousaboutautism.org.uk/understanding-autism/know-your-normal-research-four-out-of-five-young-people-with-autism-experience>
 Access to MH services is necessary, but even more important is addressing the causes of this anxiety, stress and MH deterioration by making

- SEN provisions,
- Facilitating/creating peer buddies, senior peer mentors,
- Peer ASD acceptance training (awareness presentation)..
- Skills coaching - how to cope with particular challenges, not basic bus rides
- Counselling/psychotherapy for emotional understanding and support

PhD students reporting anxiety for being completely isolated from their peers, health limiting levels of stress, failing to cope and not knowing how to access support.

<https://community.autism.org.uk/f/health-and-wellbeing/15475/advice-needed-i-think-i-might-be-damaging-my-health>

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/15367/has-anyone-reversed-social-exclusion>

Autistic people are not asked about their needs and support in transition! Transition problems are not understood, parents are ill equipped to support effectively through transitions, other services lack the essential ingredients of 1:1 life coaching and psychotherapy.

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/9520/the-transition-into-adulthood>

Women in particular seem to experience serial breakdown in employment as they may successfully mask but become increasingly fatigued by the effort involved leading to mental health problems and/or breakdown of the employment.

How well were you supported when the autistic person you care for or provide support to moved within schools or between schools?

Not Answered

Additional information:

This question is not asked of autistic people, it should be!

Parents of young autistic adults do not have the relevant advice and resources to support autistic young people through transition. The crisis comes as a surprise

and parents are improvising without the right help and support. Often MH support, counselling and 1:1 coaching, work experience placements etc are needed for

autistic people, but parents don't have the access to that.

Sometimes parents struggle to cope financially with the transition because of demand for transport etc.

For transitions, there is a need for compulsory ASD acceptance training for the peer group, appointed/volunteer peer buddies, senior peer mentors to support and

guide into coping with new emerging demands of the new setting. Coaching into independence, individual 1:1 life skills and independence coaching by the

relevant peers - e.g, for a university student on how to cope with university challenges relevant to the individual, high level skills they struggle with from those who

successfully coped with those specific skills. Not a one size fits all about taking a bus trip or going to the local shop... People also need sources of emotional

support

What would help:

Life skills 1:1 coaching relevant to the individual, understood in broad terms, not in terms of bus trips, transition coping skills, university

coping skills, career skills,

independence skill, relationship skills,

Psychotherapy / counselling

A supportive community - autism forum, asd acceptance training, buddies mentors

This includes:

- **nursery to primary**
- **primary to secondary**
- **secondary to further and higher education**

Poorly supported

If you want to give us more information about this, please tell us here.

Parents of young autistic adults do not have the relevant advice and resources to support autistic young people through transition. The crisis comes as a surprise and parents are improvising without the right help and support. Often MH support, counselling and 1:1 coaching, work experience placements etc are needed for autistic people, but parents don't have the access to that.

Sometimes parents struggle to cope financially with the transition because of demand for transport etc.

For example, how well were the needs of the person you are caring for understood?

This question is not asked of autistic people, it should be!

If they needed adjustments, such as, starting and finishing lessons at slightly different times, having supportive equipment or a member of staff, or changes to the school building etc: were these adjustments made?

What would have made the biggest positive difference to your experience as a carer of an autistic person moving within or between schools?

Additional information

This question is not asked of autistic people, it should be!

For transitions, there is a need for compulsory ASD acceptance training for the peer group, appointed/volunteer peer buddies, senior peer mentors to support and guide into coping with new emerging demands of the new setting. Coaching into independence, individual 1:1 life skills and independence coaching by the relevant peers - e.g, for a university student on how to cope with university challenges relevant to the individual, high level skills they struggle with from those who successfully coped with those specific skills. Not a one size fits all about taking a bus trip or going to the local shop... People also need sources of emotional support

What would help:

1. Life skills 1:1 coaching relevant to the individual, understood in broad terms, not in terms of bus trips, transition coping skills, university coping skills, career skills, independence skill, relationship skills,
2. Psychotherapy / counselling
3. A supportive community - autism forum, asd acceptance training, buddies mentors

If the autistic person you care for has experienced physical health problems, how effective were healthcare professionals in supporting them to manage these or get better?

Mixed, some good support but also short comings

If you want to give us more information about this, please tell us here.

Q22 Additional information

Within the NHS understanding of the needs of ASD individuals is improving once a diagnosis has been achieved. However, there are issues with third-party providers who often seem to have been given no information and whose systems are not set up to take it into account. ASD people often find communication very difficult, and health providers can become irritable. ASD people need very clear instructions to take home and providers need to give enough time for an ASD person to think about their answers.

If the autistic person you care for has experienced mental health problems, how effective were healthcare professionals in supporting them to manage these or get better?

Effective

Mixed, some good support but also short comings

Not effective at all

They couldn't access any support! I'm not sure

Not relevant to me

If you want to give us more information about this, please tell us here.

Additional information

The help that's really helpful is scarce. An integrated lifespan approach would be more effective.

It is difficult to access appropriate mental health support, there are long delays.

- There is no access to affordable psychotherapy, insufficient capacity
- Peer support is very rarely available - we would like it but we have (collectively in different regions) never been offered it so cannot comment on its effectiveness. We would like to explore this area and develop better provision.
- Life skills coaching 1:1 is nonexistent, but would make huge difference. It should be defined more flexibly as skills relevant to the barriers individuals face in their specific circumstances

Research has indicated that young adults with autism are in a continuous state of stress, anxiety and depression that at times escalates into a crisis.

<https://www.ambitiousaboutautism.org.uk/understanding-autism/know-your-normal-research-four-out-of-five-young-people-with-autism-experience>

This continuous anxiety needs alleviating via availability of peer emotional support and advice, life coaching and psychological counselling, 1:1 or in a group, but based on individual needs.

Many high-functioning ASD individuals use their abilities to research and adapt to explore self-help strategies including meditation, yoga and other holistic strategies. Whilst these can help retain balance in the context of overall support, they cannot substitute for adequate life-coaching. We are also aware of an increasing tendency towards 'app-based' support and we have tried various app-based support offers including those informed by research with autistic people. However, we have found these to be orientated towards children and, furthermore, we would question the research base informing them - in some cases, we have found such apps actually increase anxiety. Much of development, like google glasses for autism, is informed by ABA, the coercive normalising of autistic behaviour to appear normal, rather than function well on the inside, which many autistic individuals experience as emotional abuse and trauma. Research indicates that many children subjected to ABA programmes develop PTSD.

There may be some positive possibilities for using technology-based solutions to assist with specific issues such as challenged executive functioning as they can be very useful in scheduling, planning, navigating etc along the lines of 'extended cognition'.

We have found schemes such as the 'sunflower' schemes at airports to be a very simple way of reducing anxiety by signalling discreetly to staff that the individual may experience communication challenges. If such schemes were integrated with a programme of increased awareness this could considerably help ASD adults navigate everyday life with lowered anxiety.

There may be a scope for organisations to have policies to handle communication, not to force interaction and demand the expected socialising from autistic people, for example on supermarket check-out.

As a group we are exploring how we might sustainably develop an online mutual support network for ASD adults without intellectual disabilities. This will need specialist moderation but should be designed, built, and run by and for ASD adults themselves with ASD adults trained in moderating, safeguarding more vulnerable participants, and giving advice in a safe way. We believe that such a facility will significantly positively impact the mental health of ASD adults without learning disabilities. Isolation is a major cause of depression and suicide as well as the relentless pressure of negotiating everyday life and communication. Peer to peer support from autistic people will enable to harness skills and experience with dealing with our everyday challenges and share it with people who face similar challenges and need advice and support.

If the autistic person you care for has been admitted as a mental health inpatient (for example to an Assessment and Treatment Unit, or to

hospital) was a Care and Treatment review carried out or a Care, Education and Treatment Review ?

[For example a Care and Treatment Review](#)

[For example a Care, Education and Treatment Review](#)

I'm not sure

If you want to give us more information, for instance how the reviews supported or didn't support their needs, please tell us here.

Additional information

How well was the autistic person you care for supported by health, social care, education and employment services from aged 18 and older?

WellMixed, some good support but also short comings

Poorly

I am not sureNot relevant to me

If you want to give us more information about this, please tell us here.

For example, how well did services such as health, social care, education and employment work together to provide support to the autistic person you care for?

And did this change as the person you care for or support got older?

Additional information

There is a total disconnect, services are disjointed, not integrated and do not address the issues and priorities that make the biggest difference to the autistic people. They provide what they have, not what is needed.

We feel strongly that there should be frameworks for involving ASD adults in the design of ASD services at an early stage at local and national level so that ASD adults understand resource limitations and can work with providers to involve ASD adults as a resource to inform and extend provision. This could call for autistic expertise on the national scale, so the quality of input is not limited by local fragmentation. It could take form of an expert patient /expert user participation in the design of the service.

An online autistic community and peer to peer support network at a national scale could help isolated autistic individuals to find their communities of interest and sources of advice and support that is specifically relevant to their individual problem or interests. This way a scale could be achieved for a service, or activity that would never make the short list at the local level.

What would AS services look like in a perfect world?

Holistic, integrated, preventative, life span

National framework, no post code lottery and variation

Defined and designed by autistic people

Based on progressive vision of autism, social model of disability, autism acceptance

Supporting personal growth and life skills as defined by autistic people themselves, support and coaching in coping with autism in achieving life goals.

Support for health needs, for the entire family, for employment, aging, housing.

Life skills defined individually in broad and flexible terms by autistic individuals. For some it is taking a bus, for others it is avoiding fall into depression, starting a family, or even retaining their job in professional capacity.

How would you rate the understanding of the following people, if you have come into contact with them,

5 = very good understanding of how to support and communicate with autistic people

1= no understanding of how to support and communicate with autistic people.

Rate professionals who directly provide services, care and support to autistic people

	5	4	3	2	1	Does not apply to me
GPs	GPs5	GPs4	GPs3	GPs2	GPs1	GPsDoes not apply to me
Nurses	Nurses5	Nurses4	Nurses3	Nurses2	Nurses1	NursesDoes not apply to me
Hospital doctors	Hospital doctors5	Hospital doctors4	Hospital doctors3	Hospital doctors2	Hospital doctors1	Hospital doctorsDoes not apply to me
Mental health professionals	Mental health professionals5	Mental health professionals4	Mental health professionals3	Mental health professionals2	Mental health professionals1	Mental health professionalsDoes not apply to me

Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists5	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists4	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists3	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists2	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists1	Other health professionals such as for example Occupational Therapists, Speech and Language Therapists, Opticians, Dentists, Health Care Assistants and Pharmacists Does not apply to me
Social workers	Social workers5	Social workers4	Social workers3	Social workers2	Social workers1	Social workers Does not apply to me
Headteachers	Headteachers5	Headteachers4	Headteachers3	Headteachers2	Headteachers1	Headteachers Does not apply to me
Teachers	Teachers5	Teachers4	Teachers3	Teachers2	Teachers1	Teachers Does not apply to me

Response ID: ANON-YWQM-P7VQ-V

[Type here]

[Type here]

Nursery workers/ Child Carer	Nursery workers/ Child Carer5	Nursery workers/ Child Carer4	Nursery workers/ Child Carer3	Nursery workers/ Child Carer2	Nursery workers/ Child Carer1	Nursery workers/ Child CarerDoes not apply to me
Teaching assistants in classrooms	Teaching assistants in classrooms 5	Teaching assistants in classrooms 4	Teaching assistants in classrooms 3	Teaching assistants in classrooms 2	Teaching assistants in classrooms 1	Teaching assistants in classrooms Does not apply to me
Solicitors	Solicitors5	Solicitors4	Solicitors3	Solicitors2	Solicitors1	SolicitorsDoes not apply to me
Police officers	Police officers5	Police officers4	Police officers3	Police officers2	Police officers1	Police officersDoes not apply to me
Magistrates	Magistrates 5	Magistrates 4	Magistrates 3	Magistrates 2	Magistrates 1	Magistrates Does not apply to me
Staff in the bank	Staff in the bank5	Staff in the bank4	Staff in the bank3	Staff in the bank2	Staff in the bank1	Staff in the bankDoes not apply to me

Rate other types of staff

5 4 3 2 1 Does not apply to me

GP Receptionist	GP Receptionist5	GP Receptionist4	GP Receptionist3	GP Receptionist2	GP Receptionist1	GP ReceptionistDoes not apply to me
Hospital porters	Hospital porters5	Hospital porters4	Hospital porters3	Hospital porters2	Hospital porters1	Hospital portersDoes not apply to me
Transport staff	Transport staff5	Transport staff4	Transport staff3	Transport staff2	Transport staff1	Transport staffDoes not apply to me
Social care staff helping you in the home such as a Care Assistant	Social care staff helping you in the home such as a Care Assistant5	Social care staff helping you in the home such as a Care Assistant4	Social care staff helping you in the home such as a Care Assistant3	Social care staff helping you in the home such as a Care Assistant2	Social care staff helping you in the home such as a Care Assistant1	Social care staff helping you in the home such as a Care AssistantDoes not apply to me
Staff working in social services departments	Staff working in social services departments5	Staff working in social services departments4	Staff working in social services departments3	Staff working in social services departments2	Staff working in social services departments1	Staff working in social services departmentsDoes not apply to me
Staff working in the jobcentre or on the telephone helpline	Staff working in the jobcentre or on the telephone helpline5	Staff working in the jobcentre or on the telephone helpline4	Staff working in the jobcentre or on the telephone helpline3	Staff working in the jobcentre or on the telephone helpline2	Staff working in the jobcentre or on the telephone helpline1	Staff working in the jobcentre or on the telephone helplineDoes not apply to me

Staff working in the Local Authority housing department including benefits assessors	Staff working in the Local Authority housing department including benefits assessors 5	Staff working in the Local Authority housing department including benefits assessors 4	Staff working in the Local Authority housing department including benefits assessors 3	Staff working in the Local Authority housing department including benefits assessors 2	Staff working in the Local Authority housing department including benefits assessors 1	Staff working in the Local Authority housing department including benefits assessors Does not apply to me
Staff working in the Local Authority benefits department	Staff working in the Local Authority benefits department 5	Staff working in the Local Authority benefits department 4	Staff working in the Local Authority benefits department 3	Staff working in the Local Authority benefits department 2	Staff working in the Local Authority benefits department 1	Staff working in the Local Authority benefits department Does not apply to me
School receptionist	School receptionist 5	School receptionist 4	School receptionist 3	School receptionist 2	School receptionist 1	School receptionist Does not apply to me
Special Educational Needs Officer (SENCOs) in schools	Special Educational Needs Officer (SENCOs) in schools 5	Special Educational Needs Officer (SENCOs) in schools 4	Special Educational Needs Officer (SENCOs) in schools 3	Special Educational Needs Officer (SENCOs) in schools 2	Special Educational Needs Officer (SENCOs) in schools 1	Special Educational Needs Officer (SENCOs) in schools Does not apply to me
Lunchtime staff in schools	Lunchtime staff in schools 5	Lunchtime staff in schools 4	Lunchtime staff in schools 3	Lunchtime staff in schools 2	Lunchtime staff in schools 1	Lunchtime staff in schools Does not apply to me

Probation staff	Probation staff5	Probation staff4	Probation staff3	Probation staff2	Probation staff1	Probation staffDoes not apply to me
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If you want to give us more information about this, please tell us here or if you would like to tell us about any other people not included in the list above.

Further information

- Access and support with employment
- Support in relationships that is not based on a deficit model of ASD in adulthood, but informed by the double empathy problem [\[https://network.autism.org.uk/knowledge/insight-opinion/double-empathy-problem\]](https://network.autism.org.uk/knowledge/insight-opinion/double-empathy-problem) and is supportive of developing effective communication with equal focus on the needs of both partners.
- Training professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who understand ASD and actually listen to autistic people.
- We have concerns that research ethics for ASD research is, again, skewed towards families and children and has insufficient regard towards the agency of autistic people. It is also weak in relation to a range of ethical concerns. These topics include the very concept of autism itself, the question whether autism is primarily an identity or a disorder, the ethical questions that parents of autistic children face, metaethical questions, the ethical consequences of epistemological questions, and a cluster of questions related to social justice, stigma, and paternalism. <https://onlinelibrary.wiley.com/doi/pdf/10.1111/phc3.12559>
- Use of language about autism.(broad based, beyond autistic/with autism) 'Nothing about us without us'.
- Equal justice in dealing with autism hate speech and harmful content online about autism. This ranges from dangerous 'quack' cures to public forums where dehumanising and ableist models of of relationships with autistic people took hold. Autism hate speech is being normalised and malicious stereotypes spread without challenge with autistic people being even censored under the guise of support. Media stereotypes and what amounts to 'hate speech' against autistic people may inform professional practice negatively and result in unnecessary problematising of autism and a failure to consult and involve autistic people. Discriminatory attitudes normalised by such content are then spread to all parts of of society, such as employment.

Dealing with professionals such as solicitors, teachers, medical professionals etc presents particular challenges for autistic people who need more unambiguous communication and more

time to deal with issues, to fully understand and to fully communicate back and to be sure the professionals have understood them. This is recognised in, for example, double GP appointments but for professionals such as solicitors this results in higher bills. There should be reasonable adjustment whereby autistic people's needs are better financially supported.

Continue First Save and come back later...

Being part of the local community

This section is about how autistic people feel within their local community. By local community we mean the people who live in their area.

Has the autistic person you provide either unpaid or paid support to told people, such as their friends and the people they may study, work or take part in leisure activities with, that they are autistic?

If you support several autistic people you may want to choose one of them to consider

Yes

No

If you want to give us more information about this, please tell us here.

For example, if the person you support or care for has not told others they are autistic , why is this?

Additional information

There are prejudices and stigma in society, discriminatory attitudes. Autistic people experienced not being taken seriously after disclosure, 'friends' cutting contact, opponents of opinions use autism to invalidate autistic opinions and contributions ('She's a patsy' <https://www.spiked-online.com/2019/04/22/the-cult-of-greta-thunberg/>), attack their very human rights and autonomy (Letter from Human Rights Watch: By denigrating the young Swede's commitment because of her autism, the author attacks people with disabilities and their recognition as full-fledged citizens with an important role to play in societal issues. By deciding to target Greta Thunberg's autism to try to disqualify her speech, Laurent Alexandre harms all people with disabilities. <https://www.hrw.org/fr/news/2019/04/18/lettre-de-human-rights-watch-lexpress-en-reponse-la-tribune-de-laurent-alexandre-sur>), pathologize their normal behaviour <https://www.mumsnet.com/Talk/relationships/3552950-does-dh-have-asperger-s>, people experience isolation and discrimination.

Some people want to use understanding of autism to humiliate and autistic people in public for fun or to undermine their ability to fully participate in society

<https://twitter.com/HelenDale/status/1120759250387701767?s=20>

Social media organisations preclude autistic people from participating in discussion about them, segregate, silence them and delete their contributions.

After disclosing employers ignore the disclosure and keep on arguing 'we all do that' and start using the knowledge about autism to find faults, to undermine autistic people. Disclosure often leads to dismissal.

Predominant stereotypes and conceptions about autism act as a barriers for true good communication and acceptance even within the family, they are disabling

Brett Heasman (LSE) discusses his recent study published in the journal Autism, "Perspective-taking is two-sided: misunderstandings between people with Asperger's syndrome and their family members". https://www.youtube.com/watch?v=TSMF_3f0Q0c&feature=youtu.be

Focus on autistic problems like theory of mind distracts from seeking two sided understanding <https://semioticspectrumite.wordpress.com/2018/01/26/the-belief-in-theory-of-mind-is-a-disability/>

Women with ASD may present differently from the 'masculine' model leading to further discrimination including refusal by communities, employers, and health professionals to believe that a woman is living with ASD (even when medically diagnosed). The 'masculinisation' of ASD can also lead to distressing gender confusion among women living with ASD.

There are also particular concerns around safeguarding young adult ASD women who are exceptionally vulnerable to childhood victimisation, sexual exploitation and relationship abuse. "More recent research interviewing 182 parents of children with ASC found high rates of reported physical abuse (18.5%), sexual abuse (12.2%), or both kinds (4.4%), though no information on the sources of this abuse was noted (7). Studies have also found high rates of peer victimization in children [65–77%; (6, 9)]. Studies of adults with ASC have largely focused exclusively on sexual victimization. In a college sample, students with ASC were twice as likely to report unwanted sexual contact compared to students without ASC (10). In an online survey,

70% of adults with ASC reported experiencing some form of sexual victimization after age 14 and into adulthood, compared to 45% of those without ASC (5). Authors have suggested that increased risks of bullying, physical, and emotional abuse may also be present in adults with ASC due to heightened social vulnerability (11, 12).“

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5980973/> Such experiences are traumatic and yet victims and survivors are only offered psychological support in acute crisis. We would like to see more research exploring to what extent social and communication issues experienced by people living with ASD - and particularly women with ASD - are exacerbated by the legacies of traumatic victimisation. No significant differences were found between groups on perpetration. Therefore stereotypes on websites such as Mumsnet that ASD men are 'abusive' in relationships is not supported by research.

Women with ASD may appear to be masking effectively whilst experiencing health-threatening levels of stress and exhaustion: <https://www.emeraldinsight.com/doi/abs/10.1108/AIA-09-2018-0036>

There is a strong need for more research and for the appropriate education of diagnostic services as well as the wider public in the gender-specific implications of ASD. Much regional provision omits support for young adults in particular which might do much to safeguard young ASD people from this prevalent legacy of traumatic abuse.

Do you think the person/people you support can take part in the things that are important to them within the community?

This could include shopping, travelling, taking part in sports and other leisure activities. For a child this may be going to school, taking part in hobbies and interests outside of school.

If you support several autistic people you may want to choose one of them to consider.

Yes

No

Some but not all activities I'm not sure

If you want to give us more information about this, please tell us here.

For example, if you do not feel the autistic person/people you care for or provide support to can take part in the things that are important to them, please tell us what those things are and why you think they can't take part in them?

What do you think would allow them to do these things?

Additional information

Local 'community' in its current meaning is too fragmented and restricting for many autistic people. Being a minority of about 1% of the population, autistic people need a community at a national scale to access advice, support, skills, knowledge, relevant to their specific problem, to find friends and people with common interests. At the local community level the diverse and specific problems and interests of autistic people might never have the scale and priority to be funded and delivered. There is a need to achieve this on a 1:1 or small group basis, specific to the need of the individual and it is only possible on a national level.

The activities described are too narrow and are insufficient to lead a full fulfilled life on the par with NT people (For an adult, shopping, travelling, taking part in sports and other leisure activities. For a child this may be going to school, taking part in hobbies and interests outside of school). Shopping is a necessity, not community participation. An odd trip once a month with a volunteer/stranger is not a meaningful community participation. Autistic people need to find their 'tribe', be part of a community that is actually understanding and supportive, they need social support. They need to partake in meaningful pursuits and form meaningful relationships, on the par with NT people. This means full participation in education, employment, leisure and family life

1. Start to address the underlying difficulty of autistic people - support their personal development and life coaching in attaining their goals. Professionals to guide us of all ages to develop, be independent as possible (which is probably individual). Support individual development. Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who understand ASD and actually listen to autistic people, process what is actually said.
2. Another resource that I would like to have would be life skills development summer camps. They have a lot of these summer camps for AS children and teenagers in the U.S., but there aren't many for adults. It would be very useful to be able to attend a 2-week summer camp, where they can teach some basic life skills and provide some team-bonding training. It would be a great way to make friends and learn skills.
3. Ideally there should be support groups in every area, separate from social groups. These should be run by someone from the local autism services and should perhaps cover a different topic that people diagnosed with AS as adults may be struggling with.

Even if they only ran once a month, it would be good to have the option to be able to go along, learn new information, meet other adults newly diagnosed with AS and swap ideas with both them and the person running the group.

Do you think the autistic people/person you care for has ever experienced any of the below because they are autistic?

	Yes, they have often experienced this	Yes, they have sometimes experienced this	No, they haven't experienced this	I'm not sure
Hate crime	Hate crime Yes, they have often experienced this	Hate crime Yes, they have sometimes experienced this	Hate crime No, they haven't experienced this	Hate crime I'm not sure
Bullying	Bullying Yes, they have often experienced this	Bullying Yes, they have sometimes experienced this	Bullying No, they haven't experienced this	Bullying I'm not sure
Discrimination	Discrimination Yes, they have often experienced this	Discrimination Yes, they have sometimes experienced this	Discrimination No, they haven't experienced this	Discrimination I'm not sure
Harassment	Harassment Yes, they have often experienced this	Harassment Yes, they have sometimes experienced this	Harassment No, they haven't experienced this	Harassment I'm not sure

How would you rate the understanding of the following people, organisations and businesses if you have come into contact with them?

Where 5 = very good understanding of the needs of autistic people and 1= no understanding of the needs of autistic people.

	5	4	3	2	1	Doesn't apply to me
Autistic person's family and friends	Autistic person's family and friends ⁵	Autistic person's family and friends ⁴	Autistic person's family and friends ³	Autistic person's family and friends ²	Autistic person's family and friends ¹	Autistic person's family and friends Doesn't apply to me
Staff in shops, banks, restaurants and pubs	Staff in shops, banks, restaurants and pubs ⁵	Staff in shops, banks, restaurants and pubs ⁴	Staff in shops, banks, restaurants and pubs ³	Staff in shops, banks, restaurants and pubs ²	Staff in shops, banks, restaurants and pubs ¹	Staff in shops, banks, restaurants and pubs Doesn't apply to me
Transport staff – buses, trains, taxis, underground trains ('the tube'), trams	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams ⁵	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams ⁴	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams ³	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams ²	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams ¹	Transport staff – buses, trains, taxis, underground trains ('the tube'), trams Doesn't apply to me

Response ID: ANON-YWQM-P7VQ-V

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Staff at leisure centres, sporting events, libraries, theatres and cinemas	Staff at leisure centres, sporting events, libraries, theatres and cinemas ⁵	Staff at leisure centres, sporting events, libraries, theatres and cinemas ⁴	Staff at leisure centres, sporting events, libraries, theatres and cinemas ³	Staff at leisure centres, sporting events, libraries, theatres and cinemas ²	Staff at leisure centres, sporting events, libraries, theatres and cinemas ¹	Staff at leisure centres, sporting events, libraries, theatres and cinemasDoes n't apply to me
Staff running youth activities	Staff running youth activities ⁵	Staff running youth activities ⁴	Staff running youth activities ³	Staff running youth activities ²	Staff running youth activities ¹	Staff running youth activitiesDoes n't apply to me
Staff in other leisure facilities	Staff in other leisure facilities ⁵	Staff in other leisure facilities ⁴	Staff in other leisure facilities ³	Staff in other leisure facilities ²	Staff in other leisure facilities ¹	Staff in other leisure facilitiesDoes n't apply to me
Employers	Employers ⁵	Employers ⁴	Employers ³	Employers ²	Employers ¹	EmployersDoesn't apply to me
The general public	The general public ⁵	The general public ⁴	The general public ³	The general public ²	The general public ¹	The general publicDoesn't apply to me

How would you rate the understanding of the following people, organisations and businesses if you have come into contact with them?

If you want to give us more information about this, please tell us here

Additional information

As previously noted, extension of the 'sunflower scheme' at airports to other travel, shopping, sport, leisure and community facilities could be massively beneficial.

Some of autism awareness has led to stigmatisation of autism due to the language of deficits and assumed primacy of the neurotypical way of communication and empathy. Accommodating the autistic way of being and functioning is marginal to the discourse. For many autistic people this created as many problems as it solves.

The 'problem' of autism is primarily the double empathy gap that needs to be bridged by both sides. There is no point in putting all the burden of bridging this gap on autistic people, they can't do that alone, it doesn't work. The framework of developing intervention and services based on the power imbalance in the professional- patient model and involvement of the knowledge of autistic people only on a limited tokenistic level should evolve toward more participatory model lead by autistic (self-)knowledge. The increasing pressures on communication and sensory intensity of the modern life cause an increasing number of autistic adults to seek diagnosis, often triggered by life events like loss of employment or family breakdown. Autism doesn't have to lead to these outcomes. The diagnosis should be the key to unlocking the understanding and removing the barriers.

There is no point in stigmatising and isolating, pushing autistic people out of mainstream society into the confined space of being care receiver - this undermines the value and health of autistic people and increases the cost to society due to the need to provide for the treatment of mental health and physical comorbidities, unemployment, family breakdown, poverty etc.

By creating a culture where autistic people are equal, with valuable contributions to make, by supporting and coaching autistic people to function well in line with their potential, we will improve health, wellbeing and reduce costs...

To achieve this is it essential at this point in time to change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.

In line with the Equality Act, disability is a different way of doing things, the reasonable adjustment for autism is to accept and respect the autistic way of being, of communicating, understanding and processing the world.

The equality in law of disability hate crime, disability hate speech and regulation of autism hate content online have a role to play in fostering autism acceptance in society.

Support:

1. **It should be holistic.** The holistic approach to health needs and life skills, family support, personal development. all the services integrated better. Psychologists, psychiatrists and developmental disorder services, 1:1 support, life skills coaching,

family support, employment, social care, housing. The probable pattern within many families is undiagnosed autism followed by years of difficulties then initial contact with services due to related problems (depression, anxiety, OCD, psychosis) which are picked up as if they've suddenly come out of nowhere. When really I think the undiagnosed autism with no awareness, insight, support or help was the soil on which all of the other issues grew.'

2. Start to address the underlying difficulty of autistic people - support their personal development and life coaching in attaining their goals. **Professionals to guide us of all ages to develop, be independent as possible** (which is probably individual). **Support individual development.** Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who understand ASD and actually listen to autistic people, process what is actually said.
3. A **national service framework for autism**, like the one for older people. Care needs to be standardised throughout the UK, autistic people need to be recognised as having as many differences between us as NTs at the moment we all seem to get lumped into the same mould for garnering all of this support. There should not be post code lottery, **national standards** that we can expect will be adhered to from assessment to diagnosis and beyond.
4. Some **service to help with symptom management [also for co-occurring conditions]**. Autistic people have to put a lot of effort every day into symptom management with minimal or no support.
5. Support for people, including HFA **into employment**, not means tested, not only for families on benefits. People wasting their talents at home and going through circles of depression are more expensive to society than people who are having fulfilling work and paying taxes. Every large employer should have a link person who is an advocate for autistic adults who could also cascade train their teams where needed, much as in nursing we have link nurses who specialise in say, diabetes or palliative care and cascade any new info to the rest of the team.
6. **Employment mentoring and coaching**, aiming to also help people in professional and managerial roles to cope and retain their highly skilled employment. Like business mentors and career coaches, but autism focussed. Too many people here are managers and engineers hopping from job to job, ending up in lower skilled roles. They could even be fee based to those who can afford. It is not like Access to Work, about paying for reasonable adjustments, but about personal effectiveness coaching for coping and getting acceptance in those managerial occupations, it should be 1:1 for the person,, not dependent on the employer like access to work, it should not require disclosure and formal dx.
7. Mental health **support, diagnosis and counselling services for family members, family therapy, relationship counselling and coaching.** Not based on models promoted by some autism hate groups, but based on the double empathy model and using ethical counselling. This could be a 'buddy' system where NT's are trained in communicating with AS people and can give advice on handling NT's in one's life (work

and personal) and T partner are trained by autistic buddies to connect with autistic partners .

8. **Signposting.** Continuous 'hand-holding'. **A co-ordinator** to act as a kind of hub for an autistic individual and signpost, reliably and promptly, to services that can help with specific needs as they emerge. A detailed, agreed plan would help.
9. **Psychological support:** Individually tailored psychological support involving a detailed assessment and formulation of issues, thus maintaining causes and a collaboratively constructed way forward. The support **MUST** be informed by autism awareness and **NOT** off the peg
10. **Family support:** Autism is a family issue and once one person is diagnosed, others should have the offer of assessment straight away. Family dynamics can be affected in a number of ways so this should be recognised and acted upon. Too many individual issues dealt with by separate departments, with no autism awareness and no joining the dots.
11. Life coaching for adults through the life-span. This could also be fee-based for those in work.

More research needed:

1. Why people are bullied, discriminated against at work, why disclosure often leads to dismissal? What would normalise acceptance in workplace?
2. How to bring ASD teenagers with MH breakdown back into health, studying and being productive?
3. High quality ethical research into the relationships and marriage, based on the non-ableist model of the relationship and double empathy gap. Assessing and understanding both partners focussing on improving communication.
4. There should be more research in interventions and models of support that are effective and make a real difference to the wellbeing and quality of life of autistic people, more effective therapies for autistic individuals with co-occurring health conditions. There appears to be less research in this area than there is in trying to prove theories behind a deficit model that perpetuates exclusion of autistic people in society. Other less derogatory theories have gained credence lately but do not attract the same level of financial support, while in fact many autistic people identify with their analysis and recognise it as yielding more effective and relevant interventions.
5. Research needs to be more collaborative and inclusive.

Continue First Save and come back later...

Developing skills and independence and working to the best of abilities

This section is about autistic people developing their skills and feeling supported to be as independent as possible

If the person you care for is over 16 years old, how well were they supported when they left school or college and moved to make decisions about independent living and/or training or work?

WellMixed, some good support but also short comingsPoorlyI am not sureNot relevant to me

If you want to give us more information about this, please tell us here.

Many autistic people are late bloomers and their psychological maturity and life skills are often not in sync with their age. School leavers are expected to conform to the standards and skills of a NT 18 years old, while autistic people are not ready, so they struggle with the skills and psychological factors which are hidden from professionals, autistic people's main struggles are not recognised, there are no provisions through SEN, DSA and anything else.

<https://community.autism.org.uk/f/parents-and-carers/15481/when-to-pull-the-cord-parents-of-adhd-aspie-19-yo-need-help-transitioning-him-to-independence>

This is a spot on description,

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/9520/the-transition-into-adulthood>

The transition into Adulthood

CASE STUDY [assuming we have permission?]:

Hiya, I'm a student who will soon be embarking on the second year of university. I feel like an utter mess. Well to be honest i always have, since the age of 2 and 1/2 yrs old (from what i can remember).

However ever since i have been classed as an adult, I've felt immense amounts of pressure to fit that perfect model of a "Normal Adult". I've always felt different but when i was younger i just always told myself that one day I'll be normal and just "get" things like other people do. Nope.... that didn't happen and probably never will.

I try and please everyone in my life, as i really dislike being criticized and making people upset. I try and change myself to fit everyones standards but it just isn't possible. Either way someone

who i care about always gets hurt. I'm fed up and just don't feel like I'm smart enough to live this complicated life. I'm always stressed, as somehow I'm frequently doing something wrong. I've hit a point now where I feel like giving up. I put in hours and hours into studying but with the second year approaching very near , it scares me. The only thing i really have going for me is my education. Other than that I'm a failure at life (dealing with social situations, and making the right choice). I get really hurt by people who tell me that "You're not normal", " You're weird", "You need to change ". I've been altering my self my whole life. Just how much more do i need to change? When will it stop? . I feel like if i change anymore i won't be myself, I'll become a robot. I get it, I'm weird for having the mentality of a child, but that's me. I'm always eager for trying new things and when i like something i can get deeply invested. I'm told "people you're age are nothing like you. They act mature, and let go of their childish habbits. They prioritise what's/ who's more important better than you do".

I can't sleep at night and feel like I'm going mad. I don't know what's right and what's wrong. Life is too complicated and i don't think I'm doing things "properly".

To be honest I haven't told anyone how i feel because no one in my life understands me, they just pity me and think I'm not up to scratch. I hope someone here will understand how i feel.

For example, did they have a plan for leaving school and if so were they happy with the planning process?

It's an empty token exercise. Form filling with no difference being made to the autistic person. It is all down to ourselves or the families, their research, resources and connections of the parents. At college we asked about work experience, they said use your personal network... which autistic people don't have.

What would help massively:

Early at school, in year 8 or 9 and in year 10/12 a work experience trying different professions everyday for a week or two. To get a taster, to understand what different industries do, what different departments within the company do. One of the problems is that autistic young people can't imagine what it is like, what is involved and how they can react to that environment, how they are suited to that. Autistic people really need a taster. This would also help to motivate and make plans, to research careers and make applications - it would really engage from within, not because they have to do it but because they are really interested in a career and motivated to work towards it..

There should be a scheme hereby all big companies offer such work experience to autistic teens, at the appropriate level,. For some vocational, for others various departments in the company, so young people could understand, what do finance do, what does engineering do, what is marketing analytics, etc.

Autistic people should be offered such work experience and internships free of selection designed for the NT pool and increasingly and unnecessarily focussed on personal characteristics modeled on NT 'norm'. First because is primarily to enable autistic people to understand the work requirements and how they are suited to this. It also excludes autistic

people through psychometric testing, through 'assessment centres' and interview processes that focus on demonstrating that the candidate meets perfectly the mental image modeled on the NT way of functioning. The definition of disability is doing things differently and this important factor is insufficiently understood and researched in relation to autism.

Autistic people need 1:1 life coaching in preparing and managing the transition, which could also take form of job coaching similar to executive coaching but focussed on coping with autistic barriers, enabling personal growth.

Supported employment services tailored to the individual and the level of work they aspire to do should be developed and delivered by autistic people with suitable experience relevant to the career aspirations of the applicants.

Autistic adults often have employment gaps and supported employment services and employer policies should be developed to help autistic people of all ages to regroup, review their skills in a structured way, to build confidence and autism coping skills in finding a new employment or career.

Did the school or college provide support in seeking employment/careers advice?

Additional information

It is token activity. There is good support available to autistic people at many universities primarily driven by the respective departments that frequently encounter autistic students (just one of a few good examples is the department of Computer Science at the University of Southampton). Support at the secondary school and Further Education level is primarily dependent on parental social capital.

To what extent do you agree or disagree that the autistic person you care for or support has been supported to get a job if they wanted to get one?

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree don't know Not relevant to me

If you want to give us more information about this, please tell us here.

Additional information

The facts speak for themselves. 77% of autistic people want to work, while only 16% are in employment.

Management attitude and peer bullying or isolation are biggest problems. Too often disclosure leads to disciplinary procedures and loss of employment. Disclosing can just be used as grounds to find faults. Many autistic people feel they are not being taken seriously, their careers

and development stalling after disclosure. Their needs being dismissed as 'we all have to do that', there is a misconception that reasonable adjustments are unjustified favours and excuses, for which autistic people are facing peer disapproval and victimisation. Reasonable adjustments are often tokenistic, rather than addressing the real barriers for the individual.

Autistic people live in a continuous anxiety about isolation, bullying and loss of employment. 1:1 long term job coaching, career coaching, similar to executive coaching but focussed on coping with autistic barriers, tailored to the individual could help to develop the coping strategies. There needs to be a link between Occupational Health, Mental Health First Aiders, Diversity Champions and associated contacts (Mental Health Services/Condition advocates) in all large employers along with autism positive progressive acceptance training for Management and staff, delivered by actually autistic people. Senior Managers should be seen participating in such training and role modeling inclusion and acceptance.

To achieve this it is essential at this point in time to change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.

If the autistic person you care for, provide a service to or support has a job, how supportive do you think their employer and the people they work with have been to them?

Supportive
Some support, but also some shortcomings
Not supportive
I'm not sure
They don't know the individual is autistic
Not relevant to me
If you want to give us more information about this, please tell us here.

For example, has the employer of the autistic person you care for or support made adjustments to help them in the work place or to help them with their work?

Additional information

There are islands of good support. Access to Work scheme has been a good step forward, however it's capacity and scope is limited and the adjustments often tokenistic and limited in impact.

Predominant stereotypes and conceptions about autism get in the way of positive inclusion policies within the businesses. Reasonable adjustments are often ineffective and tokenistic, especially in skilled occupations with complex requirements, often they fail to address the real barriers autistic people face. The knowledge base, the capacity of organisations providing access to work support is inadequate, the inclusion criteria leave too many people without the help they need.

On a practical level

1. There is a need for government policy to change the discourse about autism in society.
2. There should be compulsory autism acceptance training delivered by autistic people with experience relevant to the employer, so they could engage with specific realities of the business.
3. Senior managers should be encouraged, be seen participating in autism acceptance training and role modeling the inclusive accepting behaviours
4. Given insufficient depth of understanding of the autistic barriers, a process of reviewing practices should be developed to identify barriers autistic people face in work places and effective reasonable adjustments for those barriers identified by autistic people to inform good practice.
5. There is a need for research to understand the dynamic of isolation and bullying in the workplace, feeding into good practice. This isolation is a source of continuous anxiety for high functioning autistic people.
6. Internal appraisal practices and processes should also be reviewed to identify hidden barriers and move away from measuring performance and potential by comparison with the neurotypical model ways. Disability is a different way of doing things and autistic way of being, processing and achieving goals should not be a barrier to autistic talent contributing to full potential.

About progress and priorities for future action

This section is about finding out where you think progress is being made to improve the lives of autistic people. It is also about finding out what you think the most important things are that need to be done in the future to improve the lives of autistic children, young people and adults.

Based on your experience and perspective, please give an example of where you think progress has been made in your local area to improve the lives of autistic people and of their families and carers?

Based on your personal experience, please give us an example of where you think progress has been made in your local area to improve the lives of autistic people?

??

Please give us an example of where you think progress needs to be made in your local area to improve the lives of autistic people and of their families and carers?

Please give us an example of where you think progress needs to be made in your local area to improve the lives of autistic people?

High functioning autistic adults are a resource, not a cost to society. The voice and contributions of high functioning autistic adults should be fully utilised and their needs should not be left unmet. We are a resource and source of knowledge in supporting autistic people in guiding and designing services and organising and delivering it ourselves, creating a space and a process where autistic people can connect and support each other, contribute to the public debate. There is a thriving autism industry that does not sufficiently use the talent and skills of autistic people who are underemployed.

The prevailing deficit based medical model of autism has left the voice and the needs of high functioning autistic people out of the public discourse and without support we need. Whilst the

impacts for ASD individuals without learning disability are less catastrophic, there is still a very significant negative impact on life expectancy and employment. Autistic adults have an understanding from within and lived experience of the condition and a relevant contribution to make into the understanding, the priorities and the effective solutions to the challenges autistic people face. We are not passive patients, but people with agency and autonomy and a key contribution to make into decisions about ourselves.

As “Just 16% of autistic adults are in full-time employment, and another 16% are in part-time employment, even though at least 70% want to work.” There is a strong economic argument, plus an incontestable moral case to provide appropriate assistance. These figures mean that over 100,000 adults would like to be in full time employment. We are no more desirous of being a financial burden on society than we are of continuing to struggle with suicidal thoughts.

If the autistic community were to be given the resources to change these figures, I am certain we would be successful. We are more knowledgeable about the condition than any number of ‘experts’ who have demonstrably failed us and consequently, society.

The cost of supporting someone with ASD as an adult without learning disabilities could be greatly reduced if, instead of largely ignoring us as a ‘less needy’ group and engaging with us only in acute crisis, we were given resources to organise ongoing mutual support networks working with employers, education providers, families, local authority and NHS provision.

Autism acceptance. The increased autism awareness did not result in desired level of inclusion and acceptance of autistic people in employment and social life. The prevailing discourse focuses on deficits reinforcing the perception that autistic people are only able to contribute if they are ‘performing’ communication in a neurotypical way on the neurotypical terms. This is a circular argument that is a barrier in itself to inclusion and acceptance of autistic people. The masking required to ‘perform’ in a neurotypical way is the very cause of distress and mental health problems. Essential and primary to all this is the active effort in changing the public discourse about autism from the medical deficit model towards accepting and accommodating our differences and recognising the value of our talents and contributions, removing the structural barriers and enabling autistic people to overcome our difficulties from within.

To achieve this is it essential at this point in time to **change the language and discourse about autism in society, to de-stigmatise autistic traits and de-normalise ableist bias in talking about autistic deficits.** The definition of disability in the Equality Act and doing things differently and the significance of autism as a different way of being and processing the world is insufficiently understood in this context.

The language about autism in public discourse research and social media should be reviewed with the full participation of autistic people.

There is a need to establish **Equal Justice** of criminalising disability hate and autism hate crimes on the par with racial hatred. There is a need for the prohibition of **disability and autism hate speech** and relevant regulation of **harmful content on social media.**

Support and services preserving the employment and family unit of high functioning autistic adults would represent a cost saving. High functioning adults in employment and good health make an economic contribution and make good parents - therefore can raise our own autistic children with far less intervention. Loss of employment is rather the cost of exclusion and discrimination than a lack of capability to make a valuable contribution.

Access to Psychotherapy and Mental Health support to address the co-occurring and comorbid mental health needs and high suicide rates of autistic people of all ages, on an ongoing preventative basis and not only at the time of crisis.

Support and coaching of autistic adults, especially those without intellectual disability into employment, tailored to their aspirations, talents and skills. Such support should be specialised, tailored to autism and not fragment and limited by the postcode lottery and scale at the local level. All autistic people who can and want to work should receive help that is relevant to their aspirations. A support that is not means tested, linked to ESA and not limited otherwise by the current criteria that exclude most high functioning autistic adults.

Most importantly there should be tailored support and job coaching for high functioning autistic people to retain employment and progress their careers, to overcome the specific barriers they face, tailored to the individual.

Support during diagnosis. There is a need to increase the capacity and reduce lead times and remove the postcode variation in access to the diagnosis and offer people who initiated the diagnostic process and are often in crisis a sign posting coordinator, a hand holding guidance, an introduction into the ASC, an access to a supportive community and peer to peer advice on specific barriers affecting the individual.

Support, assessment, diagnosis and relationship counselling for the whole family and spouses in coping with challenges of autism and disability within the family and in developing and maintaining effective communication and bridging the double empathy gap, informed and supported by double empathy based science. Such family support and relationship counselling cannot be developed based on dehumanising ableist model of the relationship, pseudoscience and emotionally abusive practices promoted by autism hate groups. Rather it should harness the full scope of peer to peer support and knowledge within the autistic community.

Front loading and fast tracking diagnosis and SEN support. Much of the angst and mental health problems affecting autistic adults originate in delayed diagnosis and inadequate SEN provision at school and the adversarial fraught process of getting this support. This contributes to MH problems and employment prospects of the young people and also affects the MH of the parents, siblings, puts strain on the whole family and could lead to family breakdown. Front loading support and fast tracking the diagnosis and support for all members of families affected by autism would release the pressure.

Life coaching, to address the underlying difficulty of autistic people causing their anxiety and mental health problems - support their personal development and life coaching in attaining their goals. This way disjointed 'interventions' and theories could be brought together into practical use by autistic people in addressing their real needs. Professionals to guide us of all ages to develop, be independent as possible, support individual development. Life skills defined individually in broad and flexible terms by autistic individuals. For some it is taking a bus, for others it is avoiding fall into depression, starting a family, or even retaining their job in professional capacity. Train professionals on a progressive non limiting model of ASD to respond to the needs of autistic people and support them in their coping. personal development and fulfilment of their life goals. Professionals who respect autistic people and actually listen to what is actually said.

Coaching in transitions. Autistic people are late bloomers and face particular challenges in transitions. Transitions time is where autistic people are particularly vulnerable, and need tailored 1:1 support in developing the coping strategies and life skills. There is a particular difficulties for young people leaving school and failing to cope with the new changes and demands, often resulting in educational placement breakdown, mental health crisis and a state of confusion with which parents and services are ill equipped to deal. A tailored 1:1 life coaching services for individuals of all functioning level and all ages, tailored to their particular challenges and informed by experience of autistic people who have successfully overcome those barriers would address the real factors underlying continuous stress and anxiety in which autistic people live.

Ethics of ASD research and service development. The genetic research into autism is in urgent need of ethical safeguards. Research ethics for ASD research has insufficient regard towards the agency and autonomy of autistic people. The focus should shift for genetics in rodents towards informing support systems that improve the health, wellbeing and quality of life of autistic people. It is also weak in relation to a range of ethical concerns. These topics include the very concept of autism itself, the question whether autism is primarily an identity or a disorder, the ethical questions that parents of autistic children face, metaethical questions, the ethical consequences of epistemological questions, and a cluster of questions related to social justice, stigma, and paternalism.

Based on your experience and perspective, what do you think the most important things are that the government should do to improve the lives of autistic children, young people and adults?

Please list up to 5 things and please put them in priority order

1 being the most important and number

5 being the least important

1. De-stigmatize autism in the public discourse, de-normalise ableist bias of NT behaviour being the only right behaviour, provide Equal Justice - same laws for disability and autism hate speech as for racial hatred, regulation of autism hate content online.
2. Psychotherapy, MH, suicide
3. Personal coaching, counselling, mentoring, peer to peer support, non means tested, not only to those eligible for social care, not only for those on MH pathway
4. Support to gain and retain employment, HFA, non means tested
5. Support for relationships, starting and the family and keeping it together. Informed by the double empathy model and equality. Not based on autism hate groups like Faaas and Different Together, not based on Maxine Aston discriminatory and degrading ideology that cause psychological harm and advocates emotional abuse and financial exploitation of autistic people.

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Before you submit your response

We have a few questions we would like to ask to help us improve future consultations.

How did you hear about this consultation?

Social Media

Received an email

Word of mouth (family, friend or colleague)

Direct communication from third sector organisation or regulatory organisation

Broadcast news (TV or radio)

GOV.UK or other government website

Newspaper (online or print)

Website (non-government)

Response ID: ANON-YWQM-P7VQ-V [Type here]

[Type here]

Other

If you answered other, please specify

How satisfied were you with using the digital online consultation form?

Very satisfied :

Satisfied

Somewhat satisfied

Disappointed

How could we improve this service?

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