

## **Response 1**

1. Autistic people and their families have little/no support if there is no additional diagnosis of a learning disability. This fundamental lack of service results in increased numbers of people with autism going through the mental health, criminal justice and homeless services. Opportunities for support for these people would be the first step to promoting healthier lives for themselves and their families.
2. Autistic people don't have services to choose from, so choice and control does not exist. Being unable to access services is disabling for many people who otherwise would only need a very minimal amount of support.
3. There are many autistic people that would benefit from a minimal amount of support, but enough to provide a "safety net" of support if needed. This support is currently not offered by any one service - and has previously been accessed through the now-struggling one-stop-shop. People who should be able to access these services have nowhere to turn, and instead are being referred to community mental health teams, who are unable to provide this type of support. This cycle systematically disables people who would otherwise be able to live independently with a minimal amount of support.
4. People with autism who would like to access autism-specific groups currently have none to choose from unless they also have a learning disability. These people are then unable to access their community because they have no means of support.
5. Provide services for people with autism.

## **Response 2**

1. Treat them with respect. Stop enabling the Police and other institutional organisations to criminalise those with ASC because they find them "difficult". Provide people with ASC with the education and employment that they are entitled to. Stop allowing schools, colleges and Universities to get away with blue murder by not providing properly trained staff and appropriate resources.

People with ASC particularly those who are high functioning are discriminated against in the workplace and are kept out of work in Scotland because of the backward ways of employers. THIS HAS TO STOP.

Government needs to be informed and advised by the Autistic Community in all their endeavours to improve the lives of those with ASC and this needs to be a long term permanent dialogue. Not a one off consultation. This could be facilitated by the NAS and Autism Initiatives etc.

2. Make sure the people that they interface with at service points are properly experienced and educated. Make sure that people are employed to assist and guide

those that require it. These assistants also need to. Be properly experienced and trained/educated.

3 Give them enough money for a start! If you dont fix the employment situation then you will have to adequately fix the bennefits system. Make sure that organisations like the NAS and Autisim Initiatives are properly funded and are overseaing all implementations that seek to empower those with ASC towards independant living. Stop acting like an intolerant authoritarian regime and give people what they need. Stop enabling organisations to create barriers for those with Autism

4. Educate the nation about ASC .....PROPERLY!

Make sure diagnosis is conducted as and when aproprate and in GOOD TIME. (Backlog is currently horrendous and totally unacceptable. Ammend disability access legislation to ensure companies and or organisations are addressing the needs of tjose with ASC aproprately (at the moment the establishment is failing those with ASC catastrophically) Regularly engae and consult with the FULL autistic community to ensure that legislation is effective and appropriate.

Furthermore those with ASC are somtimes high functioning with elementsof cleR genius. Tjis is under utilised in society. These people should be encouraged and cellebrated not vilified for there differences then ridiculed and ostracised by those with considerably lower intelligences.

Give me a job. I will make a major contribution to your Autism Stratergy. For the People by the people. That is the way forward. Stop giving jobs of this nature to those without ASC!

I have been engaging with the GTCS about the way it and teacher probationer staff in local authorities have messed up my carreer. NOTHING HAS BEEN DONE ABOUT THIS. Must I tolerate this blatant discrimination? Who will sort this out if organisations like the [REDACTED] can not police themselves and correctly and responsibly audit for ASC then what hope is there for wider society?

If I hear nothing back in person about this then It is clear to me that this consultation is a hoop jumping Government farce.

5. Ensure that Autistic people are represented by people with ASC at all levels of society. I am a 44 unemployed professional awaiting contact from you. Offer me a job. The [REDACTED] and the [REDACTED] Council has RUINED my teaching carrer through corruption and an inability to adress their responsibility to me as a Teacher with ASC. Why am I not working in [REDACTED] where I belong? Why are there no jobs for me? I should be in employment. Why is this not the case? Like most things on the West coast of Scotland. Out of site, out of mind

### Response 3

1. Training - a greater understanding of how autism affects people is essential. Many Professionals do not seem to have more than a rudimentary understanding of autism. Professionals still consider that having high functioning autism or Aspergers Syndrome means that autism has a 'mild' effect on the individual. There is currently no diagnostic service for Adults with Autism in our area and anxiety and stress levels are put down to mental health issues instead of recognising these relate more to sensory issues and neurological issues. Explaining how someone should behave in a situation where they are feeling very anxious and stressed does not help the person when they are in the situation of being overwhelmed. A number of people with Aspergers I know have had to learn about their own sensory processing issues as they find it hard to recognise themselves. Without access to clear information, at a stage which they can manage, people are not being educated about their condition in this area. The Menu of Interventions shows how people with ASD should be supported. Continue to support people to feel safe and express themselves and be really engaged with their community and be listened to and consulted in a way that suits them.

Helping people with ASD to participate in community life, education and employment is essential to their wellbeing and ability to live independently. However, just because people see the outcome of being supported effectively, they do not see the support needed to achieve the outcome.

Help to build on independent living skills which lead to more independence, enable them to work to their full potential and to be able to live the life they wish.

At the moment people with ASD and their families feel like they are being treated inequally and that because their needs are those of personal care, as much as being supported not to feel isolated, to be listened to and to be treated with respect and dignity, they are being treated by Health and Social Care in a way that is causing them greater problems and creating additional support needs, such as with Mental Health.

To really help us we need:

- Professionals to better understand how ASD affects people (as individuals).
- To be included in planning for communities / access to appropriate services.
- Access to someone who understands how ASD affects them and to help them communicate, navigate systems and feel supported by someone they trust, and in a way that suits them.
- Take a lead in the process so that it can be controlled in a way that they understand and makes sense to them.

- For the Scottish Government to look at the wider picture and push for recognition that by not supporting someone to achieve their outcomes, the cost to the Scottish Government is significant. In terms of police time, criminal justice and the cost to the Scottish Economy is excessive and amounts to ridiculous losses over a person's working life - only 15% in full time employment.

- People who have a good working knowledge of ASD need to be assessing people, not people experienced in working with Mental Health or Learning Disabilities who have had 'Awareness Training' on ASD.

2. A bottom up approach needs to be developed and people who are affected by ASD (right across the spectrum) need to be including in the decision making process.

A holistic approach needs to be taken in terms of how funding is released and in my personal opinion, the Scottish Government needs to look at how the lack of support for this highly vulnerable group of individuals, impacts across all aspects including housing, benefits, self directed support / health services and the criminal justice service as long and the Scottish Economy. Lost productivity and the right to live ordinary, fulfilling lives should be fundamental to each and every person's life. A long term approach needs to be taken and if support is not forthcoming through Health and Social Care Partnerships, Housing Services, Benefit Systems to help these people at a pace which suits them and they can manage, these people are left feeling that they are burdens to the state of their families. This is completely unacceptable.

The Scottish Government needs to work closely with the ASD community and provide funding for this vulnerable group directly rather than passing funds to the local authorities etc to deal with by sourcing a national organisation which has no local knowledge. Continued support of the local resources the Scottish Government has supported via the Autism Innovation Fund, by taking the proportion of funding which would be given to local authorities and ensuring that it is used to support local third sector organisation. Control needs to be with the community organisations and engagement from Local Authorities needs to be obligatory from their side. The model of the Public Social Partnership's (PSP's) where the community takes the lead is, I believe a really valuable model but it must be that it is the 'community' which leads and not the statutory organisations as this has been shown to work much more effectively for people. However, this model does not work well if H&SCP's etc take the lead and must be lead by the Third Sector. However, many Third Sector Interfaces just cause additional barriers to be put in place so it must be embedded in the community itself to make this a success. This has been evidenced in the past. It may be something to work towards as little real commitment from statutory organisations has been shown and is also evidenced by the recent Audit Scotland report on SDS. Community third sector organisations are key to achieving real change in this field. Autistic people who make up the Autistic community are said to

be hard to reach but this is because the approach with consultation from statutory organisations continues to be 'come to us' and not 'we will come to you'.

3. I believe the only answer is to vire the money directly to local communities and not send it through Health and Social Care Partnerships, DWP, and local authorities (ie Housing) for the decisions to be made. A top down approach in this area is not to be trusted unless money is ring-fenced for the specific purpose and to be spent in local communities.

Invest to save, best value for money all needs to be looked at when supporting individuals affected by ASD to learn the skills they needs, as individuals to lead happier, healthier, more independent lives.

Giving people the opportunity to be involved is essential for giving people affected by Autism a sense of purpose, place and value.

Give people affected by Autism a real platform to highlight what they can achieve and how hard it is for them every day, all day and help educate those who enter their lives to understand and recognise the challenges they face. Make training fundamental and essential in this field and not just as basic awareness for those who assess, treat and support those with Autism.

Give people with ASD and their carers a clear pathway which does not create barriers (such as too many assessments and too many different people in their lives and too many hurdles to jump). In our area you need to have a mental health assessment as there are no diagnosticians in the region (which covers 3 Local H&SCP areas) and GP's are refusing to allow a diagnosis without re-referring to the MH Service for them to agree the diagnosis rather than just signing of the professionals report so that someone can have a reduction in their Council Tax rate. This is ludicrous and additional strain and stress and anxiety is what is created for the person with ASD as a result. Making things easier would mean there is less chance of the person with ASD disengaging with their community. They have enough to cope with without adding additional burdens - and these are burdens to the person with ASD and cause carers issues in supporting them through the processes which are too long and too onerous for someone with ASD to cope with.

4. We need to create places in the community where people with ASD feel safe to come, or when needed go to them. They need support to be active citizens, but when supported can be incredibly open and creative and can be invaluable to their local communities.

In order to be able to participate in society and be active citizens people with ASD need to be recognised, respected and included but they need this on their terms and need to be able to familiarise themselves with the venues, the process etc. If they are sought out and treated as if their views matter, they care achieve so much and this approach needs to be achieved.

It is the person with the lived experience who is an expert on their autism and not the person who has been on a day's training. This needs to be key in understanding and working with people with Autism. Many people who are high functioning can provide us all with a really useful insight into how autism affects them and give us a better understanding for those who are non-verbal too. Although non-verbal people with ASD can also educate us as long as we work in a much more accessible way. Making areas Autism Friendly is a start but actually making this a reality relies on a greater emphasis being placed on awareness raising. The onus should be on statutory organisations to come to the individuals and groups where they are safe and able to have their opinions heard, or where they have someone who can advocate on their behalf.

5. Make sure they are given the same kind of equality as those who have physical disabilities.

Give them a voice and a platform

Help educate and create a workforce which truly understands the challenges faced. Expect inclusion to be required from statutory organisations.

Continue to raise the profile

Recognise the need for a holistic overview of how lack of service provision or support , creates more problems and impacts not just on one budget (ie H&SCP) but also on the whole of the Scottish Economy.

Recognise the need for funding to come directly to community resources and not be filtered through statutory organisations which do not then value their community resources by supporting them.

Help such support in the community to be recognised, valued and supported to continue to provide essential services for people with ASD (as a marginalised group in society).

#### **Response 4**

1. There are some fundamental barriers for autistic people:

- Systemic barriers such as service silos re learning disability and mental health. The lack of response to autism in its own right means that we are constantly seeing people falling between gaps, we have known this for decades yet there is no resolution in sight
- Access to basic health care is often prohibited due to poor understanding of the spectrum of autism and of some of the very real barriers sensory processing and anxiety issues can cause for people.

- Access to services and professionals that understand their needs is essential for individual and family health. There is an erosion of specialism in services for autistic people that we need to recognise is unethical and halt. Yes, we have to promote and value inclusion and build capacity in generic services but we have to secure the specialist services and associated knowledge base in order to have the capacity to achieve this.
- Post diagnostic support for individuals and families is vital; there are some effective low cost models of support yet no national response.
- Commissioning of services that focus on well being and health
- Investment in developing evidence based practice and practice based evidence in services that support autistic people

2. A first principle here has to be to ask autistic people and let them lead the debate.

In service terms this requires less of a focus on controlling “behaviour” and more of a focus on enabling healthy and happy lives, acknowledging the need for stress reduction. People with autism and a learning disability are often marginalised and have very restricted lives with little control. We need to accept this is a reality, avoid tokenistic approaches and invest in technology and methodology that enables us to hear the authentic choice of people.

The culture in some services undermines autistic voice and does not enable control, this is often as a result of poor understanding of autism as a multi-dimensional and complex spectrum.

It is often the case that services focus on behaviour particularly when staff feel challenged or deskilled by behaviour. The interpretation and deeper understanding of such behaviour is critical as it is often an anxiety response that should indicate something is not going well for that individual in terms of their own personal wellbeing, their skills or the environment in which they are in.

3. Recognise that autonomy is a critical aspect of independence.

Independent living looks different for different people however we need to recognise the full economic cost of providing support to be independent. We perhaps need to conceptualise what we mean by this, as interdependence is the reality for most people. Autistic people often have more limited social networks and so have fewer resources to draw on. Independence is not just about making your own tea. We need to support people to develop a sense of self, communication and assertiveness, self esteem and many other skills that enable people to make their own judgements about the type of life that is right for them.

4. Adopt a citizenship model to service commissioning and provision that takes account of the capacity of the service to enable citizenship in terms of employment/occupation, participation and accessibility of educational opportunities. This requires funding of the full economic cost so that we can move beyond services provision that has a 'life and limb' mind-set to one that recognises that autistic people deserve access to services and staff that fully understand their emotional, physical and life long learning needs.

This can't be one sided, capacity in the community, education and public services in terms of understanding autistic people needs to be promoted.

5. Recognise autism as an entity in its own right. The layers of complexity created by the various segments of the autism spectrum combined with a variety of co-morbid conditions causes autism to straddle multiple functions – particularly health and social care. Functional organisation is important but not sufficient because it leaves no-one in charge of processes which straddle multiple functions. This is not to imply that there is some form of conflict between processes owners (e.g. health and social care), just a lack of consideration of the individual's interaction with the other process. The process owners may have markedly different views on how to proceed.

This can result in the individual being classified e.g. as a "patient" or as a "service user" according to where he comes to the attention of government services, and his/her other needs are not addressed.

The logical implication is that the issues are better focused on the individual than on the mainstream processes. Focusing on processes rather than on problems produces an inadequate personalisation of service and it this is why people can fall into the gaps in service provision.

Addressing the various elements of a complex condition naturally produces a series of tailor-made interventions which are outside the normal policies and procedures of the state.

Conventional quality improvement policies in local government tend to focus on process improvement i.e. they are managerial tools for improving the agency's processes. By contrast a problem-solving approach is an operational way of working on external harms.

We know that the different segments and the different co-morbid conditions (which are not the same thing) are what place autism into different service categories/institutional structures. Any of these institutional structures alone is poorly adapted to catering for individuals who may present differently to education, mental health services, social care or even the criminal justice system. This point at first appears a little counter-intuitive: that although autism in its own right needs specialist attention and services, the co-morbid conditions and needs that usually come with it



do not make those specialist services exclusive providers, but they function in a constellation of different services meeting the needs of individuals.

This suggests additional resources specifically to manage all the various requirements of complex individuals. This may seem impracticable in the current economic climate. It is important that all the agencies of the state recognise that for such a complex multidimensional phenomenon as autism, staff in all disciplines must recognise that they may only be seeing one facet of the individual's condition and adopt an individual-focused approach (i.e. a problem-solving approach) if all the individual's needs are to be met and quality of life maximised. In this context autism might well prove to be a useful test-bed for the integration of health and social care.

A vital first step towards this goal and the dispelling of the myths which surround autism is the recognition of autism as an entity in its own right.

### **Response 5**

1. Compulsory training in up to date Autism, especially in Women & Girls for;

- All nursery, primary and secondary teachers
- Medical professionals; GPs, hospital staff (nurses, doctors AND consultants)
- Mental Health Services professionals CAHMS, CPNs, Crisis Teams, Clinical Psychologists, Consultant Psychiatrists and ALL staff in Mental Health Hospital Units
- Social Work & Social Care Agencies (at ALL levels)
- Police
- Dentists and dental surgery staff
- + Tailored Mental Health Services inc. Diagnostic and Psychological Therapies for Autistic people; for Children & Adolescents AND Adults
- + Mental Health Hospital Units specifically for Autistic People; seperate tailored facilities for adolescents PLUS adults
- + Autistic units within prisons (and training for all staff)
- + Undertake a Scottish Government marketing campaign to educate Services / the public on Autism and dispel some of the misheld myths; a hard hitting media campaign which breaks the 'traditional' stereotype of how Autistic people may look and behave and highlight the little-known aspects of Autism esp. how differently Women and Girls might present to a more 'traditional' male presentation

2. A flag at top of all Autistic people's medical files which highlights they are Autistic (even if, on the surface of it, they 'don't look Autistic' esp. in Women & Girls)

+ Kindness, compassion and understanding in dealings with Autistic people; Autism is often a hidden disability and many Autistic people will 'mask' their difficulties to try 'fit in' / not be perceived as 'stupid'; this does not always mean they found a certain task easy; it could simply mean they were able to camouflage their difficulties at that moment in time; be mindful they may then need a significant 'decompression' time thereafter

+ Respect and make reasonable adjustments to accommodate an Autistic person's needs; all medical staff should familiarise themselves with, and apply any specialist reports and recommendations i.e. from Speech & Language Reports, Mental Health Professionals etc

+ Quiet Waiting Areas for Autistic people within GP surgeries, hospitals etc

### 3. Compulsory training in all NHS and local authority staff

+ Introduction of a robust peer support / mentoring service / workshops; to teach and guide Autistic people in meaningful day to day coping and functioning skills

+ Vital that 'Transition Teams' are set up within CAMHS and Social Work to help ensure a smooth transition from Child to Adult Services

+ Training of / guidelines issued to college, universities and apprenticeship programs staff

+ Easier access to Self Directed Support for Autistic people

### 4. Education and training of all NHS and local authority staff

+ Education of the public

+ Real meaningful supports that are easier to access that make a difference to an Autistic person's life i.e. Self Directed Support budget, peer mentoring, coping skills workshops etc

+ Kindness, compassion, understanding and making reasonable adjustments "

### 5. Urgently amend / update existing Autism Strategy for Scotland by holding in-depth consultations with professionals who work at the coalface of Autism everyday [REDACTED] / The Autism Academy UK (TAAUK), [REDACTED] @ Scottish Autism / SWAN and the many other companies / individuals across Scotland

+ Make the guidelines in the Autism Strategy for Scotland legally binding so when a school, medical professional, criminal justice system etc doesn't adhere to guidelines, they can be held accountable "

## Response 6

1. There needs to be more recognition of the condition and the effect on the individual and others. A big step forward in assisting those affected would be if there was adult diagnosis assessments completed through the NHS rather than for individuals going to private consultants.

There is no recognition of Local Authorities that those affected need support with structuring their lives. Stress needs to be managed appropriately, as any new situation is viewed like the climbing of Mount Everest.

When a crime has been committed the Police and Crown Office should take serious consideration of ASD. During police interviews an appropriate adult should be present at all times. I would invite this support during court hearings too.

Good local services had to close their doors as funding was withdrawn. ASD in my opinion remains an invisible condition that professionals and the public feel is something that sufferers can snap in and out of. That is certainly not the case!

2. Esp. adults are being disadvantaged, as there are no services out there. Most local authorities do not have the skilled workforce or resources to support ASD adults. Several Care Homes struggle to meet the needs of residents that have never had an assessment carried out.

Please involve autistic people, not just those with high functioning Asperger's, but all of us, incl. those with multiple needs. Maybe CARE STANDARDS for ASD might be a way to go.

Presently, everyone is aware of the multiple Dementia Awareness Raising Sessions with hospitals, shops and work places being accredited as Dementia Friendly. I would invite something similar to promote ASD.

3. While I appreciate that resources are tight and most rely on family support, I would like to see more therapeutic services to assist with teaching and enabling coping strategies. I too would appreciate if the criteria for self directed support was broadened to include ASD. At present most are set back as not needing services, which is very frustrating. There needs to be a recognition that some things ASD sufferers cannot do for themselves; one wouldn't push a wheelchair user into a pool or leave them at the bottom of the stairs. Social Workers when conducting their assessments, with the help of an Independent Advocate should listen to our individual needs!

4. Have ASD friendly places in the public. Train the public and professionals to assist us in managing our condition more appropriately. If given clear guidance and structure, outburst can often be minimised. Have more high profile A list people be open about their condition! Resource schools to offer opportunities! Have

professional bodies like local authorities and health boards work together more closely, not just pass the buck.

5. Release funding to Health Boards in order to diagnose ASD in adults and subsequently for Local Authorities to assess unique circumstances and be in a position to provide services, offer respite etc.

## **Response 7**

1. Mandatory training for all public bodies [NHS Staff, Police, Fire, Local Authority, HSCP, Education and so on]. Some people with AS have had difficult experiences with engagement and therefore are reluctant to engage later. A better understanding of Autism will help people engage with public bodies which will help them access better support to enjoy healthier lives.

Autism service provision to be made available for every local authority/HSCP across the lifespan. This should be a statutory responsibility placed on Local Authorities/HSCP. People with autism never 'fit into' a service [such as mental health or learning disability - Autism is neither a learning disability or mental illness]. People with autism are also not having their needs assessed as accurate as they should be [social Work assessing need]. This is due to social workers [through no fault of their own] not having as much experience or knowledge to understand how autism impacts on each individual, therefore meaning they can't assess need of autism accurately.

Autism service provision should be made across the life span for individuals and families to access whenever they need. This should be a support a statutory support service in it's own right, This could be a place of safety for people to access when people need support. This could be due to needing to move house, change of circumstances, transitions through life, loss of job, housing dispute, benefit/financial difficulty, difficulty engaging with other professionals such as NHS, Education, Police, Court and so on. By having this support available for the times that people need it would help individuals with autism so so so much. This approach prevents things becoming crisis, it also helps people & families with autism open doors and increase social mobility - to access new areas, opportunities and better life opportunities.

These statutory services could help families with on-going support, training, mentoring and promoting social and recreational opportunities - all of which is more or less non-existent in Scotland.

Every service wants this - Social Work, Housing, Employers, Further Education, Education, CAMHS, Community Mental Health Teams, Police, NHS, GP's - people with autism want it - families with autism want this - so why are we not doing this?

If it is a monetary decision, what I would say - by funding such provision as mentioned earlier would take pressure off of all the system and therefore be more

economical in terms better output with the other services. Also, it really isn't a monetary reason not to do this. If all individuals were to request that their needs are assessed by either the Social Work Scotland Act 12, or Children's Act 23 & 24, then this would cost Local Authorities/Health & Social Care Partnerships money anyway. Having statutory provision may actually be financially more viable. Individuals and families should have the support of both in order to help.

**AUTISM IS NOT A MENTAL HEALTH ILLNESS.** There needs to be a national recognition that autism is not in any way shape or form a mental illness/concern. Autism has somehow been understood to be covered as a mental illness through the Mental Health Act 2003, however this seems to be inaccurate. The Millan Report recommended [4.2 I believe] that a learning disability should be seen a mental illness/disorder, and that autism should be seen as a learning disability - therefore meaning that autism is covered as part of the Mental Health Act 2003. However, from my perspective, this recommendation was never put into the Act, as autism is not mentioned in the legislation, codes or guidance and therefore it should not be applied, but somehow it is in practice? How can it be part of the act if it isn't mentioned? I think it was recommended but never implemented, but people assumed it was and therefore have used it in practice - this is the view of the autism community.

This needs to be reviewed by the Scottish Government as individuals with autism have had statutory powers used in their lives due to no other reason than having autism, this is unfair and it stops people with autism engaging with services because they are scared that the Mental Health Act will be used in some way to comply with treatment.

Individuals & families with autism are constantly referred to CAMHS & CMHTS, and then they are not offered a service because the CAMHS & CMHTS say that autism is not a mental health need. This is extremely distressing for people & families with autism, and professionally challenging for CAMHS & CMHT professionals. A review of Mental Health Law, and an acknowledgement from the Scottish Government will start to identify that statutory provision for autism will be a step in the right direction for years of heart ache for individuals & families being referred to mental health services as a result of poor translation of what was recommended and what was actually put in the Mental Health Act.

2. Social Workers need to be trained to a high level to understand how to assess autism. This is the only way at present that people & families with autism can access support. If Social Workers cannot assess autism needs, then they cannot give proper choice and control over their own lives.

Have a national code of conduct for supporting people with autism. This therefore means that services can be held accountable to provide a more autism friendly

service. This would be much easier to do if it was nationally agreed that autism wasn't a mental health concern.

3. Autism service provision to be made available for every local authority/HSCP across the lifespan. This should be a statutory responsibility placed on Local Authorities/HSCP. People with autism never 'fit into' a service [such as mental health or learning disability - Autism is neither a learning disability or mental illness]. People with autism are also not having their needs assessed as accurate as they should be [social Work assessing need]. This is due to social workers [through no fault of their own] not having as much experience or knowledge to understand how autism impacts on each individual, therefore meaning they can't assess need of autism accurately.

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These statutory services could help families with on-going support, training, mentoring and promoting social and recreational opportunities - all of which is more or less non-existent in Scotland. This would help individuals & families live more independently in Scotland.

Every service wants this - Social Work, Housing, Employers, Further Education, Education, CAMHS, Community Mental Health Teams, Police, NHS, GP's - people with autism want it - families with autism want this - so why are we not doing this?

If it is a monetary decision, what I would say - by funding such provision as mentioned earlier would take pressure off of all the system and therefore be more economical in terms better output with the other services. Also, it really isn't a monetary reason not to do this. If all individuals were to request that their needs are assessed by either the Social Work Scotland Act 12, or Children's Act 23 & 24, then this would cost Local Authorities/Health & Social Care Partnerships money anyway. Having statutory provision may actually be financially more viable. Individuals and families should have the support of both in order to help.

4. Every Local Authority/Health & Social Care Partnership to have a local autism networking group made up of Social Work, Housing, Employers, Further Education, Education, CAMHS, Community Mental Health Teams, Police, NHS, GP's - with the

autism community to be part of this group & decision making. Having a neurodiverse may actually help look at more efficient ways of progressing forward.

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5. Give the autism clarification on the point that autism is not a mental health illness. An apology that the flawed understanding that autism is somehow covered by the Mental Health Act would be a strong message to the community that the government are wanting to move in the direction. Also, possible some sort of support put in place for people who feel that they have been at the receiving end of the act, for no other reason other than having autism. Statutory provision for autism across the country. That autism is seen as a neurological development condition in its own right. Mandatory autism training for all public bodies. this should be directed from NHS Education Scotland what the training should be - to ensure consistency across Scotland. As part of good practice, any individual/family to be offered an assessment of need [Social Work Scotland Act 12, Children's Act 23 & 24], even as early of the

point of enquiry as diagnosis times are taking too long. Even, if it isn't autism, families are still in need of support.

### **Response 8**

1. By considering the whole family: most services focus on the child's needs but it is the family which will be implementing them. For example: disabled sports are great- to take an older child with autism may require finding childcare for younger kids which might be difficult. For each family there will be a different aspect of health that needs focus. And finding out WHY that aspect is difficult.

2. Many kids with autism may just opt out of life unless encouraged to do otherwise. Where appropriate, people can be given a choice within limited options. Information should be available in several formats.

3. This needs to be done step by step. The police should be made aware of vulnerable people so that those people can attempt more independence and know that there's a safety net.

Anxiety is often a big issue so teaching young people how to cope if things go wrong.

Educating the public on how to interact with those who are disabled rather than ignoring them.

4. This depends more on the rest of society. People need to be educated that autism is a spectrum and many will have normal intelligence whereas others might not, and it doesn't depend on behaviour or ability to speak.

5. Give them jobs.

### **Response 9**

1. Understand that autistic people and their families are as diverse a group as any other group of families in Scotland. One size does not fit all.

When trying to offer help (for autistic people) understand that autistic people often have sensory issues. So it's no good just trying to suggest eat more fruit, veg etc. The smell of these foods may be making the person heave. Or the noise in a gym may be uncomfortable to them.

Families for many are an important part of autistic peoples support network. It's important to give these families access to information, so that they can support. Don't assume that the autistic client will pass on information.

Don't always assume that the autistic person has learning difficulties. They may be socially and emotionally functioning at a younger age than their chronological age but be above average intelligence.



2. While autistic people who are more severely disabled by autism have to rely on family and other people to advocate for them; for all users of these services, being asked about their needs when they come in to the system and having opportunities to ask for modifications as and when their needs change.

Help and advocacy, when the great lumbering DLA and officialism cause financial glitches. Or just don't get how autism/Asperger's affects a person's life.

G.P.s and the health service are often a primary source of help. But I feel sometimes when an individual is a more able adult, issues should be discussed with them, to get their view.

3. Only 14% of people with autism are in employment, according to wildlife presenter Chris Packham. I can only personally speak from the point of view of a parent of an above average intelligence person with Aspergers. I feel that many autistic people fail to gain independence, because they cannot be financially independent. Whenever we asked for help for our daughter, it was voluntary charity shop jobs. Perhaps a bit of understanding that not everyone is suited to this type of work? It is the assumption that the autistic person has some source of financial support which upset me most. We have to (willingly) financially support our daughter, while she completes an Open University degree. She found herself a voluntary job which is suited to her needs. Hopefully paid employment will follow afterwards. But long term, some sort of safeguard system where someone can check up on an autistic person if they live alone. Not everyone is good at asking for help.

4. Too often people with autism are seen as people you do things for. No one asks what they can do. Lack of understanding, and assumptions from an early age well into adulthood is a major issue for anyone who is autistic. The assumption that your child /adult has learning difficulties is an issue which is very annoying for us as a family. Educating the public, that don't seem to understand that not everyone is like 'rainman'.

We as a family have hit some obstacles in the past. Often from unexpected sources like Senior medical personnel, and further education staff. We have found the Police officer on the beat helpful. But the senior officer in the office was extremely lacking in understanding. So well done to officers on the beat. But how about training for more senior staff. Maybe the major thing that could help all autistic people. Is to understand that not all autistic people want to spend their lives doing activities for autistic people. They like people from the non autistic world too.

5. Virtually all training for work is aimed at those aged 16 to 25 year old. Some understanding that because of social and emotional issues, some people on the autistic spectrum don't mature or feel able to access training or work until they are older. On this subject. It's all very well offering 'special' college courses. But some autistic people would like to attend the courses designed for ordinary human beings. Help autistic people who are able, to access work and financial independence. But

for those less able, set up the benefit system, to acknowledge that Autism is a life long condition.

### **Response 10**

1. The families should feel totally supported by all professional agencies ie occupational health, speech & language therapists, social work, day services, police, education etc

2. Day services must be expanded & persons working/supporting autistic people should be supported & educated.

Schools must be staffed to meet individual needs.

Safe environments should be provided for all people with autism outside the home ie there should be meeting rooms/areas etc within communities with activities/facilities to suit the needs of individuals with autism.

3. I'm not sure this is an option. In my opinion most people with autism require support & supported living to ensure their safety & well being.

4. This too is very difficult to ensure. Do autistic people want to be fully integrated? I feel we should consider that some may want to be in a community where there are people more like themselves. Most people chose to luv & socialise with people whom they share common interests.

5. Provide them with a safe non judgemental environment in which to live.

### **Response 11**

1. Increase accessibility of Health services and general services so that people are confident that they will be given courteous non judgemental services whatever their needs. Encourage specialist support but avoid new 'institutions' and places that are only for those with diagnosis (including eliminating the one-stop shops). People should be able to be supported to be part of diverse local communities.

2. By promoting human rights and a fair society. By realising that personalisation, choice and control are not just about SDS and that people should be able to exercise this whatever their route/option to service provision. Scotland generally should try to combine all the anti-stigma campaigns for a variety of things - eg Stick your lables, Seeme to form one movement that simply suggests we all treat each other with respect and dignity.

3. Each person has their own unique needs. Autistic people can live independent lives but maybe do not want (like most of the rest of us) to live independently. Having an independent life might mean living with friends, families and partners who autistic people have mutually dependent relationship with. For people with autism who have behaviour which challenges us (to the extreme) we must get better at providing good support within community settings.

4. We must nurture autistic people as children and give them good support, care and education and support their parents to maintain this.

We need to recognise that not all (autistic ) will want the above but for those who do we must give them the right support and generate expectations that their Human rights will be upheld and fulfilled.

5. Learn how people with autism might be affected by SG decisions and consider how all their policies will impact on people with Autism and mitigate any potentially negative impacts.

## **Response 12**

1. Firstly the institutions of health, welfare and education as well as many NGOs need to understand that autism pervades all areas of life. This requires a fundamental change in attitude from many individuals working in these places. Many people working for these organisations are not good at enabling individuals, despite phrases such as 'patient-centred', 'individual care', 'integrating services' these are often used in an empty way. Many of these people do what they think the person with autism wants, not what the person with autism is asking for. People with autism often have their direct experience of poor services ignored. It appears that the smooth running of a job/department or charity or the feelings of the the person working for the organisation appear more important than helping the person with autism.

Stop seeing people with autism as a problem and change the attitude of staff. You are not helping people if you tell them what you think is useful, if you say you will do something then don't do it, if there is no actual service available and string people along.

Why do people with more apparent 'disabilities' get help and other health sectors- such as CVD and diabetes get such massive funding, research and actual medical and social help.

Why do people with autism have to fund their support systems according to their income when someone with CVD can have £10,000s worth of surgery and decades of medication paid for by NHS regardless of their income bracket?

Much of autism challenges are associated with the environment of living being unsuitable- overcrowded schools, overcrowded cities, lack of housing, lack of fully, genuine integrated services and most of all atrocious communication between the organisations allegedly there to help the individuals with autism. There is no coherent, joined up practice or funding for autism in Scotland.

Finally the most significant issue is that this is a 'strategy', not bound in law, in England and Wales it is law. Until autism services are legally required to be provided

by local authorities, health boards etc, they will continue to shirk their responsibilities and fail autistic persons and their families.

The health care system is broken and so compartmentalised, with major internal and external communication issues that it is a minefield for anyone to navigate, add to this the attitude of many staff to people with autism and little wonder many autism people and/or their families are marginalised and demoralised and sometimes even suicidal.

Stop talking about what has to be done and actually do it.

Have national databases of services and give this information and arrange access to these services during diagnosis.

Actively look for undiagnosed persons with autism.

Ensure autism services are integrated into mainstream healthcare, not sidelined in mental health services- Autism is a predominantly a sensory diversity and communication diversity, not a mental health issue, although people with autism may have secondary mental health conditions.

Finally look at the whole person, what is going on in their life, do they actually have a support network, or is it an 'on paper' thing, what services are they actually getting and how can you help them access more, better suited services and how is this funded. If I had a heart attack or was in a car crash the whole system would be buzzing around me fixing things and being fully funded.

How many more 'car crash of lives' do autistic people have to live and die in before the government takes action to enable them to live a healthy life?

2. Listen. Listen. Listen. Be open and honest about what your service/charity/department can offer. Be clear with your time frame.

If the person does not appear to understand, your job is to translate into language and more importantly actions that are beneficial and measurable.

Services also have to be there in the first place and knowledge of how to access them has to be disseminated throughout the health and social care and charities and schools and police, ambulance services etc, so each individual working in the system does not just pass the buck to the next person for the responsibility and duty of care for the autistic person.

Currently there is a 9-5, Monday to Friday service at best. What about the majority of the week, how are people supposed to live their lives and get help when eg phoning for an ambulance results in the police being sent instead of a trained medical professional?

Many people in services try to control the person with autism, this can result in an escalation of distress for the autism person. Staff should be calm, considerate and consistent and not adrenaline junky, highly reactive types- this is a poor mix with many autistic people. Sadly acute health services often attract these adrenaline junkie types so A&E can be an extremely distressing event, on top of the primary need for healthcare in the first place.

Also ensure you have autism services accessible to all regardless of age, gender, cognitive ability etc. Currently there is a skew for child services and persons with learning disability, with less or no services or funding for adults, females and non-learning disability persons."

3. Diagnose early, small class sizes and closed room (not composite classes in open plan spaces) with lower light, decent sound proofing in rooms, in all schooling, not just primary. Have more green spaces around schools and use them. Stop building high rise schools. Have teachers move to pupils, have blocks of same subject lessons, especially in secondary school, to avoid quick turnover of places, subjects, people, environment. Make clearer rules in schools and stick to them, have them written down and pupils to sign up for code of conduct and staff too. Have quiet places for break times, smaller rooms for eating in etc.

Stop pushing for group nursery education from such a young age, it will just escalate (time wise) autism in people.

A good start in life and a decent education and social skills learnt in a lower stimulation environment is important for managing things in adult life. This is for mainstream schools especially since many people with autism are in standard schooling and some would not be over the threshold of diagnosis if the environment for schooling and living was better.

4. Treat them as useful individuals not as problems. Look at and focus more on what they can do, not what they have challenges with and build on these positives. Being told constantly how poor you are at something and how disordered or challenged you are does not aid your health, it leads to demoralising you and hopelessness.

The language used in the diagnostic process, as well as by many healthcare and other professionals is derogatory at best and highly damaging at worst.

Autistic people are not disordered they are different.

There are supposed to be layers of law to protect people from discrimination for differences, yet people with autism are regularly discriminated against, even by services and charities set up to 'help' them.

Maybe put less emphasis on large community and large society and learn from small inclusive, enabling communities such as Camphill, where people live and work

collectively and those with eg autism are not treated as being a problem or disabled but a useful part of the community.

Try to build on and assist the person around their home/living space and gradually radiate out from there, if and when they are wanting to or able to.

5. Make the provision of all inclusive autism service a legal requirement throughout Scotland. That is true health equality

### **Response 13**

1. Reduce stress for the carers. My husband and I care for our 2 adult daughters. As their carers, our joint income is £9568 per annum. We have a £20 a week food budget. We work long hours but cant afford to eat properly. Just because our children are now adults, they still need us. We cannot give up our caring commitments.

2. Assign a social worker to have regular reviews to see how the person is enjoying life and to make sure choices and services are offered which would be beneficial, instead of waiting until families are at breaking point.

3. They still need support in ALL aspects of life. Shopping, communicating, bills, personal care, transport, regular activities to provide focus to the week. Someone to co-ordinate and keep them organised and safe.

4. As above - have lots of activities and clubs throughout the week to give structure where they meet different groups of people. They shouldn't always have to 'fit in', the community and society need to be more aware and educated about difference and not shun, belittle, bully or ignore. We had to install CCTV because of our community's youth targeted our family home because we are different. Police were involved.

5. It's not that simple. There is so much involved because for each person it could be a different area of their life that needs improving.

### **Response 14**

1. Inclusion- often leading an isolated life and activities and facilities are not autism friendly. We avoid busy places and can be socially isolated. There are very little choices for autism friendly places to go. We often have to travel over 100 miles for health check ups etc.

2. Communication - I have felt professionals are worst at communicating. Often plans are made before parents and children are even spoken to. We are often the last to know about changes to services. Changes to services have been made with no communication with parents, carers or those with ASD and often its to late once we here.

Good communication and honesty.

Policies are in place but not put into action.

Involving parents etc from beginning in any decision making.

SDS is not good as not enough services are taking this up in our area and services are depleting fast. I have two boys with ASD and they don't attend any groups.

3. Safety is the biggest concern. Self help skills are important and must be encouraged from early age. Others understanding of visuals etc. Better education for those with ASD, more emphasis on self help and teaching them life skills rather than maths and English. Accommodating different ways of learning They are often made to fit. Services should be adapted to them not them adapting for us.

4. Autism is still poorly understood. The isolation is difficult as shops, cafes etc are not accessible for ASD. The sensory overload is difficult. New buildings should all be built with sensory needs as priority, lighting, flooring, windows etc. Making those with ASD cope with environmental issues is detrimental to their learning and development.

5. Give them support. Information is not forthcoming. As a carer for my sons both with ASD there is no support and living on carers allowance and DLA is difficult. I am continually fighting for my sons rights and this is unfair. I'm using so much energy on fighting with service changes and poor awareness of ASD. All professionals should have ASD training, education, health, social, police etc

## **Reponses 15**

1. access to diagnostic services across the life span.

- access to post diagnostic support throughout the persons lifespan

- access to forums where loneliness and isolation can be mitigated by peer support, social support etc...

- create a more autism informed community where people with autism can be involved in the life of the community.

- provide people with autism short breaks where both the cared for person, and their parent carers can get short breaks in the caring role

- provide people with autism and their parent carers with subsidised access to health clubs, and other recreational facilities

- produce much more positive literature and publicity about autism strengths and assets instead of deficit based impairment focus.

2. provide a range of autism informed services which people with autism can choose to access as and when they feel it is relevant to their particular needs.

- provision of imaginative one-to-one support/befriending/ /mentoring programmes as well as group provision.

- support people with autism into gainful employment, and sustain meaningful employment by deploying mentors and advisors who can inform and educate employers as well as people with autism.

- ensure that clear and accessible public information is produced consistently across the country - too much variation in practice leaves something of a postcode lottery in accessing supports and information sources.

- create clear diagnostic pathways for adults who do not have either learning disabilities or mental health problems. - most adult with autism have neither.

- ring-fence budgets for creating supports for people with autism instead of being incorporated into the Additional Support Needs (ASN) agenda.

3. create greater awareness of autism and the need for specific strategies in relation to housing, benefits, employment and training opportunities.

- create autism 'hubs' where people with autism and their families can go to meet others in the autism community and receive moral, practical and social supports.

- consider the provision of autism champions within all services who will inform service development.

- create a network of mentors/advisors who can help people with autism, and employers support and sustain their positions in the longer term.

- raise levels of autism informed practice within the general workforce - particularly first responders in Police, Fire, Ambulance and A&E services.

4. appoint an autism champion at national level. The 'big players' within autism do not represent the entire community, and an elected/nominated champion should be accountable to the entire autism community, as well as seeking a mandate to raise issues of priority and concern at ministerial level.

- create local autism champions to represent the autism community in Community Planning Partnerships, Integrated Joint boards and third sector forums.

- involve people with autism in decision making processes within Joint Boards.

- promote autism as part of a neuro-diverse Scotland i.e. 'See Me' for example.

- create more autism-friendly spaces within offices, workplaces, and the community in general.



5. The provision of legislation would move from implementing discretionary 'powers' centring on the Scottish Strategy for Autism, to statutory 'duties' where autism supports and services can be set into a legislative framework.

This would allow a rights-based approach to be adopted by people with autism and their parent carers, where they can be appraised of their rights to supports and services.

The provision of more ring-fenced budgets to create a network of autism specific support throughout Scotland.

## **Response 16**

1. People should not be refused a diagnosis of autism because they have an exceptionally high IQ, are aged over 50 or are female. We should also be entitled to the same health services as the rest of the population. I've been refused any diagnoses (even for a slipped disc), tests (except for anaemia, repeatedly, even though it was always negative), test results, or treatments. I've only been offered counselling or psychotropic drugs, even though I am not mentally ill. (Professor Simon Baron-Cohen has said autism is biological, not psychological.) GPs, nurses and dentists have shown no awareness of the needs of autistic people, or our difficulties. I was asked by one GP when I showed him a list of my symptoms to 'say it in my own words'! The registrar psychiatrist who was supposed to be assessing me for ASD was actually trying to find childhood trauma, of which there was none. She altered all my words, and I was told the psychiatric nurse also didn't think I had Aspergers. It takes someone highly specialist and experienced to give an autism diagnosis to an intelligent, older female, not a nurse and a student psychiatrist!

Biomedical treatments consisting of a super-healthy diet and carefully selected supplements, as well as avoiding pharmaceuticals, are now repairing my health to a certain extent, but I get no practical or financial help with this from the NHS.

2. I've suffered life-long, daily, violent persecution from government authorities and their private sector partners, because of being autistic. When I've appealed for help to Advocacy Services in two different local authorities I've suffered further threats and abuse from them, and refusal of help. When my sons have supported me they've suffered persecution also. One area in which I do have control over my life is in owning my home. Several authorities have tried every means they could think of to dispossess me of my home, even making me bankrupt because I can't afford council tax because I'm refused welfare benefits (in common with many autistic people). The sheriff said my autism was irrelevant, and the accountant said I should get help from the NAS, but refused to make allowance for me himself, even aggressively trying to force me to shake hands. Would someone with Downs Syndrome or a wheelchair user be treated with such lack of consideration? I was also asked the same questions more than once. Autistic people become aware that they don't understand what others mean, so if we're asked the same question twice we think

we've misunderstood it and give a different answer. This is taken as a sign that we're lying!

My present local authority have also made our lives miserable, with one lot of 'neighbours from hell' after another. Their anti-social behaviour officers have then lied about the decibels, and the police told me it was understandable for the males to make sexual threats against me because they were upset at having their party ended at 2.30am!

3. I receive no social support. When I had a slipped disc my GP told me to stay in bed for a week. He knew I lived alone with my two sons aged 15 and 11, but no support was offered. My 15 year old, also autistic, told me afterwards he didn't know how he would cope looking after the three of us in an isolated house heated by solid fuel, in temperatures below -20c. By age 18 he had to give up full time education to provide for us as well. When I finally got a home help for two hours a week she abused us too, and her supervisor said to me 'Couldn't HE do the cleaning?' looking at my son! Both my sons have been deprived of their childhood and their education because of all the abuse we have suffered. The younger one was even refused his Child Benefit. This constant persecution persists to this day, and we have been unable to get help from anyone. One son has left home, and I live with the other in extreme poverty and isolation. Is that what you mean by living independently?

4. When in Scottish state schools I was subjected to corporal punishment, never for bad behaviour but always for short term memory failure. Once I was threatened with it by a singing teacher who kept all the windows open, and I had kept my gloves on. I now know that Raynaud's syndrome is one of my symptoms, as well as memory problems. When I related this to the psychiatrist assessing my ASD she omitted to put in her report that it was not for bad behaviour. A few weeks later there was a play on BBC Radio 4 about corporal punishment in Scottish schools. I've listened to radio 4 all my life and on no other occasion have I heard this topic mentioned. The abuse continues.

I had to give up my career as a school music teacher because my GP refused me a sick note for severe allergic rhinitis, which made that job impossible. Later, I got an indefinite sick note for 'depression' rather than addressing the cause of my allergies!

Because of my childhood experiences of school, and aware that my older son would have even greater difficulties than I did (though not yet aware that it was autism) I decided to home-educate my sons. We have subsequently been pushed into increasing isolation by the violence of all sectors of the community towards us.

5. There can be no possible explanation for sixty-plus years of daily violent persecution by the government against an autistic person other than that the condition is iatrogenic, and therefore must be covered up. I can't escape the conclusion that it's no coincidence that my father was Senior Lecturer in Pharmacology at [REDACTED] University, and had worked on vaccines for the war

effort in the 1940s. He was a conscientious man whose aim was not to make money but to relieve suffering. So that would have made him unpopular with big pharma/government. In any case, no-one should be blamed for having a genetic predisposition, because of which they've sustained a vaccine injury. So the single thing is prevention, and for those already here, and end to the violence.

### **Response 17**

1. access to timely and appropriate health care provision. Urgent need for training of health care staff, as too few are knowledgeable and skilled to identify autism, and provide appropriate care and treatment.

Training of Police and prison staff - they must learn that their behaviour towards autistic people may have unintended consequences. Training and CPD updates are essential.

2. Ask them - rather than stating the words 'person centred' Services must fully embrace the sentiment of person-centred approaches.

3. Provide training and skills development opportunities. Invest in community initiatives and projects. Have greater authority over local authorities to ensure they pledge to integrate autism friendly approaches into community living.

4. Ensure there is not last minute consultations that are oversubscribed meaning autistic people cannot access them!

Public advertising campaigns - public health initiative that is Society driven and focused.

5. Invest more funding, and outsource work to experts who know what they're doing.

### **Response 18**

1. Currently there is no legal right for individuals with Autistic Spectrum Disorder (ASD) to access assessment. It is imperative that the diagnostic process for individuals with ASD is free, accessible and that individuals are notified of their legal right to independent advocacy under section 259 of the Mental Health (Care and Treatment) (Scotland) Act 2003. This will help individuals with ASD to know their rights, understand the options available to them and to access other services and sources of support.

It is important to note that though the assessment process for children is different to that of adults, children with ASD also have a legal right to independent advocacy. It is also essential that the assessment process is clear, accessible and consistent across local authority/NHS board areas.

Support and services (including mental health services) need to be well signposted, co-ordinated and collaborative. It is essential that health and social care

professionals involved with individuals with ASD implement a human rights based approach, and that GPs take a proactive approach as individuals may have problems identifying health issues.

We recommend that the hospital passport scheme be made available to individuals with ASD in health and social care environments to help them convey their specific needs, their preferred communication methods and persons they would wish to support them. This scheme promotes greater agency and helps to ease the process.

Health and social care assessments should reflect an accurate picture of the needs of the individual, and be conducted by professionals who have a solid understanding of the individual and of ASD. It is vital that those individuals with ASD are adequately assessed and should other conditions manifest, that they are sufficiently diagnosed, treated and monitored.

It is vital to provide families, carers and others who may be involved in the lives of individuals with ASD with sufficient information on accessing education, training and employment, housing and independent living, finance, social activities, quality of life and relationships. There should also be support available specifically for carers in the form of financial assistance, short breaks/respite and other services that can help them to lead healthier lives.

Robust qualitative data from personal experiences of individuals with ASD on the uptake of services would help researchers to understand which services contribute to a good quality of life and what areas require development.

2. It is essential that a human rights based approach is applied to social care plans for individuals with ASD, and that support and services are tailored to their unique set of needs in order to enable them to make their own choices and decisions. An emphasis should be placed on building capacity and supporting individuals with ASD to lead fulfilling lives.

Supported Decision-Making can enable individuals to know their rights, to consider their options and to make their own choices regardless of capacity. It allows individuals independence, agency and respect as equal citizens.

Independent living can support individuals with ASD to have proper choice and control over the services they use and about their lives as a whole.

There have been concerns around the uptake, transparency and implementation of Self-Directed Support and we feel that this strategy presents an opportunity to address these concerns and to ensure that eligible individuals are notified of their rights; that SDS implements the PANEL principles and that sufficient funding is provided in order to meet the needs of the individual, allowing them to thrive not just survive.

3. Independent living services should incorporate a human rights based approach ensuring that individuals with ASD have the same rights as any other citizen. The twelve pillars of independent living should be implemented to enable individuals to lead independent, fulfilling and healthy lives. The pillars are as follows:

- Appropriate and accessible information
- An adequate income
- Appropriate and accessible health and social care provisions
- A fully accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance
- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self-advocacy
- Availability of peer counselling

Local authorities, health and social care partnerships, integrated joint boards and voluntary sector organisations need to ensure that transitional support takes a human rights based, pro-active and engaged approach that takes into account the wishes and needs of the individual, and provides the minimal disruption possible – this could be achieved through the design and implementation of equality and human rights impact assessments.

4. By cross referencing the Human Rights Act with the Equalities Act and building a human rights based approach into all services, the Scottish Government would help to ensure that autistic people are active citizens, fully integrated and able to participate in their communities and society.

Children with ASD have a legal right to education and to any additional support that they may require. It is essential that education professionals (from early years' to higher education) have an awareness and understanding of autism and that educational institutions have sufficient funding to provide the support that individuals with ASD need in order to reach their potential.

Support to access employment is vital in helping individuals with ASD to be active members of society. This assistance needs to continue and be tailored to help the individual within their work environment, ensuring that employers have all the training, information and tools necessary in order to best support the employee.

Co-production would be a good method to involve individuals with ASD in the shaping, delivery and reviewing of public services.

It is essential that any adaptations made by communities (autism friendly screenings, quieter shopping times etc.) work to integrate individuals, not segregate them.

5. By ensuring that individuals have access to independent advocacy, the Scottish Government could significantly improve the lives of people with autism.

To highlight the impact that independent advocacy can have on the lives of individuals with ASD we have included two case studies from The Advocacy Project in Glasgow:

#### Case Study 1 (Miss P) Glasgow Integrated service

Miss P contacted her local Autism Resource Centre and was informed by a staff member about advocacy support as she stated that she was experiencing exacerbated anxiety and stress about an upcoming appearance as a witness in court.

It was important for the advocate to explore the communication needs because due to Miss P's condition she experiences difficulties with verbal and nonverbal communication which includes the understanding and processing of information. Miss P also has epilepsy and is prone to seizures.

Miss P was invited into the office to attend an appointment face to face; as this was her preferred method of communication as well as emailing her advocate.

Miss P told her advocate that she had witnessed a physical assault and had to provide a statement to the police which has led to her now needing to attend court as a witness. Miss P states that she has never had to attend court before, and is worried about this as she can't remember details of her statement and finds it difficult to attend new places and navigate processes.

The advocate and Miss P form an advocacy service agreement which details agreed actions and support which documents Miss P's desired outcomes which are:-

- Reduce symptoms of stress and anxiety and ensure the wellbeing of Miss P's mental and physical health
- Ensure the options are fully explored with Miss P in relation to her having to attend and be supported with process with any reasonable adjustments being

made which take into account her condition

The advocate supports Miss P to contact the clinical team and GP to gather the necessary evidence detailing Miss P's condition and requests a letter requesting 'soul and conscious' excusal from court. The GP was of the view that due to Miss P's condition she should be considered as a 'vulnerable witness' and with special measures in place Miss P can attend court. The special measures offered at court included; a 'supporter' for the court and access to the adult's statement prior to giving evidence. Miss P in agreement with this and feels this will help reduce her anxiety and stress.

The advocate supports Miss P to contact the Procurator Fiscal with request for special measures and witness services are put in place which secures Miss P a supporter at court as well as access to her statement in advance of her attendance.

Advocacy outcomes reported;

- Reduced stress and anxiety and improved wellbeing
- Views were listened to and heard
- Exercised choice and preferred options

#### Case Study 2 (Mr X) Glasgow Integrated service

Mr X contacted The Advocacy Project by email and states that he is struggling to access services in his local area. He has contacted his local council but has not had a response. Mr X states he is exhausted as he is experiencing barriers to accessing information & support which is having a detrimental impact on his wellbeing. He indicates that he is struggling to cook for himself, is feeling isolated, and unsure of any social groups in his area which he would be keen to get involved with. Mr X states that he suffers badly from sensory overloads and struggles with communication on the phone. Mr X has aspirations to attend further education but feels that this is not possible without support.

The advocate invites Mr X for a face to face appointment and agrees supports with Mr X to:

- Access information about his diagnosis and sensory overload
- Contact the local council in relation to their response to Mr X in order to explore needs assessment
- Liaise with the local Autism Resource centre in relation to local groups and activities in the local area
- Contact the local college and attend meeting to discuss additional support needs available

Mr X reports that he is attending college with support of a minute taker. He is also aware of local services and reports he is feeling more confident and in control.

Advocacy outcomes reported;

- Improved social inclusion and avoided segregation
- Improved aspirations
- Increase confidence, personal control and autonomy

## Response 19

1. Being able to live a healthy, fulfilling and rewarding life is important for everyone. However, too many autistic people currently struggle to unlock the support they need to lead the healthy life they would choose. Below, we have outlined some of the main obstacles that autistic people face in accessing health services.

### Diagnosis Waiting Times

Getting a diagnosis is a critical milestone for autistic people and key to them living healthier lives. It can offer a gateway to accessing the right support as well as providing an explanation for years of feeling 'different' or helping a parent to understand their child better. Delays in diagnosis mean delays in getting the right support and all the associated problems that entails: 60% of local authorities agree that having a diagnosis means someone is more likely to get support<sup>1</sup> and for those autistic adults who don't receive support, 73% told us they would feel less isolated if they were able to access it<sup>2</sup>.

Research from Goldsmith's University suggests that, on average, children wait 3.6 years to receive an autism diagnosis after first seeking professional help, while adults wait an average of two years.<sup>3</sup>

In addition, our 2013 *Count Us In; It Pays to Listen* report found that:

- 42% of respondents said the process was too stressful.
- 27% of respondents said they had been misdiagnosed.
- 6% of respondents had paid to access diagnosis.

Currently in Scotland there are no autism-specific diagnosis waiting times targets. In 2011, the Scottish Strategy for Autism recommended that an assessment of national waiting lists be undertaken to clarify the extent of delays. The Autism Achieve Alliance (AAA) published their findings in 2014, using a recommended maximum waiting time of 119 days from having an initial referral to sharing a diagnosis as a target to measure performance against (from recommendations issued in National

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<sup>1</sup> Daly, J. (2008). *I Exist: the message from adults with autism in Scotland*. London: The National Autistic Society

<sup>2</sup> NAS Scotland (2013), *Count Us In*.

<sup>3</sup> <http://www.autismdiagnosis.info>



Autism Plan for Children (2003)). The AAA report in Scotland identified that 59% of adults and 74% of children took longer than 119 days to receive a diagnosis and that the average diagnosis waiting time for children was 331 days, with the longest individual case in their study taking over five years. This underlines a wide variation diagnosis waiting times across the country.

We welcome the steps that the Government have taken since the strategy was last refreshed in 2015 to address this issue, particularly the improvement programme which is underway across NHS Boards to improve diagnostic services and increase diagnostic capacity. We also welcome the publication of new guidelines on 'Assessment, diagnosis and interventions for autism spectrum disorders' by the Scottish Intercollegiate Guidelines Network (SIGN). We have long been campaigning for better recognition of autism among adults and for many years have called for action to improve the diagnostic process for autistic adults. We therefore particularly welcome that the new guidelines cover all ages and replace previous guidelines that only covered children and young people.

However, there is still a lot of work to do if we are going to address this issue. Our *Count Us In* report made a key recommendation in 2013 that there should be an NHS HEAT target for post-diagnostic support which hasn't been met.

In England, the Government has recently committed to collecting and publishing the average waiting time for an autism diagnosis assessment. It is expected that this data will be recorded from April 2018. While collecting this information is just one element of what is needed for us to have a better understanding of the autistic population, it's a significant and positive step.

In light of this, we believe that as part of the final phase of the Strategy the Scottish Government should develop a Local Delivery Plan (LDP) standard for autism to join the many others that are currently in place, such as dementia post-diagnostic support and the treatment time guarantee. This would require local authorities and health boards to devise a local plan which would include how they would develop and maintain a diagnostic pathway.

Recommendation:

- The Scottish Government should record, publish and monitor autism diagnosis waiting times in every area.
- The Scottish Government should develop a Local Delivery Plan (LDP) standard for autism.

## Data

The Strategy recommends that at a local/community planning level there is a process for data collection to improve the reporting of how autistic people many people receive services and inform the planning of those services.

Each local authority, as community planning lead, is asked to develop this through an area autism strategy. A number of approaches to data collection can be taken and we would recommend a range of data sources on autism be used, if possible, to form a picture of local need. We often find in local strategies that the prevalence rate is applied to the local population for both children and adults. This is a starting point but it cannot develop a picture of who requires services or support and what type of service they may require.

We believe the main issue concerning data collection and autism is that much of the adult population is hidden or invisible but the needs and support of children are much better recorded.

Data recorded on Additional Support Needs in School by the Scottish Government and local authorities has identified what appears to be most of the expected school age population who would be estimated to be on the autism spectrum. This suggests that most autistic children and young people are at least being identified.

For adults the picture is quite different. The Scottish Commission for Learning Disability (SCLD) collates the eSay data set which is focused on people receiving social work support who have a learning disability or are autistic. This data does not gather information on autistic adults who do not receive services and therefore does not address the whole population. It also varies significantly in how it is collected between local authorities and it may be the case that autism is still not recorded, particularly where an individual has other support needs and where their autism may not have been identified. Many adults, and in particular older adults, will therefore be 'invisible' and services are too often not available to support people on the autism spectrum.

Just as the presentation of autism varies across a spectrum, the needs of autistic people vary greatly. A greater understanding of the autistic population could significantly contribute to the planning of services and monitoring of the outcomes that the Strategy is seeking to achieve.

In addition, for the final phase of the Strategy, as stated above we believe that the Government must make a commitment to gathering diagnostic information, outlining exactly where autism is going to be recorded.

### Recommendations:

We believe that the final phase of the Strategy should commit to the following,

locally and nationally:

- Recording diagnosis waiting times
- Recording autism in social care records
- Collecting data on the employment rate for autistic people
- Ensuring autism is recorded in all newly devolved benefits systems.

### Improving GP records

Linked to the above point, the Government should look to improve the recording of autism in primary care records. We have been calling on the Government and NHS England to improve the recording of autism in individuals' GP records, which was also reflected in the Government's Think Autism adult autism strategy. This will have two key benefits:

- GPs will be better able to make reasonable adjustments for autistic people, meaning the GP will better equipped to support their autistic patients
- Anonymised data from GP records will give a picture of the health (including mental health) needs of autistic people.

This will be crucial to addressing mental health inequality, and help the right support to be put in place at the right time. Following campaigning from the National Autistic Society in England, the National Institute for Health and Clinical Excellence supported this recommendation in summer 2016.

### Recommendations:

- The Government should use the Strategy to outline actions to ensure that autism is recorded in GP records.

### Autism and Epilepsy

Autistic people appear more likely to have epilepsy than the general population. About [one in every 100](#) people has epilepsy and autistic people are thought to be at heightened risk, with between [20% and 40%](#) having epilepsy. This rate increases steadily with age.

In their 2016 report looking at premature mortality and autism, research charity Autistica highlighted evidence from Sweden that suggests autistic people are at greater risk of dying prematurely, often decades before their non-autistic peers<sup>4</sup>. The

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<sup>4</sup> Autistica (2016), *Personal tragedies, public crisis - The urgent need for a national response to early death in autism*

research behind this report suggested that across every major cause of death in Sweden, mortality risk is increased in autism, but early deaths due to epilepsy and suicide were found to be particularly high. Other research has shown that autistic adults who also have a learning disability have been found to be almost 40 times more likely to die from a neurological disorder relative to the general population – with the leading cause being epilepsy<sup>5</sup>. While we do not know what the situation is in Scotland, there is little reason to think that it would be substantially different.

In their report, Autistica called for a national response to this issue, including from the Scottish Government. They recommended that there should be increased investment in research and evidence gathering in order to gain a better understanding of the link between autism and epilepsy, using the emerging findings to develop better treatments. We echo this recommendation and believe that the final phase of the Strategy should commit the Government to undertake work on this issue to inform policy and practice. We also believe that the Scottish Government should launch a review into mortality and autism, to find out more about the health of autistic people. This should then be used to develop actions to tackle the key causes of premature mortality.

Recommendation:

- The Government should commission research into autism and epilepsy, as well as a review into mortality.

2. The respondents to our *Count Us In* consultation, autistic people who are experts in their own condition, told us very clearly that making choices was fundamentally important to maintaining a sense of control over their own lives, and that their self-esteem was affected when they couldn't take part in decisions affecting them. The report found that 91% of respondents want more say over their support.

Some autistic people will need significant support to make and communicate decisions. Not all autistic people have the capacity to make choices about every aspect of their lives, but everyone should be supported to take part in as many decisions as possible.

Many others need support to communicate their views, particularly those who cannot communicate using words and the availability of accessible information can be an issue for many autistic people.

It is therefore vitally important that autistic people are able to access advocacy services when they are needed. Respondents to our *Count Us In* consultation told us that:

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<sup>5</sup> 3 Hirvikoski, T. et al. (2015). *Premature mortality in autism spectrum disorder*, *The British Journal of Psychiatry*, 207(5)

- 37% wanted advocacy support.
- Only 16% had access to advocacy.
- 66% had not made use of an advocacy service.

In addition, of those responding to our survey:

- 49% said that a lack of understanding of autism has made it difficult to get the support they need.
- 45% hadn't been able to ask for support because of a lack of information.
- 48% wanted help with social skills.

In relation to 'choice and control', we also believe that there have been instances where commissioning or tendering processes have made it difficult for specialist autism providers to operate. Like many other organisations within the third sector, we were disappointed with the Scottish Government's announcement that the majority of the contracts for specialist employment services in the new Fair Start Scotland initiative are to be managed by generic providers who, in our experience, cannot provide the specialist service (based on good understanding) that autistic people need. It is vital that the strategic commissioning process ensures that autistic people have maximum choice of potential services available to them, including specialist autism providers.

#### Recommendations:

- Autistic people or their families should be empowered to advocate for themselves, through good transition planning and support after diagnosis.
- Autistic people or their families should have access to independent advocacy services from advocates who understand their needs, as a way to help them access services. Having access to advocacy services can provide the temporary but specific help that people need.
- Local autism strategies should map independent advocacy services that are available across all the services that autistic people need to access.
- Specialist autism providers, and the expertise that they can provide, should be enabled in the commissioning processes.

#### Criminal Justice System

It is our view that the Criminal Justice System (CJS) is failing autistic people and that this must be addressed. In our experience, autistic people are no more likely to commit a crime than anyone else. However, our research indicates that as many as

a third of autistic adults may have been a victim of crime<sup>6</sup>. We know that autistic people can be vulnerable to exploitation from others due to their condition, leading to them either inadvertently committing a crime or becoming a victim.

The Strategy aims to ensure that mainstream services are better equipped to support autistic people. We believe that this ambition can only be met if further action is taken to make sure that the CJS is set up to support and understand them. Looking at the learnings of Keys to Life, we recommend that a task and finish group is established to identify the clear actions that need to be taken to ensure that autistic people are treated fairly and appropriately – whether they are a victim, witness, suspect or offender.

We also wish to highlight our charity's work with HMP Feltham, where for nearly two years we have worked to improve the way they support autistic offenders in custody, leading to them to becoming the first prison to receive Autism Accreditation, our internationally-recognised process of support and development for all those providing services to autistic people. This is important as a relative few adjustments can go a long way to providing a more suitable environment for autistic people, which will help ensure that prisons and our justice system are more effective in rehabilitating offenders whilst in custody. We would encourage the Scottish Government to commit to ensuring that all criminal justice agencies are accredited by the end of the Strategy's lifespan.

#### Recommendations:

- The Strategy should commit to setting up a task and finish group looking at key actions needed to ensure there is a clear plan across the CJS, so that different agencies can meet the specific needs of autistic people.
- The Scottish Government should commit to ensuring that all criminal justice agencies receive Autism Accreditation by the end of the Strategy's lifespan.

3. Autism is not a mental health condition and it is perfectly possible to be autistic and have good mental health just as this is possible for anybody else. However, all too often, due to a lack of recognition of their autism and because of a lack of appropriate support, many autistic children and adults develop mental health problems. This can prevent them from living the independent lives that the strategy aims to deliver for autistic people in Scotland.

Research has shown that more than 70% of autistic children have a mental health problem<sup>7</sup>. There is also a high prevalence of mental health problems in autistic

<sup>6</sup> Unpublished stat for *I Exist* research (Daley et al 2008 Glasgow: NAS)

<sup>7</sup> Simonoff E. et al, *Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample*, 2008, Journal of American Academy of Child and Adolescent Psychiatry 47: 4: 921-929

adults. Research suggests that 16 – 35% of autistic adults have a comorbid psychiatric disorder<sup>8</sup>. In addition, our own research indicates that a third of autistic adults in Scotland have developed severe mental health problems due to a lack of support<sup>9</sup>.

#### Recommendations:

The National Autistic Society Scotland made a number of recommendations in our submission to the Scottish Government’s consultation on the 2017-2027 Mental Health strategy. We believe that these recommendations need to be enacted upon if strategic outcome three is to be realised. They are:

- Identification and diagnosis of autism in both children and adults must become a priority for the NHS to help ensure early support for this ‘at risk’ group and prevent the development of mental health problems among the one in a 100 autistic people in Scotland.
- Where autistic people develop mental health problems, professionals need to ensure they can adapt their practice appropriately to meet their needs effectively
- Ensure that NHS workforce training strategies include appropriate levels of training in autism for all relevant professionals, especially GPs, health visitors, paediatricians, child and adult mental health professionals, speech and language therapists and occupational health professionals.
- Make sure that the prevention of mental health issues among autistic adults is prioritised.
- Make sure that local authorities are commissioning a range of provision at local level to meet the needs of their local population of autistic people. This will include low level interventions like social groups, advocacy and counselling as well as more intensive support.
- Make sure that mental health professionals in Scotland are equipped to support autistic people who also have a mental health problem and are able to adapt mental health treatments effectively.
- Invest in research to identify how best to adapt mental health therapies for autistic people.
- Issue guidance for mental health services on the reasonable adjustments they could be making to mental health settings to meet the needs of autistic

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<sup>8</sup> Royal College of Psychiatrists, *Good practice in the management of autism (Including Asperger Syndrome) in adults*, 2014, Royal College of Psychiatrists

<sup>9</sup> *Daly I Exist: The Message from adults with autism in Scotland 2008* The National Autistic Society Scotland

4. Initial Teacher Education: Getting the right education and support is a top concern for many of our members and other people who contact us. Parents tell us they want a range of provision for their children, including access to support in mainstream schools, special schools, resource bases in mainstream schools and dual placements. But we know that parents often have to fight to get the support their children need. If we are to ensure that autistic people are able to live their lives as active citizens who are fully integrated and able to participate in their communities and society then this needs to be addressed.

In order to achieve this, we want to make sure that every new teacher in Scotland is trained to work with autistic pupils. While autism can present some challenges, we know that a child who is understood and supported can make excellent progress. Having teachers who are properly trained and have the necessary tools to support the inclusion of autistic children and young people in mainstream education services is a vital component of this.

Currently, there is no requirement for new teachers in Scotland to learn about autism. The 2016 *Pupil Census* figures show that of the 170,329 school pupils in Scotland with an Additional Support Need, 13,423 are autistic. The vast majority of these pupils are in mainstream schools and so every teacher will have autistic pupils in their classes throughout their careers. It is because of this prevalence that we believe that autism should be included as a specific topic in Initial Teacher Education in Scotland.

Autistic children and young people (and their parents) are clear about the need for teachers to have a better understanding of autism. In a survey we carried out in 2015 on what our charity's priorities should be, 70% of Scottish respondents identified teacher training as the most important change that needed to happen in our education system.

In addition, the Additional Support Needs Tribunals for Scotland's 11th Annual Report shows that cases involving autistic children and young people account for 65% of the references they received between April 2015 and March 2016. We often hear from the parents of autistic children and young people that they often have to go down this route of dispute resolution because a child's needs are not understood by education professionals and therefore, not being met appropriately.

From 2018, autism will be included in the Initial Teacher Training framework in England – meaning that all new teachers will learn about autism in their initial training. This framework states clearly that all trainee teachers should learn how to adapt their teaching strategies so that autistic people are fully included and helped to succeed. This was a direct result of a campaign by the National Autistic Society,



called *Every Teacher*, which called for all teachers to be trained in autism. Moreover, in England the Government fund the Autism Education Trust who provide continuous professional development for education staff. They have trained over 150,000 staff.

We believe that autistic pupils in Scotland should also be taught by teachers who have an understanding of autism.

Recommendation:

- The Scottish Government should commit to making autism a compulsory element of the initial teacher education framework in Scotland.

We also believe that at this stage of the Strategy it is important to identify what the national picture is in relation to education support, an issue that is addressed by local autism strategies. As part of the autism strategy funding package, the Scottish Government provided £35,000 to each Local Authority to develop a local autism strategy and associated action plans. There are no Local Authorities in Scotland without either a published (draft) strategy or action plan. However, there are significant variations within these strategies and action plans, with differing core outcomes. It is difficult to evaluate the progress being made across the entire country as the timescales for Local Authority strategies and action plans vary.

Recommendation:

- We recommend that a list of key indicators of success is devised to provide a standardised metric to measure the impact of local authority strategies in a number of areas, including education. These indicators could include whether or not a lead has been put in place, whether capacity building training has been developed and which services are offered. This information could be gathered in a similar way to the Department of Health's [autism self-assessment framework](#), which aims to enable local strategy groups in England to review their progress and support future planning with partners.

*Importance of Continuing Professional Development*

It's imperative that teachers, and the schools they work in, have the training and resources to meet the needs of autistic children and young people. That's why we believe that more needs to be done to ensure that teachers who are already qualified have access to training in autism as part of their continuing professional development. While we welcome the development of the Autism Toolbox for teachers, we believe that it is important to continue to explore the possible introduction of a programme, similar to the Autism Education Trust, in Scotland.

Recommendation:

- The Scottish Government should explore the possible introduction of a programme, similar to the Autism Education Trust, in Scotland.

Employment

Another aspect of life that autistic people tell us is particularly important is addressing the autism employment gap. Unfortunately, we know that autistic people are significantly under-represented in the labour market. According to a 2016 survey of over 2,000 autistic adults, or people responding on their behalf which was published in our *Autism Employment Gap Report*, under 16% are in full-time paid work, a figure has remained similar since 2007<sup>10</sup>. Only 32% are in some kind of paid work (full and part time combined), compared to 47% of disabled people and 80% of non-disabled people<sup>11</sup>. Crucially, four in 10 autistic people working part time told us that they want to work more hours.

We have already stated our disappointment in the Scottish Government's decision to award the majority of the contracts for specialist employment services in the new Fair Start Scotland initiative to non-specialist providers. We have heard from autistic people that generic providers delivering these services aren't always able to recognise when specialist support is needed, nor are they incentivised to procure it. It is vital that the Government now ensures that all organisations that have been awarded these contracts can offer appropriate specialist support, or commission it from other specialist providers if needed.

Recommendations:

Our *Autism Employment Gap Report* made a number of recommendations for both the Scottish Government and local authorities to consider in order to reduce the autism employment gap, and in turn ensure autistic people are able to live as active citizens.

During the last phase of the Strategy, the Scottish Government should:

- Make sure it is monitoring work outcomes for autistic people in the new Fair Start employment programme.
- Note the recommendations of the England 'Maynard' taskforce on apprenticeships and look at the scope for implementing them as part of the

<sup>10</sup> A 2007 survey by the National Autistic Society (I Exist, NAS (2008) found that 15% of autistic people were in full time employment. The new survey was 15.5% and does not represent a statistically significant change

<sup>11</sup> Disabled people and non-disabled people figures from Office for National Statistics (2016) Dataset: A08: Labour market status of disabled people (20 July 2016).

apprenticeships programmes in Scotland.

- Make sure that local autism strategy working groups include representatives from employment agencies (e.g. local Jobcentre Plus).
- Make sure that local autism plans include strategies for getting more autistic people into work.

### One Stop Shops

We believe that the One Stop Shop model has worked well and have proved to be a valuable resource. Indeed, they continue to be impactful in areas where they have been kept open. However, we are disappointed that sustaining the One Stop Shops did not form part of local autism action plans. We believe that autistic people and their families who live in areas without One Stop Shops are disadvantaged by not having access to this type of service.

5. We share the Scottish Government's ambition for Scotland to be the best place in the world to grow up. For autistic children and young people, a vital part of this will be ensuring that they have an education that is suited to their needs. In a survey we carried out in 2015 on what our charity's priorities should be, 70% of Scottish respondents identified teacher training as the most important change that needed to happen in our education system.

As highlighted earlier, we also know that the Additional Support Needs Tribunals for Scotland's 11th Annual Report showed that cases involving autistic children and young people account for 65% of the references they received between April 2015 and March 2016. We often hear from the parents of autistic children and young people that they have to go down this route of dispute resolution because a child's needs are not understood by education professionals and therefore, not being met appropriately. The evidence received by the Scottish Parliament's Education and Skills Committee when undertaking research into how Additional Support for Learning is working in practice was clear in highlighting the pressure on the education system in relation to autism.

We believe that making sure that every new teacher is trained to work with autistic pupils will help address these problems. While autism can present some challenges, we know that a child who is understood and supported can make excellent progress. Having teachers who are properly trained and have the necessary tools to support the inclusion of autistic children and young people in mainstream education services is a vital component of this.

### **Response 20**

1. Basically to constructively and seriously listen; listen, take onboard and act upon, through consultation, from autistic people and their families, their unique and

important perspective, experiences and viewpoint; of the many barriers, challenges and battles we face as the vulnerable, but very able, when given the chance to, to being able to positively, constructively and equally be involved in the many areas of society, employment, local services, public transport etc. By promoting the fact of how the Scottish nation would be improve and enriched by the genuine and full 'inclusion' of vulnerable but every able autistic people and their families unique life experiences and concerns, at every level, in the area of decision making process, from the Scottish government down.

2. There really needs to be a definite willingness and change of attitude to how autistic people and their families are treated by many areas of the services etc. so we are not having to continually fight to have our voice heard, and services that improve our lives, more readily implemented and maintained; and all this constant struggle to achieve this, due to a tiresome and damaging lack of basic autism awareness, lack of care, understanding and common courtesy, in us having to continually explain how this lack of understand on a regular basis, makes our lives more stressful because we are different and have genuine fundamental rights, to be treated more equally and fairly, for example there are definite parameters in what constitutes a 'hate crime and victimisation', written down by the Scottish Government; but we have experienced a lot of apathy in the police and criminal justice system, where these guidelines have not be followed up and led to increased and unnecessary trauma and reduced choice and control.

3. By ensuring that autistic people are given access to appropriate diagnostic services and where there is greater awareness of autism, in the areas of the services, so that they are not misdiagnosed and then spend years suffering the consequences of this and being left with more mental and emotional damage that takes years to recover from and robs them of their quality of life and unable to live independently because you have to have the correct diagnosis, so you can get the right help, care, support and treatment and a lot more through needs to be put into investing in autism specific communities, sot that we can recover and then contribute to that community and feel well and safe to do so.

4. All levels of government, local authorities police, the criminal justice system, planning, NHS, doctors, shops, the media etc. really need to have autism awareness training by appropriate autistic representatives, from, like in the Highlands, the brilliant one stop shop, to be invited to give staff training in autism awareness and exposure by not just listening, but a genuine willingness to re-educate and widen their understanding and have autistic people involved in how policies of these different areas are formed, as there is lack of foresight into the vulnerables needs in e.g. housing and how services are delivered!

5. In the Highlands, please give the one stop shop (Autism Initiatives) continued and long term funding and a more permanent premises to conduct their vital support to all of us in the Highlands. Their unique professional and caring support, have been a

real lifesaver to many of us and our families; you must recognise that this is more than just funding and premises, it is about a community of vulnerable autistic people, who need a place of safety; please see the autistic perspective, take the politics out of it, give us all some continuity and peace of mind and support their vital community support and be part of something that truly works for us all and doesn't damage us anymore!