



Public Health
England

Protecting and improving the nation's health

Autism Self-Assessment Exercise 2016 Personal Stories

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: [@PHE_uk](https://twitter.com/PHE_uk)
Facebook: www.facebook.com/PublicHealthEngland

Edited by Susannah Baines and Chris Hatton
For queries relating to this document, please contact: ltd@phe.gov.uk

© Crown copyright 2017

You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit [OGL](https://www.nationalarchives.gov.uk/ogl/) or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published: June 2017
PHE publications
gateway number: 2016675

PHE supports the UN
Sustainable Development Goals



Contents

About Public Health England	2
Executive summary	4
Planning	5
Training	9
Diagnosis	13
Care and Support	21
Accommodation	38
Employment	42
Criminal Justice System	57
Education	58
Health	60
General	63

Executive summary

This is the third time that the Autism Self-Assessment Framework (SAF) exercise has included an opportunity for local authorities to share up to five self-advocate stories. These were to illustrate one or more of the questions in the self-assessment exercise. There were over 240 stories in total, although this figure includes some stories which were clearly not from self-advocates and some stories which were repeated across more than one comment box.

Some of these stories are the words of people with autism. Others have been written by carers or advocates about their own experiences, or on behalf of people with autism. The stories cover a range of experiences, both positive and negative.

All the stories were read by the editors and are presented here under the themes applied to them, and are designed to be read in conjunction with Autism Self-Assessment Exercise 2016: Detailed report and thematic analyses, describing the findings of the Autism SAF. If stories were not given a category by the contributor the editors have placed the story under the most appropriate theme. The themes are:

- planning
- training
- diagnosis
- care and support
- accommodation
- employment
- criminal justice system
- health
- general

The stories have had any identifying information, such as the names of people or places, removed or replaced with pseudonyms. Some stories have been lightly edited, either because they were over 2,000 characters long, or to make them easier to read. A small number of stories were not included if at least one editor considered that the material in the story placed a person at risk of being identifiable, or if they were general descriptions of a service or job role rather than a story about a particular person's life.

We are extremely grateful to all the many people who contributed the stories. Between them we think they give a rich, varied and at times surprising set of views of the lives of people with autism today

Planning

As an autistic self-advocate, I am very happy with the level of involvement autistic people have in [area]'s autism strategy. Along with six other self-advocates from the autism self-advocacy groups that the council provide, I am a part of [area]'s Autism Planning Group, which meets six times a year to make decisions on implementing the autism strategy. At the meetings we are able to speak freely, and our opinions are welcomed and encouraged. We are listened to and our feedback is equally taken into account as other APG members. For any decision, self-advocates are asked for our ideas and opinions, and are invited to do things like sit on panels, and contribute to documents.

Outside of the APG, the relevant [area]'s staff are easily contactable. This autism-centred ethos extends to many of the groups and projects that [area]'s fund. I am a member of one of the aforementioned autism self-advocacy groups. Autistic people have a central role in deciding the content of our groups and the projects we work on. These groups enable us to connect with fellow autistics, get involved in campaigning for greater autism awareness and improvement to services, and - via feedback from self-advocates representing at the APG - for the APG to share news and opportunities with the autistic community.

For example, last year before I was in the APG, I heard about the council's autism awareness campaign through the self-advocacy group and was able to participate in street awareness raising. I am also involved in services that are funded by [area]'s through their small grants for autism-related projects.

Some of these projects enable autistic people to further participate in the autism strategy. One of these is [named] trainers, in which people on the autism spectrum deliver training to educate people about autism. [Area] has utilised [Named] trainers to train some council staff in autism awareness.



Meeting 18 carers who have sons and daughters who have gone or are about to go through transitions, carers said that they had different experiences of transitions and on the whole it was not as positive as it should be.

There is a lack of information about transitions and people do not always get the information they need when they need it. There is not a clear pathway to explain who does what and when. One person said: "Adult social care and the school know my son has autism and he has a diagnosis. But, I still had to chase things up as no one told me what I needed to do.

Surely the transitions team should contact me automatically to explain what options I have and when teams would contact me". People said that they didn't even get a leaflet they could refer to. A couple of people didn't know what transitions were and what they did. Carers said that the different teams and people they have to talk to can make it really hard to understand what the process is. They said they have to talk to so many people, particularly when they are trying to get a diagnosis that they really don't understand what is happening.

They do not feel the pathway is clear and there is a lack of written information about the processes they will go through. People said that they would like a person to talk to when they have an enquiry about what is happening to their case. They said when they have to phone adult social care via the customer services they are put through to duty staff who do not understand the case. There needs to be better partnership work with schools to make sure there is clear information about what service choices there are and what to expect as children begin to look at adult services.

One care said that staff across services need to be more knowledgeable about the options available and to not dismiss some services because historically they have not been deemed 'good' as others.



I care for my fun-loving, minimally verbal 18-year-old autistic son. My son also has epilepsy and requires a high level of support and care and will continue to do so for the rest of his life. I became alarmed at the lack of specialist autism support locally for young autistic adults. I felt unsupported in finding appropriate post-16 provision and had no choice but to send him to an autism school out of the borough.

He will need to stay in college until he is 25 but there aren't any autism colleges in our borough. In 2015, I was pleased to hear that my council was developing an autism plan but I was concerned that no one had spoken to carers of autistic people about this. With support from [organisation], I addressed the Health and Wellbeing Board, along with an autistic local resident. We told them about the lack of services for autistic young people when they leave school and asked them to fully involve autistic people in their plans. Parents have a constant worry about the lack of provision for their autistic young people, particularly when they leave education.

They often end up at home under-stimulated, which negates some of the positive input that has gone into educating them. Parents may have to give up work to care for their son or daughter when they leave education. Our young people need meaningful and stimulating support such as autistic adult day centre activities and high-quality accessible services with trained staff. They need support, understanding and opportunities.

Caring can be tough. I work full time. I have a five-year-old daughter and an older son who was paralysed in an accident. I am proud of my family and I rarely ask for help from others. But it is still important to me that my son has a safe, secure and happy future. Our borough has a new autism strategy board and I am the carer rep. I value this chance to represent local parents and carers of autistic young people on the board. Our young people need a voice if they can't speak for themselves.



I would like to share my experiences of my son's transition from children's services to local adult services. He has a diagnosis of autism and OCD. At no point was there any involvement from professionals to provide me with information about the transition process. I had to lobby, with the help of local organisations, for over a year after my son turned 18 to get any assistance.

When he was finally assessed, he was left in temporary limbo as it was not clear what organisations would be able to support him. Because he did not have global learning delay, initially the [area] Learning Disability Service did not feel he met their criteria. It was then left between Adult Mental Health and Adult Social Care to see who could best meet his needs. Eventually, a special case was made and the [area] Learning Disability Service agreed to support my son. I feel, however, there should be a dedicated adult autism group within [area] which specialises in autism, along the lines of the [area] Learning Disability Service which could pool together all autism specialties. In [area] at the moment either a young person reaching adulthood will be left with no support or support patched together by LDD services. I don't feel this can offer the specialised care young autistic adults require.

This links to the lack of post-18 provision either in colleges or day centres that are ASD-specific. I would like to highlight a particularly bad experience my son had at a local project. A member of staff reported my son to the police when he became upset in a manner that was typical of people with autism. The case was dismissed by the police but we feel that this would not have happened in the first place if the staff from management to individuals working in the classroom had had meaningful autism training.

Our son still suffers from anxiety and fear of the police a year on from the incident. We also have concerns about accessing personal budgets. Although it is national policy that people should have a personal budget we are involved in a protracted dispute about obtaining one for our son's education. We have identified provision that meets his educational needs at a fraction of the cost of LDD-allocated provision but [area] will still not release the budget.

For people with autism who typically have a spiky profile with highly specific needs personal budgets can provide them with the bespoke programmes they need

specifically in the absence of specialised autism provision in the borough. On the bright side we have had positive experiences from dedicated professionals who have done their best for him. One of the most positive experiences has been a local arts organisation for people with disabilities which has provided a supportive and stimulating experience. Our GP has also been very supportive of us and always sought the best for our son.



I've been involved with development of the local autism strategy on the APB and sub-groups. I'm satisfied that the APB is making progress in various areas such as training and employment. There are plans to reduce diagnosis waiting times, but it remains to be seen if these will succeed.

I remain concerned that only a small proportion of the expected number of autistic adults have actually been diagnosed. This must make it difficult to anticipate what the needs of the undiagnosed group are. We do, however, have increasing involvement of some autistic adults in the local support group, and we need to find ways of getting regular feedback from them to inform the autism strategy. Due to having a reasonable amount of time available, I tend to get put forward as a representative, and I'm very conscious that to do this well I need to get other people's views as well as voicing my own.

I find the amount of paperwork involved in APB and sub-group meetings rather daunting. I have past experience of office work and complex documents, which helps, but I'm probably not as adept at taking it all in as I was when I was younger. I doubt there's a solution to that. It's not a vocabulary issue so easy-read isn't the answer.



It took a lot of planning and information gathering on my part which again was helped because of my working on the Special Education Needs and Disability Group, (SEND) this plan will be used to help shape what will happen next when college finishes. The social worker involved in his plan was very helpful and supportive. I hope all parents will have the same experience when developing their plans.

Training

I try to contact various organisations via call centres and receptionists, I find the systems frustrating due to the long call waiting times and being unable to make contact due to meetings, sickness and holidays, the uncaring attitude of many receptionists make me angry. I deal with people in shops, rail and bus stations trying to buy tickets. I find many people unhelpful due to lack of training on autism issues and other mental issues. I find these episodes distressing.



I've delivered autism training for employers, including the Fire Service.



[Name] is very calm, supportive and encouraging and inspires confidence, both in her and her abilities and in me. She understands the difficulties that I have, eg in communication and talks to me in a way that generally reduces my panic and anxiety and enables me to see things in a more positive light. She has arranged repairs in my flat and accompanied me to meetings that were way beyond my ability to manage on my own and by taking the pressure off me to communicate, has enabled me on a number of occasions to find my own voice knowing that [name] will help to explain things when I get stuck.

A good example of this is when we carried out a training session on Asperger's with a room of my work colleagues. I was in a real mess beforehand and didn't think I would be able to say anything at all. However, with [name]'s help and support, it went really well and improved my relationships with those around me. I also appreciate her patience and understanding and her practical support when she recognises the limitations of what I can manage at the time, eg when I was so overloaded that I wouldn't have been able to remember to post the letter to the DWP.



I find that the levels of services for a child to adult seeking for a diagnosis for autism is not easy. My experience with my son was very traumatic and frustrating. I was misunderstood and my parenting skills were constantly challenged. Having the diagnosis gave me the opportunity to find ways to help my son and to know how to manage his behaviour, but having ADHD support is very poor when requesting help from service providers.

They seem to ignore what I was explaining and would compare what they thought triggered his behaviour or that I was exaggerating.

There is a lack of services, resources, information and respite services that offers an individualised programmes. With cutbacks, the services targeted for those with autism does not help as there is not enough trained staff who understand autism.

Lack of trained staff for the elderly with autism that is overlooked causing more additional stress and sensory overload to those in later life with care workers who have no proper training about autism apart from a few one or two day courses. This is not enough.

No two autistic individuals are the same and when comparing to my son's needs his needs are a constant struggle as those making decisions based on reports and panel discussions to make a final decision how funds to be allocated for an individual is unfair. It would be fair if service providers are trained with input from autistic specialists and also to include autistic speakers or guests to share their experiences.

Need accessible services where frontline staff, security, restaurants, public sectors, human resources, GPs being trained on autism as many families and also I have experienced too the lack of understanding from GPs who have no knowledge of autism. What would be useful to host a range of autism workshops that are held throughout the year identifying the difference between those living with autism and social communication disorders to non-autistic.



I am a high-functioning autistic person with Asperger's Syndrome. During my childhood I was diagnosed early by a doctor and had great support from a special needs nursery and that nursery had great teachers and staff. As I got into my teens, I was considered going to a special needs secondary school but my mum put me in a mainstream school, great decision because I was high functioning and it would decline my development.

This is where things got very difficult because of the lack of preparation and solutions in a mainstream school because of I was falsely accused of blowing a computer because [there is] a red button in a computer [which will] make [it] explode which is false. I protested my innocence they didn't believe, shouted at me and I got angry, confronted the teacher and lightly pushed away because [they were] in my way.

I was expelled after the explosion. I moved to another mainstream school in [area] there were no problems because my mum went to the school and gave each teacher way to handle me and it was success.

I am 'Not Someone To Cause Trouble' but I have felt troubled by the police simply by crossing the train platform, for looking suspicious and being searched for no reason. After 18, things got very tough for services taken away from and support living [with] Asperger's Syndrome and literally no one to support me except my mother and family.

So I went through depression because of lack of support and I dropped out of college in computer game development. So it is pretty much me and my mum to support me and I pretty much had to figure out solutions in life with many trial and error. I feel services do not have enough trained staff that specialise in autism, especially once we leave school.



I have been assisting in autism training for quite a few years now. It started by a chance meeting in [supermarket], I got chatting to a lady, she told me a friend of hers was going to start giving autism training and needed anyone on the spectrum who may come along and give students their side of things. I felt very pleased and very willing to meet her friend.

I began to assist on courses by answering any questions and telling my own experiences with different matters, mindful of all of us on the autism spectrum being individual and different. Helping with training enables me to understand more about my condition, I find it also very therapeutic. I enjoy meeting new people and I do this meeting new students who work in supporting roles such as support workers, job trainers, social workers and very occasionally carers. When I talked to Rachel I observed that she wore soft trainers and I was pleased she let me feel them as I love soft textures.

We had a good chat and got to know each other. Another aspect is learning of problems cropping up with others on the spectrum who are supported by students on the courses, such as a young man who has got aggressive tendencies being misunderstood of innocent intentions, gets carted off to a police cell overnight having been taken handcuffed in a police van which would have been very traumatic. I would very much like to help other groups such as police, teachers and hospital staff.



Experiences with public services which have been unhelpful and harmful. Staff who have only a surface level of understanding of autism but think they know better than me about what it is like and don't understand that it affects each individual individually, who don't take the time or trouble to understand how my autism affects me. Staff lack of experience, lack of willingness to spend time building a relationship with me and a lack of understanding of the implications for them and me of the tasks they are undertaking. Staff who are not allowed sufficient time to do a job properly and who are unable or unwilling to make the time to do it properly.

Organisational systems which dictate that staff cannot remain involved with me so that we are able to build a relationship of trust. This means that each time a new person gets involved we have to start from scratch again. It takes me a long time to trust people and to open up to them and the revolving door approach to allocating staff means that no

one ever really understands my needs properly and I am left having to try to give the same information over and over again and have to put right the misunderstanding and misinformation which comes when one person writes something down and another reads it. True understanding is lost between what the writer meant and what the reader thinks they meant. In addition, the practice of removing support when it works not only hinders but feels abusive.

Time and time again over the years when I have demonstrated severe need and been in crisis support has had to be fought for, taking time and costing a packet, only to be removed again once it begins to work and the problem which led to it being provided begins to resolve. Then off we go again I go into crisis, the battle for support begins again taking a huge toll on me and my family/carers till support is put back in place. The issues diminish and the support is removed and off we go again..... get the picture?

Diagnosis

The birth of our son brought its own challenges. I've never been great at adapting to change. In fact, I've always become upset by it and it was no different with the arrival of this little person. I found myself unprepared for the changed reality of our situation. I recognise now that I sunk into a depression that took at least a year to clear.

As time passed and I felt more and more able to connect with this little person who had for a long time felt like an invader. I realised what I had not been able to feel but which had been there all along. I love him with an intensity that is staggering and almost frightening. I always have and always will.

As our son grew we began to notice things in his development that felt not quite right. The first thing was that holding him was very much like trying to cuddle an ironing board, there was no eye contact whatsoever and many more things that we didn't quite understand. We began to research and as we did we came to a conclusion, it seemed our little boy might be autistic – but what's more, another eureka moment, it seemed that I had traits that were similar. It was that point three and a half years ago that set in motion the events that led us to where we are now. I'm extremely grateful to the NAS website and the forums on there that gave us the strength to consider that both my son and I might be on the spectrum.

Considerations led to a request for diagnosis and three years down the line, both my son and I have been diagnosed. We have understanding, we have peace and we have a sense of where the spectrum will take us. The most important thing for me is that our son doesn't have to struggle like I did.



I was also referred for diagnosis via mental health. This is an incorrect route and I know of other individuals who have also been referred in that manner.

There is a seeming lack of post-diagnostic support for adults who do not have an LD but need SALT or sensory therapies. It would appear that this is because suitably trained professionals are not specifically commissioned by the NHS to work with high-functioning adults.

Thankfully, I feel so passionate about the world of autism and making positive changes that I have fed back information to the Board's Diagnosis, Assessment and Support Planning subgroup with regards to my experiences. In January 2015, I fed back to the group that I had been referred via a mental health route. This was the catalyst to resend the pathway to the CCGs so that they could remind GPs of the steps that they should be taking with individuals embarking on the journey to possible diagnosis.

Throughout the whole of my time with the Board, I have been able to draw upon my experiences and those of peers, in order to inform the Board of gaps in services and of areas where myself and my peers feel that there could be improvements. These suggestions have been and continue to be followed up by the Board and its relevant subgroups.



I am an autistic adult and run an adult support group. I also have links with a local NAS branch. I can confirm that despite an adult diagnosis pathway being circulated in my locality, that there are still many adults struggling to enter the pathway. I regularly receive reports from adults who have gone to their GP to be told that: "There is no such thing as autism" or "Why would you want a diagnosis/label?" or "Haven't heard of the pathway."



I had problems because of a late diagnosis of issues with mental health. I was offered therapy to help with mental health and anxiety but suffered because this wasn't picked up earlier for one reason or another. I tried to address this but was then told that the occupational therapist was no longer dealing with my case and I am not getting the support.



Being finally able to get a formal diagnosis was a major thing. We failed to get one through schooling and still had to wait once there was a referral, but it is now finally confirmed. I know it doesn't mean that services suddenly get switched on, but we know what we are dealing with, what the condition is and what the condition isn't.



It had been mentioned as a child that I might have autism. I have always felt that something was not quite right. I have always felt that what I was doing was uncomfortable. At first my GP referred me to [group], this was no help and not suitable. Then one day the GP rang and suggested putting through for an assessment. The assessment took two and half hours and was confusing. Found the story very difficult.

After my assessment I was sent a confirmation letter. I did not understand all the numbers in the letter and found it very confusing. Although what was written in the letter was very straightforward. I didn't really want any support but I was able to talk to the Autism Community Development Worker when I need to. I am currently learning to cope with unexpected change.



The idea that I was autistic has been floating around in my head for quite a while. I just never felt like I fitted in very well with other people and I always knew something was

different about me. My first GP wasn't supportive at all and wouldn't refer me for an assessment. He insisted it was all mental health-related and wouldn't hear why I thought I had autism or why I wanted an assessment. The psychiatrist also wouldn't listen to me and said it was borderline Personality Disorder rather than Autism/Asperger's. I moved to a new surgery and I saw another GP who was really supportive and agreed that an assessment was necessary. I didn't really receive any support during or after my assessment apart from a one-off session with my previous therapist.

I found the verbal feedback useful but the diagnosis was quite overwhelming so it was difficult to know at that time what questions I wanted answers to. The written report was lacking in detail, and I didn't find it helpful at all - all it had in it was my scores within the assessment, and that I met the criteria for a diagnosis. However, I did receive support from the Autism Development Worker after. At the moment I am currently working as a TA for a primary school.



I was struggling after two redundancies in quick succession and I was feeling depressed. My GP referred me to [group]. While at [group] it was suggested that I seek a diagnosis. It was extremely lucky that the psychologist at [group] recognised something in my manner which led to my referral. After my assessment I received a letter suggesting that I should meet with the psychologist if I had any questions. During this session I was referred to the Autism Community Development Worker. I have met with the Autism Development Worker a few times since. I was dismissed from another job and in despair I contacted the Autism Community Development Worker seeking some advice. She is very supportive. I am now planning to find another job.



For a long time I've suspected that I've had an Autism Spectrum Difference (ASD) condition of some form. I have found it difficult to make friends and fit in with my peer group for much of my life and (probably as a result of this) have often had periods of anxiety, low mood and low energy levels. I am 33, and when I recently moved back to [City] to be with my family I started seeing the Crisis Resolution Home Treatment Team and attending courses at the recovery college. I found out about a local autism support service provided by a national autism charity and started attending sessions and joined their social group.

They offered to write a letter of support for a diagnostic assessment that I could give to my GP. At the next GP appointment therefore when we were talking about the assessment I showed the GP the letter. This letter seemed to get the GP to start to notice the situation and the urgency more and I found the GP surgery much more proactive about getting me funding for an assessment at a different centre that would assess me sooner.



My son is a 50 year old who has been in full-time employment all his adult life and is able to live on his own with some support from his family. Four years ago, I discovered that he had been financially exploited by several people. As a result, he was heavily in debt with payday loan companies. The police were unable to help, so I went with my son to his GP. She referred him to the Adult in Need Services. He was interviewed over the telephone and told that there were people a lot worse off than him. On the advice of the GP, my son was seen by a psychologist. The recommendations in his report were that my son should be assessed for ASD and treated for moderate depression. The GP referred him for this assessment, which was refused because he was not a danger to himself or anyone else and there were, according to the psychiatrist, no co-morbidities.

My son is now on medication and has had CBT for his depression. I then went to my local councillor and my son was referred to Adult Social Services. An assessment for ASD was necessary, so the GP applied again for this. This second referral was refused because the CCG were unable to fund for ASD assessment. In the meantime, the result of a genetic test I had requested revealed that my son has a chromosomal disorder, which is probably the source of his autism. As a result, he can now have support and protection from the Adults in Need Service. This whole process has taken over three years at considerable financial cost to me and caused a great deal of anxiety.



My son is now aged 18 years and managed to do quite well at A level, and is therefore deemed "OK". He has no diagnosis but I'm sure his is on the spectrum and we are trying to have him assessed. He is trying to sign on for benefit, but has been deemed "fit to work" by a GP who has only seen him twice in the last four years and doesn't know him. He can't manage work situations and finds it difficult to communicate and has started to realise this himself. He has been offered an assessment but has turned this down. He is unable to cope with every day things and is struggling but can't get any support financially. We are stuck.



As a 20-year-old man I was assessed as having a diagnosis of Asperger's by the [named] service. I had managed to make my way through school without a diagnosis and without any additional educational support. I was unhappy at school. Following school I enrolled in college to undertake a qualification in child care.

Following my diagnosis, and with the support of my GP and social services I applied for a job working in a private day nursery. It did take a year after my diagnosis to get any support from social care. I went for an interview and was offered the job. I could tell my employer about my diagnosis and anticipate what impact it may have during my working day. I have future aspirations to become a SENCo.

I feel that my diagnosis has improved my relationship with my father as he better understands how I am feeling and my needs. (This individual told his story at a recent event).



I was diagnosed under the new [city] Adult Autism and Neurodevelopmental Service in 2014 and have been receiving post diagnostic care and support under [city] Adult Autism and Neurodevelopmental service. The post-diagnostic support in groups was a pilot at that time so we were the first diagnosed groups to go through these groups. I also received seven one-to-one sessions with a psychologist, it was very helpful to share experiences with other autistic adult and be around people like myself.

I learned a lot about myself from both the groups and one to ones but I still have aspects of my autism I don't understand and I don't know how to manage any of the issues myself. I knew about the service that was to be created before it was up and running as I had done my research. The staff at [city] Adult Autism and Neurodevelopmental service are wonderful and listen; the service is user led and that is brilliant. However, what is apparent is that [city] Adult Autism and Neurodevelopmental service is understaffed and under-resourced so the staff are stressed, waiting times are ridiculously long, I have been waiting for two years to see the OT who I have heard is brilliant but she has a huge waiting list.

I have heard that the art therapist was brilliant but now she has gone and isn't to be replaced. What I am struggling with now is post-diagnostic support, both clinical and social care my needs are not being met. There is no definite pathway through the process from pre-assessment to post-diagnostic support.

All of the staff including the admin staff at [city] Adult Autism and Neurodevelopmental service are very caring, compassionate and really listen. Receiving a diagnosis has changed my life, it has been a positive change because I now understand myself more and how my autism affects me.



I am a person with autism and I wasn't diagnosed until I was in my 40s. I have always struggled with relationships and in work and have never known the reason why. Once I received my diagnosis I was provided with information about what autism was and told I was entitled to an assessment under the Care Act. I decided that I didn't want an assessment at the time and just knowing I had autism was enough for me to deal with. I was given a number in case I changed my mind about the assessment. I do access some services in the community and am happy that they support a range of people, not just people with autism.



My son will be 50 next April and has never had an official diagnosis of being autistic. When he was 12 months old our then GP, (now deceased) sent him to see a specialist with a letter referring to “this autistic infant” but at the end of it all we were never given a diagnosis of autism. We were told that our son had suffered brain damage either before, during or immediately after birth but the extent was unknown. We were not given any other information or support by either our health authority or social services back then. Over the years, ourselves as parents, his teachers at [named] school and care assistants at [named] Day Centre (closed down some years ago) all recognised that our son was autistic. Several years ago during his 30s he was treated for depression by Dr [name] (no longer practising in [town]) and she referred to our son as being autistic but even she didn’t offer us any written diagnosis.

I have spent all my adult life trying to get the best support for my son but feel he has and still is been badly let down by not having an official diagnosis and therefore missing out on appropriate care and support. He has been in a supported living environment for over 13 years and has a dedicated staff team, all of whom recognise and accept he is autistic along with having a severe learning and physical disability, however, I feel that the autism training that the care agency provides for the staff is basic to say the least, it seems that the term ‘learning disability’ is all encompassing and is used to avoid a multitude of associated conditions.



[Name]’s attention was drawn to a forthcoming local seminar about autism. She contacted the local support group organising the event and disclosed that she felt she might be autistic. [edited] [Name] says: “I am so glad that I attended the seminar because it helped me deal positively in getting a diagnosis. That has helped me feel much more confident and relaxed and happy with my condition.”



Thank you very much for progressing things so quickly. I have received the report, and am actually very impressed by not only the amount of detail included, but by how much the doctor paid attention to everything being said. After many years of having not understood the problem at the core of my difficulties, this is very welcome. I will send the application form for the card off this week. I really appreciate you having included a copy of the report for that as it really saves a lot of time and complication for me. I am interested in the mentor service and may well look further into that, but I am not certain at this stage as I think it would be very difficult to find a person who has experience with or understands the way in which autism seems to give me difficulties with language.

My mother appreciates the information for carers and though some of the group functions and facilities may not be of much help to her at this time, she is very likely to

use the other services. There is one thing I wanted to say where I mentioned that I didn't think [county] mental health services were taking my concerns very seriously. I really want to mention that I was referring to the experience I had at [organisation] and that ever since I first had an appointment with yourself at [organisation], I have been very impressed by the concern and attention to detail shown at every stage.

While there is much to be done until things really turn around, for the first time in at least half a decade, I feel I have some degree of hope for the future and this has all taken place since your services based in [city] have begun to help me. Thank you again for everything you have done so far.



[Name] is currently in hospital and as his father I have had numerous meetings with professionals about what he needs to enable him to make progress towards discharge into the community. From these meetings it feels like we take two steps forward and then three backwards. There appears to be a complete lack of co-ordination in respect of support services for those people with autism without a learning disability. The Care and Treatment Reviews are supposed to help, but services are identified, but then when they assess they say they cannot meet his needs. He has received some speech and language therapy support but there is no dedicated service.

The ward does not appear to have staff with a full understanding of how to engage and work with someone like my son. Care on mental health wards is not catering for patients with Asperger's. The environment is stressful and restrictive. Staff are not trained and processes are not equipped to handle the needs of the patient. There are no acute wards or residential services suitable for patients with Asperger's. I have not been offered a carers assessment but I have had support from the carers group and do feel carers are involved in planning services in the broader picture.



Many thanks for arranging the referral to the [area] Autism Diagnostic Service. I met with [name] and a psychologist on Friday and they have diagnosed that I do have Asperger's Syndrome. I also wanted to feedback that [name] and the psychologist that I met, I do not recall his name, were excellent. They were particularly empathetic to my wife who accompanied me which was much appreciated. Although it has taken a long time I am very pleased to have ended up in such capable hands.



I was unaware of my Asperger's status until 2014 and while it explained a lot, why I was different, it did not help to come to terms with my two parts. One being different and one with a recognised syndrome! Initially it was very confusing not knowing whether I was just different, but now I had a recognised syndrome! Also, I wondered if it was the new enlightened me or the old perceived persona for protection against the world that

controlled my thoughts and actions! At first I thought knowing about my Asperger's would solve everything but all it does it make me 'second guess myself'; all I seem to do is question myself: "Is that the Asperger's or my old ignorant self?"

I tried through the initial medical channels to get some treatment, but before my diagnosis the only support was in the wrong places and this was revisited at different times over three years. I have been confirmed as not having dementia or Alzheimer's, and some medical issues were treated, some with more success than others.

I met procrastination and prevarication in trying to get psychiatric help while waiting for my Asperger diagnosis, and received counselling which was not really apposite to the problem. After nearly three years I got my verbal diagnosis, but I have been delayed and obstructed trying to get help for my memory and other issues. The latest is a further six months before I can start therapy! I am consciously seeking medical help and hoping after three years plus to get my other problems, both mental and physical, sorted but I was and am being thwarted by the medics. Initially they waited until I become 65. Now I have to start all over again with the Aged Team, until then I cannot start mending.



Hello, I am now in my 40s. When I was 18 I went to college and continued to struggle. Writing was difficult because my memories and thoughts wouldn't connect to paper. I found organising my practical work impossible. I felt sad I always struggled. When I left I got my first job which was as a care assistant in a nursing home. Other people always seemed to know what to do next.

Sometimes I was chastised and my learning was labelled in an unpleasant way which I had no apology for. After that I had a long run of different jobs which did not last but gave me some money. Even to this day I have no support. In my 20s I was diagnosed with a long list of conditions: Dysexecutive syndrome, pragmatic disorder, short-term sequential memory. I was finally diagnosed with Asperger's in my late 30s.

It is good to be diagnosed but while others get support I am often misunderstood. In fact Asperger's has badly affected my learning. Because of my good manners and the way I come across, I have always been denied any kind of support. For [organisation], I will need someone to help me organise, plan and remember to do things. I need lists in sequence for every step of what I need to do. Having a talent is good but it's not functional without support.

Care and Support

It feels everything has to be a battle and a long wait for anything. It took a long time to get an assessment of adult care but once we did the specialist autism social workers have been fantastic, I can't fault them.



One-to-one support helped me in the months after my diagnosis when I was needing support to understand it. Just by being there when there was no other support specifically autism related. I'd have found life a lot harder. There needs to be more awareness of the different way that women on the spectrum present. I have people saying all the time: "Well, you don't seem very autistic!"



Autism impacts on every aspect of my life. It limits how I do things, where I can go, when I can go, what employment I can achieve, limits what community activities I and my family can participate in and my relationships with others. I worry constantly about everything which impacts on my mental health, sleep and physical health. I have anxiety-related stomach problems. I need to take medications for depression, anxiety and stomach problems. I can't eat properly. I am only able to undertake low-paid employment as I find increased responsibilities and change stressful.

Also, I have social interaction difficulties, am often misunderstood or I experience bullying in the work place. I find understanding my and other people's feelings impossible and I internalise all my feelings which creates stress. My black and white thinking, anxiety and difficulty in coping with change impacts not only on me but also my family. I find it hard to communicate with my partner and children and show affection. Also, I have no meaningful friendships. Continued support provided by [support group] has been really helpful as I have someone to talk to on a regular basis and am able to talk through problems, decisions and put things in perspective through discussion. I find it particularly helpful as my social worker enables me to identify and understand my feelings. She enables me to discuss my anxieties, put them in perspective and act upon them as felt most appropriate after discussion.

Since being supported by [support group] I have managed to find different employment as needed due to being bullied at my last work place and also have begun to practice showing affection to my family through regular hugging. I continue to be anxious on a day-to-day basis but I am now hopeful that over time this will reduce with support and strategies to help me understand and manage my feelings in the long term. I think what helps me the most is that I trust in my support worker who I feel has good knowledge of autism, life experience, who I am and my abilities.

.....

I was finally diagnosed with autism at 55 years of age. After years of having a support worker for helping me with my mental wellbeing as I also suffer from depression, I finally got my autism diagnosis. I now no longer need support from my support worker and my partner also goes to the Autism Social Club twice a week which is where I am now also able to attend too. This is based in the city and not the county where we live although everyone in [county] can go to this social club. There does not seem to be any other support places in the county for adults with autism or I have not been offered anything else.

.....

My son has Asperger's, now aged 19, main issue is social anxiety and depression plus sensory processing disorder and poor executive functioning. Diagnosed by CAMHS age 16 after six years of "anxious school refusal". EHCP issued age 18, now at special FE college. Good experience: Adult mental health services (NHS) – seen for assessment two years post-diagnosis – depression and anxiety. Psychologist adjusted her style for communication issues, took an accurate history, referred to psychiatrist for medication which worked. Although other treatment options very limited (CBT only – not clear if this would have been adapted for ASCs) and no other onward referrals (eg OT) were made, treatment worked, he felt understood, we felt listened to.

Bad experience: Education – pre-diagnosis of ASC, schools said he had no SENs, made no referral for out-of-school support (CSS) until we requested it after eight months of school absence, CSS and school blamed us for son "opting out" and ignored his obvious severe anxiety, denied knowing their statutory responsibilities in detail. Post-diagnosis, EHCP applied for. SAS claimed my son was "not behind" academically (factually incorrect) and agreed to assess only under legal pressure. Assessment inadequate – child development paed got facts wrong and failed to ask about issues common in ASCs. Assessments by OT, SLT, physio all refused because there was no existing NHS referral – three-month delay in being informed of this. Lack of NHS support was due to late diagnosis or no NHS service.

Progress made once legal officers got involved and tribunal cancelled at five days' notice when EHCP agreed in full. Treatment from the schools and CSS left us worried about our son, humiliated, angry at being lied to, let down and questioning our own abilities as parents. SAS staff were nice but the unit's approach made us frustrated, fearful about our son's future, angry that our son's problems were not accepted or understood and disappointed by delays and late concession.

.....

I was diagnosed with autism as an adult in my 50s, for me this was a diagnosis that carried a lot of stigma. For most of my life I felt judged by others as being unintelligent,

but this wasn't the case. Getting the diagnosis has helped me to understand myself – but what about everyone else? Particularly when most people think of autism as a male condition, or associate it with learning disabilities. I am an able person, so accessing support after the diagnosis was difficult. I felt very isolated and wanted to meet others like myself. I was able to work with someone from the county council who has helped me develop a local support group. This was a big struggle for me and I couldn't do it without support. I work hard to organise myself, but organising a group would have been too big a challenge.

As the first meeting approached, I was fearful of going to a meeting with people I didn't know and wasn't sure how I would get on in a group. I was surprised and overwhelmed at the initial meeting, it was a frightening experience for me. With time to process the discussions, and with support, I persevered and for the last six months a small group of adults with autism have been meeting regularly to discuss specific topics, facilitated by a worker from the county council, sometimes with other professionals who we have invited. It hasn't been easy but it has been good to meet people I can relate to and empathise with which has helped to reduce my feelings of isolation. As a group we have learned about ourselves, each other and about things we can do which may help us on a day-to-day basis.



[Name] was referred to the autism service from his GP for assessment, prior to [the referral] he had seen a counselling psychologist as he was having problems with progression at work and also issues with his landlord. [Name] was assessed by the autism service and diagnosed with Asperger's Syndrome. The autism service provided him with some short CBT-based psychological input to provide him with alternative strategies to manage depression and moods.

“This is just a short note to state very many thanks for the full and comprehensive summary case notes that you provided last week. They provide a concise and useful outline of the work carried out during the sessions. I have just finished an extended set of night shifts and am able to confirm that I still attempt to incorporate elements of the compassionate toolkit into everyday routines. I think about elements of them most regularly.”



The local support service has been providing an excellent Asperger's support service which is finally turning some things round for me and the counselling I received through [Name]/IAPT was very good too. What did not work so well was trying to understand different service offers and pathways from one service to another. When one service did not suit me I had to push harder to get the help I needed.



Thank you... to [named support group] helping me to get as far as now – I have human friends whose company I can enjoy without needing drink – that is enormous progress and my teachers have been all of you at [named support group]”.



I have found more confident working in the [named] project both with my admin skills and skills that I could use for work but also in myself. I have learned a lot about how charities work and how partnerships form and work. I have also a great opportunity to be part of the steering group which has enabled me to represent people with autism on this board, but also I have learnt how issues are discussed and debated. I have enjoyed working on this project as I have seen a difference it has made in [area] as [area] is starting to acknowledge those with autism who do not have a learning disability. I feel more supported in my community and feel that if I needed help I have got places that I could turn to for help and support.

I have met lots of new people from various walks of life and I have been able to learn how to interact with various people in a variety of settings. This will help me in the future find a job. [Organisation] has been very supportive of me and have encouraged me to improve my understanding and skills. I am still improving but I know with their help I will be able to be the best that I can be and achieve my potential.

The [named] project in [area] has brought hope to me that I am cared about in society. I feel valued now more than ever before. However, there is still a long way to go for this project and all the amazing people I have met who are working on it are so enthusiastic and see the importance of it, that I know we can really develop something special here in [area] for people across the whole of the spectrum, enabling them to reach their full potential. I want to say thank you for the [named] project.



My son is 32 years old. He has learning disabilities with severe autism and challenging behaviours. He has lived in this borough all his life. He received a provisional diagnosis of autism when he was four years old, and this was fully confirmed at the age of 11. We were given several options for his schooling and selected a local special needs school. His time there was happy and he left at the age of 19. There was no appropriate college provision, so he attended a local day service specifically for adults with learning disabilities and autism. He continues to attend this service, which is excellent and meets his needs very well.

Seven years ago, he moved from our home into a self-contained social housing flat, with one-to-one support. His support in his flat is managed via DP, and we employ his support staff. The funding for his package is high, and it is covered 50/50 by NHS and the local authority, but he is currently being considered for full NHS CHC funding.

The consultant psychiatrist, attached to our LD team, sees him regularly at his day centre. Medical visits in general can be difficult, but special arrangements have been put in place for these.

Access to the wider community facilities in our highly populated suburban environment can be extremely difficult so these are limited – funding for two-to-one support is provided for this. He is unable to access public transport, but has a motability car available for his sole use. Travelling in heavy traffic, the ever increasing use of ‘traffic calming’ and cycle lanes, are a real problem for our son, for which there is no apparent solution. Fortunately he is able to access some excellent specialist services (hydrotherapy pool, sensory room, disabled swimming club).



I am a 35-year-old woman on the autistic spectrum. I have been using an information, signposting, advice and support service delivered by a national autism charity. So far the sessions have been very good and I feel much more relaxed on leaving the sessions knowing that I have been understood and given the chance to talk about what is bothering me. Even though I have atypical symptoms, they are not derided by my consultant. She has helped me in preparing for work and wants to continue to do so. I like her because she is very flexible and tries to understand me as a person rather than categorising, as we all have different levels of autism.

I also make use of the women’s group where we meet on the first and third Wednesdays of the month to discuss issues which concern us. I have found it very useful to talk about problems and find solutions with the other ladies as normally I would not complain if I were unhappy about something. It has raised my confidence and self-esteem just to feel someone else thinks along the ways that I do. This was not the case when I went to school many years ago! Nobody had then picked up on autism and I think this is why my family find it difficult to accept my condition now.

The support for people like myself was just not there and we were often not understood. I believe that teachers should be trained to pick up on autistic traits or behaviours and other conditions which cause problems at school (for instance social isolation) which is more common if you have pathological demand avoidance (PDA) or autism/schizophrenia. There should also be more information about ADD and ADHD and its effect on adulthood. As I clearly have a mental health condition and am waiting for a diagnosis of possible ADHD, I really believe it to be important that people in my category are seen frequently by someone. I think a health visitor would be ideal.



One of the most debilitating symptoms for those on the spectrum is anxiety – it can be crippling and can lead to isolation. Little support is available and it can be extremely debilitating for those who suffer with it. It is not given the importance it deserves, and requires careful and exhaustive management, and often this is underestimated. Some of those with symptoms as children (diagnosed or not) are now being picked up by drug and alcohol services as adults, as they use drugs or alcohol as a means of dealing with their anxiety – this is having a knock-on effect on those services, particularly if the person was not diagnosed as a child and now has no diagnosis as an adult. I have first-hand experience as a parent as to how these services are impacted upon as a result of those on the spectrum suffering crippling anxiety and the input from services this needs in later life.



I have Asperger's Syndrome. I have difficulty processing information quickly. I can get distracted. I have problems communicating socially and building relationships. I sometimes have problems planning ahead and my thinking can be inflexible. The befriending service has helped me be more social. The autism workshop is useful for basic advice but has not helped me as much as I thought it would. [There should be a] autism walk-in centre, guide to becoming an independent adult, workshops for parents/guardians and relatives of autistic people, family day to raise awareness of services available.

At the moment all I can think of is having two additional subjects for the workshops. The first can deal with decision-making and automatic thinking. There have been times where I have done or said something impulsively without thinking about the consequences. The second can be about future planning and life milestones. My dad is hoping that I could get married so that there can be someone to look after me.



I have been a member of [locality] befriending for three years and absolutely enjoy the activities and topic sessions. I have increased my confidence on travelling independently to a variety of locations outside of my comfort zone and have meet new and lasting friendships with other service users. I was suffering from quite extreme anxiety towards meeting new people and travelling independently but have found new ways to cope with these things. When I joined the project I did not contribute towards the discussions and talk to others, but now I have got used to the other group members I speak more freely



My social worker referred me for an advocate as I was just about to have an assessment for support. At first I didn't know what an advocate was but when I met them they explained their job and how they could support me. I decided that I would like their support; they helped me prepared for the assessment, so I felt prepared. When the

social worker did the assessment the advocate made sure I understood and I was listened too, they also made sure the meetings weren't too long as I struggle to concentrate. My advocate understood me and helped me get my point cross. Then when I got the assessment back they helped me go through it to make sure I was happy with it. This helped as it was very long. After this they helped me think about how my support would work best for me.



During 2016 I have received support from the [Named Community Team], which is under the umbrella of the in-patient directorate. I met with the team manager, and my new key worker from the housing association. My new care co-ordinator and I met several recovery workers prior to being discharged from hospital and into the care of the service. I was also involved in interviewing various staff members. I have been happy with some aspects of the service but not others. [Named Community Team] has many dedicated, committed staff who work to the best of their ability, and when I was initially discharged from hospital after several years, I would undoubtedly have ended up going straight back in within a month had I not had the support of [Named Community Team].

The information I received wasn't clear and easy to understand. Communication can be poor, and there can be inconsistency, both of which I find difficult to contend with. I also struggle a lot when new members of staff are taken on and I have to get to know them. One of my biggest problems is the lack of understanding of autistic spectrum disorders, and people not understanding that I can have a very high IQ and communicate well intellectually, but at the same time have all the difficulties attendant with an ASD including difficulties communicating emotions and needs (and communicating at all when distressed).

With some staff I feel listened to, and with others I don't. I need people to understand where I am coming from, and why I behave the way I do – that I am not just being 'difficult' or unpleasant. I don't feel understood by most people I come into contact with. [Named Community Team] has supported me intensively while I got used to living in the community again, it has kept me from needing re-admission to hospital. I think the lack of understanding of ASDs in the service is mirrored in all mental health services.



My mum helped me secure a referral to social care for an assessment following a period of me not leaving the house. The process was very supportive; I met with an autism specialist social worker and a social worker student, who both helped me look at what support I could access, they helped me get a personalised budget. They put me in touch with [organisation] and their project, [name]. My social worker attended a meeting with me to talk about how I could use my personalised budget.

I have been attending [organisation] since October 2015, since starting there I have had a few review meetings with my social worker to check everything was going okay. When

I started at [organisation] I didn't go out much at all except for when with my family. Since starting support I have been involved with multiple projects which have helped me to increase my confidence, gain work experience, build my CV as well as move into my own flat, all through using my personalised budget and [organisation] help to support me to do this.

[Project] at [organisation] has supported me to engage in many activities including creative writing through Ignite Imaginations where I was paired with a professional writer who helped me to start my creative writing piece that I wanted to do but didn't know how to. I am also with support completing a [IT qualification] which I am really enjoying. I am now settled into my own flat, am feeling much more confident about myself and have even hosted a few nights at my new home with a small group of friends. Without the help of social services in [town] and my personalised budget I wouldn't have been able to do what I have over the past year.



I was finally referred to the Adult Autism Care Team after visiting my GP over my concerns with my son's wellbeing. This process altogether took nearly two years after being referred initially to a paediatrician at [hospital] which took six months to receive an appointment. In the meantime he had turned 18 so when we finally attended the appointment we were told we would have to be passed over to the adult team. After waiting nearly a year, we had a visit from an assessment officer who did an assessment and it was decided my son would get extra help through funding from direct payments.

The assessment process was pretty straightforward and involved a few visits from the assessment officer to get to know my son and draw up a picture of his daily routine. We then had a visit from the financial assessment team who were very helpful in dealing with the money side of things. Once we found out we would receive funding we had a visit from the direct payment team who were very helpful in explaining what was involved and helped me set up a payroll service and PA insurance.

We currently get funding for six hours with a PA and four hours with a job coach. The PA accompanies my son on places of interest to him and supports him in his daily activities. The job coach is currently working closely with us to find suitable employers to try a secure a job trial leading eventually to a part-time job. Overall, I have been very pleased with the services we have used once we finally got to the assessment stage.



I have been requesting support for my son through social services ever since his behaviour became difficult to manage due to his diagnosis of Asperger's Syndrome and ADHD. I was repeatedly told by social services and CAMHS that he didn't meet the criteria for support or intervention. He eventually did begin to receive support from

CAMHS in his teenage years, but upon turning 19 was discharged and not picked up by any adult mental health team, as he did not meet the criteria, despite having enduring mental health needs in relation to affective disorders (primarily caused by lack of early intervention). Upon turning 18 he was picked up by the adult autism team as a result of a safeguarding concern, and the support he has received from that service has been exceptional. He is now for the first time in his life receiving appropriate support in relation to his social care needs.

The assessment process was excellent and showed evidence of good understanding of his condition and how it affects my son. The support from the financial assessment team highlighted the benefits he should have been entitled to, so he is now maximising his income. He receives a personal budget to enable him to access appropriate support and reduce social isolation. I am grateful for the excellent support my son is now receiving, but appalled that it took over 15 years for him to be treated in a person-centred way.



I am a mum to a 28-year-old man who was diagnosed with autism when he was two years old. He lives at home with me. I tried everywhere to get [name] involved in what he loved doing – films but no one would engage. I was contacted to tell me about a project that was being developed and it came at the right time. [Name] had got to a point where he would not leave the house; he would stay up all night and sleep all day. He did not eat properly, he did not wash and he was becoming aggressive towards me.

Somehow I persuaded [name] to come with me (he does not travel independently) in a taxi 20 miles to where the hub was being developed. He had not been out of the house for over three years. [Name] was immediately engaged with [name] from [organisation] and [name] who co-ordinated the project. They were doing a short video about another service in the carers centre building. [Name] took charge of the filming and was directing people and getting the best shots under the guidance of a professional. I had waited four years to see this happen – he had become so reclusive, non-engaging and clinically depressed and this day he was like a different person. He edited the video and was so proud to see his name in the credits.

Having the autism hub is great as it is something he is interested in – if it was everyday he would come every day! The hub adjusts his sleep patterns and gives him something to look forward to. It has provided me with an opportunity to give him a bit more independence doing things with people who have a common interest. Today is the first time he will be coming home from the session in a taxi on his own...a day I never thought could happen!



I am a 43-year-old adult who just got diagnosed with autism/Asperger's two years ago, so I have lived until now without knowing of my autism and all the difficulties that it has brought to my life. If I was a child just being diagnosed, then there would be a plethora of help and activities for me to engage with. This opportunity that [named] project has brought to autistic adults is a rare one, as there is virtually no help at all for adults with Asperger's/people on the spectrum. This could also be a route into [city]'s film industry so I have a lot of gratitude for everyone involved in making this opportunity happen.



Hi everyone I'm [name]. The staff at my service call me Head Gardener. I love gardening. I've got a lovely rockery at home, which has got lights, gnomes, all kinds of things in it. At the old resource centre I tried really hard to keep on top of the garden but because it was open to the dual carriageway, people would throw their rubbish over all the time, once someone threw a cash box over.

Back at the old place whenever I wanted to cut the grass I would have to ask if there was a driver who could get me petrol for my lawnmower but often there was no one free. By the time there was a driver free, the weather would have changed. Now we are in the new service the garden is beautiful and private. I have worked closely with [name] and [name] from fundraising. Together we have made lists for tools, plants and equipment which we have needed for the garden and I've loved going shopping for everything. [Name] has helped me by clearing the patios and putting things together like our wheelbarrows and greenhouses. Myself and my mate [name] do all the garden maintenance.

Recently [name] introduced me and [name] to [shop]. At [shop] you can pick up a brochure or two and while I was looking through the brochure I found a strimmer which I needed which is battery operated. I've since also found and bought a battery operated lawnmower. Now I can do my grass whenever I want to. The lawnmower is also really light so I can lift it over the wall in the front garden.



I hope this story helps other young people with a diagnosis of autism in [town] and that the story helps to develop a better understanding of autism while services are more helpful. I was born very premature. When I was nine years old I was diagnosed with autism. They told my mum that this was probably due to being born so early. I had to have some operations when I was a baby on my eye as I had a minor impairment.

At the age of nine I didn't really understand what was wrong, or what autism was. I remember getting into trouble at junior school a lot and being very angry all the time. I also didn't make friends easy and felt teachers didn't understand me and that they didn't like me. I was referred to CAMHS (Child and Adolescent Mental Health Services) when I was younger, I can't remember the age exactly. The service was really good.

I remember them coming to see me, and they helped me with coping strategies. They helped me by showing me other things to do when I was anxious or angry. Sometimes I would listen to music as that would distract me, and also hit my pillow when I felt very angry. With autism it takes a while to trust people. I don't think teachers understood that.

At the minute I have a social worker; I've had three over the years. I get to know them. They help me and discuss things with me, like if I'm interested in any groups they will find out about them for me, so I can choose if I'm interested or not. I found changing to adult services better, as there is much more support. I didn't feel I got much support when I was younger, there just seems to be more help and support now. I feel happy now. I have money in my bank account; it's quite a bit, more than I ever thought. I get Disability Allowance and something else.

All I've wanted to do is get a job and work full time to earn my own money. My social worker told me about supported employment in [town]. That's people who have helped me to get this job. Having money means I don't worry about things. My family are very proud of me.

I do reception work. I started as a volunteer with supported employment. I went to see them and we talked about my goals to get a job. I started working here after some training. A worker came with me as a volunteer and helped me in doing tasks until I got to know what I should be doing. It made me feel supported and like I wouldn't do anything very wrong. After a bit they didn't come in so much, but they are always at the end of the phone if I need them. They still visit though. My goal is to work full time and be independent. [Town] has been good especially the supported employment service. I do six hours a week. The manager really likes me. The manager says I am a hard worker. When a paid role came out I applied. I thought I would get it as the Manager says I am a hard worker and always smiling. I did try and do full time, but got ill, it was just too much for me, and I couldn't cope. But I have another job as well now at a library; I do six hours as well there too, so that is 12 hours a week. I eventually want to do full-time work. I feel really proud and good in myself. I am working towards full-time work with supported employment and the help of my social worker.

In terms of hospitals and things like that I don't use the hospital really. I haven't been since I had my eye surgery when I was a baby. My doctor is good. The practice understand me, they think I am funny. When I go for my bloods done the nurse books two appointments, as she knows me and I don't like injections, so I jiggle about a lot. I also think things are different when you are young. CAMHS were really good for me and using coping strategies helped me. I now take tablets for my anxiety so it's a bit better.

I am made up with my life now, when I was nine I never thought I would be this happy. I love working. I now earn my own money and have independence and feel less anxious. I'm doing what everyone else is doing, and I have a future. In terms of things that could be better, I'd say, understanding in schools of autism and behaviour and how to support younger people. Information and training. More opportunities for employment services so people can get jobs.



I access public transport and community activities with support from my PA paid for with direct payments. This has helped me to become more independent and has enabled me to go on holidays with my youth club which I love.



[Name] started attending [Named] day centre in October 2015. [Name]'s transition was described as very slow as [name] does not respond well to change. [edited] [Name] 's family have state: "We have been overwhelmed by the support we have received from [named] day centre. The staff there have been amazing with our daughter [name]. Helping us through a difficult time when she refused to leave the house."

They never gave up helping and trying to get [name] to the day centre and after about six months they achieved this. [Name] loves going now. We are so grateful to those amazing staff members.



We have had good experiences of services for our daughter. She was diagnosed at age three and provided with excellent pre-school support including sessions with a worker who advised on play strategies for us to work on, and speech therapy support. Our daughter received a statement prior to starting primary school so a classroom support assistant was identified ready for her to start school.

We were in a pilot group to receive direct payments for short break support. We received good support initially to help set up the system, advertise for and employ a PA, etc. However, this support soon disappeared once the pilot was over and was not available to new families coming through. We were again on a pilot for an individual budget and received good support with setting it up. However, we were one of very few families to successfully complete the process. Again the support soon disappeared once the pilot was complete and does not seem to be available to families coming through.

We are now waiting for our daughter's statement to be converted to an EHC plan. I do not feel that we have been involved in this at all. We have not heard anything about what is happening and when it will be completed. Our daughter should be in transition to

adult services soon. I do not feel we have received much information about what will be available to her post-18.



I contacted adult social care in 2013 to ascertain what help and support I could get. I was told I didn't qualify for services as I didn't meet the criteria. I suffered a breakdown as a result. After the Care Act came in I was advised to re-contact adult social care, I really didn't want to be in the same position of being told I don't meet the criteria! However, after being constantly pushed by my parents I re-contacted adult social care. I now get support to help me live independently as I now realised I lived on my own but was never independent. The support I get are to assist with cleaning my flat, paying my bills, etc.



The formation of [autism] support group operates in my town. It runs every month and is facilitated by a senior manager from [autism support group] and a specialist mental health practitioner. It is a place where people with autism and family members and carers can meet and share experiences and struggles. Before I started attending the group I felt I was the only person who felt the way I did and also felt very isolated and accessing information was difficult. I have learned so much about autism from listening to guest speakers and talking to other family members and made some valuable friends.



I have engaged with our autism forum since 2013 as a self-advocate and regularly use the local NHS adult autism service and other services. Overall supportive and driven service providers engage well but wider change is so very difficult and exactly what needs to change is not yet understood.

My experience of services generally is that the message articulated to those on the spectrum is that: "You will be supported and protected." However, when those on the spectrum look to engage services they find them very limited.

Council services are becoming increasingly pressured. The threshold for accessing support goes up, reducing the number of people eligible. Duty of care is ignored because the resources required to implement care are simply not available. The thresholds for access to services appears so high now that people who are severely mentally ill may not be treated.

My local area has one of the NHS's best adult autism groups - one that provides both post-diagnostic services and signposting to other services. Their ability to connect people on the spectrum to other services and having embedded social workers and other third-party providers is extremely valuable. The service has linked me to other

people with the same diagnosis, which has been beneficial, but the service is limited when it comes to the management of extreme distress, or treatment of cumulative trauma. I am not convinced that true management of lived experience is offered by any of the official services.

One of the greatest needs of the autistic community is for increased awareness amongst the public and employers that “meltdowns” are involuntary emotional de-regulation and not tantrums. While I believe that supporting the most critical cases is the priority, I do not believe that there is sufficient awareness that relatively simple preventative measures will reduce the number of cases that become critical. The significance and usefulness of preventative approaches is greatly under-estimated.



My son is 33, diagnosed with Asperger’s and dyslexia at age 16 also diagnosed with chronic anxiety depression and PTSD, following a bad experience with a mental health clinician, subject of a complaint upheld by the ombudsman. He is highly intelligent, an IQ of 130+ and had enjoyed a 14-year career in the [employer]. They were mainly supportive acknowledging both his disability and value by agreeing many reasonable adjustments to working conditions.

Six years ago he was promoted to executive grade, had a mortgage and things looked bright. But sadly he had a mental breakdown not recognised by his managers and causing a downwards spiral. He lost his house, voluntarily downgraded [edited] and hours to keep his job and finally after 300 days off sick at nil pay was given ill health retirement. So he had to move back to live with ageing parents and subsist and be dependent on a small occupational pension, his only guaranteed income. Throughout this time he was a CMHT patient but was discharged in 2016 as they felt unable to provide him with the therapy he needs. He has suffered frequent serious autistic meltdowns including several attempts to end his life and we had to ask the Crisis Response and Home Treatment Team for help.

This organisation is misnamed - it only responds to crises out of hours abrogating daytime responsibility to CMHT (who discharged him) will only respond on the phone and won’t visit home. A request for home treatment was rarely accepted but only for day visits of one hour or so for three/four days max. Despite statutory requirements of the Autism Act clinicians are still untrained or receive minimal online awareness training. Frontline staff should be specialist trained - I’ve yet to meet any who admit receiving this. At night there are only ever two people on duty to cover the whole county and only one of these is a qualified clinician, not specialist autism trained. At best the service available is inadequate, particularly for the 128 hours a week “out of hours”, at worst it is dangerous.



[Name] is my 23-year-old daughter diagnosed with ASD at age 11. [Name] also has moderate learning difficulties and epilepsy. Special education was excellent; adult social care does not meet her needs. [Name] has been passed from LD to CMHT back to LD in one authority and adult social care in another. Five years after requesting housing and direct support the rollercoaster of emotions that we have been through is difficult to put into words. Broken promise after broken promise from one social worker after another. [Name] is still living at home with broken promises of adequate housing being delivered on numerous occasions; eight different social workers; failure of direct payments either due to money being provided but no services available to purchase (paying back over £8000 in two years) or services being available and no direct payments being made (six months later and still no money and therefore insufficient service provision.

Similar experiences within two different authorities. Complaints to local authorities and our local MP have resulted in no change to her life; no home, no job, limited social life and increased mental health issues. We are a very disillusioned mother and daughter with increasingly deteriorating health.



I have been diagnosed with autism and have other problems. I have not had a helpful response when I have asked for an assessment to see if I can get other support with my autism. There was a response saying they “did not do autism”. There is a lot to do in [city] and I hope this self-assessment moves things forward.



My social worker has been instrumental in getting me CBT and counselling which have made a huge difference to my life. The CBT got me to think about how I can break my emotional cycles because they were getting too much for me to handle. Also, the CBT and helped with my assessment of how people interact with me and how to interpret them. Counselling has changed my life completely as it has helped me with my confidence and it has helped me deal with a lot of long-term issues that I have been facing both at work and at home.

Aside from counselling, my social worker has provided a very sympathetic ear to my problems with people I know who had been sending me threatening text and voice mails. She has helped maintain the peace and she has provided a lot of support to me through mediation and advice.

In addition to this she has also provided recommendations to our local specialist employment support to help me look for another job. My social worker was also very instrumental in getting me to be a member of local autism group which has made a huge difference in my social life and it has helped me become a more rounded person. It has also meant that I have now got a larger circle of friends. Without them none of this

would have been possible and I owe a massive debt of gratitude. I can't thank her enough.



My son has Asperger's Syndrome and has come close a nervous collapse, caused by anxiety and the child/adult transitions. During his first relapse he should have been seen by CAMHS, but was bumped to AMHS. After parental intervention he was seen by a Psychiatrist who deferred to IAPT. (The local AMHS does not help autistic people according to AMHS and IAPT staff). IAPT was not suitable for my son, but MIND were simply brilliant. While my son was under the care of IAPT they were obstructive and disingenuous. They always hid behind patient confidentiality and data protection. They were not interested in talking to carers; I was left with the lasting impression that as a primary carer I knew nothing. My son doesn't use telephones, but IAPT always wanted to do everything by telephone. Appointments were always on IAPT's terms and the environment is jail-door friendly. [edited]

MIND were warm and caring. MIND adjusted their appts to suit my son and listened to me. MIND's therapeutic approach worked whereas IAPT's rigid CBT and cavalier attitude was a failure. Contrasting by phrase I would use "Not fit for purpose" for IAPT, and "simply extraordinary" for MIND.

There is a teacher at his school who is very supportive, and she commented on the change she has observed in him. She said that "although she couldn't put her finger on it, something has changed for the positive". I hope this (accessing MIND) will become available to people with ASD ASAP.



We are writing to thank [organisation] for the support they have given to [name] and ourselves. [Name] was becoming isolated and increasingly anxious and we didn't know where to turn for help. We discussed his issues around socialising, meeting people his own age, independent travel and anxiety at a meeting for carers of adults with autism. MAIN was present and offered help, explaining we could self-refer if [name] had a diagnosis of autism. We were also advised to contact social care direct about the anxiety. When we did we were told to contact the GP.

The GP admitted she knew little about autism but was very supportive referring [name] to the Mental Health Team, where he was assessed and referred to [organisation]. He continues to be helped by the GP for anxiety. We are very impressed with [organisation] and grateful for their support. [organisation] enjoys the social activities organised by [organisation], which enabled him to meet new friends and take part in various activities. He has been supported to achieve his ambition of taking the bus independently to meet a friend. He now has the confidence to do this and has completed two solo journeys, which has made the world of difference to him. We look forward to attending workshops

in the future, to help us better understand autism and deal with the issues it raises. One of our main concerns is that of caring for an older adult with autism as we ourselves age and we hope this support might help us to cope with this situation.

Having not known where to look for help we are now progressing and through the carers group run by [organisation] and the [named] carers, we have been able to address some key issues eg access to services, employment and the care of older adults with autism. We hope to work with you in the future to address these issues. Finding an organisation to help and support [name] has been life-changing. Without [organisation] we would be dealing with everything on our own. We are grateful for all the help and support.



I used to have a job but due to high levels of anxiety I haven't worked for over five years. After contacting autism [organisation] I have begun a volunteering programme with them to try and help me get used to going to different places and seeing different people. I still find this really difficult and I haven't always been able to make it but I hope to complete the programme so that I can get my confidence back.

Accommodation

Getting somewhere to live can be very hard. If you go through the online application process you need to work very quickly. A lot of people with autism who don't know how it works will struggle and if you can't respond quickly you will miss your chance.



Hello, my story is that being autistic can be really difficult especially my time in supported housing was quite difficult as the support workers didn't often turn up or were late and didn't really seem to understand me. This led to me having high anxiety most of the time, when I challenged them they told me I didn't appear like I needed help all the time.

My experiences with the jobcentre have been nothing but a nightmare the way they have spoken to me and have tried to make me apply for jobs with lots of travelling because apparently we are meant to travel at least 90 mins each way to look for work, so the idea of doing this is really overwhelming. The fact also I've not seen a DEA since [my first] appointment I feel lack of support when attending jobcentre.

Also with regards to the situation I had with the police when I had a hate crime happen to me last year, they didn't seem to want to take it seriously, it wasn't until I had help from the hate crime service that I felt supported, I feel this shouldn't of had to happen and I dread it to happen to somebody else on the spectrum.



Our son moved into supported living in December 2015 from our family home. He has high-functioning autism and when he moved into his home he was receiving around 13 hours of support per week. We his family have had good contact with his support provider and in particular his individual support worker and we have been told that that he is doing so well that he will soon be ready to move to more independent living with little or no support. He has also told us how settled and happy he is.

This is where he will encounter a problem. He will fall foul of changes in the new housing benefit rules. If he takes up a tenancy now in the private sector he would be only entitled to the shared room rate of around £59 a week. If he secures a flat in the social sector he will be okay for the time being, but from April 2018 he will be in the same position. The reason for this is he is under 35 and he is not in receipt of DLA (mid/high rate care component) or PIP (daily living). Sharing has not worked out for him, and it is now evident that he will always need to live on his own and we are unsure and worried that this will not happen.



I am so happy to be given the opportunity to live as independently as I can but with support when I need it. I do love my flat and the support from my key worker as it has helped me to do voluntary work. I now go to the gym three times a week. I have support with my shopping/ budgeting to help me buy better food. I don't buy so many takeaways now. I know that I will be able to live more independently in the future when I move from here.



There is NO offer locally for Asperger-friendly housing eg, flats/sheltered housing where adults with Asperger's can live independently but with appropriate support, for example with a warden on site, or with an outside agency coming in on, say, a weekly basis, to help with practical matters relating to paying bills, making appointments with authorities, accessing the community for outside hobbies, etc.

My son, who has a diagnosis of high functioning autism, is struggling to find work. He has been trying now for over a year, and has had many interviews, but no luck with a job offer. A [Name] County Council appointed company called [employment support organisation] are working with him to give advice on job hunting, CV writing, and also to go to interviews with him if he asks for it. All to no avail so far. I think people with autism need tailored employment, set up by the government, to help them feel like valued members of the community. They have a lot to give, but need special provisions in order to access the job market.

My son has recently lost his dad, who was a terrific carer for him for many years. Now he has two close family members left, his mother and his elder brother. What will happen when they are no longer here to care for him? He is unable to think ahead, organise himself, work out what's needed and who to contact. He has NO social worker to contact, and no other emergency help to access as far as I am aware. It makes me wonder if [Name] County Council are quite prepared for the worst to happen before they will step in and help. If my son is left on his own to cope, he might quite soon end up on the streets, and from there it's a short step to a worsening situation.



I am experiencing trouble with my neighbours in my council flat - they make lots of noise and I am very sensitive to noise, I have raised this with the housing team and they sent the noise patrol, but they don't understand that my autism makes me more sensitive to noise than other people.



I have lived in a shared house for four years. I am now bidding for a flat of my own so that I can live more independently. My support worker comes every day, she has helped me with my budgeting and bills and also helped me to apply for PIP. We recently had a

BBQ in the garden. All my friends and family came. I think I will miss the company as I live with (another tenant) but he does not want to move yet.



I live in a very big house, in my own one-bedroom flat. I feel very safe here. My support worker comes to see me two times a week. Support staff come here every day to see all of us. I have OCD. My support worker helps me to throw away things that I don't really need and helps me with my cleaning and laundry. My support worker comes to appointments with me and has also helped me to apply for benefits. This took a long time and I had to appeal. Now I have more income. We have a large garden with foxes who live in the bushes at the bottom. I have tried to live in a block of flats but I became very nervous of my neighbours and would not go out. I was offered a chance to move here and now I feel safe.



I was no longer able to stay in the child foster placement and my advocate helped me understand the options open to me about where I was going to live. Many things were being presented to me at that time and I was finding it difficult to understand the options. The range included my own flat, shared lives, supported living or residential care. The advocate explained to me the different types of settings and what each placement could offer. My advocate explained that they would help me understand the options and enable me to have my say and my voice heard. On a couple of occasions I met with my advocate and social worker at the same time. This was good because the social worker would have some new places that I could think about and look at.

After a few meetings I was thinking I would like to live independently however, I had been living in foster care and I didn't know how I would manage. The social worker suggested Shared Lives, with the support of the advocate it became clear to me that this might be a good option. It looked similar to foster care but the family would help me prepare to become more independent. The social worker explained that they would start the assessment process for me to move to shared lives. After several meetings, discussions and consultations a family within the Shared Lives scheme were identified as possible placement. I met with the family and I had several visits to their home including dinner and tea visits. It soon became clear that I would like to live with this particular family and that they were ok to have me within their home. With the support of the advocate I was able to ask the social worker to proceed with the plans for me to move.



In 2015 I asked the council for help with managing my garden as I am a widow and live on my own. A tenancy support worker called in to see me without informing me when she was coming she just arrived on my doorstep. She continued to visit me sometimes coming near the time she said and at other times not. She seemed intent on finding

things for me to do such as visiting places locally but not offering to go with me to show me how to get there or finding voluntary work in a charity shop.

I found her arrival without warning, lack of punctuality, lack of understanding of fear of new places and an inability to go by myself and difficulties with maths and many people overwhelming and though I tried to explain my autism and these problems to her she did not understand and accept them but repeated her inappropriate suggestions at each visit. I asked her not to continue visiting as all I was hoping for was help with my garden but she continued to call and leave cards through the door when I avoided her visit by being out. This led to me getting a letter from her alleging that I had vacated the property because I had not contacted her or been in when she called.

I find speaking to strangers on the phone difficult and there is only a generic phone line to the Housing Department and so it is very expensive to ring on a mobile as you are passed from people to people – none of whom I knew and when I sent texts they were not responded to. This year she called with a colleague who was a support worker who promised to sort out my garden issue but I have heard nothing back from her despite texting her.

Since being diagnosed as an adult I have never got any help or support from the council only from charities and their staff and services but these have often only been short-term in response to a particular need. I have never had an assessment of my ability to live day-to-day and support needs to live an independent life as a full and equal member of society.

Employment

I have tried for over 15 years to get a job but no one thought I could do it. Somebody believed in me and I work three hours a week. It has given me confidence and made me feel good about myself.



Without employment support for my son I would have gone under long ago. His job coach found him his first job after college, supported him at work, supported him between jobs, with the job centre, with getting linked in with a psychologist, and with the next interview. They still support him at work whenever he needs it. There have been issues and difficulties all the way through, but he is still in work seven years later.



The staff at the Job Centre understood what I needed and helped set me volunteering objectives that I could achieve.



My adopted son [name], has moderate learning difficulties and had help in school and college up to the age of 18. After this, job searching and failed interviews caused him severe frustration. He got Xmas work with Royal Mail in 2008, and three 12-week casual contracts through 2009. By the end of this, his behaviour was getting worse and he was withdrawing into himself.

In November 2009, following further assessment he was diagnosed with Asperger's. The whole family felt such relief at knowing this. [Name] got help to manage his temper and social interaction, began to attend a group for social and employment support, and got help from the Job Centre.

With support from [Employment support] at the interview, he was offered hospital domestic work starting in January 2011. This didn't go well, and the job coach often had to step in and see his supervisor. Being a zero hours contract he was offered less work until this ended in May 2011.

[Name] got work experience with Tesco as a shelf stacker in November 2011 and Christmas casual work with Royal Mail. In 2012 [name] met the Social Care Team, attended an employability workshop and got full support to search and apply for work. This led to a job at [retailer]. This was not without incident, his job coach called in about monthly. I was always able to call her should the need arise.

It has been nailbiting at times and on several occasions we feared he would lose his job. When difficulties arose, the job coach was exceptional. They agreed with the store

manager and [name] that, if he gets worked up or stressed, supervisors will let him take time off the till. This gives him time to calm down and gather his thoughts. [Name] has been reassessed by the Adult Social Care team and is now preparing for independent living.

He is doing voluntary work at the local football stadium, which he applied for on his own initiative. The club is very supportive. [Employment support] has been life changing for [name] and us, his parents



After I left college I started volunteering at the [tourist attraction]. I was put on the gardening team, and I'm not very good at gardening. I was the [tourist attraction] for three months, and didn't leave on very good terms. One of the managers told me I needed anger management. After volunteering at the [tourist attraction]. I was a young Games Maker at the London 2012 Olympics where I was one of [number] people with disabilities working the Aquatics Centre.

[Organisation] took me on as a volunteer, and I started supporting people to access their local community and to build up people's confidence and self esteem. I started helping out with [Organisation]'s groups. I supported people at a sports group, an arts and crafts group and the [named] supported swimming session. I also worked in the office, as an admin assistant. I did this job for three years. I ran some groups on my own and ran a supported swimming session which had up to 25 people. I also used to help with people with their money handling skills, and putting stuff in the locker.

I enjoyed that job, it brought out my empathetic side. The people I supported knew I had a disability and I felt that they trusted me with their emotions. I felt they opened up to me and told me how they were feeling. I enjoyed having responsibility and it gave me purpose in life. Before I had the job I used to lie in bed until 4:00 in the afternoon and go to bed at about 5:00 in the morning. I also used to watch TV all the time and was an isolated person. I also used to be quite lazy, and was called the Homer Simpson of the family. Now they call me Mr Awesome.

I feel like volunteering helped me to turn my life around. I don't get paid for my work, but do get paid expenses of around £50 a month. My volunteering helps me feel more valued in the community, which leads to lots of good things in my life



The employment service builds up a relationship with work places prior to supporting people to work there. [Name] said he really likes the support worker "he's really great I can talk to him when I want, he's there to help. He helped me learn the work and make friends with the people there. The manager is really good and knows me now. The staff know how to help me do the jobs." The goals that the service were trying to help me

with were applying for what benefits I could and moving out from living with family into a place of my own, both of which I would feel a lot more comfortable doing with support. It has been a great help so far and I would love to continue receiving that help. I would love to access the service's help with communication skills and a career plan at some point. Talking to you was such a relief; it's like a lifeline speaking to someone who really understands Asperger's!

I was diagnosed with autism spectrum disorder in December 2015. Previous to my diagnosis I had been off work for three months with social communication disorder, social anxiety and, as a result, depression. It was a tough time but slowly things were turning around. I had found a new job, much more suited to me than the bank I had worked for, for nine years. It was immediately clear to me, that I was not suited to working in a bank at all. It was an environment filled with just the types of social interaction that I struggle with; it was a pressurised, fast paced and treacherous environment.

I became a union representative and that became my saving grace. I found every single meeting I attended as a rep a challenge but I also enjoyed them and, when it became clear that I was an effective rep I found pride in my abilities that I hadn't felt for a long time.

However, I started to feel lost and confused, as though my freedom had been taken from me and, once again, I started to struggle. I fell behind with my targets at work and the more I was required to sell, the less I wanted to. Eventually, I was given an ultimatum by a boss who completely misunderstood me. I think my boss thought I was difficult by design. I wasn't, I was simply being asked to do things that I found extremely difficult. My boss told me unequivocally, that I should consider my options; I felt that that meant I should leave, though I had no job to go to.

The meeting ended there, I left for the day and told my wife. She was devastated but then I mentioned something that my manager had suddenly mooted – what if I were to consider part-time instead, less hours, more time for myself, and significantly, lower targets. I took on the offer. For the rest of my time there, I remained part-time and it had huge benefits but it also had its less beneficial points, less money for a start. As ever my wife was there to support me – to hold me up.



My son left college in 2014 having progressed as far as was possible considering his learning difficulties and diagnosis of Autistic Spectrum Disorder. As his mother I was keen that he should not withdraw from society, which would have been damaging to his mental health. I wanted him to be involved in as many activities as possible. However it was not always easy to place him appropriately, especially as the fact that I care for him fulltime negated any budget that he might have received from social services. It was a

great relief to me when he was given access to the [supported employment service] I felt that some of the responsibility was being shared.

My son has always wanted to be a “working man” who “works for a living”. Despite supporting his ambitions I was doubtful that they were achievable given the statistics for autistic people in paid work and was happy for him to be involved in volunteering projects to give him a sense of worth and increase his self-esteem.

During our initial meeting my son told his connector about his ambitions and that he enjoyed working in gardening and being outside. I was amazed when half an hour after our meeting had ended the connector called to tell me she had been into a local retail store approached the manager and secured a meeting for myself and my son with a view to a supported work experience placement. After ten weeks of working, first one day then two and with the connector gradually withdrawing support, we were absolutely thrilled when he was offered paid work of twelve hours a week.

The outcome is above and beyond what we could have hoped before we started working with the [supported employment service]. My son gets so much more than monetary value from his job. He feels valued, useful and part of a team. To see him preparing for work proudly pinning his name badge onto his uniform is a joy to behold. It is also extremely reassuring to know that, should any problems arise, the [supported employment service] are on hand to help.



Even when subtle, ASD may profoundly affect a person’s financial, relationship and employment prospects. This statement from commissioning guidance rings true to me, as does the statement that autistic people have 70% risk of a mental health needs. I’ve struggled with depression most of my life. Only recently for a few months did I manage a relationship and a paid job simultaneously. I have an IQ well in excess of 150, but despite 15 years of contact with mh services, autism was never raised.

Autism groups have proved a comfortable place to ‘be myself’. I attend a monthly peer support group at the NHS autism clinic. I hope meeting other autistic people will help us understand any common characteristics. This is the only support for autistic adults in my area, despite statistics suggesting need is higher than elsewhere. Although diagnosed autistic, I have not yet had an opportunity to discuss my exact differences from typical people, or how they affect me. I've been compensating for so long, I've forgotten what I'm compensating for. Help with social skills in late adolescence might have prevented loneliness, suicidal behaviour and dropping out.

I can plan, but find it hard to execute a plan without getting distracted, or to set my own goals in the first place. Sometimes it is hard for me to know what other people find contentious or hard to understand – so sometimes I omit information others would find

significant, or provide so much context, pattern or theory that it distracts the listener. It would be helpful if services were prepared to fully engage with written communications and other media.

Earlier recognition and assessment, plus knowledge about personality and psychological diversity, might have obviated years of ineffective treatment and led me to appropriate help. Instead I was steered towards psychoanalytic or psychodynamic therapy, which was consistently unhelpful. I believe this is a common story, especially among the autistic women I know.



I joined [employment support organisation] last year hoping to find a paid job at the end of the internship. When I started my work placement at the [Named] Hotel, there were a few hiccups and I was finding it difficult to settle into doing things differently. I worked in three different departments and was given lots of support, training and encouragement by the job coaches and the college. I managed to learn the different jobs in all the departments that I worked in.

Soon everyone started to notice a positive change, even my family! I was told that I had learnt loads and had grown into a responsible and skilled member of the team. As I was about to finish my internship, they helped me to apply for jobs and my job coach supported me in the interview. I got the job at the [Named hotel] in [City], working as a food and beverage assistant. I really love my new job and now I want to get my own place to live.



Several times at my local Job Centre a DEA (Disability Employment Adviser) told me that I should not mention my disability in my CV. I said I felt that it was important to leave this in as I didn't want to work with a company that would reject my CV on these grounds. Their view was that this would hamper my job prospects, saying that they knew of one autistic client of theirs who had been rejected by an employer as they didn't have wheelchair ramps (despite the client not being in a wheelchair). This was given as a cautionary tale with no mention of them correcting this discrimination. Later, I asked the National Careers Service (NCS) to review my CV, we worked on a new draft together but it was only later that I saw that the NCS had removed all mention of my disability against my wishes.

When I got in trouble for thinking that having JSA (Job Seekers' Allowance) meant that I didn't have to pay dental bills the DEA said that I had signed to say that I understood my benefits. They did not accept that these were hard to understand or that they had a duty to explain them properly. Despite my MSc I still struggled, so later, when I had to fill in a form to reapply for JSA I asked for the help. I explained that I felt that my disability made the form hard to understand and another member of staff told me about Welfare Rights

who were able to help me. Last time I met them they didn't agree that they should have told me about welfare rights, I would often leave their office with the impression that I'd wasted their time. They have said that they don't think that they can help me and having worked with them before and after autism training I noticed no change in their attitude - in fact the cautionary tale was delivered after the training. I seriously considered making an official complaint. I have found other members of staff at the Jobcentre to be helpful and accepting of my personal choices and feel that the DEA is not very understanding of the needs of disabled people.



I have had support from Access to Work (ATW) for over 10 years now. It used to be relatively straightforward to obtain. You were allocated a dedicated person who knew your case and was able to deal with any queries effectively and efficiently. Now there is a call centre, so each time you have to re-explain the issues. For those with autism this is a significant issue.

In addition, because of concerns about fraud, the criteria have been tightened to such an extent that legitimate claims are not getting through. It does not help that the advisers have no idea about the challenges of running your own business. My business has almost been a casualty twice. It is only a sheer refusal to give in by both me and support worker that has kept us going.

The first major battle concerned eligibility. Because I was not drawing a salary, I wanted to stay on ESA. It took months to find out about and then obtain permission to be on "supported permitted work". Only when I mentioned it to the advisor, did Access To Work provide a fact sheet on it. Why is this being kept a secret? In order to get onto "supported permitted work", we had to cut and paste part of the government website to convince the ESA adviser that it existed!

The second battle was the requirement to show business viability. The request was for a business plan and a three year financial forecast of sufficient quality to get funding from a bank. Leaving aside banks not funding early stage ventures and that ATW staff's ability to tell good documentation from bad, this requires two weeks of full time work to produce. It is hard enough running a business when you are autistic without those who are supposed to be helping you putting more hurdles in the way. Eventually someone from DWP was tasked with sorting this out and further ATW Funding was granted. ATW have told me that they have now made this easier as a result of my and others' complaints. I am very relieved that I do not have to reapply until this time next year.



I lost my job at a university in 2014 because of my autism. I was awarded an ill-health retirement pension because the occupational health doctor believed that I was unfit for work. I applied to ESA and was put in the support group without a medical. I believe that

these decisions were correct because there is no way that I would cope any more with mainstream employment. However, I also know that if I don't work, the social isolation I share with many autistic people would lead to a severe deterioration in mental health to the point of being suicidal.

The solution was to make my own employment. Almost two years later my company is still going, despite rather than because of the actions of adult social care. The statutory guidelines state that aspirations and planning for the future should be considered when assessing financial contributions for adult social care. It is my experience that Adult social care completely ignores this part of the guidelines.

The change in circumstances led to a financial assessment. It took six months for the outcome of this to be communicated to me. The assessed contribution is unaffordable and takes away control of my own finances – one of the few things I do understand. With the help of the ombudsman this might now be at a more reasonable level, but I do not know because I have had no communication from the council for months.

I asked for a social worker who knows something about autism back in February 2016. I am still waiting! My case is particularly complex because I have very complex needs. I am extremely intelligent and generally come across as high functioning. But in some areas I am actually very low functioning. Not even a specialist autism service is able to cater for my needs. I have been in limbo for months with very little support. This is impacting on my ability to grow a business effectively and impacting on the quality of my work. My experience is that [area] is going backwards in adult social care provision for autism.



I am 28 years old and was diagnosed with autistic spectrum condition back in 2005, at the age of 17. Receiving a late diagnosis meant that I had missed out on any additional support that I might have otherwise been entitled to throughout high school. I ended up leaving school prematurely, at the age of 15, with no formal qualifications. Depression, anxiety and social isolation ensued, and with little support available, opportunities were next to scarce. Fortunately, a family member supported me to put in a claim for Disability Living Allowance and Employment and Support Allowance.

Luckily, I did go on to find employment eventually, courtesy of the support received from my personal tutor at [Town] College. She had previously worked for [organisation], an organisation she introduced me to by taking me along as a guest to its annual general meeting in December 2007. I ended up completing two weeks' work experience with [organisation], and then went on to participate in a young people's residential which focused on rights and leadership in March 2008.

In the September of that year they offered me a paid position of 21 hours per week, and I remained in this post until the summer of 2010, when I decided to return to college on

a full time basis in order to work towards my Level 3 OCR Diploma in Business Administration, which I went on to successfully attain. I remain in contact with [organisation], and I have continued to do some work with them on a range of projects in recent years.

In the spring of 2014, I assumed a position as an administrative support assistant with a local council. In this post I was based on the reception at one of the council's day opportunities services for people with profound and multiple learning disabilities. This was a 12-month contract of 16 hours per week, but unfortunately I received inadequate support and I ended up leaving prematurely due to renewed symptoms of anxiety, and was forced to put in a new claim for Employment and Support Allowance.

In September 2015, I received a telephone call from an adviser at my local Job Centre, inviting me to attend a work focussed interview. I was in receipt of Employment and Support Allowance at the time. I was so keen to get back into employment that I welcomed this opportunity. At the appointment, they explained the options that were available to me, and I ended up agreeing to participate in an eight-week work experience placement, as part of the government's Welfare to Work scheme. I really enjoyed the placement, as it enabled me to meet some very inspirational people. I received lots of praise from my colleagues for supporting a team of fellow volunteers to oversee the completion of a very important filing task, something which I assumed sole responsibility for.

The supervisor invited me to share my work experience story at a regional DWP management event in Birmingham. This appealed to me as a very exciting opportunity, so I agreed to do this. The event went really well and I received a standing ovation for my performance, and a very good reference from my supervisor.

Most recently, I have worked as an independent travel trainer for the local council. In this opportunity I was responsible for providing tailored support to individuals with learning disabilities and special educational needs wanting to gain the skills and confidence required for them to carry out a journey using public transport independently. Unfortunately the hours were irregular and I ended up leaving the position in July this year, after only a few months in employment, due to personal issues. On the plus side, I did achieve a level 2 qualification in teaching independent travel.

I am now under my local Job Centre again, where I am signing on for Jobseeker's Allowance every two weeks, having had my most recent claim for Employment and Support Allowance turned down, having scored zero points at a DWP work capability assessment. Overall the advisers at the Job Centre have been quite supportive and understanding of my needs. However, it seems to me that many DWP employees are not very familiar with hidden disabilities. In fact some of the advisers I have spoken to have admitted that they cannot define autism.

As a person with ASC, I find it particularly challenging to both find and sustain suitable employment and this is not helped by the fact that I can only work part time due to anxiety. Navigating the current welfare system is equally difficult and frustrating. I personally feel that more needs to be done in order to provide ongoing support to jobseekers on the spectrum in terms of helping us to find and maintain meaningful employment that enables us to utilise our skills and attributes.

What good support looks like to me: I personally think that although knowledge of autism is slowly improving over the years, and work place adjustments are being made, there still seems to be a lot of stereotyping when it comes to deciding what support a person on the spectrum actually needs. In my case, I think that autism and problems with anxiety etc. have often been overlooked by employers because of how well I present myself. In the case of the administration job with a local council it was the fact that they employed me at a time when cuts were being made within the council, and they did not have the resources to adequately train me. I coped well at first, but then they put me in a position where I was solely responsible for manning the reception, despite not being familiar with all the procedures. The resultant anxiety is what drove me to quit the position.

In an ideal world I think I'd benefit from more specialised careers advice that can help me to identify suitable employment opportunities that reflect my skills base and the amount of hours that I'm comfortable working, and possibly even being supported to identify self-employment opportunities. I have always limited my work to part time, but this can further restrict the amount of suitable opportunities that are available. When it comes to dealing with the DWP, I'd like them to be more familiar with the range of hidden disabilities, and how they can impact on individuals. It should be about working directly with the individual, and not the box-ticking exercise that it often appears to be. I struck a really good working relationship with the supervisor when I did the work placement at the Job Centre. He saw a lot of potential in me, which was good. But when I explained to him that I have a diagnosis of autism/Asperger's it was obvious that he did not know what this meant. I found this frustrating, because I believe that many of the skills and attributes that he and his colleagues had identified in me are unique to my autism.

I think that more should be done to implement the Autism Act, and this should be extended to include how the Job Centre, and the wider DWP delivers its service, and provides more tailored support to those who need it. It's very frustrating having to go through the rigmarole of having to reapply for unemployment benefits, after a job opportunity does not work out. I think DWP staff should be made to undergo mandatory autism training that is delivered by jobseekers that use the service.

.....

I have received services from the [supported employment service]. I received a recommendation 11 years and immediately telephoned and was provide with a thorough description of the service. Their website is very user friendly and informative. Their information is clear, relevant, appropriate, clearly explained and easy to understand. This I feel is provided in a caring and attentive way. I am happy with the service I received, it has enabled my daughter to access and keep her paid job. It provides ongoing support for both my daughter and her employer. When I contact the service I feel listened to, they are lovely, caring, empathetic people who at the same time are wise, knowledgeable and professional.



OK, first of all I left school in 2006 and gained five GCSEs at A-C level. Then I went on to [Named] College, where I did maths, accounting, physics and further maths. I stayed there for four years. I did AS maths over two years, then I did A2 maths with AS further maths in my third year and further maths A2 in my final (fourth) year. I think I finished college with B in maths, C in further maths, C in physics, E in accounting, D or E in performing arts (I just tried this in my first year because I liked drama at school)

After this I went on to study maths (surprise!) at [name] University, with mixed results. I really enjoyed the experience, but generally, I struggled with the course as most of it was a lot different. I just scraped through my first year with about 45% overall. In my second year I was offered support through DSA. I had a notetaker and digital recorder, but I didn't use them to best advantage. The course was hard and after a while I lost interest, so I failed my second year. The support was good and I should have used it properly, but I wasn't used to the independent nature of it (compared with college).

After coming out of university having failed, I was unemployed for a while – about eight to nine months. After looking for a while and applying for many, I was offered an apprenticeship at [shop]; this was my first paid occupation. It went well for about two to three weeks, because that is how long they wanted me in the office for – where I applied to be. After this, I was kicked out of it and into the warehouse downstairs. I can't describe how much of a stupid idea this was (not that they knew at first), or how bad it was for me in nearly every way you could imagine. Nobody understood my autism, my difficulties, my lack of speed.... so I stood out like a sore thumb basically. I was asked to do picking, unpacking new stock, postage, putting items together etc – all in a timely fashion, in a freezing cold warehouse in winter. I couldn't physically do all these things anywhere near as fast as they expected. They called me into their office after about five weeks of me being in the warehouse, just after a new project manager was recruited – who presumably saw me dawdling about with a miserable face. They failed to put me back in the position I applied for, or explain why they took me out in the first place, but first asked if there was any way they could help me downstairs.

“Maybe you could let me play music on my iPod?” That didn’t go down too well either, and I was then sacked.

In May 2014, I found [organisation] – and I’m so glad I did. It is one of, if not the most unique place I’ve come across. The principal officers are pretty much putting their whole lives into this organisation, trying to get as much funding as they can. I didn’t realise this, or understand what [organisation] was really all about, until a while afterwards, but have certainly learned a lot. Anyway, I was volunteering at [organisation] at first until they had enough funding to start paying me.

...Or until I started my second apprenticeship, which came first in July 2014. This seemed okay at first – it was at [company name] in [town]. The owners had come from [location] and seemed friendly and patient. They were willing to give me a chance, after they learned in my interview that I had autism/mild learning disability. So for the first three weeks or so, things seemed fine. Into my second month, the owners seemed a bit less patient and expected me to start learning things faster. They asked me to do more work upstairs in their store room and archive room – which was a horrible, hot, very messy, dark room in their loft with a low ceiling and beams running across it. It should have been illegal to have that as a working room – I would even call it dangerous. There was also a very awkward day – in the office – where I could not concentrate at all on my work, because two female staff members were having a long conversation about pregnancy, which I couldn’t exactly join in with. So after about 90 mins of this, I finally said in a very awkward and abrupt way: “I can’t concentrate because you’re talking all time :-S I’ve got no work done!” I’m sure you can guess what happened next.

Luckily, I had [organisation] to fall back on, and it didn’t take long before I started going there again. In October 2014, they started paying me – and I landed on my THIRD apprenticeship. Bear in mind, by this point I was nearly 25 and still had never had a fully paid job. But it was still money – and more money than Job Seekers’ Allowance. Anyway from this point, things went a lot more smoothly. I’ve done so many different things at [organisation] that I can’t remember many of them. Ultimately, everything I do at [organisation] can be done at my pace. I did finally start getting paid the full living wage in October 2015, and in January 2016 I bought my first car and now drive to work! (Or anywhere I want in my time!) Thanks very much for reading this, I know it’s a bit lengthy. Kindest regards.



I have been attending day services for over 10 years and I have always wanted to have a job, in the day services is a chance to get some experience of being in work, it teaches you how to get to work on time, how to deal with customers, how to cook and service people. We have people from the general public who come into the place where I work and I think that this has helped me a lot. With the experience that I got from this placement, I gained a certificate in food hygiene, and a certificate and diploma in

catering and customer services. With help from staff I now have a job in catering. I am really happy with my new job.



I have autism and Asperger's and when I first came to [organisation], I struggled to communicate my feelings, particularly when I felt anxious. I couldn't relate my experiences in a relevant way, which hindered my job searching, but I really wanted to find a job. Regular contact with my employment adviser enabled me to build up a trusting relationship. Once I understood that they were trying to support me in dealing with situations I found difficult, I started to progress and by seeing how my actions led to bad things sometimes happening, I was able to make better choices. My adviser helped me to write a new CV and I was helped with job applications and practice interviews. Soon I began to see what I could do rather than fear where I might go wrong. I really wanted to do retail work, so a work trial at [retailer] was arranged by my employment adviser, this meant that I did not have to have an interview, which I find very stressful. For the first few weeks I was accompanied by my employment adviser. Having this support in place made me less anxious. As I had decided to be open about my autism, my colleagues made some allowances for me. I had regular visits from my adviser and when a vacancy came up, my boss was so pleased with my work that she offered me a paid job for 16 hours a week, which later went up to 22. I was delighted as I loved working there and had also made some nice friends. I was given some help from [organisation] to apply for tax credits and this gave me more money to spend, which was brilliant. Because I was doing so well at work my employment adviser stopped coming out to see me so often, but I know that I can call her at any time. I am happy at work and am feeling much more confident and happy than I used to.



Employers are reluctant to take people with autism on. If they understood a bit more I think it would be better. I am also partially sighted. If employers see that someone is partially sighted they can help, but autism affects different people at different times in different ways and they struggle with that. I am loyal, understanding and people with autism can see beyond themselves because we've had to learn how people respond to us. I have great difficulty going out to places like bars and pubs without someone to support me. By volunteering at [autism organisation] I have helped run events and met members of the public and helped them understand autism. I do not get any social care support from social services – I was referred to social services but when they saw me they said I didn't need support or help because I live with my parents, but I can't even cook for myself. I need travel support to get to job interviews – I've been promised travel support from a number of organisations that work with disabled people but have been let down. It's only when I came to {Organisation} and asked if they wanted volunteers that I found something that worked for me and helped me and it's given me a lot of confidence.



Our son [name] was diagnosed with autism at four years of age, following which we have constantly tried to ensure he had the support to reach his potential. The transition from children to adult services proved to be particularly difficult as we researched to find support that would enable [name] to become a productive member of society. Initially we were offered support that provided a safe but not stimulating environment.

'[employment support]' offered the opportunity to help [name] develop. The ethos of providing appropriate support to allow a young adult to venture into a work environment matched our own goal for [name]. Despite [name]'s often challenging behaviour the one-to-one support he was given developed an individual program for [name] which involved carrying out work tasks [name] then mimicked until he became proficient. [Name] is now able to work alongside the one-to-one and has successfully gained a small number of hours seasonal employment for which he is paid in kind.

[employment support], and the structured one-to-one support, has enabled [name] to exceed our expectations. He has managed to learn and take on increasingly difficult tasks most, recently hedge cutting something we had never imagined [name] safely doing. [Name]'s attention span has increased since commencing [employment support] and he is happier and more content with his life.

Our son will require care for the rest of his life and should outlive us, his parents. It is important to us that he lives a fulfilling and productive life and it is vital that he continues to develop so that when we are no longer here his life will continue to have a purpose. We recommend that you challenge your service providers to help you get what your dependent needs so that they are prepared for when you are no longer around....You will also get a thrill in seeing them succeed in doing things you may have thought was not possible for them.

[Name] has now reached a point where he and his one-to-one need more opportunities for work. It is hoped the local authority will be able to create further employment opportunities for [name], with a bit of joined-up thinking this could/would reduce transport costs currently paid by the council. It is then hoped that more employers will come forward to give more opportunities for adults with autism/learning difficulties.



I enjoy work, it gives me a purpose. I like working with my one-to-one and enjoy being part of a team. I have learned new skills and enjoy learning new things. My one-to-one now trusts me to complete a task, this is a nice feeling. I enjoy being paid in kind but it's even better when it's money. I think that working is good and it is what normal people do. I would like to thank my one-to-one for enabling me to do all this.



Within the work place I have found a significant change. Although I have not shared the Asperger's Syndrome directly with the executive team that I am part of, I was able to share with all of them that I was aware that I can act to hastily and was poor at understanding others feelings. I asked to have regular one-to-ones with each of them and encouraged them to share directly with me where I could have improved. Each of them responded favourably although I have found that generally I have had to arrange the one-to-ones, typically off site over a coffee to give a more relaxed environment for them to feel able to share their thoughts about what I could do differently. This has worked very well and has helped me to get a better understanding of my peers.



I left college two years ago and after going to social groups through autism [organisation] I decided to ask them about finding employment. After meeting with an adviser we set up a structured plan to help me find work through their employment service. After several unsuccessful interviews I managed to secure a job in my local area. Although this job is difficult at times I am always able to access support from autism [organisation] if I need to.



I was diagnosed with autism as a middle-aged man. I was anxious about it, but [organisation] provided practical support and understanding for many parts of my life which had previously been restricted or inhibited by the undiagnosed condition. Individual help and speaking with someone with experience and dedication is priceless, making sense of a complicated problem and learning there is no "standard" autistic person, I gained a new perspective on my life. Advice included suggestions on books and websites, involvement with activities dedicated to the autistic community. The range of help makes a huge difference. My big problem is work. Work colleagues do not know about my autism. I was offered sound advice and help in this area.

There is office politics, of no interest to me but exhausting. Background noise is distracting and painful. Knowing [organisation] go to the workplace, explain my needs in a positive light, provide clear advice on employment issues and suggest positive answers to potential problems makes a large difference. What are referred to as crises, shutdowns or meltdowns are impossible to describe but terrifying to experience. From the outside, it seems someone is just angry or frustrated.

The effects on the inside destroy coherent thought, robbing autistic people of the calm they crave. These problems have been reduced, decreasing in frequency and intensity which is a relief. My quality of life has changed greatly. I have tools to cope with the daily turmoil most people think of as normal due to the staff at [organisation]. Individual counselling has allowed me to understand and control many of the downsides.

I am better prepared to survive modern life, practical ideas on stress management reducing my anxiety. I accept difficult situations more easily, recovering from the worst quicker than before and am less plagued by petty fears. I contribute more at work and feel more confident exploring new opportunities. I have peace of mind knowing help is there and people care.



I left college two years ago and after going to social groups through autism [organisation] I decided to ask them about finding employment. After meeting with an adviser we set up a structured plan to help me find work through their employment service. After several unsuccessful interviews I managed to secure a job in my local area. Although this job is difficult at times I am always able to access support from autism [organisation] if I need to.

Criminal Justice System

The police service was accessed on three occasions because our autistic adult son went missing overnight three times in the last 12 months. On each occasion we reported him formally as a missing person. They treated the matter urgently as a priority since our son is a vulnerable adult and very quickly sent out officers to interview us at our home. Patrols were alerted all over the area with our son's description and photograph, and on each occasion they were able to find him and bring him home, on two occasions within two to three hours of our reporting him missing.

The officers treated us with courtesy and understanding, as they did with our son also, once they had located him. They listened carefully to our concerns and explained clearly how they would attempt to deal with the situation. They showed some knowledge and understanding of autism, perhaps more knowledge than in 2013 when there had been a similar incident, which suggests that they had received some specific training in awareness of autism since 2013. We were very happy with the service offered by the police, who are the agency who have helped us more than any other with problems relating to our son's autism.

I joined the Partnership Board in November 2013 in order to contribute, where possible, to the delivery of the autism strategy but also to offer challenge to the local authority and to support change based on personal negative experiences. I have a real passion about the criminal justice element of the strategy fuelled by experiences we had as a family, connected to my son who has autism.

Initially I was disappointed as there was no progress due mainly to difficulty engaging with key partners. I began to attend the National Autistic Society regional meetings and attended training and a Conference on Criminal Justice and Autism. Hearing about good practice around the country made me feel saddened that so little progress was being made locally but hopeful that things were beginning to improve nationally. My feeling was that behind each piece of best practice was a committed individual, usually with a personal vested interest in improving the lives of people with autism. We have now begun to make considerable progress locally, due mainly I feel to the involvement of a police inspector who has brought his passion to the group and begun to drive forward the criminal justice agenda by raising the profile of autism and beginning the engagement process with other partners. We still have a long way to go but I am beginning to feel more optimistic for the future.

Education

The college now has two calm safe spaces for students with autism which can be used for personal study, calm/breakout space or at break times. Here are some comments from the people who have used the spaces:

“I like this place as somewhere to chill in the morning before college”

“It is quiet and no one bothers me”

“Nice place to be with friends without any hassle”

“Good meeting point before the lesson, I can calm down a bit after travelling on the bus”

“I like quiet, college can be very loud and busy. No one hassles you in the hub”

“I like the fact I can close the door and get left alone”

“I can be quiet and think about stuff”

“I feel calm and safe in this room. I can be myself”



University was tough and there was fear too and it never really left me. The social aspect was a major struggle but the hardest part was the seminar sessions. Smaller groups sitting in badly designed rooms whilst the tutor sat in the middle and asked for our thoughts. I became so preoccupied with my fear of talking out loud in front of people I stopped being able to concentrate on what was being discussed. I fell behind then I stopped attending then I started failing. In my first year I had to resit a number of essays; my tutor's comments were highly negative and disparaging. In my second year the lecturer in charge was much more approachable. He was thoughtful and saw through my various shortcomings and looked instead at what I was saying and he gave me confidence. I didn't stop being frightened at every seminar session but I engaged with the subject.

I was so caught up in the idea of completing the degree I didn't give any thought to what I would do next. I had a vague idea about going into teaching but when I finally found the courage to speak to the careers service at university, I found that I was well behind with the preparatory work. As always I felt like I'd missed something that was abundantly clear to everyone else but just wasn't to me.

I left university and was hugely disappointed with my results. I received a 2:2 and even now I'm embarrassed to say that aloud, although I don't know why. I'm able to look back with the benefit of a diagnosed hindsight and take pride in that result; it was achieved in spite of the condition I then had no idea about. I can't help wondering what might have been had I known and even with hindsight I remain disappointed, what if I'd attended university with the support now offered to diagnosed students? Could I have performed better in presentations, organising my work, getting things handed in on time? It still feels that by the time I was just getting to grips with how academic study works I was at the end of my time there.



My son received a SEND at age six. It supported him well school to college when we were asked by LPW to sign Section 139a, which ceases to have effect from December. My son still needs support in education and when I contacted the LA, I was told to apply for statutory assessment again. I think we were ill-advised to transfer to the 139a as it was not explained that my son would no longer receive educational support to the age of 25 years and that the 139a would cease to have effect at some point in the future.

The statutory guidance published by the departments of health and education says: “xi. The legal test of when... young person requires an EHC plan remains the same as that for a statement under the Education Act 1996..., it is expected that all those who have a statement and who would have continued to have one under the current system, will be transferred to an EHC plan – no-one should lose their statement and not have it replaced ... simply because the system is changing.”

So has the local authority misinformed us or are we still entitled to use the statement that we hold or has this been nullified by the 139a?

The social care assessment and plan we requested from social services was well researched and direct payments were offered.

The local police are very supportive, appropriate and understood my son’s vulnerability. The ‘Safe Places’ such as libraries and police stations, certain shops is helpful and supportive.

Support for young people with autism regarding eg managing finances/ social support/ educational needs is not easy to access: how to contact the appropriate department is not clear from the local authority website and many of the link pages are no longer available. There are few social support activities for young people over 18 years with autism. My son is therefore becoming more socially isolated. The attitude of many people in health care is often defensive and the processes are not always helpful nor transparent.

Health

On one occasion I attended accident and emergency department with breathing difficulties. After being taken into a room and told by the nurse to 'take a seat', I was shouted at because I took a 'seat' on a chair and not on the bed. I was then left for a long time in a room where all I could hear was the noise of a very ill child screaming. I couldn't see any solution within the hospital so I walked out and made my way to the next nearest hospital where I was treated with a nebuliser and steroids.



I'm a man with Asperger's syndrome and severe anxiety was referred to the Crisis Resolution and Home Treatment Team (CRHT) for support overcoming mental health crisis and suicide attempt. The referral process was confusing and contradictory with different information passed to the individual, carer and paramedics on scene. This caused considerable confusion and anxiety.



I have a lot of stress and anxiety when I have to go to see the specialist at the hospital. The waiting room at the hospital is noisy and overcrowded and I always have to wait a long time. They change the doctor without any prior notification and this upsets me and the meeting and appointment times are just not thought out. Also when I need to speak to the council I have to ring the council's customer service centre and sometimes it takes them a long time to answer the phone. My last complaint was not being dealt with very well as my support got changed recently without any understanding of how much distress and stress this causes me. I rang to tell them this but people do not understand that I cannot deal with things when they are changed quickly.



My biggest concern for my autistic son is his complex congenital health conditions. Being autistic he needs me to accompany him to his medical appointments. As a child he was always under the same holistic medical team, but now nearing his thirties, he attends what I call "body part" specialists in mainstream health services. They don't always have an understanding of his ability to process what is said to him in a brief appointment and then put actions into the existing routines of his life. The consequence of not carrying out such actions is very difficult for someone on the spectrum. I project manage his health and work on prevention rather than catch up, but there is no one in the professional community to take over my role. He does not qualify for medical support. Poor health management has a consequence of going to A&E.

He has lived in several supported living placements since leaving his out of county educational placement. Disappointingly, the adult placements haven't been as good and have broken down due to a poor understanding of his needs, and so I pick up the

pieces and project manage his social care support too. Having over all sight of health and care, I can see how important it is that the social care support needs to take some responsibility for his health issues. Poor management can led to flare ups.

I'm not a young parent, and I'm so worried about what will happen to my son when I'm not here. I'm afraid that the professionals will be playing catch up with his health, costing the NHS a lot of money, and without exaggerating, possibly costing my son his life.

We have recently secured a tenancy for a council flat which has had a new kitchen and bathroom but the rest needs a lot of TLC, as the previous tenant left under a cloud. We need to totally kit it out too and do all of this before he moves in otherwise it'll be extremely difficult to do anything around him. It is hoped he will settle and be happier here.



I am a 42-year-old graduate with autism. Following a bout of severe depression I was referred to a mental health charity. Unfortunately their initial contact takes no account of autism and is entirely dealt with by a telephone questionnaire. This process takes approximately three quarters of an hour. I found this extremely distressing as autistic people cannot operate on the phone and most especially for this length of time. I needed to be seen face to face and with an advocate presence to make sure I was both understanding and being understood. I was in such turmoil that I talked total nonsense and as a result the charity called social services and reported me as being a risk to children. I should not ever be put into such a stressful situation without somebody to help me control my anxiety.



Because I am on the 0-25 Special Education Needs and Disability Group, (SEND) I have gained knowledge to be able to work with [children's hospital] consultants regarding transition. We are fortunate to have a consultant in endocrine who has a vision for developing a new model for transition for the YP with complex health conditions, he is working with a consultant from the [main] Hospital, I am hopeful that this will be beneficial for future young people similar to [name]. [Name] is still receiving his care from [children's hospital] although he is 22.



GP appointment for medical review, I went with my son [name] to the appointment but as young man in his early 20s, he saw the doctors on his own. He was upset on the way home saying he heard the three medical staff loudly whispering: "He is autistic." [Name] said to me: "I am autistic NOT deaf." This affected his mood for several days. I [name] had a really positive experience with 14 weeks of intervention from the [Named] Team (community support). I did two interesting volunteering placements which I hoped would help me get some work, but when the support finished (it was only time limited) I did not

feel able to attend without it. I lost my motivation and now stay at home in my bedroom. I know there are support services out there, but I need support and funding to access them.

[Name] had run up an unarranged overdraft (just because the money appeared to be there). As his parent I contacted the bank and explained the difficulties faced. They obviously would not discuss my son's personal details, but were able to remedy the situation, and gave me sound advice, and it has not happened again. Most people are willing to respond positively and help, if time is taken to explain, and they understand the situation. People can be so kind!



I know the hospital is having major works done at the moment, but the current waiting area is totally unsuitable for someone with autism. Can't there be some quiet area set aside? The attitude of the receptionists hardly helps either. They seem oblivious to autism and the consequences of what sensory overload can do. This is despite warning them of the consequences. Autism is hard enough without the people who are the first point of contact not getting it.

However, the consultant and radiologist who attended my son yesterday were exemplary. They simply got autism and its consequences. This is in total contrast to some (one was exceptional) of the A&E reception staff. Is it possible to provide some information (of what they can expect to happen) where a patient is in the queue? As you can imagine this is of great benefit to autistic people and those who care for them. So from my point of view the hospital is making progress, but still more to do.



I am an autistic person who uses my GP surgery and the hospital regularly. It is important for me to be treated in the correct manner. This is why I'm asking for a list to be compiled, of GPs and others, yet to be given basic autism awareness training. This will enable them to be targeted by the council as not complying with the law as it stands: that all healthcare institutions must be given basic autism awareness training by someone who has a diagnosis of autism. This has been the law of England and Wales since March 2015. So far most GPs and the hospital, for shame, have not complied. As the lead body enforcing this legal requirement, the council should name and shame those who have not complied.

General

Everyday activities such as queuing at a check out, waiting for a bus, waiting for your appointment are all filled with unpredictability which causes anxiety for my daughter. On top of this, sensory perceptual differences mean that the closeness of people, noises of children, certain sounds and smells cause discomfort and pain for her. Just about everywhere is a potential nightmare when out and about for my daughter. Her experiences of the world are that it is confusing and frightening most of the time. This may lead to strange looking or unexpected behaviours that most public places and the people in them are not prepared for and do not understand.

Appointments that are allowed at a quiet time and where it is likely to be on time are most helpful. Consistency of staff is also a great help. Outings are planned carefully at quiet times with all details given to my daughter beforehand to enable the best chance of success for her. Many professionals and services do not understand the need for this detailed information that is needed to pass on to my daughter in a format that she will understand. The world of services is not good at keeping to times and often you find that the person you were to see has been replaced and you are seeing someone different. This can especially be the case with GP surgeries but also in other services and education. These kind of inconsistencies are a barrier to my daughter accessing the services she may need.



I run [named], a local charity in [town]. We support people with autism by offering employability skills, we provide a safe space for people in distress and have a sensory room with changing room and toilet.

Regarding training: we offered [county] Police some free training but they did not take me up on it. I thought I could offer a lot of insight from personal experience.

Regarding diagnosis: I would have thought the numbers of people getting a diagnosis would be higher. I see a lot of people coming through the door who have had a recent diagnosis. Also, I certainly think there should be an automatic trigger, where people are referred to social care as soon as they receive their diagnosis. This is very important.

Regarding local innovations: we would like to be involved with the Safe Places Scheme and work together on it. We have offered a safe place for people for twelve months now.

Also, in the case of OT assessments and services, most autistic people won't have physical disabilities. However, they might have dyspraxia which could be tackled by OT services, but because they are not physically disabled they won't be eligible.

Regarding carers being offered carers assessments: I am aware of people who have not been offered assessments because I have mentioned it to them and they were not aware of their right to an assessment prior to that. However, whether that is due to them not being known to anyone or people not routinely offering assessments I am not sure -

it could be either or both. Regarding care and support: we need a pathway for people who are not eligible for social services support. They definitely need to know what is available for them. It happens sometimes when CAMHS signpost people to us, but a thorough, official pathway that everyone knows about would make it much better.



My daughter has always loved drama and any opportunity to perform on stage. However, accessing mainstream arts programmes for people with autism who have co-occurring mental health conditions can be difficult. People with autism generally experience some difficulties with motivation and organisation however, acting and drama has always enabled my daughter to be the best she can be.

My daughter recently had an opportunity to attend a well know known [City] theatre school for a week. She amazed everyone with her motivation, her commitment and performance on the final night. This wouldn't have been possible without the help and support of her HAS social worker who patiently communicated over several months with the theatre school to ensure reasonable adjustments could be made.

The experience was a huge success from my daughter's perspective as she felt everyone was welcoming, inclusive and understanding of her condition. This positive and uplifting experience helped to mitigate some of the negative feelings she had been experiencing around autism acceptance and inclusion over many years.

We are very grateful to my daughter's dedicated social worker for making this a reality.



In the past [name] has experienced intolerance from people when her son has displayed challenging behaviours when accessing services in the community. In [name]'s experience the intolerant reactions exhibited by some people to the challenging behaviours displayed by individuals with autism often prevents parents from taking their children out in public because it becomes too stressful.

At the February APB, [name] gave a presentation on the Autism Stress Cards scheme that she has pioneered. The Autism Stress Cards use a traffic light system to highlight levels of stress and the cards are used to explain that an individual with autism is asking for support.

The aim of the scheme is to raise awareness amongst places that offer services to the public such as supermarkets, banks and libraries. [Name] approached the Child and Adolescent Mental Health Service (CAMHS) to ask for details of parents of individuals with autism. Five families took part in the pilot and reported that the cards helped them to manage stress levels which ultimately had a positive impact on their children.

[Name] approached retailers in a large [town] shopping centre who felt they lacked sufficient knowledge of autism, feeling that it would be inappropriate for them to intervene or offer assistance to people displaying challenging behaviours even if they could see that a situation was developing. Following this, an awareness event had been

held at the shopping centre over three days for retail managers and the scheme has since been rolled out in a number of stores.

[Name] presented the scheme to the APB and a self-advocate stated that he believed the stress cards to be a very helpful support structure for people with autism, noting that he believed the scheme should be rolled out nationally.



[Area] is an understanding borough, more understanding than other boroughs that I have lived in. There is always a lot going on.



I think we're lucky to live in [borough], which is on the whole a tolerant and diverse borough. My son, with severe learning difficulties and health problems as well as autism, has always been treated with support and affection by his local community. He has become well-known in local shops and cafes and - now he's older - the local pub! Even on the occasions when he's been overwhelmed and lashed out or been disruptive, people have been understanding. I feel the local authority has been supportive too, which is increasingly difficult when budgets are being cut. At times when there are different opinions as to how/where his needs can be met, I have been able to negotiate rather than go into battle with local officers. I believe that the jointly commissioned and pooled funding of the NHS and social services budgets to provide a combined learning disability partnership for adults has been a great strength of the borough, and there is an atmosphere of commitment to partnership working with families.

I think autistic people and their families also benefit enormously from having an excellent, family-friendly voluntary organisation in the borough, which provides high-quality practical, day-to-day and advocacy support and works well as a channel of communication regarding family concerns into the various partnership boards that operate at borough level.



I have known I am autistic since I was five. I am almost 18 and attend a specialist autism college. It's good to understand myself. It helps me explain to others why I think and act the way I do. I find it hard to be rushed, to put thoughts and feelings into coherent sentences and not having enough warning about changes in plans. I misunderstand social cues from others. Misunderstandings aren't just one sided and escalate tensions and problematic situations. This is a problem when I am involved in non-routine activities, especially out in public. I hate being the focus of attention and this leads to a vicious cycle where I think I am embarrassing myself, which makes me anxious.

I avoid unfamiliar situations which makes my parents and carers worry about me being isolated and living independently. I become anxious if I feel confused or overwhelmed. This makes me unable to control my mood and occasionally I become physically aggressive. In public places like supermarkets, I try hard to control my anxiety more than usual making me more stressed when I try to remove myself from a situation to calm down. Over-stimulating, noisy places make this worse. I am learning mindfulness at school.

I have diagnoses of dyspraxia and Attention Deficit Disorder. The dyspraxia makes tasks that require co-ordination difficult eg carrying things and navigating around people in a room. Everyday tasks can be tricky, slow and frustrating. It takes me longer to get dressed, wash, bath and prepare food. I find it hard to organise myself.

On the positive side, I am very mathematical. I am studying A-levels and hope to go to uni. I am able to focus really well on tasks I enjoy and always want to try to complete them as soon as I can – for better or for worse!

I often forget things I find uninteresting or tedious which makes me somewhat worried about being able to live independently – paying bills, cleaning, buying food for meals or remembering to meet up and communicate with people.



I used to eat lots of sugary stuff like star bursts, fizzy pop, sweet and sour and things like that. Staff had spoken to me about how much sugar I was eating regularly and one day a member of staff downloaded an app called sugar smart. Basically the app scans the bar codes on products and tells you how much sugar is in that item. It tells you by showing you a picture of how many cubes of sugar are in each product. In a big bottle of Fanta there is loads of sugar. I used to buy two two-litre bottles a week. I used the app to scan the food in my cupboards and found that I was eating more sugar each day than is recommended. Now I don't eat as much sugar I've swapped fizzy stuff for apples and grapes. These are still sweet but they are not as bad for me. I now buy fruit juice or have a cup of coffee.

I have also used the app to play word games, crosswords and word searches which is helping me with my spelling. Sometimes I use the iPad if I go for a walk with staff. We have an app called Walk meter. This is really good because it tells you how many calories you have burned. It tells you how many minutes you've walked and how far. It shows you on the map where you are and you can find new routes and go to different places.



I am 19 years old and autistic. I have anxiety and OCD. I found it very difficult to leave child and adolescent mental health services. I felt very comfortable with the psychiatrist

there. My new one at [area] Learning Disabilities Service is very stand offish and I don't think understands me. I think the new building [area] Learning Disabilities Service is in is the worst kind of building for anybody with autism. I get scared and anxious when I go there. It is too noisy and too open. There is no private space and even the rooms have glass walls.

I feel the local hospital could be more autism friendly. I hate sitting in the waiting room where people are staring at me when I have to go to appointments with my mother. The other local hospital was much better because they found a room I could sit in where I didn't have to be around other people. I also feel when I am not in school that it can be hard to meet people although I like the local performing arts and media college a lot.



A client who has been using one the iPads regularly was asked the following questions:

Q: What do you like to use the iPad for? A: Google maps.

Q: Why do you look at Google maps? A: To look at the places. To look at the parks I can go to on my car Journeys with friends.

Q: What do you like to check? A: I like to check the roads we will travel on and I remember them very well.

Q: Is there anywhere else you look at on the maps? A: I use the maps to see [area].

Q: Why do you look at [area]? A: Because I will talk about [area] with Mum and staff. It's got a water fall and a cave it has and I want to have a look.

Q: Do you like use the iPad? A: Yes I do.

Q: Do you think it helps you? A: Yes it does.

Q: Do you use the iPad for other things? A: I like to look for music I like on the iPad. I check google for Smash Hits Party 88 and Smash Hits Party 89. I look for the lists of the songs and the minutes.



[Name] aged nine has ASC, Co-Morbid ADHD and PDA, below is a list of past and present everyday experiences we have had whilst dealing with public services. The information details the intricate detail that we have to plan for in order to support him effectively:

Public transport

Negatives:

1. Actually getting to the bus, train station etc. (as it is a change in routine and change in general).
2. The time on the boards for the arrival of transport, [name] is very literal so for example 'the train will arrive at 10am' [name] will be looking and asking several times per minute 'what time is it' and then if it reaches the time stated and still no transport [name] finds it very hard to adapt to the change in time and me not being able to give him a definite answer as to when it will be arriving.

3. The noise, smell, overcrowding all play a major part in [name] feeling uncomfortable and this is displayed by [name] leaping, jumping, clenching fists, and being loud or abusive as a way of him trying to cope.

Positives:

1. Once we are on the public transport [name] seems a lot calmer although still 'stimming' I can redirect his attention to more positive thoughts.
2. Arriving at our destination and [name] overcoming his fears and discomfort.
3. Praise for [name] doing so incredibly well, and [name] feeling proud of himself which spurs him on for the journey back.

Parks, play areas, etc

Negatives:

1. [Name] loves the idea of going outside to have an adventure, however he finds it so very difficult and again shows all the signs as mentioned above whilst on our way, even when he is excited about going to an actual place to play he still struggles with not knowing how many people are going to be there and all the outside noise, the main issue we have found and one of the most worrying is when we are out and there is a loud noise this could be anything from a bus stopping, car beeping its horn or someone running past singing/shouting etc., [name] has a sensory overload and will just RUN, this happens very often where he has blocked out and forgotten all once taught knowledge of road safety and ran across the road without stopping or looking, and I have had to grab him out of the road and pull him back, only when I have knelt down in front of him and 'snapped' him out of it does [name] then realise that he could have been hurt or worse, then we have to deal with that meltdown of what could have been. As [name] is getting older I want him to have his independence so when we are out I allow him to walk ahead if he chooses to, but I make sure he is close enough for me to be able to get him if need be.
2. [Name] has very little coordination so when we are out he can easily fall or if he is 'peaking' (this is the stage where things have started to get to much for him, sensory wise) then he cannot focus on what or who is around him and can fall over or bump into things.

Positives:

[Name] loves to play outside and loves to roll play and if the play area is too busy for him we go off and have our adventures where [name] can run and play on the field acting out scenes from his favourite program, we take picnics and find a nice quiet area to talk, [name] does however love to find a friend in the park to talk to and play with, he is quite sociable which I think is a real pleasure, and if he is not finding it all too much [name] will have a wonderful time.

School

Negatives:

1. [Name] can find it very hard to cope in the main stream side of school so will spend most of the morning and afternoon in the ASC base without this base [name] would get

very frustrated and have constant meltdowns because of the sensory issues, [name] still has meltdown in the base now, where he will become violent and hit out or scream abuse, [name] also self-harms by banging his head on any hard surface, biting or hitting himself with objects.

2. [Name] has very little concentration until things are explained to him in stages and if around him are of the right setting (not too loud or over visually stimulating) then he finds it better to focus and get his work done.

3. [Name] struggles to put pen to paper and finds it very difficult to write for a long time, this alone can result in him having a violent meltdown.

Positives:

[Name] is high functioning and craves and absorbs information, he loves to learn and is proud of his achievements. As any child he loves playtime and enjoys spending time with his friends in a controlled environment.

Overall:

[Name] struggles with leaving the house and we have to plan everything in advance, even a trip to the park has to be wrote on the calendar for him to 'get used to the idea' but we make it a happy time when we do and he is always proud of himself for overcoming a difficult situations, [name] is a remarkable young man, and he never fails to impress me and make me proud, he works hard to overcome difficult times, and is working very hard not to self-harm when he is feeling frustrated, we have a very good routine at home, and I really do believe that having a solid routine is the key to a calmer home and calmer [name].



I have a concessionary bus pass which I am able to use at any time, the pass allows me to use buses, ferries and trains. I will not board a bus if it is packed, I will wait for another bus to arrive. You can tell which bus drivers have 'had training' they will wait for you to find a seat and sit down before they move off.



Users of a local autism specific community interest company were asked for their views.

"I feel [town] offers me a lot of activities which is all with my friends."

"I don't know who will support me into employment."

"I feel [town] offers me help."

"My social worker has spoken to me about it, however, I don't want to live alone."

"I did work experience at (local college). I felt uncomfortable there. I am building my skills and confidence at (local provider)."

"Apart from (local provider) I have had no support finding employment."

"I think [town] Borough offers me a lot I get to do lots of activities and choice but I have to travel out of [area] for them."

"I don't know any adjustments to council, NHS, bus drivers, can sometimes not understand my autism."

“(Local provider) staff help me and support me all the time.”

“Drs are very helpful they make me feel relaxed.”

“Local care and support settings help my needs because they understand my needs and what helps me. Some people don't understand autism and can upset me.”

“From when I was diagnosed the doctors were really friendly however they could have explained my condition in more detail some people wasn't understanding.”

“I feel [town] offers me all the support and help I need. I feel [town] Borough are doing really well for me.”



Stakeholders reflected on their experiences of being autistic in [town]. They feel that [town] as a place and its public services do not understand as well as they could what the needs are of autistic people. They do not feel that autism as a condition is as well supported as others.

“Feel they haven't understood autism needs.”

“People don't understand autism properly.”

“There seems to be more help for certain groups and none for other groups.”

“There aren't any adjustments been made?”

“The money is not going to the right places. More needs to be done with public transport if not enough people are getting on the bus. Rather than removing service they should look to have it at another time. Some people rely on those services not everyone has a car.”

“Haven't really come across anyone that seems to have had much training in supporting autism.”

“As autism is a new thing it's difficult even now for people to understand and allow time towards with autistic people, have to look at things how they see them”

“Not much though autism seems to be a hard condition to generalise as each autistic person is affected differently.”

“Not at all after continued ringing for advice help or support we are still not getting anywhere”

“Hard to get through to phones nowadays plus the stupid automated system that wastes so much time and money it is better to just get through to a human straight away”

“There doesn't seem to be enough support for either. Trying to get support has proved difficult and still no positive outcomes”

“They don't help for long enough because they don't really understand people with autism. They come and go before you have had proper help.”

“There is a cut-off point of age 25 which I don't agree with as only recently people are being diagnosed with autism so by the time they find out their problems they are past the age and receive no help to get into work and are expected to work for free and if you have no experience there is no money to help to learn new skills such as engineering which the government is trying to get more people into. You are expected to use your own money which you don't have as you are unemployed.”



I struggle to have face-to-face meetings with people as I have some real anxiety issues. I recently went to the bank to make a withdrawal. The person serving me in my bank stated quite clearly my signatures did not correspond. My only means of identification was my provisional driving licence which was 10 years old and again did not reflect my current signature. I was unable to deal with the situation - I found it very stressful and couldn't process what the person was saying which may it really difficult to respond back to the questions I was being asked.



I visited the theatre today to try and book tickets for my 14-year-old son who has ASD and struggles with anxiety. I know that he will find going to the theatre to be hugely challenging but as this is one of his GCSE exam texts I really want him to have this experience.

I can't thank the staff of the theatre enough for their support and care during this visit. I spoke to a number of staff and they all showed a high level of professional understanding and empathy in relation to the challenges faced by those caring for/those who have autism. I rarely encounter this support as I battle with systems and organisations to try and help my son navigate the social world. The theatre and concert hall have recently received an award from the NAS for their commitment to enabling those with autism to access performances. Clearly this is well deserved and I want to acknowledge what a difference their support has made to me.



We visited the theatre today for the afternoon performance of Aladdin. Huge thanks are offered to the staff who were around in the foyer area. Unfortunately, I had to come out with my youngest son who was in tears before it even started so we left and sat in the quiet area. I then noticed when it started that there was a screen just above the entrance so we stood watching and as we did we had bean bags and chairs brought over. The kindness was lovely and actually made me cry. We managed to sit and 'watch' until the interval and then we left. Although we were unable to watch it properly it was a positive experience and will have a positive impact if we want to visit again.



I am an autistic person who uses the buses around [town]. It's important to me as an autistic person that I know the correct procedure; this is because part of the core of my condition is a pronounced reliance on repetitive routines, which I can't change. This is why I am asking for the following to be printed somewhere on the disabled user card: Please show the front of this card to the driver when boarding the bus, then place the card face down on the machine next to the driver. I think this would be helpful to my needs; and also for the prevention of fraud.