

## Autism Engagement Feedback

## APPENDIX 2

### Background and Context

During September and October 2019, a series of engagement events were undertaken with providers of Social Care and Health services, professionals and most importantly people with lived experience of Autism, to inform the development of this Plan. The events were intended to explore what life was like for people with Autism and their carers, and how well the Council and Clinical Commissioning Groups were perceived to be performing against the 15 “I Statements” from the “Think Autism” national strategy. To supplement the engagement events the Council also established an on-line survey for people unable to attend the events or whom wished to contribute in this way.

The key outcome of this engagement process is that people have told us that, of the 15 national “I Statements” they feel the most important for them and therefore the areas the Council and CCG need to primarily focus on are:

- I want services and commissioners to understand how my Autism affect me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies;
- I want to know that my family can get help and support when they need it;
- I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process;
- I want staff in Health and Social Care services to understand that I have Autism and how that affects me;
- I want Autism to be included in Local Strategic Needs Assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with Autism

This engagement process also identified the following key themes:

- A need for more consistent training and awareness of Autism across all services and staff working in those services;
- There is a lack of support, timely or otherwise, particularly for those aged 18 years and above and post diagnosis;
- A need for increased communication and sharing of information, across all professionals, to prevent individuals having to repeatedly tell their story;
- Concerns raised specifically in relation to the recent changes in the CCG’s provision of Diagnostic services
- A need for clear advice, guidance and signposting, from staff that understand Autism, to what is available in local communities whether that be from the public, private or voluntary sectors
- Need to focus on an individual’s Health and Wellbeing, not their diagnosis

To refresh the Autism Implementation plan, engagement was undertaken with individuals with lived experience, families, carers, professionals and providers of services to find out how well we are delivering on the 15 ‘I’ statements that are part of the ‘Think Autism’ national strategy. The statements have been grouped into three key areas as follows:

### An equal part of my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be considered when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be considered.

### The right support at the right time during my lifetime

7. I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with autism.
8. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

### Developing my skills and independence and working to the best of my ability

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

### **Attendance at events and online submissions**

Three drop-in events were held. One for professionals and providers, and two for individuals with lived experience, families and carers. There has also been the option to complete an online questionnaire.

21 people attended the event for Professionals and Providers.

31 people attended the event for people with lived experience, families and carers events.

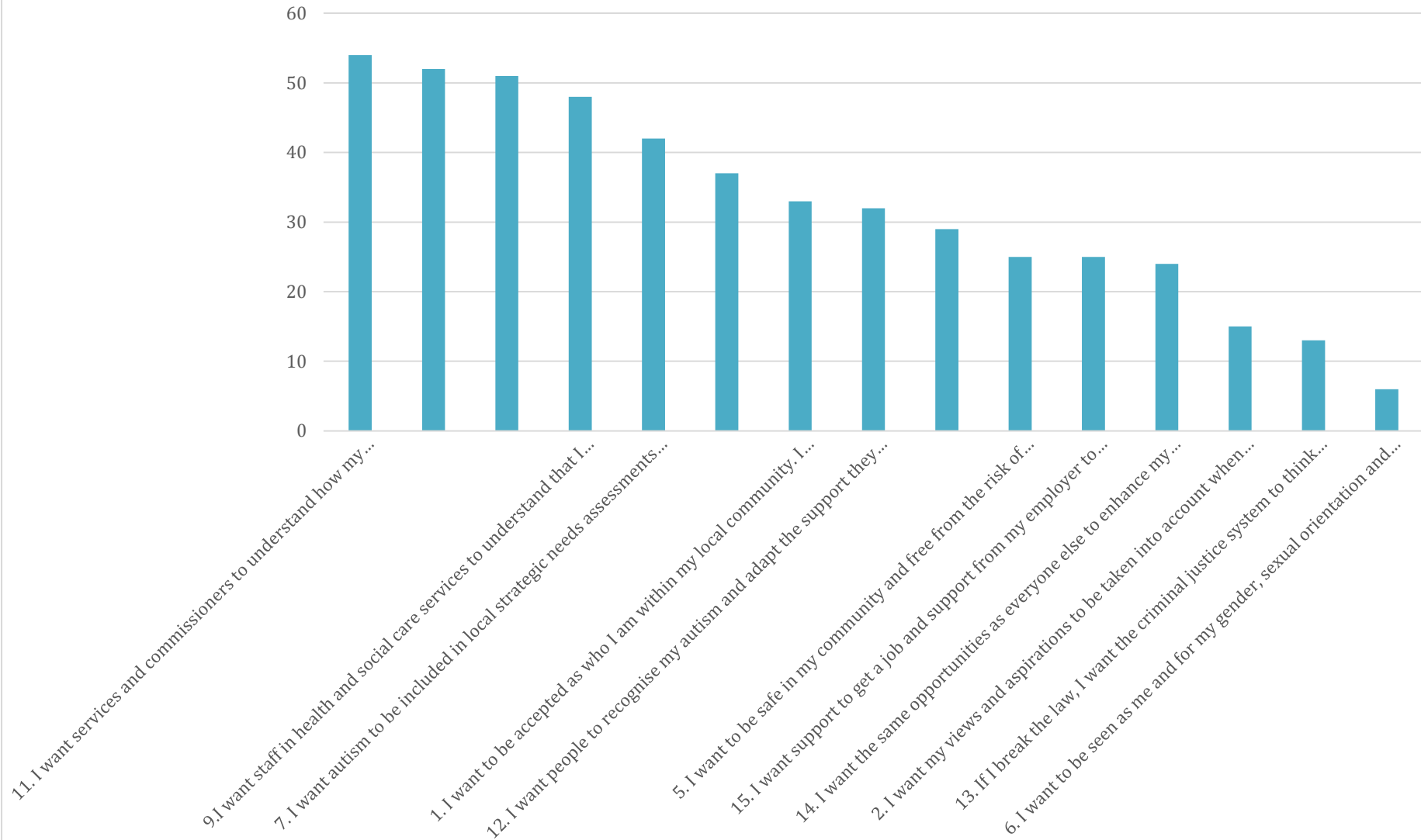
83 people submitted a response to the online questionnaire.

### **Top 5 Priorities**

Overall the following top five statements (in no particular order) were identified to be the most important to address, in order to improve people's lives in a meaningful way.

- Statement 7 - I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with autism.
- Statement 8 - I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
- Statement 9 - I want staff in health and social care services to understand that I have autism and how this affects me.
- Statement 10 - I want to know that my family can get help and support when they need it.
- Statement 11 - I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.

### Top 5 Priorities





## Summary Feedback

### 1. An equal part of my local community

Individuals with lived experience, families and carers	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>Experiences of professionals that understand autism make a huge difference. Ad hoc examples given of a doctor, local PCSO's, community psychiatric nurse and a provider.</li> <li>Facebook is good at looking at what is available in the local area.</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>All residential and day care services need to have knowledge and training around autism and an internet connection.</li> <li>Local charities and people with lived experience help. More could be done with proper funding of services.</li> </ul>
	<p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>Lack of knowledge on what is on offer in the community and support available. Also need support to access this information e.g. a helpline or a handbook</li> <li>Lack of support for carers</li> <li>Lack of understanding of autism particular noted around NHS services, rely on the families to understand the individual – continuous training needed</li> <li>No coordinated approach to support and no communication between services. If Health and Social Care cooperated would create a more successful service.</li> <li>Lack of reasonable adjustments</li> <li>Lack of understanding around appointments for individuals, length of time offered, the right approach to take, understanding the anxieties the person is experiencing etc</li> <li>Autism isolates the individual and the family – suggested community champions, support plans to be more inclusive of the community</li> <li>People are not safe in the community</li> <li>People with autism and their families are judged</li> </ul>
Professionals and Providers	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>Good support provided by voluntary organisations in North Staffordshire</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>Lacking in support for adults</li> <li>I think a lot of training has been done around autism. However, there is a lack of skills for people to adapt their knowledge to support individuals</li> </ul>

	<ul style="list-style-type: none"> <li>• Main worry is the future, when parents and carers are no longer around</li> <li>• Sexual health services and education are needed</li> <li>• There are various communities (online, social, geographical and peer etc)</li> <li>• One size does not fit all. Everyone presents differently</li> </ul> <p>Negative: Most people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Not enough awareness and true understanding of autism</li> <li>• Everything stops when the person reached 18 years of age</li> <li>• Not enough activities and support available. It is not known what is available</li> <li>• Most people want basic human rights</li> <li>• Reorganisation of services, threshold criteria changes don't help</li> <li>• There is too much emphasis on support from the voluntary sector</li> <li>• Education of the general public is needed</li> </ul>
Online Survey	<p>Positive: Some people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• Not the me part, but my race, gender, sexuality and religious views are less well accepted</li> <li>• Race and sexual orientation have a much bigger understanding and acceptance than autism</li> </ul> <p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• People don't need to be experts, but a basic understanding would be good. Suggested an autism friend programme in the same way as the dementia friends programme</li> <li>• People are often willing to make adjustments but are unaware of what these might be. If I am struggling with communication explain these can be an extra burden. Training or a guide of simple steps that managers within SCC NHS should help my constant need to explain</li> <li>• Waiting rooms for services are not autism friendly</li> <li>• Although Staffordshire have an online portal as a single point of contact for this info most families still do not know about it. The info within Staffordshire connects isn't always easy to navigate either even for those who are good with technology! You have to have an idea of what it is your looking for to even be able to find it so it's not helping families that are feeling isolated or lost and have no idea what's available to them</li> </ul>

	<p>Negative: Most people commented that we are not doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• There is very little evidence locally of any interventions to make life easier for people with autism</li> <li>• No services or support groups available to help or is a postcode lottery or limited. Support groups also need to be inclusive or working parents and run at times to suit this. Support needed post diagnosis.</li> <li>• Had a bad experience where an employer would not make reasonable adjustments for me</li> <li>• A recognised information pathway to find information on connecting with specific groups, organisations attached to learning disabilities is needed</li> <li>• Services are based in Stafford and it can be difficult for people with autism to travel</li> <li>• I couldn't carry on at College so left. I am not support and have been left 'to get on with it'</li> <li>• Issues with bullying at school and in the community. People with autism do not feel safe wherever they go</li> <li>• Perhaps providing formal training opportunities for NHS and SCC staff and opportunities to talk to autistic people could will develop awareness and then understanding before acceptance</li> <li>• Many people commented on the loss of the expertise of Midlands Psychology and feel unsure as to what is available</li> <li>• Issues around accessing CAMH's Services were highlighted</li> <li>• Our experience of hate crime with our child and within education has been mentally damaging for our son, he is scared to go out of the house, anxiety has increased, and he suffers with severe depression</li> </ul>
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2. The right support at the right time during my lifetime

<p>Individuals with lived experience, families and carers</p>	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• The Police have been good in the local area and when a person with autism went missing</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Better behaviour support and planning needed</li> <li>• Transition across all services needs to be better</li> <li>• Suggested the use of an autism passport</li> <li>• Looking at the future when carers and family no longer able to care. Limited work undertaken around future planning</li> <li>• Accessibility of services, not all people with autism want to go and meet a GP face to face.</li> <li>• Need autism friendly organisations</li> <li>• Improvements needed for help and support in crisis situations</li> </ul>
	<p>Negative: Most people commented that we are not doing well at all. Comments included:</p>



	<ul style="list-style-type: none"> <li>• More training needed for staff when questioning people with autism</li> <li>• Once have a diagnosis, then what? No support offered</li> <li>• Services and places are not autism friendly or are slow to adopt the approach</li> <li>• Individuals are 'shoe horned' into services instead of services being flexible and appropriate for them. We are all individuals with differing needs</li> <li>• System is too hard to navigate to get help and support in the home</li> <li>• We are not smart enough with the services we offer. Being smart does not mean you have to spend money</li> <li>• Need individuals and families to be safe at home – this is not always the case due to lack of support</li> <li>• Some people, due to the lack of support, can end up in the criminal justice system</li> <li>• Lack of training and awareness especially in the education system. Some not getting the best out of education and come are not getting any</li> <li>• Parents feel they are in a constant battle trying to get support for their child</li> <li>• Lack of training, awareness and understanding across all organisations</li> <li>• Long wait time for diagnosis and assessments and sometimes they are not good</li> <li>• Families and carers are not involved in each step when they should be</li> <li>• Personal and person-centred approach has to be just that, discretion to adapt to the persons needs. Support planning needs to be consistent and real, encompassing the individual needs even if outside of the norm or usual pathways</li> <li>• Transparency and communication are lacking across all stakeholders</li> <li>• Services are discriminating against me because I cannot access the mental health service, they discharged me because of my autism</li> <li>• Assessments have to be done with families not to families and young people. With dignity and experience and understanding. This is not happening</li> <li>• Regular quality assurance checks of assessments and more accountability in all areas is needed</li> </ul>
Professionals and Providers	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• There is a growing knowledge around autism</li> <li>• The Carers Hub is piloting an autism roadshow in Tamworth</li> <li>• The Autism Outreach Team offer a great service</li> </ul> <p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Services and Commissioners need to be up to date on resources and forward thinking</li> <li>• Advocacy and person-centred support tools are not at the forefront as it once was</li> <li>• Reliance on voluntary sector provision – should all be joined up</li> <li>• People get in the Criminal Justice system due to lack of support. There is little understanding of autism in the</li> </ul>

	<p>prison service</p> <ul style="list-style-type: none"> <li>• Assessments can be lengthy</li> <li>• More involvement in transition is required</li> </ul> <p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>• Huge differences between North and South diagnostic services</li> <li>• Some mental health services will not work with individuals until they have had an autism assessment which creates delays</li> <li>• Families often have to reach crisis point before they get support</li> <li>• Lack of accessible information for children and young people</li> <li>• All comes down to lack of funding</li> <li>• Many services feel ill equipped to work with adults with autism</li> <li>• It is not clear who does what and when. Passed around between services</li> </ul>
Online Survey	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• The independent support groups that are in place are going above and beyond for parents and children</li> <li>• Really good support from the Autism Outreach Team in transition to reception this year</li> <li>• Contact with Staffs police has been structured, polite and positive</li> </ul> <p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Mixed experiences of diagnosis and the Autism Outreach Team</li> <li>• Awareness is increasing but still poor</li> <li>• People claim to understand however they are very patronising</li> <li>• Schools struggle to understand autism and how it can affect children and importantly how to help children through the school day</li> <li>• The only support families get is peer support</li> <li>• Sainsburys recently introduced a sunflower lanyard to identify people with hidden disability's which is a big help. More providers need do this</li> <li>• I have no experience of the Criminal Justice System as yet, but this is something I really worry about</li> </ul> <p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>• People are uncertain about the new diagnostic for children. Waiting lists have now come into force when they were not there previously and there is feeling of lack of support after diagnosis. Not the same service</li> <li>• Lack of support and some families had to pay privately because of this</li> <li>• People feel support has been removed in a number of cases</li> <li>• There is limited support for parents and their wellbeing</li> <li>• Autism does not fit well into existing services</li> </ul>

	<ul style="list-style-type: none"> <li>• Some people felt that changes are done with finances rather than service users in mind causing unnecessary distress</li> <li>• Concerns raised as residential overnight stays have been stopped</li> <li>• Struggling at school as they are unable to implement autism strategies without diagnosis</li> <li>• More support is needed for those going through significant change</li> <li>• Autism and Mental Health services need to be joined up</li> <li>• Support for all transition scenarios is lacking</li> </ul>
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3. Developing my skills and independence and working to the best of my ability

Individuals with lived experience, families and carers	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• Local charities work well to support people. They need more funding</li> <li>• Help from an Occupational Therapist would help people to be more independent</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Lack of reasonable adjustments and understanding from employers</li> <li>• Transport can be a huge issue</li> <li>• Job Centre Plus staff need to have proper training and understand that a person with autism will still need support once they have started the job</li> <li>• The respite offer does not include people with autism</li> <li>• Increase in training, awareness and understanding needed across all stakeholders at all levels</li> <li>• Include training at university</li> </ul>
	<p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>• Support is needed throughout including when looking for a job</li> <li>• There is a need for job coaching for people with autism. There is a need for a mentor or a buddy to help and support the person in the workplace</li> <li>• There is a lack of support around paperwork for carers</li> <li>• There is a lack of individualised communication</li> <li>• Lack of local transport links</li> <li>• A wider range of support is needed outside of normal working hours</li> <li>• Professionals expect too much of people with autism to integrate into 'normal life'</li> <li>• There is a lack of clear pathways for people to navigate</li> <li>• Job Centre Plus has no system in working with people with autism</li> </ul>

	<ul style="list-style-type: none"> <li>• Employers need to understand complexities and have patience</li> <li>• Post college / university too many fall off a cliff edge and are left unable to find anything suitable for them to do</li> <li>• Better opportunities at college needed</li> <li>• Life skills training is lacking</li> <li>• Lack of support to enable people to become independent</li> <li>• Independence is about what the young person wants and not what society expects. Listen to them and family</li> </ul>
Professionals and Providers	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• All jobcentres can offer 'retention' a neutral body to work with customers and employer with agreement of all parties with the aim of the customer staying in employment</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• All job centres are working with employers on our disability confident scheme to encourage employers to offer employment to people with disabilities - we need to do more</li> <li>• Life skills are encouraged in special school – what happens when my child leaves education?</li> <li>• Some people will never be able to work in formal employment. Their skills are lost because the benefit system does not recognise the value of volunteer roles.</li> </ul>
	<p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>• There is a massive reduction of work opportunities and support for people with autism</li> <li>• Transport funding cuts are creating huge barriers to engagement, inclusion and independence</li> <li>• Support available to employers is limited. Creates a barrier for employers. If support was there employers could directly employ more people with autism</li> <li>• Lack of understanding of people's difficulties and how they might develop skills</li> </ul>
Online Survey	<p>Positive: A few people commented that we are doing well. Comments included:</p> <ul style="list-style-type: none"> <li>• Current school and autism outreach doing well</li> </ul>
	<p>Neutral: Some people commented that we are not doing so well. Comments included:</p> <ul style="list-style-type: none"> <li>• Education is key to finding meaningful employment</li> <li>• Getting on the employment ladder is important, but anxiety provoking. Opportunities need to be given to allow people to show their skill set</li> <li>• People have a job but have struggled at times to remain in employment</li> </ul>
	<p>Negative: Most people commented that we are not doing well at all. Comments included:</p> <ul style="list-style-type: none"> <li>• More organisations across Staffordshire should be creating opportunities for people with Autism. There are not enough opportunities or understanding</li> <li>• I would like to do so much more with my life, however I am getting held back by the lack of support available</li> <li>• There is no flexibility in support</li> </ul>

	<ul style="list-style-type: none"><li>• There are not many people with special educational needs and disabilities working in the community</li><li>• No experience as yet and would not know where to go for support</li><li>• No confidence or encouragement to join in</li><li>• Some have been turned away by the job centres</li></ul>
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### What is missing?

Of the 15 statements, above, we asked stakeholders if they thought there was anything else that is missing. Comments included:

- Missing early intervention
- Is there an ethical framework and Quality Performance Assessment for the third sector/ voluntary organisations on what they offer?
- Need to focus on health and wellbeing and not the diagnosis. We all want the 'I' statements
- Resource Front Door adequately - staff who understand what is out there for people with autism. A staff lead in Staffordshire Cares
- No services available for people who are an elective mute
- Consultation with people with autism on what they would like to see
- Affordable housing with is appropriate
- Crisis intervention
- School holiday and respite support, social clubs
- Lack of adult services
- Create a gallery of successful inspirational local autistic people or a place to display artwork in Staffordshire Place

