

# Autism Matters

## Engagement report

A summary of what we did, who we spoke to and what they told us.

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Published in February 2020

## Contents

Summary .....	2
Introduction .....	3
How did people get involved? .....	3
Who did we speak to?.....	4
The Changing Landscape of Autism in North Yorkshire – how did we do? .....	4
Theme 1: Support for people with autism and their families.....	4
Theme 2: Assessment and diagnosis .....	9
Theme 3: Raising awareness and training .....	10
Theme 4: Information and signposting.....	11
Theme 5: Education and employment.....	12
Theme 6: Supporting people with autism during key life changes.....	15
Theme 7: Working together.....	16
Developing future plans and priorities .....	17
What are we doing next?.....	18

## Summary

The Changing Landscape of Autism in North Yorkshire is the county's current autism strategy. It was published in October 2015 and ends in October 2020. In preparation for the strategy ending North Yorkshire County Council has:

- Written a progress report to summarise the work undertaken by different organisations to implement the current strategy;
- Begun drafting an all-age autism joint strategic needs assessment. This will bring together what we know locally and nationally about autistic people and their families to help us provide the right support at the right time; and
- Spoken to people as part of the Autism Matters engagement exercise.

Autism Matters ran from October – December 2019. Its aims were to ask people how they thought we did on implementing the current strategy and better understand what is important to people when developing future plans and priorities.

People could get involved in Autism Matters in a number of ways. This included completing our survey, contacting the team via a dedicated email address, attending one of the fourteen engagement forums or by attending a focus group. In total we spoke to 438 people across the county who shared over 2,000 comments. This included approximately 130 autistic people.

### How did we do on the current autism strategy?

We asked people to tell us how they thought we have done so far on each of the seven themes within the strategy, choosing one of the following responses: great, could do better, not great or don't know. Overall, people feel there is still work to do on all areas of the current strategy. On raising awareness and training the majority of respondents said we could do better. For the other six themes the majority of people said we did not great.

### What do people want us to focus on next?

Moving forward people clearly identified receiving a timely diagnosis with relevant information and support available during the diagnosis and families of autistic people getting help and support when they need it as top priorities for any future work.

Following diagnosis and support for families, people want us to look at making sure autistic people are accepted and safe in their communities, giving them the same opportunities as everyone else to be independent including getting and keeping a job, and ensuring services know how to make reasonable adjustments for autistic people.

### What's happening next?

We will complete the all-age autism Joint Strategic Needs Assessment. We are aiming to publish the final needs assessment by the end of June 2020. We will use the information from this engagement and the needs assessment to write a revised plan and speak to people about how to achieve the new priorities in their area in summer 2020.

## Introduction

The Changing Landscape of Autism in North Yorkshire is the county's current, all-age autism strategy. It was published in October 2015 and ends in October 2020. The strategy aims to "ensure that services are identified, commissioned and improved to meet current and future needs and improve services for people with autism." It identified seven key themes with associated actions to achieve this:

1. Support for people with autism and their families;
2. Assessment and diagnosis;
3. Raising awareness and training;
4. Information and signposting;
5. Employment and education;
6. Supporting people with autism during key life changes; and
7. Working together.

In preparation for the end of the current strategy the county council has:

- Written a progress report to summarise the work undertaken from October 2015 to October 2019. This brings together work undertaken by a number of teams and organisations to implement the current strategy including Health and Adult Services, Children and Young People's Services and the Clinical Commissioning Groups covering North Yorkshire;
- Begun drafting an all-age autism joint strategic needs assessment. This will look at what we know both locally and nationally about autistic people, their families and the support they need throughout their lives. By bringing both local and national information together we can write an updated action plan to continue supporting autistic people and their families in North Yorkshire;
- Spoken to people as part of Autism Matters. The aim of this engagement was to help everyone involved in delivering the current strategy and future action plans better understand how we did on implementing the current strategy and what is important to people for future work. Autism Matters ran from October – December 2019.

This report provides a summary of the Autism Matters engagement. It details what we did as part of Autism Matters, who we spoke to and what they told us. For further information on the progress report and the needs assessment please visit [www.northyorks.gov.uk/autismmatters](http://www.northyorks.gov.uk/autismmatters) or email the team at [autismmatters@northyorks.gov.uk](mailto:autismmatters@northyorks.gov.uk).

## How did people get involved?

There were a range of different options for people to provide feedback:

- An online survey with both paper and easy read versions was available;
- A dedicated email address was set up;
- Fourteen engagement forums were held with two in each district. These comprised a drop-in element as well as a workshop that people could register for in advance; and
- NYCC staff visited various teams, support groups and organisations in their respective areas to hold focus groups.

## Who did we speak to?

In total we spoke to 438 people during the engagement. This includes:

- 130 people on the autism spectrum (30%)
- 85 family members, friends and carers of people on the autism spectrum (19%)
- 116 health and social care professionals working with autistic people (26%)
- 91 people working for organisations including in the voluntary sector which support autistic people and their families (21%)

## The Changing Landscape of Autism in North Yorkshire – how did we do?

A progress report was written looking at the current strategy. It detailed what we said we would do under each of the seven themes, what progress had been made and areas where we know we still have work to do. This report and summaries of the findings were made available throughout the engagement. A copy of the report can be downloaded at [www.northyorks.gov.uk/autismmatters](http://www.northyorks.gov.uk/autismmatters).

Looking at this information we asked people to tell us how they think we did on each theme. Overall people told us that although some progress has been made on each theme there is still a lot of work to do to achieve the original vision set out in “The Changing Landscape of Autism in North Yorkshire”.

People shared lots of suggestions and ideas about what we could do differently in future either to continue work which has been started or address some of the ongoing issues identified. All of the suggestions people put forward have been recorded and will each be considered when we are looking at what we do next.

A summary of the feedback we received for each theme is detailed below. Each theme also includes a short summary of what we said we would do in the 2015 strategy.

### Theme 1: Support for people with autism and their families

We know that it can be challenging for people on the autism spectrum and their carers to know where to go for support. We said we would:

- Ensure that the support available is of a high standard;
- Support active engagement of people with autism in local communities;
- Ensure that all mental health staff can identify the mental health needs of people with autism effectively, particularly during a crisis; and
- Help people with autism to feel included and safe within their communities.

### Feedback summary

#### Accessing Support

- People can have difficulty accessing support if they do not have a formal diagnosis.
- People told us they have had difficulty accessing support until they, their child or their family has gone into crisis.

- People would like more help to contact and access services. One person told us they feel they are expected to contact services themselves despite them feeling very anxious about this.

#### Assessments and support plans

- People stressed the importance of ensuring that someone who is being assessed has the opportunity to be involved in the assessment and is appropriately supported to do this.
- People agree that support needs to be provided in a bespoke, person-centred manner. Autism affects people differently and employing any kind of one size fits all approach does not work.
- Staff fed back that there can be a disconnect between those assessing someone who look at their potential and support providers who don't always see their role in developing that potential. Sometimes they can end up providing more support rather than up skilling people.
- Staff also identified issues around systems not always being flexible enough to meet people's needs. For example, staff cannot complete an assessment for someone on the autism spectrum as quickly as for someone who is neurotypical as they need more time to get to know the person. However until the assessment is complete people cannot access the support they need. The system counts the days the assessment is left pending which pressures staff.
- Some parents feel that social services can be too quick to assume that they have support from their families without fully understanding each family's circumstances. For example, other family members may not have time to help support the child or the relationship may have broken down.

#### Benefits and application forms

- People told us that application forms are often not autism friendly. This included Short Breaks, Disability Living Allowance, Personal Independence Payments and applications for housing.
- People told us they can find it difficult to provide the required supporting evidence for benefits claims if they are not able to access post-diagnostic or specialist support.

#### Carers of autistic people including parents

- People told us that the pressure on carers is "huge". They want to be involved in decision making. In some people's experiences they are still contacted as an "afterthought" rather than being involved throughout the process.
- Gaps in support for carers of autistic adults was identified.
- A lot of people talked about "fighting" and "battling" to get support for the person/child they are caring for. They feel they have had to be "pushy" and their experiences have left them feeling "frustrated and exhausted." They were also concerned, however, that the people who do not have the skills and/or confidence to take a more forward approach would be left without the support they need.
- People told us there is not enough support on offer for families who are "struggling to understand their children and manage what can be very challenging behaviour." A number of parents said they would like more information and support around their children's sensory needs.

### Community support

- People were happy that progress is being made, however were clear that they still have difficulties. For example, a lot of shops have an autism hour and there are autism friendly film showings, however the times can be difficult for people to get to.
- Families told us that accessing sports facilities with an autistic child is difficult. They end up travelling to access more autism friendly places but this has cost implications.
- As one person told us, “autism is a very complex condition and expecting people in the community to offer informal neighbourly support or through an organised initiative can be a very unpredictable business. Community hubs that have set up in recent years seem to be able to reach out to elderly people and young families, but do not cater very well for harder-to-reach groups such as vulnerable adults of working age”.

### Housing

- People talked to us about the importance of being able to access appropriate housing. One group said that “housing is a big problem” and felt that “co-ordinated support doesn’t exist.”

### Independent living skills

- People agreed that at the moment autistic people do not always have the same opportunities as everyone else to learn independent living skills.
- There are people in their 50s and 60s whose parents have died and they have no independent living skills.
- Some of the health and social care staff who provided feedback said that although they were aware of support in the community such as the Safe Places scheme, many of the autistic people they work with would not use it as they would not be able to go out into the community on their own.
- People would like more travel training to build up independent living skills as they feel travel and transport is a barrier.

### Local support

- The support available for people varies depending on where they live.
- People want support to be available more locally. A number of people told us they were aware of services in other towns, but due to issues with transport or work commitments they were unable to access them.
- People commented that a lot of the support that is available more locally is led by voluntary sector organisations.
- Some families told us they are considering moving away from their support networks so that they can be closer to services.

### Mental health

- People have had mixed experiences with mental health services, sometimes dependent on the staff they see.
- People reported a lack of accessible, reasonably adjusted and specialist mental health support in North Yorkshire. A number of people told us about the lack of specialist autism counselling in North Yorkshire and the impact this has had on them.

- Some people said that once mental health services found out they were autistic they were discharged from the waiting list without being told. These people were not referred on to anywhere else but still needed support for their mental health.
- People are concerned about a lack of support for teenagers with Aspergers who go on to experience complex and enduring mental health problems from being fitted into mainstream services.

#### Peer support

- Peer support for both children and adults was identified as a “huge” gap. While people recognised that not everyone will want to attend a peer support group, and that “just because someone has autism does not mean they always want to do things with other autistic people”, they need to have an opportunity to speak to other people who have had similar experiences.
- Some people and families come together “haphazardly” to form their own support groups. People told us that this is important, however they talked about the risk that inconsistency in levels of support could be developed across the area and what can happen if people become dependent on groups which “at any time may not exist anymore”.

#### Police

- Some good practice and experiences with the Police have been shared, but in other instances opportunities to make things easier for people hadn’t been done. For example, Police arrived at someone’s home with blue lights despite being asked not to.
- Generally people would like to see the Criminal Justice System be more flexible for people on the spectrum.

#### Safety including being safe online

- A number of parents talked to us about their children not always being safe in the community. One person said “my son regards everyone as so nice. He wouldn’t recognise a threat”. Another talked about how their son is vulnerable as he is easily manipulated by others but is unable to see it.
- Some autistic people told us that they don’t always feel safe in the community “even when staff are with them”. They felt that if they were able to feel safe “everything would naturally follow”.
- People talked about how social media can affect people and the dangers it can represent for people who are more easily manipulated or do not know how to process what they see. For example, one young person has been sent pictures of self-harm and made herself physically sick because she does not know another way to process the anxiety she feels having seen the pictures.

#### Social groups

- People told us there are not enough social opportunities for young people to engage with and some of those that are running are difficult for them to access.
- In several areas of the county people noted a lack of social groups for adults.
- People would like more support to access groups for people who have become isolated.
- People told us there is a gap in social groups for autistic people who do not have a learning disability. Some people have been told they are “too high functioning” to attend certain groups.

- People would like a broader range of support and activity groups. People shouldn't assume that autistic people and people with a learning disability only want to do arts, crafts and gardening.
- Not all autistic people like big groups. They can find them intimidating.

#### Specialist support and reasonable adjustments to other services

- The combination of a lack of specialist autism services and mainstream services not always providing reasonable adjustments can leave people with autism and their families feeling vulnerable and isolated. People with autism but not a learning disability seem to be disproportionately affected as they don't "fit" the boxes for mainstream services or specialist learning disability services.
- A lack of specialist support in North Yorkshire has resulted in people being sent out of area.
- Where reasonable adjustments had been made people were clear about how much their experience of services and support was improved.
- Autistic people do not necessarily want to go to specialist autism support groups, rather they want mainstream support groups to be accessible to everyone.
- A lot of people talked to us about the difficulties they have faced in getting reasonable adjustments in a variety of settings. This included attending health appointments, difficulties with time-limited services, in the workplace, at school and when attending social groups.

#### Staff providing support

- Feedback highlighted the importance of consistency in staff members providing support, however many people have experienced abrupt and/or frequent changes in the people supporting them and their families. Where changes have resulted in gaps in support while an alternative arrangement is put in place, for some people this has led to issues with anxiety, mental health problems and meltdowns.
- Inconsistency in staff involved in assessments and support planning means "continually having to get to know a new worker and repeating information already shared. This...leads to a delay in moving things forward as you constantly have to go back to the beginning."
- People have had experiences where issues with staff capacity and training have led to issues with providing the appropriate level of support to people. For example, one person talked about review meetings not being organised for someone attending college even though they had an EHCP. Another person talked about staff at college not being trained adequately to meet the person's needs. Consequently 1:1 support was not provided, the young person was bullied and had a nervous breakdown.
- People are concerned that by moving to generic teams the skills associated with learning disabilities and autism is being lost.

#### Support for children and young people

- There needs to be more support for young adults who may or may not have a diagnosis, especially women.
- People told us there is "very little" support for any child without a learning disability or those with a PDA diagnosis.

#### Transport

- People talked about issues travelling around North Yorkshire, and how the links that are available are often "busy, inappropriate and expensive".

## Theme 2: Assessment and diagnosis

We know families and people with autism wanted to receive a diagnosis closer to home and without waiting for long periods of time. We said we would:

- Provide accessible diagnostic services;
- Review the existing pathways to make sure it meets people's needs;
- Ensure people have the opportunity to provide feedback; and
- Review the post-diagnostic support available.

### Feedback summary

#### Accessing diagnostic services

- A significant number of people are still having problems accessing diagnostic services. People shared feedback around difficulties getting a referral from their GP in the first place, some of whom did not "see the point" of a referral.
- The current diagnosis service for adults is based in York which presents significant difficulties for some people in accessing the service. For example, if they have to go on a bus or train "this can be very loud with lots of people causing sensory issues and highly stressful environments for autistic people".
- There are long waiting times for diagnostic assessments for all ages. The majority of people who fed back around the diagnostic process said that while they had no complaints about the assessment itself, they could "in no way" describe the process as timely.
- Some people have had to go out of area to get an assessment and diagnosis.
- Some people were discharged from children and young people's diagnostic service in Scarborough following commissioning changes and had to be re-referred to the new service.
- Some GPs told us they have experienced "significant" difficulty referring children for an autism diagnosis and have had referrals returned to them. They felt the referral process is too complicated and confusing.

#### Cygnet training for parents

- Some people told us they thought Cygnet training was ok but would benefit from "modernisation" and "needed to be a bit more specific".
- Both families and professionals highlighted that access to support such as the Cygnet programme is dependent on having a diagnosis. Many families can therefore go for up to 2 years "struggling to manage". Some of the teams to which they can be referred to in the meantime expressed concern about their ability to provide specialist support in the interim and would welcome more training. By the time they have a diagnosis and can access Cygnet parents, families and carers have already done significant research and when they get on it the course is offering them nothing new to learn.
- Some people told us they would like more information on transitions and PDA to be included in Cygnet.

#### Information about the diagnostic process

- People would welcome more information about the diagnostic process and what to expect. This would help alleviate stress when going for an assessment.

- GPs would also like to have more information to be able to tell people what will happen after a diagnosis.

#### Post-diagnostic support

- Once people have received a diagnosis, many reported feeling “lost”, “alone” and “isolated”, “without the support they needed or the knowledge of how to navigate the services and support available to them”. Parents stated that they don’t “automatically” know how to support their child following a diagnosis. Staff feedback included concerns over limited options to signpost people to following diagnosis.
- For the adults diagnostic service people need to travel back to York to get the post-diagnostic support. For some people this is very difficult.
- In Craven post-diagnostic support is not funded through the commissioned diagnostic service, and has to be accessed by application to the Individual Funding Request panel, via GP referral. People have found the process “complicated and bureaucratic”.

#### Pre-diagnostic support

- People told us there is no pre-diagnostic support available. To access specialist support people need a diagnosis, however with the long waiting times and difficulties accessing diagnostic services people and families go for a long time needing support but unable to access it.

### Theme 3: Raising awareness and training

We know autistic people and their families would like to access mainstream services and find suitable reasonable adjustments have been made to ensure provision is autism friendly. We said we would:

- Raise awareness of autism generally within local communities;
- Map current training on autism throughout public sector agencies in North Yorkshire
- Support the development of universal, targeted and specialist training opportunities available to all public sector agencies; and
- Encourage frontline services to become autism friendly.

#### Feedback summary

##### Awareness and training for staff providing support

- It was acknowledged that a significant amount of autism awareness training has been put in place which is positive. Feedback did, however, show that there is still work to do to raise awareness and increase understanding of autism in educational settings, amongst health and social care staff and in the criminal justice system.
- Schools don't always understand autism and the challenges pupils with autism face. All schools need to be able to recognise autistic traits in children earlier so support can be in place.
- Where health and social care staff don't understand autism it is more difficult for people to access reasonably adjusted support. Feedback highlighted that where reasonable adjustments are put in place they can greatly benefit someone on the spectrum and their family, but when they are not the fallout can be huge. This includes meltdown, crisis and impact on people's mental health.

- Feedback from staff from various organisations shows they would welcome more training. Some staff expressed frustration where they were being asked to provide specialist support where they felt they did not have sufficient training to do so. Other staff said they have been on several courses relating to autism but wanted to make sure their training was maintained.

#### Awareness in the community

- People told us there is still a need for more public awareness not just about autism in general, but more specific information about how people may present, hidden disabilities and difficulties and how best to communicate and respond when someone is having difficulty. This will help people feel safer in the community.

#### Different presentations of autism

- Some people who are aware of autism generally are not aware of its complexity and the variety of ways people can present and the issues they face.
- People told us there is a need to increase understanding around how people cope in different ways and how they might behave when distressed or in sensory overload. People could then understand that a situation might not be what it looks like. For example, one young man copes at school by wearing a hoody and having the hood up. However he was "continuously chastised" for doing so.

#### Stigma and misconceptions

- People still encounter stigma and misconceptions based on historic assumptions and information.
- Some people are still bullied because of their autism.

### Theme 4: Information and signposting

We know navigating services can be difficult for people with autism and their families and it can be difficult to understand different access criteria. We said we would:

- Improve the way we communicate with people on the spectrum and their families
- Provide easily accessible information about autism;
- Improve information and signposting available; and
- Make it easier for people to know how to access appropriate services and support.

#### Feedback summary

##### Accessible information

- The information which is available is not always provided in accessible formats such as easy read.
- Autistic people often prefer to communicate in writing rather than on the phone. People want this to be taken into account when contacting statutory organisations.
- A lot of information is available online but not everyone is able to or comfortable going online.

### Awareness of the current autism strategy and associated work

- A lot of the people we talked to did not know about the current autism strategy for North Yorkshire. Most people also had not heard about a lot of the work which has been done so far to implement it. This included staff in health and social care as well as the public.

### Finding relevant information and support

- People reported that they do not know where to go to get help and advice, with both families and staff concerned that some people are falling through the cracks and not accessing support they are entitled to due to a lack of awareness on what they can access.
- People told us that the information they have been given is not always relevant to where they are. For example, in Helmsley GP surgery they are “overloaded” with information about services in York and Scarborough.
- A lot of people we spoke to were unaware of at least some of the services and groups which are available to them.
- Staff told us they can get confused as to what is available to autistic people and families. They said it is difficult knowing where to signpost people to as there are a limited number of organisations who can provide support and getting information from them to give to people can be problematic.
- People want more readily available information which is relevant to them in terms of subject and area e.g. transitions support in Selby or peer support in Thirsk.
- A number of people told us they would like more information and support to find Personal Assistants.

### Gaps in available information

- People said information on key life stages and how to support people during the transition is not readily available. For example, parents told us they are unaware where to find help and advice as children get ready to move to university.

## Theme 5: Education and employment

Many young people find school difficult and understanding of autism varies significantly across educational settings. We also know not enough people with autism are able to find or maintain work. We said we would:

- Improve the knowledge, understanding and inclusive practice in educational settings (0-25);
- Develop appropriate peer support for children and young people with autism;
- Work with schools to become autism friendly; and
- Improve and expand employment opportunities for people with autism.

### Feedback summary

#### Appropriate education settings including specialist education services

- Concerns were raised about a lack of educational spaces within the local area that can meet children and young people’s needs. For example, one person said the nearest “proper” specialist school to Craven was in Leyburn, which, given the distance, would have significant impact on families.

- People said there is less provision for young autistic girls than young autistic boys. One person said a number of girls in the Knaresborough area have been unable to find schools that can provide the support they need. They are now being home schooled which increases the risk of them becoming socially isolated.
- People were concerned that specialist services in education have shifted to a consultative model without sufficient investment in staff training. One person was concerned that specialist support is being “watered down” as teachers are asked to advise on interventions for very different conditions and educational needs, “often without an investment in their training”.

#### Autism awareness and support in schools

- It was acknowledged that a lot of work has been done to raise awareness in schools, however many families are still experiencing difficulties in getting support for their children. For example, families have met with school staff to agree support for their children yet find nothing has been put in place when the child starts. Families therefore want to see all mainstream schools being consistently accommodating and understanding of those with a diagnosis.
- Teachers can struggle to understand the differences in the autistic way of thinking and to adapt their teaching to meet the sensory, educational and mental health needs of these pupils.
- People told us that autism awareness “seems to drop off” in secondary school education and above. They were unsure if this was due to children not having a specific teacher for a length of time and being in a more fluid environment.
- People said autism isn’t being talked about in schools “despite being part of the PSHE curriculum”.
- People are concerned that schools feel unsupported with interventions to support social skills and emotional understanding. They said it would be better if theoretical training and advice was followed up by practical demonstration and specific support with implementation.

#### Autism awareness in the workplace

- People fed back around a lack of understanding in the workplace. Examples included an inflexibility around the work environment, not having things explained appropriately and being unable to keep to routines. After a short work placement as part of a degree, one young person was left with significant mental health issues as a result of the difficulties they faced at work.
- We had feedback from autistic people saying people assume they know what is expected of them as an employee, but often they don’t.
- People said employers are not always aware of what they’re legally bound to do to support autistic people in the workplace.
- People felt that employer “ignorance” leads to people being discriminated against because there is a worry over what reasonable adjustments are and what is needed.
- People told us that the social aspect of employment can often be the most daunting; how the person will “fit in” with other staff.
- People would like to see North Yorkshire County Council do more to become an autism friendly employer and in so doing encourage other organisations to follow.

### Education, Health and Care Plans

- A number of parents told us they have difficulty getting schools to input into an EHCP application “even with a diagnosis”. They feel that without input from schools the application might be weaker and fail resulting in an appeal. People are worried about this “reluctance” because without an EHCP “some specialist schools are simply out of reach for families”.
- Parents find the EHCP form complicated and would like more information and support to help them fill it in.
- People feel there can be a breakdown in communication regarding EHCPs, saying they are not updated to reflect a child’s changing circumstances. Minor amendments could have a “lasting impact on the relevance of the information” in the EHCP.

### Employment opportunities

- People are concerned with the limited scope of employment opportunities available to autistic people. For a lot of people opportunities available to them tend to be shop work and volunteering which is not always suitable or what people want to do.
- When people approach employers they are unlikely to look at job carving or adapting the role. One young person felt that when applying for a job she had the option of either lying about being autistic in order to secure an interview or being honest and “inevitably be rejected”.

### Recruitment

- Job adverts don’t always talk about what organisations “actually do”. This can be confusing and unhelpful for autistic people when looking for a job.
- People told us about difficulties with interview panels who “just don’t get it”. Standard lists of questions and interviewing techniques are “not good”. People would like to see more reasonable adjustments as part of recruitment processes such as interviews by Skype, pre-interview training and discussions around working from home.
- People commented that most job adverts say people need good communication skills “whether you do or not” which puts people off.

### Routes into employment

- People feel there is a lack of variety in terms of further education and training as a route into employment.
- A number of people talked about the difficulties autistic people can have at university, with several parents telling us their children had to drop out as they couldn’t cope with the transition.

### Support to find and keep a job

- Feedback from a number of groups including NYCC staff and the public showed concerns around the availability of employment support. Following a review of the Council’s offer people need to have eligible needs in order to access the Supported Employment team. Although employment support is available from Living Well if someone does not meet eligibility criteria, Living Well can only support people for 12 weeks. People stressed that this is insufficient time to get to know someone on the autism spectrum and provide the support they need. One person described Living Well as a “really good service but not enough”.

- People told us they have had mixed experiences at the Job Centre. They staff aren't always aware of autism and how to support someone on the spectrum.
- If someone is struggling at work staff at the Job Centre can work with the person and their employer to help them resolve issues and stay in the job, however feedback from staff indicates not a lot of people know about this. As a result most of the people they support come to them when they are unemployed.

#### Unpaid work

- People are concerned about vulnerable adults including autistic people being engaged in unpaid, "sheltered" work for which they are not paid without the prospect of moving into paid employment. One person described how autistic people "are encouraged to give their time in working environments and are kept there for many years under the guide of 'building skills' when in fact they never move on". The person asked "is it fair for us to just watch them work?"
- Other people talked about how autistic people can become "trapped" in voluntary work, and how in other cases people are themselves paying to attend these placements as work.

### Theme 6: Supporting people with autism during key life changes

We know key life changes such as moving from school to university or employment can be particularly challenging for people with autism and their families. We said we would remove the perceived 'cliff edge' for young people and their families through implementing a seamless model of support and provide high quality support locally to meet the needs of autistic people.

#### Feedback summary

##### Different transitions in people's lives

- Autistic people need support at key times in their lives and not just transition from children's to adult services. This includes puberty, going to secondary school, going to university, looking for a job, moving house, relationships, bereavement and planning for the future.

##### Gaps in support provision

- People felt children have more support than adults. Others experienced a gap in support between 16 and 18.
- One parent described how it is difficult to get support for her 21 year old daughter as "she is too old for child services but not old enough for adult services".
- One group described a "void" at transitional stages in autistic people's lives. People in the group had had experiences of losing the support of "entire medical teams" when someone turned 18.

##### Local support

- People shared issues accessing services to support transition in some areas of the county as, although services are available, they are not local and people are expected to travel. This can be extremely difficult for some individuals due to anxiety and/or financial restraints.

### Transitions in education

- In some people's experience there have been delays in EHCP reviews and getting plans in place.
- Some people said they haven't seen an improvement in the move from primary to secondary school. They highlighted that without an EHCP children aren't able to go to a specialist school.
- Concerns were expressed around young people that have not been through disabled children's services and only become known at 18 when they are high risk. If people are managing in general education they're not on anyone's radar and come to light just as they are leaving school.

### Theme 7: Working together

We know it is important to get all agencies that work with or support people with autism to play a part in implementing the aims of this strategy. We said we would:

- Improve communication with the voluntary sector;
- Continue to ensure people with autism and their families are centrally involved in developing autism support in North Yorkshire; and
- Share progress and celebrate success.

### Feedback summary

#### Communications and sharing information

- People feel professionals do not always communicate effectively with each other, "sometimes even if they are based in the same building".
- A number of people talked about how they have been "passed from pillar to post" when trying to find the right person to speak to and get support.
- People want organisations to be better at sharing information so they don't need to keep repeating themselves every time they speak to someone new.

#### Involving autistic people, carers and families

- Autistic people and their families don't feel their voices are taken into account when decisions are being made. They feel this is important and would welcome opportunities to get involved.
- A number of people said they want to be more involved in the development of information materials.
- Feedback highlighted some trust issues between families and professionals. Some parents fed back that professionals don't always listen to them and that, despite their hard work, there can be a "constant lack of understanding".
- A number of responses showed that parents do not feel "championed". Consensus that they know their child best but they feel the social worker's opinions carry more weight "even though they don't really know the child. Parents only seen as best person when the social workers don't have time or desire to help."

## Joint working

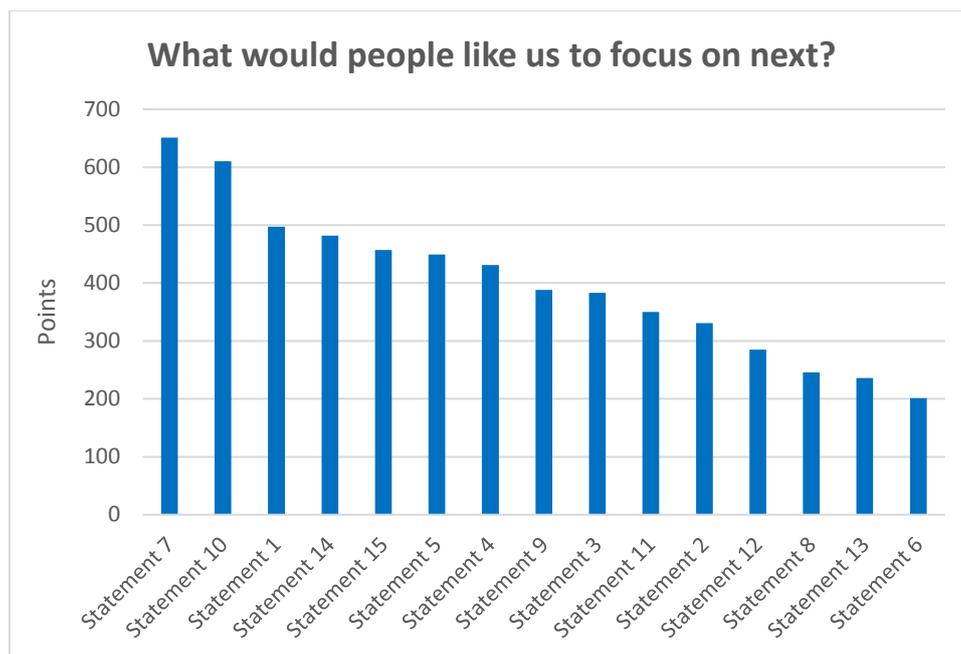
- Health, education, social services and providers need to work better together with each other, with families and with people on the spectrum to improve support, exchange knowledge, inform each other's priorities and avoid duplication.

## Developing future plans and priorities

In order to understand what is most important to people when deciding what we look at next we developed 15 statements based on the 15 priority challenges for action in the national autism strategy Think Autism. The adapted statements were as follows:

1. Autistic people are accepted within the community.
2. The views of autistic people are taken into account when decisions are made in local communities.
3. It is easy for autistic people to connect with other people with autism, including peer groups and family support groups.
4. Services know how to make reasonable adjustments to include autistic people. Staff are aware and accepting of autism.
5. Autistic people feel safe in the community. They do not experience discrimination, hate crime or abuse.
6. People respect and take into account the gender, sexual orientation and race in decisions about autistic people.
7. Autistic people receive timely diagnoses from professionals. Relevant information and support is available during the diagnosis.
8. Autism is appropriately included in local strategic needs assessments.
9. Staff in health and social care understand autism and how it affects people.
10. Families of autistic people can get help and support when they need it.
11. Services and commissioners understand how autism affects people differently at different times of their lives including leaving school and getting older.
12. Health and social care professionals understand autism and know how to adapt the way they provide other supports that autistic people need.
13. The criminal justice system understands autism and knows how to support autistic people.
14. Autistic people have the same opportunities as everyone else to enhance skills and be as independent as possible.
15. There are supports for autistic people to get jobs and keep them.

We asked people to rank these statements from 1 – 15. We know that all of these statements are important, so we asked people to rank them in order of what they would like us to look at first. When looking at people's choices, the statements were allocated points based on where people had ranked them with the top statement receiving 15 points and the last statement allocated one. The table below shows the order in which people ranked them.



Overall, statements 7 and 10 concerning receiving a timely diagnosis and families getting help and support when they need it were clear priorities for people.

Following diagnosis and support for families people want us to look at making sure autistic people are accepted and safe in their communities, giving them the same opportunities as everyone else to be independent including getting and keeping a job and ensuring services know how to make reasonable adjustments for autistic people.

## What are we doing next?

We are continuing to develop an all-age Joint Strategic Needs Assessment for autism. This will look at what the national priorities are for autism, what we know about autistic people, their families and carers in North Yorkshire, the support they are receiving and gather more information on what the gaps are.

We will then use the feedback from this engagement, the completed Needs Assessment and what we know is still outstanding on the current autism strategy to develop a refreshed vision for the future and a new action plan.

We are aiming to publish the final needs assessment by the end of June 2020. We will then write a revised plan and speak to people about how to achieve the new priorities in their area in summer 2020.