




Northamptonshire  
County Council

## Cabinet Meeting

Tuesday 13 November 2018

### Agenda Pack Four for the following Cabinet reports:

 Denotes a key decision

Item No.	Subject	Page No	Responsible Cabinet Member	Contact name & Tel. no. (01604)
14. *	Northamptonshire All-Age Autism Strategy <ul style="list-style-type: none"><li>○ Annex 1 - All Age Autism Strategy Consultation Report</li><li>○ Annex 2 – Questionnaire And Full Results</li></ul>	3 – 25  26 - 100	Councillor Naden-Horley/	Bob Fletcher 363938



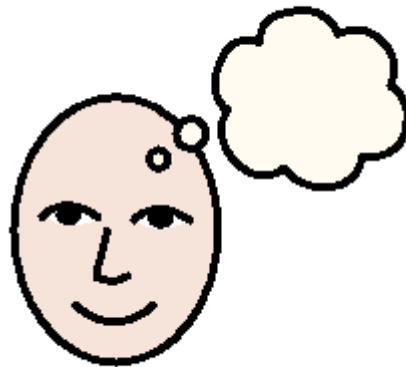


# **NORTHAMPTONSHIRE COUNTY COUNCIL**

## **Consultation on the draft Northamptonshire All Age Autism Strategy**

### **Consultation Analysis Report**

**August to October 2018**



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**Owner:** NASS, Northamptonshire County Council

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## 1. Introduction

Northamptonshire County Council (NCC), in partnership with Corby CCG and Nene CCG, produced a draft All Age Autism Strategy in response to the Government's Autism Strategy, Think Autism. Autistic individuals are important members of Northamptonshire's population and local demographics tell us that the number of children and adults being referred for an autism diagnosis is increasing.

Northamptonshire's draft All Age Autism Strategy was co-produced with involvement and engagement from a broad range of contributors, a number of whom are autism experts by virtue of lived experience.

The consultation sought views and comments from all interested parties to help influence the design and development of the final strategy. It was also an opportunity to instigate a wider conversation about autism and to dispel some of the myths surrounding people living with autism.

This report is an analysis of the information and data gathered during the consultation held between August and October 2018.

## 2. Background

Northamptonshire's draft All Age Autism Strategy sets out five local, multi-agency priorities and details how and when they will be met. The strategy requires an interagency response aimed at addressing the mental, physical, and emotional wellbeing of individuals, families, and carers living with autism, together with their housing, education, employment, social, and support needs. Given the nature of autism these needs cannot be met with information and advice alone. A proactive response from a range of universal agencies and organisations is required.

Northamptonshire's All Age Autism Strategy is committed to both the development and improvement of service provision and the overall experience of autistic people and their families. This will require a radical change in attitudes, involving honest and respectful collaborations. Continuous improvement of services can only be achieved by a well-trained, confident, and competent sector wide workforce.

### **The 5 priorities**

The earlier autism is identified, appropriate interventions started, and reasonable adjustments made, the better the outcomes. Key to success is the delivery of the following five priorities:

1. Raising awareness and understanding regarding the complexity of Autism.

2. Providing effective, quality assured, pre and post diagnosis support.
3. Enhancing education, employment, accommodation, social and leisure opportunities.
4. Promoting seamless progression throughout periods of transition
5. Providing effective and enabling care and support.

The All Age Autism Strategy sets out the detail of the five priorities along with national and local context including data and recommendations.

The aim of the consultation was to give an opportunity to check that the correct priorities are identified and to help with the development of the action plan.

### **3. Consultation Methodology**

The following outlines the public consultation methodology used to generate the material / data for analysis.

The consultation audience comprised of the following groups:

- Children, young people and adults living with autism (with or without a formal diagnosis of autism) and their parents, families, carers
- Stakeholder organisations with specific interest in autism
- Residents of Northamptonshire (i.e. the public)

Consultation was supported by Northamptonshire County Council's Consultation, Equalities & Accessibility Team (CEAT) and a Digital Improvement Officer. Professional leads from Northamptonshire Healthcare Foundation Trust and NCC were involved throughout and specialist advice was taken on communication methods. The consultation was hosted on a microsite within NCC's website and signposted by partner organisations.

The consultation was widely promoted focussing not only on people known to NCC and the CCGs because of a formal diagnosis of autism and their families/carers but also those not currently on NCCs/the CCGs radar.

To appeal to the broadest range of people possible, particularly those with autism and young people and address a variety of learning styles, a range of accessible consultation materials were produced and developed as follows:

- A dedicated online microsite containing:
  - a copy of the full draft strategy;

- an online questionnaire suitable for all
  - all the accessible/easyread consultation materials as described below
  - video animation of the five priorities; and
  - short plain English descriptions of each priority with clickable tiles leading to fuller explanations including actions and outcomes
- Accessible consultation materials using a mixture of plain English and Easy Read principles, utilising symbols where appropriate including:
    - an Easy Read version of the strategy;
    - a slide presentation with key information;
    - a discussion toolkit containing suggested activities and the materials for a facilitated group session;
    - a feedback form; and
    - a questionnaire suitable for all
  - Regular social media messages
  - Emails directly targeted at specialist support groups and schools and other key stakeholders
  - Articles in Northants Easy Read News (currently produced by CEAT)

The questionnaire is available at Appendix 2 and all other materials are available on the microsite

Separate accessible activities were developed for use by NCC and NHFT officers for use on a stand at the Rockin' Roadrunner Festival in September. The day long festival is aimed at people with disabilities and their families, friends and supporters. A description of the activities and the evidence gained from visitors to the stand is summarised in the feedback below.

## **4. Summary of Feedback**

This is an extensive summary of the feedback received from all the formats made available.

Please note that the term 'autistic person' reflects the term used in the strategy and current language. The term 'autism' includes everyone on the spectrum, whatever their ability and whatever their age.

### **4.a. Overall conclusion and summary**

Overall the strategy was welcomed and the priorities and actions agreed as the right ones.

A total of 162 questionnaires were received with the largest group of respondents (41.7%) being carers of an autistic person.

The majority of the total respondents found the strategy easy to understand but fewer respondents who identified as autistic found it easy.

The majority of respondents agreed with the vision in the strategy. A higher proportion of people who identified as autistic agreed with the vision than the total respondents.

A large majority of respondents to the questionnaire agreed with Priority 1 including those people who identified as autistic. Fewer of the total respondents were sure that the actions were the right ones than people who identified as autistic. Nearly all of the people who identified as autistic thought the actions were the right ones compared to the 77.8% of the total group and the 18% who said don't know/not sure.

A large majority of all respondents to the questionnaire agreed with priority 2 including those who identified as autistic. No one who identified as autistic thought the actions were not the right ones whilst 5.3% of total respondents did not think they were right. Around 15% of both said don't know/not sure.

A large majority of respondents to the questionnaire agreed with Priority 3 including people who identified as autistic. Around three quarters of those who identified as autistic thought the actions were right with the remainder unsure. More of the total group thought the actions were right but a small number thought they were not.

The majority of all respondents to the questionnaire agreed with Priority 4 including people who identified as autistic. Fewer people who identified as autistic thought the actions were the right ones with a fifth saying don't know/not, nearly double the proportion of total respondents.

A majority of respondents agreed with this priority and few said don't know/not sure. A higher percentage of respondents who identified as autistic said they did not agree but this amounted to two people.

## **4.b. Detailed Feedback**

The feedback is grouped under the opening questions in the questionnaire then by the five priorities as far as possible. There is a section containing general feedback that did not fit into these categories followed by the equality monitoring information, summary of emails and letters, social media and digital report and finally the Rockin' Roadrunner event.

In addition to the general summary of total responses to the questionnaire, specific responses provided by those who identified themselves as autistic people are highlighted as these are particularly important in finalising the strategy and actions. The full range of verbatim comments entered into the questionnaire can be found at Appendix 2.



Not all respondents answered every question and so percentages are shown based on the number of respondents to each question. Some questions asked respondents to enter free text to explain why they rated a question as they did. There is a brief summary of the most apparent themes to emerge from these questions and a full list of the comments is attached in Appendix 2.

**Opening Questions**

*Question: Please tell us a little bit about yourself and why you are completing this questionnaire?*

A total of 162 questionnaires were received with the largest group of respondents (41.7%) being carers of an autistic person. Autistic people with or without a formal diagnosis accounted for 14.2% of respondents. Of these 4.9% also had a learning disability. A further 8.6% of respondents said they were supporting an autistic person to complete the questionnaire and 2.5% of these also had a learning disability. It could therefore be assumed that 22.8% of respondents may be autistic. 11.7% of respondents stated they are professionals supporting autistic people, 4.3% said they did not want to answer and 1.2% said they did not know or were not sure. The remaining 19.1% responded as ‘other’. Many of these had a different family relationship or caring role.



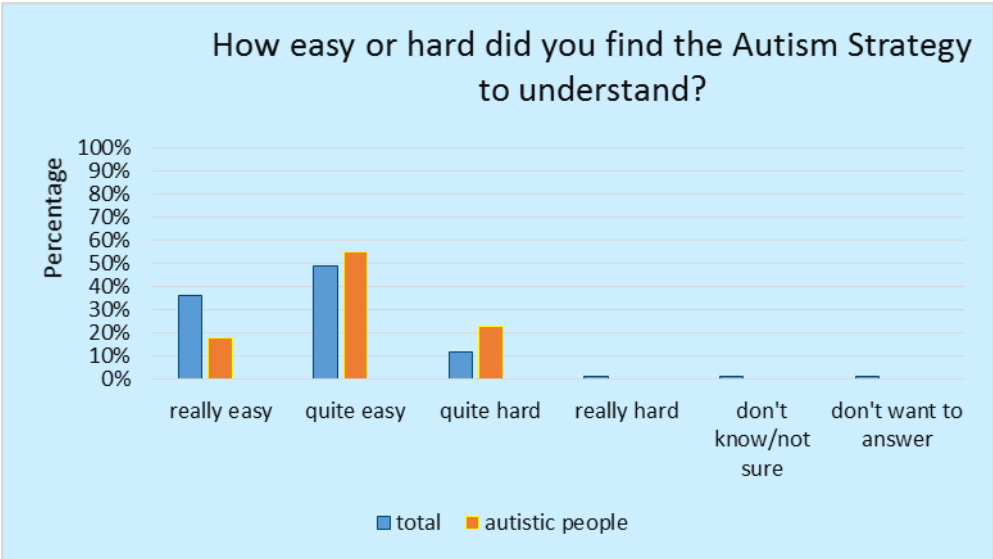
Full description of respondents:

I am an autistic person (either with or without a formal diagnosis)
I am an autistic person (either with or without a formal diagnosis) and I have a Learning Disability
I am supporting an autistic person (either with or without a formal diagnosis) to complete this questionnaire
I am supporting an autistic person (either with or without a formal diagnosis) who also has a Learning Disability to complete this questionnaire

I am a carer for an autistic person (either with or without a formal diagnosis and either with or without a Learning Disability)
I am a professional supporting autistic people (either with or without a formal diagnosis and either with or without a Learning Disability)
Other (please give details):
Don't know or not sure
I don't want to answer this question

Question: How easy or hard did you find the Autism Strategy to understand?

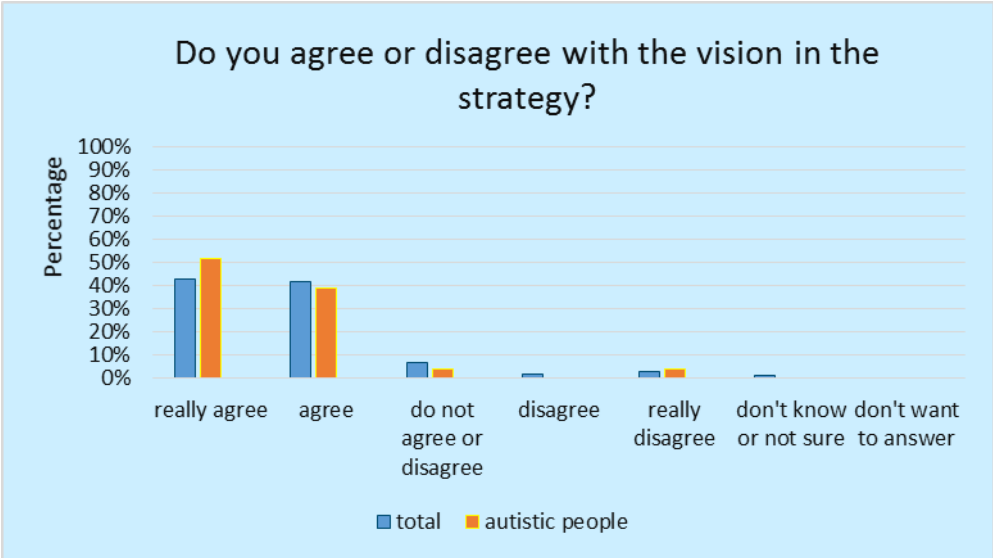
160 respondents answered this question. 85% of respondents stated that the strategy was either really or quite easy to understand. 11.9% found the strategy quite hard to understand and 1.2% (2 people) found it very hard. The remaining 1.9% said either did not know/not sure. A smaller proportion of people who identified as autistic, 72.7% found the strategy really easy or quite easy to understand. 22.7% found it quite hard to understand and 4.55% (1 person) really hard.



When asked why they gave their answer 3 out of the 8 people who identified as autistic commented positively about the clarity and layout, 3 made neutral comments, 1 found having draft behind the text difficult and 1 stated the strategy was all talk and no action and they did not trust it would be delivered due to staff performance. Of the additional 45 total comments there were 23 positive remarks about the style, for example, Plain English, easy read, clarity and the video. Whilst 3 mentioned that an individual would find it difficult to understand because of their learning difficulty, dyslexia or autism. The majority of the remaining comments referred to the 'lack of specifics', or a 'coherent action plan', 'what it is actually going to do', 'how things will happen beyond vague statements' or variations on this theme.

*Question: The vision is to develop and improve services and the experiences of autistic people and their families in Northamptonshire over time. Do you agree or disagree with the vision in the strategy?*

All the respondents answered this question and 21 of the 23 people (91.3%) who identified as autistic either agreed or really agreed with the vision. 1 neither agreed or disagreed and 1 really disagreed. A slightly smaller proportion (86.5%) of the total respondents either agreed or really agreed. 7.36% neither agreed nor disagreed whilst 4.9% either disagreed or really disagreed.



In response to the question about why they gave their answer, of the 69 comments made a large number expressed their feeling that the vision is good or valid but it is hard to see how it will be made a reality. Some pointed to current financial difficulties of the County Council making it unrealistic especially as they believe some of the implementation will come at a cost. Half of the comments provided by the 10 people who identified as autistic referred to their negative experiences of getting help, support or opportunities.

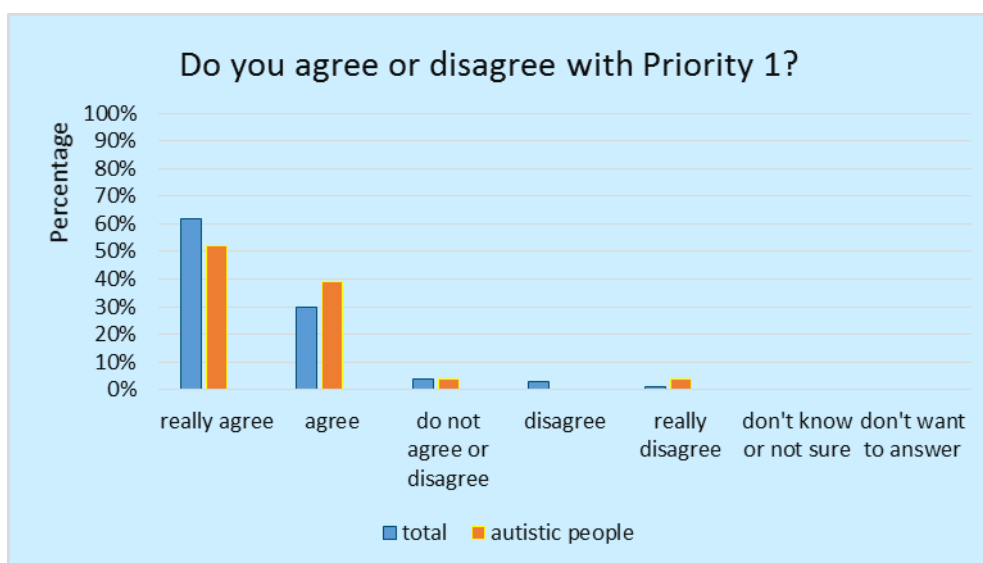
Written correspondence referred to a need for a lot more detail about what will actually be done to deliver the strategy, the use of SMART targets and quality assurance. This was reflected in the responses in other formats and in reference to each priority.

## Feedback by priority

### Priority 1

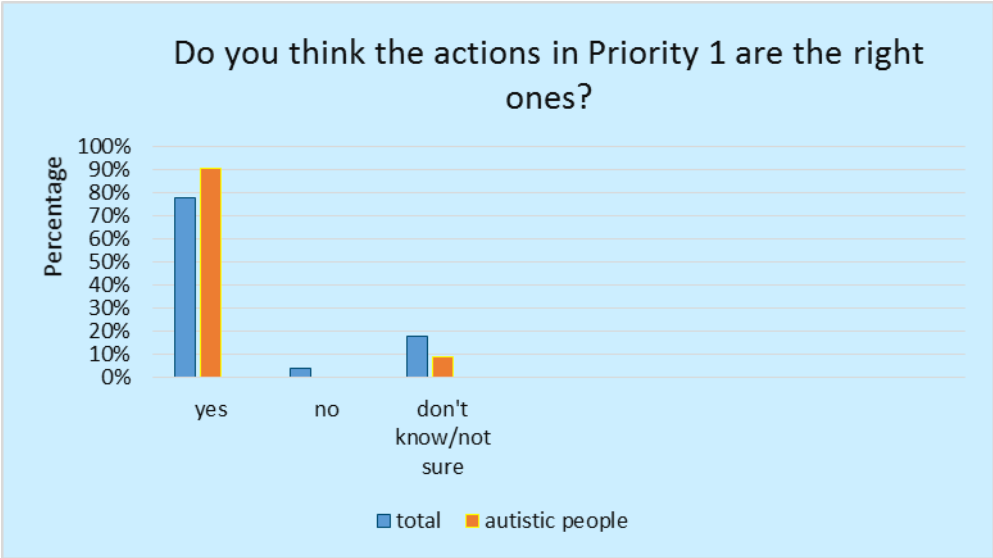
*Question: Do you agree or disagree with Priority 1: Raising awareness and understanding regarding the complexity of autism?*

All people who identified as autistic answered this question and more than 9 out of 10 (95.7%) either agreed or really agreed with Priority 1, only one person neither agreed nor disagreed and none disagreed. Only slightly fewer (91.8%) of the 61 of the total respondents that answered agreed or really agreed, 4.1% neither agreed nor disagreed and the same number (6) either disagreed or really disagreed.



In relation to this question all but one of the comments by people who identified as autistic reinforced how important it is to raise awareness of autism and this related to a range of groups including professionals, communities and society as a whole. This is reflected in the total responses but in addition there are a number of notes that urge recognition of autism as distinct from other disabilities, as being complex and hidden.

Respondents were also asked if they thought the actions in Priority 1 were the right ones and if any actions were missing or should change. All of the 23 people who identified as autistic answered this and 91.3% said yes whilst only 2 stated they didn't know/not sure. 144 of the total respondents answered with 77.8% saying yes, 4.2% saying no and 18.1% don't know/not sure.



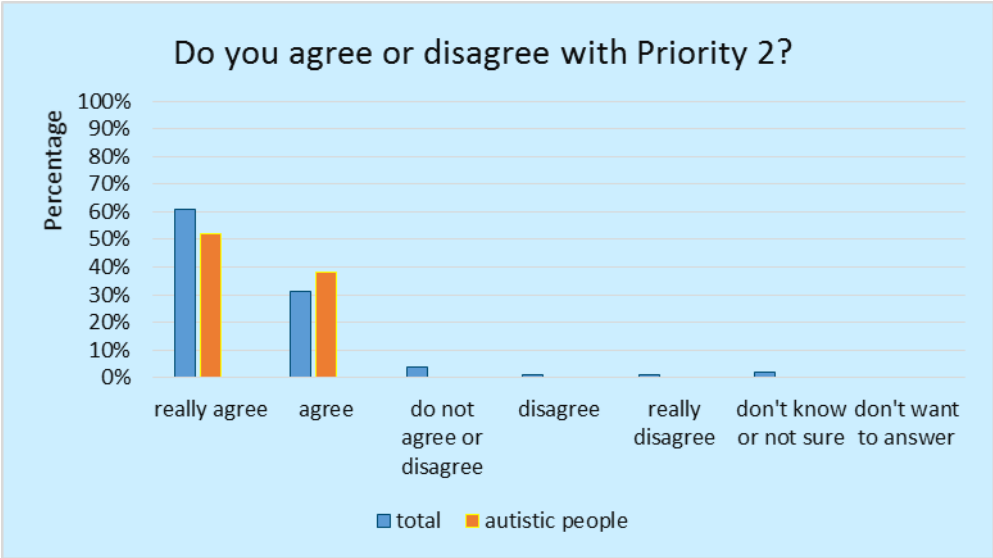
One person identifying as autistic suggested an additional action to run workshops about autism. Other respondents also suggested workshops plus online resources and a few suggested that better defined outcomes or agreed standards are required.

Other sources of feedback suggested that all social workers and teachers should receive basic training and all awareness training should involve participants with a lived experience of autism.

**Priority 2**

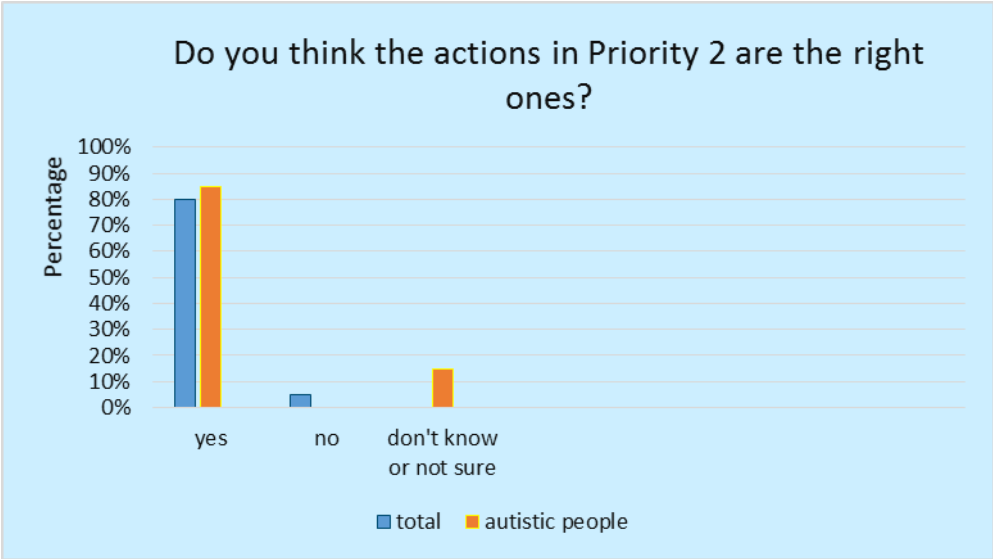
*Question: Do you agree or disagree with Priority 2: Effective, quality assured, pre and post diagnosis support?*

21 of the 23 of the people who identified as autistic answered this question and 90.5% agreed or really agreed with Priority 2. Just 2 neither agreed nor disagreed. 135 of the total respondents answered and 92.6% agreed or really agreed. 3.7% neither agreed nor disagreed whilst 1.5% disagreed or really disagreed.



When asked why they gave their answer 4 of the 7 people identifying as autistic referred to the significant wait for a response or lack of any sort of support even after a diagnosis. There were 55 responses in total to this question and the comments strongly echo the feeling that there is little or no pre or post diagnosis support for very long periods of time or never. A few respondents suggested this should be the number one priority and mentioned the negative impact on the individual and their family, partly because of the need to ‘fight’ for support.

Respondents were also asked if they thought the actions in Priority 2 were the right ones and if any actions were missing or should change. The majority of the total 132 respondents and the 20 who identified as autistic said yes, actions were right, 79.5% and 85% respectively. No one who identified as autistic said they were wrong but of the total 5.3% said they were. Around 15% of both said don’t know/not sure.



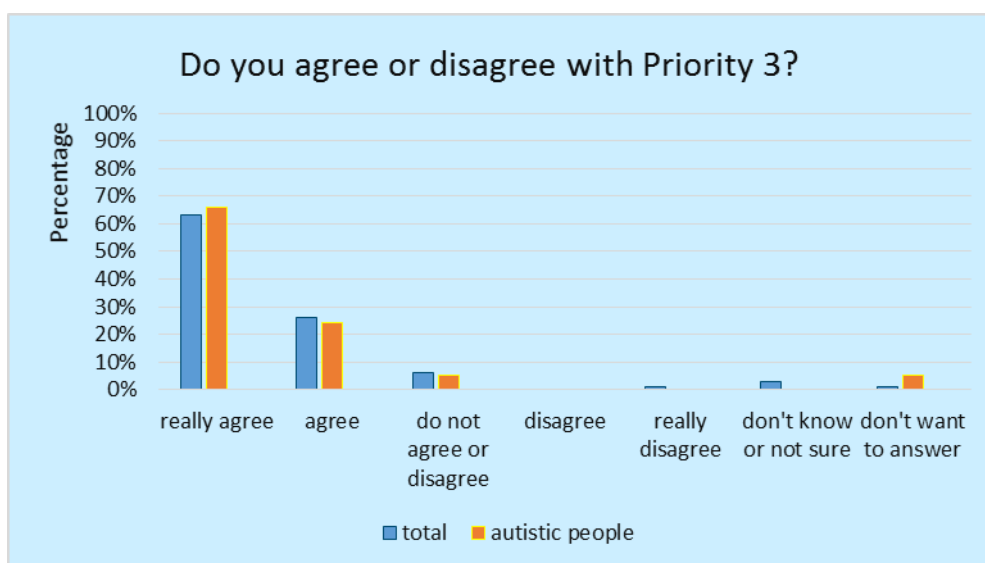
Changes or omissions in Priority 2 included making things more accessible and easier to understand for individuals with no support from friends and family; support being individualised and made available when it is needed rather than a once only offer; and a variety of comments again asking for more detail and timescales for delivery. Amongst the comments about personal difficulties with diagnosis is one alluding to under diagnosis in girls and the subsequent harm.

Other sources of feedback also pointed out the under diagnosis of girls as they are ‘clever’ at masking or playing down any difficulties they might be experiencing. Some respondents also felt that post diagnosis support is currently either non-existent, intermittent or inconsistent for both autism and other related health issues and is only gained by the repeated request by really insistent families. A plea was also made for respite for exhausted parents. Sources of support are viewed as too Northampton centric.

### Priority 3

*Question: Do you agree or disagree with Priority 3: Enhancing education, employment, accommodation, and life opportunities?*

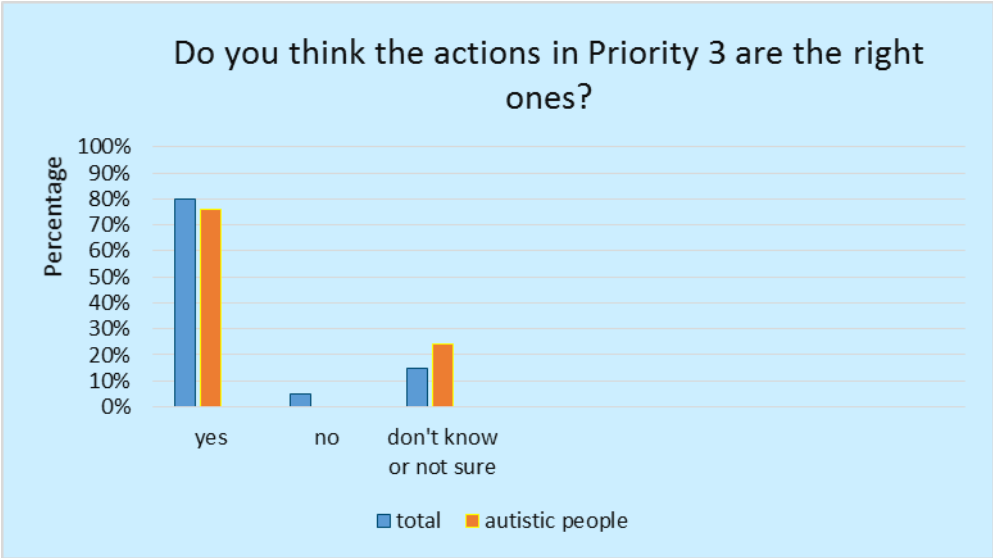
90.5% of the total respondents (134) either agreed or really agreed with Priority 3; 3.6% neither agreed nor disagreed; 1.5% really agreed; 2.2% said don't know/not sure and 1.5% did not want to answer. All but one of 21 of the people who answered this question and identified as autistic either agreed or strongly agreed with Priority 3. The remaining person neither agreed nor disagreed.



When asked why they gave their answer a number of the 56 respondents focussed on the need for educational support in order to transition into employment and /or to make the best use of life chances and increase social confidence. Whilst increasing employment opportunities and help to achieve employment was supported some respondents are sceptical about the existence of such opportunities and help and the likelihood of gaining the understanding of or successfully engaging with employers/businesses. Others indicated that autistic people had much to offer in the workplace and others suggested that early and long term personal plans are key to success.

76.2% of the people identifying as autistic thought the actions in Priority 3 were the right ones whilst the remainder said don't know/not sure. 80.1% of the total respondents said yes the actions are right, 4.6% said no and 15.3% said don't know/not sure.

Other sources of feedback suggested that positive social relationships are important in achieving full potential. A number felt that more reference should be made to the important role of education and early intervention. Also that Education, Health and Care Plan (EHCP) should continue to play a key role. There is a view that there is a lack of youth groups for autistic people.



When asked about changes or omissions to Priority 3 a number of people felt there was less clarity about what the actions were compared to other priorities. The responses tended to be negative about the likelihood of meaningful job opportunities rather than courses or ‘dead end’ jobs. Individual comments indicated that additional actions are needed on early years/school/early intervention/people who are home educated and more of an emphasis on empowerment and independence.

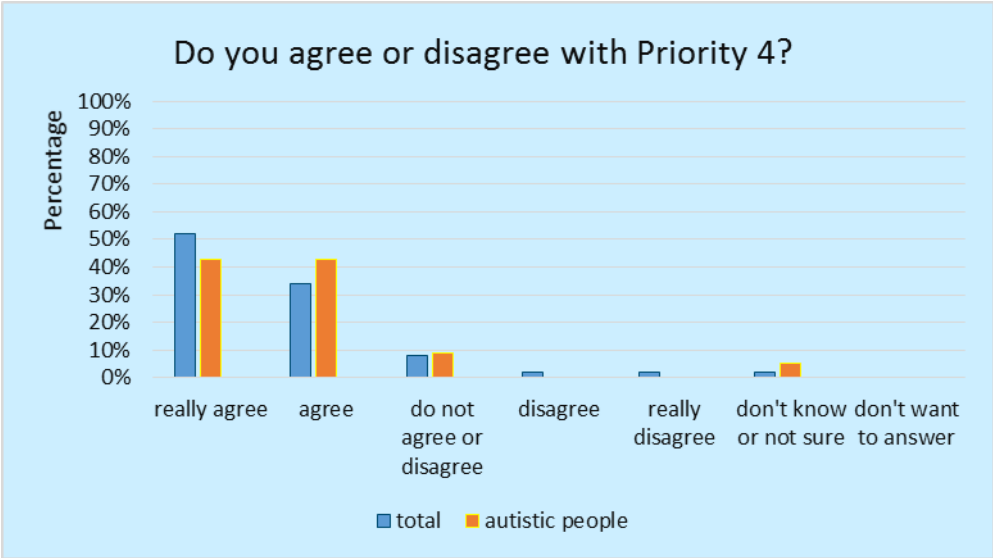
Other sources of feedback stressed the need for early intervention and education including support for families. It was also suggested that more and better use should be made of EHCP’s in accordance with the guidance. Some feedback suggested that the needs of autistic people in mainstream education are neglected.

**Priority 4**

*Question: Do you agree or disagree with Priority 4: Seamless progression throughout periods of transition?*

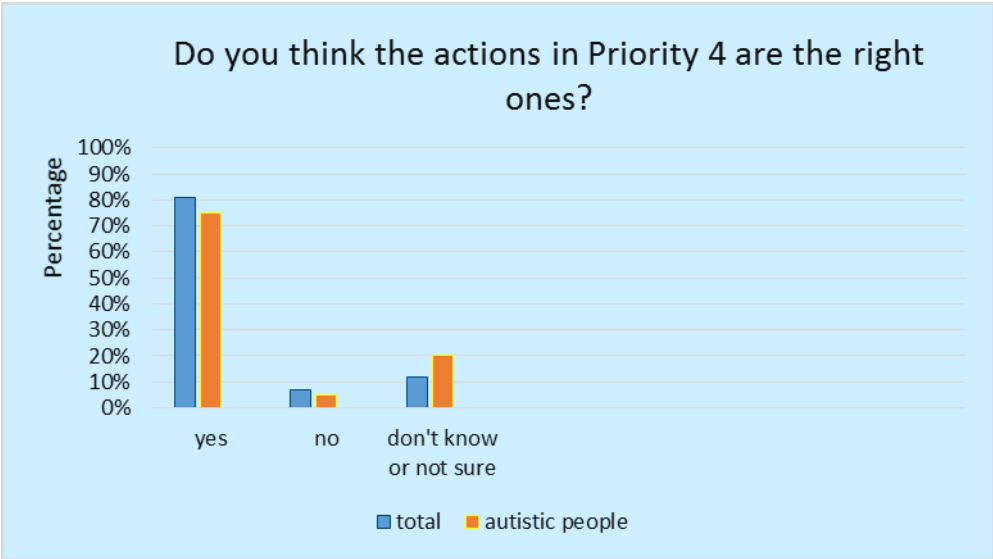
A total of 131 people answered this question and 87% either agreed or really agreed with Priority 4 whilst 7.6% neither agreed nor disagreed. 3% disagreed or really disagreed and 3% said don’t know/not sure. Similarly 85.7% of the 21 people who identified as autistic either agreed or really agreed but none disagreed.





In relation to this question, 4 of the 5 people who explained their reasons and identified as autistic were emphatic that support during any period of transition is crucial and should carry on throughout their lives. The remaining person expressed the same opinion made throughout that they had no confidence in the delivery of the strategy. Similarly the comments from 42 other respondents echoed the view that support through transitions throughout life is vital and movement between services should be seamless. This second group, however, expressed concerns that this is a long way from the current position and not likely to be achievable.

Of the 127 total respondents, 81.1% agreed that the actions in Priority 4 were the right ones whilst 7.1% thought they were not. A further 11.8% said don't know/not sure. Of the 20 people who identified as autistic, 75% thought the actions were right, 5 did not and 20% said don't know/not sure.



Fewer comments were received about the actions that were missing or should change for this priority. Some concerns were expressed about the resources being available to achieve the actions and although collaboration was supported there was a plea to make sure consent is gained before sharing information. It was also suggested that autism leads should have qualifications and experience.

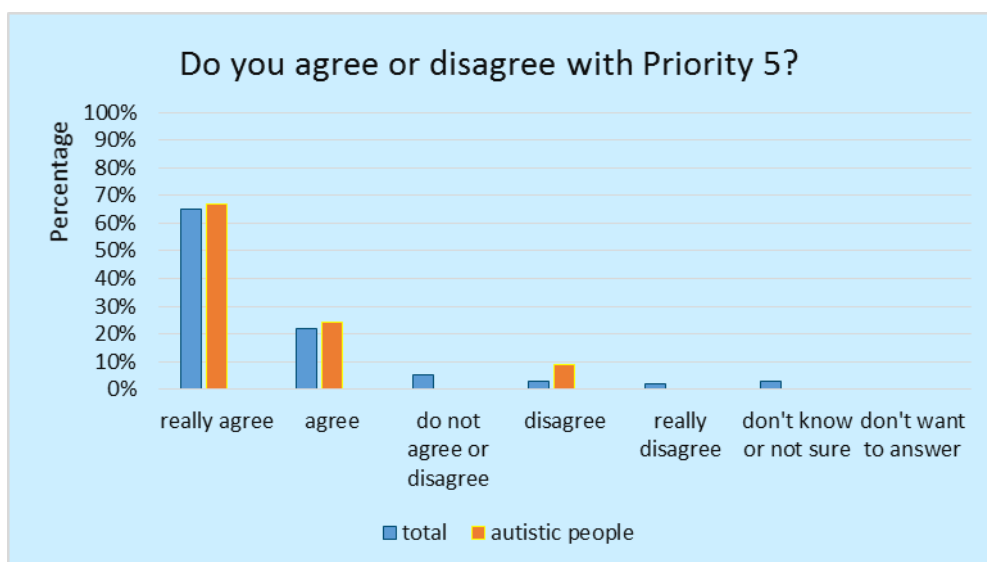
One piece of written correspondence noted that “Change in itself is a source of anxiety for people with autism, and on top of this meetings and procedures often cause great stress and anxiety.” Others also said that having to repeatedly explain needs makes matters worse.

**Priority 5**

*Question: Do you agree or disagree with Priority 5: Providing care and support that empowers autistic people?*

86.9% of the 130 total respondents either agreed or really agreed with Priority 5 whilst 4.6% either disagreed or really disagreed and 3.1% said don't know/not sure. Of the 21 people who identified as autistic that answered, 90.5% either agreed or really agreed and 9.5% disagreed.

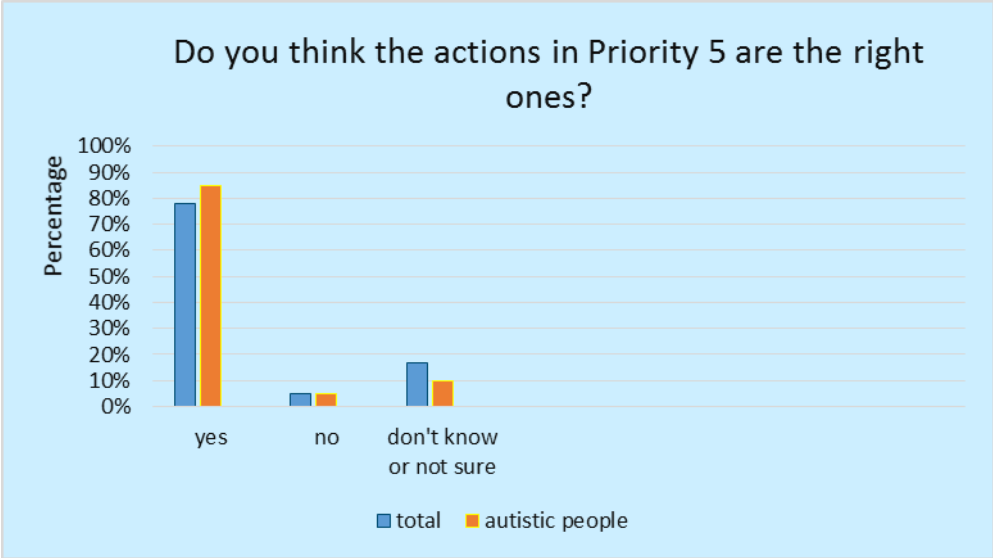
Other sources of feedback suggest that support will only be successful if teaching is on a one to one basis and tailored to how the individual sees the world and that communication strategies and approaches to supportive behaviour and understanding are required.



The comments from 7 people who identified as autistic were supportive of Priority 5 but 3 pointed out that there was a lack of understanding that they might need support to be independent or motivated as they were in work or appeared to be coping. The 40 comments from the total respondents were also strongly supportive of the priority

and although many felt it was a right for anyone, it was not generally understood and needs to be tailored to individuals.

Of the 121 total respondent, 77.7% thought the actions in Priority 5 were the right ones, with 4.9% saying they were not and 17.4% don't know/not sure. There was a little more certainty from people who identified as autistic as 85% thought the actions were right, 5% thought they were not and 10% said don't know/not sure.



In total 19 respondents (including 4 who identified as autistic) commented on the actions in Priority 5 and these tended to be negative about the current situation and the ability to deliver the actions in the future. One suggestion was made to have a panel of individuals, carers and professionals to work alongside the multi-agency team to keep it person-centred.

Some written correspondence supported Priority 5 but recognised it as a real challenge to deliver. Co-production and continued involvement in the development and delivery of the strategy was reinforced and seen as vital to success.

*Question: Please tell us if we need to look at anything else in the Strategy?*

There were 64 responses to this question including from 13 people who identified as autistic. There were general comments concerned about funding/deliverability and about more support for autistic people and their carers from trained professionals, also some that reinforced the actions already in the strategy. Other more specific comments made are summarised as follows:

- Autism is not a standalone condition – it can be associated with other conditions and attention should be given to these including other learning difficulties
- Education, Health and Care Plans are still crucial
- There should be a standard diagnostic process across the county
- Access to mental health services for high functioning teens

- Individuals should determine how they define their autism
- Support to obtain benefits
- Respite for parents
- Applied behaviour therapy (Applied Behaviour Analysis or ABA) is abusive and should not be used by NCC
- Sensory processing should be part of the assessment
- Housing and homeless claims should accommodate Autism and reasonable adjustments should be made
- Emotional mental wellbeing activities/hobbies/interests which can be accessed alongside increased social support groups
- Quality assurance
- Working with charities that already provide support and working with autistic people as employees or volunteers or parents that have expertise
- Early intervention and integration in society i.e. education
- Ensure the autism champions are passionate about it and not just given the role for the sake of it or their level in the organisation.
- Autism alert cards (other Safe cards not appropriate)
- A crisis support team who have real knowledge of autism
- More user friendly website and phone numbers that can be used when someone is struggling with support
- Autistic advocates
- Good practice model and training in the Criminal Justice system including Magistrates and Crown Court
- An early focus on individual interests alongside social skills, to build these strengths that can lead to employment
- Make sure there are no acronyms in diagrams
- SMART targets
- Short term support is potentially wasted as it takes time to build a relationship with an autistic person
- Support services are Northampton centric

### **General feedback from all sources**

A few respondents to the consultation disagreed with the term 'autistic people' and suggested use of the term 'people with autism'.

There were numerous negative comments about the ability to achieve or deliver the strategy and actions.

One person took the opportunity to say any money should be given to libraries.

One person objected to the use of the word 'less' instead of fewer' in the easy read version of the strategy.

One person thought the consultation was aimed at groups and not individuals.

## Equality monitoring

NCC's standard equalities monitoring questions were adapted to include only crucial information about the respondents including those who identified as autistic or supported those that were. Although most individuals answered these questions, not all respondents chose to complete this section of the questionnaire and not everyone answered each question. (98.5% of responses were individuals and 1.5% or 2 from groups). It should be noted however, that some groups responded using other methods.

The largest number of respondents (39.8%) said they live in Northampton Borough. The lowest number contributed from Wellingborough and Corby boroughs (both 6.3%). None of the respondents identifying as autistic said they lived in Corby.

Most of the total respondents stated that they were female (67.8%) compared to the 60% of people who identified as autistic and stated they were male. All but 4 of the respondents stated their gender identity was the same as at birth and none of these identified as autistic.

Most respondents were aged between 30 and 49 years (43.8%). The next largest group of total respondents was aged between 50 and 64 in comparison to people who identified as autistic for which it was 19 to 29 years.

A large proportion of the 50 respondents said they had a disability with mental health highlighted most frequently, followed by a learning disability then physical health. This was mirrored by the 16 respondents who identified as autistic.

When asked if they thought they had an Autistic Spectrum Condition (like Autism or Asperger's Syndrome), 28.9% said yes.

Predominantly, respondents identified themselves as White British (84.2%), although 100% of people who identified as autistic said they were White British.

Respondents were asked about their work situation and 28.6% of those who identified as autistic said they were in paid work whilst 19% are in full time education and 9.5% said they are unable to work. 53% of all respondents said they are in paid work and 4.3% said they are unable to work.

90.5% of respondents who identified as autistic described themselves as single compared to 28.9% of the total.

Just under half of people who identified as autistic said they lived with family whilst slightly less said they lived in their own home. Of the total respondents, 37.3% said they lived with family and exactly half said they lived in their own home.

Full equality statistics from the responses can be found in Appendix 2.

## Letters and emails

Correspondence was received from 6 members of the public, Northamptonshire People First, Shooting Stars (a facilitated group feedback form), Healthwatch, Arnold House Children's Home, the Children and Young People's Commissioning Leads at NHS Nene and NHS Corby CCG, NASS Learning Disability team, Northamptonshire Special School Head teachers (NSSH), plus general agreement to the strategy from the Mental Health Transformation Board. Collyweston Parish council replied but stated they had no feedback.

Most correspondence from the members of the public described their difficult personal journeys as people who identify as autistic or their experiences supporting someone/some people with autism either personally or professionally. Where possible specific comments have been added to the feedback about the appropriate priority above.

Northamptonshire People First thought the priorities were good in principle but questioned if they could be put into practice because of financial constraints. To be successful the group thought the right kind of support is key, professionals need to be understanding and caring but above all support needs to allow time for a consistent, positive approach.

Overall the 13 young people at Shooting Stars agreed with the 5 priorities but felt most positive about Priority 4 relating to seamless transition.

Healthwatch welcomed the strategy and its stated intentions but also raised a number of questions and concerns that they did not feel were addressed in the document. The organisation stated that it was pleased to see the acknowledgment of some of the problems with the current pathways and services and it was in agreement with some of the stated actions. The organisation went on to make suggestions under each priority for further actions and improvements. There was also a strong thread of working in partnership with, involving or co-producing with "autistic people and parents/carers of children with autism in the design and delivery of services." An additional recommendation was made for "an independent advocacy panel [to be] formed that carers/service users can contact to raise issues with services to ensure that their voices are heard."

Arnold House Children's Home suggested that the term people with autism should be used instead of autistic people as the child comes before the disability in their service.

The CCG commissioning leads made a few general comments that included: there is not an equal emphasis on adults and children; there is a lack of local data and information or examples of good integrated pathways; and it is unclear what the actions will achieve or if some of the evidence described is already available. Detailed and specific questions and suggestions were also made page by page. The Commissioning leads went on to recommend an Autism specific Joint Strategic Needs Assessment, scoping of current services, definition of what good ‘looks like locally’ and involvement of autistic people and their families / carers in this.

A letter sent on behalf of Northamptonshire Special School Head teachers (NSSH) expressed disappointment that special schools were not included in the development of the strategy although they also recognised that there were a broad range of other contributors. They felt there are strengths in the vision but some missed opportunities such as more attention to support for children and young families, robust measurable outcomes and some aspects of Quality Assurance. Other comments, such as those about transitions and other learning difficulties reflected responses to the questionnaire.

Following group discussion the NASS Learning Disability Team expressed their strong agreement with all the 5 priorities and went on to describe why they thought they were so important. In addition they echoed other respondents by saying that early intervention based on individual need is key.

### **Social media and digital report**

The use of a microsite and promotion by social media was successful in ensuring the strategy and consultation were widely shared. A detailed digital report is available separately.

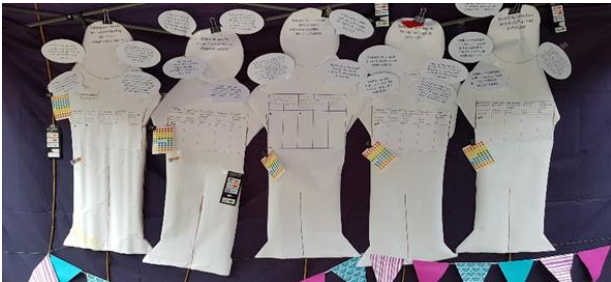
In summary:

- Content on Facebook was widely shared.  
The first 3 posts: reached 27,300 people; were clicked 1,373 times; and received 361 engagements
- Website visitors: There were 1,954 unique page views of the autism consultation homepage during the consultation and in the first 24 hours it was the third most visited page on the site behind the NCC homepage and school term dates
- There were a number of high profile positive references to the strategy and consultation including by the BBC and Northants Telegraph
- Referrals to the website are summarised in the table below.

Source	Referrals
Facebook	741
Google	589
Northampton Chronicle and Echo	106
Twitter	104
Informer	72
Bing	57
BBC	31
NHFT intranet	9

The Responses received on social media were in the main based on personal experiences of the current pathway and services. The majority of these experiences were negative and are focussed on the slowness of pathways and diagnosis, inadequate education and funding, training of staff and general criticism of the Council itself.

**Rockin’ Roadrunner event**



The aim of attendance at the Rockin’ Roadrunner event was to reach people who may not ordinarily be linked in to the activities of the Council, and to offer an alternative method to gain qualitative evidence. Activities were developed to complement the online microsite and other accessible materials. The focus was on the priorities and actions.

In summary more than 40 people including youngsters, family members, and carers, many with a lived experience of autism took part and 31 responses were recorded. Almost all of the people that visited the stand agreed strongly with the priorities. The results reinforced the work of the strategy development group and its inclusive



methods that involved people with lived experience throughout. Visitors made some important additional comments that are incorporated above.

## **5. Conclusion**

Substantial feedback was received to this consultation from autistic people, families and carers, professionals, and interested members of the public, which, when combining questionnaire responses with attendance at events and letters and emails, totalled over 200 responses.

Overall the strategy was welcomed and the priorities and actions agreed as the right ones.



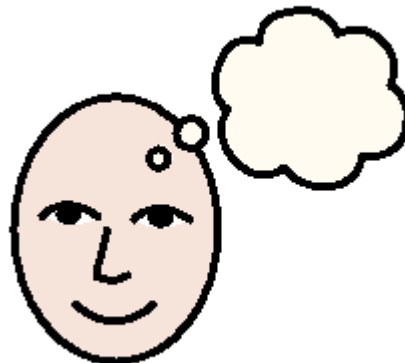
# **NORTHAMPTONSHIRE COUNTY COUNCIL**

## **Consultation on the draft Northamptonshire All Age Autism Strategy**

### **Appendix 2 – Copy of Questionnaire and Full Results (redacted where appropriate)**

**August to October 2018**

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**Author:** Consultation, Equalities & Accessibility Team, Northamptonshire County Council

**Owner:** NASS, Northamptonshire County Council

# Have Your Say about Northamptonshire's All Age Autism Strategy 2018-2021

## Questionnaire

We would like to know your views about the Autism Strategy for Northamptonshire.

This draft Strategy was written by a very mixed group of people in a steering group that included autistic people and family members and carers. It says how different local organisations in Northamptonshire will work together to support autistic people of all ages in a much better way throughout their lives.

Please read the draft Autism Strategy and then tell us your views by filling in this questionnaire. There is also an **easy read copy** of the Strategy. What you tell us will help us to understand what is important to autistic people and their families and make sure that we are focusing on the right things. What you say will be part of a report with many other people's feedback, so you will not be personally identified and your views will help to decide what goes in the final Strategy, , which will be agreed and adopted by local partners.

We understand that some people find it hard to fill in questionnaires, so please feel free to ask a family member, friend or carer to help you fill it in. If you need help to fill in this questionnaire and have no family or friends that can help you, then please call the telephone number below and we can offer some help.

You do not have to answer all of the questions. You can tick the box to say you do not want to answer and move on to the next question.

If you have any queries, comments or would like a copy of this survey in another format (including larger print) you can contact us by email, post or telephone. You can also read the supporting information and complete the questionnaire on our website. Our contact details are as follows:

**Email address:** [consult@northamptonshire.gov.uk](mailto:consult@northamptonshire.gov.uk)

**Website:** [www.northamptonshire.gov.uk/autism](http://www.northamptonshire.gov.uk/autism)

**Telephone:** 01604 367253 (NASS Business Support)

**Postal address:**

Consultation, Equalities & Accessibility Team

Northamptonshire County Council

One Angel Square

Angel Street

Northampton

NN1 1ED

The deadline for completing this survey is 5pm on Sunday 7<sup>th</sup> October 2018.

**Thank you for helping us by completing this questionnaire.**

1. Please tell us a little bit about yourself and why you are completing this questionnaire (please tick one ✓):

There were 162 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I am an autistic person (either with or without a formal diagnosis)	9.26%	15
I am an autistic person (either with or without a formal diagnosis) and I have a Learning Disability	4.94%	8
I am supporting an autistic person (either with or without a formal diagnosis) to complete this questionnaire	6.17%	10
I am supporting an autistic person (either with or without a formal diagnosis) who also has a Learning Disability to complete this questionnaire	2.47%	4
I am a carer for an autistic person (either with or without a formal diagnosis and either with or without a Learning Disability)	40.74%	66
I am a professional supporting autistic people (either with or without a formal diagnosis and either with or without a Learning Disability)	11.73%	19
Other (please give details):	19.14%	31
Don't know or not sure	1.23%	2
I don't want to answer this question	4.32%	7
	Answered	162
	Skipped	2

Other:

- I am a parent of a person with autism
- 1 5 and 6
- Friend of person with asd
- I have Asperger's Syndrome with a formal diagnosis.
- I am autistic, and care for autistic child
- resident's panel
- I taught Autistic children for 16 years
- Parent of Autistic Person, not just a carer.
- N/A
- Mother of an autistic child
- I am a Mother of an adult with Asperger's Syndrome.
- Library Manager who meets Autistic people daily
- have foster grandchildren with autism
- I also have autistic children and grandchildren
- I am step mum to a child with autism
- Interested resident.
- Autistic single mother of an autistic child
- I'm Autistic myself. I care for 3 people who are Autistic and I'm run a support group for people on the spectrum.
- I am a support worker for an autistic person with a learning disability.
- I run a support group for sufferers of depression and anxiety. Meetings are held at Mind.... some members have autistic spectrum disorders
- Invited to respond
- N/A
- I know several people on the autistic spectrum (none in county). And I have seen mental health issues swept under the carpet by service providers. This has to stop.
- Friend of someone with 19yr old probably autistic son

- I'm a parent of a autistic female and also work for a local organisation supporting autistic adults.
- an interested Northamptonshire Council taxpayer
- My brother is autistic and has LD
- I am the grandparent of an autistic child
- My grand daughter has Autism.
- Concerned observer
- on the panel

2. How easy or hard did you find the Autism Strategy to understand? Please tick one ✓

There were 160 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I found it really easy to understand ★★★★	36.25%	58
I found it quite easy to understand ★★★	48.75%	78
I found it quite hard to understand ★★	11.88%	19
I found it really hard to understand ★	1.25%	2
Don't know or not sure	1.25%	2
I don't want to answer this question	0.63%	1
	Answered	160
	Skipped	4

3. Why did you give that answer?

There were 53 responses to this question.

- I am a former professional qualified to degree level and am used to accessing information from reports
- Clear layout and aims
- The plan is unclear as to how. No specifics or strategy as such over and above what should be in place at present
- Based on my background it was easy to read however I feel that it lacks a coherent action plan. Lots of information to explain and justify and then little what the strategy will do to make a real difference.
- It isn't a difficult strategy to get to grips with!
- Written clearly in easy to understand language
- It was quite clear in the message it's was trying to put across
- It was clear and concise. The font used was good. It was simple and didn't cause confusion.
- It was easy to understand the words.
- It is not written in plain English and is too vague
- 5 simple caregories
- I dont think it would be easy for someone with learning difficulties to understand
- Well laid out - but big wall of text.
- I have aspergers
- Because it doesn't cover any of my concerns and leaves things up in the air. Shouldn't a lot of these be covered already anyway?
- Bullet points after each paragraph helped to understand and breakdown ls meant by each section
- My autistic daughter also has Dyslexia, so she would struggle
- I found it easy to understand but would be interested to know more about the specifics.
- It was clearly explained.
- Sometimes I do find it tricky to understand something when reading about something at first. But when I read it again, not



only will it be clear, but to ensure myself that I understand the information correctly that I want/need to acknowledge.

- Sometimes it does get tricky if I didn't understand reading something at first. But when I read it again, not only will it become clear, but to ensure myself that I get correct information that I want/need to acknowledge.
- because I am not sure how it will help the young men, (my sons) that I care for.
- All talk and no action, no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance)
- it read well but not really clear on what it is going to actually do.
- It doesn't explain how things will happen beyond vague statements.
- all good intentions, need to see them followed through
- The text was in a good font, format and used clear and plain English words, phrases, paragraphs, etc. Thank you
- It was clearly laid out and easy to follow.
- There is an overall lack of specific information about each area of the strategy. there is no in-depth explanation about what this will look like at service delivery level, what agencies will be involved or any outline around joint funding. Much of this information given in at a surface description level and as such does not provide enough information for individuals to provide clear feedback on their opinions.
- Easy to read, split into sections with good explanations
- rather a wordy document
- Very simple and shallow statements
- I am also a retired Nurse so very used to reading papers.
- read the easy read version which was easy to understand
- The information is clear and concise.

- The word draft behind the writing didn't help processing the document and was distracting
- I personally found it easy to understand but to be honest, some parts were a bit wishy-washy and I can see how someone with ASD and/or a learning disability might not fully understand the strategy as it's currently written.
- Some of the terms need explaining more in practical terms.
- I was disappointed to read 'autistic people' as this creates a label. 'People with autism' would reflect the person first and diagnosis after.
- Because autistic people see the world from a different angle and as such it is difficult to communicate.
- I thought it was straight forward and to the point
- Some parts needed re-reading to understand fully
- clear font, sections and headings
- quite clear
- Seems clear, but requires funding. No mention of how this might be achieved.
- Short and easy to understand
- I have just read it
- DCYPG - what is that? What are the other acronyms in the central box of the diagram? But the text is brilliantly written in Plain English - a welcome improvement on previous NCC consultations.
- some of it was difficult to follow
- Visual presentation made it clear and easy read format showed all the process
- What is the reality of what you are suggesting? You state it is with less money so be clear - what is being removed?
- What is the threshold for support? What support is actually available? Not clear at all.
- I think it sets out the strategies they are hoping to achieve in a good way.

- I watched the video and skimmed through the points below. It looks clear on the objectives that you are trying to achieve.

4. The vision is to develop and improve services and the experiences of autistic people and their families in Northamptonshire over time. Do you agree or disagree with the vision in the strategy? Please tick one ✓

There were 163 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with the vision ★★★★★	42.94%	70
I agree with the vision ★★★★	43.56%	71
I do not agree or disagree with the vision ★★★	7.36%	12
I disagree with the vision ★★	1.84%	3
I really disagree with the vision ★	3.07%	5
Don't know or not sure	1.23%	2
I don't want to answer this question	0%	0
	Answered	163
	Skipped	1

5. Why did you give that answer?

There were 69 responses to this question.

- I agree with the principles of the vision, but feel that it is lacking in its substance
- At a time of severe financial pressure I feel this, whilst important, is a relatively low priority
- The vision is obviously a perfectly valid desire however from reading it, I still believe that people will slip through the services offered by virtue of not having the 'right' criteria or diagnosis
- All young people and adults with any learning disability need support
- I think there are strengths with the vision however missed opportunities. Whilst a broad range of contributors have been cited in the strategy there was no engagement with special schools. I believe this was a missed opportunity especially as "Northamptonshire has chosen to take an all age approach to its strategy in order to ensure commitment and collaborative working services. The strategy also mentions the importance of early intervention however little attention has been given to young children and how they and their families can be supported rather than situations escalating to a crisis.
- I agree that services and experiences of autistic people and their families needs to be improved, but I am unsure that the strategies have been fully thought out or outlined within the policy. It is all a bit vague and doesn't really go far enough or have sufficient detail to ascertain whether this will improve on what is offered now (which is my experience is nothing)!
- Hasn't this been the main focus for years and nothing has changed
- I think it's a good vision, a real reality? Now that's something quite different.
- A lot more needs doing in people understanding autism and how it effects different people in different ways..so that part of the plan is a positive part

- It is a good vision. How it will be implemented is not so clear.
- Parent of an autistic child - So I agree with this vision
- I agree because it does show what we need. I don't strongly agree because it is too simplistic and sadly unrealistic.
- 5 main points in agreement.
- I have had mostly bad experiences when it come to getting help
- I have been given very little support that I need from the council last year I was in women's refuge and really didn't support from social services but I never got it even now I live on my own with no help or support so I agree with the vision hope you can improve.
- It isn't made clear what the vision is or how it is to be achieved.
- The vision should be to improve and develop services and experiences as soon as possible, not "over time".
- Loads of well meaning waffle but no specific proposals that could be thought about
- I work alongside many professionals that either have lack of knowledge or understanding of children and young people with autism which has often caused a lot of unnecessary stress and strain on the family
- I feel as a parent there needs to be more support and education available, so we can help our child at home instead of trying to figure it all out ourselves
- Sadly, we have had very little support to date so not sure if this new strategy will really change anything.
- The strategy is so vague it doesn't really say anything.
- It definitely needs improving.
- I also believe that there needs to be more emphasis on supporting children who do not meet a 'diagnostic threshold' for ASD, as many children are referred for assessment who do not meet the criteria for a diagnosis, but have significant

difficulties and some 'traits' of ASD. Many children are referred for assessment because families are informed that they cannot access support unless they can achieve 'a diagnosis for their children'.

- I want The best future for my child.
- As we got to know more about autism, the more we learn enough information necessary towards learning support and everybody else. So then we will give out enough support and opportunities for people with autism in order for them to cope and understand the world better.
- As we understand more about autism and how it works in people of all ages, the more were given enough necessary information about how we can give support and opportunities in many ways possible.
- The vision sounds too good to be true. I am not sure how easy it will be for autistic people to access
- Funds should be spent on all Libraries first.
- Apparently autism is not a disability according to ncc for a bus pass so how and why do they have an autism strategy and why is it not effectively publicised properly . bs if u ask me
- no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance and conduct)
- They couldn't get any worse than they are now. You are starting from a low standard.
- It seems no funding means you cant spend money so it seems like a good plan to make the voluntary sector be involved in peoples care.
- Because from accessing the service to get a consultation to diagnosis is shocking, but once a diagnosis is received instead of being a gateway to support its just a wall of bureaucracy and challenge.

- The 'cradle to grave' support implied in The Vision 'should' provide the optimum support environment for all as we, folks with Autism, (& carers, support staff) move through our respective life challenges. My comments / reservations are:
  1. Will sufficient funding ( i.e. no more cut-backs) be available and allocated appropriately
  2. In the past I have seen similar cradle to grave services being setup which have not been taken up or used by key support groups, e.g. perhaps the Mental Health Community Team, which for example have not contacted me to invite me to any group discussions about this new Autism Strategy
  3. There seems to be an-going disconnect between key Autism support groups which despite the cradle to grave approach within the strategy are not to my knowledge involved, e.g. The NAS, their Autism data is quoted in the strategy document but their input and help seems not to be required??
  4. This is a Northamptonshire county based strategy. I wonder how it fits with other counties & what shared resources could be co-ordinated?
- More support is needed for autistic adults who still struggle in society.
- More support is needed to encourage autistic adults to find suitable employment and to live independently
- It is vitally important to have a clear plan of action in place so that people are not lost in the system.
- at present not enough detail is included in how this vision will look on practical level, therefore unable to say how this may improve lives. Also no evidence based information to show that this is the most appropriate suggestion or the effect on outcomes or impact of the change.
- I agree with the vision and if it is done properly I think this will be really good for individuals with autism. However, I would like it to say somewhere how important it is to involve carers

and also look at carers needs to be able to support their loved ones appropriately as this saves the authority loads of money.

- Often people with autism still struggle to access services required
- More awareness will be helpful for autistic people in the way they are being treated and how their reactions and behaviour is understood
- But this should already be in place. All the areas suggested are just common sense. There is already access to training and information on the internet. Professionals will not prioritise this strategy and there is no money to implement it as you have already stated.
- Can't see how it is going to be delivered with so many cuts in all services being made.
- The vision is good but the training required would cost a lot of money and be taken out of the pot that is supposed to provide services for the autistic group. Also the vision needs a date to be achieved by and not "over a longer period of time". Use more autistic people and you won't need so much training.
- I believe that services for autistic people can be improved, particularly for those leaving education and entering work.
- I believe they need improving
- Improving anything for people with ASD and their families is always going to be good...as long as it sets out what it says it's going to do. Saying something in a strategy is easy; putting it into tangible outcomes not so easy.
- Private providers and professionals supporting young people with ASD need more of an awareness of individuals needs and how to support them, NOT JUST ONLINE TRAINING!
- The report lacks a dispassionate viewpoint and would need to be integrated across a broader strategy.



- The proposal is leaving a lot of the process to the same so called professionals who parents often struggle to listen to their concerns.
- Appears comprehensive.
- Although within the autism community our knowledge and understanding of the condition is always improving within society in general there is still a complete ignorance of what autism actually is. There is also a widespread belief that all autistic people will present the same (lack of eye contact, unsociable etc). I work in the NHS and am shocked by how many people working within the hospital have no knowledge of the condition. This can cause huge problems for patients who do and do not have a diagnosis and it may affect their care and how they react to staff. I'm also very concerned about acceptance and understanding of people with autism in the workplace and their ability to find employment.
- I agree with it as that's how it should be but people always find loopholes to not do the things they're meant to do which can make it hard to put strategies in place.
- Because autistic people ought to be heard and is no indication of intelligence, often autistic people are of a very high intelligence it is just that they cannot make themselves understood or interpret the feedback they are given correctly.
- The services have been reduced over the years and they also do not represent all individual-if you don't fit neatly into the criteria you don't get the support or right support and it is really important for individuals to access support when they need it but ensuring it is the correct support
- My [relative] was told 10 months ago that she is likely to have higher functioning ASD following 10 months of CAMHS support. This diagnosis made a huge difference to her, lots made sense and after reading all about it she started understanding herself better and thriving more. She was referred for formal

diagnosis to ASD team. She is now preparing to go to uni...because she does not have a formal diagnosis we were unable to access the residential course that her prospective uni runs and sounded brilliant and would have made a huge difference to her. We have also been told she could have had a learning mentor funded by the DSA who would meet weekly with her as a mentor/coach type role; again would be great. Instead due to the long wait just for a screening appointment despite being told by a psychiatrist and mental health professional that this is her likely diagnosis she is going to be starting uni with none of these things in place. To have support prior to diagnosis, as this strategy indicates would have been great and maybe we could have got access to what would have benefited her in a more timely way

- I believe that there is currently support but am worried that with the cuts this will go. I know of one person who will lose their much needed support as a result of the proposed cuts.
- Same response as in 4!
- I feel as a parent to a young boy with Autism we all need to help create the support and opportunities for everyone, children and adults in Northamptonshire
- because autism can be a problem for some what you suggest sounds like a good idea
- Ever since the Victoria Climbié case, there has been talk of 'learning the lessons' about agencies communicating better with each other, yet still these cases happen. Sharing pure data ('Counterpoint' initiative) was wrong-headed and I resigned...after training to decide on exceptions. I hope this policy will enable professionals, volunteers and carers to communicate and cooperate effectively in future.
- Current services for adults are non-existent or have long waiting lists for input. Feel very much alone with no help for our autistic daughter.

- Again, this is a vague 'plan' of ideas talking about 'support' but not spelling out what you mean. Autism champions - what exactly will they be doing day to day? Looks like another exercise of providing meaningless words with little content. Actually explaining the specific services you intend to cut or create would be helpful rather than vague notions. Eg delivering training to who? Training delivered by? To benefit? We need specifics. How are we expected to have an opinion on such broadly worded proposals - what are you actually doing on a practical day to day level?
- I really hope they make it better for autistic children and adults. The world is a hard enough place for autistic individuals as it is.
- I work with people with autism and LD, I think that sometimes people can have unrealistic expectations of what is acceptable treatment, quality of life and difficulties especially at school age. Having this strategy is good to bring awareness to some issues that need addressing.
- The principles are sound and solid, but there needs to be rigour to the process and sufficient funding to deliver these changes.
- I agree with it but because of your silly stupid cuts because of your overspending makes me wonder if you will actually deliver it.

6. Do you agree or disagree with Priority 1: Raising awareness and understanding regarding the complexity of autism?

There were 146 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with Priority 1 ★ ★ ★ ★ ★	61.64%	90
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I agree with Priority 1 ★★★★	30.14%	44
I do not agree or disagree with Priority 1 ★★★	4.11%	6
I disagree with Priority 1 ★★	2.74%	4
I really disagree with Priority 1 ★	1.37%	2
Don't know or not sure	0%	0
I don't want to answer this question	0%	0
	Answered	146
	Skipped	18

## 7. Why did you give that answer?

There were 61 responses to this question.

- I agree with the priority in principle
- The more people who begin to understand the needs and individuality of autistic persons the better
- Autism is a complex disability and any awareness raising is vital, however how is this different from raising of awareness of other disabilities
- Lack of understanding results in inadequate support.
- I think that this is an important point but believe it should be priority 2, and providing services should be priority 1
- Whilst I agree awareness need raising I don't think it is necessary the LAs job
- There are many people on the autistic spectrum who aren't getting the help they need, for example those who may have more than one autistic spectrum disorder/condition.

- It has been seriously lacking for a long time. Especially with schools and police
- Raising awareness is important
- Very important as half the battle is raising awareness
- I think priority one should be opportunities.
- Because we need to accept autistic people as themselves. They should not have to mask to fit in with society.
- It's really important to raise awareness and have professionals trained. I have worked with SEND services who were amazing and really got me and my needs but when I went to adult services they seemed to forget my autism. My mum says she thinks training sessions for her were helpful especially the sensory one and she was able to understand my sensory needs more
- Yes more people at the council need to understand that it is a hidden disability.
- Because you are setting yourself up to fail if you believe that people on the ASD spectrum can be safeguarded if services are to be cut. Also, the Police are to be involved I assume? Given my own dealings with the Police and how I was let down I think this is a huge task that cannot be implemented effectively.
- It's so important for people in the community or professionals to understand me so I can access my community or services to help me live a quality of life that I deserve
- Lack of understanding is usually where the breakdown happens for the family, especially when the young children go to mainstream school
- A bit concerned about the lack of one to one support
- Common sense really, is this a strategy?
- Support should be priority 1

- I also believe there needs to be wider understanding of what are 'differential' diagnosis, or more understanding of mental health and attachment disorders that often present like ASD.
- It's important for everyone to become aware and understand about the autistic spectrum. This will implement awareness more in people so then it becomes easier towards people within the spectrum.
- It's important for people to become aware of ASD including it's signs and the diagnosis. So then it becomes easier towards people with autism and the learning support team will come up with new and helpful solutions and strategies.
- But I am sceptical that the general population will be accepting of the proposal
- Funds should be spent on all Libraries first.
- All professionals should be trained to identify children with autism as early as possible, especially in females, as they present differently
- All talk and no action, no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance)
- as it is a spectrum and people have different needs this needs to be recognised that one size does not fit all.
- Too many "professionals" do not understand Autism. Start there and build.
- Not readily recognised as a disability or as a benefit to society
- The most important priority should be the projects for each individual diagnosis with autism.
- been a long time coming
- Extract from the National Context - Defining Autism section of the strategy document: "Autistic individuals experience the world differently and often view autism as a fundamental aspect of their identity. Autism is not an illness or disease. In order to de-medicalize autism, thereby removing the overuse

of inappropriate terminology, support is growing for the reframing of autism as a socially constructed human difference rather than a pathology."

As I understand Autism, (personal experience, Asperger's Syndrome), issues are twofold; firstly the majority rule, so as I behave and relate differently to others, I am the outcast and have spent my life being frustrated, angry and depressed. Secondly, the 'local' country culture dictates how people are supposed to behave and relate to others, so different cultures imply a different set of rules which have to be adhered to if one is to be accepted or outcast of course. So, I firmly believe that we need to spend time & effort in schools, youth groups, NHS support delivery groups & prisons spreading practical knowledge and information to all; Autistic AND Neurotypicals alike. In my view there's a vital need to let pre-autistic-assessment folks, of all ages know that people who feel 'different' or socially out of step/awkward are not alone or outcasts, they just may not know or understand the rules set by the majority in their local country. "Socialeyes" is an excellent example of brilliant training that would benefit Neurotypicals as much as Autistic folks; indeed they probably have a greater need.

- Raising the profile of autism and education people about it helps people to understand, empathise and support.
- I agree that with increased awareness, professionals will be able to support people with autism more appropriately
- Autism is very complex and not always obvious
- The process of recognising firstly lies schools, parental concerns or GP's. There is no use recognising the condition if there is no quick and seamless referral system.
- Autism is not simple and effects people in different ways. we need help to remove the stigma attached to autism.
- Education is the key to understanding

- People don't understand autism as most of us "mask" to fit in then suffer chronic illness, fatigue and mental health problems as a result
- I think society has a long way to go to understand autism isn't about being stupid or being damaged or less than neurotypical people, especially parents with children in or starting the diagnosis process
- There is such little awareness (especially by teaching staff in both primary and secondary schools) of ASD, that a major overhaul in the training of NCC/LA/academy employees is needed. Our child was failed at primary school and secondary mainstream. He finally got an EHCP and a place at a special school but I wouldn't say it had much to do with the professionals involved and much more to do with me researching and fighting at every turn for my son to get the support he needs.
- Many providers/care managers do not have the proper experience and knowledge on what individuals need. The ones that do are limited because of funding and inadequate provisions in Northampton.
- This should be part of a greater strategic thrust.
- Autistic people should have more of a voice when raising awareness. Only we can tell you how autism feels.
- Although autism is becoming more recognised over the last few years it has mainly been for those with more severe autistic behaviours so still very visual . I also had the experience a few weeks ago where my son was spoken to as if he was deaf when having an asthma check up .
- Please see my previous statement. People with autism need to feel able to integrate and to feel comfortable in workplaces and schools.
- When you've met one person with autism then you've met one person with autism. Autistic people may have similar traits



but they are all individual and experience autism in different ways. Awareness needs to be made that women/girls portray autism in a different way to men/boys. Training is vital for all involved with people on the asd spectrum.

- Autism is a complex condition and helping people have a better understanding is a must
- if people are more aware then it can empower individuals with autism and help us to access society more. Awareness should be delivered by those with autism and knowledgeable professionals
- My daughter also has [redacted] and I put a lot of issues down to this; following informing her teacher [redacted] and other within school they were not surprised by the diagnosis but had never raised this concern having been at the same school for nearly 7 years
- I think there is information available it is whether people want to be aware of the issues others have. In other ways I do not see why Autism has to be greatly focused upon. Many people carry on their lives very well with a diagnosis
- It needs to be done
- It's vital that the public, and people whose job is to support individuals with the condition, share a clear understanding of what it is, and how to establish what support is needed.
- My son is [redacted] with Asperger's, the ignorance of professional people regarding all aspects of autism is heartbreaking.
- Raising awareness by doing what and with whom? Who will be doing the awareness raising . What are their skills and qualifications? how are you tackling this on a county wide level? Is this more than a tick box exercise - how will you actually know that there is widespread, in depth understanding and how will you provide this with less funds? If it is not widespread and in depth it will be meaningless and if

you are not reaching a high proportion of the county it will be pointless. Difficult to judge if your priorities are right as there isn't enough actual description of the service you will be providing.

- Because there is not enough awareness yet, so anything that raises awareness is brilliant.
- More waffle, action is needed!
- I stated why in Q.6
- Not the most important priority in my opinion
- Awareness underpins everything else

### 8. Do you think the actions in Priority 1 are the right ones?

There were 144 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

Yes	77.78%	112
No	4.17%	6
Don't know or not sure	18.06%	26
	Answered	144
	Skipped	20

### 9. Do you think any of the actions in Priority 1 should change or are there any actions missing?

There were 33 responses to this question.

- There needs to be measurable outcomes
- As with all the priorities the actions are not specific or targeted, they are fairly wide and so open for interpretation
- I think the evidence on the action plan are too generic often stating whether a task has been done rather than what difference the actions will really make. Would be helpful to state intended impact - link with what success will look like.

- The quality of the training sounds a bit unspecific. There should be one agreed training standard, delivered by fully qualified people who not only have the theory but also have a long track record of working with those with ASD.
- Police and school personnel training should be mandatory
- Very little detail on how it is to be achieved
- It is impossible to make everyone be accepting and aware. Being clear about autistic people's rights will mean more to some people than training them about autism.
- There should be robust access to diagnostics. This should be from a variety of sources including primary care, health visiting, school etc. Training for frontline hospital staff would be helpful but maybe crowded out in busy schedules.
- have workshops for people to learn more about autism
- Need to be more realistic on what can be achieved.
- They're ok. Think it should have been done a long time ago
- One to one advice and support
- Understanding and awareness of who?
- Ok
- More acknowledgement of higher functioning autism. It's a difference not a disability, focus on the positives.
- I think that with no money there is little chance that it will work
- no trust in council to satisfactorily deliver on plan (this isn't down to money this is down to inadequate staff performance)
- online resource would be good.
- It's not just staff in the service, teachers in schools and colleges, police and ambulance staff, anyone who can come into contact with an Autistic person in need should be suitably trained.
- The individual project is unique for each person.
- going to be a hard task, leaflets are no use maybe something in the curriculum would be advisable
- As per my note in 7. Above

- I think they have been comprehensively outlined
- What actions???
- Sorry I need to refer back to the strategy to answer this. This questionnaire does not allow me to do this. Perhaps but bullet point as the top of this question page to refer to.
- Secondary staff need specialist training (and not only the sendco). Even with a diagnosis of ASD, my sons school teachers at secondary still had no idea that every child with asd is different and did nothing to support him and assumed he was coping. He was regularly given punishments and detentions because the staff didn't see bullying and assumed because he basically selectively mute, that he was feeling ok. They didn't pick up on his difficulties with writing and still gave him piles of homework he couldn't do. He was simply failed. All school staff need in depth ASD training and should be able to differentiate more effectively for those children who need it.
- A broader approach to disabilities is needed, not to focus on one aspect.
- As previously stated awareness needs to bring understanding and autistics should have a voice.
- autism something that needs to be explained and people made aware
- n/a
- Hard to measure progress.
- I am not sure about the Autism Champions. I think it would be practically very difficult.
- Instead of wasting money on committees, because I think most people are aware of autism. Get involved!

10. Do you agree or disagree with Priority 2: Effective, quality assured, pre and post diagnosis support?

There were 135 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with Priority 2 ★ ★ ★ ★ ★	61.48%	83
I agree with Priority 2 ★ ★ ★ ★	31.11%	42
I do not agree or disagree with Priority 2 ★ ★ ★	3.70%	5
I disagree with Priority 2 ★ ★	0.74%	1
I really disagree with Priority 2 ★	0.74%	1
Don't know or not sure	2.22%	3
I don't want to answer this question	0%	0
	Answered	135
	Skipped	29

11. Why did you give that answer?

There were 55 responses to this question.

- it is obvious that this is necessary and anything is better than being patted on the head plus diagnosis and being told that everything would fall into place for us now which was my experience with both of my children. Nothing could have been further from the truth!
- We had no support after a diagnosis
- It seems that a lot of issues around non-diagnosis are not because of lack of identification, but because of clinical diagnosis which is then a barrier to any support

- I believe that this should be priority 1 - my son was diagnosed 2 years ago with ASD and I have not received any help or support. The Consultant at NGH stuck a label on him and said they only diagnose not treat. The GP can't help as they don't offer this and the Council didn't know who/where I could go for help. This needs to be addressed for the autistic person but also for the family who want to support them.
- I feel this should be ur number 1 priority! I have had to fight for 7 of my 8 yr old life and I'm still no closer. Being left can n does distort family's
- Again across County this has to be clear for portage. Health visitors sencos etc. It should be mandatory training not optional
- There are those who are left confused after receiving their diagnosis. They need time to adjust.
- There is very little support at the moment
- Vital
- Yes. quick diagnosis and support while waiting is essential
- I really agree that support is necessary - but where will that come from with no money?
- Yes. Needs to be positive support of autism . (Keep applied behaviour therapy (aba) out of ncc)
- Yes you need a easier to understand way of offering support and quicker response I am still waiting for someone to get back to me.
- Because it sounds like a good idea but without time frames it's hard to say. Would this be ongoing support or just a couple of sessions? Can people easily access this service? If it is just for a few sessions is it really worth it? There needs to be a longer term strategy for helping people that struggle to come to terms with there diagnosis.

- There is nowhere enough support with pre and post diagnosis. Pre diagnosis, there is nowhere near enough support or help in schools and waiting for a diagnosis can take years.
- Yes as some families really struggle with what to do next especially if referrals to other services take a long time or if they get turned down for the services support
- Again this is so vague, what support exactly? Support can mean anything.
- Support and understanding of their own Autism is priority
- The concern I have for supporting children and families whilst undergoing assessment is that it is really difficult for families at present to access this, but also that professionals tell us that many families feel support offered will not have an effect if they believe their child has Autism - which is not true
- I agree because it's also vital that every person with autism should be given extra support in efforts to adjust and extend their learning process to make things easier for then towards understanding.
- As we get very little support for one son at the moment and none for the other I am sceptical
- Funds should be spent on all Libraries first.
- Parents of an autistic child need a timely diagnosis, so they can be helped to support their child's behaviour, because it can be very disruptive to family life, & schooling can be affected.
- If u work and are an autistic adult does that mean you get no support as I dont , as my support got cut by ncc cuts
- Again no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)

- not sure all high functioning adolescents would agree to be on a database - as its hard to get them to accept help in the first place. but a good idea non the less.
- We didn't receive either pre or post diagnosis support so don't know what it looks like.
- Getting a diagnosis was difficult enough, but the fact that there has been literally zero support afterwards has been very difficult.
- Our experience of both pre and post diagnosis was shocking and any improvement has to be welcomed
- we experienced over a 12 month wait without communication then to be told yes it is autism
- "Effective" is a word created by Marketing people.....and it means everything and nothing. Does the strategy doc include a solid, logical and useful definition
- A diagnosis can be daunting, but often very helpful to person and carers
- Suppose that's difficult to implement without any funds
- How on earth are you going to do with without more resources? My son was diagnosed at the age of 27. We had no support at all. I had to push for help and the help was very limited.
- There has been little or no support after diagnosis for a lot of people.
- There has been little or no support after diagnosis for a lot of people.
- Currently my son has been referred from the paediatric team to the community team for motor tic syndrome / Tourette's and ASD that was 2 years ago and we have never found out who the community team are, more needs to be dong to stop them slipping through the cracks. Also invitations to appointments should have more about what to expect at the appointment, it can be very unsettling if



you don't have much experience to arrive in a hospital setting to meet a stranger and talk about your shortcomings with no prior information, a print out with a photo of the person the appointment is with, office or map (are there toys?) and what to expect would be hugely beneficial for children

- Post-diagnosis Support is currently laughable. There is no support post-diagnosis if you went private, as we did. You have to fight for any help at all...which thankfully I had the ability to do. Had I been working full time or even part time, I don't think I'd have had the mental capacity to keep on struggling to get our son the help he needed. Even with help from Specialist Support Services, that support is very sporadic and only every now and then. For a child with ASD, a regular pattern of support is needed, not once every couple of months or less!
- Many young people are not diagnosed with ASD and leave school with no support only their parents or care givers. Finding suitable employment/ accommodation and friendships is hard for them.
- Again this must be part of a bigger strategy.
- Since my sons diagnosis six years ago I haven't had any support until the last few weeks for his anxiety issues . I haven't been able to find out how or where the support can be accessed and have had to rely on the Internet
- Currently, after diagnosis there is no clear, individual pathway to support. This is very difficult and frightening for both parents and people with autism themselves. Especially if they have little or no understanding of autism.
- Pre-diagnosis is so difficult with no clear process, no clear timescales and early intervention not being put in place. Post-diagnosis - you are just left to get on with it with a pack of outdated leaflets. Reliance on parent led groups to get

through the minefield of both pre & post diagnosis because there isn't always the professional support.

- In principle, support throughout is ideal. However, with constraints on the NHS and support agencies, I am not sure it could be achieved
- Already justifies this
- I think that currently the diagnostic process is not as efficient as it could be, nor is the support provided as good as it could be.
- some are worse than others so it would be to the parents or individual what support they needed
- In a neighbouring healthcare trust, I have seen departments finding excuses not to offer support to individuals who have difficulty expressing their feelings or complying consistently with arrangements. Nobody picked this up and no doubt some teams considered this a saving of resources.
- Post diagnosis for my son was 8 appts with the Transition and Liaison Team, and that was it.
- Need more awareness and better diagnosis for people lower on spectrum
- Currently no post diagnosis support other than courses.
- When my daughter was diagnosed in 2004, there was little help available, or that we were made aware of. More help is needed to enable parents/carers to make the right steps forward.
- Support YES!
- This is where people need a lot of support, its a difficult time for the family and support to transition through the process is needed because there are a lot of unknowns for the family. Plus the person involved needs to have a clear view of what is happening to prevent any anxiety.
- after my son was diagnosed with asperger's syndrome at the age of 20, it has been really difficult to access the right

support for him. GPs, ASD teams, etc need to work together to support people with autism after diagnosis as my son was left on his own after his. I've had to fight to get him support from ASD team which to this point has not been satisfactory

12. Do you think the actions in Priority 2 are the right ones?

There were 132 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

Yes	79.55%	105
No	5.30%	7
Don't know or not sure	15.15%	20
	Answered	132
	Skipped	32

13. Do you think any of the actions in Priority 2 should change or are there any actions missing?

There were 25 responses to this question.

- Priorities are again too non-specific. There needs additional resources allocated for those identified as needing diagnosis as until a clinical diagnosis given you cannot access services. Quicker diagnosis would support access to services
- I'm not confident that the action plan is robust enough to secure the desired outcomes.
- The sexual discrimination in diagnosing autism, and recognising autism in girls and putting them forward needs serious attention. It is ruining girls lives

- Vague and little detail on how it is to be improved and paid for when service cuts eg educational psychologists in schools are leading to longer delays in diagnosis
- You need to make it more accessible and easier to understand especially for autistic people that don't have any family or friends that support them.
- A timeframe on how long these services were available would be a better indicator on whether this would work or not.
- Heavy reliance on the role of professionals and little about empowerment of individuals and families
- I think it's important for people to be able to have post support when they are ready not just be offered once and you take it or don't. It can take time to process what it means to you and to be ready to understand the diagnosis
- No
- There should be good communication between services and only 1 or 2 contact person for all services. Too many organisations, too complicated and too many different people.
- What support is there for higher functioning autism?
- I think the idea of the actions is right but whether they would get to the autistic people that need them, I am not sure. At the moment my son gets no support, and I am not sure that anyone even knows that he needs it
- Again no trust in council to satisfactorily deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- This is very vague with no real assurance support will be offered. There needs to be consistency in the services offered. Far too often services have been closed, moved or transferred. You don't see the same person or you see someone who clearly isn't competent.

- Fast diagnosis we know lots more than 25 years ago
- As per my note in 11. Above
- Difficult to implement as every case is different and hence one needs very specialised staff
- Needs should be considered not just a label. There are many people without any diagnosis who receive no help or support.
- Further, broader, modelling required
- Yes. There has been a landmark ruling concerning schools making reasonable adjustments for young people with autism with regards to exclusions. I feel that one of your main priorities needs to be working with both primary and secondary schools to reduce exclusions. This may come into awareness raising.
- treating everyone the same
- n/a
- Serious shake up of adult services required not just talking groups and fact finding groups
- it would be good to be able to share data within health and social care
- I have concerns that funding will not be there to deliver these.

14. Do you agree or disagree with Priority 3: Enhancing education, employment, accommodation, and life opportunities?

There were 134 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with Priority 3 ★★★★★	62.69%	84
I agree with Priority 3	26.12%	35

★★★★★		
I do not agree or disagree with Priority 3 ★★★★	5.97%	8
I disagree with Priority 3 ★★	0%	0
I really disagree with Priority 3 ★	1.49%	2
Don't know or not sure	2.24%	3
I don't want to answer this question	1.49%	2
	Answered	134
	Skipped	30

15. Why did you give that answer?

There were 56 responses to this question.

- This all sounds good if the person has been correctly diagnosed and all other diagnoses have also been properly considered so that the person cannot be disregarded as 'just' having Aspergers and therefore not deserving of help which again is my experience with both of my children who did not reach their potential at school and for whom the lack of support caused illness and mental ill health.
- Again, how? I'm unsure that in a strategy you can 'make sure'. "Removing barriers" has been a phrase for professionals working with children and young people with learning difficulties for the last 20 years, the strategy does not give any more detail as to how this will be done
- There is little attention given to education despite it being a priority.
- Life opportunities would be better/greater if the diagnosis and support was given at an early age to ensure that the child is

educated and can achieve their potential - this doesn't happen currently and I am unsure whether it ever will in Northampton

- How on earth are you going to get employers engaged? Apprenticeships are only good for those who have good GCSE grades. Cs and above. This is barring a lot of our talented ASD students from having a variety of options. They are locked into level 1 courses. Disgraceful. There should be a special post 16 provision to allow our students to retake their GCSE before entering college.
- There are people on the spectrum who really want to work but aren't getting the help to be able to. I have a friend who is multiple ASD/C (condition), who has been turned away from agency work often when having turned up at the employers
- It's not just access to benefits people may need but actual support in applying for benefits in a system weighted against them. People may need champions to help with applying for benefits and support them at interviews where they may not be able to adequately express their needs.
- People with Autism are no-where near meeting their potential, especially women.
- Even with diagnosis- schools & employers need to make the necessary adjustments
- Opportunities are the main area that we need to focus on. We need to see many more Autists in work, in college and on apprenticeships.
- My son isn't at this level yet so can't give a good answer.
- I think having support by someone who came into school helped me understand my emotions but also helped teachers help me better. I would like more support to be able to access work or further education. I wish my SEND worker from SSS could help me longer instead of the person from adult services

- More work places should be given the support to recruit people with Autism
- Being homeless last year was very difficult for me and I felt the council did not understand what my difficulties were as someone with autism and being homeless.
- If what you are proposing could be enforced effectively then it would be a brilliant idea. I am very sceptical though that local businesses would make any further concessions for people with ASD. The way it is worded "to encourage" doesn't go far enough. It should be mandatory that any business makes the right changes for people with ASD. Don't just encourage them - make them do it.
- These areas can make a difference on the quality of life
- Some families have no clue what the future holds for their child young person with a diagnosis. Having more information on this may help them look forwards more positively
- Would like to see better support and advice prior to and during educational transition. Not leaving it mostly to schools to deal with and it needing to get to crisis point before help is forthcoming.
- This sounds a bit more specific.
- This should be linked throughout life, and support should be constant, otherwise they will drop out.
- Like everybody else, autistic people should have the rights in having opportunities including reaching towards their ambition in job occupations and other life choices. It be even better if they were given an helping hand in reaching their goal in order to make better life choices.
- Again I agree, but am sceptical that the support will be available
- Funds should be spent on all Libraries first.
- Support in education is important so that life chances are enhanced



- Again no trust in council to satisfactorily deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- Removing barriers to employment - difficult for them to perform in interview without telling employer have autism and the lack of understanding by employers of what it may or may not mean for them. Help for self employed ? they need to meet clients/gain trust and also need understanding when not able or willing to communicate their needs. Its hard out there for them - they are normal and the rest of us are the abnormal ones !
- We have received no help in ensuring our sons education or access to employment. He left school at 16 and that was that, options fell through and life stopped. Our only relief came in finding help from a small local charity.
- There are no mentions of respite for families so siblings and parents can access activities that are impossible or very difficult with their autistic family member. Also, in terms of leisure opportunities, not all autistic people want to socialise with other autistic or disabled people which is what a lot of the present schemes involve
- If you are 'lucky' enough to be diagnosed, a personal care plan can be devised to support/mentor you to develop your skills
- Build the self confidence is the most important in development of integration in social /strategic/educational/life.
- we felt 'out of sight, at least we are doing something' was good enough for our concerns, more was needed
- I am most worried about finding suitable employment and to live independently
- people with autism should be supported to gain full time employment as they have so much to offer in workplace if given correct support.

- These are important for autistic people. They need to be integrated in society and be able to lead an independent life (if possible depending on the degree/type of autism)
- Yep correct. My son who was a [redacted] had to retire from teaching as he was not supported in his workplace.
- Everyone needs to be offered the same opportunities without prejudice.
- My daughter has been homeless for a year and has been assaulted on 4 occasions this week alone with police attending 3 times. She is considered "safe" living in a tent. It's disgusting. She is 20 and has lost her job because she presents as homeless.
- As well as school age support, I know there is very little support once a child gets to 18. I'm worried for my son that he will struggle to enter the world of employment without significant help. Enabling CAMHS to support anxiety in children with ASD might be a start. CAMHS is currently not fit for purpose and is failing our kids by refusing to support beyond initial assessment.
- This is such a big concern as when you leave education support is limited, especially with no clear diagnosis. People need direct/companionship and help with looking for employment and finding suitable friendship groups, they need support with independence and planning so they are able to have the confidence to do every day to day things. People need a voice and a choice on what they need and want. Volunteers and providers should have knowledge on how to support an individual to do this.
- See previous
- An emphasis needs to be made to change outdated myths about autism. Like it is rare in women or that "high functioning" individuals don't need as much support.
- My son does receive support at school but this has mainly been due to the fact that I have worked hard at informing

them and working closely with them. However the support has mainly been keeping him at school and 'happy' so he can be to go into an environment that he finds difficult to learn a curriculum that he is not developmentally ready for. He is about to start his last year of GCSE of which he is unlikely to pass any due to his development, anxiety etc. We have no support for transition after this and I don't know where to find any help as to what he can do at 16. I just get told college but although he will be 16 he is small and young for his age (more like 10/11) and would be very vulnerable in an adult environment. He would also be a flight risk if he could leave when he wanted to and I am extremely concerned but don't know where to get advice.

- Rather than assuming that people with autism prefer their own company, we should be channelling their interests in a productive way (towards employment and integration). Too many people with autism who have great skills and knowledge are overlooked for employment simply because we are not aware of their interests and skills and they have not been encouraged to use these skills.
- From experience there is a fear factor of whether to tell employers that you have Autism due to the stigma attached to it. Many a time I've had to support my husband within his workplace to get them to understand his needs. I'm the one he calls when he is struggling. My son who is 18 will face the same issue when he enters the working world. Parents always have to battle their way through the education system to get the correct support with or without a diagnosis. It shouldn't be that hard to get early intervention. Doctors/paediatricians should have specialist training to undertake the diagnosis of Autism not just do it because they have an interest in the subject.

- Giving people with autism these opportunities will be a massive help to their lives
- People with Autism should have the same life opportunities as those without.
- depends how bad autism is whether they would fit in in and what sort of employment
- All of these categories require communication and in some cases negotiation and compromise skills - both as a service provider and as a service user. Support and training will be essential to get this right for individuals.
- My son was not diagnosed until he was 32. He is a clever man, if he had been diagnosed as a child and with the right support who knows what he could have become.
- Support getting into work and keeping job is very important
- Again nothing out there at the moment
- Employer engagement is a decent aspiration but possibly wishful thinking in practice.
- All of the above are important, there are not enough specialist schools, employment opportunities, accommodation to house autistic individuals, or life opportunities out there at the moment to enable them to live successful lives.
- Employment needed, accommodation needed. We already know this!
- Education is where a lot of support is generally needed to support with behaviours that challenge and sometimes a child can miss out on education because of it.
- Many people with autism have so much to give if they receive the right support.

16. Do you think the actions in Priority 3 are the right ones?

There were 131 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

Yes	80.15%	105
No	4.58%	6
Don't know or not sure	15.27%	20
	Answered	131
	Skipped	33

17. Do you think any of the actions in Priority 3 should change or are there any actions missing?

There were 25 responses to this question.

- see above
- Huge areas are missing e.g. early years, schools, early intervention
- It all sounds good in practice but a bit fanciful. Our kids end up in dead end courses, jobs with no futures or no jobs at all. Unless they are academically bright they have little hope of choice.
- As above, it's not just access to benefits but also support in applying for benefits that is required. Investing in supporting people to get the benefits they are entitled also benefits the council in providing additional money for supporting people.
- Girls with autism may need different types of support, as autism can affect them very differently. Employers should be made very aware of that.
- How do you get rid of employment barriers. Too vague and no detail on how it will be achieved
- Be more understanding with people that find themselves homeless and also have autism.

- Mandatory enforcement of businesses to provide adaptations for people with ASD and penalties if they refuse.
- No mention of how to link with the vast numbers of Home Educated Children with Autism. Heavily reliant on the role of professionals and nothing about empowerment of individuals
- There needs to be clear plans, qualified professionals, more appropriate accommodation for people with no learning disabilities but still need person centred support and most importantly people who have lived experiences are contributing along with professionals and not as a token gesture as a paid qualified person. There should be autism leads in schools, gp surgeries, hospitals & accommodation
- Constant support throughout life.
- How do those with higher functioning autism get good jobs? They have the skills but need to overcome the social stigma.
- Again no trust in council to satisfactorily deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- I can only hope this works in a positive way and not just to push someone into job which is unsuitable.
- This wasn't clear as to what you are actually doing it just seems you are going to make a charity deal with this.
- lots of appointments? no money? how will this work
- Please see my note for 11. above, thanks.
- Include independent living
- It's hard to remember the actions when on this form. I don't want to go back to read them elsewhere in case I lose everything I've already entered on this form.
- See previous
- Yes but there needs to be more understanding of autism across all ETE providers especially schools (mainstream and

special schools). Young people are being diagnosed with ASD at a very late stage and they have therefore gone through their schooling without the right support which impacts on their academic achievements which then go on to affect their life chances and opportunities.

- if seemed more difficult to see what this will look like-it looked more wishy washy. I would like to see individuals and carers involved in what this would look like. I know better what accommodation, employment or social support I need than professionals
- n/a
- I think that when schools get it right, its life changing for students. There is no mention in the actions about education or schools. Its all about employment. School life is really important for about 13 years.
- I have concerns that funding will not be there to deliver these.

18. Do you agree or disagree with Priority 4: Seamless progression throughout periods of transition?

There were 131 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with Priority 4 ★★★★★	52.67%	69
I agree with Priority 4 ★★★★	34.35%	45
I do not agree or disagree with Priority 4 ★★★	7.63%	10
I disagree with Priority 4 ★★	1.53%	2

I really disagree with Priority 4 ★	1.53%	2
Don't know or not sure	2.29%	3
I don't want to answer this question	0%	0
	Answered	131
	Skipped	33

### 19. Why did you give that answer?

There were 47 responses to this question.

- Transition services totally unavailable for my children and I fear they would still slip through the service requirements within your proposal. And yes this would have been useful to them! Despite being signposted to them several times by other services we were still not deemed eligible
- In the year that funding for transitions support in education has been cut - Prospects are no longer supporting schools - I do not see how NCCs approach to supporting young people into adulthood is compatible with this priority. Transitions times are difficult for all young people, and especially those with additional needs. This priority seems as if will be to the detriment of the wider population as NCC cannot fund a universal service for young people with SEND
- Its all very well putting words together but the actions are whats needed - having a policy and filing it to 'tick the box' does not make this an efficient or effective service
- Autistic people don't handle change and need extra support through transition
- Vital for individuals who struggle with change
- Any kind of transition is difficult - so seamless transfer is essential



- It's a great idea but we are 5 million miles from that today. Achieving that is a huge undertaking. I don't have faith in NCC to achieve that.
- Nursery to school to secondary to further education is extremely important to avoid autistic people falling through cracks.
- Why would this ever not be done?
- OMG this would help me so much if I had support with leaving school and knowing what I could do and having support to have a good life
- Yes the council needs to understand that support should not stop when a autistic child grows up we have it for life we don't get better with age.
- Because in most I agree with what is being laid out. However, it is important for the Autism Crisis Team to be an independent unit and not just a breakaway arm of the Mental Health Crisis Team though it is important for both teams to cooperate with each other. I do have concerns over how this is going to be funded though.
- Transitions really halter a person with autism's progress in all aspects so this is really important.
- Most passionate about this one! Schools must do more to understand autism!! I have heard too many times threats of exclusion, or children regressing due to not having the right support during transitions. Transitions should include more formal meetings where notes are taken and signed by all with agreed actions! Too many times school agree and then don't deliver causing many problems for the whole family
- As previous answer
- Yes, our experience with the so called 'ASD/ADHD team' was terrible compared to the paediatrician who was great.

- Transition from one action to another is very difficult for autistic people, just leaving the house can be a massive challenge. So to focus only on milestones in life is missing the point.
- I currently feel there are too many services providing support that are not joined up and working together, or collaboratively, leading to inconsistent approaches, with different philosophies and principles.
- Extra support is mandatory when a person with autism is going through certain things that he/she is not familiar with and is not sure how to handle that change. This will help them adjust towards transitions to learn how to handle things better.
- you cannot argue with the idea, but with no money, who will implement it, and how will these autistic people be recognised that they need this support
- Funds should be spent on all Libraries first.
- Change is very difficult for people with autism, even small changes such as a supply teacher, can cause distress.
- Again no trust in council to satisfactorily deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- Again - will depend on level of need. some need help but cannot accept they do!
- I followed the American TEACCH programme which supports the autistic person from " cradle to grave" and did not stop when the person left school
- There is currently no transition through services. One team pushes you out as soon as possible and you go on a waiting list for the next and are ignored.
- The sooner support services start to engage with each other the better; the priority is the individual rather than the service provider

- There seems to be more support available for vulnerable children but these vulnerable children turn into vulnerable adults and that's where the support stops
- this is so important to prevent person with autism becoming distressed or forgotten about
- A theoretical statement...
- I am not an expert here but is this not common sense and what we would aim for for everyone?
- Primary to secondary, even with diagnosis, is currently a total joke! Sending a little booklet with a few badly taken photos of the new school isn't what I would call a proper transition pack! Obviously, I'm only talking about our school, not others but the 'transition' here was non-existent.
- This is the most important time for a young person, professionals should work together to put a plan in place with the individual. Children services should have links with Adult services, something that was piloted but never continued. Schools should link in with services to gain more knowledge and support young people with the transition to further education, employment and recreational activities when they leave school.
- Only if applied across all services, not just autistic care.
- We know that transitions can be very difficult for those with autism and they and their families need as much support as they can get. Not just through school but throughout their lives.
- My son has just been discharged from his paediatrician now he is 18. There is no transition help for him now he is going into adulthood unless he goes to the GP to ask what service he goes to next. There should be a handover to one service to another without having to start again. Not all young people with Autism have EHC plans so won't get the

transition help they need. Yet again down to the parents to do it on their own.

- moving from one thing to another can be so tough so this would be really helpful
- Again already explained, because she is still awaiting formal diagnosis she has no support for her transition to uni; we will be doing our best but feel the situation could be much better supported
- Why shouldn't transition be seamless?
- it will be better for the individuals
- People with autism are generally upset by change of any kind. Someone they can learn to trust to see them through the big changes makes all the difference. Every staff member, in every sector that they move through, needs to know how to assist this process in every, different, case.
- Being a child then adult with something like autism is difficult. Transition between Chams and adult has been awful
- My daughter has recently gone from children's services to Adult Services and the transition has been awful. There is little to no consultation between services.
- Gobbledegook!
- Change is a difficult time for people with autism and having a planned seamless transition is something that would benefit them greatly.
- There are currently too many barriers to service users and their families, it should be a seamless process.
- People with autism find change particularly difficult. However, if managed correctly, any distress caused by important transitions in life might be lessened.

20. Do you think the actions in Priority 4 are the right ones?

There were 127 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

Yes	81.10%	103
No	7.09%	9
Don't know or not sure	11.81%	15
	Answered	127
	Skipped	37

21. Do you think any of the actions in Priority 4 should change or are there any actions missing?

There were 19 responses to this question.

- see above
- Some of the actions are in place eg. 4d(i) why repeat surely better to QA.
- There is little genuine good advice about next steps. As for housing forget it. There is nothing. If our young people want to live in there own flat there are no provisions. For old people there are tons of sheltered housing for our young people nothing,.
- This needs a massive overhaul. The services are not there for a smooth timely transition. Very little appropriate resources out there for 18+
- I would like to have my worker from sss stay with me or be able to pay them with the money mum gets to help me get out
- Adults with autism needs to be a focus.
- Concerns about sharing information between agencies - must only be done with full consent. Reliance on professionals again

- Have autism leads that have qualifications and experience not just token gestures on paper
- Help daily to get to one place to another, transition from home to work for example, and walking in with person to work and letting boss know of any issues. Very complicated transition to work.
- I would like to know how all these Priorities can be implemented with no money
- Again no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- Having groups set up, a group for this a group for that. You are in danger of things happening in isolation and not being collaborative.
- These hopes and wishes MUST become something tangible. Too often people are asked what they need/hope for and are badly let down because nothing comes of it
- Transitions for each individual are not necessarily governed by their birth age but their development age
- Yes but teams and schools should be knowledgeable and support the individuals with a clear plan as many transition teams lack the knowledge of ASD .
- See above.
- I feel that there needs to be a focus on young people with Sufism transitioning between the youth offending team and probation. The police, probation, YOT and social care need to fully understand the challenges faced and how the criminal justice system can further isolate and compound the difficulties for people with autism.
- n/a
- I have concerns that funding will not be there to deliver these.

22. Do you agree or disagree with Priority 5: Providing care and support that empowers autistic people?

There were 130 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

I really agree with Priority 5 ★★★★★	64.62%	84
I agree with Priority 5 ★★★★	22.31%	39
I do not agree or disagree with Priority 5 ★★★	5.38%	7
I disagree with Priority 5 ★★	3.08%	4
I really disagree with Priority 5 ★	1.54%	2
Don't know or not sure	3.08%	4
I don't want to answer this question	0%	0
	Answered	130
	Skipped	34

23. Why did you give that answer?

There were 40 responses to this question.

- This is a very important area for all young people and adults with SEND
- Why is this priority 5??????
- There are not enough agencies you can go to to provide specialist sitting or support.
- Sometime we just need the motivation. Need an incentive.

- As previously stated, one role of the team should be supporting people in getting the benefits to which they are entitled, providing additional funding for support.
- It is necessary.
- Empowerment is important to help individuals be more independent if possible
- Yes. Listen to autistic people as to what they want/feel. They are the real experts.
- I would like support to be more independent. I wish my counsellor at the lowdown could help me in the community as well or my SEND worker instead of the adult services as they dont help or understand why I don't want to do anything with them
- Because I don't really know very much about e Positive Behavior Support model. If this somehow includes ABA then I would have to give this a big fat NO. ABA is detrimental to people with ASD.
- They deserve to thrive just as much as anyone else
- Well this is a tricky one isn't it, genuinely empowering people and helping them to make good decisions is one thing, casting them off to fail and make bad decisions and end up in crisis because they are now 'independent adults' is another.
- This is big, they should have control with thoughts to carers input and expert knowledge. People SHOULD listen and implement.
- Autistic people should always be treated fairly as it would help them become positive towards things as well as their well being, instead of them focusing on the negatives. This will help them to have a better lifestyle in knowing how to cope with things.
- Because it is common sense
- Funds should be spent on all Libraries first.



- Parents of young children showing autistic tendencies need to be empowered & a portal they can access would be very helpful.
- Being autistic and working means ncc dont believe your autistic , I'm autistic and work so where is my empowerment ncc !
- Again no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- Awareness of not wanting to highlight condition when it would help them a lot is truly hard to convey to person with autism. Needs careful training and awareness raising everywhere.
- Everyone deserves the right to be able to progress and grow in life and not just be left to stagnate.
- So agree! We have found plenty of care services but few providing a mentoring service and have had to 'buy' individual services to develop confidence and learn new skills on a 1:1 level, which have then been challenged when the accounts submitted as they do not follow the normal services provided. The fact they are working seems irrelevant!!!
- People should always be empowered never disempowered
- I think autism is misunderstood - empowering?
- Very difficult to achieve this with autistic people as it is such a wide spectrum of issues.
- I think it needs to cover the people who are autistic but not autistic enough for the NHS to diagnose as well - some people mask well until a period of life that is stressful, a diagnosis should be made even if support isn't required at the time

- It's really important that those that want to be empowered are, but it's wrong to assume that every child/adult with ASD will be able to cope on their own.
- Totally agree more support is needed. Too many young people leave school with plans that have not worked for them due to lack of knowledge of their needs. Professionals and schools need to work together to do this. There are too many young people not leaving the family home unless with their carers or parents this is because of their needs not being met and them not being supported better through transition from education to work.
- Again a whole care strategy must be applied with a broader approach to the service as a whole.
- I definitely believe that all people with autism should be able to access support to enable to access all the things that neuro-typical people can with the correct care & support.
- I believe everyone with extra needs should have help and support, so it's difficult to place one person above another
- My daughter has done all her own research into ASD and said to me I'm just wired differently; her research was completely empowering for her and she was able to come to terms more easily with this and motivated to understand what she finds difficult and hence what to avoid and when to be mindful of situations she is in. She also doesn't give herself a hard time about why she does not always act and feel how she used to think she should which then caused her much anxiety.
- Support should be given to enable those with autism to lead as normal a life as possible.
- care and support is what is needed in most cases
- People with autism have bags of potential that mainstream life does not recognise and empower. Hopefully as attitudes

change with the implementation of these priorities, support will be more forthcoming from the general public, workplace, etc in the longer term.

- For years we have been banging our heads on brick walls, now let them have their voices heard.
- Totally agree!
- I do like this idea but maybe hard to implement if the right care companies are not involved to maintain a high standard of care.
- Unfortunately people with autism are vulnerable and can misunderstand what they are being told or can be overly influenced so I have concerns that they may be manipulated if they are empowered to make decisions and may not make the right decisions. Impartial advice needs to be available.
- again, I believe people with autism have so much to give and society in general can benefit from this if we give the right support and guidance

24. Do you think the actions in Priority 5 are the right ones?

There were 121 responses to this question. The graphs are shown in Appendix 1 containing the consultation analysis report.

Yes	77.69%	94
No	4.96%	6
Don't know or not sure	17.36%	21
	Answered	121
	Skipped	43

25. Do you think any of the actions in Priority 5 should change or are there any actions missing?

There were 19 responses to this question.

- Actions are too narrow.
- The actual means of providing this support, the funding for it and the extra workers needed isn't clearly explained
- The council broke me last year with their lack of understanding of my condition every time I got off the phone with them I would be upset and confused by the whole thing I still don't like getting in contact with the council.
- I agree with other agencies being involved so long as they all receive the same training and there is open dialog between all agencies involved.
- The whole strategy seems to suggest Autistic people can only live with the support of professionals - most currently manage without - empowerment means working to ensure individuals need professionals less - not embedding professionals in every stage and having to have a professional to ask if you feel empowered. Empowered individuals do not use professionally run services
- Person centred happens in children's teams but goes out the window in adults. No one thinks outside the box. Listen to what people want and think about strategies to make processes better. Visual learners don't stop being visual learners when they become adults just the type of strategy may be needs changing not stopping
- Currently this isn't happening, autistic people at the council are not given reasonable adjustments and treated carelessly. Their opinions and needs are overlooked. Housing is impossible, not appropriate emergency accommodation or very little permanent housing available. They have a right to be independent of their parents/carers if that's what they wish. Housing/social services and health

should all be linked and work together to house an autistic person. Currently NOT happening at all, they work against each other.

- I feel that they could be 'Pie in the Sky' without the money to implement
- Again no trust in council to satisfactorily deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- Another group, you are going to spend a lot of time talking about change and not delivering.
- There is too much responsibility placed on families and not enough support for autistic people to become more independent
- There is no normal but whatever service works for an individual to support and develop them as an independent person has to be accepted by the decision makers/budget holders as an acceptable cost when a personal budget is provided
- Leave out
- Yes but people supporting them need to have more knowledge on their needs and ASD
- See above and previous answers
- but would be good to have a panel made up of individuals and carers and professionals working alongside the multiagency team to ensure everything doesn't become corporate and turns into cutting costs and services and not having the person at the forefront
- n/a
- They like independence, but need some one for support if necessary.
- All the right points are there, however from experience these tasks tend to be on paper only and actually put into actions. This to me is the most crucial part of the process. If

this side of things are not monitored appropriately they it can all unravel and the good work that has been put in place before hand will not be effective.

26. Please tell us if we need to look at anything else in the Strategy:

There were 64 responses to this question.

- My understanding is that less and less EHCPs will be issued and the amount is significantly small in any case so to make this the only criteria for progressing people forward is short sighted. I consider that my young people even with their formal diagnosis would still be lost in Northamptonshire's vision and would miss out significantly on proper support. Forgive me, but Autism is not usually a "stand Alone" condition there are significant overlaps with other conditions which are very difficult to diagnose accurately and once the term Learning Disability is not applied the support available dwindles to nothing and people start to ask what the problem is it is 'just ' Aspergers never mind the anxiety and depression that goes along with it. It didn't matter that my son who is highly intelligent left school with only 2 GCSEs having been unable to attend most of the time due to anxiety - that was a barrier to his learning if he had been correctly diagnosed with dyslexia also along with possible dyspraxia and ADD which he screened for he would have had a learning disability and received better support and possibly a statement. It is through his own hard work and my support which has meant that despite having once lost his job through incapacity (mental ill health) he is managing to hold down another job with difficulty. this is at expense to my own health bearing in mind that I have

another young person who I have struggled to support through school also absences due to anxiety with no support. we could get no support because it was considered that for her getting Cs and Ds instead of the A\*s she was originally predicted was ok (they wouldn't have found this acceptable for their own children I suspect) These so called High functioning individuals are in danger of being lost to society if they also do not receive correct diagnosis of comorbidities and if they do not have family who are able to support and actually fight for them. I can safely say that every day is and has been a battle to survive. Please give them and their families better consideration because, even if they do not show it which as we all know is common in Aspergers they are most certainly struggling to come to grips with the world and their place within it. In our case, certainly my children's intelligence and good behaviour at school was a distinct disadvantage!!

- I am concerned that the special schools as a sector were not consulted in the development of the strategy - across the sector we have a raft of experience and knowledge, being a central point of contact for parents, health and social care.
- I think attention also needs to be given to those who have a diagnosis of ASD and learning difficulties. The strategy is very narrow. Whilst I acknowledge there has to be clear parameters I think there are significant gaps in the strategy.
- Support for newly diagnosed children and their families has a massive gap in Northamptonshire - this needs to be addressed as a matter of urgency. Early support and intervention can save years of frustration for both the child and the parents
- The same diagnose process across the county and clear steps for parents to follow

- I think the plan is specifically vague. A lot is open to interpretation.
- Access to mental health services for high functioning autistic teens
- According to the Online Autism Awareness Course, an individual can determine whether they wish to be referred to as having an Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC). I personally say I have an ASC as Disorder implies that you have something significantly wrong with you. We are just wired differently.
- Please provide support for people to obtain the benefits to which they are entitled. People with autism don't necessarily know their needs and can easily be discriminated against by the benefits system. This can lead to lack of self-worth, hardship and deterioration in physical and mental health. By supporting these people to get the right benefits can not only improve the lives of those affected but also bring in additional funding for support and improving quality of life.
- All the way through there are lovely ideas, but the practical application is lacking. Under current funding levels the aims of the strategy are no-where near met, there is no special support for girls and women for example. Where will all the extra workers and funding be coming from?
- Failed to realise that this cannot be achieved on the current budget. More investment is needed to improve services and facilities
- Where is the funding coming from? So many cutbacks - how will you be able to provide these changes with no additional money?
- Yes - the ability of NCC to provide the support, funding, care and strategic planning to roll any of this out given the mistakes of the past and the absence of support at the moment. Providing this rosy future where everyone is



accepted, employed and supported despite NCC being bankrupt is not very realistic.

- Ensuring that families are fully supported and have access to additional support
- Follow up with health professionals after a diagnosis
- Parents/carers desperately need help with restbite! Most groups/play groups u have to remain with the child at all times, so does not give us a break either to go shopping or spend time with siblings
- Just keep aba (applied behaviour therapy) out of ncc. It is abusive and denies autistic children a voice
- Sensory processing needs to be part of the autism assessment and supported as it is part of the spectrum and has a huge impact on the individual suffering with it
- More support for adults with Asperger's and autism would be a great help for me personally
- Please look at the right people to help us from childrens to adult services and also more support for my mum
- I would your help & Support to help & Support me & Disability & Disabled People to Employer Person Assistants with a lot more hours for me & Disability & Disabled People in Kettering & Northamptonshire in the UK today now
- I would like my own PA Worker & PA Staff back in Kettering & Northamptonshire with a lot more hours for me & Disability & Disabled People and please can you help & Support with it for me & Disability & Disabled People in Kettering & Northamptonshire today now?
- Please look into community assessment's last year I has one never heard back requested another one a few weeks ago still haven't got back to me and I am in desperate need of help and support which I should be entitled to according to the autism act 2009.

- To make sure that the services that have laid out in your strategy are deliverable in whole before making promises. Speaking for myself and other people on the spectrum we are used to being let down but this shouldn't be used as an excuse for climbing down on any proposals made. Some of the proposals are really good ideas. Others are sketchy at best. More dialog with people in the ASD community is essential before implementing any of the proposals in the form of online webinars or group meetings.
- More pre-diagnosis support from schools and GPs.
- How people with autism or those that care for us can help and be included. Give them jobs they could do better than professionals
- I agree with all that has been mentioned! Am wondering how this will be done when training is already sparse due to lack of funding but also training opportunities have taken a massive dip too? This all should be an integral part of any professional working with children and young people somit filters through society, not just services like the specialist support service who are actually relied on too much and not always listened too! Treasure those services!!!
- The biggest issues must be early diagnosis and meaningful employment or occupational activity after 18.
- Housing and homeless claims should accommodate Autism and reasonable adjustments should be made, equality act. This isn't happening with Kettering Borough Council.
- I do not think this strategy will be effective if there is not also a strategy for supporting thousands of children who struggle that are not Autistic, but are often referred for assessment. There are more of these children and many professionals have anecdotally informed my service (Diagnostic service), that they make referrals to 'go through the motions', 'tick the boxes', or because the parents have 'pressured them into

making a referral', even though they do not feel the child has Autism. These types of children or scenarios need robust support, so that not all children with difficulties are sent down a 'diagnostic' pathway.

- You need to look at how you would fund this
- You should be safeguarding all Libraries first, before addressing this issue.
- Seamless diagnosis, rather than a piece meal approach
- Emotional mental well being activities hobbies interests which can be accessed alongside increased social support groups long term care support provision provided consistently not irregularly
- Autism is a disability ncc please accept this .
- Again no trust in council to satisfactory deliver on plan (this isn't down to money this is down inadequate staff performance, staff will always make excuses)
- High functioning autistic persons are the most difficult to help, they have no need of it in their own heads and do not think of them selves as needing help. this is going to be hard. mine is now 29 and needs it some times.
- Working with charities that already provide support, they have been the lifeblood to so many families because of the void in local services. You could learn a lot from what is there already. I worry you will take from them and put at risk the quality support they provide.
- Volunteers! There may be many people like myself with extensive experience of autism who are no longer working and who may have something to offer in terms of supporting a family in their locality.
- Respite for practical tasks and for autistic people to practice independence away from families
- Yes. Greater public awareness to this consultation!! I only found out about it by accident- we could have been

notified when our monthly DLA statement was sent out, or greater social media promotion. Understand your audience better right from the start

- For integration early in society it will be a good options to try to keep in normal education program all the children's with this diagnostic of autism, to receive the same education both parts :1)autism diagnostic persons ;2)non diagnostic autism persons.
- As I'm now in my mid-sixties it's a tad late for me, LOL. However, I sincerely believe that the focus and attention of NHS Autism support service senior management appears to have completed a U-turn over the past 10 years. I find it very encouraging and heart-lifting. I hope their political will and support of MP's etc is as positive & practical.
- What is the time period for this to take effect?
- How you will ensure this happens and how you will do it is going to be important. Involving individuals with autism and their carers. Ensuring the autism champions are going to be passionate about it and not just given the role for the sake of it or their level in the organisation. I have met so many passionate staff who have been so supportive but unfortunately they are at the bottom of the chain so have no say or involvement in things like this but they are the people that get it more than the managers who make the decision. Legally this should have been in place before now so it is important to get it right or at least have the right people involved. There are specialist SEND teams and the transition team who should liaise together much more as I think this would support individuals and the transition better while enabling staff to share training and knowledge.
- Autism alert cards has been highlighted by people with autism as a potentially useful tool in managing their anxieties in the community. Safe cards are not appropriate

for this group of people. (please change music on video-thanks)

- More staff to cut down waiting times and enable speedier diagnosis. Help and support also needed for high functioning adults.
- Give information how to deal with autistic people e.g. some cannot bear to be touched or cannot stand loud noises.
- Helping parents and carers with children or adults with autism. We've had no support at all.
- There needs to be a crisis support team who have real knowledge of autism. Too many professionals have no idea of the reality of ASD. There needs to be more autistic people involved in the process.

27. Are you answering this questionnaire...

There were 131 responses to this question.

As an individual	98.47%	129
On behalf of an organisation or group	1.53%	2
	Answered	131
	Skipped	33

28. If you are answering this questionnaire on behalf of an organisation or group, please write the name of the organisation or group below, and your role or job title.

There was one response to this question.

- Northamptonshire Depression Support

29. Where in Northamptonshire do you live?

There were 128 responses to this question.

Corby borough	6.25%	8
Daventry district	7.81%	10
East Northamptonshire district	12.50%	16
Kettering borough	12.50%	16
Northampton borough	39.84%	51
South Northamptonshire district	11.72%	15
Wellingborough borough	6.25%	8
Other (please say where)	3.13%	4
	Answered	128
	Skipped	36

Other:

- Raunds
- The whole of Northamptonshire
- West Haddon
- Mawsley

30. Sex - Are you:

There were 121 responses to this question.

Male	28.93%	35
Female	67.77%	82
Prefer not to say	3.31%	4
	Answered	121
	Skipped	43

31. Is your sex (called your gender identity) the same as the gender you were given when you were born?

There were 121 responses to this question.

Yes	96.69%	117
No	0%	0
Prefer not to say	3.31%	4
	Answered	121
	Skipped	43

32. How old are you?

There were 121 responses to this question.

0-10	0%	0
11-16	1.65%	2
17-18	0.83%	1
19-29	14.88%	18
30-49	43.80%	53
50-64	23.14%	28
65-74	12.40%	15
75+	0%	0
Prefer not to say	3.31%	4
	Answered	121
	Skipped	43

33. Do you think you have a disability? If yes please tick any of the boxes that are right for you:

There were 50 responses to this question.

Mental health	42.0%	21
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Physical disability	20.0%	10
Learning disability	30.0%	15
Hearing impairment	8.0%	4
Sight impairment	6.0%	3
Prefer not to say	22.0%	11
Other (please say what)	20.0%	10
	Answered	50
	Skipped	114

Other:

- ADHD Dyspraxia OCD Dyscalculia
- Dyschronia
- Autism
- Autism
- Specific learning disability
- N/A
- Asperger's Syndrome, i.e. a socially constructed human difference
- Parent of an adult with Asperger's
- Autism and chronic migraine. (Chronic fatigue )
- Autism
- None.

34. Do you think you have an Autistic Spectrum Condition (like Autism or Asperger's Syndrome)?

There were 121 responses to this question.

Yes	28.93%	35
No	66.12%	80



Prefer not to say	4.96%	6
	Answered	121
	Skipped	43

35. What is your ethnic origin?

There were 120 responses to this question.

White British	84.17%	101
White Irish	0.83%	1
White Gypsy or Traveller	0%	0
Other White	2.5%	3
Indian	0%	0
Bangladeshi	0.83%	1
Pakistani	0%	0
Chinese	0%	0
Other Asian	0%	0
Black Caribbean	0%	0
Black African	0%	0
Other Black or Black British	0.83%	1
White and Black Caribbean	1.67%	2
White and Black African	0%	0
Other Mixed or Multiple	0.83%	1
Arab	0%	0
Prefer not to say	5.0%	6
Any other ethnic group, please say below	3.33%	4
	Answered	120
	Skipped	44

Other:

- Romanian

- English
- English
- White English

36. Employment status – are you:

There were 117 responses to this question.

In full time education	4.27%	5
In training	0%	0
An apprentice	0%	0
In paid work	52.99%	62
A volunteer	5.98%	7
Not working	9.40%	11
Unable to work	4.27%	5
Prefer not to say	5.13%	6
Other, please say what	17.95%	21
	Answered	117
	Skipped	47

Other:

- I am an unpaid carer for my children 23 & 18 and also part care for 4 elderly relatives
- Full time carer
- Carer
- Carer of 2 autistic children
- Full time carer for my two autistic sons
- Retired paediatric nurse
- Retired
- Retired Nurse Practitioner.
- Retired

- Stay at home mum
- Parent of child with high functioning ASD.
- Houseperson & volunteer
- Pensioner
- Full time carer for an autistic child
- Retired
- Retired
- Self employed
- Retired
- Retired
- Semi-retired
- Retired

37. Marital status – are you:

There were 118 responses to this question.

Married	45.76%	54
Single	28.81%	34
Civil partnership	0%	0
Widowed	2.54%	3
Cohabiting or living together	11.02%	13
Prefer not to say	6.78%	8
Other, please say what	5.08%	6
	Answered	118
	Skipped	46

Other:

- In a relationship
- Child
- Divorced
- Divorced

- Not living with partner
- Divorced

38. Living arrangements – do you live...

There were 118 responses to this question.

With family	37.29%	44
With carers	0%	0
In supported living	0%	0
In your own home	50.0%	59
In residential care	0%	0
Prefer not to say	7.63%	9
Other, please say what	5.08%	6
	Answered	118
	Skipped	46

Other:

- Partner
- I
- In a house!
- Rented private accommodation
- With my children
- Rent my own home