




Northamptonshire
County Council

Cabinet Meeting

Tuesday 13 November 2018

Agenda Pack Three 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">• Report• Appendix 1• Appendix 2	3 – 14 15 – 76 77 - 84	Councillor Naden-Horley/	Bob Fletcher 363938
	This pack contains the report, Appendix 1 - Northamptonshire All Age Autism Strategy and Appendix 2 – Equalities Impact Assessment			



CABINET

13th NOVEMBER 2018

**DIRECTOR(S) OF: ADULT SOCIAL SERVICES: ANNA EARNSHAW AND CHILDREN
FIRST NORTHAMPTONSHIRE: WALTER MCCULLOCH**

**CABINET MEMBER WITH RESPONSIBILITY FOR ADULT SOCIAL SERVICES:
COUNCILLOR SANDRA NADEN-HORLEY AND CHILDREN'S SERVICES:
COUNCILLOR VICTORIA PERRY**

Subject:	Northamptonshire All Age Autism Strategy
Recommendations:	<p>Cabinet is asked to:</p> <ol style="list-style-type: none"> 1) Take into account the outcomes of the consultation detailed within Section 5 (below) and the appendices to this report; 2) Take into account the outcomes of the Equality Impact Assessment detailed within Section 6; 3) Approve and endorse the five priorities identified within Northamptonshire's All Age Autism Strategy, namely: <ol style="list-style-type: none"> i. Raising Awareness and Understanding regarding the complexity of Autism; ii. Providing effective, quality assured Pre and Post Diagnosis support; iii. Enhancing education, employment, accommodation, social, and leisure opportunities; iv. Promoting seamless progression throughout periods of transition; and v. Providing effective and enabling care and support. 4) Agree that the following recommendations contained within the All Age Autism Strategy should be adopted and implemented via the delivery of the Local Action Plan: <ol style="list-style-type: none"> i. Reconfiguration/realignment of current service provision ii. Exploration of the development of a multi-disciplinary autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.

	<ul style="list-style-type: none"> iii. Implementation of a clear process for recording autism as a primary support reason iv. Service provision for autism and Learning Disabilities should be separate v. Development of best practice autism standards covering the following themes: <ul style="list-style-type: none"> • Knowing the individual • Environment • Collaboration vi. Implementation of outcome-focused, joint commissioning and interventions, vii. Sector wide workforce development viii. Establishment of a multi-disciplinary network of Autism Champions across Northamptonshire. ix. Embedding of continuous practice development and quality assurance <p>5) Agree that, once these recommendations have been approved, the draft All Age Autism Strategy be amended and authority to sign off the final strategy be delegated to the Directors of Adult Social Services and Children First, Northamptonshire, in consultation with the relevant Cabinet Members.</p>
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1. Purpose of report

1.1 This report provides members of the Cabinet with an update on Northamptonshire's All Age Autism Strategy, the consultation process and feedback, the key priorities, recommendations, and intended outcomes.

1.2 Please note that this report has been prepared using a font recognised and recommended by the National Autistic Society as being autism-friendly.

2. How this decision contributes to the Council plan

2.1 The Council's vision is to make Northamptonshire a great place to live and work. This is achieved through increasing the wellbeing of your county's communities and/or safeguarding the county's communities.

<p>This initiative specifically delivers increased wellbeing and/or safeguarding by ensuring that:</p>
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|---|
| <ul style="list-style-type: none"> • Keeping vulnerable people safe. • Keeping people who are not classified as vulnerable, safe. |
|---|

- Complying with statutory duties where there is not a risk of harm.
- Providing services that have a clear cost avoidance impact.
- Supporting the democratic process and engaging with local communities beyond statutory requirements.

3. Background

- 3.1 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. The financial implications of autism are significant. Latest figures from the National Autistic Society (NAS) indicate that for someone diagnosed as autistic, the lifetime cost equates to £3.1m; for someone with autism and a co-occurring learning disability, the cost increases by 50% to £4.6m. These figures include the "hidden" costs of family carers and voluntary services. Effective early intervention is crucial to reducing long term dependency, promoting independent living, enhancing coping strategies, championing emotional and physical wellbeing, and reducing the number of high cost interventions.
- 3.2 Autism is characterized by unique social interactions, non-standard ways of learning, keen interests in specific subjects, inclination to routines, challenges in typical communications and particular ways of processing sensory information.
- 3.3 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. Autistic individuals, their families and carers, have a great many gifts and strengths. With the right sort of support, all can learn, develop, and live more fulfilling lives of their own choosing.
- 3.4 However it needs to be acknowledged that living with autism is often stressful and stress is linked to episodes of mental and emotional ill health. Late adolescence and early adult life are times of increased vulnerability. An individual's quality of life, as well as that of their families or carers, can be substantially affected. Where no crisis pathway is in place, autistic individuals often fall through service gaps. The long term nature of autism, and any variation in the severity of impact, means that the needs for individuals, families, and carers are not directly comparable with people requiring care and support for other reasons.
- 3.5 A significant proportion of autistic adults across the whole spectrum experience social and economic exclusion. Autism has lifetime consequences, with a range of impacts on the health, economic

wellbeing, social integration and quality of life of individuals with the condition and also their parents, families and the wider community. Many of these impacts can be expressed as economic costs.

3.6 In a number of cases, autism exists alongside a severe disability, necessitating a coordinated health, education and social care approach. Equally, there are individuals who do not require full-time, ongoing service provision but who may require only occasional support at certain times.

4. Rationale for developing an Autism Strategy:

4.1 National Autism Strategy: A local Autism Strategy will ensure we are meeting the requirements of the national Autism Strategy and accompanying statutory guidance. This strategy was first published in March 2010 following the Autism Act in 2009, and was most recently updated in January 2016. Statutory guidance was produced in March 2015.

4.2 Self-assessment: A local Autism Strategy will enable issues identified in our local self-assessment framework to be addressed.

4.3 Legislation: A local Autism Strategy will help ensure we are meeting the requirements of the 2014 Care Act in relation to autistic children, young people, and adults.

4.4 Transforming Care Programme: A local Autism Strategy will ensure we are working in accordance with the Transforming Care (Winterbourne View 2011) agenda thereby focussing on the development of services and support for people with a learning disability and/or autism who display behaviour that challenges. The strategy sets out an expectation that more community services will be developed with a view to reducing the number of autistic individuals accessing in-patient facilities as a result of crisis.

4.5 Demand: A local Autism Strategy will help address the issue of an anticipated increase in demand for autism-related support. Based on a local population of 733,128 (2016 data), it is possible to estimate that 9,530 children, young people, and adults live with autism. If we include families and carers, autism is part of daily life for 11,912 people in Northamptonshire.

4.6 In terms of adults formally diagnosed with autism in the form of Asperger's Syndrome, NASS data for 2017/18 shows a 6.5% increase in customers (rising from 74 to 79) with costs up by 19%. When factoring in those adults with 'complex' autism (co-occurring diagnosis of Learning Disability,

Physical Disability, Conduct Disorders etc.), the total number of adults receiving a service from NCC is 374.

4.7 Northamptonshire Healthcare NHS Foundation Trust (NHFT) provides support via a specialist ADHD/Aspergers team (separate child and adult provision). Throughout 2017 the team received 1079 referrals. Of these, 50% (539) related solely to autism (including Asperger's and generalised ASD) whilst 103 of the referrals related to co-occurring ASD and ADHD. Of the 539, 61% (327) requested a diagnostic assessment.

4.8 Data analysis suggests that 55% (180) of the total seeking assessment will complete the process. However, over 90% (175) of those completing assessment will receive a formal diagnosis. In order to highlight discrepancies related to localised recording of autism, it is worth noting that, according to the national dataset, it is estimated that Northamptonshire would have the following across the county:

- Under 18's (forecast) diagnosed ASD: 1680
- 18 – 64's (forecast) diagnosed ASD: 4357
- Over 65's (forecast) diagnosed ASD: 1243

Total number of people with ASD in Northamptonshire forecast as **7280**

5. Consultation and Scrutiny

5.1 Northamptonshire's All Age Autism Strategy is the result of a joint strategic initiative involving the following statutory partnerships:

- Adult Social Services
- Children First, Northamptonshire
- Nene and Corby Clinical Commissioning Groups
- Northamptonshire Healthcare NHS Foundation Trust

5.2 A number of focus groups and work streams resulted in formulation of the strategy. 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 Strategy represents a milestone for autistic individuals throughout Northamptonshire.

5.3 All those involved remain at the centre of Northamptonshire's ambition to improve the lifelong journey of autistic individuals and their families. All are passionate regarding the case for change. The embedded Action Plan should be used as a measure of success.

5.4 Financial costings, customer numbers, and future projections contained within the strategy are a snapshot and are, therefore, correct at the time of writing. Alongside continuous updating of commissioning intentions, data regarding customer increases within specific geographical areas will be added when available.

- 5.5 The formal public consultation ran from 15/08/2018 to 07/10/2018 targeting an 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)
- 5.6 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 from partner websites.
- 5.7 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.
- 5.8 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,
 - 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)

5.9 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. Analysis of the feedback from all consultation methods is available in Appendix 1.

5.10 Feedback in brief:

- The majority of the total respondents found the strategy easy to understand but fewer respondents who identified as autistic found it easy (85% versus 72.7).
- Of the additional 45 general comments there were 23 positive remarks about the style, for example, Plain English, easy read, clarity and video.
- The majority of respondents agreed with the vision in the strategy. Key theme is 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 making it unrealistic especially as they believe some of the implementation will come at a cost
- There is overall agreement for all 5 priorities - all priorities received a very high level of agreement (either agree or really agree) – ranging between about 85 to 95%
- 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.
- people identifying as autistic referred to the significant wait for a response or lack of any sort of support even after a diagnosis. A small number of 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.
- there was a focus 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. Respondents 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.
- Consultation responses and feedback will be used to inform and shape the final version of the strategy

5.11 The matters set out in the report have been subject to scrutiny in the form of cross party briefings held on 27/09/18 and 12/10/18

6. Equality Screening

6.1 Outcomes of EQIA are positive for Sex, Age, Disability, Race and Ethnicity, Religion or Belief, Human Rights, and for families and carers. The remaining protected characteristics are assessed as neutral and the action plan within the strategy directly addresses inequalities. The action plan will be continuously monitored and adverse effects will be addressed thereby ensuring that the strategy meets the requirements of national legislation and guidance. The full EQIA is available at: <https://www3.northamptonshire.gov.uk/councilservices/adult-social-care/policies/Pages/EqIAs.aspx>

7. Alternative Options Considered

7.1 No other options have been considered as the Autism Act (2009) places a statutory requirement for Local Authorities and Health to put in place a local plan for Children, Young People, and Adults with Autism Spectrum Disorder. In addition, the five priorities set out at Recommendation 3 (above) are nationally recognised priorities.

8. Financial Implications

8.1 Approval of the recommendations contained within the strategy has no financial implications as subsequent actions will be implemented using existing resources and partnership working

9. Risk and Business Continuity Management

a) Risk(s) associated with the proposal

None

b) Risk(s) associated with not undertaking the proposal

Risk	Risk Rating
Non-compliance with statutory legislation and requirements; Autism Act 2009, Transforming Care guidance 2012, Care Act 2014, Children and Families Act 2014 (incorporating SEND), NICE guidelines 2016.	Red

10. List of Appendices

Appendix 1: Northamptonshire All Age Autism Strategy

Author:	Name: Bob Fletcher Team: Commissioning
Contact details:	Tel: 07841 784953 Email: bob.fletcher@nass.uk.net
Background Papers:	Draft Northamptonshire All Age Autism Strategy – available at https://www3.northamptonshire.gov.uk/councilservices/council-and-democracy/have-your-say/Pages/past-consultations.aspx
Does the report propose a key decision is taken?	NO
If yes, is the decision in the Forward Plan?	YES
Will further decisions be required? If so please outline the timetable here	NO
Does the report include delegated decisions? If so, please outline the timetable here	YES – once recommendations have been approved the draft strategy will be amended and subsequently delegated to Directors of Adult Social Services and Children First, Northamptonshire for approval and sign off.
Is this report proposing an amendment to the budget and/or policy framework?	NO
Have the financial implications been cleared by the Strategic Finance Manager (SFM)? Have any capital spend implications been cleared by the Capital Investment Board (CIB)	NO – no financial implications at this stage as Cabinet being asked to adopt strategy recommendations
Has the report been cleared by the relevant Director?	YES Name of Director: Anna Earnshaw
Has the relevant Cabinet Member been consulted?	YES Cabinet Member(s): Victoria Perry and Sandra Naden-Horley
Has the relevant scrutiny committee been consulted?	NO
Has the report been cleared by Legal Services?	YES
Have any communications issues been cleared by Communications and Marketing?	YES

<p>Have any property Issues been cleared by Property and Asset Management?</p>	<p>N/A</p>
<p>Have the Procurement Implications below been referenced in the Paper:</p> <ul style="list-style-type: none"> • Have you evidenced compliance with the Council's Contract Procedures Rules? • Have you made clear in this paper where you are seeking Cabinet to approve an exemption from the Contract Procedure Rules and detailed the risks and mitigations? • Have you identified any EU or UK legislative risks such as non-compliance with the Public Contract Regulations Act 2015, transparency and open competition? • Have you identified the procurement risks associated with a contract? 	<p>N/A</p>
<p>Are there any community safety implications?</p>	<p>Yes - The strategy notes that a disproportionately high number of offenders and victims of crime are autistic. The strategy therefore aims to:</p> <ul style="list-style-type: none"> • reduce and improve both autistic individual's, and the wider autism community's interaction with the criminal justice system • address the fear of both crime and involvement in the wider Criminal Justice System within the autism community • Rebuild the poor reputation of service delivery with the Criminal Justice System • Decrease the impact crime and disorder has upon quality of life within the wider autistic community

Are there any environmental implications:	Yes – see above
Are there any Health and Safety Implications:	No
Are there any Human Resources Implications:	NO
Are there any human rights implications:	NO
Constituency Interest:	ALL

Northamptonshire's All Age Autism Strategy 2018 – 2021

Raising Awareness and Understanding regarding the complexity of Autism

Providing effective, quality assured Pre and Post Diagnosis support

Enhancing education, employment, accommodation, social, and leisure opportunities

Promoting seamless progression throughout periods of transition

Providing effective and enabling care and support



Corby Clinical Commissioning Group and Nene Clinical Commissioning Group

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Foreword

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 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.

The financial implications of autism are significant. Latest figures from the National Autistic Society (NAS) indicate that for someone diagnosed as autistic, the lifetime cost equates to £3.1m; for someone with autism and a co-occurring learning disability, the cost increases by 50% to £4.6m. These figures include the "hidden" costs of family carers and voluntary services. Effective early intervention is crucial to reducing long term dependency, promoting independent living, enhancing coping strategies, championing emotional and physical wellbeing, and reducing the number of high cost interventions.

The Strategy has been developed against a backdrop of financial constraints and organisational change across the public sector. Everyone involved in co-producing the Strategy recognises the need for a personalised approach to ensure support is formed around the person, thereby enabling them to take control and make real choices about how they lead their lives. The outcomes identified within the document will need to be achieved within existing resources, either by maintaining current services or redesigning provision. This presents a challenge for all involved and requires a shift away from traditional ways of thinking towards innovation in terms of new approaches; this approach is crucial if we are to develop a truly responsive service to meet the needs of Northamptonshire's autistic residents.

The Strategy will enable partners to work much closer together to support autistic people, according to their own unique needs, resulting in a person-centred, outcomes-focused approach. Collaborative Education, Health and Care planning should ensure continuity of care and support. Timely diagnosis and early intervention should prevent delays in service provision. Effective staff training should enable the right support at the right time thereby reducing and delaying the number of inappropriate referrals and interventions.

Lesley Hagger

Director, Children First Northamptonshire

Northamptonshire County Council

Anna Earnshaw

Director of Adult Social Care

Northamptonshire Adult Social Services (NASS)

Co-Production and Consultation

Northamptonshire's All Age Autism Strategy is the result of a joint strategic initiative involving the following key partners:

- Adult Social Services
- Children First, Northamptonshire
- Nene and Corby Clinical Commissioning Groups
- Northamptonshire Healthcare NHS Foundation Trust

A number of focus groups and workstreams, co facilitated by Louise Kirby (Lead Practitioner Autism Practice and Assurance, NHFT), and Bob Fletcher (Commissioning Manager – Autism, NASS) resulted in the following document. 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 Strategy represents a milestone for autistic individuals throughout Northamptonshire.

All those involved remain at the centre of Northamptonshire's ambition to improve the lifelong journey of autistic individuals and their families. All are passionate regarding the case for change. The Action Plan embedded within this document should be used as a measure of success.

Financial costings, customer numbers, and future projections contained within the strategy are a snapshot and are, therefore, correct at the time of writing. Alongside continuous updating of commissioning intentions, data regarding customer increases within specific geographical areas will be added to this document when available.

The Strategy links with the:

- 2018 Refresh of the Think Autism document

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

- Northamptonshire Transforming Care Partnership: Children's and Young People's Action Plan (2016-19)

https://www.neneccg.nhs.uk/resources/uploads/The_Northamptonshire_Transforming_Care_Plan_Publish_June_2016_pdf.pdf

- SEND Strategy and Action Plan (2017-20)

[https://www3.northamptonshire.gov.uk/councilservices/children-families-education/SEND/local-offer/Documents/Northamptonshire%20SEND%20Strategy%202017%20\(002\).pdf](https://www3.northamptonshire.gov.uk/councilservices/children-families-education/SEND/local-offer/Documents/Northamptonshire%20SEND%20Strategy%202017%20(002).pdf)

and feeds into the:

- Disabled Children's and Young People's Delivery Group
- Northamptonshire Transforming Care Operational Group Workstreams
- Multi agency Learning Disability Improvement Plan.

Terminology

For consistency with the National Strategy and associated guidance, recent research into terminology, and in line with an aim to de-medicalise autism, the terms 'autism community', 'autism' and 'autistic' will be used in the context of the Northamptonshire All Age Autism Strategy. These terms are taken to cover various descriptions of autism, diagnosed or otherwise, and include Autistic Spectrum Disorder (ASD), Asperger's Syndrome, Autistic Spectrum Condition (ASC) and neuro-divergence.

Autistic person – refers to children, young people and adults, pre or post autism diagnosis, and encompasses the breadth, complexity and diversity of autism across a wide spectrum of ability.

Parent(s) and Families- includes biological, birth, foster and adoptive parent(s) and families

Carer - someone who's looking after a partner, friend or family member who's not able to manage by themselves

Child – as defined by the Children and Families Act as being up to 16yrs old and of compulsory school age. However, in other areas of law, 'child' is a person under the age of 18.

Young person – aged between 16-25yrs old

Adult – any person over the age of 18yrs

National Context

Defining Autism

Autism is characterized by unique social interactions, non-standard ways of learning, keen interests in specific subjects, inclination to routines, challenges in typical communications and particular ways of processing sensory information.

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. Autistic individuals, their families and carers, have a great many gifts and strengths. With the right sort of support, all can learn, develop, and live more fulfilling lives of their own choosing.

However it needs to be acknowledged that living with autism is often stressful and stress is linked to episodes of mental and emotional ill health. Late adolescence and early adult life are times of increased vulnerability. An individual's quality of life, as well as that of their families or carers, can be substantially affected. Where no crisis pathway is in place, autistic individuals often fall through service gaps. The long term nature of autism, and any variation in the severity of impact, means that the needs for individuals, families, and carers are not directly comparable with people requiring care and support for other reasons.

A significant proportion of autistic adults across the whole spectrum experience social and economic exclusion. Autism has lifetime consequences, with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with the condition and also their parents, families and the wider community. Many of these impacts can be expressed as economic costs.

In a number of cases, autism exists alongside a severe disability, necessitating a coordinated health, education and social care approach. Equally, there are individuals who do not require full-time, ongoing service provision but who may require only occasional support at certain times.

Parents, families, and carers seek a formal diagnosis of autism for a variety of reasons. However, autism may not be the best, or only, explanation for an individual's behaviours. Psychological issues may present in the form of obsessive behaviour, speech and communication problems, developmental delays, and social isolation. However, as a stand-alone set of symptoms, these do not equate to a diagnosis, formal or otherwise, of autism.

Attachment Disorders, as with many mental health concerns, should be viewed as a spectrum. Some mild cases can be more easily addressed, while others may become formally diagnosed as a disorder. For some the effects are minimal, for others, the effects are emotionally traumatic.

Reactive Attachment Disorder is considered one of the more severe attachment problems. It is not a common condition and not every child who has experienced emotional and physical neglect alongside the associated trauma will develop it. Those that do are likely to be very withdrawn and seem emotionally detached.

ADHD, either Inattentive, Hyperactive-Impulsive, or a combination of the two is the most common neurobehavioral disorder in children. It usually starts at about 18 months old, but symptoms normally become noticeable between the ages of 3 and 7. It's more common in boys than in girls. ADHD is often described as a chronic sense of feeling overwhelmed. Associated symptoms and behaviours include risky or impulsive actions, sleep problems, poor stress management, and increased feelings of anxiety.

Avoidant Personality Disorder is characterized by feelings of extreme social inhibition, inadequacy, and sensitivity to negative criticism and rejection. Yet the symptoms involve more than simply being shy or socially awkward. Avoidant personality disorder causes significant problems that affect the ability to interact with others and maintain meaningful relationships in day-to-day life. Symptoms include a variety of behaviours, such as fear of criticism or rejection, low self-esteem, and self-isolation.

Obsessive-compulsive disorder is a type of mental ill health. People with OCD can have either obsessive thoughts and urges or compulsive, repetitive behaviours. Some have both obsessions and compulsions.

Autism in adults is much more common than many people think. It has been suggested that if all adults in the UK were assessed, the proportion identified with autism would probably reach 1.3% of the adult population (more than 700,000 adults). If you include families and carers, it is estimated that autism would be a part of daily life for 2.8 million people.

A National Autistic Society (NAS) study reported that, in terms of adult health and wellbeing:

- 63% of autistic adults perceive that they do not receive enough support to meet their needs
- 67% have experienced anxiety
- 33% have experienced serious mental health problems because of a lack of support

In terms of quality of life:

- 75% do not have any friends or find it hard or very hard to make friends
- 72% would like to spend more time in the company of other people.

In terms of autistic adults making a positive contribution:

- only 15% are in full-time employment
- 66% are not working at all (including figures for voluntary employment).

In terms of autistic adults having choice and control:

- 14% live in their own flat or house with support
- 37% would like to live in their own flat or house with support
- 27% have a person-centred plan or care plan.

In terms of autistic adults experiencing freedom from discrimination:

- 60% have experienced problems trying to receive support from local authorities or health authorities.
- 42% of these people were told this was because there were no appropriate services.
- More than 70% of those who live on their own have been bullied or harassed.

Autistic individuals, their families and carers face many barriers when attempting to access the support and services they require including:

i. Autism being misunderstood by professionals and wider society

It can be difficult for professionals from all disciplines to recognise that a person is autistic, particularly if there is a mistaken expectation that a learning disability should also be present. In reality, estimates suggest that only 50% of autistic individuals have a co-occurring learning disability.

ii. Difficulty with the support and services they need to live independently in the community

Northamptonshire has chosen to take an all-age approach to its strategy in order to ensure commitment and collaborative working across services. By working in partnership with individuals, families, and carers, gaps in provision can be identified and predicted, therefore ensuring that resources are used wisely which, in turn, should enable smoother transitioning from children's to adult services, and into older age.

iii. Difficulties with gaining long term meaningful employment.

It is believed that only 15% of autistic individuals are in full-time employment and 9% are in part-time employment. 79% in receipt of out-of-work benefits say they would like to work, but require the right support. What is more, 26% of autistic graduates are unemployed; around twice the proportion of any other disability group (Association of Graduate Careers Advisory Services).

For an extensive overview of issues surrounding the workplace please follow the link below:

[http://network.autism.org.uk/sites/default/files/ckfinder/files/NAS%20TMI%20Employment%20Report%2024pp%20WEB%20\(002\).pdf](http://network.autism.org.uk/sites/default/files/ckfinder/files/NAS%20TMI%20Employment%20Report%2024pp%20WEB%20(002).pdf)

iv. Ethnicity

Ethnicity remains a key determinant of health inequalities in England. Individuals, families, and carers from Black and Minority Ethnic (BaME) communities face disparity in relation to healthcare access, positive outcomes, culturally sensitive support and innovative forms of engagement.

Autism within BaME communities is less likely to be diagnosed, and those affected by autism are unlikely to be in receipt of appropriate service provision.

For a comprehensive overview of the challenges for families affected by autism from BaME communities follow the link below:

<https://www.autism.org.uk/~media/NAS/.../NAS-Diverse-perspectives-report.ashx>

v. Gender

It is becoming clear that women of all ages and ethnicities may be under-represented in terms of diagnosis. Published studies reveal high rates of suicide among autistic individuals, with women at greatest risk of taking their own lives.

A gender-specific diagnostic model that encompasses the varied ways in which autistic traits present would go a long way toward reducing the invisibility of autistic girls and autistic women.

For a comprehensive overview of the challenges facing girls and women living with autism follow the link below:

www.nasen.org.uk/.../download.D7B94242-69B6-48DF-97A30FDCD4EB2BB4.html

vi. Transitions

Until relatively recently, transition for an autistic individual has been viewed as a relatively narrow concept; the time when a child or young person moves from one school to the next or is preparing to leave formal education completely. However there are many more periods of transition, moving from one class to another, having a new teacher, and transferring between classrooms and lessons. Some periods of change present as particularly stressful. Transition from children's to adult services is a particularly traumatic time and a lack of planning often leads to frustration, bewilderment, anxiety, stress, fear and trauma. Significant problems have often been caused by poor information-sharing between children's and adult services.

Effective planning will identify future needs across different agencies, including education, employment, housing and social care. There is a clear need to know how many autistic young people are leaving school over the next five years and the type of support they are likely to need in order to commission accordingly.

In terms of facilitating effective transitions, good practice highlights the need for:

- full participation of autistic young people and their families
- comprehensive multi-agency engagement
- provision of high quality information for effective transition planning
- Significant and meaningful choice.

vii. Housing

Within the autism community, almost half of adults over 25 continue to live in the family home and over half are dependent on their parents for financial support. Moving out of the family home is one of the biggest milestones in a person's life. However, for autistic individuals this can be a long and challenging process. Coordinating choices for suitable accommodation, as well as identifying the necessary support services can be complicated. More often than not, choice and control remain aspirational rather than the reality.

Altogether there are about 366 units of supported living, many of which are in small properties sharing with one other person and often with a sleeping-in room for a member of staff.

Autistic individuals require a variety of different housing options, ranging from semi or fully independent, through supported living and Shared Lives, to clusters of bedsits or small group homes. Many autistic adults continue to be placed in traditional, large residential services due to lack of alternative provision. Often these are adults with profoundly debilitating sensory, perceptual and social difficulties. The environment proves highly inappropriate resulting in episodes of extreme anxiety leading to an increase in support needs.

It is essential that the location of a person's home reflects their individual needs and preferences. The accommodation, unless purpose built, is likely to require adaptation whilst consideration will need to be given to sensory and sensitivity issues (sounds, lights, colours and smells). Ideally, housing and support should be delivered by separate providers so that the need to move house following a change in support provider is minimised. However, taking into account economy of scale, this does not exclude suitable providers delivering both. A comprehensive study, entitled 'living in the community: housing design for autistic adults' can be accessed by following the link below:

<http://network.autism.org.uk/knowledge/insight-opinion/living-community-housing-design-autistic-adult>

National Policy and Statutory Responsibilities

The National Autism Plan for children was published in 2003. This was followed by The Autism Act in 2009 which placed a number of obligations on a range of public bodies to improve opportunities for autistic people. In 2010 'Fulfilling and Rewarding Lives' provided a clear direction in terms of how public services must transform to better address the needs of autistic adults. More recently, 'Think Autism', published in April 2014 and refreshed during 2018, shared detailed consultation and research into the views of autistic people and their families on how progress has been taken forward in implementing the 2009 Autism Act. In March 2015 'Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy' was also published.

More general advice and guidance appears within the following documents:

Transforming care: a national response to the Winterbourne View Hospital Review (2012)

The response outlines a programme of action introduced by the Department of Health. It requires the NHS and Local Authority commissioners to complete a 3 stage process, in order to comprehensively review the care of "people in hospital with learning disabilities or autism with mental health conditions or behaviour that challenges" placed outside of their local area.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

<https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf>

The Care Act (2014)

The Act brings care and support legislation into a single statute. It is designed to create a new principle where the overall wellbeing of the individual is at the forefront of their care and support. It also requires the promotion of integration of care and support with local authorities, health and housing services and other service providers to ensure the best outcomes are achieved for the individual.

<https://www.legislation.gov.uk/ukpga/2014/23/contents>

Children and Families Act 2014 (incorporating SEND)

The Act transformed the process by which children and young people with special educational needs (SEN), including those who are disabled, accessed outcome based support. The Act extended SEND entitlement from birth to 25, giving children, young people and their parents greater control and choice in decisions and ensuring needs are properly met. There is now a single assessment process for children with special educational needs or disabilities, supported by an Education, Health and Care (EHC) plan.

http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf

NICE Guidelines

Autism spectrum disorder in adults: diagnosis and management
Clinical guideline [CG142] Published date: June 2012 - Last updated: August 2016

<http://www.nice.org.uk/guidance/cg142>

Autism spectrum disorder in under 19s: recognition, referral and diagnosis
Clinical guideline [CG128] Published date: September 2011 - Last updated: December 2017

<https://www.nice.org.uk/Guidance/CG128>

Local Context

Our Vision

Northamptonshire's All Age Autism Strategy is committed to both the development and improvement of service provision and the overall experience of autistic people, their families and carers. 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. Best Practice suggests Practitioners and Commissioners should:

- Challenge the existing model(s) of care and the accepted societal norms, both of which unintentionally reinforce inappropriate service provision.
- Provide pre and post diagnosis support via outcomes-focused, needs-led, integrated interventions.
- Champion joint commissioning across Health, Social Care, and Children's services thereby assisting in the development of a competent and confident workforce.
- Promote the right support at the right time to those with low level needs as well as those with the most complex needs.
- Ensure autistic individuals, their parents and carers are involved as equal partners and the third sector as key providers of information, support, and advocacy.
- Develop a robust Quality Assurance process in order to evaluate effectiveness and use the intelligence gained to be clearer about future commissioning.
- Implement specific autism related outcomes to measure quality of providers thereby ensuring they have the requisite knowledge and skills to effectively support autistic individuals
- Support and promote wide ranging, life enhancing opportunities for autistic individuals, their families and carers.

Our Principles

This vision, and delivery of key priorities, will be underpinned by the following principles:

Collective responsibility – supporting autistic individuals is not the responsibility of a single agency; everyone should work in partnership to solve even the most complex of problems

Early Support and Intervention for autistic children, young people, and adults – delivered by a competent and confident, sector wide, workforce skilled in the early identification of autistic traits

Inclusion - the majority of autistic children, young people, and adults should, with reasonable adjustments, be able to access appropriate universal services

Localisation – autistic children, young people, and adults can expect service provision that promotes meaningful engagement and reasonable adjustments in their local community

Personalisation - an individualised approach embracing choice, control, and reasonable adjustments for autistic children, young people, and adults

Co-production – autistic children, young people, and adults are active participants in decision making and help to develop and shape services

Partnership – integration, joint commissioning and co-ordination of approaches to deliver better outcomes for autistic children, young people and adults

Culture Change –we need to think in different ways, create alternative methods for delivery and develop more flexible approaches to support autistic children, young people, and adults

Demographics

Demand for care and support continues to increase whilst massive reductions in resources impact on frontline services. Changing public expectations together with extreme budget pressures, mean that individual Agencies will struggle to provide services in isolation. As a result, the development and expansion of the autism community is vital for future sustainability. Value for money will continue to drive all commissioning decisions inevitably leading to a greater focus on:

- Growth of active citizens and voluntary action through effective third sector engagement within local communities.
- Increased third sector opportunities to design and deliver public services
- Promotion of both the third sector and the wider autism community so that they have the opportunity to influence policy and decision making
- Development of robust and effective third sector infrastructure support

Estimates suggest there will be around 450 more autistic adults by 2025 than there were in 2015 and around 350 of these will be aged 65 and over.

Northamptonshire Adult Social Care figures indicate that, during 2016/17, seventy four (74) adults living with autism were in receipt of services costing £1,280,724 (an average of £17,307 per customer). Nine (9) customers were in receipt of services relating to Supported Accommodation, costing £103,366 (an average of £11,485 per customer). A further twenty two (22) had not received care and support in the current year but were known to the Local Authority. Of the combined total (96), nineteen (18%) were categorised as 'high functioning' and eleven (2%) were receiving services.

During 2017/18 the total customer number rose to seventy nine (79), an increase of approximately 7%. It is not clear whether the increase is reflective across all areas of the Autistic Spectrum. Associated spend increased to £1,527,719 (an average of £19,338 per customer). Twelve customers are in receipt of services relating to Supported Accommodation, costing £315,025 (an average of £26,252 per customer).

Data obtained from the Adult Mental Health and Individual Package of Care (IPC) Teams indicate the provision of services to 82 adults formally diagnosed

with autism (across the spectrum). Of the total, 17 (20%) have a single, primary diagnosis of autism. The remaining 65 (80%) have a range of secondary diagnoses. The total cost relating to the cohort is in the region of £1,500,000 and provides:

- community packages (including CCP and/or day services)
- full-time nursing placements
- full-time residential placements
- supported accommodation placements

The remaining 4 are, or have been, in 100% health funded placements (locked rehab/low secure). In terms of a gender split, 67 are male and 15 female. The average age of the customers is 36 (the youngest being 20 and the oldest 75).

Due to data collection and management differences, it is likely that the same autistic individuals appear in separate Health and Social Care systems and are therefore 'double counted'. It is also probable that the difference in recorded numbers (79 and 82) is the result of autistic individuals only being known to Health related services and are therefore not accessing social care and support or vice versa.

Accommodation

Independent and supported accommodation remains a significant issue, as there are currently insufficient options for autistic individuals. Taking into account both the current number of individuals living in supported accommodation and the estimated rise in the autism population, it is likely that provision will need to be increased by at least 7%. This is, however, a conservative estimate based on available data.

The demand for autism-specific supported living is generated by autistic young people moving to adult services, existing residential placements coming to an end, and autistic individuals living with elderly parents who are no longer able to provide the support required. An increase in Supported Living provision will improve opportunities for autistic people to live in suitable accommodation based on their current and potential future needs.

Specialist accommodation and service provision is also required for autistic individuals returning to Northamptonshire from out of county hospital, residential, and educational placements.

In order to understand the types of accommodation and services needed for young autistic people the assumption is that each year, on average, Adult Social Care (ASC) will be supporting 38 clients through the Transition Team. The strategy assumes that a third are going to require their own tenancy in a

supported living environment (13), a small proportion will be supported in a care home setting (5) and the vast majority will be supported in their own home, foster placement or school (20).

We therefore recognise that the County needs to develop 13-15 units of supported living per year for all new ASC funded younger adults coming through the Transitions Service. In order to achieve this, existing provision will need to be remodelled and new schemes commissioned.

Within the Adult Transforming Care cohort (long and short term care and support) thirteen (13) adults will require specialist step down accommodation. Of the total, five (5) individuals have a primary diagnosis of autism.

Our 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

We aim to significantly improve knowledge and understanding regarding the breadth and diversity of autism across a wide spectrum of ability thereby laying the foundations for a better future for all those living with autism within Northamptonshire.

2. Providing effective, quality assured, pre and post diagnosis support

We aim to develop a clear and consistent pathway that offers advice, guidance, and support based on individual need. Care and support will be delivered by a confident and competent workforce.

3. Enhancing education, employment, accommodation, social and leisure opportunities

By placing the views, wishes and feelings of individuals, families, and carers at the centre of personalised planning, Northamptonshire intends to:

- Ensure access to supported opportunities irrespective of an individual's level of ability
- Increase awareness of autism amongst employers

- Encourage reasonable adjustments
- Support Disability Employment Advisors to gain specialist autism knowledge
- Promote apprenticeship schemes, job coaching, work experience, and self-employment

4. Promoting seamless progression throughout periods of transition

Develop clear and consistent pathways and support at times of key transitions

5. Providing effective and enabling care and support

Person-centred care and support focuses on positive outcomes, autistic people are better able to manage their own lives.

DRAFT

Existing service provision

Based on a local population of 733,128 (2016 data), it is possible to estimate that 9,530 children, young people, and adults live with autism. If we include families and carers, autism is part of daily life for 11,912 people in Northamptonshire.

i. Autistic Children

NCC Team	Child in Need (CIN)	Child Protection Plan	Looked after Child (LAC)	Total
Disabled Children's Team	84	6	18	108
LAC/Leaving Care Teams	8	0	19	27
Safeguarding Teams	25	10	10	45
Total	117	16	47	180

Most recent SEND data (2017) identifies 1404 autistic children. The table below details the geographic spread:

District	ASD
Corby	115
Daventry	138
East Northamptonshire	132
Kettering	161
Northampton	577
Out of county postcode	17
South Northamptonshire	146
Wellingborough	118
Total	1404

Children and young people, with or without a formal diagnosis of autism, are supported through mainstream education and specialist settings and will be represented in one or more of the following service areas:

- The Disabled Children's Team (DCT)
- Specialist Support Services
- The Intensive Support Team
- The Children's Community Team for People with a Learning Disability (CCTPLD)
- Child and Adolescent Mental Health Service (CAMHS)
- Children and Young People's ADHD/ASD (CYP ADHD/ASD)
- Looked After Children (LAC)
- Young People's Drug and Alcohol Services
- Leaving Care (LC)
- Youth Offending Service (YOS)
- Eating Disorder Services
- Safeguarding Teams
- Acute inpatient settings
- Teaching Schools

In terms of consistency and effectiveness, recent research by The National Autistic Society (NAS) revealed a serious lack of understanding and support, with some families reporting that they have had to wait for years to receive help. Many parents, young people, and professionals were concerned that CAMHS did not have the knowledge or the skills to identify or treat mental health problems in autistic children.

Differences in data collection and management methods make it very difficult to be precise regarding the number of autistic children and young people known simultaneously to CAMHS and Local Authority Children's services. However, it is likely that the number of autistic children and young people receiving a CAMHS service in isolation is within the range of national averages. A similar scenario is likely to be the case with the specialist ADHD and Aspergers Team. However, the number of referrals for an assessment is likely to be significantly higher than the national average.

i. Autistic Adults

In terms of adults formally diagnosed with autism in the form of Asperger's Syndrome, NASS data for 2017/18 shows a 6.5% increase in customers (rising from 74 to 79) with costs up by 19%.

Autism Type	Long Term Primary Support Reason	Day Care	Direct Payments	Home Care	Residential	Supported Living	Total unique clients
LD - Aspergers Syndrome/High Functioning Autism	Learning Disability Support	6	32	3	2	11	49
	Mental Health Support		17		1		18
	No Relevant Long Term Support Reason				1		1
	Personal Care Support		4	1		1	6
	Support for Social Isolation or Other Support		5	1			5
LD - Aspergers Syndrome/High Functioning Autism Total		6	58	5	4	12	79

When factoring in those adults with 'complex' autism (co-occurring diagnosis of Learning Disability, Physical Disability, Conduct Disorders etc.), the total number of adults receiving a service from NCC is 374.

Autism Type	Long Term Primary Support Reason	Campus Reprovision	Day Care	Direct Payments	Home Care	Nursing	Rehab + Respite	Residential	Supported Living	Total Unique Clients
LD - Autism (excl Aspergers Syn/High Functioning)	Learning Disability Support	7	39	173	8	1	3	55	40	275
	Mental Health Support			3	1					4
	No Relevant Long Term Support Reason			1						1
	Personal Care Support		1	4				1	3	8
	Support for Social Isolation or Other Support		2	6					2	7
LD - Autism (excl Aspergers Syn/High Functioning) Total		7	42	187	9	1	3	56	45	295

A significant number of individuals living with autism are likely to be combining existing coping mechanisms with the support of families, friends, and carers. Individuals may not be known to the local authority or partner organisations and therefore only estimates of the total numbers of those living with autism are available. In reality, it is highly likely that any figure will be an under estimate. As a result of this, it is difficult to determine a true picture in relation to the money spent on service provision. As part of the implementation of the strategy, it is imperative that further work is undertaken in order to obtain a comprehensive understanding of the needs of the autism community in Northamptonshire.

Adults with or without a formal diagnosis of autism will be represented in one or more of the following service areas:

- Short Term Enablement and Prevention Services (STEPS)
- The Learning Disability Team
- Mental Health and Crisis Pathways
- ADHD/Aspergers Team
- The Community Team for People with a Learning Disability
- Drug and Alcohol Services
- Prison, Probation, and wider Criminal Justice systems
- Eating Disorder services
- Acute inpatient settings
- Complex Older Persons Services

It is vital that, in order to provide an all-encompassing service, Northamptonshire's All Age Autism Strategy recognises the need to reach far and wide. As such;

- Innovative service provision, alongside progressive workforce development, should embed good practice within hitherto 'invisible' settings such as Prisons, Probation, and the wider Criminal Justice systems, Drug and Alcohol services, and Childhood Sexual Exploitation teams.
- There should be an emphasis on service provision that proactively promotes wellbeing and independence
- There needs to be a greater emphasis on de-medicalisation throughout the autism journey
- Service provision must include multi-agency communication, cooperation, integration, resulting in fluency of delivery.
- Proactive, confident, and competent multi-agency early intervention, delivered by an autism aware workforce, should be the norm. Crisis intervention should be viewed as the last resort
- The lack of both quality and consistency of autism-related data recording and management needs urgent attention
- Development of a Northamptonshire Quality Assurance (QA) Scheme to support a continuous cycle of self-evaluation and development against standards that include tailored communication methods and recognition of sensory, communication and environmental needs is recommended.

Based on eligibility criteria being met, specific support includes:

- Support to set targets or outcomes and monitor progress.
- Support to set strategies and interventions.
- Advice or support regarding specific area of need.
- Support and advice at times of transition
- Assessment of learning environment and development of appropriate interventions and strategies.
- Signposting to other services and support.

- Monitoring of care or support package.

Northamptonshire Healthcare NHS Foundation Trust (NHFT) provides support via a specialist ADHD/Aspergers team (separate child and adult provision) offering group work for those with a diagnosis and separate groups for significant others. Ad hoc, 1:1, support with tutors/employers is available, as are time-limited supported peer groups promoting meaningful social activities.

Throughout 2017 the team received 1079 referrals. Of these, 50% (539) related solely to autism (including Asperger's and generalised ASD) whilst 103 of the referrals related to co-occurring ASD and ADHD. Of the 539, 61% (327) requested a diagnostic assessment.

Data analysis suggests that 55% (180) of the total seeking assessment will complete the process. However, over 90% (175) of those completing assessment will receive a formal diagnosis.

The Community Team for People with a Learning Disability (CTPLD) provide a range of support for individuals, families, and carers with complex and co-existing diagnoses (LD/Autism/ADHD).

The Planned Care and Recovery Team (PCART) provide Mental Health and Crisis pathways.

There are a number of Voluntary Sector agencies (commissioned and non-commissioned) providing a range of community-based services.

Transforming Care Cohort

Transforming Care is the government's national programme to improve services for **children, young people, and adults with learning disabilities and/or autism, who display behaviour that challenges, including those with a mental health condition**. The aim is to make sure more people are living in the community, with the right support and, wherever possible, close to home.

The so called 'Golden Threads' of Personalisation, Empowering People, Working in Partnership with Families, Integration, and Whole Systems Working aim to achieve the following 'concrete' outcomes:

- Bed closures
- Independent community living
- A move away from restrictive service models
- Implementing Community Services

The Transforming Care programme is focussing on:

- more choice for people and their families, and more say in their care
- providing more care in the community, with personalised support provided by multi-disciplinary health and care teams
- more innovative services to give people a range of care options that meet individual needs providing early, more intensive support for those who need it, so people can stay in the community, close to home
- for those who do need in-patient care, ensuring it is only for as long as they need it

According to the findings of a recent National Autistic Society (NAS) report entitled 'Making Transforming Care work for autistic people' (2017) approximately 2,500 children, young people, and adults are currently accommodated in an inpatient mental health facility. Over 40% of this group are formally diagnosed with autism (without a co-occurring Learning Disability). The report notes that the proportion has increased since data collection began in 2015.

Autistic people are nine times more likely than people in the general population to commit suicide yet there is often no specialist support above and beyond the level non-autistic individuals can expect.

Locally, the Transforming Care cohort constitutes adults detained in either high, medium, or low secure in-patient units and children and young people accessing care and support via specialist in-patient service provision. Formal diagnosis includes autism (both with and without a co-occurring learning disability), and enduring mental ill health. A small number are also subject to Ministry of Justice restrictions. However, referrals are increasing both regionally (East Midlands) and nationally. Girls account for the largest growth with figures stating that 11 per cent (69,000) of 16-17 year old females in England are known to have had an open referral with NHS-funded secondary mental health, learning disabilities or autism services during 2016/17. Two per cent (1,300) of this group were admitted to hospital as part of their referral.

There are a number of individuals who neither fit the Transforming Care criteria nor access, and are therefore unknown to, mainstream services. As a result, they receive little or no support. Where post-diagnosis support is offered, provision is often worse than that which existed pre-diagnosis.

Prisons and the wider Criminal Justice System

Research, peer reviewed or otherwise, relating to the prevalence of autism within the Criminal Justice System is significantly lacking. However, it is widely accepted that, in terms of the Criminal Justice process, autistic young people and adults frequently experience increased episodes of trauma due to their additional needs going unrecognized. Within the prison system it is likely that autistic individuals will be subjected to bullying and exploitation, resulting in self-imposed social isolation. At the time of writing, there is only one prison nationally that is classed as 'friendly' by way of NAS Autism Accreditation.

Northamptonshire provides Health, Social Care, and Children's services across three local establishments. Currently, HMPs Onley and Ryehill report numbers of autistic prisoners significantly below the national average, whilst Rainsbrook, a secure training centre for male and female young people aged 12 to 18 years who meet the criteria for a custodial sentence or secure remand, reports no young people with a formal diagnosis of either autism or a learning disability (the national average is generally accepted as 0.6 – 1.2% amongst young people in the general population and 15% among young people in custody).

However, the issue of a lack of awareness and recognition of autism occurs even earlier in the criminal justice process. For a comprehensive overview, and an online resource relating to questioning an autistic individual as either a defendant or a witness please click on the link below:

<http://www.theadvocatesgateway.org/>

NHS England Liaison and Diversion (L&D) initiatives

The L&D Programme was created in 2010 and has developed into a strong cross-government initiative, with partners from:

- Department of Health
- NHS England
- Home Office
- Ministry of Justice
- Youth Justice Board
- HM Courts and Tribunals Service

- Public Health England
- Offender Health Collaborative
- Bradley Review Group
- National Offender Management Service
- Crown Prosecution Service

L&D initiatives were a direct result of the Bradley Report (2009). Specialist service provision aims to identify people who have mental health, learning disability (with or without co-occurring autism), problematic substance use, or other vulnerabilities/differences (including autism) when they first come into contact with the criminal justice system as suspects, defendants or offenders.

The service can then support people through the early stages of criminal system pathway, refer them for appropriate health or social care or enable them to be diverted away from the criminal justice system into a more appropriate setting, if required.

L&D services aim to improve overall health outcomes for people and to support people in the reduction of re-offending. It also aims to identify vulnerabilities in people earlier on which reduces the likelihood that people will reach crisis point and helps to ensure the right support can be put in place from the start.

Locally, the team delivers the above aims by way of:

- A full assessment of a vulnerable individual's needs
- Multi-agency collaborative practices (police officers, court services, solicitors, and prison staff) designed to promote seamless packages of care and support
- Adaptive processes designed to include vulnerable individuals at all points of the criminal justice process.

Time2listen

During 2018 Northamptonshire Police and Crime Commission launched Time2listen, a consultation designed to address poor service delivery in relation to mental ill health, Attention Deficit Hyper Activity Disorder (ADHD), or autism and the lack of awareness in Northamptonshire of each cohort's experiences of the service provided by the police, and the wider Criminal Justice System.

The process aimed to:

- consult with people who have a Mental Illness, ADHD or autism and their carers about their experience of the Criminal Justice System and support services that work alongside it
- capture experiences of those professionals and support agencies, to understand the mental health pathway and service provision
- capture experiences of those who work in frontline roles, and how effectively organisations work together.

In terms of service provision relating to autistic individuals, their families, and carers the following recommendations highlight the need for all criminal justice agencies to undertake ongoing workforce development and training in order to:

1) Improve knowledge of autism and the potential impact it has on individual behaviours and experiences. Frontline practitioners and support staff should be offered training focussing on communication skills, low arousal, and de-escalation techniques. A long-term multi-agency programme of training should be developed and delivered by individuals with lived experience alongside autism practitioners.

2) Increase awareness of referral processes, advice and guidance options, and support services.

3) Promote collaborative work between Northamptonshire Police, Adult Social Care, Children First Northamptonshire, and families/carers regarding appropriate alternative responses or actions that reduce criminalisation of autistic people.

4) Actively campaign for the provision of care and support prior to the point of crisis, thereby minimising the need for a criminal justice intervention.

For a comprehensive overview, and to read the full report, follow the link below:

<https://www.northantspcc.org.uk/time2listen/>

Strategy Recommendations

In line with the 5 priorities identified within Northamptonshire's All Age Autism Strategy, the following recommendations should be implemented through delivery of the Action Plan:

- I. Reconfiguration/realignment of current service provision
- II. Explore the development of a multi-disciplinary autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.
- III. Implementation of a clear process for recording autism as a primary support reason
- IV. Service provision for autism and Learning Disabilities should be separate
- V. Development of best practice autism standards covering the following themes:
 - Knowing the individual
 - Environment
 - Collaboration
- VI. Implementation of outcome-focused, joint commissioning and interventions,
- VII. Sector wide workforce development
- VIII. Establishment of a multi-disciplinary network of Autism Champions across Northamptonshire.
- IX. Embedding of continuous practice development and quality assurance

Delivering the 5 Priorities

Each priority has a summary of recommended actions, [shown in blue](#), which should form the basis for development of action plans with SMART objectives for implementation.

Priority 1: Raising awareness and understanding regarding the complexity of autism

Ambition: to significantly improve knowledge and understanding regarding the breadth and diversity of autism across a wide spectrum of ability thereby laying the foundations for a better future for all those living with autism within Northamptonshire.

Success will look like:

Recommended appropriate autism knowledge required for staff who provide general support to autistic individuals is identified and specified.

Recommended specialist autism knowledge required for staff who have a direct impact on, and make decisions about, the lives of autistic individuals is identified and specified.

Increased number of people completing autism training appropriate to their role.

Autism Champions in services operating as a network group and acting as change agents to develop autism practice in their services.

Reduced number of inappropriate referrals and interventions.

Reduced number of people with autism reaching crisis point which has previously resulted in unnecessary hospital admission.

Number of people accessing online portal for information and advice.

Reduced number of reports of discrimination, hate crime and abuse for all individuals with autism.

The Raising Awareness and Understanding group (TFG1) will work on the following national actions:

- Health and care staff, and staff in organisations with public-facing responsibilities, who provide general support to autistic individuals have **appropriate knowledge** of the condition
Think Autism refresh March 2018 – Domain 2 Workforce Development
- Health and care staff, and staff in organisations with public-facing responsibilities, who have a direct impact on, and make decisions about, the lives of autistic individuals have appropriate **specialist knowledge** of the condition
Think Autism refresh March 2018 – Domain 2 Workforce Development

This will be delivered through the following **local actions**:

- Developing a multi-tier local training framework – varied training according to professional role and level of involvement with autistic individuals, their families and carers.
- Developing an autism champion network of knowledgeable individuals in each of the key services that support autistic individuals, their families and carers to promote consistency, clarity and to play a role in a continuous cycle of improvement of autism practice
- Developing an online information and advice portal providing a range of information on services and support for autistic individuals, their families, providers and organisations in a proposed partnership with the University of Northampton.
- Ensuring people with autism are safe in the community and free from the risk of discrimination, hate crime and abuse

Priority 2: Providing effective, quality assured, pre and post diagnosis support

Ambition: to develop a clear and consistent pathway that offers advice, guidance, and support based on individual need. Care and support will be delivered by a confident and competent workforce.

Success will look like:

Access to pre and post diagnostic support is improved, in particular for older adults, women, young people, and children

The Diagnosis and Post-diagnostic support group (TFG2) will work on the following national actions:

- Awareness of diagnosis waiting times and post diagnostic outcomes (indicators in MHSDS), focus to include older people, under diagnosis in women and children
Think Autism refresh March 2018 – Domain 1 Measuring, Understanding and Reporting needs of autistic people
- GPs aware of patient's condition (establishment of Autism Register)
Think Autism refresh March 2018 – Domain 1 Measuring, Understanding and Reporting needs of autistic people
- Timely access to adult autism diagnosis
Think Autism refresh March 2018 – Domain 3 Health, Care and Wellbeing

This will be delivered through the following **local actions**:

- developing a clear, consistent, step by step, all age pathway for pre and post-diagnostic support
- developing consistency in data recording and management of autism diagnoses

- the development of an all age database of those diagnosed with autism
- Obtaining a comprehensive understanding of the needs of the autism community in Northamptonshire

Priority 3: Enhancing education, employment, accommodation, social and leisure opportunities

Ambition: By placing the views, wishes and feelings of individuals, families, and carers at the centre of personalised planning, Northamptonshire intends to:

- Ensure access to supported opportunities irrespective of an individual's level of ability
- Increase awareness of autism amongst employers
- Encourage reasonable adjustments
- Support Disability Employment Advisors to gain specialist autism knowledge
- Promote apprenticeship schemes, job coaching, work experience, and self-employment

Success will look like:

An increase in availability of appropriate accommodation, autism-friendly employment opportunities, peer mentoring schemes and meaningful social and leisure options

The Exploring Life Opportunities group (TFG3) will work on the following national actions:

- Access to an appropriate range of accommodation options
Think Autism refresh March 2018 – Domain 5 Participation in Local Community
- Easy access to, and positive experience of, employment and benefits pathways
Think Autism refresh March 2018 – Domain 4 Specific Support
- Support is provided to autistic people to help them retain employment, and support them in their work setting
Think Autism refresh March 2018 – Domain 4 Specific Support
- Easy access to public transport
Think Autism refresh March 2018 – Domain 4 Specific Support
- Support is provided to autistic people to help them retain employment, and support them in their work setting
Think Autism refresh March 2018 – Domain 4 Specific Support

This will be delivered through the following **local actions**:

- Easy access to, and positive experience of, meaningful social and leisure opportunities
- Removing barriers to employment
- Ensuring autistic individuals, their families and carers have clear information and advice about, and access to, an appropriate range of accommodation options, including financial information to support financial capability among autistic people and how to manage personal finances and household budgeting.

Priority 4: Promoting seamless progression throughout periods of transition

Ambition: To co-produce and implement a local Transitions pathway

Success will look like:

All agencies will work together to support transitions

The Step by Step Guide to Transitions group (TFG4) will work on the following national actions:

- Appropriate support to identify and follow aspirations when transitioning from education
Think Autism refresh March 2018 – Domain 4 Specific Support
- Successful transition of people preparing for adulthood across education, health, employment and social care spheres (participation in employment considered in needs assessments and care and planning process takes account of work opportunities)
Think Autism refresh March 2018 – Domain 5 Participation in Local Community

This will be delivered through the following **local actions**:

- Develop multi-agency processes to facilitate transition planning at key stages for autistic children, young people and adults.
- Ensure key transitions are well-planned for and managed.
- Promote proactive transfer of information from one establishment or agency to another.
- Champion good communication and application of data, personalised induction processes and involvement of the individual and their families.

Priority 5: Providing effective and enabling care and support

Ambition: Care and support will meet need and support autistic people to progress.

Success will look like:

Person-centred care and support focuses on positive outcomes, autistic people are better able to manage their own lives.

The Providing Effective and Enabling Care and Support group (TFG5) will work on the following national actions:

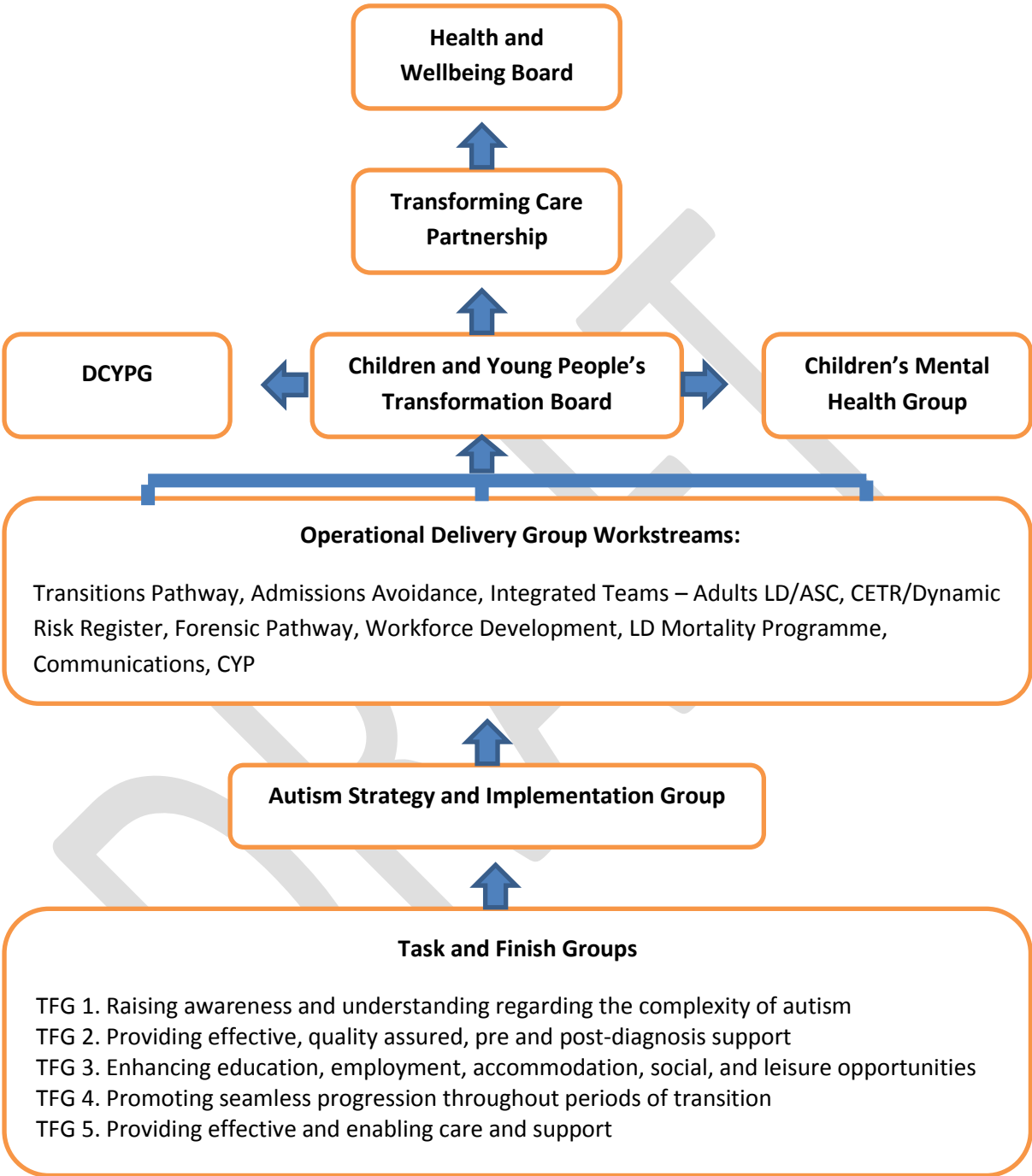
- Reasonable adjustments enable people to access public services
Think Autism refresh March 2018 – Domain 5 Participation in Local Community
- Preventative support in line with Care Act 2014
Think Autism refresh March 2018 – Domain 3 Health, Care and Wellbeing
- Widespread use of tailored communication methods and recognition of sensory, communication and environmental needs
Think Autism refresh March 2018 – Domain 3 Health, Care and Wellbeing
- Timely and appropriate mental health support
Think Autism refresh March 2018 – Domain 3 Health, Care and Wellbeing
- Specific support available to people within criminal justice system
Think Autism refresh March 2018 – Domain 4 Specific Support

- Making Transforming Care work for autistic people (Transforming Care 2012)

This will be delivered through the following **local actions**:

- Exploring the development of a multi-agency autism team, covering mainstream services, schools and families, with Crisis Response as an integral part
- Embedding a Positive Behaviour Support (PBS) framework within the wider service model
- Developing Northamptonshire Quality Assurance (QA) Scheme to support a continuous cycle of self-evaluation and development against standards that include tailored communication methods and recognition of sensory, communication and environmental needs
- Improved partnerships between autism-specific and wider mental health service provision
- Ensure the needs of autistic individuals are met within the wider Criminal Justice System

Governance of the Delivery Plan



Sector Wide Workforce Development and Training

Whilst basic autism awareness training is a key requirement, continuing sector-wide Workforce Development is needed in all areas covered by the Strategy. When professionals understand autism, the positive effects on the individual, their families, and carers can be immense. By ensuring that all staff are better able to identify potential signs of autism and reasonably adjust their own behaviour and communication, the benefits of an enabling environment will apply to all individuals with autism, regardless of age.

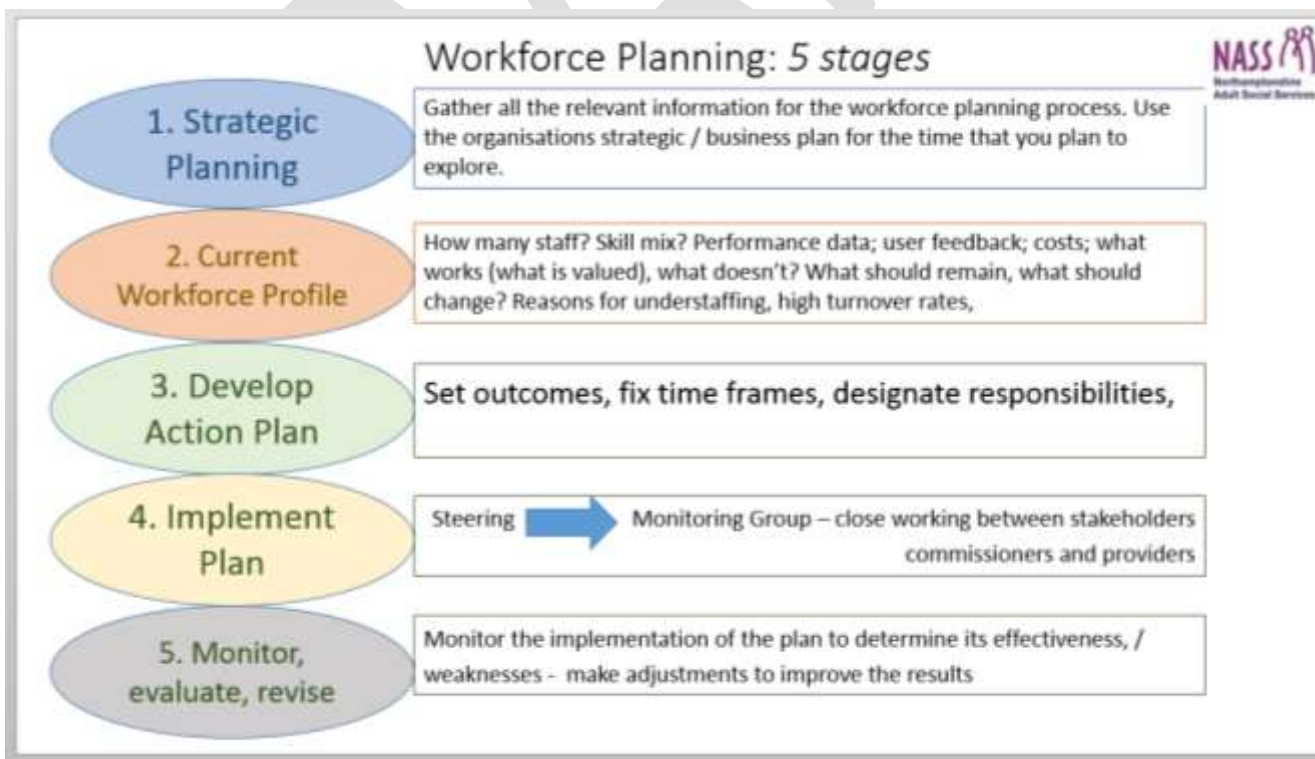
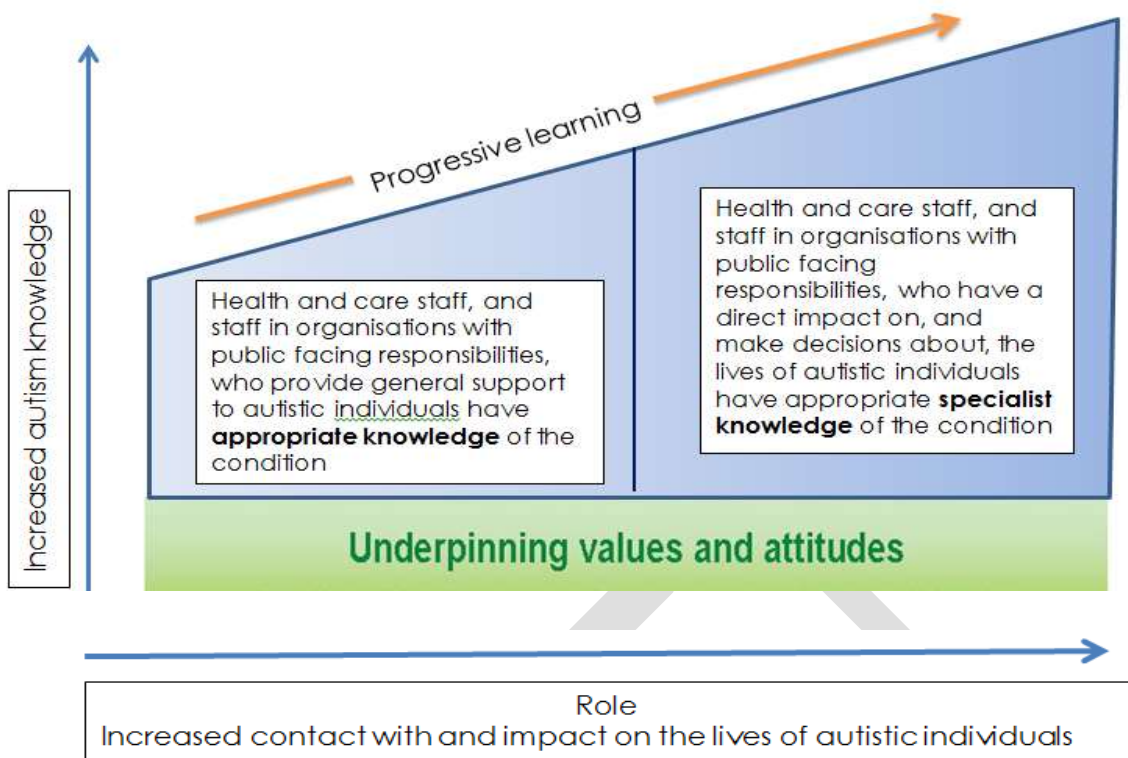
Principles underpinning ongoing development include:

- focusing on outcomes and promoting wellbeing
- recognising the importance of utilising the skills and knowledge within the community
- ensuring quality and appropriateness of provision
- supporting sustainability and sufficiency
- embracing choice and personalisation
- engaging in co-production with autistic individuals, their families, and providers of support services
- integrating with sector-wide services.

Ideally, those in posts which directly impact on, and make decisions about, autistic individuals should be able to evidence the knowledge, skills, and competence required. Such practice should be a main feature across the spectrum of autism-specific service provision.

Enhanced training, alongside embedded Autism Champions, allows both NHFT and NCC to meet the requirements of the Care Act by providing 'expert consultation' where a needs assessment is carried out by a member of staff with limited autism experience (Care and Support (Assessment) Regulations 2014).

http://www.legislation.gov.uk/ukxi/2014/2827/pdfs/ukxi_20142827_en.pdf



Workforce Shaping *Working with all stakeholders to:*

- assess and predict demand
- map current and plan future workforce against the demand
- Agree priorities and values

← Strategy

Planning →

Workforce Planning

- Who is needed? – *qualified? Specialist? Generic?*
- How many? – *individuals? Teams?*
- Where? – *stand alone? add-on?*
- When? – *early intervention needed?*
- What? *What the workforce does (tools used & pathway created)*

Monitoring →

Workforce Development: the ongoing monitoring of skills and training needs

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Action Plan

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

1. Raising awareness and understanding regarding the complexity of autism					
1a Developing a multi-tier local training framework – varied training according to professional role and level of involvement with autistic individuals, their families and carers.					
Task	Lead	Timescale	Links to other strategies/action plans	Resource Implications	Evidence
1a i – conduct an audit of expertise and availability of training providers, including consideration of participant feedback, to produce a database.	Lead practitioner autism. Reporting through governance structure	Nov 18	Northamptonshire Transforming Care Partnership Children and Young People's Action Plan Dec 2017/Refreshed March 2018	Analytical support Quality assurance support Key Stakeholders Autism Lead Practitioner Autism Lead Commissioner	Completed database
1a ii – develop	Lead practitioner	Nov 18		Learning and	Learning objectives

learning objectives and outcomes for different tiers of training	autism. Reporting to operational delivery groups			development support Key Stakeholders Autism Lead Practitioner	and outcomes for each training tier
1a iii develop proposals for different training approaches		Nov 18		Learning and development support Key Stakeholders Autism Lead Practitioner Autism Lead Commissioner	Meeting notes and actions
1a iv – involve people impacted by autism in developing training programmes		Nov 18		Key Stakeholders Autism Lead Practitioner Learning and development support	Meeting notes and actions
1b Developing an autism champion network of knowledgeable individuals in each of the key services that support autistic individuals, their families and carers to promote consistency, clarity and to play a role in a continuous cycle of improvement of autism practice					
1bi Establish Autism Champion Network Group with representatives initially from NHFT NASS and Local Authority	Lead practitioner autism. Reporting through governance structure LD Managers	Nov 18	Think Autism – 2018 refresh	FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Learning and development support Analytical	Proposal and Terms of reference Minutes from inaugural meeting.

				support Quality assurance support Key Stakeholders	
<i>1bii</i> All the services that we commission will be expected to identify a local autism champion.	Commissioning Manager Autism	Apr 19	Strategic Commissioning Local Offer Think Autism	Autism Lead Commissioner. Autism Lead Practitioner. Clinical and managerial leadership	
<i>1c</i> Developing an online information and advice portal providing a range of information on services and support for autistic individuals, their families, providers, and organisations in a proposed collaboration with the University of Northampton.					
<i>1ci</i> – explore possibility of involvement and collaboration with the University of Northampton Changemaker initiative and NHFT service provision	NHFT	Nov 18	Northamptonshire Autism Strategy Action Plan Priority 2 Priority 3 Priority 4	FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Analytical support Specialist Procurement and Contracting support Quality assurance support Key Stakeholders	Implementation plan
<i>1d</i> Ensuring people with autism are safe in the community and free from the risk of discrimination, hate crime and abuse					
<i>Task</i>	<i>Lead</i>	<i>Timescale</i>	<i>Links to other strategies/activities</i>	<i>Resource Implications</i>	<i>Evidence</i>

			<i>on plans</i>		
1d i – Align all age autism strategy with Time2listen	Lead Commissioner Autism Police and Crime Commission	Nov 18	Think Autism	Lead Commissioner Autism	Alignment

2. Providing effective, quality assured, pre and post diagnosis support					
2a Developing a clear, consistent, step by step, all age pathway for pre and post diagnosis support					
<i>Task</i>	<i>Lead</i>	<i>Timescale</i>	<i>Links to other strategies/action plans</i>	<i>Resource Implications</i>	<i>Evidence</i>
2a i - Review the existing pathways to diagnosis with diagnosticians across the County considering the autism specific diagnostic tools used in assessments and reflecting on the diagnostic changes in DSM-V and forthcoming ICD-11	NHFT Strategy task and finish groups reporting to Head of Psychology and existing governance structures	Apr 19	Think Autism	Clinical and managerial leadership Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Review documents
2a ii - Diagnosticians across the County consider and agree standards for	NHFT Strategy task and finish groups reporting to Head of	Apr 19	Think Autism	Clinical and managerial leadership Analytical support	Standards adopted by individuals and teams who undertake

<p>autism diagnosis across services encompassing the varied ways in which autistic traits can present across the genders and with reference to NICE clinical guidelines including how the new diagnosis is recorded.</p>	<p>Psychology and existing governance structures</p>			<p>Quality assurance support FTE: Autism Leads across NHFT and NCC</p>	<p>diagnostic assessments.</p>
<p>2a iii - Establish clearly written pathways to diagnosis for children and adults, including clarity on reason for entering the pathway and whether a diagnosis should go ahead. Write up pathways in a format that is accessible (Service leaflets and Information on Internet). Ensure information about pathways is shared with public, health, social care, education.</p>	<p>NHFT Strategy task and finish groups reporting to Head of Psychology and existing governance structures</p>	<p>Apr 19</p>	<p>Northamptonshire Autism Strategy Action Plan 1d</p>	<p>Clinical and managerial leadership support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC</p>	<p>Completed diagnosis pathway. Directory of individuals and teams who undertake diagnostic assessments. Services, individuals and families are aware of information and how to access it.</p>
<p>2b Developing consistency in data recording and management of autism</p>					

diagnoses.					
Task	Lead	Timescale	Links to other strategies/action plans	Resource Implications	Evidence
2b i –To establish local agreement on a consistent method of recording an autism diagnosis including the Read Code to be used consistently by GPs to record autism.	CCG/NASS/Children First, Northamptonshire Leads NHFT	Apr 19	Think Autism	Clinical and managerial leadership Analytical support Quality assurance support	Agreement reached, standards documented
2c The development an all age data base of those diagnosed with autism					
2c i - Establish integrated information and intelligence, to include process to keep up to date, across Adult and Children's Services enabling us to know and understand our local population and their care needs and pathways and local spend, which will assist us in commissioning autism services based on population data.	Lead Commissioners Autism and Children First, Northamptonshire	June 19		Clinical and managerial leadership Analytical support Autism Lead Commissioner Key Stakeholders	All age data base populated with a system for updating established

2d Obtaining a comprehensive understanding of the needs of the autism community in Northamptonshire

<p>2di - Undertake a full needs assessment to identify the needs of the population with autism living in Northamptonshire, including work to understand the population with autism who have other protected characteristics</p>	<p>Lead Commissioners Autism and Children First, Northamptonshire</p>	<p>Apr 19</p>		<p>Analytical support Clinical and managerial leadership FTE: Autism Leads across NHFT and NCC Key Stakeholders</p>	<p>Completed needs assessment</p>
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3. Enhancing education, employment, accommodation, social and leisure opportunities

3a Easy access to, and positive experience of, meaningful social and leisure opportunities

<i>Task</i>	<i>Lead</i>	<i>Timescale</i>	<i>Links to other strategies/action plans</i>	<i>Resource Implications</i>	<i>Evidence</i>
<p>3a i – map existing provision and identify gaps</p>	<p>Lead Practitioner Autism Commissioner</p>	<p>Apr 19</p>		<p>Clinical and managerial leadership Analytical support Quality assurance</p>	<p>Identification of gaps with strategic response to need</p>

				support FTE: Autism Leads across NHFT and NCC Key Stakehold ers	
3a ii – Develop an action plan to address gaps with a focus on promoting existing autism activities to all, encouraging activities that are available to the general public to become autism friendly and where possible work with voluntary and community groups to support the development of new activities (within existing financial resources).	Lead Practition er Autism Commissi oner	Apr 19	Northampton shire Autism Strategy Action Plan Priority 1	Clinical and manageri al leadership Analytical support Quality assurance support Autism Lead Commissi oner Autism Lead Practition er Key Stakehold ers	Action plan with SMART targets timescales and responsibilit ies
3b Removing barriers to employment					
3b i - Raise awareness amongst employers about the potential benefits of employing people with autism.	EADS practitione rs Recovery College Lead	Apr 19	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd Northampton shire Autism Strategy Action Plan Priority 1	Clinical and manageri al leadership Learning & Developm ent Support Analytical support Quality assurance support	Visit notes and outcomes. Increased number of employers willing to employ autistic people who are suitable for achieving job specification or use

				FTE: Autism Leads across NHFT and NCC Key Stakeholders	autistic volunteers
3b ii - Explore partnership opportunities with employers to raise awareness of the needs of autistic individuals and reasonable adjustments to accommodate these	EADS practitioners Recovery College Lead	Apr 19	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd Northamptonshire Autism Strategy Action Plan Ambition 1	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Partnerships established with employers. Increased number of employers willing to employ autistic people who are suitable for achieving job specification or use autistic volunteers
3b iii - ensure access to supported employment opportunities	EADS practitioners Recovery College Lead	Apr 19	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd SEND Strategy and Action Plan 2017-2020 Priority 3 (3.4)	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Increased number of autistic people in supported employment
3b iv - Support	NHFT	Apr 19	Northampton	Key	Feedback

<p>Disability Employment Advisors to gain specialist autism knowledge</p>			<p>shire Autism Strategy Action Plan Ambition 1</p>	<p>Stakeholders Learning & Development Support Quality assurance support FTE: Autism Leads across NHFT and NCC</p>	<p>forms from autism training. Evidence of reasonable adjustments to accommodate autistic individual in their practice and autism knowledge reflected in their advice</p>
<p>3b v - Promote apprenticeship schemes, job coaching, work experience and opportunities for self-employment, that includes real skill development as well as dialogue with the individual, and often family members, regarding strategies for continuing and increasing success</p>	<p>EADS practitioners Recovery College Lead</p>	<p>Nov 19</p>	<p>Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd SEND Strategy and Action Plan 2017-2020 Priority 3 (3.4)</p>	<p>Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC</p>	<p>Feedback from individual and families. Increased number of autistic individuals report satisfaction in their development. Progress data.</p>
<p>3c Ensuring autistic individuals, their families and carers have clear information & advice about, and access to, an appropriate range of accommodation options, including financial information to support financial capability among autistic people and how to manage personal finances and household budgeting.</p>					
<p>3c i - Identify housing issues for people with autism and link with Housing Officers to explore opportunities to address these</p>	<p>NASS Workstream task and finish groups</p>	<p>Apr 19</p>		<p>Key Stakeholders Analytical support Quality assurance support FTE:</p>	<p>Housing issues identified and addressed</p>

				Autism Leads across NHFT and NCC Clinical and managerial leadership	
3c ii - Support housing agencies and councils to raise awareness and understanding of autism amongst their staff, and to review their policies and practices	Lead practitioner and Lead Commissioner Autism	Nov 19	Northamptonshire Autism Strategy Action Plan Priority 1	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Policies and practices amended
3c iii - Continue to encourage the development of a range of new and innovative housing options offering care and support, and support people to access mainstream housing where they can have a tailored package	Lead commissioner Autism	Nov 19	Think Autism	Key Stakeholders Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Increased accommodation provision

of support from a provider of their choosing, using a personal or a managed budget.				Clinical and managerial leadership Specialist Procurement and Contracting support	
3c iv - Offer autistic individuals the opportunity to live as independently as possible and to exercise choice and control in their lives and support people with autism (where appropriate) to move from residential care to independent/supported living.	NASS	Nov 19		Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Specialist Procurement and Contracting support Transition teams	Autistic individuals are showing clear evidence of progression in terms of independence

4. Promoting seamless progression throughout periods of transition					
4a Develop multi-agency processes to facilitate transition planning at key stages for autistic children, young people and adults.					
<i>Task</i>	<i>Lead</i>	<i>Timescale</i>	<i>Links to other strategies/action plans</i>	<i>Resource Implications</i>	<i>Evidence</i>

<p>4a i – Children and young people with autism who have an EHCP have future support needs and transitions to adult care mapped into their plan.</p>	<p>Link with Transition Pathway Working Group</p>	<p>Jan 19</p>	<p>Transforming Care CYP Action Plan. Area 5 SEND Strategy and Action Plan 2017-2020 Priority 3 (3e)</p>	<p>Key Stakeholders FTE: Autism Leads across NHFT and NCC</p>	<p>Increased use of EHC plans by workforce across services Reduced number of escalations at transition points Reduced number of complaints</p>
<p>4a ii - Increase understanding of the aspirations of people with autism in transition across all settings, emphasising choice, to promote adults with autism receiving appropriate support to facilitate those transitions in their lives.</p>	<p>NASS Transitions Teams / NHFT Children First, Northamptonshire</p>	<p>Jan 19</p>	<p>Transforming Care CYP Action Plan. Area 7 Northamptonshire Autism Strategy Action Plan Priority 1</p>	<p>Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership</p>	<p>Reduced number of escalations at transition points Reduced number of complaints</p>
<p>4a iii - Establish clearly written outline pathways for transitions for children and adults,</p>	<p>NASS Transitions Teams / NHFT</p>	<p>Jan 19</p>	<p>Northamptonshire Autism Strategy Action Plan Priority 1d</p>	<p>Clinical and managerial leadership Analytical support Quality assurance support</p>	<p>Published step by step transition process</p>

<p>allowing for flexibility and contingency options. Write up pathways in a format that is accessible (Service leaflets and Information on Internet). Ensure information about pathways is shared with public, health, social care, education with proviso that each transition pathway will be adapted and tailored to the individual and their personal aspirations</p>				<p>FTE: Autism Leads across NHFT and NCC</p>	
<p>4b Ensure key transitions are well-planned for and managed.</p>					
<p><i>Task</i></p>	<p><i>Lead</i></p>	<p><i>Timescale</i></p>	<p><i>Links to other strategies/action plans</i></p>	<p><i>Resource implications</i></p>	<p><i>Evidence</i></p>
<p>4b i - Support Transition workers to gain specialist autism knowledge</p>	<p>Lead practitioner Lead Commissioner autism</p>	<p>Apr 19</p>	<p>Northamptonshire Autism Strategy Action Plan priority 1b</p>	<p>Key Stakeholders Learning & Development Support Quality</p>	<p>Feedback forms from autism training. Evidence of reasonable adjustments to</p>

				assurance support FTE: Autism Leads across NHFT and NCC	accommodate autistic individual in their practice and autism knowledge reflected in their advice
4c Promote proactive transfer of information from one establishment or agency to another.					
4c i – Key agencies refine a process for information sharing at transition points, including before and after diagnosis.	Lead practitioner Lead Commissioner autism CCG/NASS/Children First, Northamptonshire		Northamptonshire Autism Strategy Action Plan Priority 2	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Information process in place, agreed and communicated across services
4d Champion good communication and application of data, personalised induction processes and involvement of the individual and their families					
4d i – Any EHCP of a child or young person with autism is based on a thorough assessment of their holistic needs engaging education, health and care professionals as appropriate	Link with EHC stakeholder group. Head of H&C partnership. Link with digital roadmap pathway	Apr 19	SEND Strategy and Action Plan 2017-2020 Priority 2 (2.2)	Key Stakeholders FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Parental feedback and satisfaction Comprehensive EHC plans

e					
4d ii - Promote agreed sector wide autism standards with consideration to knowledge of the individual, environment, and collaboration	Lead practitioner	Apr 19	Northamptonshire Autism Strategy Action Plan Priorities 1 and 2e	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Autism standards agreed and implemented.

5. Providing effective and enabling care and support

5a The development of a multi-agency autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.

<i>Task</i>	<i>Lead</i>	<i>Time scale</i>	<i>Links to other strategies/action plans</i>	<i>Resource Implications</i>	<i>Evidence</i>
5a i - Identify gaps, scope current crisis provision for autistic individuals without a learning disability	NASS/NHFT/Children First, Northamptonshire	Jan 19	Transforming Care	Analytical support Quality assurance support Key Stakeholders Clinical and managerial leadership FTE: Autism Leads across NHFT and NCC	Analysis of impact of current support preventing autistic individuals' needs escalating to crisis point and recommendation on whether a specific Autism Crisis Team is needed.

5b Embedding a Positive Behaviour Support (PBS) framework within the wider service model

5b i - Ensure	NHFT Autism Lead and PBS Lead	Apr 19	'Developing a shared culture of	Key Stakeholder	Effective protocols established
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autism is represented in Northamptonshire PBS pathways and that PBS and autism standards align and complement each other	linking with PBS TFG		Positive Behaviour Support' Northamptonshire Transforming Care Partnerships TFG	s Analytical support Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Number of restraints are reduced
5c Developing Northamptonshire Autism Quality Assurance (QA) Scheme to support a continuous cycle of self-evaluation and development against standards that include tailored communication methods and recognition of sensory, communication and environmental needs					
5c i - Consult on proposed standards for providers with autistic service users	Lead Practitioner Autism Commissioner	Apr 19	Northamptonshire Autism Strategy Action Plan 4dii	Key Stakeholders Analytical support Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Autism Standards agreed to be used for QA process
5c ii - develop 'Challenge Partners' visit framework	Lead Practitioner Autism Commissioner	Nov 19	Northamptonshire Autism Strategy Action Plan 1b	Key Stakeholders Clinical and managerial leadership Quality assurance support	Peer assessment observation framework produced and agreed for use in QA process

				Autism Lead practitioner	
5c iii - Conduct a small pilot of proposed Northamptonshire QA Scheme that links in with Autism Champions network	Lead Practitioner	June 19	Northamptonshire Autism Strategy Action Plan 1b	Key Stakeholders Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Results of pilot
5c iv - feedback from all involved in pilot study to inform review of process	Lead Practitioner	July 19		Key Stakeholders Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	feedback
5d Improved partnerships between autism specific and wider mental health service provision					
5d i- Autism champion(s) embedded within all age Mental Health services	Lead practitioner autism. Reporting through governance structure LD Managers	Nov 18	Northamptonshire Autism Strategy Action Plan 1b	Key Stakeholders Analytical support Clinical and managerial leadership	Services are aligned

				Quality assurance support FTE: Autism Leads across NHFT and NCC	
5e Ensure the needs of autistic individuals are met within the wider Criminal Justice System					
5e i - Develop partnership arrangements with criminal justice agencies	YO teams Probation Police Link with Forensic Pathway Working Group	Nov 18	Transforming Care Forensic Pathway Time2listen	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Specialist Procurement and Contracting support	Effective protocols established

Version History	Date	Summary of Changes
0.1	18.05.18	Draft 1
0.2	13.07.18	Draft 2
0.3	23.07.18	Draft 3
0.4	07.08.18	Draft 4
0.5	13.08.18	Draft 5 – consultation document

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Agenda Item No: 14 – Appendix 2

Name of proposal/policy	Northamptonshire All Age Autism Strategy	Budget number (if applicable)	N/A
Service area responsible	Adult Social Services and Children First, Northamptonshire	Cabinet meeting date	13/11/2018
Name of completing officer	Bob Fletcher	Date EqIA created	13/08/2018
Approved by Director / Assistant Director	Anna Earnshaw/Ken Fairbairn	Date of approval	

The Equality Act 2010 places a 'General Duty' on all public bodies to have 'Due regard' to:

- Eliminating discrimination, harassment and victimisation
- Advancing equality of opportunity
- Fostering good relations

We do this by undertaking equality impact assessments (EqIAs) to help us understand the implications of policies and decisions on people with protected characteristics – EqIAs are our way of evidencing this.

All assessments must be published on the NCC equalities web pages. All Cabinet papers where an EqIA is relevant **MUST** include a link to the web page where this assessment will be published. If you require assistance in getting your EqIA published, please contact equalities@northamptonshire.gov.uk

PART 1

Description of current provision/policy and main beneficiaries/stakeholders

- Current service provision not aligned to a co produced strategy
- Joint working is 'silo' based and beneficial partnerships with stakeholders remain limited
- Delivery fragmented across statutory and voluntary services

Description of proposal under consideration/development

All age, localised, strategy that meets the vision and requirements of national legislation and guidance by :

- Raising Awareness and Understanding regarding the complexity of Autism;
- Providing effective, quality assured Pre and Post Diagnosis support;
- Enhancing education, employment, accommodation, social, and leisure opportunities;
- Promoting seamless progression throughout periods of transition; and
- Providing effective and enabling care and support.

Data used in this Equality Impact Assessment (general population data where appropriate but each EqlA should contain information on people who use the service under consideration – if this is not applicable to your proposal then you probably do not need to do an EqlA)

Data Source (include link where published)	Please summarise what the data tells us – for example “X number of people use this service, X are male, Y are female etc”
Statistical evidence gleaned from current NCC data	In terms of adults formally diagnosed with autism in the form of Asperger's Syndrome, NASS data for 2017/18 shows a 6.5% increase in customers (rising from 74 to 79) with costs up by 19%. When factoring in those adults with 'complex' autism (co-occurring diagnosis of Learning Disability, Physical Disability, Conduct Disorders etc.), the total number of adults receiving a service from NCC is 374. Northamptonshire Healthcare NHS Foundation Trust (NHFT) provides support via a specialist ADHD/Aspergers team (separate child and adult provision). Throughout 2017 the team received 1079 referrals. Of these, 50% (539) related solely to autism (including Asperger's and generalised ASD) whilst 103 of the referrals related to co-occurring ASD and ADHD. Of the 539, 61% (327) requested a diagnostic assessment.

	<p>Data analysis suggests that 55% (180) of the total seeking assessment will complete the process. However, over 90% (175) of those completing assessment will receive a formal diagnosis.</p>															
<p>POPPI and PANSI data and analysis</p>	<p>In order to highlight discrepancies related to localised recording of autism, it is worth noting that, according to the national dataset, it is estimated that Northamptonshire would have the following across the county:</p> <ul style="list-style-type: none"> • Under 18's (forecast) diagnosed ASD: 1680 • 18 – 64's (forecast) diagnosed ASD: 4357 • Over 65's (forecast) diagnosed ASD: 1243 <p>Total number of people with ASD in Northamptonshire forecast as 7280</p>															
<p>JSNA</p>	<p>Based on a local population of 733,128 (2016 data), it is possible to estimate that 9,530 children, young people, and adults live with autism. If we include families and carers, autism is part of daily life for 11,912 people in Northamptonshire.</p> <p>Autistic children by Team:</p> <table border="1" data-bbox="1153 1045 2128 1420"> <thead> <tr> <th>NCC Team</th> <th>Child in Need (CIN)</th> <th>Child Protection Plan</th> <th>Looked after Child (LAC)</th> <th>Total</th> </tr> </thead> <tbody> <tr> <td>Disabled Children's Team</td> <td>84</td> <td>6</td> <td>18</td> <td>108</td> </tr> <tr> <td>LAC/Leaving Care Teams</td> <td>8</td> <td>0</td> <td>19</td> <td>27</td> </tr> </tbody> </table>	NCC Team	Child in Need (CIN)	Child Protection Plan	Looked after Child (LAC)	Total	Disabled Children's Team	84	6	18	108	LAC/Leaving Care Teams	8	0	19	27
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Safeguarding Teams	25	10	10	45
Total	117	16	47	180

Most recent SEND data (2017) identifies 1404 autistic children. The table below details the geographic spread:

District	ASD
Corby	115
Daventry	138
East Northamptonshire	132
Kettering	161
Northampton	577
Out of county postcode	17
South Northamptonshire	146
Wellingborough	118
Total	1404

Tick the relevant box for each line by using a capital 'P' to make a <input type="checkbox"/>	Based on the above information, what impact will this proposal have on the following groups?			
	Positive	Negative	Neutral	Unsure
Sex	x			
Gender Reassignment			x	
Age	x			
Disability	x			
Race & Ethnicity	x			
Sexual Orientation			x	
Religion or Belief (or No Belief)	x			
Pregnancy & Maternity			x	
Human Rights (Please see articles in toolkit)	x			
Other Groups (rural isolation, socio-economic exclusion etc)	x			

Initial impact	
Explain your findings above	Actions identified to mitigate, advance equality or fill gaps in information
<p>1.1 Northamptonshire's All Age Autism Strategy is the result of a joint strategic initiative involving the following statutory partnerships:</p> <ul style="list-style-type: none"> • Adult Social Services • Children First, Northamptonshire • Nene and Corby Clinical Commissioning Groups • Northamptonshire Healthcare NHS Foundation Trust <p>1.2 A number of focus groups and work streams resulted in formulation of the strategy. 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 Strategy represents a milestone for autistic individuals throughout Northamptonshire.</p>	<p>Alogside ongoing work highlighted in the Action Plan, priorities and recommendations contained within the strategy will address diagnosis identified inequalities</p>

<p>1.3 All those involved remain at the centre of Northamptonshire's ambition to improve the lifelong journey of autistic individuals and their families. All are passionate regarding the case for change. The embedded Action Plan should be used as a measure of success.</p> <p>1.4 Specific focus has been placed on diagnosis imbalance relating to females and individuals from Black and Minority Ethnic communities</p>	
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Do you need to undertake further work (e.g. consultation, further equality analysis) based on the impact and actions identified above? If yes, set this out below and then carry out the work and complete Part 2

8 week public consultation

PART 2 – if required

Consultation, follow up data and information gathered from actions identified above

	What does this information tell us?
<ul style="list-style-type: none"> • The majority of the total respondents found the strategy easy to understand but fewer respondents who identified as autistic found it easy (85% versus 72.7). • Of the additional 45 general comments there were 23 positive remarks about the style, for example, Plain English, easy read, clarity and video. • The majority of respondents agreed with the vision in the strategy. Key theme is 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 making it unrealistic especially as they believe some of the implementation will come at a cost 	<p>Amendments required to the strategy, prior to adoption, in order fully reflect the consultation feedback</p>

- There is overall agreement for all 5 priorities - all priorities received a very high level of agreement (either agree or really agree) – ranging between about 85 to 95%
- 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.
- people identifying as autistic referred to the significant wait for a response or lack of any sort of support even after a diagnosis. A small number of 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.
- there was a focus 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. Respondents 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.
- Consultation responses and feedback will be used to inform and shape the final version of the strategy

Final impact analysis (taking the findings from Part 2 into account) – including review date if required

Northamptonshire all age autism strategy will address inequalities. Outcomes embedded within the action plan will be continuously monitored and corrective measures taken if required

