

Northamptonshire's All Age Autism Strategy 2018 – 2021

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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.

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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.



**Theresa Grant, Chief Executive
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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](#)
- [Northamptonshire Transforming Care Partnership: Children's and Young People's Action Plan \(2016-19\)](#)
- [SEND Strategy and Action Plan \(2017-20\)](#)

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.

National Context

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

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.

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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.

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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:

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- 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:

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.

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.

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, read this [National Autistic Society report](#).

Ethnicity

Ethnicity remains a key determinant of health inequalities in England. Individuals, families, and carers from Black and Minority Ethnic (BAME)

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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.

See a [comprehensive overview of the challenges for families affected by autism from BaME communities](#).

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.

See a [comprehensive overview of the challenges facing girls and women living with autism](#).

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

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- comprehensive multi-agency engagement
- provision of high quality information for effective transition planning
- Significant and meaningful choice.

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.

Read a comprehensive study, called [Living in the Community: Housing Design for Autistic Adults](#).

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

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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.

- [Transforming Care – final report](#)
- [Transforming Care – model service specification](#)

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.

- [Care Act 2014](#)

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.

- [Children and Families Act 2014](#)

NICE Guidelines

[Autism spectrum disorder in adults: diagnosis and management Clinical guideline \[CG142\]](#)

Published date: June 2012 - Last updated: August 2016

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[Autism spectrum disorder in under 19s: recognition, referral and diagnosis
Clinical guideline \[CG128\]](#)

Published date: September 2011 - Last updated: December 2017

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

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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.

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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.

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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:

i. 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.

ii. 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.

iii. **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

iv. **Promoting seamless progression throughout periods of transition**

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

v. **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.

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.

Autistic Children receiving support from Children First, Northamptonshire

CFN 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 current geographic spread. Further data analysis is required

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in order to identify and separate autistic children who do not have a co-occurring Learning Disability.

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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

Autistic children and young people, with or without a formal diagnosis, 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.

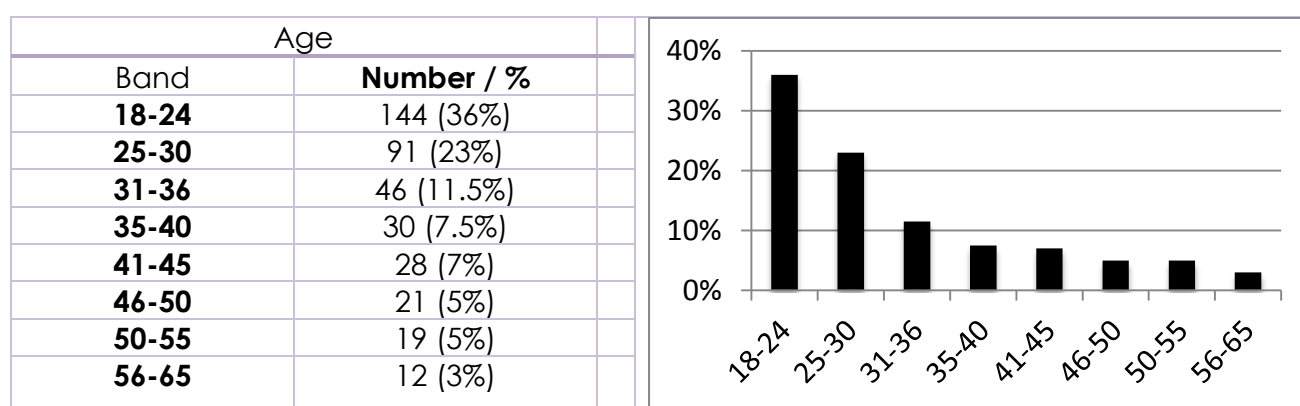
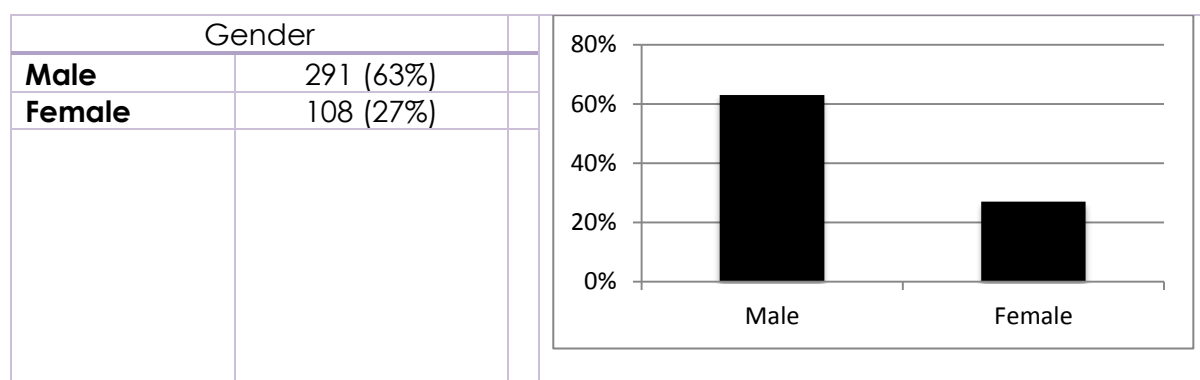
Differences in data collection and management methods make it very difficult to be precise regarding the number of autistic children and young people known simultaneously to CAMHS and Local Authority Children's services. However, it is likely that the number of autistic children and young people receiving 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.

Autistic Adults

Analysis of Autism data:, September 2018

As part of the co-production of an All Age Autism Strategy work was undertaken to analyse available data, stored as electronic records, on the Carefirst system. With particular reference to Workforce Development, the purpose of the analysis was to explore the choices people with a diagnosis of Autism were making when utilising Direct Payments as a means of obtaining support. This would then inform the wider strategy and help to identify the type of workforce and interventions that would be needed to deliver the strategy and address people's needs.

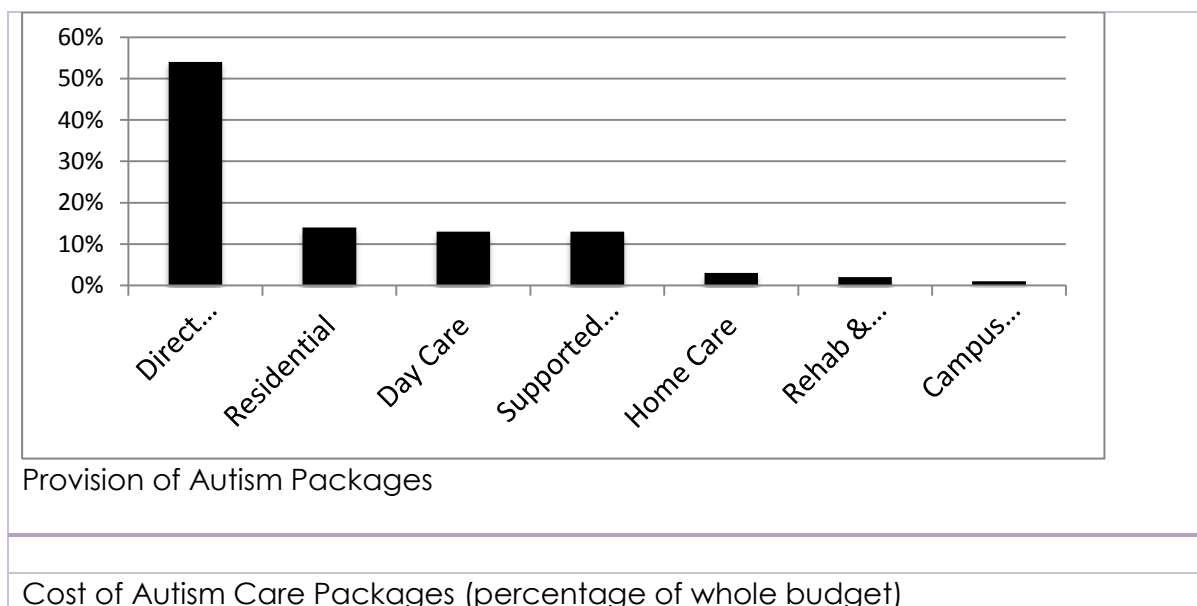
Data identified 399 adults with a diagnosis of Autism receiving packages of care and support. Of these 216 used Direct Payments to access service provision. It was decided to initially concentrate on his cohort to influence workforce development. In total there were 556 Packages of care with an overall cost of £13,327,331 (average £33,401 per head)



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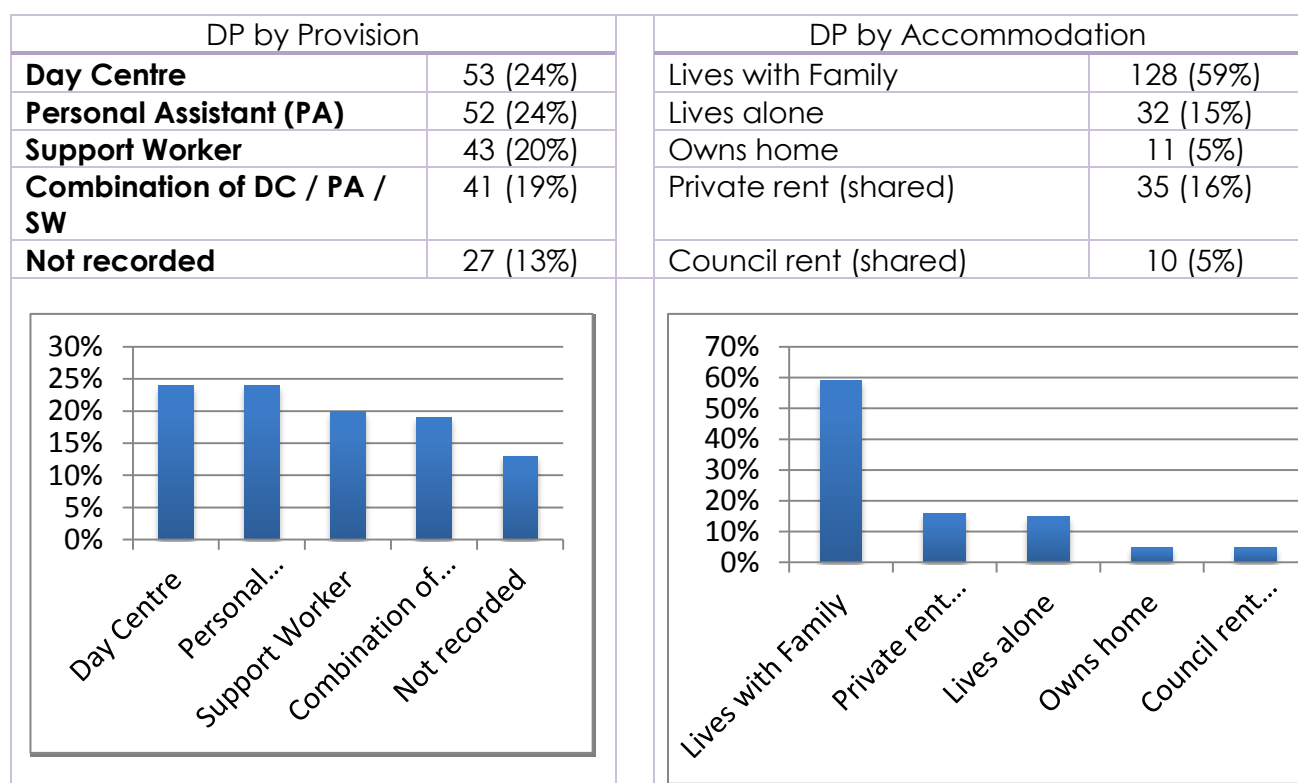
Ethnicity		Diagnosis	
White British	349 (87%)	Autism	184 (46%)
Any other Black Background	6 (1%)	Autism / LD	85 (21%)
Any other White Background	5 (1%)	Asperger's / Autism	71 (18%)
White and Black Caribbean	5 (1%)	Asperger's / Autism / Men' Hlth	21 (5%)
Any other Mixed Background	5 (1%)	Autism / Physical condition	18 (4%)
Caribbean	5 (1%)	Autism / Mental Health	10 (2.5%)
African	5 (1%)	Autism / Long Term Condition	10 (2.5%)
Any other White Background	4 (1%)		
Any other Asian Background	2 (1%)	Autism by Team	
Bangladeshi	2 (1%)	Learning Disabilities Team	221 (55%)
Indian	2 (1%)	Transitions Team	131 (33%)
Pakistani	1 (1%)	Mental Health Team	28 (8%)
White and Asian	1 (1%)	Physical Disabilities Team	13 (3%)
White and Black African	1 (1%)	Other	6 (1%)
Chinese	1 (1%)		
Not recorded	3 (1%)		
Provision & Cost			
Provision	Number	Cost (annual)	Ave per head
Campus Re-provision	5 (1%)	£437,251 (3%)	£87,450
Day Centre	53 (13%)	£619,125 (5%)	£11,681
Direct Payments	216 (54%)	£4,349,604 (33%)	£20,137
Home Care	12 (3%)	£231,294 (2%)	£19,274
Rehab & respite	6 (2%)	£84,760 (1%)	£14,126
Residential	55 (14%)	£4,870,452 (35%)	£88,553
Supported Living	52 (13%)	£2,734,842 (21%)	£52,593
Totals	399	£13,327,331	£33,401

Northamptonshire's All Age Autism Strategy 2018 – 2021



Direct Payments

216 (54%) people were identified as receiving Direct Payments.



Outcomes		Reviews	
Number of care plans with measurable outcomes	9 (4%)	Number of care plans reviewed within last 12 months	111 (51%)

A significant number of individuals living with autism are likely to be combining existing coping mechanisms with the support of families, friends, and carers.

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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.

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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

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.

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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

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- 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.

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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, visit the [Northamptonshire PCC website](#).

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:

1. Reconfiguration/realignment of current service provision
2. Explore the development of a multi-disciplinary autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.
3. Implementation of a clear process for recording autism as a primary support reason
4. Service provision for autism and Learning Disabilities should be separate
5. Development of best practice autism standards covering the following themes:
 - a. Knowing the individual
 - b. Environment
 - c. Collaboration
6. Implementation of outcome-focused, joint commissioning and interventions
7. Sector wide workforce development
8. Establishment of a multi-disciplinary network of Autism Champions across Northamptonshire.
9. Embedding of continuous practice development and quality assurance

Delivering the 5 Priorities

Each priority has a summary of recommended actions 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

Our 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 in 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.

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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

Our 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

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Our 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

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- 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

Our 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

Our 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.

Northamptonshire's All Age Autism Strategy 2018 – 2021

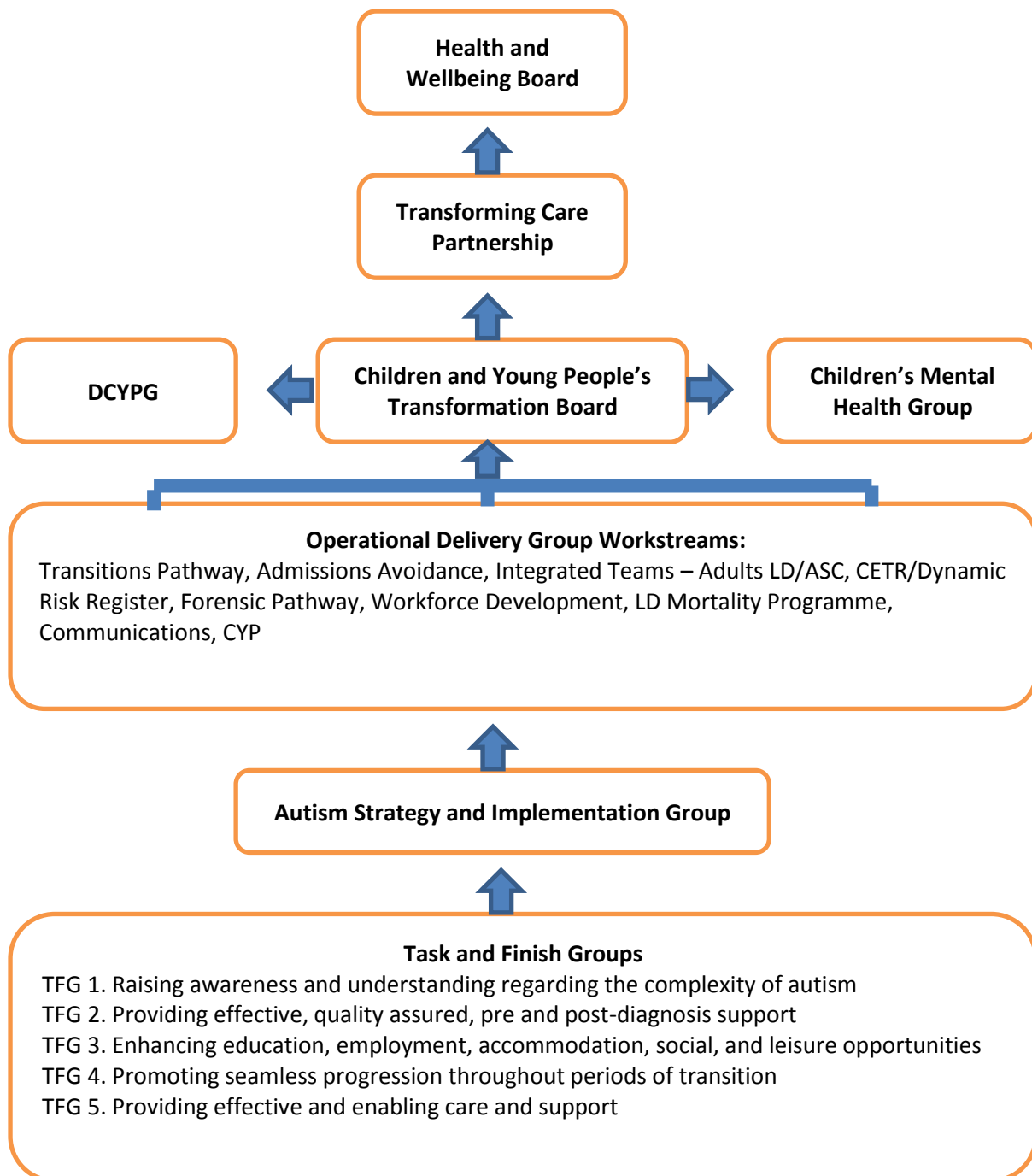
The Providing Effective and Enabling Care and Support group (TFG5) will work on the following national actions:

- 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](#)

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

Raising awareness and understanding regarding the complexity of autism

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	i. conduct an audit of expertise and availability of training providers, including consideration of participant feedback, to produce a database.	ii. develop learning objectives and outcomes for different tiers of training	iii. develop proposals for different training approaches	iv. involve people impacted by autism in developing training programmes
Lead	Lead practitioner autism. Reporting through governance structure	Lead practitioner autism. Reporting to operational delivery groups		
Timescale	Nov-18	Nov-18	Nov-18	Nov-18
Links to other strategies/action plans	Northamptonshire Transforming Care Partnership Children and Young People's Action Plan Dec			

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	2017/Refreshed March 2018			
Resource Implications	Analytical support Quality assurance support Key Stakeholders Autism Lead Practitioner Autism Lead Commissioner	Learning and development support Key Stakeholders Autism Lead Practitioner	Learning and development support Key Stakeholders Autism Lead Practitioner Autism Lead Commissioner	Key Stakeholders Autism Lead Practitioner Learning and development support
Evidence	Completed database	Learning objectives and outcomes for each training tier Meeting notes and actions Meeting notes and actions	Meeting notes and actions	Meeting notes and actions

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

Task	i. Establish Autism Champion Network Group with representatives initially from NHFT NASS and Local Authority	i. All the services that we commission will be expected to identify a local autism champion.
Lead	Lead practitioner autism. Reporting through governance structure LD Managers	Commissioning Manager Autism
Timescale	Nov-18	Apr-19
Links to other strategies/action plans	Think Autism – 2018 refresh	Strategic Commissioning Local Offer Think Autism
Resource Implications	FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Learning and development support Analytical support Quality assurance support Key Stakeholders	Autism Lead Practitioner. Clinical and managerial leadership
Evidence	Proposal and Terms of reference Minutes from inaugural meeting.	

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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.

Task	i. explore possibility of involvement and collaboration with the University of Northampton Changemaker initiative and NHFT service provision
Lead	NHFT
Timescale	Nov-18
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan
Resource Implications	FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Analytical support Specialist Procurement and Contracting support Quality assurance support Key Stakeholders
Evidence	Implementation plan

Ensuring people with autism are safe in the community and free from the risk of discrimination, hate crime and abuse

Task	i. Align all age autism strategy with Time2listen
Lead	Lead Commissioner Autism Police and Crime Commission
Timescale	Nov-18
Links to other strategies/action plans	Think Autism
Resource Implications	Lead Commissioner Autism
Evidence	Alignment

Providing effective, quality assured, pre and post diagnosis support

Developing a clear, consistent, step by step, all age pathway for pre and post diagnosis support			
Task	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	i. Diagnosticians across the County consider and agree standards for 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.	i. 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.
Lead	NHFT Strategy task and finish groups reporting to Head of Psychology and existing governance structures	NHFT Strategy task and finish groups reporting to Head of Psychology and existing governance structures	NHFT Strategy task and finish groups reporting to Head of Psychology and existing governance structures
Timescale	Apr-19	Apr-19	Apr-19
Links to other strategies/action plans	Think Autism	Think Autism	Northamptonshire Autism Strategy Action Plan 1d
Resource Implications	Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Clinical and managerial leadership Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Clinical and managerial leadership Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Standards adopted by individuals and teams who undertake diagnostic assessments.	Standards adopted by individuals and teams who undertake diagnostic assessments.	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.

Developing consistency in data recording and management of autism diagnoses.	
Task	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.
Lead	CCG/NASS/Children First, Northamptonshire Leads NHFT
Timescale	Apr-19
Links to other strategies/action plans	Think Autism
Resource Implications	Clinical and managerial leadership Analytical support Quality assurance support
Evidence	Agreement reached, standards documented

The development an all age data base of those diagnosed with autism	
Task	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	Lead Commissioners Autism and Children First, Northamptonshire
Timescale	Jun-19
Links to other strategies/action plans	
Resource Implications	Clinical and managerial leadership Analytical support Autism Lead Commissioner Key Stakeholders
Evidence	All age data base populated with a system for updating established

Obtaining a comprehensive understanding of the needs of the autism community in Northamptonshire	
Task	i. 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.
Lead	Lead Commissioners Autism and Children First, Northamptonshire
Timescale	Apr-19

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Links to other strategies/action plans	
Resource Implications	Analytical support Clinical and managerial leadership FTE: Autism Leads across NHFT and NCC Key Stakeholders
Evidence	Completed needs assessment

Enhancing education, employment, accommodation, social and leisure opportunities

Easy access to, and positive experience of, meaningful social and leisure opportunities		
Task	i. map existing provision and identify gaps	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	Lead Practitioner Autism Commissioner	Lead Practitioner Autism Commissioner
Timescale	Apr-19	Apr-19
Links to other strategies/action plans		Northamptonshire Autism Strategy Action Plan Priority 1
Resource Implications	Clinical and managerial leadership Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Key Stakeholders	Clinical and managerial leadership Analytical support Quality assurance support Autism Lead Commissioner Autism Lead Practitioner Key Stakeholders
Evidence	Identification of gaps with strategic response to need	Action plan with SMART targets timescales and responsibilities

Removing barriers to employment			
Task	i. Raise awareness amongst employers about the potential	ii. Explore partnership opportunities with employers to	iii. Ensure access to supported employment opportunities

Northamptonshire's All Age Autism Strategy 2018 – 2021

	benefits of employing people with autism.	raise awareness of the needs of autistic individuals and reasonable adjustments to accommodate these	
Lead	EADS practitioners Recovery College Lead	EADS practitioners Recovery College Lead	EADS practitioners Recovery College Lead
Timescale	Apr-19	Apr-19	Apr-19
Links to other strategies/action plans	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd Northamptonshire Autism Strategy Action Plan Priority 1	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd Northamptonshire Autism Strategy Action Plan Ambition 1	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd SEND Strategy and Action Plan 2017-2020 Priority 3 (3.4)
Resource Implications	Clinical and managerial leadership Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Key Stakeholders	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Visit notes and outcomes. Increased number of employers willing to employ autistic people who are suitable for achieving job specification or use autistic volunteers	Partnerships established with employers. Increased number of employers willing to employ autistic people who are suitable for achieving job specification or use autistic volunteers	Increased number of autistic people in supported employment

Task	iv. Support Disability Employment Advisors to gain specialist autism knowledge	v. Promote apprenticeship schemes, job coaching, work experience and opportunities for self-employment, that includes real skill development as well as dialogue with the
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		individual, and often family members, regarding strategies for continuing and increasing success
Lead	NHFT	EADS practitioners Recovery College Lead
Timescale	Apr-19	Nov-19
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan Ambition 1	Autism East Midlands 'Connect to Autism' initiative TRACK nn Ltd SEND Strategy and Action Plan 2017-2020 Priority 3 (3.4)
Resource Implications	Key Stakeholders Learning & Development Support Quality assurance support FTE: Autism Leads across NHFT and NCC	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Feedback forms from autism training. Evidence of reasonable adjustments to accommodate autistic individual in their practice and autism knowledge reflected in their advice	Feedback from individual and families. Increased number of autistic individuals report satisfaction in their development. Progress data.

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<p>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>Task</p>	<p>i. Identify housing issues for people with autism and link with Housing Officers to explore opportunities to address these</p>	<p>ii. Support housing agencies and councils to raise awareness and understanding of autism amongst their staff, and to review their policies and practices</p>	<p>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 of support from a provider of their choosing, using a personal or a managed budget.</p>
<p>Lead</p>	<p>NASS Workstream task and finish groups</p>	<p>Lead practitioner and Lead Commissioner Autism</p>	<p>Lead commissioner Autism</p>
<p>Timescale</p>	<p>Apr-19</p>	<p>Nov-19</p>	<p>Nov-19</p>
<p>6Links to other strategies/action plans</p>		<p>Northamptonshire Autism Strategy Action Plan Priority 1</p>	<p>Think Autism</p>

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Resource Implications	Key Stakeholders Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Key Stakeholders Learning & Development Support Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Key Stakeholders Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Specialist Procurement and Contracting support
Evidence	Housing issues identified and addressed	Policies and practices amended	Increased accommodation provision

Task	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.
Lead	NASS
Timescale	Nov-19
Links to other strategies/action plans	
Resource Implications	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Specialist Procurement and Contracting support Transition teams
Evidence	Autistic individuals are showing clear evidence of progression in terms of independence

Promoting seamless progression throughout periods of transition

Develop multi-agency processes to facilitate transition planning at key stages for autistic children, young people and adults.			
Task	i. Children and young people with autism who have an EHCP have future support needs and transitions to adult care mapped into their plan	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.	iii. Establish clearly written outline pathways for transitions for children and adults, 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
Lead	Link with Transition Pathway Working Group	NASS Transitions Teams / NHFT Children First, Northamptonshire	NASS Transitions Teams / NHFT
Timescale	Jan-19	Jan-19	Jan-19
Links to other strategies/action plans	Transforming Care CYP Action Plan. Area 5 SEND Strategy and Action Plan 2017-2020 Priority 3 (3e)	Transforming Care CYP Action Plan. Area 7 Northamptonshire Autism Strategy Action Plan Priority 1	Northamptonshire Autism Strategy Action Plan Priority 1d
Resource Implications	Key Stakeholders FTE: Autism Leads across NHFT and NCC	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership	Clinical and managerial leadership Analytical support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Increased use of EHC plans by workforce across	Clinical and managerial leadership Analytical support	Published step by step transition process

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	services Reduced number of escalations at transition points Reduced number of complaints	Quality assurance support FTE: Autism Leads across NHFT and NCC	
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Ensure key transitions are well-planned for and managed.

Task	i. Support Transition workers to gain specialist autism knowledge
Lead	Lead practitioner Lead Commissioner autism
Timescale	Apr-19
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan priority 1b
Resource Implications	Key Stakeholders Learning & Development Support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Feedback forms from autism training. Evidence of reasonable adjustments to accommodate autistic individual in their practice and autism knowledge reflected in their advice

Promote proactive transfer of information from one establishment or agency to another.

Task	i. Key agencies refine a process for information sharing at transition points, including before and after diagnosis.
Lead	Lead practitioner Lead Commissioner autism CCG/NASS/Children First, Northamptonshire
Timescale	
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan Priority 2
Resource Implications	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership
Evidence	Information process in place, agreed and communicated across services

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Champion good communication and application of data, personalised induction processes and involvement of the individual and their families		
Task	<p>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</p>	<p>ii. Promote agreed sector wide autism standards with consideration to knowledge of the individual, environment, and collaboration</p>
Lead	<p>Link with EHC stakeholder group. Head of H&C partnership. Link with digital roadmap pathway</p>	Lead practitioner
Timescale	Apr-19	Apr-19
Links to other strategies/action plans	SEND Strategy and Action Plan 2017-2020 Priority 2 (2.2)	Northamptonshire Autism Strategy Action Plan Priorities 1 and 2e
Resource Implications	<p>Key Stakeholders FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership</p>	<p>Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership</p>
Evidence	<p>Parental feedback and satisfaction Comprehensive EHC plans</p>	Autism standards agreed and implemented.

Providing effective and enabling care and support

The development of a multi-agency autism team, covering mainstream services, schools and families, with Crisis Response as an integral part.	
Task	i. Identify gaps, scope current crisis provision for autistic individuals without a learning disability
Lead	NASS/NHFT/Children First, Northamptonshire
Timescale	Jan-19
Links to other strategies/action plans	Transforming Care
Resource Implications	Analytical support Quality assurance support Key Stakeholders Clinical and managerial leadership FTE: Autism Leads across NHFT and NCC
Evidence	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.

Embedding a Positive Behaviour Support (PBS) framework within the wider service model	
Task	i. Ensure autism is represented in Northamptonshire PBS pathways and that PBS and autism standards align and complement each other
Lead	NHFT Autism Lead and PBS Lead linking with PBS TFG
Timescale	Apr-19
Links to other strategies/action plans	'Developing a shared culture of Positive Behaviour Support' Northamptonshire Transforming Care Partnerships TFG
Resource Implications	Key Stakeholders Analytical support Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Effective protocols established Number of restraints are reduced

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				
Task	i. Consult on proposed standards for providers with autistic service users	ii. Develop 'Challenge Partners' visit framework	iii. Conduct a small pilot of proposed Northamptonshire QA Scheme that links in with Autism	iv. Feedback from all involved in pilot study to inform

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			Champions network	review of process
Lead	Lead Practitioner Autism Commissioner	Lead Practitioner Autism Commissioner	Lead Practitioner	Lead Practitioner
Timescale	Apr-19	Nov-19	Jun-19	Jul-19
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan 4dii	Northamptonshire Autism Strategy Action Plan 1b Northamptonshire Autism Strategy Action Plan 1b	Key Stakeholders Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Key Stakeholders Clinical and managerial leadership Quality assurance support Quality assurance support FTE: Autism Leads across NHFT and NCC
Resource Implications	Key Stakeholders Analytical support Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Key Stakeholders Analytical support Clinical and managerial leadership Quality assurance support FTE: Autism Leads across NHFT and NCC	Key Stakeholders Clinical and managerial leadership Quality assurance support Autism Lead practitioner	Key Stakeholders Clinical and managerial leadership Quality assurance support Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Autism Standards agreed to be used for QA process	Autism Standards agreed to be used for QA process	Peer assessment observation framework produced and agreed for use in QA process Results of pilot	Feedback

Autism champion(s) embedded within all age Mental Health services

Task	i. Autism champion(s) embedded within all age Mental Health services
Lead	Lead practitioner autism. Reporting through governance structure LD Managers
Timescale	Nov-19
Links to other strategies/action plans	Northamptonshire Autism Strategy Action Plan 1b
Resource Implications	Key Stakeholders Analytical support Clinical and managerial leadership

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	Quality assurance support FTE: Autism Leads across NHFT and NCC
Evidence	Services are aligned

Ensure the needs of autistic individuals are met within the wider Criminal Justice System	
Task	Develop partnership arrangements with criminal justice agencies
Lead	YO teams Probation Police Link with Forensic Pathway Working Group
Timescale	Nov-18
Links to other strategies/action plans	Transforming Care Forensic Pathway Time2listen
Resource Implications	Key Stakeholders Quality assurance support FTE: Autism Leads across NHFT and NCC Clinical and managerial leadership Specialist Procurement and Contracting support
Evidence	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
1.0	05.07.19	Final version – accessible document